Title:

Understandings and Perceptions of Spirituality held by Multidisciplinary Professionals Involved in a Community-Based Palliative Care Organization: Implications for Professional Practice.

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Statement of Authorship and Sources

This thesis contains no material published elsewhere or extracted in whole or in part from a thesis by which I have qualified for or been awarded another degree or diploma.

No parts of this thesis have been submitted towards the award of any other degree or diploma in any other tertiary institution.

No other person's work has been used without due acknowledgment in the main text of the thesis.

All research procedures reported in the thesis received the approval of the relevant Ethics/Safety Committees.

Signed:

Dated:

J. Fletcher

Statement of Appreciation

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Abstract

As a universal human experience, spirituality is innate to humanity. Nevertheless, the attempt to define spirituality within health care has led to a range of diverse and often nebulous definitions. Holistic practice within palliative care includes the physical, psychological, social, and spiritual aspects of human beings, all of which can facilitate pain for the terminally ill. Commonly, spiritual pain is inadequately addressed within palliative care. This is due to spirituality not being identified or performed by multidisciplinary professionals, who feel untrained and inadequate for the task due to a lack of education or professional development in the area of spirituality. As a part of holistic practice these professionals are called to provide basic spiritual care and make timely spiritual referrals within their everyday practice. A lexicon of spirituality was required to bring appropriate language for the identification and provision of basic spiritual care and judicious referrals to spiritual professionals.

As more terminally ill people indicate a desire to die at home, true holistic palliative care that is community-based is becoming crucial. For this research study a small community-based palliative care organization, Ballarat Hospice Care Incorporated, was chosen to be the case study. Understandings and perceptions of spirituality and spiritual care were developed and articulated through extended focus groups and semi-structured individual interviews with members of the multidisciplinary team. The employment of a hermeneutic phenomenological theoretical perspective allowed the essence of the experience of spirituality at BHCI to emerge and be given language by those who worked there. van Manen's four fundamental lifeworld existentials of lived space, lived time, lived other, and lived body were used as guides to reflection and interpretation of the textual conversations. Consequently, the definitional framework applied in this research study was of spirituality as connectedness with Self, with Other, with the world, and with mystery/transcendence, not

static, but constantly evolving towards ultimate unity. Correspondingly, it also was useful to apply the concept of disconnectedness which identified experiences of possible spiritual pain and despair. This spirituality schema brings common language to what had previously been seen as an ill-defined concept. The connectedness and disconnectedness framework is accessible and can be practically employed to assist the multidisciplinary team in defining and identifying spirituality and spiritual care. Importantly, it is inclusive of all people regardless of belief, values, and personal meanings.

In true hermeneutic phenomenological fashion, a spiritual screening tool, Connecto (Appendix H), emerged from the textual conversations and was developed by a professional trained in interpretive traditions and disciplines of spirituality. A simple, elegant device based on the theoretical framework of connectedness, Connecto transcends specific beliefs and allows the patient to identify meaning, and whether religion is significant for them. Transferable across contexts, Connecto explores spiritual strengths, spiritual distress, and a person's current spiritual state. Connecto uses information that emerges through ordinary conversation, and therefore it requires no awkward list of questions or specialised language. As a result Connecto is a product of this research study that may be useful at BHCI, but it also has the potential to be useful in other palliative health care organizations. Therefore recommendations are made regarding the findings of this research study and their potential to inform future practice in community-based palliative care and for the implementation of Connecto into orientation and professional development programs.

Chapter One: Introduction to this Research Study

> "Death frightens us, it terrifies us, it becomes a threat that shatters every dream, every promise, it severs every relationship and interrupts every journey. This happens when we consider our lives as a span of time between two poles: birth and death....If we give ourselves over to this mistaken vision of death, we have no other choice than to conceal death, to deny it, or to trivialize it so that it does not make us afraid" (Pope Francis, 2013).

Benjamin Franklin (1789) said, "In this world nothing can be said to be certain, except death and taxes." Death is an ordinary and natural part of life, the only certainty for all of humanity, but rarely talked about (P. McGrath, 2002). While it is considered a primal fear (Penson et al., 2005), death can however be experienced with meaning and peace (1999; Koenig, 2002; Puchalski, 2002), and this is the aspiration of the specialist field of palliative care (Palliative Care Australia, 2012).

The Problem to be Investigated

Palliative care is health care for the dying and focuses on symptom relief when cure is not thought possible. The World Health Organization (WHO) (World Health Organisation, 2005), calls for palliative care to be based in holistic care, that is care that takes into account the whole person. Holistic palliative care integrates the physical, social, spiritual, and emotional care of each individual and is delivered by a professional multidisciplinary team.

The context for this research study was a small community-based palliative care organization in rural Victoria, Australia, Ballarat Hospice Care Incorporated (BHCI). At BHCI the inclusion of spiritual care within holistic palliative care created a conundrum. Very few education, orientation, or professional development programs target the spiritual aspect

of care, and consequently this lack of preparation can leave the multidisciplinary team ill prepared to provide true holistic care.

The literature, too, is dogged by a lack of clarity when it comes to definitions of spirituality (P. McGrath, 2002). Further, a lack of a common language around spirituality (P. McGrath, 2002), together with a public taboo about both death and spirituality (Swinton & Pattison, 2010; Tacey, 2000), leads to a cultural and organizational silence around spiritual issues. This lack of conversation results in the multidisciplinary team experiencing decreased confidence about providing basic spiritual care and can also cause hesitation about referring patients to spiritual support (M. Holloway, Adamson, McSherry, & Swinton, 2011). The multidisciplinary team members are all experienced professionals in their own disciplines as well as in palliative care which meant it was not appropriate, nor would it have been well received, to impose understandings of spirituality and spiritual care from outside of the organizational culture. This research study, informed by the literature, aimed to initiate organizational conversation about spirituality and spiritual care, thereby assisting personal understandings to emerge and become communal understandings and perceptions.

Supplementary to the issue of lack of language, was a lack of research into community-based palliative care and this is significant when increasingly terminally ill people wish to die at home (Department of Health, 2011; M. Holloway et al., 2011; Weitzen, Teno, Fennell, & Mor, 2003). This research study intended to explore the unique features of community-based palliative care, to determine how spiritual care fits within it.

In this research study the understandings and perceptions of spirituality and spiritual care held by the multidisciplinary team, shaped by, and outworked within the organizational culture, were gathered and interpreted into an organizational understanding. This was situated within the literature to provide an evidence-based working lexicon for spiritual conversation, spiritual screening, and referral to spiritual support. To this end, the theoretical perspective of

hermeneutic phenomenology was chosen as the foundation for a case study methodology. It was further intended that the findings of this research study would be used to provide recommendations for professional development and orientation programs about spirituality and spiritual care that were organization specific to BHCI.

BHCI is a community-based palliative care organization located within the City of Ballarat. Famous for its gold, architectural heritage, and horticulture, Ballarat, with a population of 92,000, is one of Australia's largest inland cities, and the third largest city in Victoria (City of Ballarat, 2011). Located in a key strategic position in regards to Victorian freight, tourism, and commuter routes; the current major industry in the area includes manufacturing, tourism, information technology, and education (City of Ballarat, 2011). The city boasts two university campuses, Australian Catholic University, Aquinas Campus and the University of Ballarat, and these academic institutions enhance the depiction of Ballarat as a knowledge-based city. This boast is further encouraged by the Councils' "Learning City" program, promoting lifelong learning for all residents (City of Ballarat, 2011). In contrast however, Ballarat (City of Ballarat, 2013) runs at higher than the state averages for:

- unemployment;
- behavioural health risk factors leading to chronic disease and early mortality;
- death due to suicide and self-inflicted injury;
- significantly higher rates of family violence.

While 27% of Ballarat households are people who live alone, which is higher than the state average (Australian Bureau of Statistics, 2013a), there was strong community connectedness reported by 96% of the population (City of Ballarat, 2013). A Personal Wellbeing Index Survey taken in 2011 showed Ballarat residents had a significantly higher than average match between a person's hopes and expectations and their present experience, resulting in strong

quality of life indicators (City of Ballarat, 2013). The local government area of Ballarat experiences an average of 1,200 deaths each year (Australian Bureau of Statistics, 2013a).

Situated centrally in Ballarat, BHCI is an independent non-government organization with links to Grampians Regional Health, Palliative Care Victoria (PCV) and Palliative Care Australia (PCA). This totally community-based palliative care organization provides treatment and nurture for those diagnosed with a terminal illness, provided within the home of the patient. Their primary objective is to provide specialist palliative care equitably and responsively within available resources, and promote palliative care values within the community (Ballarat Hospice Care Incorporated, 2013). The BHCI logo shown in Figure 1 symbolises the circle of life, with the swirled lines representing people walking along side each other through the journey of life, dying, and death.

Figure 1. *The Logo of Ballarat Hospice Care Incorporated.*

This figure represents the philosophy that acknowledges the patient as a whole person in their own social context. The BHCI mission statement reads:

> Ballarat Hospice Care, using a skilled, multidisciplinary team approach facilitates, with compassion, the provision of home-based holistic palliative care, to anyone facing end of life issues (Ballarat Hospice Care Incorporated, 2013).

BHCI provide in-home nursing care and equipment provision for patients; along with social, welfare, and spiritual support workers, and volunteer support to help break social isolation and assist with transport and the like. While we reside in a death-denying society (Moore,

2009), to work in palliative care where *success* is measured in terms of *a good death* requires an optimistic view of humanity and of life itself (Paulson, 2004). Breaking the silence surrounding death, illness, suffering, grief, and loss within our culture is something which can bring hope to communal life: this is a value held by BHCI. Throughout the 2012-2013 financial year BHCI cared for 539 patients, with an average length of stay being 120 days (Ballarat Hospice Care Incorporated, 2013). This resulted in 13,948 patient-related home visits made by members of a multidisciplinary team of fifteen part time staff: nurses, doctors, welfare workers, volunteer co-ordinator, and spiritual support worker (Ballarat Hospice Care Incorporated, 2013).

A core value of BHCI holds that suffering, grief, loss, and death are a part of life (Ballarat Hospice Care Incorporated, 2013). The majority of healthy Australians when asked designate their home as the preferred place to die, however national place of death statistics from 2010 indicate only 16% of people achieved this, while the rest died in inpatient facilities such as hospices (10%), nursing homes (10%), and hospitals (64%) (Department of Health, 2011). With 25-50% of the 144,000 deaths in Australia each year being from a terminal illness with death anticipated by clinicians and family, the implication is that palliative care needs could be experienced by between 36,000 and 72,000 people (Department of Health, 2011). In the state of Victoria in 2012, community-based palliative care was received by 15,323 patients, provided by 39 community palliative care services (Palliative Care Victoria, 2014), one of which was BHCI.

Historically, care for the dying and the terminally ill was performed in the home, but dying and death has been "increasingly relinquished by families to charitable institutions, to newly emerging acute hospitals or simply left to chance" (Rosenberg, 2011, p. 15). Death has moved away from being the home (up to the early 1900s), to the hospital, to the hospice (1960s), to palliative care both inpatient and community based (1980s) (Puchalski, 2002;

Rumbold, 2003). Within Australia, the principal treatment focus of palliative care is enhancing the quality of life for people diagnosed with a terminal illness and who have little or no likelihood of cure (Palliative Care Australia, 2005). With the aspiration of relieving symptom distress, rather than curing disease, services offered are multidisciplinary in nature, with provision for physical, emotional, social, and spiritual care as required across the duration of the illness (Kellehear, 1999).

Palliative care grew out of the hospice movement which was founded by Dame Cicely Saunders, a trained physician, nurse, and medical social worker who began working with the terminally ill in 1948 (Saunders, 2002). Saunders' (2002), approach to death, dying, and pain control was revolutionary, so too her focus on enhancing patient connections and relationships. The identification and labelling of the Total Pain model (Saunders, 2002), acknowledged the physical, psychological, social, and spiritual aspects of pain.

In the late 1970s an alternative model of healthcare was conceived that recognized more than the biological symptoms of the patient: the biopsychosocial paradigm of holistic care included the psychological and social contexts in conjunction with the biological (Sulmasy, 2002; Weiss, 1980). In the 1990s spirituality was tentatively added to the paradigm: the biopsychosocial-spiritual model[1] which community based palliative care is founded on. This challenges the purely biomedical model control of the dying process acknowledging the dying person has a psychological, social and spiritual context (Rosenberg, 2011).

The total pain model (Saunders, 2002), with its inclusion of physical, psychological, social, and spiritual needs was a forerunner to the biopsychosocial-spiritual model (Sulmasy, 2002). Sulmasy (2002, p. 32), highlighted the importance of this approach:

[1] The Biopsychosocial-spiritual model is described further in the review of the literature from the research context, Chapter 3, pp.58.

> A human person is a being in relationship – biologically, psychologically, socially, and transcendently. Illness disrupts all of the dimensions of relationship that constitute the patient as a human person, and therefore only a biopsychosocial-spiritual model can provide a foundation for treating patients holistically.

This mysterious disruption requires a process of meaning-making. Whether considered religious, spiritual or neither, a fundamental human desire is to understand and make some sense of, or interpret, an experience through meaning-making (Frankl, 1992; Magolda & King, 2012). Whether consciously or pre-consciously, meaning-making and meaning-seeking brings the need to incorporate spirituality into the care of the person (Boston, Bruce, & Schreiber, 2011; Brera, 2011). The biopsychosocial-spiritual model can holistically bring *life while dying* into the home and the context of the patient. It is the insight and understanding of the professionals from the multidisciplinary team who work within this model of holistic care, in the particular organization of BHCI, that this research study was interested in exploring.

Increased spiritual well-being, with an accompanying sense of meaning and purpose to life, was linked to an increase in coping and a decrease in feelings of hopelessness and anxiety in patients with advanced cancer (Ben-Arye, Bar-Sela, Frenkel, Kuten, & Hermoni, 2006). This indicates the usefulness for spiritual care within palliative care. The WHO (2005), along with national and state peak bodies such as Palliative Care Australia (PCA) (Palliative Care Australia, 2005), and Palliative Care Victoria (PCV) (Palliative Care Victoria, 2006), consider spiritual care as an important and equal component within the provision of holistic palliative care by all professions within the multidisciplinary team. Not only does spiritual care facilitate meaning, hope, and healing, where treatment is no longer available (Kellehear, 1999; Koenig, 2002; Puchalski, 2002), but *learning to die* itself can be

seen as a spiritual endeavour, and a creative act of the spirit (M. Holloway et al., 2011; Koenig, 2002; Kubler-Ross, 1969/2011; Walter, 2002; J. White, 2004).

Within health, the specialist field of palliative care emphasises quality of life and the embracing of living through the terminal journey until death. Confrontation with a fatal prognosis threatens our very existence, and brings up existential questions of identity and legacy: Who am I? Will I be remembered? Existential crisis, the crisis of being, meaning, and purpose, brings spiritual pain and disconnectedness to the forefront for the human who travels through the traumatic journey of palliative care (Burke & Neimeyer, 2012; Puchalski, 2002; Swinton, Bain, Ingram, & Heys, 2011). The capacity to entertain new ways of being in the world and finding new ways to make meaning is founded in spirituality (Burke & Neimeyer, 2012). The relational and connective features of palliative care easily position themselves within a definitional framework of spirituality as connectedness with Self,[2] with Other,[3] with the world and with mystery/transcendence (de Jager Meezenbroek et al., 2010; de Souza, 2006; Ellis & Lloyd-Williams, 2012).

The research conversation of this research study involved spirituality and spiritual care. Spirituality is derived from a Latin term meaning *breath of life* ("Spirit", 2014), and in Hebrew *breath* figuratively defines *life* (H 7307 Strongs Concordance). It is poignant, then, that spirituality in palliative care can be depicted as *life while dying*. This aligns with a value held by BHCI, to encourage people to live until they die.

In recent years there has been a great increase in interest around spirituality, particularly within the health discipline (Stefanek, Green McDonald, & Hess, 2005; Weaver, Flannelly, & Oppenheimer, 2004). For some, this was a move to bring a sense of humanity

[2] *Self* is used throughout the research to refer to the inner self, also acknowledging that each human being bears the image of the Transcendent within the true self. "If I find Him I will find myself and if I find my true self I will find Him." Thomas Merton (1972). *New Seeds of Contemplation*. New York: New Directions Books, p. 36.
[3] *Other* is used as a personification of, and encounter with, the collective other. Michael Buber (1957). *I and Thou*. Edinburgh:T. & T. Clark, uses 'I-Thou,' or Other, describing encounter that is based in relation, and has capacity to lead to transformation of both the I and the Thou.

into the more functionalist medical model where the patient is often identified by their affliction (Beveridge, 1998; Borrell-Carrió, Suchman, & Epstein, 2004). Whereas for others it was an acknowledgement of the importance of spirituality in daily concerns for patients and health professionals alike (M. Holloway & Moss, 2010). One argument that arises in the literature is the need to keep spirituality tied to religion (Koenig, 2008; Pargament, 2013), while others experience spirituality and religion as two separate entities (Lee, 2002). Nonetheless in this research study, the contention is that spirituality is perhaps best presented as a continuum ranging from secular spirituality through to religious spirituality (S. A. Murray, Kendall, Boyd, Worth, & Benton, 2004). Transpiring in the everyday of life and intrinsic to the human person (de Souza, 2009a; Fisher, 2011; Sulmasy, 2002), spirituality is relational, based in the connectedness of all things (Bennet & Bennet, 2007; de Souza, 2009b). However, like the word death, the term spirituality is fraught with the silence of a public taboo which has resulted in a lack of definitional clarity, and spiritual conversations and spiritual care being poorly attended to (P. McGrath, 2002). Common etiquette says, "Don't talk about sex, politics, or religion;" which appears to be a powerful principle in the Australian psyche. Within this culture, topics such as the divine, religion, or spiritual beliefs are rarely talked about, with personal faith not considered an appropriate topic for polite conversation (T. Kelly, 1990). Further Tacey (1995, p. 5) states "Australian society is notorious for its brute masculinity, its tough machismo, its laconic shyness, its disregard for the interior world and its disrespect for the non-rational world." This pragmatic characterization supports the argument that there is little dialogue regarding personal interior issues, let alone spiritual ones. Consequently any attempt at a spiritual discussion is laden with levels of unfamiliarity, misunderstanding, discomfort, and a lack of common language.

The provision of formalised spiritual support at BHCI was an integral component of the original inter-disciplinary team in 1985 (Ballarat Hospice Care Incorporated, 2010). It

was labelled as Pastoral Care and established largely on a religious/chaplaincy role. A volunteer pastoral care position was created in 2008, and the researcher took up involvement with one or two patients and their families on a regular basis. In 2010 the practicum units for a Master of Practical Ministry were sponsored by BHCI, which led to more client and organizational involvement for the researcher. After three years as a volunteer within pastoral care at BHCI and the culmination of the study, the researcher was employed in the pastoral care position in November, 2010. At this time, with consultation between the Executive Officer (EO) and the other staff members of the allied health team, the job description and title was changed to more adequately reflect the nature of the position: Spiritual Support worker.

Holding the position of spiritual support worker placed the researcher on the Quality Committee working through the criteria of National Standards Assessment Program (NSAP) guidelines (Palliative Care Australia, 2011). The aim of NSAP is to support improvement towards best practice, accreditation, and adherence of the National Palliative Care Program in specialist palliative care services (Palliative Care Australia, 2011). This quality improvement program, based on WHO and PCA standards of holistic care, (Palliative Care Australia, 2011; World Health Organisation, 2005), assists consistent and cyclical self-assessment and quality improvement. Through involvement with the accreditation process the researcher became aware of gaps in and around spiritual practice at BHCI. An examination of the organizational literature exposed a lack of policy and procedure regarding spirituality, spiritual screening, and spiritual referral resulting in spiritual practice that was predominantly *ad hoc*, subjective, and unmeasurable. If spiritual care is given at all, then it is given from a personally held philosophy, conscious or pre-conscious (Emblen & Pesut, 2001). While this information brought up many questions, the obvious place to begin was with the question: What is spirituality at BHCI?

There appeared to be four issues contributing to the predicament of spirituality at BHCI:

- a lack of common language and understanding about spirituality and spiritual care by management, staff, patients, and carers;
- a lack of organizational education and training regarding spirituality and spiritual care;
- a lack of guidelines at BHCI resulting in spiritual referral that is ad hoc and unmeasurable;
- a lack of policy at BHCI regarding spiritual care, spirituality, and a standardised, validated spiritual assessment tool.

All of these issues could be addressed through organizational conversation, education, and training in spirituality and spiritual care.

Unsurprisingly, it would appear the Australian cultural approach to spirituality as a taboo permeates BHCI culture impacting individual staff, patients, and carers. As a spiritual support worker in community-based palliative care, the researcher was often asked the question, “What is it that you actually do?” Within the organization, spirituality was often misunderstood, and conversations around the topic were often uncomfortable. Other staff members in the multidisciplinary team commented on the difficulty they had describing what spiritual support was when offering services to a patient. That such experiences are common is supported by the findings of McSherry & Jamieson (2011), who acknowledged that education is important if spiritual support is to be promoted and used effectively.

For the most part it is the nurses who are the brokers for spiritual support referrals; their identification of spirituality as important is crucial for timely referrals (Harrington, 2004; McSherry & Jamieson, 2011). However, it appears that in practice, ideas of spirituality involve the ethereal and mysterious, so that a referral for spiritual support is often coupled

with the request to, “Do your magic!” These factors suggest that there is some intangible sense that spiritual support is useful and that it does something to help, however there would appear to be no actual knowledge or language to articulate just what that is.

Research with nursing managers carried out by Jenkins (2009), identified three recommendations to improve the provision of spiritual care to patients by nurses:

- the inclusion of spirituality in training and orientation;
- embedding spiritual practice within routine patient care;
- the implementation of a spiritual assessment tool.

These findings are consistent with the lack of policy within BHCI towards spirituality and spiritual support. The first finding, the need to address training, was a basic factor in eliminating the ignorance around spirituality within the organization. Finding two, the need for routine spiritual care to be embedded within organizational practice, was more difficult to put into operation when there was no organizational understanding of what spirituality was and what spiritual care could or should incorporate (Jenkins et al., 2009). Finally, there was a clear indication that a spiritual screening tool was vital for appropriate and timely referrals to spiritual care.

Informal evidence from referral notes, team meetings, and handover discussions identified three main patient issues that resulted in a referral for spiritual support at BHCI:

- on initial assessment, the patient has indicated that they are religious and would like to receive spiritual support;
- on initial assessment, or throughout admission, the patient and/or carer is highly emotional, characterized by tears, anger, hopelessness or acopia;
- throughout admission the patient is non-compliant with medication and/or self-care protocols.

These referral issues formed the shape and structure of spiritual support in the following ways: firstly, any discussion at the initial assessment which mechanically aligned religiosity with spirituality tended to lock spiritual support into denominational dogma. Questions that ask about church attendance or religious affiliation pre-consciously provide an exclusive definition of spirituality that prevents patients from receiving spiritual support unless, of course, they or their carer advertise their beliefs or indicate that they are church goers. Secondly, referrals that ask for spiritual support on the grounds of patient distress, whether on initial assessment or throughout the patient admission, pre-consciously ally spirituality with emotionality. This also defines emotions and acopia as something that requires *fixing*, and spiritual support is assumed to be the emotional fixer. In the third instance, spiritual development is often associated with meditation, prayer, rituals, and sacraments; outward observances that exhibit order, discipline, and a moral code (Koenig, 2008). Based on the thought of Freud, modern psychology continues to emphasize the "role of religion in self-regulation, including the management of undesirable thoughts, feelings, and behaviours" (Pargament, 2013, p. 263). Research suggests that these external behaviours are often accompanied with social behaviour modification (Koenig, 2008). This spiritual model of discipline and behavioural control identified by Koenig (2008), feeds the notion that spiritual care can assist with non-compliance, hoping for a change of behaviour. Non-compliance within a health setting can be expressed through failure or refusal to take medication, or to comply with other health behaviours as prescribed by the doctor or medical team. Non-compliance referrals to spiritual support come out of a frustration with the patient, by the medical model, for not *obeying doctor's orders* but rather being a self-deterministic individual. These three types of spiritual referral dominant at BHCI mechanically align spiritual support with religion, emotionality, and some form of discipline, and have shown a narrow understanding of spiritual support. The nature of these referrals results in no support

for the spiritual needs of those falling outside this framework. That does mean that patients who have no affiliation to religion, or patients who are non-emotional, and are compliant being rarely referred for spiritual support, and consequently fail to benefit from holistic care by this exclusion (Pike, 2011).

The effect of spirituality on health and well-being is of interest to many different professions operating within a multidisciplinary team (Culliford, 2009; Dane & Moore, 2006), and it underlies the necessity of a biopsychosocial-spiritual approach in holistic patient care (G. M. Berg, Crowe, Wong, & Siebert, 2010; Sulmasy, 2002). However, interest in the functional aspects of spirituality has resulted in a disproportionate amount of research into spirituality being carried out by those with a medical or nursing background, while little research is provided from a pastoral, chaplaincy, or theological background (M. Holloway et al., 2011). This dilemma has resulted in research findings isolated from the disciplines in spirituality (such as theology, philosophy, religious studies), and their traditions of interpretation. The outcome is the lack of richness that a spiritual and/or theological basis can bring and, in turn, it may provide a narrow focus on the reductive biological and functional based representation of spirituality (Cobb, Dowrick, & Lloyd-Williams, 2012; Egbert, Mickley, & Coeling, 2004).

As there was no formal modus operandi pertaining to spirituality within BHCI, this research study, with the use of a hermeneutic phenomenological approach, set out to discover the communal understanding and essence of spirituality held by management and employees across the multidisciplines. It was expected that the drawing out and collecting of understandings and stories about spirituality at BHCI would assist with the defining of spirituality and spiritual support in an inclusive way for the workers within this community-based palliative care organization. Further, it was anticipated that the findings would lead to

recommendations for an educative professional development and orientation program which could embed a broader understanding of spirituality within BHCI policy and everyday praxis.

The Research Process

A lack of common language and understanding about spirituality leads to referral and provision of spiritual care at BHCI that is subjective and unmeasurable. As spirituality facilitates the finding of meaning (Kellehear, 1999), and the epistemological approach of constructivism deeming meaning to be constructed individually through connection with the world (Crotty, 1998), then exploration of the meaning of spirituality as it is experienced at BHCI requires discussion with individuals from the various professions involved.

> The articulation of the research problem led to the forming of the research question: What are the understandings and perceptions of spirituality held by multidisciplinary professionals involved in a community-based palliative care organization?

To address the question this research study employed the social research framework designed by Crotty (1998), which moves through the methodological design of research paradigm, the research question, epistemology, theoretical perspective, methodology, and methods.

Contingent on the research problem was the selection of an appropriate research paradigm, with the choice of either a quantitative or qualitative approach. Quantitative research is explicit and restricted, concentrating on prediction, control, and measurement using quantifiable data; while the focus of qualitative methodologies is discovery, description, explanation, themes, and meaning (Creswell, 2008; Fossey, Harvey, McDermott, & Davidson, 2002; Laverty, 2003). Therefore, the exploration of the research question which focused on the understanding and experience of spirituality and spiritual care was best addressed by a qualitative approach since this allowed participants to describe spirituality for themselves (Hodge & Boddie, 2007). The qualitative paradigm then informed the shaping of the research question which was, in turn, founded on the epistemology of constructivism

which holds that meaning is constructed by individuals as they live, experience life, and engage in the world (Creswell, 2003; Crotty, 1998; Schwandt, 1994). The theoretical perspective chosen was an interpretive paradigm, hermeneutic phenomenology, which focused on interpretation of the essence of *lived experience* and an enquiry that explored what it felt like to be involved in the experience (O'Leary, 2010), valuing direct awareness and perception (Stake, 2010). Case study was considered the most appropriate methodology with BHCI as the particular case under scrutiny. Extended focus group and semi-structured interview were used as methods for data collection. Then the lifeworld existentials of van Manen (1997), lived space, lived time, lived other, and lived body provided the framework for reflection and interpretation of textual conversations that formed the data.

Significance and Delimitations of this Research Study

While the quantity of literature about spirituality has increased in recent times, there seemed to be little that specifically addressed the multidisciplinary provision of spiritual care within community-based palliative care. Further, spirituality as an important component of holistic care was expected to be provided by professionals within palliative care, yet there has been little education or professional development given for them to do so. This research study will add to the body of knowledge around the discourse of spirituality, palliative care, and community-based palliative care practice. The strength of this research study is intended to be the provision of a spiritual lexicon developed through a framework of connectedness, in dialogue with the textual conversations, which provides the basis for the development of a tool for spiritual screening and effective spiritual referral.

It is expected that the recommendations emerging from the findings will bring benefit to both patients and their carers because the multidisciplinary team will be empowered to engage in a broader use of holistic care. Through education and training, multidisciplinary

staff will also be assisted in developing enhanced self-care options, which the literature suggests increases job satisfaction (Pesut, 2002).

Delimitations are choices the researcher makes that set the boundaries for the study. As an employee at BHCI the researcher chose to perform in-depth exploration, into the understandings and perceptions of spirituality held by the multidisciplinary team operating within this particular organization, to create a lexicon of spirituality that was pertinent to all employees. In this way it was not useful to compare and contrast understandings with other organizations that operate differently within the community-based palliative care sector. No generalizability is claimed as a result of the findings of this thesis, rather the conclusions remain applicable to BHCI and their unique model of service. However, the findings of this research study will provide guiding principles for exploration of the character of spirituality held by multidisciplinary professionals within discrete organizations. Insights into the usefulness of employing the connectedness/disconnectedness framework for understanding spirituality are included. Further the screening tool that emerged through the process of hermeneutic phenomenology reflection provides an evidence-based instrument to assist in assessment and referral. This tool will allow a determination of the current state of a patient's spirituality, it can transcend specific belief or ritual, and can potentially be implemented in many situations by many disciplines.

The Structure of this Thesis

In this thesis, precise definitions of terms, assumptions, and limitations of this research study are not presented separately, but rather are demonstrated as the research unfolds. The structure of the thesis develops as follows.

The introduction of this thesis presents the background and purpose of this study. Through identification of the research problem, context, and research focus it will:

- determine the research territory: Spirituality and spiritual care within community-based palliative care at BHCI;
- establish the niche of the research: This introduced the research problem – a lack of lexicon around spirituality and spiritual practice, and the significance of the research – it will add to the body of knowledge, from a spiritual discipline tradition, around spirituality and community-based palliative care, spiritual screening and spiritual referral. Patients and their carers will benefit through genuine holistic care, while staff will benefit through enhanced spiritual knowledge and self-care;
- occupy the niche by outlining what is going to occur within the research: The gathering of understandings and perceptions of spirituality and spiritual care held by the multidisciplinary staff at BHCI, and entwining them with the research literature to provide an evidence-based lexicon of spirituality, recommendations for professional development and orientation programs, and spiritual screening protocols (Cayley, 2013).

Chapters two and three contain a review of the present literature from two areas which inform this research study, spirituality and community-based palliative care. Chapter Two details the literature of spirituality and spiritual care. This research literature unpacked understandings of spirituality looking at the current spirituality literature, along with the religion/spiritual intersect, and literature pointing to current public discussion about spirituality. The framework of spirituality as connectedness with Self, with Other, with the world, and with mystery/transcendence was significant as in this thesis connectedness was a fundamental conception underpinning spirituality. Further, spiritual despair was identified as disconnectedness.

Chapter Three examines the literature of the context of this research study, being palliative care practice. It describes the milieu of this research study, that of community-

based palliative care practice and the position of spirituality within it. The literature examines the biopsychosocial-spiritual and total pain models, exploring disconnectedness for the palliative care patient and carer. An appraisal is given of the multidisciplinary provision of spiritual care in light of community-based holistic practice, barriers, and skill development. In addition this chapter reviews education and training regarding spiritual care provision within the context of community-based palliative care.

Following the review of the literature, Chapter Four outlines the research design justifying the chosen design applicable to the current study. Employing the social research framework devised by Crotty (1998), the chapter moves from paradigm (qualitative) and research question, through epistemology (constructivism), theoretical perspective (interpretive: hermeneutic phenomenology), methodology (case study), and methods (extended focus group and semi-structured interview). Further, the method of reflection and interpretation used with the texts of this study, van Manen's (1997), concept of lifeworld existentials is examined for its application to this research study. In keeping with the established practice of hermeneutic phenomenology this present study endeavoured to use terms and writing style which manifest the qualitative nature of the research.

Chapter Five presents the findings of this research study. Through the hermeneutic phenomenological textual conversations of focus group and semi-structured interview, the understandings and perceptions of spirituality emerged through immersion in, reflection, and interpretation on the texts.

A discussion of the interpretation and reflection on the findings of this research study, presented in Chapter Six, brings to life the characterisation of spirituality held by the multidisciplinary team at BHCI. Using examples of hermeneutic phenomenological writing, drawn from the focus groups and interviews, entwined with the current literature, five key themes were presented that rose out of the textual conversations. These brought language to

spirituality within BHCI and highlight the need for education and training. Finally, Chapter Seven draws together a brief summary of the major findings identified by this research. The spiritual screening tool, *Connecto*, which emerged through the process of immersion in the textual conversations, is introduced, described, and its implementation is discussed. The results of this research study are outlined and recommendations made for the implementation of future education and training programs, particularly through professional development and orientation programs, as well as the embedding of *Connecto* within everyday practice as a spiritual screening tool. Additionally, this concluding chapter points the way for future research study.

Chapter Two: Literature Review One: Spirituality

The previous chapter introduced the reader to the two streams within this research study: the context of community-based palliative care and the focus of spirituality and spiritual care. In addition the research question was designated: What are the understandings and perceptions of spirituality held by multidisciplinary professionals involved in a community-based palliative care organization? Alongside this, the methodological framework was outlined as well as the structure of this thesis. This chapter sets out to discuss the literature relevant to one of the streams, that of spirituality and spiritual care. It encompasses the distinctiveness of religion and spirituality in definition, need, and care, as well as the public discussion of spirituality. This review presents the current knowledge of spirituality within community-based palliative care and sets out to identify any gaps in the existing literature. This literature review is not to pre-empt the research findings by creating a strict definition and dogma around spirituality for the research to slot into, but rather to describe spirituality and acknowledge where the boundaries are within the literature so that the findings that rise from the hermeneutic phenomenological research may find a place to settle. We now turn to the literature of spirituality.

Spirituality being "life in its light and shadows" (Aghadiuno, 2010, p. 38), is seen as an imprecise and hazy concept (Fisher, 2011; Swinton & Pattison, 2010); sometimes positioned within religion (Koenig, 2007; Ranson, 2002), sometimes separate from religion (de Souza, 2009; Lee, 2002), and for many, spirituality sits somewhere between the two on a sacred-secular continuum (S. A. Murray et al., 2004). Faith and belief are seen as one of the principal forms of identity used by individuals in contemporary society, no matter where an individual places spirituality on that continuum (Gilbert, 2007). Accordingly, we begin by looking at faith and belief through religion.

Religion

Historically in the west, spirituality has been owned by religion or the church, and been understood as a longing and quest for God (Koenig, 2008; Ranson, 2002). For instance, objective religion is described as a system of beliefs, rituals, and a moral code of conduct, that is embraced through particular activity and practices: be it organizational or non-organizational (Koenig, 2008; Pargament, 1997). On the other hand, subjective religiosity is described as the self-appraisal of the importance of religion and the individualistic application of that system of beliefs (Koenig, 2008; Pargament, 1997). When firmly founded in religion, spirituality is defined as the pursuit, qualities, and characteristics of relationship with the sacred or transcendent (Pargament, 1997; Sulmasy, 2006). Religion is where the sacred and significance intersect in relationship (Pargament, 1997).

Emile Durkheim (1915, p. 433), eminent French sociologist, insists that religion is first founded in social needs, uniting communities by a common faith and that "the idea of society is the soul of religion." Emerging from within communities of faith, religion is identified as having three components: belief in and worship of a superhuman controlling power, a particular system of faith and worship, and a pursuit followed with great devotion (S. A. Murray et al., 2004). Religion provides a community with a structure of belief and ritual that assists people find meaning and hope, while also depicting how each human fits within humanity, family, and community (Pargament, Koenig, & Perez, 2000; Puchalski & O'Donnell, 2005). Religion also gives a worldview that places individual suffering inside the corporate human experience of despair (McSherry, 2005; Puchalski & O'Donnell, 2005). Prescribed religion was initiated around three thousand B.C.E. with the formulation of Hinduism; while Sikhism did not emerge until the eighteen hundreds (O'Murchu, 2004), and Baha'i in the 1860s (Cantini, 2009). However, anthropology does indicate humanity

grappling with the meaning of life and spiritual issues much earlier possibly around seventy thousand B.C.E. (O'Murchu, 2002).

It is not only in history that religion has been significant. In present day Australia, the 2011 census found that 61% of the population aligned themselves with a Christian religion, and 7.3% identified themselves as affiliated with the other four major world religions: Buddhism, Hinduism, Islam, and Judaism (Australian Bureau of Statistics, 2013b). These figures highlight that the fabric of contemporary Australia is woven with diverse worldviews and belief systems (de Souza, 2014b). In the census only 22% declared themself to have no religious affiliation (Australian Bureau of Statistics, 2013b), which indicates that for a large majority of the population religion has some role in life, giving rationale for religious care to be included within holistic healthcare (Koenig, 2008). The ABS (Australian Bureau of Statistics, 2013b) reports that, within the question of religious affiliation, Christianity is widespread across the Australian population, nonetheless Table 1 shows that other religions need to be acknowledged as a part of the religious landscape.

Table 1
Religious Affiliation in Australia

Religion			% of population
Christian Religions:			
Catholic			25.3
Protestant	Anglican	17.1	
	Uniting Church	5.0	
	Presbyterian and Reformed	2.8	
	Eastern Orthodox	2.6	
	Baptist	1.6	
	Lutheran	1.2	
	Pentecostal	1.1	31.4
Other Christian			4.5
Non-Christian Religions:			
Buddhism			2.5
Islam			2.2
Hinduism			1.3
Judaism			0.5
Other non-Christian			0.8

Note. Religious affiliation as reported by Australians in the 2011 census (Australian Bureau of Statistics, 2013b).

Table 1 indicates that generalizing about religion in this county can be complicated, where the population is actually, “partly a Christian country, partly a multifaith country, and partly a secularist country” (Bouma, Cahill, Dellal, & Zwartz, 2011, p. 4). Growth of diverse religious traditions happens in Australia as migrants settle here, bringing their own cultural identity to their new country, which can include unique manifestations of religious cultural identity (Bouma et al., 2011). This can result in multiple understandings of a particular religious worldview, and variance of observance through the different religious communities, as well as between different sects or groups within the broader religious community. For example, there are many different Christian religions which have differing beliefs and practices, and similarly there are many diverse practices amongst different Hindu, Muslim, and Buddhist adherents (Koenig, 2008; Pargament, 1997; Swinton et al., 2011). It is important that multidisciplinary professionals are aware of these differing practices and beliefs, particularly around dying and death. This is further discussed in the interpretation and revelation chapter (see pp. 224).

In spite of this diversity, one common characteristic of the different religions is their aim to shape core assumptions and an exclusive worldview (Brennan, 2006; E Kelly, 2013; Yan, Staps, & Hijmans, 2010). Or as Pargament (2013, p. 269), describes it, objective religiosity provides a “ sacred lens, a lens that colors, filters, and clarifies their view of reality.” These exclusive worldviews bring a structure of thought and belief, both communally and individually, to differing situations (Koenig, 2008; Pargament, 1997; Swinton et al., 2011). In the instance of death and dying, if the religious worldview says acceptance of death is not only a natural part of life, but also holds meaning as the passage to a better life, then religion provides some protection against death anxiety (Kim, 2009;

Rogers, 2011). However the worldview of objective religiosity can be very different to the subjective religiosity experienced by an individual. The notion of subjective religiosity recognizes that the ideas and concepts offered by an objective religious worldview are often deciphered and lived out in profoundly individualistic and personal ways (Koenig, 2008; Pargament, 1997; Swinton et al., 2011). There can be a dissonance between what a person and their religious community believe and how that person actually behaves. This can cause a disconnectedness between a person's religious worldview and their subjective personal beliefs, doubts, and feelings. In the experience of the researcher it is not uncommon for devout people to confidently espouse their objective religious worldview of death. They welcome it as the transition to a better life. Yet simultaneously they may share a subjective religiosity that creates doubt so that they may fear death, and this prompts questions about what comes after death and whether or not they will be excluded or included in the good afterlife, often understood as heaven or paradise.

Religion, as a quest for the Divine, provides a framework for the majority of Australian residents in which to make meaning of suffering and death. While the objective religion of an individual is identified by a religious label and structured meta-narrative and worldview, their subjective religious view can be complicated, complex and personal, leading to religious needs that are complicated, complex, and unique.

Religious need. Religious need emerges in an individual due to existing personal practices or former religious socialization through upbringing and religious instruction (Kellehear, 2000). Religious need can be founded in an effort to psychologically accept or move past and transcend the present, or achieve an awareness of hope, especially for those dying, and caring for the dying (Kellehear, 2000). Religious need occurs within a particular meta-narrative (E Kelly, 2013), or worldview and is seen to include belief, ritual, and practice of the following:

- seeking religious redemption through acts of reconciliation including healing of past hurts and forgiveness;
- connecting with the sacred, supernatural, or divine through prayer (both individual and communal), meditation, and corporate worship;
- experiencing divine forgiveness, mercy, grace, strength, inner peace, sense of healing;
- religious transcendence through sacred rites and rituals;
- visit by religious leaders with the provision for laying on of hands, anointing with oil, and discussion about God, eschatology, eternal life, and hope;
- religious literature and music, primary sacred writings and instructive commentary texts concerning the faith (Kellehear, 2000; Speck, 2011).

These rituals and practices indicate that a large amount of expected religious care is decidedly specialised and requires specifically religiously qualified practitioners to perform it adequately (Kellehear, 2000; E. Kelly, 2012b; Pesut, Reimer-Kirkham, Sawatzky, Woodland, & Peverall, 2012; Yan et al., 2010). For the individual the particular meta-narrative of subjective religion broadens the traverse of religion and spirituality.

Religion holds a significant place in Australia. As a longing and quest for the Divine, religion has two components. The first, objective religiosity comprises a system of beliefs, rituals, and a moral code of conduct embraced through the particular: be it organizational or non-organizational (Koenig, 2008; Pargament, 1997). Objective religiosity shapes core assumptions and a worldview or metanarrative which can make meaning out of suffering and death. On the other hand, subjective religiosity is self-appraisal of the importance of religion and individualistic application of the objective beliefs (Koenig, 2008; Pargament, 1997).

Religious need requires sensitive specialized religious care that can support the objective and subjective experiences of religiosity. However, looking at what the literature says about

religion and religious need is only one aspect of how an individual may experience spirituality.

The Religion and Spirituality Intersect

Within the literature religion and spirituality are often portrayed as overlapping in experience and concept. The fourth annual Australian Spirituality and Health conference in Adelaide in 2011 defined religion and spirituality as associated concepts, stating that "...most people experience spirituality within an organized religious context" (Spirituality and Health Australia Inc, 2011). This position is supported by Sulmasy (2002), a surgeon, catholic priest and medical ethicist, who concedes that while spirituality is mainly experienced through religious practice, some do nourish their sense of spirituality through connection in broader ways. In their research into workplace spirituality Liu and Robertson (2011), found religion to be considered a component of spirituality. John Swinton (2011), a Scottish theologian and founder of the Centre for Spirituality, Health and Disability, speaks of religion and spirituality relating to facets of human experience that are related but not the same, which is a description also offered by others (see U. King, 2008; Ranson, 2002; Tacey, 2004).

After conducting a review of thirty-five empirical studies where terminal patients were asked about their experience of spirituality, Cobb, Dowrick & Lloyd-Williams (2012, p. 1111), found: "The literature frequently used the term *spiritual* along with *religious*, often differentiating the two and sometimes conjoining them: spirituality/ religiosity," however the studies lacked any attempt to critically clarify definitions and meaning.

Research by King et. al. (2013) found that non-religious spirituality is negatively associated with mental health issues, leading them to conclude, "People who have a spiritual understanding of life in the absence of a religious framework are vulnerable to mental disorder." To be spiritual, but not religious was thought to increase vulnerability to mental illness and addictive behaviours. However, the research of McCoubrie & Davies (2006, p.

383) found “patients with high levels of existential/spiritual well-being were less likely to be anxious or depressed.” Other studies have also found that spirituality does increase a sense of well-being in cancer patients (Laubmeier, Zakowski, & Bair, 2004), in patients with lung cancer (Meraviglia, 2004), and also prostate cancer (Krupski et al., 2006). Further, Rosseau (2000, p. 2000) claims that “religious ideologies may evoke spiritual anguish and fear.”

Ranson (2002), is concerned that spirituality, adrift from religion, cannot exist on its own, needing some other context or philosophy to be aligned with. While unbound and artless, spirituality without form is also concealed, and therefore any usefulness for the common good can be lost (Kaldor, Hughes, & Black, 2010; Tacey, 2004). Conversely, O’Murchu (2004), is concerned that the current muddle between spirituality and religion relays the idea that the practice of a prescribed faith system is the only way an individual can be spiritual. He argues that such an understanding denies the existence of many who follow a spiritually based value system while wrestling with ultimate questions outside of formalised religion (O'Murchu, 2004). Alistair McGrath (1999), observes that within western thought religion has become something one believes in and is practised within denominations, with values, morals, and dogma; while spirituality has become linked more with the existential, relational, and mystical. In accord, Ewan Kelly (2012b), underscores spirituality as primarily relational saying that it is due to people being human in relationship, and not because they are religious, that makes them and their communities spiritual. Halstead and Hull (2001, p. 1541), conducting research into women with cancer, found that their definitions of spirituality incorporated, “thankfulness, peacefulness, enhanced meaning and purpose, hope, connectedness, increased strength, trust, prayer, forgiveness, and assurance of God’s presence”. This is a combination of wellbeing, anthropology, and religiosity, and the overlapping of these concepts is strongly represented in the literature (Gomez & Fisher, 2005; M. King & Leavey, 2010; Koenig, 2002; Pargament, 2007). Nonetheless, Koenig (2008, p.

10), calls for "a sharper definition of *spirituality* that retains its historical grounding in religion" for health research; a lucid and precise innovative spirituality that is connected to religion and transcendence (Koenig, 2007). However, he does admit that in health settings a broad definition of spirituality is more useful for the patient tussling with existential issues or for a sense of meaning outside of themselves (Koenig, 2008).

Existentialism focuses on *how* the individual relates to the meaning in their life, rather than verifying particular meanings (Webster, 2004). "Existential awareness allows the edge of our knowing and being to come into our consciousness" (Berryman, 2001, p. 12). Issues of meaning, identity, love, joy, reconciliation, and suffering all ask existential questions (Burke & Neimeyer, 2012; S. Nolan, Saltmarsh, & Leget, 2011; Puchalski, 2002). Existentially, spirituality brings a recognition of personal life and death (Berryman, 2001); providing a space to make sense of life, to find and preserve hope, and to discover inner resources to cope with challenging experiences (M. Holloway et al., 2011; E. Kelly, 2012b).

A majority of research literature into spirituality within palliative care comes from the US where the words *religious* and *spiritual*, and their concepts, are used interchangeably (M. Holloway et al., 2011), while in the more secular UK, research into spirituality is largely carried out by nurses who separate spirituality from religion (M. Holloway et al., 2011; Walter, 2002). Kellehear (2000), believes there has been a rejection of Christian belief in the health literature with a turning towards new age and eastern religions. Pam McGrath (2005), argues that this exploration of multiple belief systems and non-religious spiritual beliefs in the Australian pluralistic, multicultural society is a necessity that is only just beginning. However, she notes that a lack of contemporary language to speak of spiritual encounters, insights, and meaning-making that are not religious does hamper research (P. McGrath, 2005). Another language challenge within health care is the common assumption that the word *religion* is a monumental expression that holds the same meaning for all people

(Swinton et al., 2011), however, this belies the concept of subjective religion and individual expression discussed above (Koenig, 2008; Pargament, 1997; Swinton et al., 2011). These language difficulties lead to a taboo around spiritual discussion (P. McGrath, 2005; Swinton et al., 2011), as for some in our pluralistic, postmodern society words such as *religion* and *God* can actually impede their experience of spirituality (Hay & Nye, 2006).

The request by researchers and writers to keep spirituality within a religious context (Koenig, 2002; Pargament, 2013; Sulmasy, 2002), can result in an exclusively religious based spiritual care available only for self-labelled religious people. However, this approach excludes from spiritual care any patient who does not publicly identify with a specific ideology of a major religion particularly when spirituality and spiritual care has been identified as a need that is intrinsic to humanity (Bellous & Csinos, 2009; de Souza, 2009b; Ranson, 2002). The overlapping of religion and spirituality that occurs within the literature adds to the lack of clarity around them both, clouding how spirituality is seen and acknowledged.

Spirituality

As we have seen in Chapter One where the contextual scene was set, spirituality is an important and equal component of holistic care, and there is an expectation that at a basic level, it is to be provided by all professionals working within palliative care (Palliative Care Australia, 2005; Palliative Care Victoria, 2006; World Health Organisation, 2005). However, as expressed in the earlier discussion, attempts to define spirituality within the literature take a complex and convoluted route, with authors rarely operating on a common definition or even a collective appreciation of what spirituality is, other than for some reaching agreement that it is not religion (Swinton et al., 2011; Visser, Garssen, & Vingerhoets, 2010), while others state it is all about religion (Koenig, McCullough, & Larson, 2001; Sulmasy, 2006).

Emerging from the literature of business, social work, education, and health is a broadening characterization of spirituality to include more than religiosity (Barry & Gibbens, 2011; Grant, O'Neil, & Stephens, 2004; M. Holloway & Moss, 2010; Hyde, 2008b; Liu & Robertson, 2011; Walter, 2002). Offering a sociolinguistic description, Walter (2002, p. 136) describes spirituality as "a discourse used at the present time in the English-speaking world by those who wish to move beyond, or distance themselves from, institutional religion." This stance is prevalent in the literature coming out of the UK, where spirituality is becoming identified as a generic term totally disengaged from religion (Swinton et al., 2011). Walter (2002, p. 135) hypothesises that the rising interest in spirituality is based on three features of contemporary western society:

- the focus on the individual has led to a new spirituality that is a personal and exclusive inner quality;
- individualism comes with a distrust of institutional authority and fear that individual spirituality will be stifled by prescribed religion;
- answers to ultimate questions need personal engagement, rather than being authoritatively provided by religious dogma.

This individualistic spirituality focuses on making sense of life, forgiveness, inner peace, ultimate questions, and inner meaning, suggesting that spiritual need can be experienced by people who consider themselves religious, spiritual, atheist, and even agnostic (Baldacchino, 2008; Bouma et al., 2011). The individual combination of spiritual and existential strengths and needs is eclectic, broad and diverse; as unique as each human person (Swinton et al., 2011). Personally and individually positioned on a sacred-secular continuum, contemporary spirituality does require a common understanding to enable language for the articulation of shared concept, meaning, and appreciation (P. McGrath, 2002). Studying these broad

definitions of spirituality, Reader in Sociology at the University of Reading, Tony Walter (2002, p. 134), makes the point:

> Even sociology would become part of spirituality. That this most historically secular of disciplines should qualify indicates how broad spirituality has become: the academy, personal development, and health care all become ways of developing personal spirituality. So we find that a broad discourse of spirituality arises not just in palliative care, not just in nursing, but in other contemporary arenas.

Within the spiritual support language at BHCI the phrase, "I'm spiritual, but not at all religious" is often heard, and this proviso seems to be a growing trend in western society (de Souza, 2009; Pargament, 2013; Peterman, Fitchett, Brady, Hernandez, & Cella, 2002). It comes with its own contemporary acronym, SBNR, web page (www.**sbnr**.org/), and over 5,350,000 results in .27 seconds when inserted into a Google search. A review of responses from five major surveys into "I am spiritual but not religious" found Americans consider themselves decreasingly religious, and increasingly more spiritually aware (Marler & Hadaway, 2002).

Sometimes labelled the post-secular society, this era takes in various fresh spiritual worldviews, many with a focus on the individual (Watson, 2013a). Tacey (2010, p. 1), declares we are seeing the unrolling of a spiritual revolution that brings "a new interest in the reality of spirit and its healing effects on life, health, community and well-being." This escalation has also been prominent in areas of palliative care and health (Boston et al., 2011). Walter (2002, p. 135), argues that the recent insertion of spirituality into healthcare characterizes "a critique of scientific reductionism." Spirituality brings a sense of humanizing to the medical model through focus on compassionate care and practice, and concepts of suffering and inner meaning (Beveridge, 1998; Cobb, Puchalski, & Rumbold, 2012; Walter,

2002). The healing effect of Tacey's (2010) spiritual revolution is the visible increase in interest and research.

The acknowledgement of the role of religion and spirituality in peer reviewed health care journals showed a 23% increase per year for each 100,000 articles published between 1965-1994, however, since 1997 the increase has averaged 55% per 100,000 (Weaver et al., 2004). Another literature search conducted in 2005, using "spirituality and health" as keywords indicated a 600% increase in publications on spirituality and health in the preceding 10 years (Stefanek et al., 2005, p. 450). Similarly, from the year 2000 the notion of well-being has received greater interest within the literature, seeking to define, quantify, and connect it to the outcomes of religion and spirituality (Fisher, 2011; M. Holloway et al., 2011).

While the dialogue around spirituality has many voices and approaches seeking to understand and shape a definition and outworking of spirituality, there are dissenting voices in any public discussion and spirituality is no exception. Paley (2009), a senior lecturer in nursing at the University of Stirling, declares the need for keeping discourse around health issues purely secular in what he sees as a strongly secular UK. Dismissing the rhetoric of spirituality as separate from religion he ventures the opinion that, "Spirituality permits certain writers to indulge their supernatural inclinations, while reassuring sceptical readers that it is really just a matter of relationships" (Paley, 2009, p. 27). Salander (2006), too, is troubled by the notion of classifying all existential issues as *spiritual*. He proposes that spiritual is an irrelevant term and should be made defunct and replaced by *religious*, thereby broadening the gap between religion and secular existential concepts. He questions the usefulness of any spirituality research on three fronts:

- the lack of clarity about definition across research projects;

- a perceived mystification of common sense by a high percentage of Anglophone religious context;
- the overlap of existential, psychosocial, and spiritual concerns (Salander, 2006).

While agreeing with a lack of definitional clarity throughout the spiritual research, Breitbart (2007), questions the idea that spirituality is always religion-based, while a secular worldview is only linked to existentialism. Further, answering these criticisms Breitbart (2007), points to the work of existential philosophers such as Kierkegaard and C.S. Lewis who were religious, and secular scientists like Einstein and Carl Sagan who believed in a spiritual aspect to the experience of being human (Breitbart, 2007).

Spirituality within health research has been disparaged due to its overlap with existential concerns, definitional vagueness and its claim to widespread efficacy (Cobb, Dowrick, et al., 2012), but Breitbart (2007) does believe spirituality may be perceived as a universal notion that is separate from both atheistic existentialism and traditional religious thought. Brennan (2006), however, surmises that spirituality seems to be but one component and understanding of the broader construct of existential beliefs, arguing for the importance of the inclusion of both spirituality and religion due to the fact that they shape core assumptions regarding meaning and purpose for much of humanity.

The intangibility of definition continues with the frequent description of spirituality as what it *does*, rather than what it *is* (Swinton & Pattison, 2010). Portraying a series of human quests, spirituality embraces purpose, love, meaning, hope, and connectedness (Swinton & Pattison, 2010), particularly around matters of life, illness, suffering, and death, where spirituality is associated with a search for meaning and purpose (Aghadiuno, 2010; M. Holloway et al., 2011; Swinton et al., 2011; Swinton & Pattison, 2010), asking ultimate questions (Puchalski, 2002), and searching for answers (Burke & Neimeyer, 2012; M. Holloway et al., 2011). Spirituality can be at once an individual response and a corporate one,

seeking to deepen connections that increase our wellbeing in good times and to re/discover coping resources in challenging times (E. Kelly, 2012a). Aghadiuno (2010, p. 37), makes the point:

> If spirituality is authentic, it surely must be more than just a manufactured, consumable commodity. It must be something that helps us live the experience of life, death and suffering: something that truly gives meaning.

Spirituality can be a nebulous concept (Fisher, 2011), and appears to be subjectively defined in unique ways by each individual; but whether religious or not, each human being is naturally, intrinsically spiritually oriented (Bellous & Csinos, 2009; de Souza, 2009b; Ranson, 2002; Sulmasy, 2002; Tacey, 2010). The gifted biologist, Alister Hardy, in the 1966 Gifford Lecture at Aberdeen University, proposed the thesis that spiritual awareness in the human species has evolved due to its necessity for survival (Hay & Nye, 2006; McQuillan, 2006; Swinton, 2005). This biological *hard-wiring* into the human organism indicates that whether conscious or pre-conscious, each individual has the potential for spiritual awareness (McEntee, Dy-Liacco, & Haskins, 2013). Hay (2001), contends that this strongly supports the existence of secular spirituality. Certainly, contemporary brain science seems to be confirming Hardy's hypothesis. For instance, connectedness and interconnected realities, a philosophy that supports an intrinsic connectedness between humans (Laszlo, 2008), is currently moving the natural science community from the long held scientific understanding of reality and individualism towards this contemporary view from quantum physics. Within the field of neuroscience recent research into mirror neurons indicates that humans have an ability to fully empathise with Other[4]; a mirroring of their feelings (Rizzolatti & Fabbri-Destro, 2012). Study on the mirror mechanism within the brain has shown that a real sensation of the experience of Other is experienced by the observer (Rizzolatti & Fabbri-

[4] *Other*: see footnote 3, pp.8.

Destro, 2012): empathy neurons light up mirroring the experience of Other, causing the observer to feel empathy. However Dossey (2010), calls for caution regarding this hypothesis warning that it is possible the neuroscientists have it backwards, that empathy is first experienced and then lights up empathetic neurons. While interconnected realities are a correlate of consciousness, and not yet known to be a cause, the discovery of mirror neurons does suggest however that rather than being motivated by the selfish focus of survival of the fittest, humans are actually constructed to be a caring species endowed with compassion, empathy, and connectedness (Dossey, 2010). This echoes the relational philosophical thought of Durkheim (see page 22 of this thesis).

Within definitions of spirituality there is also an unstated assumption that spirituality is a constant rather than a dynamic, living concept (McSherry & Jamieson, 2011). Natural, intrinsic spirituality however is not static, but is rather an evolving dimension (Fisher, 2011), in movement towards ultimate unity (de Souza, 2009), with the capacity to be actualized, stimulated, and taught in the endeavour of unlocking inherent growth and spiritual potential (U. King, 2008). As life is not static, but is constantly presenting new challenges, so too our spirituality, as it seeks to make meaning, is constantly changing, evolving, and growing. The spirituality of each person, then, is both distinctive and dynamic (Rolheiser, 1998; Speck, 2005). This potential for evolving spiritual awareness bestows dignity for each individual, embracing the physical, psychological, social, and spiritual domains (Chochinov, 2007; Sinclair & Chochinov, 2012). Dignity is an aspect of spirituality with origins in antiquity through Christian, Jewish and stoic literature with the notion of humanity being made in the *imago Dei* or image of God (Sinclair & Chochinov, 2012), adding depth to the intrinsic nature of personal spirituality. Within palliative care, holistic care is underlined by a notion of care which favours the innate dignity and significance of each human being (M. Holloway et al., 2011; Sinclair & Chochinov, 2012). Within spiritual support, spirituality as an intrinsic

human condition necessitates an inclusive definition that can effectively provide support for each individual person, and for humanity as a whole. As a dynamic concept moving along a sacred/secular continuum, spirituality assists with making sense of life, inner meaning, and addressing ultimate questions. A common understanding is needed for articulation of shared concepts and meaning. While spiritual concepts can overlap with existential and psychosocial notions, spirituality does not equal a religious worldview, just as existential does not necessarily equate to a secular worldview (Breitbart, 2007). While researchers debate the intricacies of spirituality and attempt to define it, public discussion is rich and creative.

Public Discussion of Spirituality

In Australia, spirituality has rarely been discussed in the public domain (Ranson, 2002). Culturally, the stereotypical Aussie is strong, resilient, taciturn, and often silent when spirituality is mentioned; and while this characterization still strongly influences the social and political establishment, there is something new emerging from the bounds of history and culture that embraces broader definitions of spirituality (T. Kelly, 1990; Tacey, 1995). Ranson (2002), finds Australians to be profoundly spiritual people, however he does concede that this aspect of life is rarely the topic of conversation or demonstrated in life. Tacey (2000, p. 240), agrees with this lack of spiritual and religious dialogue, “When we Australians relax and are allowed to feel, our feelings are often religious, but our pronouncements are mostly secular...you can have as many religious feelings as you like as long as you do not talk about them in religious terms or name them “religious”.”

Alongside this lack of dialogue, however, there is a genuine yearning in the Australian psyche for inner knowing and relationship (Tacey, 2000). Australian spirituality affects authentic subjective human relationship with Other, connecting the citizenry in reciprocal responsibility (T. Kelly, 1990). The Prime Minister’s draft (23 March, 1999), of the Howard-Murray preamble for the Australian constitution included the line, “We value...

independence as dearly as mateship" (McKenna, 2000). Culturally, connection and affiliation as a foundation for spirituality sit well with the Australian psyche. A burgeoning spirituality with an Australian flavour that is culturally sensitive could sit more comfortably than any overseas import of doctrine and practice (Tacey, 1995). As spiritual opinions become more individualised and individuals move away from formal religious doctrine, it is discussion and debate that will be needed to shape new ways of making meaning and identifying the spiritual (Grant et al., 2004), and this is where this research study is positioned.

Anthropology, environmental concerns, a quest for transcendence which echoes historical religious thought, and ultimate questions are philosophies that have attracted a spiritual viewpoint and entered the public debate. Anthropology sees the human person as central (U. King, 2008), eco-spirituality places our earth as central (Berry, 2009), the unique personal spiritual quest for transcendence places the journey as central (Sulmasy, 2006), and ultimate questions address the personal aspects of meaning (Aghadiuno, 2010; Puchalski & O'Donnell, 2005).

Anthropological spirituality. An anthropological approach to spirituality believes the "crucible of life gives birth to spirituality so that human life, and life on Earth, can fully blossom and flourish" (U. King, 2008, p. 195). This focus on the flourishing of the human spiritual dimension is believed to be related to the move away from devotion of the Divine (2008), denoted by Tacey's (2004) spiritual revolution. Within our modern world the anthropological discourse, alluded to by Ursula King (2008), characterizes spirituality as an animating force that conveys capacity for personal growth, potential and transformation, meaning-making, and flourishing (Grant et al., 2004; U. King, 2008; Lysne & Wachholtz, 2011; Miller, 1999).

Contemporary secular anthropological spiritualities can be found within emerging thought in sociology, psychology, physics, biology, education, health, and business

management (U. King, 2008; Liu & Robertson, 2011; Tacey, 2004). Spirituality is seen as fluid, flexible, and singular; an intricate entwining within human psychological development (U. King, 2008; Liu & Robertson, 2011). Where unique, personal, individual transformation and flourishing is the focus (Hemsley, 2003), the spiritual life is seen as a personal and particular journey, an authentic endeavour to explore meaning and purpose in life (Hyde, 2008b; Swinton & Pattison, 2010).

Psychology points to three components that represent human flourishing: the positive personal Self[5], the positive social Self, and the spiritual Self (McEntee et al., 2013). This spiritual self symbolizes inner strength through prayer/meditation, belief in transcendence, and holding the principle of all life as interconnected. The spiritual journey with an anthropological focus demonstrates that human flourishing is supported by positive relations with others, social contribution, and social connectedness (McEntee et al., 2013).

Eco-spirituality. Eco-spirituality is the direct consciousness and experience of the sacred in the world, signifying a "synergy between science and spirituality, intellect and intuition, objectivity and subjectivity, and human and planet." (Lincoln, 2000, p. 230). Holding the earth and nature with a sacred, reverent awe is the foundation of ecological or creation spirituality (U. King, 2008; Tacey, 2004). It calls for a move towards values and principles that engender protection and healing of the planet, while also allowing space for drawing a sense of self, purpose and meaning from the tranquillity of nature (U. King, 2008; Tacey, 2004).

The motivation for eco-spirituality is the wellbeing of the planet and its resources, alongside an interconnectedness of individual and community with place (M. Holloway & Moss, 2010), where "the environment has a value, significance, meaning and context of its own" (M. Holloway & Moss, 2010, p. 157). The Deep Ecology movement, a stream within

[5] *Self* see footnote 3, pp.8.

the wider ecological movement, understands the human spirit to be the mode of consciousness in which the individual feels a deep sense of belonging, of connectedness, to the earth and the cosmos as a whole (van Schalkwyk, 2011). This ecological awareness is spiritual in its deepest essence, providing a give-and-take connectedness between the health of the environment and the health of humanity (Lincoln, 2000; van Schalkwyk, 2011), embedding a new experience of spirituality in the marvel of nature and the mystery of the natural world (Tacey, 2001). “Eco-spirituality engages a relational view of person to planet, soul to soil, and inner to outer landscape” (Lincoln, 2000, p. 228).

With a similar focus of awe towards the created world, Fox’s dialectical creation spirituality moves from the theological idea of *original sin*, to the concept of *original blessing*, a rejoicing in all of creation (Fox, 1983; U. King, 2008). Tacey (2001), too, seeks a move from a strongly prescribed focus on the *fallenness* of the world towards a celebration of the physical world, the physical body and our physical life, without the loss of a consciousness of sin and evil. O’Murchu (2002), affirms this move towards embrace and connection with the whole earth and away from spiritual alienation where the desire to save one’s self is enacted by avoiding engagement with the world, or worse, thoughtless domination. This shift towards a creation spirituality was presaged by Teilhard de Chardin, Thomas Berry, and Bede Griffiths, all contemporary theologians in the Catholic Church (Tacey, 2001). Thomas Berry, who influenced Merton and O’Murchu, declared our vocation to be the discovery of community within creation (Weis, 2003), since definitive community is the human, the earth and the universe (Berry, 2009). O’Murchu (2002), asserts that God working through creation predates any religious doctrine, and therefore creation is the foundational indicator of divine interaction with the world. It is God’s animation, sustenance and empowering of the world that eco-spirituality endeavours to honour and find connection with for personal flourishing (O'Murchu, 2008). Merton also made a shift towards eco-

spirituality with an emerging awareness of nature as sacrament, specifying God as Creative Spark; rather than being different, nature had become an aspect of creation, just as humanity was (Weis, 2003). Merton was also influenced by Meister Eckhart who illustrated creation as a performance of God's passion and ardour (Weis, 2003). Some of those elements that have been discussed in this review of the literature on eco-spirituality were, in fact, identified in research data collected from nurse participants (Lincoln, 2000). Their responses showed an awareness of five elements of eco-spirituality:

- tending: living an examined life, bringing meaning and purpose to life by engaging with the world;
- dwelling: the balance of one's inner and outer experience of the world gained through being with the seen and the unseen;
- reverence: awareness that humanity is of the earth;
- connectedness: the energy that connects nature, the environment, and the cosmos; and
- sentience: a sense of knowing and wonder (Lincoln, 2000, p. 235).

While creation spirituality conceives the presence of God to grace the world, it is within the profundity of the self this transcendence is experienced (Tacey, 2001).

Spirituality as transcendence. Spirituality is understood by Gross (2009, p. 563), as an "expression of human longing to approach a supreme entity or power situated beyond human control and grasp;" formally through *being* and structurally through religiosity or secularism. In a psychological sense, transcendence can be interpreted through a wider humanist link with the human condition, where it is the basis for human flourishing as well as the pursuit of meaning and purpose in an attempt to transcend suffering (Block, 2001; Kellehear, 2000; S. Nolan et al., 2011). From a spiritual or religious perspective transcendence for the individual is a move toward mystery, the Transcendent, the Divine, or God (Sheldrake, 2007; Sulmasy, 2006). This sacred/secular spiritual continuum provides

great scope for individual notions of transcendence (S. A. Murray et al., 2004). In order to explore these ideas of transcendence we can begin with a humanist, secular understanding.

Spirituality is a vital aspect in transcending, or going beyond oneself (Lundman et al., 2010). Transcendence expresses the idea that human beings can encounter themselves as more than just physical beings (S. Nolan et al., 2011). Humanist transcendence moves creatively through expanding self-knowledge into futuristic imagination in an experience of connectedness with mystery. As we transcend ourselves, our fallibility and our imperfection, this allows our view to be widened (E. Kelly, 2012c). Transcending the Self, a powerful coping mechanism, is an active method containing adjustment to former and current physical, emotional, and spiritual distress (Haugan, Rannestad, Garåsen, Hammervold, & Arild Espnes, 2012). Self-transcendence extends the boundaries of Self, both inwardly with greater appreciation of personal beliefs and values, and outwardly with Other, assimilating the past and the future into an enhancement of the here and now (Haugan et al., 2012; Lundman et al., 2010; Nygren et al., 2005). Manifestations of a high degree of Self transcendence include a sense of well-being, compassion, wisdom, receptivity, creativity, openness to life, self-worth, and respect for intuition (Haugan et al., 2012; Lundman et al., 2010; Nygren et al., 2005). Transcendence of the Self increases feelings of spiritual connectedness and feelings of self worth (Nygren et al., 2005). Not necessarily mystical in nature, transcendence can simply be living life more intensely and intentionally (M. King & Leavey, 2010).

Humanist transcendence is often depicted as a quest (Aghadiuno, 2010), the desire for something beyond self fulfilment (M. King & Leavey, 2010), and its acceptance within contemporary Australian society is highlighted by the adaptation of many baby-boomers moving away from organised religion towards a personal spiritual quest (Peterman et al., 2002). This quest for relationship with transcendence is unique, each person and their move towards transcendence, is exceptional, effectively making spirituality totally personal

(Sulmasy, 2006). Within education, Hyde's research (2008b), into spiritual questing and religious education found that children set out on an authentic endeavour to explore meaning and purpose in life. Three of the eight recommendations highlighted to nourish spiritual questing are particularly pertinent to the foundational thinking around this research. Investigating spiritual questing requires:

- dialogue and engagement begins where the students are within their spiritual quest;
- engagement with the shared story of the individual, encouraging contribution to the community's story;
- entwining spiritual story and language to bring potential options for genuine ways of relating and being in life (Hyde, 2008b).

These suggestions are particularly pertinent to this research study where encouraging dialogue from the coalface is a priority, and the goal is to engage and entwine the communal spiritual story, bringing common language and shared meaning.

Moving to religious transcendence, we discover that most religions endorse a transcendent reality that has the ability to deliver salvation (Hick, 2004; Sheldrake, 2007; Sulmasy, 2006). This generally immanent presence within the world and within humans can be expressed in different ways, anywhere from the non-personal Absolute, a cosmic structure or process or ground of the universe, Nirvana, Brahman, Dao, to a personal God (Armstrong, 2011; de Souza, 2012; Hick, 2004). Although doctrine of the Transcendent or Divine is not the centre of religion (Hick, 2004; Sheldrake, 2007; Sulmasy, 2006), for the religious person, understanding of life and worldview flows from their response to the Transcendent or transcendence (Hick, 2004). Further the existence of the Transcendent at the core frees the Self from the onus of creating its own significance and meaning (Lundman et al., 2010; Rohr & Feister, 2001). Even as a part of formalised religion, the Transcendent persists as an enigmatic reality, and human beings communally create religious beliefs, theories, and habits

necessary to encounter this mystery (Hick, 2004). However, whatever these traditions involve, transcendence remains outside of our human senses and understanding because it is literally transcendent (Armstrong, 2011; Hick, 2004).

Ultimate questions. Another aspect of spirituality within the public discussion is the search for answers to ultimate questions (Burke & Neimeyer, 2012; Goldburg, Blundell, & Jordan, 2009; M. Holloway et al., 2011; Puchalski, 2002). Close to the heart of what it means to be human lies this dynamic process of finding and making meaning in our lives (Blundell, 2009; Fowler, 1991). As spirituality has moved away from prescribed religion and its dogma, questions such as Where have we come from? Or Who am I? and What happens when we die? have to be engaged with by the individual (Walter, 2002). Fowler (1991, p. 32), explains the basis for meaning-making:

> Whether or not we are explicitly nurtured in faith within the traditions of a particular religion, we are engaged in forming relations of trust and loyalty to others. We shape commitments to causes and centers of value. We form allegiances and alliances with images and realities of power. And we form and shape our lives in relation to master stories. In these ways we join with others in the finding and making of meaning.

These recurrent questions of meaning and purpose intensify through existential crisis and trauma (Burke & Neimeyer, 2012; Puchalski, 2002; Swinton et al., 2011). They are extremely poignant within suffering, death and palliative care (Blundell, 2009).

To sum up, in the public discussion of spirituality four main topics present themselves:

- anthropological spirituality focuses on human flourishing;
- eco-spirituality develops a consciousness of the sacred in the world;
- psychological and religious transcendence enter the discussion with psychology focusing on the human condition pursuing flourishing, meaning, purpose and

transcending suffering in the quest to go beyond oneself, while religious transcendence seeks a transcendental reality able to deliver salvation;

- the raising of ultimate questions.

This dialogue does indicate an authentic spiritual longing in humanity to make meaning, for inner knowing, and for relationship.

So far we can see there is much ambiguity around terminology and definition of spirituality and religion (M. Holloway et al., 2011); confusion even appears amongst specialists in the field (Hay & Nye, 2006). However Watson (2009b) argues that spiritual truths are not held lightly because of spiritual diversity. Similarly, Swinton and Pattison (2010, p. 231) make the point: "There is no inherent reason why a lack of clarity should necessarily denote a lack of significance." Berryman (2001), wonders if the struggle for a definition for spirituality is due to human spiritual aspects being components of our communication system that are non-verbal. This would lead to the use of implied, nuanced connotations and subtext to indicate the non-verbal essence of spirituality, rather than the search for specific applied language (Berryman, 2001). Swinton and Pattison (2010, p. 231) concur, adding that for spirituality, "Multiple definitions may be indicative of the necessity and the flexibility of the term to meet particular needs that would otherwise go unmet."

In an attempt to define humanistic spirituality, Nolan and Holloway (2013) state: "An evolving, umbrella term, humanistic spirituality is not atheistic nor anti-God in nature, but rather presents an option to prevailing secularist and materialistic thought, allowing both secular and religious orientations to find mutual ground. However, declared humanistic writers such as Watson (2008, 2009b, 2013b) and Priestly (2000) reject this view, describing the humanistic approach to spirituality as based on a firm belief in the non-existence of God; the atheistic view. In a comparison of theism and atheism, Watson (2008) asserts,

"each term merely affirms or denies God." The foundational starting points for spirituality, theism and atheism, both include: "different beliefs, belief systems, world views, philosophies and personal beliefs" (Watson, 2008). Spirituality involves "beliefs and values which address our struggle to make meaning out of human experience...(creating meaning) through dialogical relationship with the other" (Watson, 2009a, p. 828). This is where the spiritual framework of connectedness becomes very useful.

Spirituality as Connectedness

Relationality and connection are at once intrinsic to the human person and to the exploration of personal spirituality (Champagne, 2008; de Souza, 2009a; Fisher, 2011; Sulmasy, 2002). Ranson (2002, p. 17) talks of the spiritual as holding facets of life which bring "greater depth, connection, centredness and wholeness." Tacey (2004), too, sees the spirit yearning for connection, community, and fellowship. Established in the everyday of life, spirituality as a connectedness of all things can no longer be seen purely as an internal, secluded personal characteristic; it is shown to flourish within affiliation (Bennet & Bennet, 2007; de Souza, 2009b).

The association of spirituality with connectedness or relatedness also sits well within the outcome of the USA Consensus Conference of 2009, whose goal it was to improve the quality of spiritual praxis in terminal illness (Puchalski et al., 2009). Together the conference participants, made up of medical staff, psychologists, chaplains and pastors, ethicists, and academics shaped the following definition:

> Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred (Puchalski et al., 2009, p. 887).

Similarly the European Association of Palliative Care (EAPC) reworked the above in an attempt to formulate a definition more specifically tailored for Europe:

> Spirituality is the dynamic dimension of human life that relates to the way persons (individual and community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred (S. Nolan et al., 2011, p. 88).

The EAPC stressed that difficulty in defining spirituality was due to its multidimensional nature encompassing existential questions, values, and religious factors (S. Nolan et al., 2011).

After a disciplined and prolonged immersion into children's conversation about spirituality, Hay and Nye (2006), proposed the notion of *relational consciousness* as the most fundamental human feature; the realisation that the Self is interconnected with others and the world, and for some, with God. Using this work, together with Frankl's (1992) concept of meaning and research, Swinton, Bain, Ingram, and Heys (2011, p. 644), in their study on spirituality and breast cancer, created what they describe as an "empirically oriented perspective on spirituality (as opposed to a definition)... that is clear and practical." Their description of spirituality reads:

> Spirituality is the quest for meaning, value and relationship with Self, others, and, for some, with God. This quest provides an underlying dynamic for all human experience, but comes to the forefront in focused ways under particular circumstances. This quest for meaning, value and relationship may be located in God or religion, but in a secularised context such as the United Kingdom it may reveal itself in varied forms (Swinton et al., 2011, p. 644).

For the women in Swinton's study above, the potential for a sense of healing came from the concept of a web of significant relationships, and embeddedness within its intricate nature:

"Religion was not necessary; but spirituality was central to their experiences" (Swinton et al., 2011, p. 647). In a similar vein, further studies of spirituality and cancer have identified three major themes around spirituality: relationship with Transcendence or meaning making, emotional support that affirms life and growth, and social support (Feher & Maly, 1999; Stefanek et al., 2005).

Research into spirituality questionnaires used within health research proposed the need for "...a comprehensive definition that covers several dimensions...a broad definition... of spirituality that reflects the experiences of people from different religious or secular backgrounds..." (de Jager Meezenbroek et al., 2010). In shaping a definition, connectedness was found to be an essential element of spirituality, and in particular connectedness with Self, Other, the world, and with mystery/transcendence (de Jager Meezenbroek et al., 2010). With similarity to the definitions espoused by the Consensus Conference and the EAPC above, these four elements of connectedness are well supported throughout the literature (de Souza, 2006, 2012; Ellis & Lloyd-Williams, 2012; Fisher, 2011; E. Kelly, 2012b; Liu & Robertson, 2011; Sheldrake, 2007). Suggestive of Descartes' "I think, therefore I am," Harvey (2012, p. 50) further sums up the connectedness of indigenous spirituality in the phrase "we relate, therefore we are."

The perspective of spirituality as connectedness brings an awareness of oneself as a relational being with the Self, with Other, with the world, and with mystery/transcendence (de Souza, 2006, 2011, 2012; Ellis & Lloyd-Williams, 2012; Fisher, 2011). Similarly, White (2006) highlights spirituality as including the human spirit in connection and relationship with personal exploration, with other people, the world around us, reaching out for the transcendent, and moving towards integration. Rather than being static, these domains of connectedness are an evolving cycle moving through a blurring of boundaries towards ultimate unity (de Souza, 2009b, 2011), building on and building up each connection as

progressive synergism (Fisher, 2011), or concentrated unity (Buber, 1957). The term ultimate unity was used throughout this research study.

The concept of connectedness moving towards ultimate unity (de Souza, 2009b) provides an inclusive framework for a perspective of spirituality. In a Taiwanese study with the terminally ill, researchers found four broad categories made up of ten attributes that display the essence of spirituality: communion with self (self-identity, wholeness, inner peace), communion with others (love, reconciliation), communion with nature (inspiration, creativity), communion with mystery/transcendence (faithfulness, hope, gratitude) (Chao, Chen, & Yen, 2002). These four categories of connectedness also provide a structure for the descriptive attributes of spirituality from an analysis of measures in health-related literature that assess patient spirituality as more than religion (Chao et al., 2002; de Jager Meezenbroek et al., 2010; Sessanna, 2011). Putting the two aspects together in a simple table we find expanded language for spirituality. Table 2 shows how the attributes of spirituality are associated with connectedness in the literature.

Table 2

Attributes of Spirituality as Connectedness

Connectedness with Self
acceptance, authenticity, care, comfort, consciousness, contentment, forgiveness of self, inner harmony, inner peace, peacefulness, serenity, inner strength, thankfulness, valuing, wellbeing, self-identity, self-knowledge, wholeness.
Connectedness with Other
accepting differences, caring, compassion, feeling supported, forgiveness of others, giving, gratitude, giving/receiving love, harmony, helping, interconnectedness, peace, respecting others, sense of belonging, being valued, volunteering, reconciliation.
Connectedness with the World
appreciating art/beauty/the natural environment, creativity, gratitude, inspiration, interconnectedness, peace, respecting sense of belonging, wonder.
Connectedness with Something Bigger

awe, belonging, celebrating life, faithfulness, fulfilment, gratitude, hope, interconnectedness, life meaning, purpose, mystery, meditation, peace, reason to exist and live, sacredness, secular, transcendence.

Note. Attributes of spirituality within a connectedness framework are based on the work of Sessanna (2011), de Jager Meezenbroek, et.al. (2010), and Chao, et al. (2002).

These descriptive attributes provide layers of meaning to the connectedness framework and provide nuanced understanding. They enable a blurring of the boundaries between Self and Other along the relational continuum where self is becoming one with Other, and towards the realm of ultimate unity (de Souza, 2009b, 2011).

Connectedness as employed in the literature above is not seeking to investigate the formation of the private self into the public self as elaborated by research into the inner and outer worlds within constructivist psychology (Neimeyer, 2004). However, Neimeyer's in-depth look at psychological structure within personality goes beyond the understanding of spirituality as connectedness between the self and other as presented in this research. Attributes of the connectedness framework listed above are supported by a relational continuum.

Using a relational characterization of spirituality within holistic praxis at BHCI would highlight the intrinsic dignity of each person and the inclusive nature of affiliation. The lifeworld of the terminally ill patient often shrinks as disease compromises life (van Manen, 1997). Physical decline can lead to a decrease in social engagement, in the social circle, and even the most mundane of social events (Sand & Strang, 2006; Seale, 1995). Spirituality as connectedness could be a useful framework in caring for the spiritual needs of vulnerable people within palliative care. A focus on connectedness with Self and with Other (carer/service providers/family), is a poignant place to begin in a dwindling context where one needs to look for fulfilment in less, and asks the question, What is beyond? (Kearney & Weininger, 2012). Discovering strengths and weaknesses of connectedness in the life of a

patient highlights places where specialized spiritual support could be useful and effective in this upheaval of great change (Seale, 1995). The concept of relational spirituality is culturally appropriate to diverse worldviews and constructive in the area of community-based palliative care.

Rather than pre-empt the research findings with a structured definition of spirituality, this research study employed the empirically oriented perspective of spirituality as a connectedness framework that comes out of the work of de Souza (2009b, 2011), Fisher (2011), and White (2006). Understanding spirituality through the structure of connectedness with Self, Other, the world, and mystery/transcendence moving to ultimate unity, further enriched by the above spiritual attributes, has allowed the coal-face voice to speak in dialogue with existing theory to create an empirically oriented perspective on spirituality within this unique community-based palliative care context (Cobb, Dowrick, et al., 2012).

Having looked at what the literature has to say about spirituality, the literature of the research conversation into spirituality continues with a nuanced approach towards spiritual need and distress. This is the *dark side* of spirituality and it needs to be highlighted in any discussion about spirituality if a whole picture is to be presented (de Souza, 2012).

Spiritual need. Spiritual needs are experienced by everyone, and include:

- uniqueness: the need to feel special and distinct;
- union: the sense of being united to something greater than the self such as the family, community, the world, humankind, God;
- usefulness: the need for creativity, the sense that we are on this earth for a purpose;
- understanding: the necessity to feel a deep emotional understanding of our place in the world (Aghadiuno, 2010, p. 44).

These spiritual needs are commensurate with our understanding of spirituality, as connectedness with Self is about uniqueness, connectedness with Other involves union,

connectedness with the world incorporates union/usefulness/understanding, and mystery/transcendence highlights uniqueness/usefulness/union (de Souza, 2012; Ellis & Lloyd-Williams, 2012; Fisher, 2011; E. Kelly, 2012b; Liu & Robertson, 2011; Sheldrake, 2007). When these aspects of spiritual connectedness or need are not met then personal spiritual needs become spiritual pain or spiritual distress, and there begins a personal wrestling to find meaning and purpose in whatever the current situation is that the individual is facing (E. Kelly, 2012b).

Founded on the belief that the experience of life will meet needs of meaning and purpose, spiritual pain occurs as meaninglessness when the anticipation of having needs met is faced with disappointment and existential pain (P. McGrath, 2002). Spiritual pain can lead to anxiety and depression when meaning cannot be found and life tumbles into an existential vacuum (Fillion, Dupuis, Tremblay, de Grace, & Breitbart, 2006). Conflict between what an individual believes, and their *here and now* reality, brings dissonance between hopes, values, and beliefs over and against reality – the existential experience of life (Kearsley, 2003). Within palliative care spiritual pain is a significant, complex, and personal issue (Kearsley, 2003; Kellehear, 2000).

While literature from the USA is more likely to define spiritual distress in expressions that are religious, spiritual need is described with more of a common humanity/existential approach in UK studies (Ellis & Lloyd-Williams, 2012; M. Holloway et al., 2011; Paley, 2007). We have seen in the literature that in Australia, as elsewhere, spirituality is portrayed separately from religion and is uniquely defined as connectedness with Self, Other, the world, and mystery/ transcendence (de Souza, 2009; Fisher, 2011). It is here that spiritual pain can then be easily understood and discerned as disconnectedness, the dark side of spirituality (de Souza, 2012; P. McGrath, 2002; Mehta & Chan, 2008). Disconnectedness can occur between

the Self and self, and from Other, from the world, and from mystery/transcendence (de Souza, 2012).

Spiritual Despair as Disconnectedness

Without connectedness, meaning, and acceptance, suffering induces disconnectedness, often leading to desolation and alienation (de Souza, 2012; Emblen & Pesut, 2001; Fillion et al., 2006). Spiritual pain rises when a person experiences themselves as disconnected from their inner selves and from others, or when there are alterations in significant relationships (M. Holloway et al., 2011). Rising out of neediness within the human spirit (P. McGrath, 2002; Mehta & Chan, 2008), spiritual disconnectedness is a highly personal and subjective matter that only the individual can describe and assess completely (P. McGrath, 2002). Disconnectedness can occur with the Self, with Other, with the world, and with mystery and transcendence, both psychological and religious. Disconnectedness with Self can occur when intrapersonal expectations and ideals are not attained, when self lets down the Self (P. McGrath, 2002). This can lead to rejection of the Self and can be observed in self-depreciation, fault-finding, and a focus on weaknesses and mistakes (Fillion et al., 2006). For the sick the disruption of ordinary happenings in their season of life can be experienced as spiritual disconnectedness (P. McGrath, 2002; Mehta & Chan, 2008).

Another form of disconnectedness with Self happens when an individual connects to something that is not beneficial to their wellbeing (de Souza, 2012). An example of this disconnectedness with the Self is the patient being unable or unwilling to accept a terminal illness, entering a fight to beat the disease and holding out for the notion of a cure (Wadford, 1994). The distorting of reality, that fighting spirit which society so admires, leads to disconnectedness with the Self.

When disconnectedness with Other occurs the individual experiences a paucity of protection against loneliness and alienation that connectedness with Other usually offers

(Sand & Strang, 2006). Consequences of disconnectedness with Other, from both an individual and from society, can involve conflict, fault-finding, and isolating behaviours (P. McGrath, 2002). Connectedness with the world includes an aesthetic sensitivity to the beauty around us in art and nature (Galek, Flannelly, Vane, & Galek, 2005; M. Holloway et al., 2011; Sessanna, 2011), with a sense of belonging, or having a place in the world in the here-and-now (Sachs, 1991). Disconnectedness to beauty, creation, and one's place in the world can bring about a sense of global loneliness (P. McGrath, 2002), and a depletion of meaning and purpose (Frankl, 1992).

Disconnectedness with mystery/transcendence limits the psychological ability to accept and transcend the present, or achieve an awareness of hope (Kellehear, 2000), inner strength, or flourishing (McEntee et al., 2013). Disconnectedness that occurs between the self and mystery/transcendence leads to a rationalist world where causes lead to foreseeable effects, and a hope that "given enough time, we'll arrive at explanations for everything" (Bell, 2013, p. 72). This reductionist thought holds that we have the capacity for all answers, and life, like the universe, will ultimately be just the sum of its parts (Bell, 2013). However spirituality is holistic, with the whole being more than the sum of its parts (Healey, 2009). Spirituality is an evolving process being fashioned by context, need, and individuals (Swinton & Pattison, 2010), and the hope of something bigger and beyond the individual (Lundman et al., 2010).

Where spirituality is identified as connectedness with religion and transcendence, spiritual distress as disconnectedness with religion can occur through alienation from, or negative emotional responses to, God or separation from the Church and her rituals (Burke, Neimeyer, McDevitt-Murphy, Ippolito, & Roberts, 2011; Gillies & Neimeyer, 2006). Disconnectedness with religious transcendence can happen when there is a dissonance between the desire to adhere to the dogma of objective religiosity and a differing experience

in an individual's subjective religiosity. Within this religious based approach spiritual despair is sometimes described as "the darkness," a "loss of faith," or "the dark night of the soul" (M. Holloway & Moss, 2010, p. 50). This spiritual disconnectedness is limited to religion and belief in a supreme being, defining a particular religious anguish rather than generalised spiritual despair, which is the focus of disconnectedness in this thesis.

Earlier two streams were identified in the literature, that of spirituality and spiritual care, and the literature pertaining to the research context. To summarise the review so far, the literature from spirituality has identified that spirituality sits on a sacred/secular continuum, where spirituality does not equal a religious worldview and existentialism does not equal a secular worldview. Intrinsic, dynamic spirituality addresses the making sense of life, inner meaning, and ultimate questions. While there is a lack of clarity around definition and understanding, this does not indicate a lack of significance. A common understanding is required for the articulation of shared concepts and meaning. The empirically oriented perspective of spirituality as connectedness with Self, Other, the world, and mystery/transcendence brings a framework to support this research study and the understandings and perceptions of spirituality held by the multidisciplinary team.

Chapter Three: Literature Review Two: Community-Based Palliative Care

This chapter explores the literature pertaining to the context of palliative care delivered within the community through holistic care. It explores the multidisciplinary provision of basic spiritual care, along with connected skills, and education requirements.

Historically care for the dying and the terminally ill has moved from being performed in the home to palliative care that is often provided in both inpatient and community based contexts (Puchalski, 2002; Rumbold, 2003). Within Australia, the principal treatment focus of palliative care is enhancing the quality of life for people diagnosed with a terminal illness, who have little or no likelihood of cure (Palliative Care Australia, 2005). With the aspiration of relieving symptom distress, not disease, treatment and services offered are multi-professional, with provision for physical, emotional, social, and spiritual care as required across the duration of the illness (Kellehear, 1999).

Spirituality in Health and Palliative Care

As we have noted earlier, spirituality is an important component within the holistic nature of palliative care: it offers meaning, hope, and healing, where cure is unavailable (Kellehear, 1999; Koenig, 2002; Puchalski, 2002), Further, *learning to die* itself can be experienced as a spiritual endeavour (Koenig, 2002; J. White, 2004). Spirituality, defined as *life* and *breath* ("Spirit", 2014; Jenkins et al., 2009), brings value to *life while dying*, within palliative care, indicating that a more nuanced understanding of spirituality is required to address the spiritual needs of dying patients (Pesut, 2008).

In health education research, the concept of health comprises five entwined facets: physical fitness (the absence of disease), intellectual, emotional, social, and spiritual (Hawks, 2004; Kiefer, 2008; Visser et al., 2010). This indicates the importance of spirituality as a component of health and health care. However, within the health sciences, rather than talk about what spirituality *is*, research into spirituality has taken on a principally functionalist

approach (Cobb, Dowrick, et al., 2012), examining what spirituality *does*, such as how spirituality enhances individual coping in health matters (Egbert et al., 2004), or the influence of religious affiliation (Kilpatrick et al., 2005). McClain, Rosenfeld and Breitbart (2003) looked at the effects of spiritual well-being on terminal despair, while similarly McCoubrie and Davies (2006) studied depression and anxiety, to see if spirituality had an impact. A large amount of the empirical research into spirituality and health focuses on the influence of religion on health and well-being, and has come out of the USA (Ellis & Lloyd-Williams, 2012; M. Holloway et al., 2011). Research into religious coping defines religion as a process where self-value and self-worth intersect with the sacred (Pargament, 1997). Research has been conducted into church attendance or denominational affiliation and health impact (Hill & Pargament, 2003; Koenig et al., 2001), prayer and cancer outcomes (L. E. Ross, Hall, Fairley, Taylor, & Howard, 2008), and even spiritual practice as a coping mechanism for workers in palliative care (Dane & Moore, 2006). These are the functions of spirituality and a spiritual life. The relevance of this research is that it presents spirituality as an external aspect that could play a part in positive health outcomes, or bring personal benefit, by producing cause and effect (Cobb, Dowrick, et al., 2012). This functional focus of research, similar to that of a medication (i.e. take one prayer/meditation and tell me if it affects your sleep), does establish some empirical associations of spirituality with health-related outcomes and increases objective knowledge. Nevertheless, this research does not ask the question whether function gives an adequate explanation of the influence of spirituality within healthcare? Or does the description require richer content from theology, philosophy, and cultural contexts? (Cobb, Dowrick, et al., 2012).

Further, Sloan (2006) believes it is an injustice to reduce spirituality and religion to indices that purport to measure them and their function. A function of spirituality or religion does not wholly encapsulate the encounter with transcendence or devotion (Wood, 2010),

neither does it take into account the heterogeneous forms of faith and belief apparent in healthcare: “conventional religious forms, secular spirituality and therapeutic forms of spirituality” (Cobb, Puchalski, et al., 2012, p. viii). Broader than the functionalist approach, holistic care carries a wider view of the world. Rohr and Feister (2001, p. 67) contend, “The attitude that is needed for deep and panoramic seeing is not a fixing, calculating stance, but much more an attitude of listening and trusting and waiting.”

The multidisciplinary stance of holistic care is not a team of separate professionals working from separate skill bases – the functionalist view. Rather holistic care provides for an overlapping of professionals who acknowledge the significance of differing worldviews and have the capacity to be somewhat eclectic in their approach to patient care. Swinton and Pattison (2010) identify spirituality within holistic care as striving to portray the lived experience of illness (a phenomenology of being ill), seeking to highlight human aspects often not prioritized by the medical model. Putting the spotlight on these aspects of experience for the multidisciplinary team is an objective of this research study, with the importance of bringing to prominence the meaning that is greater than the sum of the parts of disease, dying, and death. This is a view that resonates throughout the literature (Beveridge, 1998; Cobb, Puchalski, et al., 2012; Walter, 2002), and is an ideal of the biopsychosocial-spiritual and total pain medical models.

Biopsychosocial-Spiritual and Total Pain Models

The *medical model* rests on the idea that a patient is a faulty biological mechanism. This at once dehumanises the patient and creates a barrier between them and their health professional (Beveridge, 1998; Borrell-Carrió et al., 2004). In the late 1970s George Engel (1977, 1981), a New York psychiatrist, proposed an unconventional, theorized model of healthcare that acknowledged and sought out more than the biological symptoms of the patient: the landmark biopsychosocial paradigm approached holism, including the

psychological and social contexts alongside the biological (Smith, 2002; Sulmasy, 2002; Weiss, 1980). In a response to what Engel saw as the paternalistic, cold technical, biomedical approach of doctors toward patients, he devised a more empathetic view accentuating human warmth, understanding, generosity, and caring, all based on the subjective experience of the patient: from merely molecular to embracing the societal (Borrell-Carrió et al., 2004). Smith (2002) concludes that by approaching that which is the focus of medical science, the patient, through an incorporation of these interacting aspects of the human person, the medical professional is enabled to become more human (Rosenberg, 2011). Making patient need paramount, with the inclusion of interests, worries, questions, and requests, does not weaken the focus on disease concerns, but moves from an intellectual exercise to an actual scientific picture of each individual (E. Kelly, 2012b; Smith, 2002). The biopsychosocial model encourages an individually tailored approach toward individual patient care, linking science and humanism (Smith, 2002).

In the 1990s spirituality was tentatively added to the paradigm: the biopsychosocial-spiritual model (Borrell-Carrió et al., 2004; McSherry & Jamieson, 2011; Sulmasy, 2002). This holistic model acknowledges that a person is made up of the biological, the psychological, the social, and spiritual aspects: each facet relationally interacting and affecting the other (McSherry & Jamieson, 2011; Sulmasy, 2002). The biopsychosocial-spiritual model of health speaks to the reality that spiritual pain can happen within all relational dimensions;

- physical (e.g. intractable pain);
- psychological (e.g. anxiety, depression, hopelessness);
- social (e.g. disintegration of human relationships); and
- spiritual (e.g. existential crisis), or religious (e.g. crisis of faith) (Beng, 2004; Ellis & Lloyd-Williams, 2012; Sulmasy, 2002).

The internal relationship within each human person is dislocated by disease, pain, weakness, and decline. The interactionist biopsychosocial-spiritual approach to health and medicine embraces the quest for meaning-making, and consequently, it can decrease dislocation and provide support to all aspects of a patient in holistic practice (Brera, 2011; Sulmasy, 2002).

The biopsychosocial-spiritual model reverberates with the notion of the total pain model proposed by Dame Cicely Saunders, the founder of the modern hospice movement (Howard, 2001; Saunders, 2000). In the mid 1960s this innovative approach to death and dying included the identification of pain encompassing physical, psychological, social, and spiritual elements intersecting with each other (Saunders, 2002). Total pain is analogous with the overlap within spiritual pain of disconnectedness with the Self, Other, the world, and mystery/transcendence (de Souza, 2012; P. McGrath, 2002; Mehta & Chan, 2008).

The biopsychosocial-spiritual approach is also labelled the whole person or synergy model (M. Holloway et al., 2011). All of these models stress the complexity of palliative care that seeks to address the diverse and distinctive elements of each individual and their carers (M. Holloway et al., 2011). Within palliative care the multidisciplinary biopsychosocial-spiritual or total pain models of praxis are vital for the whole person to be supported in their living with a terminal illness and in their dying (Beng, 2004; Lysne & Wachholtz, 2011; Sulmasy, 2002), something considered fundamental to any compassionate patient-centred health care (Puchalski et al., 2009). This is an integrated holistic approach rather than a fragmented view that addresses separate components with discrete interventions (M. Holloway et al., 2011). Holistic care emphasizes the inimitability of each dying individual's care and is founded on the principles of "communication, consultancy and skill development" (M. Holloway et al., 2011, p. 30). At BHCI that includes communication between all the stakeholders (patient, carers, community-based multidisciplinary staff, other service providers), and consultancy and referral between differing professions in the

multidisciplinary team and external providers. Further, this research study seeks to augment skill development with basic psychosocial-spiritual skill identification and practice.

The biopsychosocial-spiritual model, with all aspects interacting relationally, allows space for the interests, worries, and questions of the patient, providing a full scientific picture of each individual (E. Kelly, 2012b; Smith, 2002). This is fundamental in palliative care if the whole person to be supported in living with a terminal illness. Other essential elements are the principles of communication, consultancy, and skill development. The biopsychosocial-spiritual depiction of holistic care brings a comprehensive response to layers of disconnectedness.

Disconnectedness in Palliative Care for the Patient

The existential crisis of being, meaning, and purpose brings spiritual pain and disconnectedness to the forefront within palliative care trauma (Burke & Neimeyer, 2012; Puchalski, 2002; Swinton et al., 2011). While spiritual pain disrupts an individual's belief or value system, it can also disturb their entire being (Aghadiuno, 2010). The hearing of a terminal prognosis confronts the patient with the reality of non-existence and ultimate disconnectedness (Bishop, 2013; Sulmasy, 2006). This is the epitome of spiritual pain. In times of trauma and change the need to use inner coping resources and make sense of life is amplified (E. Kelly, 2012b), as also is the desire to preserve one's sense of self and one's usefulness (S. A. Murray et al., 2004).

Spiritual distress within palliative care has also been shown to be associated with a patient's decreasing connection with the relationships and life situations deemed to be *normal* for their personal context (P. McGrath, 2002). This brings disconnectedness through "isolation, hopelessness, loss of confidence, struggle with changes in self-image and relationships, loss of meaning and purpose" (S. A. Murray et al., 2004, p. 43). The challenge of feeling disconnected from a life that has become unfamiliar with physical and

psychological decline, along with role changes, can bring cosmic loneliness and impose ultimate questions of meaning and purpose: Why am I here? What have I achieved? (Burke & Neimeyer, 2012; P. McGrath, 2002; Puchalski, 2002).

Further research shows that for those confronted with dying and death, spiritual disconnectedness involves distinct concerns: struggle and loneliness in the dying process; threat to the integrity of the self, identity, personal meanings, and resources; biographical pain when life has regrets; and exploration of the spiritual meaning of this illness (M. Holloway et al., 2011). Similarly, Yan, Staps, and Hijmans (2010, pp. 58-59) found seven characteristics of existential or spiritual crisis of meaning in the terminally ill:

- loneliness;
- identity crisis;
- dissolving of the future;
- fear, anxiety, panic, despair;
- powerlessness;
- awareness of finitude;
- loss of meaning.

The findings of these various research projects entwine and fall easily within the biopsychosocial-spiritual framework of internal relationship: the physical, psychological, social, and spiritual dimensions (Sulmasy, 2002). Table 3 shows how existential concerns of dying can be placed within the biopsychosocial-spiritual model.

Table 3
Biopsychosocial-Spiritual Existential Concerns

	Biological	Psychological	Social	Spiritual
Loneliness	*	*	*	*
Identity Crisis		*	*	*
Dissolving of the Future	*	*	*	*

Fear, Anxiety, Panic, Despair	*	*	*	*
Powerlessness	*	*	*	*
Awareness of Finitude	*	*	*	*
Loss of Meaning		*		*

Note. Existential Concerns of the Dying (Yan et al., 2010) and the Biopsychosocial-Spiritual Framework (Sulmasy, 2002).

The loneliness of dying means each individual takes the ultimate journey to death on their own, which involves all four aspects of biopsychosocial-spiritual pain (M. Holloway et al., 2011; Sand & Strang, 2006; Yan et al., 2010). There is an identity crisis that brings threat to the integrity of the self, and the change in personal identity and personal resources incorporates psychological, social, and spiritual pain (M. Holloway et al., 2011; Yan et al., 2010). With feelings of regret that life has not gone as one would have wished (Fillion et al., 2006), biographical pain highlights the dissolving of the future (M. Holloway et al., 2011; Yan et al., 2010). Here the self lets down the Self that is full of dreams, hopes, and plans bringing psychological, social, and spiritual pain (P. McGrath, 2002). Emotional responses towards the unknown of fear, anxiety, panic, and despair ordinarily convey psychological, social, and spiritual pain (Yan et al., 2010), but can also exacerbate physical pain (E. Kelly, 2012a). A sense of decreasing physical power and powerlessness against the disease trajectory produces pain in all four aspects (Yan et al., 2010). The struggle to accept the dying process and the accompanying awareness of finitude encompasses all dimensions of pain (M. Holloway et al., 2011; Sand & Strang, 2006; Yan et al., 2010). This involves physical decline, psychological ruminations, social isolation, and the ultimate questions of spirituality (P. McGrath, 2002; Sulmasy, 2006). Last of all, the threat to personal meanings and the exploration of the spiritual meaning of the illness encompasses both psychological and spiritual pain (M. Holloway et al., 2011; Yan et al., 2010). This wrestling with the ultimate questions of meaning, both personal and spiritual, can lead to a wilderness experience, an existential crisis (Penson et al., 2001), or a loss of anchorage (Yan et al.,

2010). It can bring the experience of a loss of faith and satisfaction in life, through loss of self (physical, identity, relational and existential), a loss of leisure and pleasure, and a loss of work (P. McGrath, 2003). This struggle with meaning-making, a universal human attribute (Fowler, 1991), longs to make sense of life, discover inner coping resources, and bring hope (M. Holloway et al., 2011; E. Kelly, 2012b).

Disconnectedness in Palliative Care for the Carers

It is not only the patient who experiences disconnectedness within palliative care, the carers of patients experience their own disconnectedness from Self, from Other, and from the world as they knew it (Carlander, Sahlberg-Blom, Hellstrom, & Ternestedt, 2011). Life changes for the carer when a patient can no longer perform the functions and responsibilities they were once capable of accomplishing within the family, within employment, and within the community (P. McGrath, 2002). Three patterns emerged in carer research that impacted upon, and modified, their self-image:

- challenged ideals are circumstances where the carer was surprised by their own actions and reactions, in particular feelings of deficiency, and anger rising from tension and tiredness;
- stretching personal limits to comply with expectations from Self, Other and society, in particular, limits of intimacy and privacy;
- inter-dependency of personal and patient need, with a decrease of personal space for the carer (Carlander et al., 2011).

In care-giver research conducted by Milberg and Strang (2007), carers reported that a balance between sharing the care with others, including professionals, and performing the care themselves could bring a sense of self-transcendence to the carer.

Issues of parting for the carer are intensely significant, including the imagination of the loss and envisaging the finality of non-existence of the patient, or wondering how to

move in the direction of an altered, but continuing existence (Sand & Strang, 2006). Further research highlights the very real issues of social isolation (Haley, 2003; Sand & Strang, 2006), and care-giver strain indicating the importance of social resources (Redinbaugh, Baum, Tarbell, & Arnold, 2003). The concept of community capacity aims to bolster and educate these social resources and is addressed by the Australian NSAP Standard #9: "Community capacity to respond to the needs of people who have a life limiting illness, their caregiver/s and family is built through effective collaboration and partnerships" (Palliative Care Australia, 2005). Prominence of this issue brought about the emergence of a Compassionate Communities Network within health in 2011, promoting palliative care. "Palliative care encourages, establishes and strengthens partnerships that support community capacity building and resilience in issues surrounding dying, death and bereavement" (Compassionate communities network, 2011). Based on the social model of health-promoting palliative care, it focuses on the social context of each person and the endorsement of best possible health, even within the existence of terminal disease (Kellehear, 2004; Mills, Rosenberg, & McInerney, 2014; Rosenberg, 2011).

Disconnectedness with Self and Other, for both the patient and the carer, is not static, but rather, like our definition of spirituality and ultimate unity, disconnectedness ebbs and flows between spiritual stability, seen as connectedness, empowerment, forgiveness, hope, restoration, serenity, and spiritual distress displayed as anger, despair, disconnectedness, fear, and guilt (Aghadiuno, 2010; Kliewer & Saultz, 2006). While spiritual pain moves back and forth along this continuum from stability to distress it is notoriously difficult to identify, as fear and uncertainty often remain concealed, even from significant others (S. A. Murray et al., 2004). In a study involving forty patients with a terminal illness, Murray, Kendall, Boyd, Worth & Benton (2004) found that while fear, distress, and uncertainty were regularly

displayed and expressed as spiritual issues to researchers, these were rarely articulated to a patient's family or even to the professional carers.

The importance of spirituality and spiritual disconnectedness, however, can only ever be classified by the individual (Bishop, 2013; Hodge, 2005; Palliative Care Australia, 2012) in accordance with the strength of the pain they experience, and with their personal fears and motives (Culliford, 2007; P. McGrath, 2002). Disconnectedness from Self, Other, the world, and mystery/transcendence is purely subjective (P. McGrath, 2002). This particular understanding of spirituality is vital for holistic care to be patient-centred in delivery. It is important that professional carers are careful not to prejudge, but allow the individual to emerge as relationship unfolds. In this space the multidisciplinary team members do not need to assess spirituality, neither decide how spirituality and religion may or may not be related; that is the decision of the patient (E. Kelly, 2012c).

Disconnectedness threatens one's identity, sense of self, and personal meaning, and brings regret and loneliness to the dying process. In the overlap of the biopsychosocial-spiritual model it is shown that all these things can exacerbate physical pain. Disconnectedness with Other affects the carer who also experiences their own disconnectedness from Self, Other, and their world. These issues of caring cause social isolation and care-giver strain, while issues of parting produce insecurity about the future. We have seen that disconnectedness can ebb and flow between spiritual stability and spiritual distress, but where it sits on that continuum can only be categorized by the individual. Disconnectedness can be ameliorated with spiritual care that is about a co-creation of sacred space (E. Kelly, 2012a). Where places of vulnerability that impact quality of life can be identified, strengths of connectedness can be enhanced, and areas of disconnectedness can be explored (Hodge, 2005). As spiritual need and disconnectedness are subjective, so too spiritual care needs to be patient driven, unique, individual, and particular.

Spiritual Care

The concept of treating the whole person with the inclusion of spiritual care is a foundational philosophy of the hospice movement (Cobb, Dowrick, et al., 2012; Saunders, 2000). Meeting the spiritual and existential needs of those within palliative care has been shown to decrease appeals for assisted suicide from patients (McClain et al., 2003). Walter (2002) considers the idea that meaning can be found by each individual, even towards death, is palliative care's answer to the euthanasia debate.

Being described as "Lifting his (sic) spirits" (Fillion et al., 2006, p. 335), spiritual care incorporates a search for meaning and purpose (Saunders, 2002; Walter, 2002), along with connectedness (de Souza, 2006; Fisher, 2011; Yan et al., 2010), compassion, hope, and forgiveness (Bennet & Bennet, 2007; M. Holloway et al., 2011; Kellehear, 2000). It brings meaning, some language, and a humanising focus to the field of health (Beveridge, 1998; Cobb, Puchalski, et al., 2012; Swinton & Pattison, 2010; Walter, 2002). Rather than approach the individual as having discrete fragments for specialised intervention (medical, psychological, social, and spiritual), the integrated, person-centred approach of palliative care sees differing needs as part of the whole (M. Holloway et al., 2011). Hartley (2012, p. 270) argues, "Most dying people will not compartmentalize their care needs. When they need to ask the big questions, it is more than likely it will be in the context of their everyday care." This provides impetus for all multidisciplinary team members to be capable in basic spiritual care skills.

Multidisciplinary provision of spiritual care. The need for any member of the multidisciplinary team to provide basic spiritual care that addresses disconnectedness and concerns of meaning, compassion, and hope is supported by health peak bodies. In their definition of palliative care the WHO includes "prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems,

physical, psychosocial and spiritual" (World Health Organisation, 2005). WHO continues: "Palliative care: integrates the psychological and spiritual aspects of patient care" (World Health Organisation, 2005). This approach leads to spiritual care being a principal aspect of the policies of palliative care peak bodies (M. Holloway et al., 2011), where there is a presumption that all professionals working within palliative care will provide basic care of spiritual needs (Walter, 2002).

PCA integrates spiritual care within NSAP (Palliative Care Australia, 2012), rather than having individual standards for the practice of spiritual support, as occurs with other peak bodies internationally (M. Holloway et al., 2011). This aligns with the concept of multidisciplinary involvement. Similarly in the UK, the Clinical Standards for Specialist Palliative Care have no individual standards for spiritual care, and the competency framework of the National Health Service in Scotland implies an awareness of, and basic skill attainment for, the provision of care for spiritual disconnectedness by all NHS staff (M. Holloway et al., 2011).

Spiritual disconnectedness plays a significant role alongside the physical, emotional, and social aspects in a comprehensive approach to the palliative process (Appelin & Bertero, 2004; Koenig, 2002; Puchalski, 2002). While there appears to be consensus about the big-picture connection of spirituality and palliation, there is little accord when it comes to the delivery of spiritual care (Boston et al., 2011; Delgado, 2005; Salander, 2006). However, it is agreed that it should be accessible to all patients, and that it is not (M. Holloway et al., 2011; Walter, 2002). Despite the meeting of spiritual needs being supported by palliative care peak bodies, the European Association of Palliative Care believes that spiritual issues are inadequately addressed (S. Nolan et al., 2011); a lack echoed in Australian research (P. McGrath, 2003).

Research indicates that spiritual disconnectedness is poorly addressed due to poor attention to spiritual research, a lack of knowledge, language, and confidence to speak of spiritual matters (Emblen & Pesut, 2001; P. McGrath, 2002), a lack of awareness regarding spirituality by the multidisciplinary staff, and an unwillingness to refer patients to spiritual support workers (M. Holloway et al., 2011). The multidisciplinary team need to understand that "the task of conceptualizing spirituality is intimately connected to the experience of the patient" (Pesut, 2008, p. 108). Equally, Walter (2002) surmises that broadened spiritual discourse with the inclusion of a psychological and individual search for meaning, gives space for all members of the multidisciplinary staff to engage with spiritual care at some level. It also builds capacity to meet end-of-life issues that can be complex and unique (Hartley, 2012), always providing avenues for consultation with, and referral to, specialist spiritual support (M. Holloway et al., 2011).

While multidisciplinary provision of basic spiritual care is instructed by peak bodies, not everyone is in agreement with this happening. Walter (2002) believes the addition of basic spiritual care on the multidisciplinary team to be an unwarranted burden. To make the point he writes:

> A survey that found that chaplains or social workers provided less nursing care than nurses would never be taken to imply that social workers or chaplains need more nursing training (Walter, 2002, p. 134).

Kellehear (2000), too, states that those professionally trained in religion and spirituality are best to deal with complex spiritual care. However, in the experience of the researcher, the patient will not necessarily differentiate between diverse professional roles, sharing immediate concerns with the next professional that comes to visit, something also pointed to in the literature (Hartley, 2012). This can be welfare concerns with the nurse, spiritual concerns with the volunteer co-ordinator, or physical symptoms with the spiritual support

worker. Further the common difference in effective full-time hours (EFT) between nurses and other professional staff within healthcare results in a nursing presence being more common in patient homes. The capacity to *seize the moment* when a patient begins spiritual and existential conversations (Hartley, 2012; M. Holloway et al., 2011) does point to the usefulness of having basic spiritual care skills and awareness across the multidisciplinary team. This requires tackling the poor response to spiritual need, the lack of confidence, and the lack of clarity around language and definition. This research study set out to highlight these issues and provide recommendations to manage them, particularly within community-based practice.

Spiritual care involves meaning and purpose, connectedness, compassion, hope, and forgiveness, that is, the bringing of a humanising focus to the field of health. The multidisciplinary provision of basic spiritual care is supported by palliative care peak bodies. Identification and assessment of spiritual need is crucial in this process, however, the addressing of spiritual issues is found to be inadequate, particularly within community-based practice.

Spiritual care within community-based palliative care. Community-based palliative care is the provision of treatment and nurture for those diagnosed with a terminal illness, within their own home. It affirms the idea of home being perceived as "a fitting death scene" (Rosenberg, 2011, p. 16). Founded on holistic person-centred care, community-based palliative care brings *life while dying* into the home and context of the patient, believing the patient has capacity to embrace life until death actually occurs (Brumley, 2012). BHCI is a completely community-based organization with all care delivered in the home of the patient.

When we turn to the literature that has explored community-based palliative care provision we find very little. The Department of Health in Australia states:

> While the importance of having a comprehensive, national data collection on community-based palliative care services is well recognised, no such collection currently exists in Australia (Australian Institute of Health and Welfare, 2013).

This deficiency in community-based palliative care research in Australia is also common internationally. Within a systematic review of palliative care literature from 2000-2010 only 9% of 248 articles addressed terminal care in the community, with only 4 articles actually investigating both palliative care and community-based practice (M. Holloway et al., 2011). These articles included end-of-life decisions made by African Americans (Bullock, McGraw, Blank, & Bradley, 2005), the response of Swedish religious communities to the palliative journey of parishioners (Grassman & Whitaker, 2007), and a community survey for preferences around end-of-life care (Schrader, Nelson, & Eidsness, 2009). The fourth, an Australian study explored the definition of spiritual care by community-based multidisciplinary palliative care staff (Bush & Bruni, 2008). This study by academics focussed on two questions: "What do you understand by the term spiritual care?" and "What does it mean for you as a health professional to provide spiritual care?", neither of which elicited answers about community-based practice. Another article by Trueman and Parker (2006) looked at life-review as a spiritual care intervention and the perception of community nurses towards using it within practice. In general then, the literature fails to address the issue of how a broadly defined spiritual care might operate within the community, or how spiritual care is, and/or could be, delivered to people wishing to die at home (M. Holloway et al., 2011). This lack leads to an appeal for the development of both policy and practice for community-based practice for the terminally ill (M. Holloway et al., 2011).

Spiritual care, however, can flourish in community-based palliative care where all practice occurs within the personal context of the patient. When spiritual care is seen as a co-creation of sacred space with another (E. Kelly, 2012b), the co-creation occurs within the

patient context, and the worker is a guest operating on somewhat flexible time. Conversations around the search for meaning and purpose (Saunders, 2002; Walter, 2002), connectedness and disconnectedness (de Souza, 2006; Fisher, 2011; Yan et al., 2010), compassion, hope, and forgiveness (Bennet & Bennet, 2007; M. Holloway et al., 2011; Kellehear, 2000), all occur with greater ease on familiar ground for the patient, where privacy is more easily maintained. The practice of ritual or spiritual practices with specialized spiritual support can also effortlessly involve carers and other family members.

For carers receiving multidisciplinary, community-based support, the mailbox conversations[6] provide unique spaces for carers to articulate private or *forbidden* thoughts, such as anger, boredom, restlessness, acopia, and fear, providing space to ask the hard questions (Carlander et al., 2011). As this time occurs randomly and hurriedly, it is a duty for the multidisciplinary staff to again *seize the moment* and provide basic spiritual care with a discussion about referral if appropriate. Biopsychosocial-spiritual care within community-based palliative care requires effective systems of referral, consultancy, open communication, and an awareness of barriers to spiritual care to keep person-centred holistic care operating well.

Community-based palliative care provides holistic care within the home and context of the patient. Research into this context is not well addressed, with calls for the development of evidence-based policy and practice. Nonetheless, palliative care within the community provides the patient with the choice of staying at home and being cared for by family with professional back-up. It includes space for natural conversations around meaning and connectedness, and disease trajectory, while breaking the taboo that keeps death hidden in medical facilities.

[6] *Mailbox* conversations are those held on the way to the car as the carer walks the professional carer out. This affords the carer an excuse to be talking with the worker, and privacy, while open to public scrutiny. These conversations are acknowledged within BHCI through informal conversation between workers and through anecdotes at team meetings.

Barriers to spiritual care. Spiritual care, as a component of holistic care, needs to be founded on the principles identified above: communication, consultancy, and skill development (M. Holloway et al., 2011). As noted previously, communication is a prominent weakness in spiritual care hampered by a lack of clarity around spiritual language, spiritual definitions, and concepts of spirituality (Berryman, 2001; Breitbart, 2007; P. McGrath, 2005; Salander, 2006). In practice consultancy is ineffective when other disciplines are uncertain of speaking about spiritual issues and showing a reluctance to refer patients for spiritual support (M. Holloway et al., 2011). A lack of skill development through professional training and orientation brings another barrier to the provision of spiritual care (Baldacchino, 2008; Benner & Sutphen, 2007; Pesut, 2002). Communication around spirituality seems to be out of sync with diverse professional languages, with the general population and with current lexical use (M. Holloway et al., 2011; Kapuscinski & Masters, 2010). The foundational issue in all these barriers is language:

- language for defining spirituality and spiritual care;
- language to acknowledge and talk about spirituality, spiritual care and spiritual disconnectedness;
- language to carry out spiritual care.

The generation of uniquely specialised professional languages brings confusion to holistic care as it attempts to embrace the biopsychosocial-spiritual domains (Hartley, 2012). Additionally Pam McGrath (2005, p. 231) makes the point that in Australia we do not have a mutual word list for spirituality and meaning making that is nonreligious. This results in difficulty around mutual understanding and meaning of spirituality for health and social care professionals (Hartley, 2012). Research shows that this leads to a sense of intimidation and uneasiness for the multidisciplinary team in communication around spiritual disconnectedness (M. Holloway et al., 2011; M. Holloway & Moss, 2010; P. McGrath,

2005), and a fear that any spiritual discussion may be experienced as an imposition on the patient (M. Holloway & Moss, 2010). In a review of published research of terminal patient spiritual need Cobb, Dowrick and Lloyd-Williams (2012, p. 1113), found:

> A gloss of coherence may obscure more specific differences to the ways in which spirituality is experienced, expressed, and understood by patients that could result in spiritual care that is insensitive, biased, or incapable of responding to diverse needs.

A superficial attempt to skim over spiritual need can impose the agenda and opinion of the professional on the patient. Co-creation of space that allows the patient's concept of spirituality to rise and be explored brings dignity and respect to the staff-patient relationship.

Communication, consultancy, and skill development require an attunement to spirituality achieved through the learning and sharing of spiritual language, which is vital for spiritual care to be an effective component of holistic care. Donmoyer (2000, p. 45) believes:

> Language....helps us think precisely and communicate our thoughts to others. It also helps create culture. A shared way of talking helps ensure not only that the world will be characterized in a similar way but also that it will be perceived similarly.

The identified barriers to spiritual care, lack of language for defining and discussing spirituality, anxiety and intimidation around spiritual discussion, and lack of shared meaning and language of spirituality, provide the impetus for this research study. Barriers to the provision of spiritual care also include difficulties in communicating by the multidisciplinary team about spiritual things due to a lack of language and clarity of definition. This combined with a lack of skill development hampers consultancy between the different professions. The intention of this research study was that the findings would provide an organizational lexicon around spirituality and spiritual care, and also inform training and professional development for other disciplines within the multidisciplinary palliative care team.

Spiritual skills development. In an attempt to address the challenge of spiritual disconnectedness being poorly addressed (P. McGrath, 2002), many peak bodies have produced spiritual competency frameworks working towards skill development for the multidisciplinary team.

Spiritual competency frameworks. Competency frameworks (Appendix F), for spiritual care rose from a combination of the inadequate availability of spiritual support workers and the need to make available some discussion with patients when spiritual issues emerge in conversation by *seizing the moment* (M. Holloway et al., 2011). The concept allows for a continuum of spiritual disconnectedness that can be met by various degrees of competence and engagement: basic spiritual care with multidisciplinary team members through to care provided by spiritual professionals (M. Holloway et al., 2011; E. Kelly, 2012b). Basic spiritual competency that includes awareness of and practice motivated by humanity, dignity, and uniqueness, alongside spiritual screening and referral, is proposed to be provided by all members of the multidisciplinary team (Bishop, 2013; E. Kelly, 2012b). On the other hand, spiritual support workers address multifaceted spiritual issues, complex spiritual assessment, and provide assistance with identity issues and existential questions (E. Kelly, 2012b).

The first competency framework of spiritual care in palliative care was developed by Marie Curie Cancer Care in 2003, and raised the profile of spirituality, spiritual disconnectedness, and spiritual care (E. Kelly, 2012a). Today, other professions, such as psychiatry and social work, are taking into account spiritual knowledge, skills and attitudes, and are implementing them into health care practice (Hathaway, 2013; Hodge, 2005). This concept does not necessarily require personal engagement with spirituality or religion, but requires that professionals engage with the spirituality of the patient/client with respect (Hathaway, 2013).

Competency models do not only outline standards and expectations, they do also enumerate, bringing language and awareness to the spiritual care that the multidisciplinary team are already providing often without anyone realising (M. Holloway et al., 2011; E. Kelly, 2012a). Holloway, et al. (2011, p. 38) found that competencies and standards help to:

- identify gaps and complementary roles;
- assist staff to consider implications for delivery of religious and spiritual care;
- provide tools to reflect on and improve current practice;
- identify training needs.

Ordinarily palliative care competency frameworks for spiritual care have four levels of care (M. Holloway et al., 2011; Marie Curie Cancer Care, 2003; Mitchell & Gordon, 2003; Rumbold & Holmes, 2011). Level One is basic spiritual care needed by all, provided by all, with an awareness of spiritual issues and skills in active listening, responding, awareness, support, encouragement, respect, and dignity. Level Two, needed by most, provided by most, includes basic screening, awareness of one's own spirituality and spiritual and/or religious needs, and the importance of verbal and non-verbal communication. Level Three, needed by some and provided by some, understands the importance of transparent silence. This level uses advanced skills of constructing and implementing spiritual care plans, empathy, hearing spiritual dynamics in conversation, and undertaking spiritual interventions such as ritual, traditional text, prayer, meditation, confession, contemplation, and story construction. Level Four, needed by few, provided by few, involves complex spiritual and/or religious needs and interventions and liaison with external resources.

In contrast to the open embracing of spiritual competency frameworks, Kelly (2012) warns against the breaking down of what is an individual vocational role, into discrete, generalized tasks, where spiritual care is an integrative approach, hoping to be woven through practice in a pressured environment. Competency frameworks focus on outcomes which

leave out the meaning that underpins spiritual care tasks and the intricate way in which these tasks connect. Similarly the imposition of a competency framework without training or sensitivity to the organizational culture is imprudent. Kelly (2012, p. 436) continues "...it (a competency framework) does not do justice to the art of healthcare where intuition, discernment, and creativity are significant."

Within the multidisciplinary team, the spiritual support worker, pastoral care worker, or chaplain, brings a particular focus and skills set. This distinctive formation of characteristics: " listening, talking, story-construction, perceiving the spiritual, counselling and so forth – that gives them their unique place within the health care system" (M. Holloway et al., 2011, p. 14). While the focus of the mainstream medical model is "what is done and when," spiritual support workers are motivated by "being rather than doing, and how care is delivered rather than what is performed and when; (that is) the quality of the relationship" (E. Kelly, 2012b, p. 472). The complex and individual nature of spiritual disconnectedness requires support based in connectedness which is to begin where the individual is, with their understanding and perception of their spirituality (Hartley, 2012; E. Kelly, 2012b). The identification and support of each unique combination of connectedness and disconnectedness, spiritual strengths and weaknesses, is the focus of spiritual care (Ellis & Lloyd-Williams, 2012), needing to always be flexible as each day and each stage confronts the patient, and their spirituality, in different ways (S. A. Murray et al., 2004). Hartley (2012) considers that the distinct and unique response between spiritual support worker and patient eliminates any magic or mystery that is occasionally linked to spirituality. Research from Scotland indicates that specialised spiritual support has been identified as providing "enhanced patient self-esteem, confidence in personal decision-making and a greater ability to self manage" (E. Kelly, 2012b, p. 474). Similarly, in the UK, spiritual support is shown to have positive outcomes within palliative care (M. Holloway et al., 2011). Scottish healthcare,

in the vanguard of holistic multidisciplinary practice, has comprehensively identified the role of chaplain on the multidisciplinary team whose skills include:

- engaging in a therapeutic listening, talking, and being present in difficult times;
- helping individuals, families, and communities in healthcare to mark significant moments in life and death using ritual and in other meaningful ways;
- resourcing, enabling, and affirming healthcare colleagues in their delivery of spiritual care – supporting them in reflecting on their own spirituality and that of patients and their carers;
- meeting the particular needs of all in the healthcare community in relation to religion and belief by promoting creative links with faith and belief groups;
- helping staff reflect on the relationship between their personal stories, and the shared story of their workplace (E. Kelly, 2012b, p. 472).

Spiritual competency frameworks rose from the inadequate availability of spiritual support workers and the need for multidisciplinary staff to *seize the day* during existential conversations. They outline standards that bring language to spiritual care that is often provided unaware. The need to begin with the spiritual understanding of the patient is positioned within the particular skill set of the professional spiritual support worker. These characteristics outlined above are where basic spiritual care skills are drawn from and placed in competency frameworks for the multidisciplinary team. They will also be used to inform this research study.

Skills. A greater understanding of the influence of relational quality between patient and healthcare professional is developing within the healthcare literature. Both vocational satisfaction for the staff and positive experience for the patient are shaped by three things:

- practitioner skill;
- *how* the skill is carried out;

- the practitioner's way of connecting with the patient (E. Kelly, 2012a).

Engaging with spiritual disconnectedness requires both skill and personal characteristics of the person offering spiritual support (M. Holloway et al., 2011). The spiritual characteristics of effective spiritual care provision within palliative care are identified as being:

- self-awareness;
- attitudes, disposition and sensitivity to spiritual issues;
- ability to confront their own attitudes towards spirituality and death;
- pursuit of personal and professional development;
- inter- and intra-disciplinary co-working within and across all professional groups;
- co-management of care of both patients and their families (M. Holloway et al., 2011, p. 30).

These personal characteristics, then, provide a fertile space for spiritual skills to grow and develop. As well, a further set of basic practice skills identified in the literature may be added to these personal characteristics. The literature identifies seven basic skill groups that provide basic spiritual care to patients in palliative care: reading the signs through identification, intuition, personal reflection, taking time to listen, combined with a co-creation of sacred space, meaning-making, and assessment. These are discussed below:

Identification. Being able to identify signs of connectedness and disconnectedness is crucial to appropriate spiritual support. Spiritual connectedness can be witnessed through aspects such as:

- inner peace and harmony;
- having hope, goals, ambitions;
- social life and place in community retained;
- feeling of uniqueness, individuality, and dignity;
- feeling valued;

- coping with and sharing emotions;
- ability to communicate with truth and honesty;
- ability to practice their religion;
- finding meaning (S. A. Murray et al., 2004, p. 41).

Whereas indications of disconnectedness can include:

- expressing frustration, fear, hurt, doubt, or despair;
- feeling life is not worthwhile;
- feeling isolated and unsupported;
- feeling useless;
- lacking confidence;
- relationship problems;
- feeling of losing control;
- questioning: “Where do I fit in?” “What have I done to deserve this?” (S. A. Murray et al., 2004, p. 41).

At the same time it is necessary to keep in mind that the individual is the only person who can truly identify and assess the impact of these features on their own life (P. McGrath, 2003). Similar to the pain-rating scale used in nursing and medicine, where the individual rates their pain experience between 1-10 (Ferreira Valente, Pais-Ribeiroa, & Jensend, 2011), so too it is only the patient who can rate the impact of any variation of disconnectedness on their spirituality. The co-creation of sacred space provides for this awareness to emerge, be identified and explored.

Intuition. Intuition too has a space to participate in the provision of spiritual care (E. Kelly, 2012a). In desiring a move from reductionist medicine to centring on person-centred care Miles (2009) calls for a reintegration of *essential arts* back into medicine. These include

the use of compassion, consolation, empathy, insight, discernment and intuition, by listening and explaining, and by being fully present to the person (Miles, 2009).

Intuition is interior knowledge accessed pre-consciously without regard for the reason underpinning the assessment (Souter, 2003). It rises out of circumstances or challenges previously encountered (de Souza, 2006), bringing imaginative thinking which can lead to transformation (de Souza, 2008). This knowledge, that is often unvoiced, is useful, but only one of many aspects of integrated knowledge required for expert practice (Souter, 2003).

Self-reflection. Honing intuition through self-reflection enhances expert practice and enables a mutual trust and knowing. Reflecting on their work with the dying, multidisciplinary professionals indicated their personal lives had been constructively transformed (Sinclair, 2011). The end-of-life experiences of their patients had taught them the value of living in the here-and-now, to contemplate the fragility of life, and cultivate connectedness (Sinclair, 2011). The reflection, acknowledgment and disclosure of appropriate emotion assisted in relational and skill development as well as personal emotional growth (Sorensen & Iedema, 2009). The provision of spiritual care is also impacted by personal attitudes held about pain and anguish, and individual identity (Smeets, 2012). Further Souter (2003) makes the point that reflection with a clinical supervisor has the capacity for more effective change to practice, than personal reflection alone. Nevertheless reflection on, and development of, personal spirituality does extend the capacity to be spiritually present with patients (Cobb, Puchalski, et al., 2012).

Taking time to listen. Spending time in an unhurried fashion is an immensely valuable skill within spiritual care. Taking time to come close, both physically and relationally, and to listen is vital to create space for the discovery of meaning and hope in times of crisis and trauma (Swinton & Pattison, 2010). Listening to the words and stories, as well as to the back story which is often swathed in spiritual dynamics (M. Holloway et al., 2011). Fears of

disconnectedness that result from being a burden, personal regret, physical suffering, and dying itself can be identified and explored (M. Holloway et al., 2011). Research exploring the spiritual needs of the dying found that patients often spoke at great length of how life *was* prior to diagnosis, determining who they felt they really were (S. A. Murray et al., 2004). Patient listening to these anecdotes provides a foundation upon which to build relationship and trust, and a space where questions can float to the surface. Spiritual care is not about bringing answers or calming distress or emotion, but rather giving the other space to be and express what is needed as the present moment dictates to them (E. Kelly, 2012b), acknowledging that with the asking of questions and expression of emotion comes the potential for exploration, motivation and change in gentle, yet straightforward ways (Hartley, 2012).

Co-creation of sacred space. Kelly (2012b), speaks of the co-creation of a space that is personally and individually sacred through recognizing and holding the pain and vulnerability of the other; this brings affirmation and a normalising of the experience. This *sitting with* to co-create sacred space can be easier to achieve within community-based care with flexibility of time, and the meeting with the patient on their own ground. The co-creation of a sacred space brings a spirit of compassion that connects the speaker and the listener (Ellis & Lloyd-Williams, 2012). This being the case, supportive presence or companionship provides a safe place to be vulnerable and weak, and the journey can be shared (M. Holloway et al., 2011). “Presence carries significant development in spiritual and existential meaning for patients as they face end of life issues” (Ellis & Lloyd-Williams, 2012, p. 260).

Meaning-making. By design, meaning-making is fundamental in human beings (Bonanno & Kaltman, 1999; Frankl, 1992), so it is common for human beings to attempt to make meaning out of illness, out of a terminal prognosis, and out of the journey through

treatment and towards death (Saunders, 2000). The exploration of existential questions such as Why? and Who am I? can suggest how the journey will be made and how the journey will affect our identity (Burke & Neimeyer, 2012). Many people find spirituality, objective and/or subjective, offers a structure within which these issues can be encountered and explored (Burke & Neimeyer, 2012). Meaning-making can provide a significant resource in spiritual coping, where particular spiritual beliefs and activities are employed to transcend stressful situations and crises (Burke & Neimeyer, 2012). Bonanno and Kaltman (1999), identify a continuum of subjective meaning for the individual from somewhat commonplace evaluations of practical themes, through tangible assessments of definite challenges, to multi-layered questions of identity and emotional well-being, all the way through to the ultimate questions of the meaning of life and death.

Disconnectedness through fear, and in particular fear of dying, is common with a terminal prognosis, and then through the illness journey as each new diagnosis brings its own "death sentence: Life as you knew it is over. Finished. However life will be from now on, it will never again be how it was" (Kearney & Weininger, 2012, p. 274). The ability to bring some level of meaning-making to this space through spiritual care challenges a reductive medical view, opening up a dialogue that can bring transcendence and connectedness (Cobb, Puchalski, et al., 2012). Some screening for identification and assessment of the presence of spiritual disconnectedness through this journey is crucial for spiritual referral and the delivery of appropriate spiritual care.

Spiritual assessment. The scientific medical model has resulted in a plethora of measures to take a spiritual history, spiritual screening, or spiritual assessment. The UK Department of Health report, "Spiritual care at the end of life: A systematic review of the literature" (M. Holloway et al., 2011) listed 35 differing practice models around spiritual

assessment. Twenty-six of these were deemed inappropriate to this study due to the following:

- ten were based in religion;
- seven measured something other than spirituality ie. the aspect of hope;
- four measures had multiple questions which made them too complicated for the context where team members were untrained in spirituality, and the measures were clearly more useful as tools for research rather than in direct conversation with patients (M. Holloway & Moss, 2010);
- three were about organizational strategic planning;
- one was based on a case management method;
- one was deemed by its authors as having low reliability within the spiritual arena.

The nine remaining models that were considered appropriate are included in the brief outlines below.

Dr. Harold Koenig (2007, pp. 42-44), the Director of the Centre for Spirituality, Theology and Health at Duke University Medical Centre and prolific author and researcher, proposes three different instruments for the taking of a spiritual assessment/history in health care: the CSI-MEMO Spiritual History, the ACP Spiritual History, and the FICA Spiritual History. All three have been researched, developed and reported by the medical fraternity.

The *CSI-MEMO*, written for physicians, evaluates five dimensions: comfort, stress, influence, member of religious community, and other spiritual needs (Lucchetti, Bassi, & Luchetti, 2013). While considered easy for the physician to use, the measure does begin with a divisive question ("Do your religious/spiritual beliefs provide Comfort, or are they a source of Stress?") (Koenig, 2007).

The *ACP Spiritual History* focuses on two faith questions and two religion-centred questions. Both are unsuccessful in opening up conversations that highlight the identification

of spiritual needs and supportive connectedness within the community (Koenig, 2007) and neither instrument addresses terminal events and issues (Lucchetti et al., 2013).

The third suggestion by Koenig (2007) is the *FICA Spiritual History Tool* which assists health professionals to include conversation about patient spirituality as an ordinary component of taking a medical history on initial assessment (Borneman, Ferrell, & Puchalski, 2010). Question topics include:

F – faith and belief;

I – importance of spirituality, faith, and belief;

C – spiritual/religious community connection and support;

A – addressing issues of need in care (Borneman et al., 2010).

This tool does have open conversational questions and has capacity for terminal issues, however it is religion based in nature with an exclusive view of spirituality.

The *Functional Assessment of Chronic Illness Therapy – Spiritual Well-Being Scale* (FACIT-Sp) set out to measure quality of life in chronic illness (Canada, Murphy, Fitchett, Peterman, & Schove, 2008), assessing a sense of meaning and peace, as well as the role of faith during illness (Peterman et al., 2002). This scale has 12 *I* or *My* statements measured on a likert scale (i.e., 0=not at all, 4=very much) and while there is a specific question about having a reason for living, the measure does not specifically address terminal issues (Canada et al., 2008).

The *Spiritual Well-Being Questionnaire* (Gomez & Fisher, 2005), which evolved into the Spiritual Health and Life-Orientation Measure (SHALOM) (Fisher, 2014), asks participants to rate their experience of maturing spiritual aspects over the last 6 months on a likert scale. Four aspects are measured: personal, communal, environmental, and transcendental spiritual well-being, with each statement beginning with *I am developing...* This spirituality measure uses the connectedness framework to define spirituality. Examples

of questions for personal items are "*I am developing self-awareness*"; for communal items "*I am developing love for others*"; for environmental items "*I am developing harmony with the environment*" (Fisher, 2014). The interpretation of the concept of "Transcendent influence" includes nineteen different mainly religious options: "Allah, Angel/s, Buddha, Deceased person, Deity/deities, Divine, Fate, Father God, Gaia, God, Heaven, Higher power, Higher self, Mystery, Otherness, Presence, Something there, Universe/universal spirit...(or) Not an area in which I believe" (Fisher, 2014, p. 10).

The *Spiritual Needs Survey* tests for seven major constructs: belonging, meaning, hope, the sacred, morality, beauty, and acceptance of dying (Galek et al., 2005). This 29-item survey, which is holistic in nature, encompasses both non-institutional spirituality as well as traditional religion, however it exclusively asks questions about being an inpatient (Galek et al., 2005).

The *Family Crisis Oriented Personal Scales* (F-COPES), a 29-item likert scale seeks to assess measures of spiritual coping in the patient and their family. Within the tool one subscale that determines spiritual support bases the questions on church involvement (Redinbaugh et al., 2003). This tying of spirituality to religion and spiritual support, specifically to church involvement, is not surprising with almost all significant measures of spirituality and their research done within a social milieu founded on Christian values (Moberg, 2010).

Alternatively la Cour and Hvidt (2010), offer an inclusive conceptual framework for existential meaning-making, using the domains of spiritual, secular, and religious, coupled with dimensions of knowing, doing and being. The questions accompanying the grid, however, are written in strong academic language (e.g. "If you have any religious elements in your worldview, to what extent can this strengthen or weaken your ability to go through this period of illness?").

Further, a methodological review of ten measures used in nursing and health-related literature to assess patient spirituality found that concepts of religion and spirituality were used interchangeably, and therefore meant that there was no measure assessing spirituality as different from religion (Sessanna, 2011). In the same way de Jager Meezenbroek et al. (2010), found that spirituality questionnaires, for the most part, measure religiosity. Hence, the researchers call for assessment and screening tools to measure the importance of personal spirituality to an individual but ones that rise above particular beliefs.

The measures discussed can be lengthy and require large amounts of concentration to assess aspects of spirituality so they are not appropriate for basic spiritual screening practice in community-based palliative care. Neither do these measures address issues of spiritual distress and disconnectedness, or present connectedness and disconnectedness on a spiritual continuum, but rather treat spiritual well-being and spiritual disconnectedness as two separate, distinct entities (Monod et al., 2011) .

A perspective held by Bishop (2013) cautions against the idolization of assessment measures, warning that unthoughtful use can lead to a patient being fitted into the tool, and then required to measure up. In fact, the way many spiritual assessment measures present religion and spirituality are based in current psychological and sociological theories which lead to shallow understandings, and "only scratch the surface of what are usually thick metaphysical-moral worldviews" (Bishop, 2013, p. 333). Watts (2008) also questions the ethos of measurement highlighting a move from a culture of the personal to a culture of audit, depersonalisation and problem solving. Spiritual care needs to be more about focussed discussion than a concentration on formal assessment (Ellis & Lloyd-Williams, 2012), more about personal stories that are embedded in larger stories of cultural, societal and spiritual understandings (Bishop, 2013). Likewise Aghadiuno (2010) raises the point that rather than

set, generalized questions, it is the story of the patient, and how they craft their narrative, that reveals the influence of spirituality within their own life.

Developed by the Mount Vernon Cancer Network (2007), the Pepsi-Cola Aid Memoir Holistic Common Assessment of Supportive and Palliative Care Needs for Adults with Cancer provides questions that can be used as ice breakers to spiritual conversations and patient stories:

- How do you make sense of what is happening to you?
- What sources of strength do you look to when life is difficult?

A parallel spiritual assessment needs tool was developed by St Michael's Hospice, Hereford (2008). Similarly the spiritual care provision working party at the 2010 National Council for Palliative Care in the UK identified three noteworthy questions to explore end of life issues:

- How do people understand what is currently happening to them?
- When life has been difficult in the past, what kind of things have helped?
- Would any of these things, or anything else they can think of, be helpful to them now? (Hartley, 2012, p. 266).

This style of questioning honours the significance held by the individual about spiritual matters (P. McGrath, 2005), is always rated by the individual (Bishop, 2013; Hodge, 2005; Palliative Care Australia, 2012) and addresses their individual concerns and motivations (Culliford, 2007). A move away from formal detailed assessment is also reflected in the literature from the medical model of professional expert (M. Holloway et al., 2011), to a tuning-in to the individual importance, character, and assessment of connectedness and disconnectedness held by the patient (Ellis & Lloyd-Williams, 2012; M. Holloway et al., 2011).

Spiritual assessment measures that are currently available are not appropriate for BHCI due to religious underpinnings and narrow or undefined conceptions of spirituality.

Many are lengthy and not suitable for basic spiritual screening. The ethos of measurement brings a depersonalisation of the patient within spirituality where the philosophy of a co-creation of space occurs through the values of the patient. Any spiritual screening tool for use by the multidisciplinary team to discern connectedness, disconnectedness, and the need for a referral, would require the following:

- a conceptualization of spirituality based on existing theory (Kapuscinski & Masters, 2010) that transcends specific beliefs (de Jager Meezenbroek et al., 2010; Sessanna, 2011);
- development input by a spiritual worker trained in interpretive traditions and disciplines of spirituality (Cobb, Dowrick, et al., 2012);
- language for speaking about spirituality that is relevant to the general population and current use (M. Holloway et al., 2011; Kapuscinski & Masters, 2010);
- space for the individual to explore what they believe gives their life meaning, purpose and connection (Sessanna, 2011);
- allowing the individual to rate the significance of spirituality for themselves (Bishop, 2013; Hodge, 2005; Palliative Care Australia, 2012), while also determining the role, if any, of religion within their spirituality (E. Kelly, 2012c);
- a comprehensive tool that screens for spiritual distress (Koenig, 2007), current spiritual state (Monod et al., 2011), and spiritual strengths (Hodge, 2005) ;
- the capacity to be embedded within routine multidisciplinary patient care (Jenkins et al., 2009).

Equally, personal characteristics and skills entwine in the provision of effective spiritual care. Qualities include self-awareness, particularly about death and spiritual issues, the pursuit of personal and professional development, and the ability to collaborate with the patient, carer, and other team members. Further skills involve identification, intuition,

personal reflection, active listening and co-creation of space, and meaning making. The ability to perform basic spiritual assessment is vital for appropriate and timely referral. A spiritual screening tool needs to be founded in existing theory and transcend particular beliefs. Using current language, space is provided for the individual patient to explore and appraise their own spirituality. A useful screening tool would have the capacity to be embedded within routine practice, granting access to spiritual distress, current spiritual state, and spiritual strengths. It is expected that education which is founded on existing theory, and which takes into account the above features, will be crucial for spiritual care that is to be embedded in the an organization. The next section investigates this premise.

Education

The literature clearly establishes the need for education and training within palliative care to provide clarity of understanding and language around spirituality, and to increase multidisciplinary skills around basic spiritual care provision and thereby increasing confidence (Cobb, Puchalski, et al., 2012; M. Holloway et al., 2011). The literature also indicates that within the highly particular environment of community-based palliative care questions of practice and theoretical foundations require ethical acuity, along with specific skills and awareness (Culliford, 2009; Hack et al., 2010; Hermann, 2001; M. Holloway et al., 2011; P. McGrath, 2002).

The majority of the literature focused on education and skill attainment concentrates on nurses and is printed in nursing journals (Catanzaro & McMullen, 2001; Hermann, 2001; Howard, 2001; Jenkins et al., 2009; Johnston Taylor, 2003; Lemmer, 2002; P. McGrath, 2002; McSherry, 2007; Miner-Williams, 2006; Paley, 2007; Pesut, 2002; Pike, 2011; Trueman & Parker, 2006; Yang & Mao, 2007), with some focus on students at medical school (Culliford, 2009; Ford, Downey, Engelberg, Back, & Curtis, 2012; Koenig, 2008; Lambie, Egan, Walker, & MacLeod, 2013; Lucchetti et al., 2012; Musick, Cheever,

Quinlivan, & Nora, 2003; Peach, 2003). Not only does this leave other disciplines within the multidisciplinary team quite bereft; it also provides an unbalanced view of holistic care.

With a thorough understanding of the biopsychosocial-spiritual or total pain models, the holistic method does not prefer one discipline over another, nor one component of pain experienced by the patient over another (M. Holloway & Moss, 2010). Holistic care is founded on the acceptance that treatment, disease management, and physical pain can all be impacted by disconnectedness in either/or the social, emotional, and spiritual realms (M. Holloway & Moss, 2010; E. Kelly, 2012a). This also points to the importance of the multidisciplinary team accumulating basic spiritual care skills, and proficiency in consultation with other disciplines to identify differing impacts on pain and distress.

The following different skills are also highlighted in the literature of training requirements:

- traits of hope, connectedness, religious matters (Swinton & Pattison, 2010), meaning (M. Holloway et al., 2011), deep compassion, altruism (Cobb, Puchalski, et al., 2012), spiritual characteristics and attitudes (Culliford, 2009);
- learning to draw out, identify and meet basic spiritual need (M. Holloway et al., 2011);
- direct, empathic communication and listening (Culliford, 2009);
- identification and effective response to unique spiritual quests (Swinton & Pattison, 2010);
- consciousness raising of the significance of spirituality for both the patient and for members of the multidisciplinary team personally (Cobb, Puchalski, et al., 2012; Swinton & Pattison, 2010);
- highlighting general practice performed ordinarily that is spiritual in nature, but not previously identified as such (Swinton & Pattison, 2010);

- providing the space to practice spiritual language and questions, and so develop personally genuine ways to approach spiritual issues with patients (M. Holloway et al., 2011);
- professional development and staff orientation programs (M. Holloway et al., 2011) incorporating reflective practice, emotional resilience, and self-responsibility (Culliford, 2009).

Many skills are considered helpful in the provision of spiritual care, and while all voices agree that education and training are necessary for the multidisciplinary team this *should* is left hanging over palliative care teams with little guidance or initiative on how this knowledge could be accumulated or taught. This is the gap in holistic practice that provided impetus for this research study. Education is required to provide clarity of understanding and language around spirituality, to increase the skills base, and therefore confidence, of the multidisciplinary team in the provision of basic spiritual care within true holistic care and to provide appropriate referrals for spiritual support.

Research Issues

The palliative care literature documents recommendations for future research include:

- research that endeavours to map out the territory and challenges, while improving the method of spiritual care (M. Holloway et al., 2011), and interpretation that transforms knowledge into evidence-based practice (Cobb, Dowrick, et al., 2012);
- clarity of definition for spirituality reinforced by contemporary understandings and established theory (M. Holloway et al., 2011);
- method that brings a coordinated style appropriate for multidisciplinary use, increasing confidence in basic spiritual care provision (M. Holloway et al., 2011);
- early identification and assessment of spiritual pain (World Health Organisation, 2005);

- research initiated from interpretive traditions and disciplines of spirituality (Cobb, Dowrick, et al., 2012).

Relevance for this research study. Four key topics may be articulated when the above recommendations are integrated with the research question for this research study: What are the understandings and perceptions of spirituality held by multidisciplinary professionals involved in a community-based palliative care organization? The integration points to the distinct need for:

- unpacking, clarification of, and a common language for spirituality;
- spirituality and spiritual care within community-based palliative care practice;
- multidisciplinary team skills in identification, assessment, and implementation of basic spiritual care;
- language and stories of spiritual support that express the communal nature of spirituality within BHCI collected, interpreted, and presented through the professional discipline of spirituality.

In addition Hyde's (2008b) research findings are relevant here as illumination about a spiritual quest needing to start with dialogue and engagement at the coalface where people are working. As well, it needs to assist in forging personal links to the communal story and entwine spiritual story and common language. This is the backbone of this research study, where we set out to glean information about spirituality, spiritual care and spiritual disconnectedness from the multidisciplinary coalface, linking communal and personal story with common language. With very little community-based research being conducted in the palliative care field, this research study seeks to address a unique gap that becomes increasingly important as more people choose to be cared for, and die, in their own home (M. Holloway et al., 2011). Cobb, Dowrick and Lloyd-Williams (2012) call for academic exploration to be performed by researchers connected with interpretive disciplines and

traditions of spirituality, in an area where the majority of published studies are by healthcare professionals that have used definitions of spirituality that are reductive and functionalist (Koenig et al., 2001; Miles, 2009; L. E. Ross et al., 2008).

Just as Ewan Kelly (2013) talks about not imposing in spiritual care with loaded questions for the patient such as “Do you feel .....?” it is important to provide space for spiritual pain to rise and be given personal expression. So too, imposing spiritual assessment tools, spiritual definitions, and spiritual practices from other organizations on the multidisciplinary team at BHCI would not allow space for a common language around spirituality to emerge, and further, it could stifle the unique flavour of spiritual care unrecognized but already operating within the organization. This, along with the clarification of a common lexicon and basic spiritual care skills appropriate for the multidisciplinary team within community-based palliative care, and the interpretation of communal understandings of spiritual support through the interpretive tradition of the discipline of spirituality, highlights the significance of the approach of this research study.

The literature from the research conversation about spirituality has identified that spirituality sits on a sacred/secular continuum. Intrinsic, dynamic spirituality addresses the making sense of life, inner meaning, and ultimate questions. While there is a lack of clarity around definition and understanding, this does not indicate a lack of significance. A common understanding is required for the articulation of shared concepts and meaning, not necessarily a tightly bounded definition. The empirically oriented perspective of spirituality as connectedness with Self, Other, the world, and mystery/transcendence brings a framework to support this research study and the understandings and perceptions of the multidisciplinary team. Spiritual need is then defined as disconnectedness.

The literature related to the research study context focused on community-based palliative care. In palliative care disconnectedness occurs with the Self through the loneliness

of the dying process, with Other through the issues of parting, with the world as physical decline occurs, and with mystery/transcendence when there is an inability to overcome the present. Holistic palliative care, with the biopsychosocial-spiritual model, supports the whole person while living with a terminal illness. It is founded on multidisciplinary team adherence to the principles of communication, consultancy and skill development and the provision of basic spiritual care. Community-based palliative care provides holistic care within the home and context of the patient providing the dying with the choice of staying at home and being cared for by family with professional back-up. Barriers to the provision of spiritual care by the multidisciplinary team include a lack of language, lack of clarity around a definition, and a lack of skill development. Personal characteristics, language, and skills entwine in the provision of effective spiritual care, and the ability to perform basic spiritual assessment is vital for appropriate and timely referral. Research and education are required to provide a common lexicon around spirituality, to increase basic spiritual care skills, and therefore the confidence of the multidisciplinary team in the provision of truly holistic community-based palliative care. In the following chapter the research methodology will outline how exploration of these objectives were accomplished.

Chapter Four: The Research Design

Chapters two and three presented the literature within which this research study was situated. The literature of the research conversation of spirituality and the research context of community-based palliative care indicated gaps requiring further research including:

- definition and language of spirituality to provide knowledge that can be transformed into evidence-based practice;
- professional development for the multidisciplinary team that enhances the current skill base and can be implemented through professional development and policy;
- spiritual care within community-based palliative care practice;

- exploration of the topics by researchers from a pastoral, chaplaincy, or theological background to unpack and clarify.

This chapter aims to set out the theoretical and methodological framework, the research method, and the research process that were used to address these key topics in the conducting of this present research study.

The Design of this Research Study: Social Research Design

The research design is the strategy that links the research question to the manner of investigation and the outcome required (Crotty, 1998). Within the social research framework of Crotty (1998) six steps are identified for research design (Figure 2), that provide structure for this chapter:

- initial reading to identify a gap in current knowledge and choice of a research framework or paradigm;
- formation of the research question;
- philosophy of epistemology;
- theoretical perspective;
- methodology;
- methods for collecting the data.

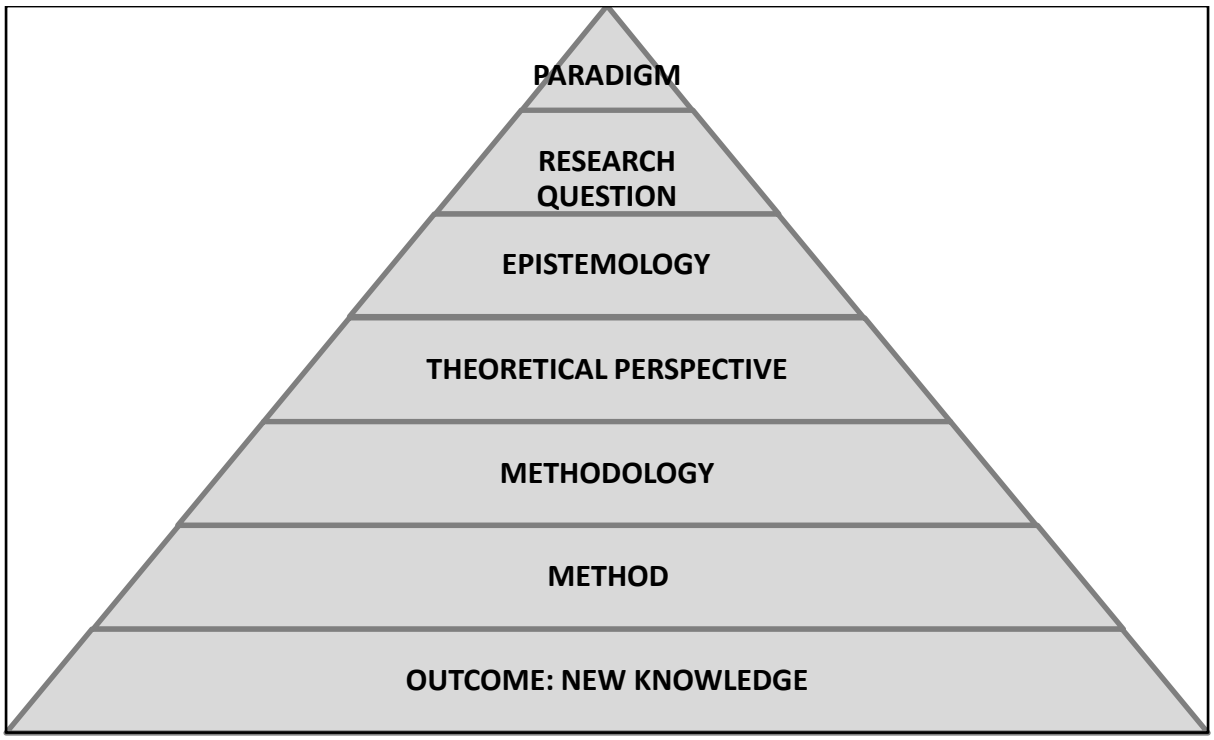

Figure 2. *Social Research Design by Crotty (1998).*
Note: This figure illustrates the components of the design of this research study and how they flow down into the creation of new knowledge.

Theoretical Paradigm and Research Question

Academic research has three chief frameworks for designing research methodology; quantitative, qualitative, and mixed methods. The choice of framework imparts direction for all aspects of the study, from the general philosophical ideas behind the inquiry, through data collection, to the mode of analysis (Creswell, 2003). Quantitative research is explicit, concentrating on prediction, control and measurement using quantifiable data (Creswell, 2008; Fossey et al., 2002; Laverty, 2003). It asks questions such as How often? and How many? (Cottrell & McKenzie, 2011). Conversely, within qualitative research the researcher formulates new information founded on the constructivist perspective, which holds that meaning is constructed by individuals as they live and experience life in the world (Creswell, 2003; Crotty, 1998; Schwandt, 1994). The researcher collects open-ended, emerging data with the intention of developing themes from that information. The mixed methods paradigm involves the use of both numeric and text based data, quantitative and qualitative data. A

match between the research problem and the research approach is important (van Manen, 1997), and is ultimately based on three things: the research problem, personal experiences of the researcher, and the audience for which the research is aimed (Creswell, 2003).

The research problem that is foundational to this study calls for a qualitative methodology, where the focus is on discovery, description, explanation, themes, and meaning (Creswell, 2008; Fossey et al., 2002; Laverty, 2003), and the qualitative researcher enquires about the How? What? and Why? of the focus of study. This approach is particularly useful where the subject matter has not been tackled before with a particular group of people (Creswell, 2003).

Subjective, qualitative designs support the investigation of resolutions to complex questions, insights, and interpretations (Cottrell & McKenzie, 2011). The interpretivist paradigm of qualitative research explores culturally developed and historically placed interpretations of the social world, with the researcher putting together a holistic, layered representation of the analysis and interpretation of participant thought and language in a natural setting (Cottrell & McKenzie, 2011; Denzin & Lincoln, 1994). Culture, within qualitative research, refers to thought and behaviour configurations of a particular social group, and within this system knowledge is group-constructed by individuals who are seen as collaborators (Crotty, 1998). The exploration of how professionals in community-based palliative care understand and experience spirituality is best addressed through this richer, interpretive, qualitative approach.

The most effective approach was thought to begin at the coalface (Hyde, 2008b), enabling knowledge of spirituality to naturally rise from within the understandings of those who worked within the organization. The next step was to use these understandings to formulate a professional development and orientation program that was organic in nature, having risen from understandings uncovered through research, which could provide context

based definitions and training solutions. For this reason the research parameters became very narrow in focus, with the desire to delve deeply into the particular context of BHCI (Creswell, 2003). Consequently the research question was produced out of the context of BHCI and the delivery of spiritual care within the organization. As the spiritual support worker the researcher was aware of a huge lack of understanding within the organization about spiritual care, and considered options to tackle the challenge to increase awareness in the unique situation of a highly secular, totally community-based service focussed on palliative care. After a great deal of questioning, reading, discussing, and thinking it became obvious that there was no appropriate tool within the literature that could be applied to teach an understanding of spirituality and how to apply it to spiritual screening and spiritual care within this organization. Out of this the research question was then formed: What are the understandings and perceptions of spirituality held by multidisciplinary professionals involved in community-based palliative care?

Epistemology

Epistemology refers to how knowledge is known, the particular way of comprehension and understanding or theory of knowledge, embedded in a theoretical perspective (Creswell, 2003; Crotty, 1998). The epistemological position of this researcher is the understanding that data were contained within the language and perspective of people and it is language and understanding that bring knowledge into being (Richards & Morse, 2007). Crotty (1998, p. 87) states that: “Language is pivotal to, and shapes, the situations in which we find ourselves enmeshed, the events that befall us, the practices we carry out and, in and through all this, the understandings we are able to reach.”

To be a human being is to be fundamentally a language being (Crotty, 1998; Ihde, 1971), with living experiences that are permeated with language (van Manen, 1997), and to be entwined within an evolving process of understanding and interpretation (Richards &

Morse, 2007). Human existence begins in a world filled with socially constructed meaning (Crotty, 1998), however individual consciousness, individual unique experience and individual perceptions are all a person can ever really know (Crotty, 1998; O'Leary, 2010).

Constructivism. Constructivism has been chosen as the grounds of knowledge for this research study. Constructivism focuses on the meaning-making pursuit of the individual mind, and the legitimacy of each individual's way of making sense of the world, seeing their meaning as worthy of value, providing an uncritical exploration of meaning (Crotty, 1998), while the focus of constructionism is the societal creation and diffusion of meaning, and the fostering of a critical spirit (Crotty, 1998).

The constructivist epistemological position holds that meaning is constructed by individuals as they live, experience life, and engage in the world (Creswell, 2003; Crotty, 1998; Schwandt, 1994). Founded in personal social and historical perspectives, sense and meaning are made of the world as humans engage with it; therefore meaning rises out of interaction (Creswell, 2003). Constructivism is an invitation to discover innovative and richer meaning through an open reinterpretation of the object, acknowledging that truth and knowledge are not discovered by mind, but rather the individual mind is active in creating and constructing reality that is both pluralistic and plastic (Crotty, 1998; Schwandt, 1994). A pluralistic view states that reality can use a variety of language systems and symbols to express itself, while plastic relates to the idea of reality having elasticity to be fashioned to fit intended actions of decisive human agents:

> We invent concepts, models, and schemes to make sense of experience and, further, we continually test and modify these constructions in the light of new experience (Schwandt, 1994, p. 126).

As an alternative to a scientific mode of investigation, the constructivist epistemological position sits comfortably within qualitative research which is largely inductive and the

researcher generates meaning from data collected in the field and alongside the naturalistic, interpretive, and hermeneutical concepts the researcher values (Creswell, 2003; Schwandt, 1994).

This constructivist epistemology speaks to how research is conducted and how the data were viewed (Crotty, 1998). Pesut (2008, p. 107) states, “Because spirituality is such a hidden and subjective realm, it requires a more constructivist approach to inquiry.” The constructivist style of this research study has been underpinned by the same considerate attention and openness to the individual and their construction of knowledge, through life experience, that is seen as essential to holistic care within community-based palliative care (Crotty, 1998; van Manen, 1997).

Theoretical Perspective

A constructivist epistemology provides the foundation for the theoretical perspective, which in turn provides the philosophical foundation for the methodology, which provides the context for the process (Creswell, 2003; Crotty, 1998). For this research study the theoretical perspective chosen encompasses two complementary qualitative approaches within an interpretivist view that can bring experience into language: phenomenology and hermeneutics (Crotty, 1998). Basic assumptions of interpretivism include the personal quest for knowledge about one’s world and life, along with the diverse layers of subjective meaning of experience (Creswell, 2003). Rather than concentrate on the reduction of meanings to a single notion, interpretivism directs the researcher to tease out an intricacy of many views.

As theoretical perspectives within interpretivism, phenomenology and hermeneutics provide the philosophical viewpoints in which the methodology is grounded. Phenomenology has a focus on thinking about phenomena with the emphasis on the tangible experience of the participant (Boston et al., 2011; Ihde, 1971); while hermeneutics is interpretive, dialectic, and linguistic in nature (Crotty, 1998; Ihde, 1971). Being enmeshed as an employee within the

organization, the perspective of the researcher is considered emic, that of an insider, and it is joined with the understanding of the participants, as the reality of spirituality at BHCI is interpreted and co-constructed communally (Cottrell & McKenzie, 2011; Hamill & Sinclair, 2010). Hermeneutics and phenomenology are both reflective human science approaches derived from a philosophy of the unique and the importance of the individual voice (van Manen, 1997). The fluid nature reveals wonder, meaning, and understanding of what is often taken for granted and pre-conscious in everyday life: not what we know but the way we are (Carpenter, 2011; Laverty, 2003; van Manen, 2002a). Hermeneutic phenomenology attempts to make sense of the individual, subjective world by using two schools of philosophical perspectives: phenomenology through the thought of Husserl and Merleau-Ponty, and hermeneutics through the philosophy of, among others, Dilthey, Heidegger, Sartre, and Gadamer.

Phenomenology. Historically phenomenology, the study of phenomena, was initially described in philosophy texts by Immanuel Kant (1724-1804) in the mid 1700s as aspects derived from his transcendental argument (Carpenter, 2011; Kant, 1781; Pereboom, 2013). Kant begins with the compelling assumption of a thought, of knowledge, or of an experience, and then reasons through to a conclusion that holds at once the necessary essence or real nature of that thought, knowledge, or experience, yet also uncovers aspects that are taken for granted (Pereboom, 2013). However it is Edmund Husserl (1859-1938), influenced by Kant, who is considered to be the father of phenomenology (Crotty, 1998; Laverty, 2003), developing the phenomenological method purported to give access to the direct lived experience or pre-reflected lifeworld (Dowling, 2007; Laverty, 2003; van Manen, 1997). Working in Germany before World War 1 Husserl was concerned that the scientific community was removing research from the world of the subjective and the everyday

experience. Husserl (1970, p. 6) emphasized his concern with the pithy statement: “Merely fact-minded sciences make merely fact-minded people,” going on to ask:

> The mere science of bodies clearly has nothing to say; it abstracts from everything subjective... But can the world, and human existence in it, truthfully have a meaning if the sciences recognize as true only what is objectively established in this fashion, and if history has nothing more to teach us than that all the shapes of the spiritual world, all the conditions of life, ideals, norms upon which relies, form and dissolve themselves like fleeting waves, that it always was and ever will be so, that again and again reason must turn into nonsense, and well-being into misery? Can we console ourselves with that? Can we live in this world, where historical occurrence is nothing but an unending concatenation of illusory profess and bitter disappointment? (Husserl, 1970, p. 7).

Husserl refined his method of transcendental phenomenology in the first decade of the 20th century (Beyer, 2013; Friesen, Henriksson, & Saevi, 2012), pursuing the study of things *as they appear* so as to reach an essential understanding of human experience (Laverty, 2003; Moustakas, 1994). Transcendent phenomenology conveys that in any given moment a phenomenon will demonstrate an incomprehensible number of unnoticed aspects, of which only some will become apparent with further examination (Beyer, 2013).

A precursor to Husserl, Franz Bretano (1838-1917), was an influential German philosopher who desired to reform philosophy to provide scientific answers in response to questions previously answered by religion (Cohen, Kahn, & Steeves, 2000; Crotty, 1998). From the work of Bretano, Husserl used *intentionality*, the defining characteristic of consciousness (Schalow & Denker, 2010), being the principle that every mental act is related to some object, that is, all thinking, all imagining, all perceiving, and all remembering are

always about *something* (van Manen, 1997), and consciousness is revealed through the study of experience (Cohen et al., 2000).

Husserl developed phenomenological reduction or bracketing, which was "a reduction from particular facts to general essences" (Cohen et al., 2000). Husserl's transcendental phenomenology focuses on the fundamental configurations that allow objects, taken for granted in the *natural attitude,* to be brought to consciousness (Beyer, 2013). This results in the view of the phenomenologist being essentially free of prejudice and open to unbiased exploration (Beyer, 2013), as the natural attitude is set aside to examine and discover the essence of a phenomenon (van Manen, 1997). Husserl believed this process was assisted by bracketing (Laverty, 2003). From the Greek word *epoche*, the process of bracketing means to abstain from judgment, suspend belief or set aside the natural attitude and historicity (Hays & Singh, 2012; Moustakas, 1994). A symbol used in the school of Mathematics, bracketing separates a particular part of an equation from the rest allowing for an isolated, separate focus on each part of the mathematical sentence. Similarly bracketing in phenomenological research momentarily holds apart the understanding and prior knowledge of the researcher from contaminating the research and the lifeworld of the participant (Hamill & Sinclair, 2010).

Maurice Merleau-Ponty (1908-1961), built on the writings of Husserl and Heidegger (detailed in the next section on hermeneutics pp. 110), supporting phenomenological reduction to discover pure phenomena. His goal was the possibility of rediscovery of experience in a pre-reflective, new light (Dowling, 2007). Merleau-Ponty was a foremost contributor for *Les Temps Modernes*, the prominent political, literary, and philosophical magazine created by Jean-Paul Sartre, who was known as the spearhead of existential phenomenology (Crotty, 1998; Reynolds, n.d.).

Merleau-Ponty moved away from Husserl's more idealistic *all consciousness is consciousness of something,* and intellectual consciousness towards developing the notion that *all consciousness is perceptual consciousness* (Flynn, 2011; Lanigan, 1988). Merleau-Ponty was one of the initial philosophers to introduce language emphasis of thinkers into existential phenomenology (Diprose & Reynolds, 2008). He cultivated *Lebenswelt,* the relationship between a person and the lived world (Lanigan, 1988), which became the heart of human and social science research (Reynolds, n.d.). *Lebenswelt* brought the initial notion of *lived body* to the fundamental structure of the existential lifeworld (Flynn, 2011), moving on to include *lived space* (spatiality), *lived body* (corporeality), *lived time* (temporality), and *lived relation* (relationality) to assist with phenomenological questioning, reflecting and writing (Dowling, 2007; van Manen, 1997). These are elements of phenomenological reflection aligned with hermeneutics that are used for textual conversation analysis within this research study.

Phenomenological research does not generate theory, but unearths the fundamental meaning and essence of an experience, or knowledge, bringing it to consciousness (Cottrell & McKenzie, 2011; Doumit, 2010; Hays & Singh, 2012; Kant, 1781). It is at once a method of investigation and a way of thinking and perceiving, a philosophy (Carpenter, 2011). Phenomenology asks the question, What is this kind of experience like? (van Manen, 1997). It allows the construction of the story as experienced in a participant's lifeworld and attempts to bring their internal meaning to understanding (Doumit, 2010). Due to their extensive firsthand knowledge of the phenomena, interviewees are considered to be co-researchers (Hays & Singh, 2012). Phenomenology is the active thinking about and comprehension of both individual and collective human experience. This can lead to a culturally competent understanding of the actual lived experience of the multidisciplinary staff members regarding spiritual support within BHCI (Hays & Singh, 2012).

The institutional story and lifeworld of BHCI provides a culture all of its own. The multidisciplines work side-by-side and the management structure is relatively horizontal. It is usual for community-based practice to be carried out through case management and care contracts negotiated between a particular nurse/worker and a particular patient providing a sequence of care (Cioffi, Wilkes, Cummings, Warne, & Harrison, 2010; Duiveman & Bonner, 2012). Similar to most community-based health practice, the BHCI staff go out on their own to meet with patients and carers. However, quite uniquely in BHCI service provision, no patient is *case managed* and therefore, the staff member who will see a patient is dependent upon who is rostered on for that particular day. As all staff, except for the EO, are employed part time, rosters are flexible, and therefore patients often see a different staff member each visit. This rotation of staff is considered a strength of BHCI, having fresh eyes each visit, as well as the familiarity each patient acquires with a number of staff members bringing familiarity when after-hours emergency calls are made. While all staff members are sole practitioners in the field on any particular day, they are team members when they return to the office and write up notes. These communal notes are patient-specific but are shared globally throughout the entire organization. This creates a culture where the sole practitioner ostensibly does not work alone: a unique team-work phenomenon.

Phenomenological enquiry requires researchers to employ fresh vision as they move towards the phenomena through the eyes of the participants (Hays & Singh, 2012). So why is the view of the multidisciplinary team so important? Research by Hyde (2008b) into "Spiritual Questing and Religious Education," found children set out on an authentic endeavour to explore meaning and purpose in life. Three of the eight recommendations highlighted for nourishing Spiritual Questing are particularly pertinent to the foundational thinking around this research study. First, dialogue and engagement begins where the students are within their spiritual quest. Similarly, if the individual employees at BHCI are

going to experience, and learn competency in, spiritual and religious care, this research study needs to begin where they are, and build on their experience of spirituality. Recommendation Four was to engage with the shared story of the individual, encouraging contribution to the community's story. The identification and nourishment of spiritual language and story at BHCI require a communal story. The seventh proposal was to entwine spiritual story and language to bring potential options for genuine ways of relating and being in life. This entwining began to occur within the focus groups as people warmed to the subject, and as the groups came to a close the debriefing indicated new understandings, and new ways of relating. The phenomenological method starts with comprehension of a participant's lifeworld, and moves towards commonalities across the lifeworlds of all interviewees. Phenomenology research believes that a fresh vision is achieved by bracketing off assumptions and values held by the researcher (Hays & Singh, 2012). The understandings and perceptions of spirituality and spiritual support held by the researcher were documented in a conscious effort to clarify these assumptions, and to be aware of their potential to become a filter through which a participant's experience was viewed (Appendix A), however the researcher does not enter the process free of beliefs and values (van Manen, 1997). Phenomenology moves from the purely descriptive towards the interpretivist when combined with hermeneutics (Mayoh & Onwuegbuzie, 2013).

Hermeneutics. Hermeneutics is a theory of interpretation that is dialectic and linguistic in nature (Crotty, 1998; Ihde, 1971). Derived from the Greek hermēneuō, hermeneutics means "to interpret," which Crotty (1998) suggests evokes a sense of wrestling with the unfamiliar to assemble something recognizable, current, and comprehensible. Hermeneutics derives from ancient Greek philosophy where the god Hermes communicated messages to mortals from the gods; however it became fundamental in the field of Biblical studies subsequent to the Protestant reformation in 1517 (Ramberg & Gjesdal, 2013; van

Manen, 1997). Martin Luther's *sola scriptura,* placed emphasis on inwardness and personal appropriation of biblical truths which opened up traditional interpretations of the Bible for questioning (Ramberg & Gjesdal, 2013).

Hermeneutics moves into philosophical circles with the work of Dilthey, Heidegger, and Gadamer, and later on Ricoeur, turning its focus to fundamental human life and existence, questioning the deepest conditions of culture and symbolic interaction (Ramberg & Gjesdal, 2013). Hermeneutics encompasses lived experience and the delight when life understands life (van Manen, 1997). This is not a cognitive process, nor does it bring about the re-experiencing of another's experience, but rather an understanding of the possibilities for oneself to experience life in different ways (van Manen, 1997). The possibilities and the lived experience of the writer reveal themselves in the text.

Wilhelm Dilthey (1833-1911), like Husserl, was concerned about the imposition of empirical science and positivism upon the study of humans (Makkreel, 2012), and set out bravely to develop a conception of experience that would embrace fullness, combining volitional and affective energy with intellectual content (Dilthey, 1996). "The clue to such an improved theory of experience lies in the experience of the poets, but the formulation of the theory requires philosophical reflection" (Dilthey, 1996, p. 4). While he was unable to develop a distinctive epistemological methodology, Dilthey did use hermeneutics to historically ground and objectively express human science (van Manen, 1997). Dilthey questioned the concept of objectivity within human science, believing researchers to be entrenched in the life they are attempting to explore (Todres, 1998), but he did believe that meaning comprises a core that is autonomous to that which was meant by the creator (Dilthey, 1996).

Another German and student of Husserl, Martin Heidegger (1889-1976), was also interested in human experience as it is lived and the quest for *being*: *Daesin*, the German

word for *being there* (Cohen et al., 2000; Collinson & Plant, 2006). With a concentration on the phenomena of *being*, the study of ontology, Heidegger attempted to understand how the human person simply *is* or finds themselves in the world (Heidegger, 1962, 2010). The meaning of *being* was not considered something mysterious, but rather like being unaware of a body part when not thinking about it or looking at it, but being very aware of it when focus turns there (Gelven, 1989).

While thought of as an existentialist, Heidegger contradicted this label insisting that it was not personal existence, but rather *being* that held his interest (Collinson & Plant, 2006). Believing lived experience to be an interpretive process Heidegger promoted the use of hermeneutics for research (Heidegger, 1962), and specifically the hermeneutic circle where understanding is shown as a movement from pre-understanding to parts of experience, to the whole of experience, and back and forth (Dowling, 2007; Friesen et al., 2012; Laverty, 2003). The hermeneutic circle reveals that each interpretation develops from preceding understanding (Grondin, 2003).

Heidegger contested Husserl's rejection of historicity, maintaining that standing outside of one's own lifeworld to see things as they appear is unachievable (Dowling, 2007), that knowing is constantly historical, and entirely united to the being of the knower (Laverty, 2003). Heidegger uses the term *lifeworld* to describe the different worlds that life intentionally decides a human enter; distinguishing between religious, scientific, ethical, and aesthetic lifeworlds which induce human action in diverse ways (Schalow & Denker, 2010). These lifeworlds are countless and distinctive, compatible with the scope of possible and actual human realities, but also include fundamental existential themes such as individual affiliation with the body, with others, with time, and the physical environment (Willig & Billin, 2012).

Meaning for Heidegger is: “found as we are constructed by the world, while at the same time we are constructing this world from our own background and experiences” (Laverty, 2003, p. 24). *Being* in the world forces the individual to question the Self, and who the Self should be and/or become in any given situation (C. Henriksson & Friesen, 2012).

Jean-Paul Sartre (1905-1980), was in the forefront of existential phenomenology (Reynolds, n.d.). Sartre set out to develop an ontological account of what it is to be human. The main features of this ontology are the groundlessness and radical freedom which characterize the human condition (Onof, 2010). Using the ideas of Husserl and Heidegger, Sartre published his major work in 1943, “Being and Nothingness” (Lanigan, 1988).

Hans-Georg Gadamer (1900-2002) considered that the research methodology of hermeneutic phenomenology illustrated how people attempt to understand the world in which they live (Cohen et al., 2000); his focus, like Heidegger, was on *being* over consciousness (Grondin, 2003). This lead to the study of how people interpret and make meaning of their lives and what they experience (Cohen et al., 2000). “Understanding speech is not understanding the wording of what is said in the step-by-step execution of word meanings. Rather, it occurs in the unitary meaning of what is said – and this always transcends what is expressed by what is said” (Gadamer, 1976, p. 6).

For Gadamer, hermeneutics was the study of texts, language, and symbolic action (Cohen et al., 2000). “Our experience of the world is bound to language” (Gadamer, 1989, p. 448), and therefore whatever is not within language cannot be understood, for language is understanding (Grondin, 2003). Gadamer further believed:

> To understand is not to control, but is a little like breathing or loving: we do not know what sustains us, nor where the wind that gives us life comes from, but we know that everything depends on it and that we do not control anything (Grondin, 2003, p. 20).

Making use of the hermeneutic circle Gadamer saw it as bringing greater coherence to interpretation by describing the continual course of revision of understanding as anticipated; all within a greater familiarity of the parts (Grondin, 2003). “There is thus an element of mystery in the arising of the understanding” (Grondin, 2003, p. 21). The understanding of a text lies in seeing it as a reply to a constellation of questions which the researcher is required to convey in words (Grondin, 2003).

In research the addition of hermeneutics, with the interpretation of meaning, to pure experience, safeguards phenomenology from the risk of becoming shallow and one-dimensional (Todres, 1998). Hermeneutic phenomenology is descriptive and interpretive, beginning with the concrete experience of the everyday, and how it is understood by the participant to construct social meaning (Cohen et al., 2000; Fossey et al., 2002; Ihde, 1971).

Hermeneutic phenomenology. Hermeneutic phenomenology encourages a devoted awareness to the dimensions and textual details of everyday lives: experiences, beliefs, and values, from a community or a person, to another community or person (Crotty, 1998). With the priority on the voice and story of the investigated (Fossey et al., 2002), hermeneutic phenomenology is a research method that provides rigorous, critical, and systematic enquiry (Carpenter, 2011), valued for its ability to draw universal understandings out of the particular (Simons, 2009).

With phenomenology studying experience, and hermeneutics focusing on interpretation, hermeneutic phenomenology brings a depth to both, being the study of experience together with its meaning, always being open to reinterpretation and revision (C. Henriksson & Friesen, 2012). It rebuffs both the phenomenological notions that the essence of experience can be segregated from the historicity and culture of the researcher, and the idea of fixed transcendental meanings (C. Henriksson & Friesen, 2012). Through language of a poetic quality, hermeneutic phenomenology encourages creative and decorative writing as

both a *process* and a *product* of research (C. Henriksson & Friesen, 2012). Hermeneutic phenomenology asks particular questions about how people interpret their life experience and make meaning of it (Cohen et al., 2000).

Alongside Gadamer, other proponents of hermeneutic phenomenology include Ricouer and van Manen. Through research into the fundamental susceptibilities and capacities of humanity Paul Ricouer (1913-2005) moved from an anthropological focus to combine hermeneutic interpretation and phenomenological description (Dauenhauer & Pellauer, 2014). Ricouer believed that whatever is accessible to us is in and through language, and language is always open to interpretation (Dauenhauer & Pellauer, 2014). Ricouer also separated time into cosmic time, the unfolding of uniform progression where any *present* comes either before or after in succession, and lived time, where the present is encountered as a lived now where certain spaces of time have increased meaning (Dauenhauer & Pellauer, 2014).

Max van Manen (1942-) (1997), is another exponent of researching lived experience by bringing hermeneutics and phenomenology together in human science. For him, hermeneutic phenomenological research begins with four underlying assumptions (Richards & Morse, 2007; van Manen, 1997):

- the focus of the research is something that is of deep interest to the researcher;
- the experience studied is a phenomenon experienced by human beings;
- the description of lived world/lived experience is the perception, and interpretation, of *how* it is, not what it is *thought* to be like;
- it is only within the context of relationship to things, people, events, and situations, that human behaviour ensues, and only in *being in the world* can that behaviour be made understandable.

Spirituality, as the focus of assumption one, has been of great significance in my life, culminating in two Masters Degrees: theology and practical ministry. Now holding the position of Spiritual Support Worker at BHCI, the understanding and experience of spirituality and spiritual support held by my fellow workers is of immense interest to me.

Spirituality, as part of the biopsychosocial-spiritual model, is a WHO (2005), and PCA (Palliative Care Australia, 2005), commitment for palliative care yet there is little direction on how that could be attended to in an organizational manner by a community-based palliative care service such as BHCI. Moreover as each human being is naturally, intrinsically spiritually oriented (Bellous & Csinos, 2009; de Souza, 2009b; Hyde, 2008a; Ranson, 2002; Sulmasy, 2002; Tacey, 2010), the experience of spirituality is a phenomenon experienced by each human being, consciously or pre-consciously, and does need to be addressed within community-based palliative care service delivery.

Based on the *how* of the actual essence of experience, and the *relational* foundation of understandable behaviour, in line with van Manen's third and fourth assumptions, the research set out to comprehend what is the *essence* of how people are in these existential relationships, while acknowledging that no inquiry is complete or ultimate (Richards & Morse, 2007; van Manen, 2002b). The hermeneutic phenomenological undertaking was to create a potential interpretation of the character of spirituality as a particular human experience within community-based palliative care at BHCI. Therefore, this research study employed the philosophy of van Manen, a principal proponent of hermeneutic phenomenology, as a research method (Friesen et al., 2012; van Manen, 1997).

Hermeneutic phenomenology is a human science which examines people from a descriptive and interpretive basis (van Manen, 1997). It is an interpretive capturing, in language and text, of the experience of living life. This research study focused on identifying the phenomenon of spirituality within community-based palliative care: what is it *really* like,

and what is *essential* to this experience (Boston et al., 2011; O'Leary, 2010; van Manen, 1997). This approach has assisted in uncovering the often pre-conscious way that spirituality presents itself in life within community-based palliative care (van Manen, 1997). When considering research style, van Manen (1997) advises the researcher to choose a method that preserves harmony with the deep awareness of why the topic is yearning to be explored. The essence and lived experience of spirituality and spiritual care at BHCI was maintained and captured through the hermeneutic phenomenological theoretical perspective.

Methodology

This research study aimed to examine contemporary notions of spirituality through a literature review and to furnish a working definition of spirituality, grounded within the literature, which provides a foundation for understanding and interpreting participant responses from professionals within community-based palliative care. The strategy of this research study drew from the multidisciplinary staff their perception of spirituality that informs their praxis within community-based palliative care and their experience of spiritual support. The strength of the hermeneutic phenomenology theoretical perspective was in having the capacity to explore, interpret, and illustrate the lived experience of spirituality within the BHCI context (O'Leary, 2010). It was the excavation, bringing to consciousness, and description of the intangible existence of spirituality in the everyday lived experience of the multi-disciplinary team that was the objective of this hermeneutical phenomenological research (van Manen, 1997), and this was achieved through the employment of a case study methodology.

Case study. Case study research is a qualitative inquiry useful for the exploration of subjective phenomena (Creswell, 2003; Simons, 2009). It is a strategy of inquiry that entails focused and in-depth multi-sourced study of one or more cases within a bounded system, and in conclusion gives a descriptive account (Creswell, 2007; Yin, 2009). Across many diverse

disciplines such as medicine, psychology, law, political science, and other social sciences case studies have a renowned and extended reputation (Creswell, 2007), where current phenomena in a real-life context require empirical inquiry (Simons, 2009; Yin, 2009). Classified by the size of the bounded case and the intent of the case analysis, case studies can comprise one individual, a collection of individuals or a program, and intent can include an intrinsic case study (focus is on the case itself), single instrumental case study (illustrating an issue with focus on one case), or a collective/multiple case study (illustrating an issue through multiple cases) (Creswell, 2007; Simons, 2009). Case study is a useful research tool when an in-depth exploration of a particular issue, within a clear-cut context, is undertaken. It pays attention to the idiosyncratic (Creswell, 2007; Simons, 2009; Stake, 2000; Yin, 2009), and also has the capacity to co-create perceived reality while, presenting the possibility of self-reflexivity for the researcher (Simons, 2009). Creswell (2007, p. 75), proposes five aspects in the procedure of performing case study research:

- determining the presence of precise boundaries around a particular case that requires in-depth understanding;
- identification of the case and appropriate case study method;
- data collection;
- analysis that engenders detailed, descriptive understanding rich in context;
- interpretation of new knowledge.

While intrinsic case study research is considered weak in the context of generalizability due to its subjective atypical nature (Creswell, 2007; Yin, 2009), Simons (2009) contends that connectedness with the preciseness of the research environment can bring about naturalistic generalization with the recognition of similarities to situations. “Given sufficient detail and rich description, a reader can discern which aspects of the case they can generalize to their own context and which they cannot” (Simons, 2009, p. 165).

For this research study, an intrinsic case study was chosen with the focus on the case of spirituality within the bounded context of BHCI. This was due to the subjective focus of real life phenomena in a precise circumstance requiring deeper understanding (Stake, 2000). The above five-step procedure (Creswell, 2007), was followed with an in-depth understanding of spirituality within *defined borders* (BHCI and spiritual care), *identifying* itself as appropriate to the method of case study. *Data collection* occurred through extended focus groups and in-depth individual interviews, and was *analysed* with van Manen's (1997), lifeworld existentials which stimulated detailed, descriptive understanding, rich in content, leading to an *interpretation* of new knowledge.

Research Methods

Two different methods of data collection within case study methodology were chosen for this qualitative study: extended focus groups and semi-structured in-depth interviews. The collection of story lends itself to both methods, and provides a form of triangulation and validation with the comparisons (Groenewald, 2004). Focus groups allow for a communal drawing out of understanding, as the contribution of one person prompts another, and layer upon layer is added to the insight. Extended focus groups are those where proposed questions are perused by the participants before the group is held (B. L. Berg, 2009), while in-depth interviews give space and privacy for one-to-one discussion, and logistically are an easier fit around shift and family commitments (Cottrell & McKenzie, 2011).

Focus groups. Focus groups are the only qualitative method for collecting data with more than one person, and in research are identified as having three purposes:

- clinical purposes to bring to the surface hidden origins of behaviour;
- exploratory objectives to cultivate hypotheses;

- a phenomenological rationale when the goal of research is to uncover feelings, behaviour and thoughts shared within common experience (Hesse-Bilber & Leavy, 2011).

This dynamic style of data collection brings not only answers to questions asked, but also response and reaction to answers of other group members. The facilitator of a focus group is commonly called a moderator. Extended focus groups are a productive, multiple conversation, which can uncover common language while initiating the development of a story (Hesse-Bilber & Leavy, 2011). The focussed conversation of homogenous focus groups provides qualitative data that allows the moderator to understand a phenomenon in detail (Cottrell & McKenzie, 2011). They can be highly flexible in numbers of participants (2-6), number of groups held (until saturation or, as within this research study until the list of participants was exhausted), and duration of interview providing fresh and richly textured awareness of a phenomenon (Cottrell & McKenzie, 2011). The unit of analysis within this style of data collection was the group (Cottrell & McKenzie, 2011). Large amounts of data can be generated by large amounts of people in a short space of time, bringing insight and exploration of unanticipated topics (B. L. Berg, 2009). However, the quality of the data can depend on the skill of the moderator to facilitate the conversation. Two particular issues to be aware of include dominant personalities, and group dynamics influencing individual opinion (B. L. Berg, 2009). Bruce Berg (2009) outlines eight basic elements of focus group research:

- clearly defined objective/research problem;
- nature of the group – homogenous (similar characteristics: all BHCI employees);
- atmosphere/environment/rapport;
- an aware listening facilitator;
- well-organized and prepared facilitator;
- structure and direction, but restrained contribution to the discussion;

- research assistance – observer/field notes regarding group dynamics;
- systematic analysis.

The moderators' guide identifies the following important aspects:

- introduction and introductory activities;
- statement of basic rules and guidelines;
- icebreaker, with shorter questions and answers;
- deeper questions (B. L. Berg, 2009).

If desired, the moderator can provide the participants with information regarding what will be discussed in the group session to allow some previous contemplation before the group discussion begins (Appendix E-3). This is called an extended focus group (B. L. Berg, 2009).

Semi-structured in-depth interview. With data collection through semi-structured in-depth interviewing the researcher approaches the world from the view of the participant (B. L. Berg, 2009). This capacity for unravelling and appreciating the experience and applied meaning of the individual person was the initiative for employing some one-to-one in-depth interviews within data collection. Cottrell (2011) states that this type of research is most productive when the research is attempting to appreciate the experience and meaning of an individual. As with focus groups, open-ended questions are asked in order to promote the loosely controlled conversation. These more in-depth dialogues have the ability to reveal attitudes and feelings a participant holds of a particular topic or experience (Cottrell & McKenzie, 2011; Hays & Singh, 2012).

While semi-structured interviews have structure, planning, and protocol, much more flexibility is possible depending on the participant (B. L. Berg, 2009; Hays & Singh, 2012). It is possible to reorder the questions, adjust the language, or change the pace to suit the interviewee conversation and experience. Probes and prompts can emerge from within the interview process, or develop further between subsequent interviews. The adaptability gives

the researcher freedom to clarify and answer questions, which leads to a fuller understanding of the phenomena as described by the participant (Hays & Singh, 2012). As well, the in-built flexibility with semi-structured interviews can offer a richer description (Hays & Singh, 2012). The unit of analysis in in-depth interviews is the individual (Cottrell & McKenzie, 2011; Groenewald, 2004).

Four different styles of questions are required for semi-structured interviewing (Hays & Singh, 2012):

- essential questions focus on the research question, drawing out explicit information;
- extra questions checks reliability, they are analogous to the essential questions but the wording is changed;
- throw-away or icebreaker questions assist in rapport development, however can be useful in analysis to bring a wholeness to the story;
- probing questions are a way to unearth more information.

Hays and Singh (2012) warn that double-barrelled questions should be avoided. Two questions in one can cause confusion and cloud the data collected.

Formation of questions. The development of questions for both forms of data collection took a singular path, driven by the work of Litosseliti (2003) with focus groups. This began with the following six aspects that are similar to those above:

- clarify the research question;
- identify key topics/questions;
- draft question order;
- allot approximate timings for questions;
- consider prompts;
- presentation and stimulus materials (Litosseliti, 2003).

Bruce Berg (2009) adds a seventh aspect, that of validating questions where a restatement of significant or sensitive questions may be worded differently.

The research question was used as the foundation for writing the questions: What are the understandings and perceptions of spirituality held by multidisciplinary professionals involved in a community-based palliative care organization? Key topics were identified that supported discussion by providing links to a wider context and lists of prompts for the moderator (Cottrell & McKenzie, 2011). Four key topics to be explored were identified within the research question of this research study:

- unpacking, clarifying and defining a common language of spirituality;
- spirituality and spiritual care in community-based palliative care;
- multidisciplinary team skills for implementation of basic spiritual care;
- stories of spiritual support that express the communal nature of spirituality within BHCI.

The first three topics lined up with the themes highlighted within the literature, while the fourth provided a distinct space for participant involvement without prompting. Significant questions for each topic area were drafted, and then the topics were placed in the most fitting sequence for a questioning route: skills through prior training, definitions of spirituality, community-based practice and personal stories. This task helped generate broad, yet focussed, in-depth discussion on the various facets of the key topics. The four key topics and the questions they generated are listed below.

The aspect of confidence was placed at the beginning of the sequence as an icebreaker, with the idea that previous training was considered to be a question more impersonal in nature.

- Multidisciplinary team skills in implementation of basic spiritual care at BHCI:
    - Have you had any training or teaching about spiritual care?

    - Do you feel confident to assess or assist patients and carers when they are in spiritual pain?
    - What might spiritual pain look like?

After addressing previous education and skills identified by the multidisciplinary team, the next topic began to identify definitions of spirituality. This was still considered impersonal, as the questions asked for more cursory knowledge.

- Unpacking, clarifying and defining a common language of spirituality at BHCI:
    - What does spiritual and spirituality mean to you?
    - What sort of words could be included in an explanation of spirituality?

Bringing common language and meaning to spirituality and spiritual care was followed by more intentional questioning focusing on context and increased objective opinion.

- Spirituality and spiritual care within community-based palliative care:
    - Do you think spiritual care is important within community-based palliative care?
    - What might it look like in action?
    - What makes community-based palliative care unique?

After exploring the unique context of community-based palliative care stories of spirituality were considered. The largely personal aspect of story collection led to this topic being placed towards the end.

- Stories of spirituality and spiritual support that express the communal nature of spirituality within BHCI:
    - Can you tell me the story of something spiritual that happened with a patient, a carer or a workmate?
    - What does spiritual support look like, sound like, feel like for those involved?

This second question spoke to validation, a differing restatement of the central question, and finished the formulation of specified questions. The question order was then concluded with an opportunity for anything unsaid to be shared. Ending questions:

- Have other thoughts, definitions or stories been prompted for you?
- Have we missed anything?

These finalising questions allowed the participants to further define spirituality and spiritual care for themselves.

Approximate timing for each key topic area was then added. The icebreaker that asked about confidence in supporting spiritual support based on previous training was allotted fifteen minutes. Similarly, fifteen minutes was selected for topic two: unpacking and defining spirituality. The focus on spirituality in community-based palliative care was given ten minutes, and a generous twenty minutes was chosen for sharing stories of spiritual support. A range of probes and prompts were devised to be employed by the moderator as required to facilitate and deepen the research conversation (Creswell, 2008; Litosseliti, 2003) (Appendix E-2).

The final aspect in question development was the consideration of presentation and stimulus materials for the research context. Passive priming of the environment was considered, with visual, aromatic, and aural prompts of spirituality. However, further consideration of context and participants led to the belief that this could leave participants uncomfortable rather than what the priming was hoping to achieve. For all focus groups, food was chosen as a statement that work time was suspended and conversation encouraged. Both the extended focus groups and the in-depth interviews were taped for later transcription. Focus groups and semi-structured in-depth interviews were continued until saturation was reached: a place where no new information was being presented to the researcher and all available participants had contributed (Cottrell & McKenzie, 2011).

Ethical considerations. Fossey (2002, p. 719) declares that values and ethics must be intrinsic within research: "participant values and personal nature of researcher-researched interactions are integral to the research process." In designing and preparing for this research study, ethical approval was sought from the Ballarat Health Services and St John of God Health Care Human Research Ethics Committee, as BHCI falls under their jurisdiction. Approval was granted on 6th September, 2012, with the HREC Reference Number: HREC/12/BHSSJOG/98 (Appendix B-1). External Ethics Approval 2013 08V was then given by the Australian Catholic University where the researcher is a student (Appendix B-2).

Participants. In community-based palliative care, where holistic care is considered important, the essence of spirituality can be explored across the disciplines. The participant pool included the EO, palliative care physician, palliative care registrar, specialist palliative care nurses, allied health staff members (social worker, welfare worker, and spiritual support worker), the volunteer co-ordinator, the administration staff and the members of the Board of Management (BOM). All staff members of the organization bring a spiritual presence to their particular discipline as they interact with individual patients and carers, which is something not always consciously recognised. All, too, have ideas of how spiritual support could look and be experienced within the organization. To gain a rich description of the essence of spirituality in a multidisciplinary organization requires input from various occupations.

Procedure. A meeting was held on Wednesday 6th February, 2013 with the EO to discuss implementation of the research at BHCI. It was decided to seek permission from all staff for a mail out, via the organizational email system. It was also agreed to hold the staff focus groups over a lunch time period, in the hope that the research would cause less interruption to work and personal lives, and lead to greater engagement. The BOM meeting to be held on the 18th March, 2013 was chosen for a focus group.

An email was written, and sent, to seek permission from staff for their address to be disclosed to the researcher for the Participant Information and Consent Form (PICF) mail out (Appendix C). Only those with an objection were required to reply. The PICF (Appendix D), along with an outline of possible questions (Appendix E-1) was posted out on the following Wednesday, with a request that they be returned the following Tuesday 19th February, when all staff were assembling for a full-day staff meeting. A list of proposed questions was sent to participants in the interest of openness and transparency, and also to prime their thinking before meeting for data collection (Appendix E-1). The PICF was posted to eighteen employees, with twelve agreeing to be involved in the research by the return of signed forms. Work rosters were examined and two focus groups were created through convenience and availability: one of four and one of six members. These dates were emailed to each employee, with the groups to be held for 45 minutes over an extended lunch break. Another email was sent to the ten BOM members, with a PICF attached, inviting them to stay at the end of a regular, shortened management meeting and be involved in a focus group.

Informed consent was sought from all participants prior to interviews through the use of an information sheet regarding the research and a specifically constructed consent form. Participants were made aware of the nature and aims of this research study and informed they would be provided with copies of their written transcripts if they chose to edit or comment on them further. Confidentiality was addressed by the use of pseudonyms on all transcripts and information that could identify participants was erased from transcripts and is not a part of the thesis itself. Participants were assured that they might withdraw from the study at any time and have all of their transcripts destroyed.

Data collection took place between March and May, 2013, with the BOM extended focus group occurring in the board room and all other extended focus groups and interviews conducted in the counselling room at BHCI by the researcher. An observer, another research

student, was present at each of the focus groups, which gave an objective set of eyes and ears assisting with triangulation of the data in the analysis stage. In total nineteen participants took part in the research, being seventy percent of the total staff.

Focus group one. The initial data collection with the Board of Management was attended by eight participants. To move away from the business context of the board meeting two bottles of wine, apple cider, and a range of cheeses were brought into the room at the beginning of the group. This provided a gasp of delighted surprise, and the desired change of atmosphere. The PICF forms were happily signed for each participant and the conversation was lively with all entering thoughtfully into the discussion. Very few prompts were required as the dialogue rolled around the table. The questions were useful in drawing out understanding of spirituality and spiritual care from the focus group members:

- How would you describe spirituality and spiritual care?
- What do you see as the roles of spiritual care at Hospice?
- How do you see spirituality operating at Hospice?
- Do you have a vision for spiritual care?

Focus group one ended with a participant sharing that the time had been *insightful* and *an enriching experience* (Appendix G, Line 51,52). The group had achieved what it set out to research: an experience of spirituality. The following day the EO sent an email to all members of the focus group thanking them for their attendance and engagement with the research. This led to an absent member making contact and asking to be included. This person was then individually interviewed at a convenient time.

Focus group two. The list of possible questions for the staff focus groups was reappraised after the first focus group. The realisation that twelve questions in 45 minutes was too ambitious brought about a decrease to nine. This, the first focus group made up of staff participants, was held over staff lunch time and began with apple cake and cream; again

an indication of a different atmosphere. One employee had not read their email and through office conversation thought they had been left off the list. This staff member approached the researcher disappointedly asking why they had been unwanted; the relief when told they were included was quite tangible. The group assembled with much chuckling over this story and again the consent forms were happily signed for each member.

As the questions were asked and the conversation unfolded the participants used probes and reflective questioning to draw understandings and perceptions out of each other. This group ran ten minutes over time, however after the participants were thanked and the recording device turned off, the discussion continued for another twenty minutes as participants encouraged each other on the growing revelation of the spiritual basis of their practice. This again was a symbol of spiritual care manifesting within the interactions of the group.

The questions were tailored towards the multidisciplinary staff working within community-based palliative care:

- Have you ever had any training or teaching in spiritual care?
- What does the word spiritual or the concept of spirituality mean?
- What are some of the words that you would use to describe what you think spirituality means or feels like to you?
- What do you think is unique about community-based palliative care?

On conclusion, as the dishes were washed in the tearoom, one participant said, “Thank you. That was very insightful.” Once more, the allusion was to an experience larger than the research questions on their own. Peter Gilbert, the National Institute of Mental Health’s national project leader, speaks of teaching social workers about spirituality, “The only way to get into this area...is to let students and staff get into it themselves before you can expect

them to explore this with other people" (Mickel, 2009). This was occurring as the focus groups met.

Focus group three. After the second focus group questions were once again open for revision. The cognitive focus of the answers started a questioning process for the researcher regarding the essence, or maybe lack of, displayed in the replies. Was the data capturing the essence of spirituality, or thoughts and actions of spirituality? Was this indicative of lack of essence about the participants or the questions, or insufficient immersion in the transcript? After looking back over the questions the researcher decided to continue with the list as it was, with the addition of a fifth question not asked in second focus group due to lack of time:

- Can you tell me a story of something spiritual that happened with a patient, a carer or a workmate?

Focus Group three began with chocolate cake and grapes, and again was held through an extended lunch break. The PICF was signed for each of the four participants present with two participants being unable to attend due to a work emergency. More concise and definite with their answers, this group too began early on to affirm each other's views and practice of basic spiritual care. The participants were all content with their input and had said all they wanted to as the time came to end the group.

Each focus group was audio-recorded by two different recording devices, the researcher using one to transcribe verbatim the interviews. An observer attended each group, operating another recording device and taking notes of observable behaviours the researcher may have missed. The verbatim was then read by the observer, while listening to the recording on the second device, to determine accuracy of transcription. Professions included in the extended focus groups and interviews were medical (nurse, doctor), administration, welfare, bereavement, compliance/volunteers' coordinator, management, and various

professionals on the board of management (company director, accountant, GP with palliative care diploma, marketing, DHS, EO, medical, lawyer).

Individual interviews. Individual interviews were held out of work hours at times that suited the participants. Those involved were chosen because of their inability to attend the various focus groups. These took place with only the researcher and participant, and one recording device.

Interview one was held with a member of the BOM who had been absent from focus group one, but was interested in being included in the study. The question list was the same as that used for the first focus group. While the possible question list was revisited after each focus group and interview with the idea of modifying it, if necessary, this was not deemed necessary and the decision was made to maintain the question list each time.

Interview two included a breadth of spiritual topics as the questions led to tangents and in-depth thoughts. A question about spiritual pain was added: When you're with a patient what might you see that would cause you to come away thinking that was spiritual distress? What sort of things might you label as spiritual distress? Or spiritual need?

Explication of the data. As the interviews were transcribed again the question rose whether they had captured the core of the experience of being spiritual, or whether the content was more cerebral. It seemed the questions had caught what people *thought* about spirituality and spiritual care in the lifeworld of BHCI, but would that result in the essence and experience of spirituality becoming apparent.

The literature on hermeneutics and phenomenology was revisited, and the researcher pondered whether what was thought to be a cerebral approach to the textual conversations had been motivated by the research question: The *investigation* of the *understandings* and *perceptions* of spirituality *held* by multidisciplinary professionals involved in community-based palliative care. Another issue was the contextual effect. BHCI is ostensibly a problem-

solving milieu, a place of *doing* for the other. Common language, then, is about deed and the perspective of another. A third impact was the professional identity of the participant: had spirituality been seen and discussed from the patients' perspective through professional ideology? However Crotty (1998) speaks of thought and behaviour as constructs of culture. The *I think* statements seemed to point to pre-conscious configurations of spirituality within the culture at BHCI. The epistemology of hermeneutic phenomenology affirms it is language and understanding that bring knowledge into being (Richards & Morse, 2007).

After some immersion in the textual conversations the transcripts were collated into subgroups for each separate question and in the rereading a sense of what each question gathered across the sum of participants began to arise and give understandings from different angles. Concurrently the text was read and reread in relation to individual groups and interviews to get a feeling for the experience of spirituality within each conversation. These two foci fulfilled van Manen's (1997) call for balancing between the parts and the whole of the textual conversations.

Explication of the data sought to unearth meaningful themes from the diverse stories of lived experience: a mining for meaning within the text of conversation (van Manen, 1997). The essence of spirituality within community-based palliative care emerged as themes and relational patterns form, while the text was probed, read, and reread (Carpenter, 2011). The use of interpretation to transform the text was the reflective process of allocating, formulating, and expressing the anatomy of the meaning of lived experience of spirituality that leads to an understanding of its essence (Groenewald, 2004). The contemplation of lived experience becomes the structure of its thematic aspects (van Manen, 1997). Themes, within phenomenology, can be identified as *structures of experience* and it is these structures, within analysis, that the research study is attempting to establish (van Manen, 1997). These themes became the strands of phenomenological description, and came about from an openness to the

capacity embedded in lived experience and the desire to make sense of a phenomenon by the use of words and insightful inventions (van Manen, 1997). When pursuing the essential qualities of spirituality exploration looked to discover facets or characteristics that made the experience what it is. In the process the indispensable quality of a theme was indicated by asking the questions: Without this theme does the phenomenon lose its elemental meaning? (van Manen, 1997).

The complete hermeneutic phenomenological transcripts have been named separately for each of the three focus groups and three individual interviews and placed within a single document, Hermeneutic Phenomenological Transcript of Textual Conversations, found in Appendix G. Within the textual conversations the participants were allocated pseudonyms in an endeavour to safeguard confidentiality.

As the researcher read, reread, and became immersed in these textual conversations the conviction that something was missing grew stronger and stronger. In due course it became obvious that there was a gap in the textual conversations. Holistic care includes spiritual support and the silence from this profession left the multidisciplinary voice incomplete. The voice of the researcher as a professional peer and member of the multidisciplinary team was missing; subsequently the researcher was required to interview herself, thus preserving harmony with the multidisciplinary approach.

Four fundamental existentials. van Manen (1997) advises consideration of a style of analysis that is harmonious with the deep awareness of the topic and its longing to be explored. There are several interpretations of the phenomenological method, however the human science approach of van Manen (1997), with the lifeworld fundamental existentials, was chosen for this research study due to the cohesion of method and research question (Carpenter, 2011).

The analysis from the human science of van Manen (1997) includes the four fundamental lifeworld existentials: lived space, lived time, lived other, and lived body (Dowling, 2007; Flynn, 2011). Lived space, or spatiality, connotes the *felt* space experienced, rather than the mathematical spaces of length or height, or the physical space of a particular room. Imagine the feeling of entering a large, cold, deserted hall where your footsteps echo on the wooden floor, the window panes rattle as the wind blows past and there is a faint musty smell hanging in the air. The effect of this lived space is completely different to entering the same physical space when a playgroup is holding their regular get-together. Now your footsteps seem silent against the chatter of children and parents, and the prams and scooters racing around. In addition the air is filled with the smell of freshly brewed coffee from the kitchen. The lived space of the first scenario is the fodder of mystery movies, with the capacity to engender anxiety and vigilance; the lived space is experienced as fearful. The same physical space takes on an entirely different experience of lived space when the play group invade and childish noises bring a sense of joy and aliveness. Within the fundamental existential of lived space humans evolve into, and feel deeply, the space they are in (van Manen, 1997).

Temporality, or lived time, refers to subjective time, which can speed up through excitement and pleasure, while often slowing down with boredom and pain. Lived time also expresses the experience of movement made through life: the young child experiences lived time as abundant and never-ending, while for the older person lived time can be experienced more as short and precious. Lived time is impacted by hopes and expectations, or lack of them. The horizon of a person's temporal landscape encompasses the past, the present, and the future (van Manen, 1997).

For van Manen (1997), lived other, or relationality, is about shared, interpersonal space. It focuses on the lived relation sustained with others and the significance placed on

these relationships. Meaning and purpose can be made out of life through the connections made and nourished.

The last of the four fundamental existentials is the lived body, which pertains to the reality that the human is always in the world in a corporeal (bodily) way, experiencing all of life and what the world offers through bodily senses. The physical body at once both reveals to the world who a person is externally, yet also conceals from the world who that person is internally. When the body is under an appreciative gaze the body may grow enhanced in its modality of *being* and surpass its usual grace and its normal abilities. However, if the body is the object of a critical gaze, it may lose its naturalness and become awkward (van Manen, 1997).

It was within the framework of the four fundamental existentials of lived space, lived time, lived other, and lived body that movement was made towards the textual conversation allowing elements of spirituality to rise and find their place. The conversations with individuals and focus group were the texts used to research the lived experience of spirituality at BHCI. Themes were used as the tool to bring shape to the shapeless, to describe the phenomenon of spirituality, acknowledging that the portrayal was always going to be a reduction of the whole, in the effort to construct a fused précis or communal story (Groenewald, 2004).

A premise that the researcher brings to both the position of spiritual support worker and to spiritual research is that spirituality is intrinsic to each human person (Bellous & Csinos, 2009; de Souza, 2009b; Ranson, 2002; Sulmasy, 2002; Tacey, 2010). The exploration of the experience of spirituality in the every day, within the BHCI workplace, has integrity with both employment and with the research method. The use of hermeneutic phenomenology puts language to the essence of the experience of being spiritual within community-based palliative care: taking the ad hoc, the pre-conscious, and the taken-for-

granted, and illuminating this as lived experience (Creswell, 1998). Further, the gathering of the experience of others assists the individual to become more experienced in the Self (van Manen, 1997).

The exploratory nature of qualitative enquiry is useful in unearthing individual unique understandings as well as perceptions held in common. Much of this research study contains a specificity to the particular organization and a uniqueness growing out of the creative efforts of the participants as they tell their story, and the retelling of the researcher (Fern, 2001). The structure of a human science theoretical perspective in research employing hermeneutic phenomenology, involves six research activities, all of which have waxed and waned in interaction throughout the process:

- *turning to a phenomenon which seriously interests us and commits us to the world* (The researcher is employed in the field and considers the research as a quest);
- *investigating experience as it is lived rather than as it is conceptualized* (Hermeneutic phenomenology is used to give space for the understandings and perceptions of the participants to rise and inform);
- *reflecting on the essential themes which characterize the phenomenon* (Immersion in the textual conversations);
- *describing the phenomenon through the art of writing and rewriting* (Reading and rereading, writing and rewriting will allow essential themes to surface);
- *maintaining a strong and oriented pedagogical relation to the phenomenon* (Understanding the science of the provision of spiritual education is the desired outcome);
- *balancing the research context by considering parts and whole* (Interplay of reading and writing from verbatim, through hermeneutic phenomenological texts, to findings and interpretation) (van Manen, 1997, p. 30).

These six research activities have been interwoven throughout the research process.

The communal story, informed and shaped by stories and the literature, then painted a picture of spirituality as experienced within the lifeworld of community-based palliative care. A hermeneutic phenomenological story that has integrity sits well, or reverberates, with participants and will be embedded within the experience of spirituality within community-based palliative care (Fossey et al., 2002). It displayed the *essence* of the lived experience of spirituality in community-based palliative care (Creswell, 1998; O'Leary, 2010); and as pre-conscious became conscious, and shared communal text was written, the inquiry sought to name and express the silence of spirituality in palliative care (Chase, 2008).

The lived experience within the four existential fundamentals of the lifeworld, lived space, lived time, lived relation, and lived body, provided a pathway for this research study to journey into the textual conversation of how spirituality presented itself in the life of community-based palliative care (van Manen, 1997) within a trustworthy framework.

Trustworthiness

Within qualitative research, to ensure trustworthiness of the text and research the criteria of credibility, transferability, dependability and confirmability are applied, which are consistent with the hermeneutic phenomenology paradigm (Guba & Lincoln, 2000). *Credibility* employs prolonged engagement to create vividness of description; requiring systematic rigor to design, data collection, and analysis (Cottrell & McKenzie, 2011). *Transferability* within the context brings thickened language descriptions of spirituality within community-based palliative care (van Manen, 1997). *Dependability,* founded on credibility, looks for genuine links in the conversation between the interpretation and the text. *Confirmability* uses reflexivity and auditing with the texts. These indications of trustworthiness merge with the reader being convinced that the research study presents the data accurately (Cottrell & McKenzie, 2011). Triangulation, too, helps confirm validity, with

more than one method of data collection being used, and searching for consistency between the two, rather than identical results.

To affirm the trustworthiness of this qualitative hermeneutic phenomenological research the criteria of credibility, transferability, dependability, and confirmability were applied (Guba & Lincoln, 2000). *Credibility* was employed with prolonged engagement in the textual conversations that have created a vividness of description and provided systematic rigor to the process of design, data collection and analysis (Cottrell & McKenzie, 2011). *Transferability* was achieved with thickened language descriptions of the experience of spirituality and spiritual care within community-based palliative care (van Manen, 1997). *Dependability* was indicated by inclusion of genuine links and quotes in the conversation between the interpretation and the text. Reflectivity and auditing, reading and rereading, writing and rewriting assisted in *Confirmability*. To further help the process of validity, triangulation has occurred with more than one method of data collection being used, and searching for consistency between the two, rather than identical results.

Validity and triangulation were supported by the use of NVivo10, an internationally renowned computer platform developed in Australia that is used for analysing unstructured qualitative data. It performs textual analysis and provides a vehicle of comparison with the hermeneutic phenomenological conclusions from the textual conversations.

NVivo 10 data analysis. Attendance at a NVivo 10 training workshop organized through ACU gave the researcher a good grounding in the use of this computer assisted thematic analysis tool for qualitative research. When the NVivo 10 program was first installed explored to gain some familiarity. The first operation performed on the data, a word frequency query, the results highlighted ‘think’ as the most frequently used word throughout the total data set with 219 occurrences. The extensive usage of this word brought up the

query: had the context and opinion been cerebral? At first this seemed concerning: did a cerebral process deny the lived experience sought by hermeneutic phenomenology?

After transferring the verbatim as separate questions into the program and establishing basic nodes that had originally emanated through rereading the transcript, the responses were able to be coded to each question by highlighting applicable text and copying it across to the nodes. After working through the responses to each question the nodes were then analysed and summarised for key words. A text search was then run on key words and concepts. This used the NVivo 10 program in a deductive method. Key words used four or more times were collected from the verbatim for each separate question and grouped accordingly. Table 4 displays the results.

Table 4
NVivo 10 Results from Verbatim as Separate Questions

Topic	Key Words
Spirituality:	acceptance, allowance, assessment, awareness, belief, care, change, comfortable, communication, connections, distress, experiences, feeling, focus, influence, integration, intuition, kind, life, living, meaning, need, peace, purpose, question, reflect, remember, still, struggle, support, talk, time, together, understand, worrying.
External spirituality:	family, mystery, religion, smoke, tradition.
Internal spirituality:	core, energy, essence, everything, human, inner, inside, person, self, spirit, whole, within.
Community-based care:	calm, caring, different, family, holistic, home, important, listen, need, nurturing, patient, religious, respect, special, spiritual, still, supporting, talk, time, unique.
Spiritual distress:	restlessness, control, questions, answers, uneasiness, time.

Note. The summary of key words for the ‘define’ node indicated ‘think’ as second only to ‘spiritual’ in use. Again what looked like a cerebral approach was evident.

NVivo 10 was then approached a second time, after additional immersion in the data, from a different starting point. This time the full transcript as a whole was entered as the source data, and then themes for nodes were directly extracted from this raw data without predetermined themes. This was an inductive, naturalistic process as themes occurred when new concepts emerged from the source. This process highlighted five significant themes: understanding spirituality, spiritual distress, spiritual care, community-based practice, and education. Table 5 demonstrates the elements within these themes.

Table 5

NVivo 10 Results from Full Verbatim

Topic	Keywords
Understanding Spirituality:	here and now; growth and evolution; innate and intuitive; inner self; connectedness with Self, Other and mystery; meaning and purpose; religion.
Spiritual distress:	uncomfortable with Self; restlessness; unexplainable and intuitive; disconnectedness with Self, Other, mystery; lack of control; decline; regret; lack of meaning and purpose; exacerbates physical pain; process of letting go, sorting out, issues of parting; “I don’t want to be here”; “I don’t want to be a burden.”
Spiritual care:	reframing; acceptance; stillness; respect; support; opening up the soul; active listening; time; side by side; faith; multidisciplinary; professional; holistic; traditional wisdom; bring death into reality; mysterious: a not-knowing; patient/carer/family need driven.
Community-based Care:	patient environment/ time/ agenda/need; patient/carer lead topics of conversation; holistic; personalised; nurturing;

	flexible; responsive; facilitation/advocacy around patient/carer need; creates community within the team.
Education:	person centred care; suspending judgment; communication: listening & common language; intuition; connectedness/disconnectedness; holistic care; Self/Other awareness; organizational values.

The findings from both of these analysis approaches from NVivo 10 (Tables 4 and 5), triangulate the data and indicate five significant themes that have surfaced from within it that support the results that emerged within the hermeneutic phenomenological explication of the findings.

Table 6
NVivo 10 Data Analysis

Spiritual Definitions

here and now, evolving; innate and inner self; connection with others; meaning and purpose; mystery and religion.

Spiritual Distress

uncomfortable with self, lack of control, restlessness, decline, regret; exacerbates physical pain; fighting death, “I don’t want to be here” and “not being a burden”; lack of meaning and purpose; unexplainable and intuitive; the process of letting go/sorting out/parting.

Spiritual/Religious Care

patient need driven, including carer/family; reframing, stillness, support, listening, side by side, acceptance/respect, time, opening up the soul; traditional wisdom, faith; holistic, mysterious: a not knowing; brings death into reality; multidisciplinary, professional.

Community-Based Care

patients’ own environment; time/agenda/conversation dictated by patient and carer; facilitates/advocates for patient/carer; holistic, nurturing, personalised, flexible and responsive; multidisciplinary in nature it creates community within the team.

Skills and Spiritual Education Identified and Sought

person centred care; suspending judgment; communication: listening and common language; intuition; connectedness; holistic care; self/other awareness; organizational values

These indications of validity drawn from explication of the hermeneutic phenomenological textual conversations and the NVivo 10 results must now connect with you, the reader, being convinced that this research study presents the data accurately (Cottrell & McKenzie, 2011).

Limitations of this Research Study

The total sample of multidisciplinary staff operating within BHCI is small and therefore it was not possible to use randomized selection of participants, however a participation rate of seventy percent of the total staff is considered to be a significant voice of the organization. It needs to be acknowledged that the constraints of shift work and a patient crisis meant that more voices could not be added. The literature acknowledges a resistance by professional palliative care staff to engagement in research within a "research naive clinical setting" (Bullen, Maher, Rosenberg, & Smith, 2014, p. 78). Further, it is possible that those who chose not to participate in the research did so because spirituality was not a main concern within their life, or perhaps within their practice. Nonetheless, the researcher considers the quality and quantity of the research to be significant and representative of the organizational understanding and perception of spirituality and spiritual care.

Summary and Significance of this Research Study

This chapter has described the theoretical perspective, research design, research process, and initial outcomes of this qualitative study into the understandings and perceptions of spirituality and spiritual care held by multidisciplinary professionals within community-based palliative care at BHCI.

> Research provides intelligible, rigorous and systematic methods to investigate and describe claims about the world that spirituality cannot avoid....there is also a need to develop and be confident in methods of inquiry that help us to better describe and understand the experience and expressions of particular spiritualities and the actual practices of spiritual care (Cobb, Puchalski, et al., 2012, p. viii).

This was the goal and quest of this research study, to systematically describe, understand, and express spirituality and spiritual care as experienced within BHCI. This research study has adhered to a high standard of the qualitative paradigm with methodology sensitive to the research question and context, triangulated analysis, and the utilization of perspectives that are multidisciplinary (medical, management, welfare, administration, spiritual). The theoretical perspective of hermeneutic phenomenology was selected due to its facilitation for reflection upon this phenomenon by the researcher. It also held the capacity of immersion and thickened language to present an innovative common language around spirituality and spiritual care at BHCI. The textual conversations have been immersed in, contemplated upon, and given thickened language through the use of the four fundamental existentials of the lifeworld. The quality and significance of the research is further shown with the alignment of spirituality within everyday clinical praxis at BHCI with those that exist within the multidisciplinary staff, reflecting community norms and expectations. The integration of research with palliative care clinical practice, providing evidence based practice, is a relatively new research field (Bullen et al., 2014). It is expected that the outcomes of this research study will lead to increased effective, evidence-based spiritual practice within BHCI policy, facilitation of relevant spiritual care as a service provided by the organization and the development of a simple tool to enable useful exploration of the spiritual well-being of palliative patients.

This chapter has made note of all the elements of the research process undertaken in this research study. Figure 3 shows the Social Research Design framework, with the research choices made for this research study, and outlined throughout this chapter, inserted within it.

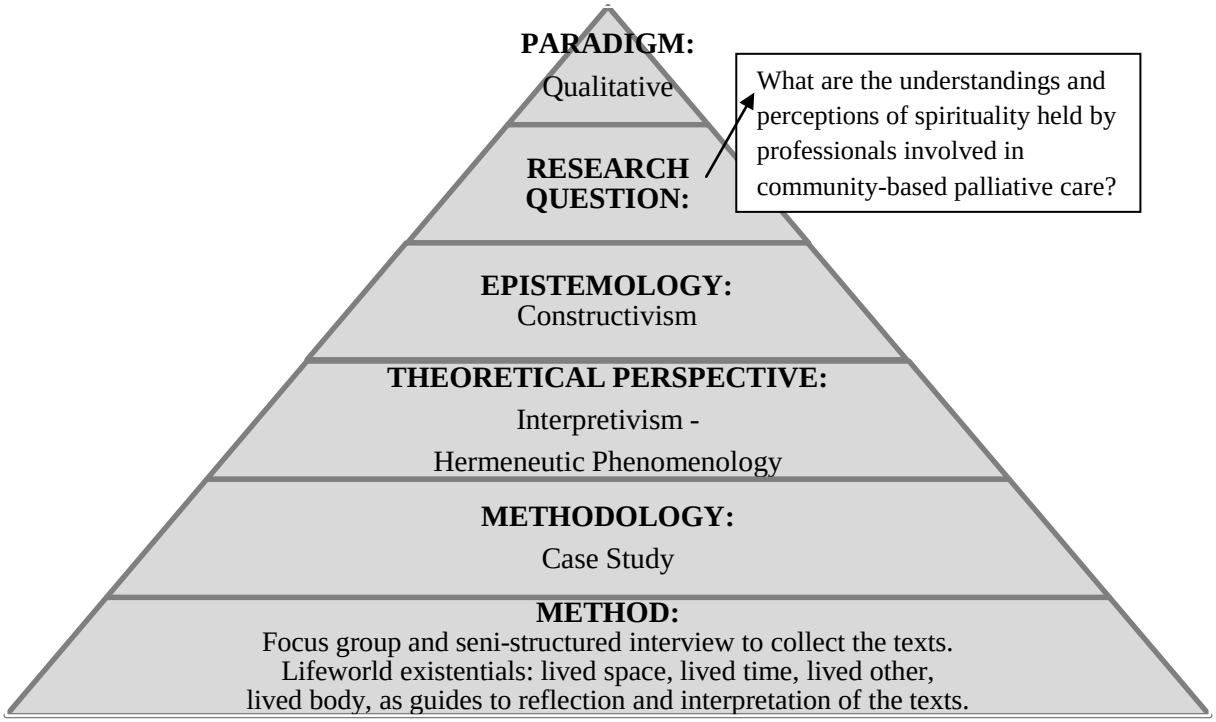

Figure 3. *The Process of This Research Study.*
Note: This figure illustrates the chosen elements of the different components of Social Research Design (Crotty, 1998) revealed throughout this chapter.

This chapter has summarised the foundational philosophical and theoretical manner in which the research was prepared for, the process by which the research ensued, and the concepts that underpinned the analysis of textual conversations bringing out the lived experience of spirituality at BHCI.

Within the following chapter the textual conversations in hermeneutic phenomenological poeticized text (van Manen, 1997) are presented through the lens of the fundamental lifeworld existentials of lived space, lived time, lived other, and lived body.

Chapter Five: The Findings of this Research Study

The purpose of this research study was to unearth some of the understandings and perceptions of spirituality held by diverse professionals working within a community-based palliative care organization, Ballarat Hospice Care Incorporated (BHCI). These findings will then provide the foundation of recommendations for a professional development and orientation program providing education and common language about spirituality within the context of BHCI. The research study was conducted by a member of staff, which assisted in the quest for credibility through prolonged engagement (Guba & Lincoln, 2000). It is acknowledged that while familiarity with the context could have biased the findings, it was also an advantage. Immersion in the work environment brought valuable insight and knowledge that an outsider could not be privy to.

Explication of the Data

Pursuant to the constructivist philosophical position, meaning is considered to be individually constructed as life is lived in the world (Crotty, 1998). A hermeneutic phenomenological approach revealed some of what was understood by the staff to encompass spirituality so that clarification and definition of spirituality would be found *with* the staff, and not *for* the staff (Crotty, 1998). The textual conversations were developed by extended focus group and individual interview held between March and May, 2013. Nineteen participants took part in the research, which made up seventy percent of the total staff. The fundamental lifeworld existentials of van Manen (1997), and the relational aspect of hermeneutic phenomenological research supplement the idea of spirituality as affiliative and connective (de Souza, 2009b).

For purposes of trustworthiness and triangulation (Guba & Lincoln, 2000), the full transcript was entered into NVivo 10, a qualitative data analysis software program, for a comparison of findings . This procedure supported the principles of *dependability*, looking

for genuine links between the interpretation and the textual conversations and *confirmability* which occurs through auditing the data. A summary of the evaluation is documented in the previous chapter (pp. 134-137).

Employing the thought of van Manen in this chapter we uncovered some of the essential meaning of spirituality as perceived by the multidisciplinary team within the specific context of BHCI. “The purpose of phenomenological reflection is to try to grasp the essential meaning of something” (van Manen, 1997, p. 77). Investigating experience as it is lived relied on immersion in the rich hermeneutic phenomenological material that was collected (van Manen, 1997). It also allowed for a process of inquiry into the meanings of spirituality as experienced, understood, and applied by the various professional disciplines at BHCI (van Manen, 1997). The data was systematically inhabited with an ethos of hospitality where, as guest, the researcher embraced the language of the host (or participant), mining and shaping, and mining again the implicit layers of meaning that rose (Finlay, 2013). The textual conversations were then written utilizing metaphor (Finlay, 2012) and poetizing which “hearkens back to the silence from which the words emanate” (van Manen, 1997, p. 13), all the time remaining aware that descriptions and data are “never identical to lived experience itself....the meanings we bring to the surface from the depths of life’s oceans have already lost the natural quiver of their undisturbed existence” (van Manen, 1997, p. 54).

From a hermeneutic phenomenological milieu, the use of van Manen’s four fundamental existentials within the lifeworld provided the framework for reflection upon the data collected and the textual conversations in order to draw out the essential meaning (van Manen, 1997). These fundamentals, as outlined in the methodology chapter (see pp. 132-133), are Spatiality (Lived Space), Temporality (Lived Time), Corporeality (Lived Body), and Relationality (Lived Other). Spatiality is the felt, lived in space of landscape or world, and spirituality has its own experience within it. Temporality is subjective lived time, and

Corporeality is our bodily existence in the world. Relationality is shared interpersonal space in which we can transcend ourselves. It is with this existential framework in mind that we move towards the textual conversation allowing elements of spirituality to rise and find their place within the lifeworld for investigation. The hermeneutic phenomenologically written texts have used pseudonyms for all participants in an effort to protect confidentiality. The complete hermeneutic phenomenological transcripts have been named separately for each of the three focus groups and three individual interviews, and all are placed in order of occurrence within a single document, Hermeneutic Phenomenological Transcript of Textual Conversations, found in Appendix G. In this thesis some of the focal points and features of the discussion have been lifted out of the dialogue of each textual conversation to introduce the reader to the uniqueness of each exchange. Wherever specific words from the textual conversations are used they are placed in italics.

Focus Group One: From Business Self to Intrapersonal Enrichment

The first hermeneutic phenomenological conversation came from the initial extended focus group held with members of the BHCI Board of Management (BOM) (Appendix G, Line 3-59). This governance body has little influence on the actual day-to-day lived world of work at BHCI, but rather focuses on global issues such as finance, risk management, and promotion (Ballarat Hospice Care Incorporated, 2013). The focus group was timed to begin at the end of a shortened board meeting, being organized for convenience and easy access of participants and researcher alike. Prior notice had been given to board members that opportunity would be given to leave should they not desire to participate. At the time two members used this contingency to depart, and eight people remained.

In this initial group there was an increase in a sense of communality within those present noted by the researcher as the group unfolded, and participants became more comfortable with the topic and more expansive in their responses. This phenomenon was also

expressed by participants in their responses both at the finish of the group, and through spontaneous feedback during the next day. Having expected a more pragmatic approach to the subject of spirituality by board members coming out of a board meeting, the researcher was surprised by the thoughtfulness and depth each fragment of conversation attracted. The following passage captures this. The group began with a question about defining spirituality.

> *"Well it's not really to do with religion."*
>
> *As more words rolled out around the table and opinion gained momentum:*
>
> *"meaning to living and dying";*
>
> *"here and now";*
>
> *"untouchable, unknowable, human";*
>
> *"But spiritual pain exacerbates physical pain."*

A different perspective then entered the conversation.

> *"I find it difficult to separate the concept of spirituality from religion. I see it more in the context of what we personally believe our life is all about."*

The researcher felt a sense of satisfaction that the conversation was flowing and people were bouncing off each other. The conversation then moved to the topic of spiritual care.

> *"Yes, meaning, that meaning of why we're actually here. Spiritual care is supporting. You've got someone who's not judging, but just supporting and helping you through to that stage that you need to be at peace...walking, side by side with you."*
>
> *"Spiritual care is not about problem solving, but about space and acceptance. And sometimes it's just a matter of listening, you may not agree, but just listen."*
>
> *"I see spiritual care as pivotal in palliative care; we need to give people an opportunity to sort out their inner turmoil. Training new people coming into the organization is really important so they can understand and provide holistic care."*

At the end of the focus group the participants were asked if there was anything pressing that they would like to add, and the following thoughts were voiced:

> *"As a participant, tonight's been really insightful. I've really appreciated the honesty, the way people have shared. So it's been an enriching experience for me personally....it's been great for us as an organization too, and as a board to group share."*

As they left what had begun as an intellectual exercise now revealed a spirit of unity and a deeper purpose. Without knowing the words, a spiritual encounter had occurred.

Explication. The explication process began with immersion. Through examination and reflection on the above textual conversation two fundamental existentials were mainly drawn on: Spatiality and Relationality (van Manen, 1997). A move into a particular Spatiality, or Lived Space, began with the researcher entering the room where the board's customary administration mode had been in operation: a *room* (that) *bustled with efficiency and anticipation* (Appendix G, Line 3). The board members were well accustomed to relating interpersonally from a governance stance, coming together to speak out of professional knowledge and experience. However, now they were invited to move out of business style and come together to share intrapersonal reflection around an alien, mysterious, and possibly uncomfortable topic. It is more than likely that wonderings arose and questions were pondered: What might I say? What might others say? What might others think? What do I really think? The hesitancy in the air, so palpable on the arrival of the researcher, fell away as wine and cheese moved into the room and Lived Space did a u-turn from business to personal. Familiar business language gave way to the familiar social convention of the offering and choosing of a red or white wine: language of connection and conviviality which encouraged relaxation. *Signalling the move into a different, unknown space, the group relaxed back into their chairs* (Appendix G, Line 4-6).

This serendipitous changing of the dynamic of Lived Space gave freedom for personal understandings and perceptions of spirituality, a hitherto undiscussed topic for this group, to float freely to the surface. In the movement from professional voice to inner voice, the conversation about spirituality appeared to constitute a spiritual atmosphere composed of an acceptance of, and connectedness with, Self[7] and with Other[8]. This encompassed the Spatiality of dignity for being and an unspoken permission for consideration of each unique personhood. The atmosphere also created a tolerance for the conversation to be entered into and withdrawn from as desired, and there was breathing space facilitated by all for the conversation to twist, turn, and evolve, taking on a life of its own. As the first question was asked and the silence broken by the first response, the conversation had begun between the researcher and one participant, then rolled out to a collective space.

Lived Other was also a fundamental experience of the focus group: a connectedness within shared interpersonal space that began with, but then eclipsed, the personal (van Manen, 1997). Moreover the space to be *attentive, but silent* (Appendix G, Line 28) acknowledged acceptance of an exclusive personal position within the collective. This provided space for some to observe, while also allowing the forthright to jostle and expand thoughts and ideas. The person-in-relation-to-the-group, which had always been experienced at a professional distance, was now moving into new waters: a Lived Other in communion. It consisted of a reflecting back and forwards of the professional self, which then moved towards the sharing of personal self, and finally, the observation of self in relation.

> *The level of disclosure deepened to the vulnerable and honest met by a respectful listening response. A consensus built, agreement noises were made, and a silence of harmony rose. Stories of connection emerged as connection crested a new summit. A*

[7] *Self*: see footnote 2, pp. 8.
[8] *Other*: see footnote 3, pp. 8.

spirit of unity and a deeper purpose (emerged): *a spiritual encounter* (Appendix G, Line 22-24,38,56-59).

The communal space provided a haven for external stories of connectedness and spiritual encounter with Other:

...family members were apologising to me for not being more spiritual (Appendix G, Line 25-26)*;*

...patients struggling with it...I've struggled with, and my colleagues have struggled (Appendix G, Line 16-17).

Within this sacred space of Relationality the interpersonal self educated the intrapersonal Self. As personal thoughts were explored and mirrored through community, so too, diverse components of the Self were encountered and self-knowledge rose. As individuals shared, and the atmosphere proved itself to be safe and non-judgmental, a snowball effect of participation grew. This Lived Space and Lived Other exemplified the connectedness that defines spirituality in the literature (Chao et al., 2002; de Souza, 2009b, 2011; Ellis & Lloyd-Williams, 2012; Swinton et al., 2011; G. White, 2006). Spirituality here is characterized by connectedness with Self, with Other, with the world, and with mystery/transcendence; and within this focus group conversation, connectedness with Self danced and twirled with Other, taking it in turns to lead. The personal purpose made space for unity and communal purpose. This dance developed further as the understandings and perceptions of spirituality waltzed with the practice of spiritual care.

Lived Space overlapped with Lived Time while spirituality was defined as being situated in the *here and now* (Appendix G, Line 12). A further unfurling understanding and perception of spirituality incorporated a bringing of *meaning to living and dying* (Appendix G, Line 11), and an appreciation of *what we believe life is about, why we're actually here* (Appendix G, Line 32,34)*:* meaning and purpose (Frankl, 1992; Puchalski et al., 2009;

Swinton et al., 2011). While spirituality has *multiple voices* (Appendix G, Line 19), which reflects the intrinsic uniqueness of each individual, it also engenders a *spirit of unity* (Appendix G, Line 58), and *consensus* (Appendix G, Line 58): a coming together in connectedness. For some it's *difficult to separate the concept of spirituality from religion* (Appendix G, Line 31), but others find it is *not really to do with religion* (Appendix G, Line 8); however, unanimously, spirituality was associated with something *untouchable, unknowable* (Appendix G, Line 13) and mysterious: connectedness with transcendence.

Spiritual care was thought to occur within the co-creation of *spiritual encounter* (Appendix G, Line 59), (it is) *not about problem solving* (Appendix G, Line 39), but was considered to be about *space and acceptance* (Appendix G, Line 39), emphasised by an absence of *judgement* (Appendix G, Line 35), particularly in the face of *regret* (Appendix G, Line 27), and spiritual distress. In practice, spiritual care was deemed to be encountered through the presence of one *walking side by side* (Appendix G, Line 36), until peace is experienced. Used as a *vehicle to get rid of the skeletons in the closet* (Appendix G, Line 14), or a place for *cleansing of the soul* (Appendix G, Line 15), spiritual care practised *acceptance* (Appendix G, Line 39), and *respectful listening* (Appendix G, Line 23). Spiritual care was considered not *a passive thing, cos it's actually quite active* (Appendix G, Line 20-21). The patient, too, actively paves the road for this exceptional step of the journey with beliefs, meanings, and connections. Training in spiritual care for new staff was considered a priority for the continuing provision of holistic care. Those who offer spiritual care use intellect and body, being and doing, to actively *wait* with the Other. This allows the living text to unfold, unravel, be told, and laid out in constant reflexivity and interpretation of the living text (Couture, 1998; E. Kelly, 2012c), and concurrently works toward the co-construction of a sacred safe space (E. Kelly, 2012c). This co-creation, a facet of spiritual care, had artlessly occurred within the Lived Other of the focus group as Self and Other interacted. Relationality

with one's Self , too, was highlighted by the avowal that this had been *an enriching experience for me personally* (Appendix G, Line 52). Spirituality had brought *meaning*. Once again Lived Space became a discernible focus as the group drew to a close and prepared to leave, and the consensus was that Lived Other had facilitated a repositioning of connection: *With the leaving, what had begun as an intellectual exercise now revealed a spirit of unity and a deeper purpose. Without knowing the words, a spiritual encounter had occurred* (Appendix G, Line 57-59).

In summation, the foremost concept that arose from this textual conversation was spirituality perceived as connectedness and the bringer of meaning. Relational in nature, spirituality was understood as bringing dignity to the being of Other, to each unique personhood, encouraging connectedness with Self, with Other, with the world, and with mystery/transcendence. Lived Space had provided a haven for this connectedness to be experienced with the co-creation of a sacred safe space. Lived Space also overlapped with Lived Time as spirituality was identified as a paradox of the here and now and yet encompassing past regret in spiritual distress and future-bound hope. Any connection between spirituality and religion was tenuous and personal to the individual. Spiritual care was seen as an active use of intellect and body to actively wait with Other, rather than being passive, or problem solving. Experienced as acceptance, respect, and journeying side-by-side, training in spiritual care for new staff was identified as a priority.

Individual Interview One: Sitting Loosely with Thoughts and Beliefs

The second conversation was held with an individual who was also involved in the governance of BHCI, but unable to attend the board meeting focus group (Appendix G, Line 349-469). The researcher had an expectation the changed context from focus group to the more intimate individual interview would result in increased interaction and discussion because of the one-to-one method. However, this didn't ensue; instead the one-on-one

context gave space for the participant to plumb personal reflection and professional memories, leading to a gentle sense of monologue. As idea built on idea, thought on thought, memory on memory, questions were asked, pondered, and answered as a personal reflection was generously offered for a public space. The following extracts indicate significant aspects that were revealed through the hermeneutic phenomenological process. As mentioned above pseudonyms were used to protect the privacy of participants.

> *As the first question was asked Peta leaned slightly forward, and keeping eye contact, quietly turned on the tap of his wisdom and experience.*
>
> *"Spirituality involves the whole person, whatever their life experiences, what they learn, what they encounter, what they discover about themselves, almost anything they are able to draw together in forming themselves as a whole person...And spiritual care endeavours to support bringing it together in ways that are hopefully constructive, creative.*
>
> The conversation turned towards the terminally ill and spiritual care. *"Those who are in the terminal phases of life, the person who is facing the end of life, I think spiritual care is important for all those people to deal with what may be unfinished...Patients seek to gather together what their life has been and affirm for themselves what they might need to affirm. We help them to make sense of it and to make meaning. People gather together the threads of their life in some way that they then can feel like "I can put that down" or "I can let that go"."*
>
> *"Gentle presence that lets people do their own work, spiritual care* becomes *important to help people find their way through the difficulties of parting...I must sit loosely with what I might think or believe, allow the other person to tell me who they are. I am suspending judgment...Listening is about being still, trying to quiet some of our own chatter to be able to hear, and cultivating a receptiveness to the person.*

Some words attempted to express what occurs for the spiritual carer offering spiritual care.

> *There's a rich human conversation going on within myself in terms of my own faith and beliefs. It is the endeavour of dual respect: self respect can lead to an understanding that recognises the Other is a Self, and of respect for that Other. Within that I have to be very careful that I don't intrude or impose on their Self."*

The focus moved from Self and on to the multidisciplinary team and holistic care.

> *"All of the people involved in hospice care need to be sensitive...Spiritual care needs to be practiced by all. Professions can have diverse worldviews, but...it is that fundamental respect for each other that brings a really holistic sense of the various disciplines working together each contributing from their discipline with that wider and deeper awareness and respect...The multidisciplinary team need education around spiritual care, helping people to be sensitive to what's happening to them; to their spirit. Assisting them to draw whatever meaning is there for them from particular events and find how they integrate that into themselves. Staff are also growing people, and they're learning people, and every engagement is a learning one...It's important for professional carers that they respect their own spirituality, open to being cared for, and can offer care to each other."*
>
> *Also, people need to cultivate those intuitive elements like hunches and ideas that seem to come out of nowhere.*

Reaching the end of the interview the researcher felt a sense of satisfaction, and the following reflection was recorded:

> *While the clock dictated the closing of the interview there was a sense that in this reflective time we too had only scratched the surface of meaning existing within this conversation of spirituality.* (Appendix G, Line 349-469).

Explication. Through a soliloquy of experience the participant was very willing to share throughout the interview. Again, the existentials Lived Body and Relationality comprised the essence of the collected textual conversation. The fundamental existential of Corporeality underlies the fact that we exist embodied in the world; and it is this body that both reveals and conceals elements of the Self (van Manen, 1997). Through the body, Peta unconsciously revealed a sacred space in the room: *an air of gentle humility...an atmosphere of confidence and privacy* (Appendix G, Line 351). A desire to be open, honest, and constructive created the challenge of paring down the reminiscence, the stories, and the knowledge. The Lived Body is portrayed as the worldly viewed expression of a spiritual body encased in the physical body; it is the holder of evolving wholeness and while it walks on the earth it contains all of life within it. Yet the Lived Body often conceals more than it reveals, leading the person on a journey of discovery as they experience and live life (van Manen, 1997). Learning, encountering, and discovering brings together intrinsic elements as one attempts to form the whole Self: s*pirituality involves the whole person* (Appendix G, Line 356), including the living of life and the dying journey.

The Lived Body of the dying is a foreign land for patient and carer alike. Decline, weakness, decay, and signs of illness not only change the physical presence and capabilities of a person, but can disrupt one's sense of self and identity, bringing a paucity of chronology and an awareness of the unfinished and the finishing. *They can't carry all they have cared for into death* (Appendix G, Line 372-373). The Lived Body again conceals: the moment of parting is a mystery of its own time. No matter the forewarning and limited prognosis, death often reveals itself more swiftly than has been contemplated. Each dying person holds a central place within their own relational web that will be irrevocably altered with their demise. The *issues of parting* (Appendix G, Line 387), are particularly poignant within

Relationality: imagination is at a loss to conceive the finality of non-existence, particularly of one familiar to our everyday: *what will life be like without...* (Appendix G, Line 385).

As Peta concealed what was considered superfluous to the task at hand, so too the person offering spiritual care is concealed within the Lived Body. While revealing respect and dignity throughout a pastoral conversation, the features of personal faith, based in self respect, engage in a purely internal dialogue: *a rich human conversation going on within myself* (Appendix G, Line 379). This dual respect in Lived Corporeality overlaps with Lived Other.

The practice of spiritual care woven through the whole interview brought a rich job description to the process. Spiritual care encompasses the provision of gentle, empathic, non-judgmental presence that cultivates a genuine *receptiveness to the person* (Appendix G, Line 427). *Sitting loosely with what I might think or believe, and allow the other person to tell me who they are* (Appendix G, Line 426-427). Creating a space where a patient and carer feel accepted, received, and listened to so they can gather together, integrate, sift through, understand and affirm those aspects that bring meaning and sense of life for themselves (M. Holloway et al., 2011; Swinton et al., 2011). At the same time, spiritual care brings a treasury of traditional wisdom and faith, which are available to be considered if called upon. These ideas highlighted the person-centred characteristic of spiritual care: g*athering together the threads of their life in some way that they then can feel like "I can put that down" or "I can let that go"* (Appendix G, Line 397-398).

While basic spiritual care was considered to be the responsibility of all employees, it could also feed the atmosphere and values of the organization as a whole (E. Kelly, 2012a; Marie Curie Cancer Care, 2003; Rumbold & Holmes, 2011). The worldviews of differing professions can meet at the axis of fundamental respect for Self and Other, which brings a holistic sense to person-centred care. The organizational values, too, bring an ideology of

fundamental respect: loyalty, trust, kindness, respect, honesty, wiliness and skill (Ballarat Hospice Care Incorporated, 2013). Analytical, intellectual skills can be woven through praxis with listening through the heart to hold a sense of the whole person: *keeping your own humanity alive and a sense of the other person's humanity and their profession as well* (Appendix G, Line 421-422).

The consensus of fundamental respect can only intentionally weave through praxis and create organizational atmosphere where some education has been given about basic spiritual care (Jenkins et al., 2009). Peta had launched into two aspects of learning which are felt to be useful in engendering a culture of respect and connection: Self awareness and Other awareness. The shared belief was that education can increase sensitivity to what is happening *in* the Self of the student, and further, education can assist staff to draw meaning from situations and then integrate this meaning into the Self. *Staff are also growing people, and they're learning people, and every engagement is a learning one* (Appendix G, Line 449-450). The fostering of intuition and hunches of Self and Other is helpful. It is important to act as a facilitator so that the patient is drawn out and allowed to speak their own words. These skills sit alongside active listening, suspending judgment, being still and sitting loosely with one's own thoughts. This quietening of our own chatter *cultivate(*s*) a receptiveness to the person* (Appendix G, Line 456). An investment in listening also acknowledges that while the spoken word can be helpful in revealing something of spirituality, words themselves *are never adequate* (Appendix G, Line 462).

However words had to suffice as spirituality was described as the centre: the centre of meaning and purpose, of integration, connectedness; where all can be incorporated to create a whole. This verbalisation of spirituality ran alongside non-verbal messages as components of spiritual practice broke the surface and then again re-entered the Lived Space of the participant. The room sat in stillness, a safe sacred space for sharing the heart, the only

rhythm coming from the passion behind the words that had flowed, been withheld and flowed again. Then with a gush came the spiritual metaphor: *I like to use the image of a lake. What we see on the surface is one thing, but what is hidden in the depths is much more? Our words are surface things and underneath there are depths of meaning, significance, that words will never adequately describe* (Appendix G, Line 463-466). Again the Lived Body rose to encompass the home of spirituality: where facets came into focus and were concealed again, and wholeness could be pursued, maintained, and contained.

In this textual conversation the Lived Body revealed and concealed spirituality in the seasons of life and death, evolving spiritual wholeness and physical decline, and all that may lie between. Spirituality became the space to gather in life, and gently choose to put it down. Spirituality within Lived Other nurtured an authentic connectedness to Other, both for the patient and carer through spiritual care, and to peers within the professional staff.
Issues of meaning and parting were faced with non-judgmental presence, traditional wisdom, and spiritual care that was aligned with the organizational values – loyalty, trust, kindness, respect, honesty, willingness and skill (Ballarat Hospice Care Incorporated, 2013). Within Lived Other education included increased awareness of Self and Other, intuition, and active listening. This training in person-centred care relied on suspension of judgment and an embracing of the whole person.

Focus Group Two: A Lexicon of Spiritual Care

A revelation and concealment of Corporeality (van Manen, 1997) was evident as the participants of the second focus group gathered for our third textual conversation (Appendix G, Line 63-191). The group straggled into the counselling room, bringing an atmosphere of hesitancy and reticence. The counselling room is rarely entered by many of the disciplines; the new environment added to the existing tension linked to the unknown of being a research participant. Nervous chatter flew around as they sat and settled. Cake was offered, but there

was a hesitancy in the acceptance. The researcher led the way by taking the first piece, and then others quickly followed suit. This group, involved in the day-to-day function of BHCI, are familiar with sharing in multidisciplinary meetings protected by their professional praxis and worldview. The formation of a group to speak uncontained by those boundaries moved participants from the professional voice of everyday operation to an inner voice of personal values. This released the capacity for a level playing field with the common goal of discovering a spiritual care method in each other. The essence of this group is highlighted by the following extract. The discussion started around training in spirituality.

> *"People never think about spirituality...If you've had no training in it, and you've never had spirituality in your whole life, it's very hard to sort of bring it into conversation."*

As the group attempted to describe spirituality the conversation broadened.

> *"I usually say feelings...I start with 'it's not religious, and its non-denominational.'"*
>
> *"nobody else sees...It's about you and you alone."*
>
> *"intuition, or I just knew."*
>
> *"inner, inside, what you're really like, the core of the person."*
>
> *"Yeah, you inside, right inside, you and you alone, which religion would come in as well."*
>
> *"the words of a song can make you cry, so it's about the inside."*
>
> *"the essence of me. The real you. My fears about me, which mightn't be real, mightn't be what anyone sees."*
>
> *"Religion could be, but doesn't need to be a part of it. Each person makes their own decision about that don't they."*

The conversation moved into understandings of spiritual pain.

> *"It's your gut too isn't it?"*

"Yeah, it's my gut I'm going on, and your feelings."

"If I was to see a patient and they weren't sitting comfortably with themselves I would see that as spiritual distress."

Community-based palliative care was a concept wholly embraced.

"We go into their home, we're in their surroundings, in their environment, so we follow them and what they want."

"Who's in control when you go into the home? They are."

"We've got the time to deal with whatever comes up, and supports to refer back to, to find the right people to look after these people."

You have flexibility?

"What hospice does is very much flexible and responsive to the situation, not task orientated. It's really person-centred."

"Yeah and the recognition that's its more than treating the disease, we'll look after the symptoms and care, and keep you as comfortable as possible."

"It's actually more individually tailored care too and holistic. We're not task oriented, and we've got the time to deal with whatever comes up and supports to refer back to. So community care has sort of a much more personalised aspect."

The notion of holistic care was addressed.

"Holistic care, which includes spiritual care, is not just looking at one medical problem, but we look at how that medical problem impacts on the person's family and those around them. We also observe how those carers are relating to that person, or how the way they care for that person affects their medical condition. So it's a two way connection thing."

"Yeah, holism is looking at the broader picture of the person; body, mind and soul, and the interplay backwards and forwards between carers and patients."

Explication. The comings and goings within this textual conversation echoed Corporeality (van Manen, 1997). Like the participant entry into the room, the exchange of perceptions regarding the nature of spirituality and spiritual care was approached with reticence, both, concealing and revealing. Like a tentative fisherman, one participant threw in a small lure to see if there was any response: *I usually say feelings...I start with 'it's not religious, and its non-denominational...* (Appendix G, Line 88). Silence fell while the bait was toyed with and then collaboration rose to the surface.

The internal personal nature of spirituality held the initial responses; descriptors like *core*, *essence*, and *the real you* were strongly endorsed. However, this intimate part of Self was treated with some detachment and distance; an echo of the old adage, "We don't talk about sex, religion or politics." Spirituality may not be initially linked to religion in definition, but it holds a similar taboo in "well-mannered conversation." *Nobody else sees your spirituality. It's about you and you alone* (Appendix G, Line 89). While the group as a whole strongly agreed vocally that spirituality was not about religion, a correlation between the two was supported in the shadows of the conversation; an anomaly which may have been pre-conscious but was not challenged by any member of the group. *Religion would come in as well...* (Appendix G, Line 92). *I refer patients to spiritual care who say they have got religious beliefs* (Appendix G, Line 82).When spirituality is completely aligned with religion it becomes exclusive and even considered unhelpful for people who have no religious affiliation. However, this denies the innate human nature of spirituality, and the need of humans to make meaning (Frankl, 1992). Therefore a lack of conversation, training, and education regarding spirituality can result in other professionals feeling inadequate in not being able to talk about spirituality or identify spiritual care. It can also lead to an unawareness of the rich and inclusive nature of spirituality that can occur when spirituality is understood as connectedness. Lack of knowledge leads to spirituality being concealed.

Continuing to allude to the concealing nature of the Lived Body, three participants clambered to locate spirituality and spiritual distress in deep and mysterious places: in the *gut*, *just knowing*, or *intuition*. A lack of spiritual identification was highlighted within the following exchange between a medical professional and an allied health member of staff:

"...and you see that as spiritual from me?" (Appendix G, Line 141-142).

"Absolutely, you do spiritual care and you don't even know that you do, and you do it brilliantly." (Appendix G, Line 143-144).

An awkwardness with the topic was emphasized as very quickly talk moved to ramifications of spirituality. This was reminiscent of the inability to describe the wind except in the experience of the effect of its blowing. While defining spirituality was a tussle, talk of spiritual effects within the Lived Body spilled out fluidly, splashing from one side of the room to the other.

I usually say feelings (Appendix G, Line 88).

Its about the fact that the words of a song can make you cry (Appendix G, Line 94).

Its about my fears (Appendix G, Line 95).

If they weren't sitting comfortably with themselves I would see that as spiritual distress (Appendix G, Line 119-120).

Being worried about end of life and where they're going (Appendix G, Line 83-84).

The observation brought the conversation to a halt: concealment. Then out of the silence the subject of *training* was considered a safe, yet revealing theme where perceived inadequacies could be justified, responsibility relegated, and personal opinion could firm up on objective ground.

If you've had no training in it, and you've never had spirituality in your whole life, it's very hard to sort of bring it into conversation... (Appendix G, Line 81-82).

You do need education on it. Which I don't think we've had (Appendix G, Line 84).

It seemed that lack of training coupled with the lack of a working language around spirituality at BHCI created a sense of incompetency and made spirituality an enigma.

The theme of Lived Body was further recognised as being introduced to the organization through the Reception area. Corporeality rotates through the front glass doors into the foyer, transporting a patient or carer from ordinary life into the palliative care context. It is there, where the story of disease is revealed, justification given for equipment needs, and the label of *terminal* shared, that spiritual care begins. For patients and carers it is at the Reception desk that many thoughts and emotions, previously kept in check by the medical model of problem solving, fail to stay concealed; sometimes they bubble up and surprise the owner. The responses to these, in those first few moments, can sometimes set the tone for the whole BHCI experience: *the front desk are the gate keepers* (Appendix G, Line 123).

Community-based praxis identifies Lived Corporeality as strongly fundamental within the day-to-day practice of BHCI, with an awareness of the physical presence of the multidisciplinary team moving into the private context and physical presence of patient and carer. While typically the home displays Lived Space (van Manen, 1997), in community-based palliative care the home also provides backdrop to a dual revelation of the Lived Body of the terminally ill. Family pictures and tasks undone amplify change and decline. As Lived Space the home provides inklings of the milieu of a person *pre-patient* and *pre-disease*, pointing to a past that is incorporated, but now purely historically, in the Lived Body of the terminally ill. Lived Time, too, sits alongside, like knives and forks in the cutlery drawer, as time becomes fluid within the Lived Space of community-based practice. Speeding up with enjoyment and crisis, slowing down with boredom, anxiety, and waiting, Temporality is bound to the needs of the Lived Body of the patient (van Manen, 1997).

The style of community-based care offered, while notable for a totally person-centred approach, also overlaps a total lifeworld approach (van Manen, 1997). Lived Space, filled with patient and carer agenda and ever changing ground, is responded to with flexibility and focus on patient need. *We go into their home...we're in their surroundings so who's in control? They are* (Appendix G, Line 148-150). Lived Time is fluid in acknowledgement of patient and carer need for support or solitude. *You come out of there and it's been a complicated visit, but you've spent the time because they've wanted to share something. It's just totally their time* (Appendix G, Line 157-158).

Relationality, or Lived Other, is fundamentally disrupted by a terminal diagnosis, and the very real threat of non-existence. It is at this time when relationships can become alien and unfamiliar that Lived Other through community-based care can provide a safe interpersonal space.

> *We've got the time to deal with it and supports to refer back to find the right people to look after these people* (Appendix G, Line 153-154).

Community-based care was believed to be highly centred on the patient and carer, and completely individually tailored. The holistic nature of care moves away from professionals being task-oriented with a focus on the disease, to a broader picture where body, mind, and spirit, as well as relationships, are taken into account. The interplay between the context and impact of disease is an individual journey for a patient and their family, resulting in a unique journey, and lifeworld, for the care team.

When the conversation faltered and *eyes studied the carpet* (Appendix G, Line 183), it was seen as a sign that Corporeality had moved into the exercise of concealment. All were thanked for their participation and the interview was brought to a close. With the ending of the focus group, bodies repositioned, the atmosphere relaxed and further familiar conversation flowed. The connectedness experienced within the group was something the

participants actively continued and were slow to move away from. Lived Other had been tasted, enjoyed, and, for a short time, had captivated the participants.

The explication of this text focused on Lived Body, and its revealing and concealing of the internal personal nature of spirituality. A person's lifeworld was considered to be at once both deeply private, yet also open, and revealed through the community-based focus of BHCI. Spirituality revealed the *core*, the *essence*, the *real you* (Appendix G, Line 91,95). Corporeally spirituality was further defined as *intuition*, a *gut feeling* (Appendix G, Line 90, 111) that could provide a sense of peace, and spiritual distress as being uncomfortable within one's Self. A lack of training around spirituality was identified, pointing to a desire for education, and a common working language. Lived Space and Lived Time were overlaid through the organizational concentration on person-centred care which was identified as holistic, personalised, flexible, and responsive while taking into account both the patient's context and agenda.

Focus Group Three: Spirituality and Community-Based Care

Similar to the previous group, participants of the third focus group were staff members involved in the day-to-day practice of BHCI (Appendix G, Line 273-345). Quite dissimilar to focus group two, this group from the beginning had an erudite feel with a sense of reverence towards the topic and process, showing no reluctance to share. The participants gave an impression of having done their homework, and they entered the room with confidence. The hermeneutic phenomenological textual conversation for this group contained three main segments around spirituality: training in spirituality, descriptions of spirituality, and community-based spiritual care. Discussion in the group around spiritual training and education brought the conclusion:

> *"So we've all brought different ideas and language, or lack of language, into our positions in the organization."*

With a sense of pre-thought spirituality was described as:

"having an acceptance of things, or letting life come to you. Those things that we can't explain...accepting of experiences like that."

"something that makes the person the person..."

"an acceptance of that which is not only within us, but that without us that doesn't necessarily have an explanation."

"It is tricky."

"a nebulous concept."

"It's kind of smoke, and you're trying to box the smoke, trying to round up the smoke."

" part of the person...the spirit, a constant."

"I see it as innate within us, but to a very small degree, and I think it's our life experience, circumstances and our phases of life that explore it, grow it, change it, influence it. Then it ends up wherever it goes in different sizes and quantities throughout our life journey."

The provision of spiritual care within the community became the focus.

Here too the primacy of care for the whole family was evident.

"It's not about a patient with a disease, but the family unit because the patient doesn't just get the illness, the family gets the illness."

"And it's nurturing without getting involved, without taking it on or telling them... listening I suppose."

The thought of presence and nurture is expanded with gusto, and stories.

"I notice it when I go out with someone that you go into the house and there's this kind of "we don't know what to do," by the time we leave there's a calm... you're not alone. And I think that alone is hard because we need one another..."

"maybe when you're talking about what the staff do it's about that begetting calm."

The distinctiveness of community-based practice continued.

"The difference in community is because you immediately come onto their turf, in their tower of strength...I think you lose a lot of that when you move into an inpatient setting."

"I agree. I think that's a beautiful example of one of the things that separates community palliative care is indeed that meeting people on their own ground."

"Yep, where they get to set some of the rules...or all of the rules."

"I think, we might go in with a goal, but it's based on the patient's idea of that goal of care..."

The conversation turned to the topic of death as a societal taboo in community-based practice.

"For me it's what we're dealing with. Because particularly in a western society it's become verboten: dying is something you do behind closed doors. For me I see the differentiation in fact is that we're actually in there talking about it and facilitating it happening in the way that families and patients want it to happen. That's obviously very unique to patient care."

Spiritual distress was the concluding theme of conversation for the group.

"Spiritual pain is an uneasiness; a not wanting to be where you are...When they're not at ease with themself."

Vigorous nods and murmurs of agreement goad the conversation further.

"I think that it's a spiralling out of control. That lack of control where you can't get hold of what you need to get hold of in life; to seek out answers; to inspire healing. Just everything seems out of their grasp. An impression of disconnection..."

"This restlessness... this unease...it's almost like you can't quite define it."

"Yeah, like an itch you can't scratch...But you can't actually say you're itchy?

The closing words for this session effectively articulated the experience of the group members in responding to spiritual disconnectedness.

> *"And I think the words spiritual pain makes me feel very very uneasy because to see someone in that pain without an ability to change it, and it's not about the physical, its the ungraspable, about the smoke, about the nebulous, about not being able to handle it, to heal it."* (Appendix G, Line 273-345).

Explication. Commencement of the third focus group conversation confirmed that they had some acquaintance with the subject of spirituality. As the lively discussion moved the researcher from passive observer to active participant, the developing conversational relation tangoed through the interpersonal space of Lived Other, and the professional Lived Body confidently gave way to what had hitherto been concealed and considered personal (van Manen, 1997). The idea of a professional development program writing spirituality onto a *blank slate* of spiritual understanding seemed preposterous to some participants who had spent much time at religious events in their childhood. It was analogous with the idea that the world is thought to be filled with socially constructed meaning, while for the individual, meaning is built from their own experience and background (Crotty, 1998; Fossey et al., 2002; Laverty, 2003). Spirituality, a form of meaning, was considered to begin in childhood and was consciously and pre-consciously written on moment by moment (E. Kelly, 2012c; Sulmasy, 2002; Swinton, 2012). However, while religious observance within the family had laid a framework for individual spiritual thought in adulthood, it was not necessarily considered a part of adult spiritual life. Education and organizational conversation about spirituality was considered useful and as the topic of religion and training was adequately settled the conversation turned to perceptions of spirituality.

Again, a sense of preparedness came to the fore and considered answers danced around each other as everyone desired to contribute. Thought and perception, like building blocks, nestled on each other, fabricating a communal understanding. The emerging edifice of spirituality was perceived as something very deep-seated and mysterious inside each person.

> *...an acceptance of things, or letting life come to you. Those things that we can't explain* (Appendix G, Line 229-230).
>
> *...something that makes the person the person, that makes us us* (Appendix G, Line 231,233).
>
> *It is tricky...Yes, it's kind of smoke, and you're trying to box the smoke, trying to round up the smoke* (Appendix G, Line 236-239).

Spirituality accommodated an innateness and constancy for all of humanity: *...and then there's the other part of the person...a constant* (Appendix G, Line 242). This innate connectedness of self to Self was not static, but rather fluid and flexible, responding to the moment-by-moment lifeworld (Fisher, 2011; M. Holloway et al., 2011; Puchalski et al., 2009; van Manen, 1997). This fluidity housed a capacity for exploration and growth with an ebb and flow towards what de Souza (2009b, 2011) describes as ultimate unity. This encouraged a collaborative interplay of influence *on* personal spirituality and the influence *of* personal spirituality on day-to-day life:

> *...spirituality is dictated to by all these things, but it's also influences all these things* (Appendix G, Line 253-254).

In this way spirituality was perceived as a support through individual phases and seasons of life, an energy that propels and motivates, inspiring and being inspired, that can bring the whisper of meaning (Puchalski et al., 2009).

> *...there are times in our lives that we need to look at that spiritual side of who we are and what's feeding us, and what's going to nurture us through a phase in our life* (Appendix G, Line 249-251).
>
> *... and I'm amazed at that energy. An awareness of what is in myself drives or encourages or influences other assets* (Appendix G, Line 265-266).

Interlaced through the sharing of understandings of spirituality were the organizational values that laid the foundation for community-based care: trust, respect, loyalty, skill, willingness, kindness, honesty (Ballarat Hospice Care Incorporated, 2013). The values lived out in the lifeworld of the participants were reflected as they talked of working in the community, and are centred on person, family and context because*...the patient doesn't just get the illness, the family gets the illness* (Appendix G, Line 282-283). Certainly, holistic care was seen to be inclusive of the whole family or social support network by the participants. A unique care that is ...*nurturing without getting involved, without taking it on or telling them... listening I suppose* (Appendix G, Line 284-285). The adjunct of a values-based presence can be a sense of calm and connectedness. *...when there's a crisis, together professional and family devise a way of dealing with it. You're not alone; and I think that alone place is hard because we need one another...* (Appendix G, Line 289-290). In that connectedness with Other, stillness is appreciated and feeds the spirit.

> *In nature things are often drawn to stillness. If you're amongst horses that are very upset, if you stand very still they will gravitate towards you. There is a desire for stillness and calm, nature does it naturally, but I think our society has made everything so frenetic, so maybe when you're talking about what the staff do it's about that begetting calm* (Appendix G, Line 291-295).

The Lived Space of community-based care expounds the landscape where human beings move and find themselves at home (van Manen, 1997). Spatiality for the

multidisciplinary team in palliative care moves from the shared peer space of the office, into the individual cocoon of the work car, and then, professionally established in the patient context. Descriptions of patient-centred Lived Space abounded, giving way to a definitive mantra:

> *...their turf; their tower of strength; places where the greatest strength is gained: the shed, the horse paddock, the garden, or clothes line* (Appendix G, Line 233-300)*; meeting people on their own ground; they get to set some of the rules...or all of the rules; it's based on the patient's idea of that goal of care* (Appendix G, Line 304-307).

Amidst the goal of care for the terminally ill, the idea of Corporeality, Lived Body, was particularly poignant; a place where being bodily in the world has an accompanying finitude and unfamiliarity (van Manen, 1997). Both community praxis and spiritual distress are influenced by this existential fundamental. Community-based palliative care, by its very presence in society, fleshes out words and actions to what is often unmentionable: dying and death.

> *...in a western society dying is something you do behind closed doors. For me I see the differentiation in fact is that we're actually in there talking about it and facilitating it happening in the way that families and patients want it to happen* (Appendix G, Line 314-317).

Spiritual distress can accompany the terminally ill in corporeal forms: lack of control, restlessness, and particularly the desire to be in the world in a different body and a different space, and maybe even a different time. This challenges a person's sense of meaning and purpose. For the patient a spiritual disconnectedness from Self, Other, the world, and mystery/transcendence (de Souza, 2012), aligns itself with a sense of deficiency of control and an inability to define or articulate it: ...*like an itch you can't scratch...but you can't*

actually say you're itchy (Appendix G, Line 338). Spiritual distress was identified as unexplainable, mystery within and without; the mystery of living in space, body, time, and relation buffeted by the mysterious cosmos.

In summary, this focus group initiated a three pronged conversation about spirituality: education, definitions, and community-based care. Lived Other provided a framework for future access to a common language, and descriptions of spirituality. Spirituality was communicated as something deep and mysterious within each person that is in fluid connectedness with self, other, and mystery/transcendence while opening up meaning and purpose. Spiritual care was described as holistic, with respectful listening and stillness in the company of Other. While spiritual distress was seen as occurring when disconnection and lack of meaning and purpose were evident. The interweaving of the Lived Space and Lived Body of community-based palliative care influences spiritual care praxis and raises the profile of the taboo of death. The Lived Body was where spiritual distress was most prominent experiencing a lack of control and restlessness.

Individual Interview Two: Asking the "Big" Questions

The fifth textual conversation is an individual interview with Ashley, a participant involved in the day-to-day practice of BHCI (Appendix G, Line 473-550). Spirituality is a fundamental Lived Space cherished by Ashley and experienced corporeally and relationally. The focal points of this entwining present a colourful and enthusiastic dialogue, and is itself a reflection of Ashley's spirituality.

> *Ashley came into the room bringing an atmosphere of excited anticipation. With a self- professed interest in spirituality, Ashley had welcomed wholeheartedly the opportunity to discuss the topic of spirituality.*

The conversation began with an understanding of spirituality.

"It doesn't mean religion. To me it means the questions that you have about who you are, why you're here, what impact you've had in your life? What might be there after my life, or our patients' lives?

Three major thoughts surfaced: peace, comfort with Self, and connection with Other.

"Being peaceful. It's based in communication with yourself and with others. Being at peace with who I am and my beliefs; feeling comfortable with what I believe... Spirituality is about connection, but I think other connections rely on you being connected and at peace with yourself. It can be described as core, or essence: it's what makes you you. But it doesn't stay static; it's obviously going to change, day to day, depending on what happens or is happening.

Spiritual distress became the next topic focus.

"I think when you settle, and you're more peaceful in yourself, I guess you're open to more things, or open to more understanding, or believing in whatever. But obviously if there's lots of turmoil going on you just need to get through this. You think, 'I've just got to get through today,' or whatever it is. When people are unsettled in themselves, and you've dealt with their physical pain or nausea and such, then I think of spiritual distress...for someone who's dying, they're going to have lots of questions. They're going to reflect on their life; they're going to worry about their family."

"For some people their religious beliefs are important...but the person still dies in their own unique way."

Finally what it is that makes community-based palliative care different was explored.

"Going to people's homes, on their ground, respecting what they want and working towards what they want and what the carers want. We respect their choices. Develop relationship. It's not just about physical symptoms, if they've got emotional turmoil,

being able to help them maybe sort some of that stuff out - so that they can die more settled. We've got that time: can allow that time for whatever they need."

There the conversation naturally ended, with a focus on the person-centred approach of palliative care (Appendix G, Line 473-550).

Explication. For Ashley, the interpersonal space of Lived Other placed spirituality at the centre with *the big questions* of meaning and purpose: Who am I? Why am I here? What impact am I having? alongside mystery and connectedness (Puchalski et al., 2009). These questions and their evolving answers interlace, informing Ashley's way of being in the world. The entwining began passionately with a declaration of spirituality bringing internal peace that ripples out bringing peace in relationship: comfort with Self that leads to relational comfort. This led to appreciation for the Other, for the world, and for mystery/transcendence, that renders an appreciation for the Self. This internal acceptance of self, self connectedness, translated to acceptance, peace, and connectedness with others, with the world, and with whatever mystery is beyond. A revolving conversation of spiritual interplay that has capacity for transcendence (van Manen, 1997).

Dredging deep Ashley discovered that within Relationality the notions of peace and being comfortable with the Self were in conscious conversation with pain, death, and the hard knocks of life. Spirituality encompassed the *good* and the *bad*, and all points between, creating an atoll of appreciation for the waves of life to crash onto. *Making the most of now and appreciating it* (Appendix G, Line 504-505).

Reflection, appreciation, wonder, and passion frolic within the Lived Space of spirituality (van Manen, 2002b), as *what makes you you* (Appendix G, Line 492) evolves. This movement animated Ashley, swelling confidence and competence, and grasping delight in the *now*. Thoughts in Lived Space focused on growth, influence and the evolving nature of spirituality. Even the stillness of personal reflection impacted on the Lived Space.

Terminal illness and death were encountered within Lived Time. The temporal elements of past, present, and future blending and fusing in the ending of life. Often it is here that Ashley finds the *big questions* of spirituality emerge and are reflected upon. How does one answer Who am I? Why am I here? and What is the meaning of all this? when time is blatantly finite and physical decline has sapped all energy? Yet most times it is the dying of the bodily self, or the death of another we are connected to, that is the catalyst for such spiritual reflection. Moving through lands of unfamiliarity and limitation raises a desire for the recognizable, and as the body declines and disease restricts physical ability, reflection on the past and new meaning for the present become the focal point. Nevertheless, whether spiritual reflection and religious thought bring peace or regret Ashley had experienced that *...the person still dies in their own unique way* (Appendix G, Line 541).

This interview with Ashley again raised essential meanings of spirituality as connectedness with Self, with Other, and with mystery/transcendence, alongside meaning and purpose, something that moves and grows towards ultimate unity. Lived Other identified spirituality with transcendence, connectedness, and with the *big questions* around meaning and purpose: Who am I? Why am I here? What is the meaning of all this? Spirituality was associated with the essence that makes a person who they are, the way of being within Lived Space, again the connectedness of self with Self that brings a sense of internal peace.

Individual Interview Three: The Missing Voice

As the researcher read, reread, and became immersed within these textual conversations concepts and thoughts appeared to crystallize then crumble, to condense again, only to move towards disintegration. Something was missing. Just as a rainbow without the colour yellow can still be colourful but not complete, so too a lack of completeness coloured and distorted the collection of these textual conversations. Holistic care includes spiritual support and this silence left the multidisciplinary voice incomplete. The voice of the

researcher as a professional peer and team member was missing, so subsequently the question arose about the perceived need and appropriateness of the researcher to interview herself. I have addressed this question from both a philosophical and a research process position.

Philosophically human science, van Manen's (1997) view of hermeneutic phenomenological research, is the study of the life world, the lived experience, "the situated meaning of a human in the world" (Laverty, 2003, p. 7). Here the researcher is not separate, but rather an integral part of the research process, for it is the interpretation of the meanings held by all participants in a social group that informs social reality (Brannick & Coghlan, 2007). Within lived experience, "Human beings cannot be separated from their relationships in the world" (I. Holloway & Wheeler, 2010, p. 220).

Wonder, too, is paramount in hermeneutic phenomenological writing, "a questioning wonder...such as when something familiar has turned profoundly unfamiliar, when our gaze has been drawn by the gaze of something that stares back at us" (van Manen, 2002b, p. 5). It was this questioning wonder that alerted me to the missing voice, and the need for it to be included in any text of the life-world at BHCI. van Manen (2002b, p. 238) continues, "The researcher is an author who writes from the midst of life experience where meanings resonate and reverberate with reflective being." Observational field notes were not appropriate for this methodology as they would have added the researcher voice as an *observer to* the *process*, which is problematic in hermeneutic phenomenology (I. Holloway & Wheeler, 2010; Thorpe & Holt, 2013). Similarly, a phenomenological reflection on the *process* would have also provided an outsider, observer voice. The choice of a phenomenological reflection *on the topic* through self-interview was an attempt to bring wholeness to the lived experience of the multi-disciplinary team, as the researcher was an ordinary participant in the life-world of the organization.

In his text *Writing in the Dark*, van Manen (2002b), explores the process of phenomenological writing through the hermeneutic interpretation of a self-interview, placing this as the first chapter. Within it van Manen states, “Therefore, it behooves us to remain as attentive as possible to life as we live it and to the infinite variety of possible human experiences and possible explications of those experiences” (pp. 7). Bullough & Pinnegar (2001) argue that the fully acknowledged self-interview places the centre of attention on the space between the self and the practice being undertaken, rather than a focus on the self. Within human science it is vital that as researchers we, “keep a close eye on our own lived experiences of the phenomenon under investigation” (Friesen et al., 2012, p. 67). In hermeneutic phenomenology, rather than bracketing prior experiences and attempting outsider objectivity, researchers within hermeneutics see prior experiences as potential sources of knowledge (I. Holloway & Wheeler, 2010).

Three features are commonly found within the process employed by hermeneutic phenomenological researchers, “their choice of everyday, common and situational subjects; their use of experiential material in their texts; and their unconventional writing style” (Friesen et al., 2012, p. 55). However, the development of academic knowledge is the whole focus (Brannick & Coghlan, 2007). Magrini (2012) elaborates, “We gather experiential data through a variety of activities and media, all of which emerges from and finds its way back to our personal experience: Observation, descriptions of others’ experiences (biography), protocol writing (the generation of phenomenological texts), interviews (*which might include self-interview*) (italics mine), journals, logs, diaries, works of art, and phenomenological literature.”

The strength of self-interview is further supported by the understanding that “subjective experience is experience in which a subject’s *attention is directed toward her own conscious events or states* in experiencing or reflecting upon them. People to whom

subjective experience is ascribed have *privileged access* to that experience. Their reports have the status of uncorrectability, and are given in the first-person singular" (Babich & Ginev, 2013). As a technique, the process of self-interview is well used within scholarly research, examples of self-interview include diverse topics such as child welfare (Brackenridge, 2006), infertility (Kirkman, 1999), lesbian identity (Crawley, 2012), and political science (Burnier, 2006). The literature supports the use of self-interview as having philosophical integrity with hermeneutic phenomenology and as a constructive element of the research process. Therefore the self-interview was conducted and included, with excerpts from The Missing Voice (Appendix G, Line 554-616) beginning with a focus on education and defining spirituality.

> *"I think there is a great need for education here about spirituality. Some type of conversation would break the current silence, and help to bring together a language so spirituality can be discussed with some common understanding and meaning."*
>
> *"To be spiritual is to be aware of the inner life, and the outer life, and the layers of interplay between them. Spirituality brings a library of meaning and motivation to my life. If spirituality is about the core or quintessence of a person, then I believe it to be a part of being human."*

Spirituality moved towards a personal understanding.

> *"Spirituality for me personally is something very deep on the inside of me that makes me me, internally a connectedness with myself. This Self connection grows out of relationship with a mysterious, yet known, transcendent Being: I consider myself as a passionate God-lover. It is within this relationship with something bigger than me that I experience nurture and nourishment of spirit...Concurrently spirituality is socially established inspiring me in the optimistic way I see the world and act within it, and then embracing that world back into myself...In varying degrees of intensity, it*

ranges from the abiding with my husband and six children to the stranger I briefly encounter in the lift. It also encompasses the planet, as I stand with others, or with myself, in wonder and marvel at the sunset, the perfumed rose bloom, or the constancy of the waves. Often it is within nature that my spirituality gets fed and blossoms; awed by wonder."

Connectedness turned to discussion of spiritual distress and disconnectedness.

"When I consider spirituality as displayed within connectedness, then the definition of spiritual distress effortlessly falls into disconnectedness. The disconnection of self with Self is common in those diagnosed with a terminal illness. Often as decline occurs for the patient they are not what they were, not wanting to go where the inevitable leads, and not wanting to be where they are in the present."

The conclusion of this interview brought thoughts of working in the community.

"The beauty of community-based care is that you have the time and opportunity to build these things, all within the patients own space and under their direction. When we enter their home and meet them in their context we get a broader picture of who they are. This creates an effective springboard towards co-creating meaning and supporting connectedness." (Appendix G, Line 554-616).

The Temporality of the life world is an expanse where spiritual *being*, or essential nature can reside gently. While reflecting on the questions and posing the answers, temporal fluidity discovered an arbitrary rhythm that provides a natural momentum. *Time holds its breath as a starting place is found, then in fits and starts the second hand seems to move erratically around the clock face* (Appendix G, Line 556-558).

Explication. The embodiment of spirituality at BHCI conceals more than it reveals. This obscuring results in misunderstandings that ultimately affect patient and family care, effectively eradicating an observed spiritual component from much of holistic care.

Conversations and training about spirituality were seen as necessary to ...*break the current silence, and help to form a language* (Appendix G, Line 561), that is common to the multidisciplinary team. One component of spiritual care, that of *being* over *doing* to co-create sacred space, was considered potentially challenging to professions involved in problem solving and tick box fulfilment (E. Kelly, 2012b).

Moving towards understandings of spirituality, the Lived Body opened up to reveal a ...*library of meaning and motivation* (Appendix G, Line 570). A spiritual stratum identified the reciprocity of influence inwards and ascendancy outwards: Was spirituality the inner essence? Was it the transcendent Other or fortuitous layers of both? The innate nature of spirituality declared itself as a constituent of humanity (Bellous & Csinos, 2009; de Souza, 2009b; Ranson, 2002; Sulmasy, 2002; Tacey, 2010); conscious or pre-conscious it revealed the uniqueness of each individual and brought connectedness of self with Self (de Souza, 2006; E. Kelly, 2012b). Similarly a connectedness with the mystery of transcendence also disclosed idiosyncratic elements highlighting the individuality of each human being. Subsequently relationship with Other and with the world continues to tell the spiritual story, layer upon layer (Chao et al., 2002; de Souza, 2006).

With spirituality defined as layers of connectedness, the Lived Body easily recognized disconnectedness as source, or description, of spiritual pain and distress (de Souza, 2012). Dislocation of the Lived Other we entertain with transcendence, with the world and with the Self or Other was perceived as a feature which unsettles and unbalances the sense of Self, the core of being:

> *Disconnection of self with Self is common in those diagnosed with a terminal illness...the patient, they are not what they were, not wanting to go where the inevitable leads, and not wanting to be where they are in the present. Time waxes and wanes with neither the past, present or future considered as comfy or secure. How*

> *does one rearrange a whole framework of one's meaning and purpose when the structure has become alien?* (Appendix G, Line 601-606).

Decline can leave a patient experiencing unfamiliarity with their own way of being in the world, both physically, and mentally (E. Kelly, 2012b). Influenced by foreign emotions, in a body that no longer performs reliably, the self in the mirror can seem strange and unfathomed. Relationships with others can be taxed by the enormity of change, bringing a reminder of the fragility of all life and the loss soon to be experienced. These layers of loss impinge upon each other, potentially initiating levels of disconnectedness. Being foreign to your own Self can ripple out over one's context and lifeworld. The existential questions of Who am I? and Why am I here? become troubling when meaning and purpose is wrapped up in the life that was past. Lived Time and Relationality are braided together in disconnectedness illustrating the unfamiliar landscape of palliative care.

Here, again, Temporality and Lived Body entwined in the description of community-based care. The uniqueness of BHCI was its intention for practice that offered the space that allowed for the time needed by the patient and family, to create a professional relationship that co-created sacred space in *their* familiar context (E. Kelly, 2012c). Time can build relationship: relationship gently gathers in time.

The question that was now posed to the researcher was: has engagement with the textual conversations influenced my words, perception, and understanding? The response appeared to be: I believe the influence to be minimal. The experience of interviewing myself was similar to looking through an old friend's new home. I was intrigued and exceedingly interested, soaking in the colours and shapes of rooms, the patterns of newly placed but familiar furniture, the rearrangement of the books on the shelf: but this was not *my* house. With no judgment, I walk through the mix of unfamiliar spaces scattered with familiar objects encountering a deep knowing that this is all outside of *mine*, deeply mundane, yes, but

owned by my friend. Familiar things are revealed and new spaces, while concealed at first glance, open up bringing new understandings. Equally the spiritual lifeworlds I have plunged into sit alongside my spiritual residence, maybe influencing the placement of a new cushion or the addition of a plant in a sunny corner, but leaving the rooms and heavy furniture intact; as they were. This is my home: my lifeworld bracketed.

This final interview highlights the Lived Body of *being* in revealing and concealing spirituality as connectedness and disconnectedness within BHCI. The concealing of spirituality appears to be assisted by an accompanying lack of common language, while the uniqueness of innate spirituality was revealed in meaning as co-creation of sacred space occurred within Lived Space. Spirituality was then interwoven with Lived Body again in the co-creation of sacred space and connectedness with Self, Other, the world, and mystery/transcendence.

Stories of Spirituality

Striking experiences of spirituality and community-based palliative care have emanated from the hermeneutic phenomenological conversations of focus group and individual interview so far within this chapter. These experiences continue with shared spiritual stories in the following section. Through the interview process participants were invited to share a story that reflected their understandings about spirituality. Seven short stories were disclosed within the diverse textual conversations (Appendix G, Line 620-702). These have been gathered together and excerpts have been presented below. It is noted here that hospitality, which was a feature of the focus groups and individual interviews, was again the research approach to these narratives. For instance, as guest the expression of the host (or participant), was both accepted and immersed within (Finlay, 2013; van Manen, 1997). Concurrently, the layers of the conversation were excavated like an archaeological dig,

discovering concealed expressions of the lived experience of the participants (van Manen, 1997).

> **Story one.** *Moving into the community, Jo did an initial assessment on a particularly unwell lady...“I talked and listened, I like that aspect, and I wrote the new wedding dates down. All the time assuring her that we did know and we did understand. Holding the contradictory is a part of caring for the individual patient.”* (Appendix G, Line 620-629).

Lived Time stretched with hope while it simultaneously shrinks inside the corporeal reality: a lifeworld of paradox. Spiritual care gently held both tracks lightly as the experience of connectedness was lived out, witnessed, and relinquished, all at once. The acknowledgement of taking pleasure in connection through talking and listening highlighted both Jo’s connectedness with Self, and then with Others; all the time providing a mysterious Lived Space that accommodated contradictory elements, both generously and without fear. Van Manen (1997, p. 102) suggests, “...the space in which we find ourselves affects the way we feel...we become the space we are in.” Jo experienced the Lived Space and held the contradictory with nonchalance, having some awareness that intellectual understanding was “embodied knowing and being” (van Manen, 1997, p. 14), and this phenomenological aspect of embodied knowing and being can be separated by great inconsistency. Being present in this seemingly absurd Lived Space was enabled by a connectedness with mystery, a transcending of the Self.

> **Story two.** *“A friend of mine was hit by a car and killed outright and I was on the same road. I remember seeing him lie in the road and his life was gone...All the time I understood that knowing where he was was not going to bring him back* (Appendix G, Line 631-637).

Lived Time waxed and waned between different aspects that played out in this vignette: speeding up in the catastrophe, slowing in the natural world. The Lived Space, too, moved between the two landscapes – one of destruction and the other of gentle, captivating environment: a surreal phenomenon which toyed with, and embraced, the mystery of both death and life.

> **Story three.** *We were strongly assured that Charlie was not spiritual and didn't have time for mystery, yet shared this story with bewilderment. "Both my partner and I had no belief in life after death, but when in hospital dying my partner had an experience of going off into a field and there was a dog and a buttercup. As I'm hearing about this...is it a vision...my dad stepped out to take a phone call from interstate. Dad returns and says the person on the phone had just seen my partner in a field with a dog and a buttercup. I don't know, maybe there's something..."* (Appendix G, Line 639-647).

Charlie appeared to be a pragmatic person who almost flippantly shared, and then brushed the story aside. The enigma of the unexplainable and beyond sat neatly for Charlie in a *past* temporal dimension. The mystery of the story and accompanying bewilderment, while very real in the telling, were pushed from the *present* horizon and left to possible interpretation in the future; yet past, present, and future all make up Charlie's landscape of Lived Time (van Manen, 1997). The relationality within this fragment revealed ripples of connectedness from Charlie and partner, through extended family, and on to acquaintance. Lived Other echoed the connectedness of spirituality with Other and with mystery.

> **Story four.** *"I can actually remember my first patient that died, and I remember him well... I went away to see another patient and when I came back and he had died. And they all looked at me and said "Will you ring the daughter?"... Anyway, I did and it*

was amazing because she had been worried and I rang her and she was fine..." (Appendix G, Line 649-662).

Lived Other again featured heavily within this anecdote. An interweaving of different layers of connectedness with Other shone a light on spirituality in interpersonal space (van Manen, 1997). The conversational relation that occurred in short, but deep, connections at time of medical crisis had the potential to lead to a "transcendence of self" (van Manen, 1997, p. 105). It is this connectedness that had impressed itself on the mind, and memory, of the narrator.

Story five. *"One client was in deep angst with having her father in her home...However the end result was that she was able to keep him at home up until the day he died. Satisfaction seems like the wrong word to me...but when I got the news about how it had come about I thought, "That's great. Good on them." Wonderful and yeah a feeling of satisfaction* (Appendix G, Line 664-675).

Relationality features strongly when stories are shared about spirituality. Lived Other can be messy and fickle as human, revealed and concealed, interacts with the revelation and concealment of another; the Lived Body. The shared interpersonal space of Lived Body is heavy with multiple levels and spaces of connectedness and disconnectedness (de Souza, 2012). Perhaps too, the idea that spiritual journeying may not lead to a sense of satisfaction unearthed a shadow side, a disconnectedness with Self (de Souza, 2012).

Story six. *" I had a bit of contact with a patient's husband when he came in to pick up things, and quite a lot on the phone after she died; organising the equipment and that sort of thing. I could tell that he felt comfortable to tell me stuff, a connection. And when he came in last week I knew that was the last time I would see him. I felt sad. When he dropped in the last piece of equipment we just looked at each other and I thought, oh I could almost hug you, but I didn't."* (Appendix G, Line 677-691).

The reception area at BHCI was identified is a Lived Space in both a physical and spiritual sense. The height, length, and depth of the quantitative physical space were shadowed by the qualitative human landscape of where people are doing, being, and finding meaning. People are affected by the space they inhabit at any particular time; even becoming that space (van Manen, 1997). An entrance into this reception space was considered to propel people into a Lived Space of trust, respect, loyalty, skill, willingness, kindness, honesty: values held in high esteem, and practiced by employees of BHCI. These values assisted and facilitated connectedness with Other.

> **Story seven.** *"One lady who was dying at home said that her grandfather was around...Another lady whose husband had died said she walked into the kitchen and she saw him. Had a vision of him: and it was him... So for me they're all amazing stories that make me wonder what else is out there and what happens after we die. I don't think we just die...* (Appendix G, Line 677-691).

A connectedness with what transcended humanity, the mystery facet of spirituality, rose within Lived Time as "hopes and expectations of life to come" (van Manen, 1997, p. 105), were pondered. The horizon of the temporal landscape stretched into an unknown, but much anticipated future. Lived Space filled with fragments of imagination, witness accounts, and myth in a search for meaning. A desire to maintain connectedness with Other transcending death is defined as continuing bonds, an inner discernment of connectedness between the bereaved and a deceased person (Gassin & Lengel, 2013). This spiritual mystery of transcendence is supported through a reconstruction of meaning, of relationship, and of the new life to be embraced: meaning reconstruction theory (Gillies & Neimeyer, 2006).

These disclosed stories of spirituality highlighted Lived Other echoing the connectedness of Self, Other, the world and mystery/transcendence, throughout life and even after death, infusing these connections with meaning and purpose. Lived Time and Lived

Space saw spiritual care holding the paradox of hope and the reality of a short prognosis, life and death, connectedness and disconnectedness. Lived Body revealed transcendence as it journeyed with Other through contradictory elements of hope and despair.

Summary of the Findings from the Textual Conversations

Phenomenological understandings do not produce a precise, orderly result, but rather expectedly the lifeworld of spirituality at BHCI has shown itself as an imprecise, irreducible, ambiguous, enigma full of possibility (Finlay, 2013; van Manen, 2011). The possibilities encountered within the textual conversations in this chapter have been unearthed using van Manen's four fundamental existentials: Corporeality, Relationality, Temporality, and Spatiality. Lived Body reveals and conceals spirituality at BHCI as both private/innate and public/communal. A connectedness with Self, Other, the world, and mystery/transcendence can also encompass religion. The internal personal nature of spirituality speaks of unique personhood, the Self, influencing seasons of life, and those of death. Lived Other also emphasized spirituality as relational showing connectedness with Self, Other, the world, and mystery/transcendence throughout life, and in death, with an evolving movement towards ultimate unity. Spirituality was considered to nurture receptivity to Other, and co-creation of a sacred space in which to address the big questions of meaning and purpose. Spiritual distress was identified as disconnectedness. Lived Time encompasses a focus on particularly person-centred care in the here and now. A spiritual aspect of community-based care holding within it the paradox of hope coupled with a reality of short prognosis. Lived Space provides a haven for spirituality as connectedness, where person-centred care can co-create space to ask: What makes me who I am? An overlap of the lifeworld existential occurred within the theme of education in spirituality. Training was identified as important to break the perceived silence and concealment around spirituality at BHCI. Conversations, education, and training

about spirituality were seen as not just important for new professionals moving into the organization, but also for current employees. Topics for education included:

- the need for a common language;
- suspension of judgment;
- active listening;
- Self/Other awareness and intuition.

All increase a sensitivity to what is happening within the Self and in the reaching out to Other. This concludes the hermeneutic phenomenological findings from the textual conversations, and provides us with five major themes identified above for discussion in the next chapter:

- Spirituality as relational based in connectedness;
- Spiritual despair-disconnectedness;
- Contrasting religious care and spiritual care;
- Spirituality within community-based palliative care;
- Lack of common language highlighting the need for education and clarity of communication and understanding.

Significance of the Findings of this Research Study

A lack of common language around spirituality at BHCI has led to difficulty in achieving the WHO and PCA directive of spiritual care as a component of holistic palliative care (Jenkins et al., 2009; P. McGrath, 2005; Palliative Care Australia, 2011; Swinton, 2012; World Health Organisation, 2005). The collection of understanding and perception within BHCI of spirituality, spiritual distress, and spiritual care, alongside the conception of education required in spirituality, can lead to organizational awareness and improved provision of spiritual care. Bringing these aspects into educative packages for orientation and

professional development empower all members of the organization to recognize spirituality and provide spiritual care.

van Manen (1997, p. 78) considers that, “Meaning is multi-dimensional and multi-layered. That is why the meaning of (spirituality) can never be grasped in a single definition.” Within this research study encounters of the understandings and perceptions of spirituality, which have initiated wonder and thoughtfulness have been shared through story-based, hermeneutic phenomenological conversations. However, it is in writing that we evaluate our thoughtfulness (van Manen, 1997). Within this explication of the textual conversations findings were interpreted through writing and rewriting as a measure and presentation of the thoughtfulness of the research (van Manen, 1997). The essence and multifaceted lifeworld of spirituality at BHCI, as displayed through the five major themes listed above (see pp. 185) will be further explored, reflected upon, and interpreted (Finlay, 2013) through the interpretation chapter following. The findings as discussed in this research study also led to the development of a spiritual screening tool, *Connecto*, which is detailed in the concluding chapter.

Chapter Six: The Interpretation and Reflection on this Research Study

This chapter provides a discussion of the reflection on, and interpretation of, the lived experience of spirituality as understood and perceived by multidisciplinary staff at Ballarat Hospice Care Incorporated (BHCI). Within the findings of the previous chapter, the understandings and perceptions of spirituality at BHCI were not separate from their meaning, but rather rose from within the organizational textual conversations of the participants. Neither were the understandings and perceptions of spirituality held separate by the researcher from the meaning spoken of by the participants (van Manen, 1997). Cobb (2012, p. 96) describes spirituality as a "vast domain that is experienced and manifest in diverse ways by individuals and communities that are complex, dynamic, and multidimensional." Accordingly, as separate voices spoke and individual words were heard, thoughts entwined with evolving and developing meaning. Now, in this interpretation and discussion stage, the voices merge to bring a melded cohesive conversation about spirituality within BHCI.

As discussed in the methodology chapter (see pp. 132), the hermeneutic phenomenological conversations from the focus groups and semi-structured in-depth interviews were placed within a single document and assigned numbers to each line to make them easy to find (Appendix G). When quotes from the research participants are used in this discussion chapter they are written in italics and each quote is followed by the line number where it can be located within the appendices section, for instance (Appendix G, Line...).

This research study has been intentionally narrow in focus to allow for discovery of a depth of diverse layers of meaning that encompass the complex, dynamic, and multidimensional nature of spirituality in the specific context of BHCI. While the research study does not set out to be readily generalizable, the discussion will show that the essential lived experience of spirituality may be reinterpreted for other sites that desire to create a site specific lexicon of spirituality.

The move towards understanding is always an interpretation that comes out of immersion and reflection (van Manen, 1997). Hermeneutic phenomenology attempts to attend to both notions of the methodology: the phenomenological methodology, which is descriptive, concentrates on the appearance of things, allowing them to speak for themselves, while the hermeneutic methodology, being interpretive, holds that even the reality of lived experience necessitates a confining by language, the human science text, which is, unavoidably, a process of interpretation (van Manen, 1997). The hermeneutic phenomenological methodology of van Manen's (1997) lifeworld existentials includes corporeality (Lived Body), relationality (Lived Relation), spatiality (Lived Space), and temporality (Lived Time). These existentials were described in the methodology chapter (see pp.132-133), and then provided the scaffolding for the presentation of the findings throughout the previous chapter. The textual conversations of focus groups and individual interviews were phenomenologically and systematically explored through these four fundamental existentials, revealing rich layers of phenomenological findings. However, the lifeworld existentials which were identified through the exploration of the data in the previous chapter (van Manen, 1997), will now be reintegrated in this chapter. They will overlap to provide cohesive interpretations and reflections of the five main themes that rose from the textual conversations:

- spirituality as connectedness and relation;
- spiritual despair-disconnectedness;
- contrasting religious care and spiritual care;
- community-based palliative care;
- the lack of a common language highlighting the need for education.

These themes illustrate the essential aspects of spirituality which were brought to life in the previous chapter of explication and findings (van Manen, 1997). They bring thoughtfulness to

the question posed in the introduction: What are the understandings and perceptions of spirituality held by multidisciplinary professionals involved in community-based palliative care? The interpretations have come about through reading and re-reading, writing and re-writing, and a weaving of the textual conversations with the phenomenological descriptions as a measure and presentation of the thoughtfulness of the research (van Manen, 1997). The first theme explored is the understanding of spirituality as connectedness and relation.

Spirituality as Connectedness and Relation

The understandings and perceptions of spirituality as experienced at BHCI are relational and connective in nature. *Spirituality is about connection* (Appendix G, Line 490). *The outer social foundation of spirituality is about my connectedness with others* (Appendix G, Line 589-590). *Concurrently spirituality is socially established* (Appendix G, Line 585). , These perceptions echo throughout the literature, where to be spiritual is to be in relationship, or to live in connectedness with the Self[9], with Other[10], with the world, and with mystery/transcendence (de Souza, 2009b; Ellis & Lloyd-Williams, 2012; E. Kelly, 2012b; Liu & Robertson, 2011; Sheldrake, 2007). The fluidity of spirituality is like a dance of connectedness swirling through time, widening and narrowing its focus as it partners with values, meanings, purpose and context (M. Holloway et al., 2011). *I think it's our life experience, circumstances and our phases of life that explore it, grow it, change it, influence it. Then it ends up wherever it goes in different sizes and quantities throughout our life journey* (Appendix G, Line 243-246). *And whether attention is paid to it or not, spirituality still ebbs and flows like the tides: at times breaking high up on the shore and making itself known loudly and powerfully, while other times quietly dragging sand back off the beach at low tide* (Appendix G, Line 571-574). While spirituality is influenced by life and context, spirituality also influences life and context, providing a collaborative interplay on day-to-day

[9] *Self*: see footnote 2, pp. 8.
[10] *Other*: see footnote 3, pp. 8.

life. *...spirituality is dictated to by all these things, but it also influences all these things* (Appendix G, Line 253-254). *My spirituality seesaws between the inner going out into the world and the influence of the world* (Appendix G, Line 587).

As a form of meaning, spirituality is already operative in childhood, being written on by life, moment by moment, sometimes consciously, but often not (Hyde, 2008a; Moriarty, 2011). Spirituality *includes how we're brought up and what we're taught* (Appendix G, Line 206-207). Rarely static, spirituality ebbs and flows in movement along a relational continuum from separateness, through connectedness with Self, Other, the world, and mystery towards ultimate unity (de Souza, 2009b, 2011). *Spirituality involves the whole person...anything they are able to draw together in forming themselves as a whole person* (Appendix G, Line 356-358). Figure 4 presents a visual representation of the continuum from separateness to ultimate unity.

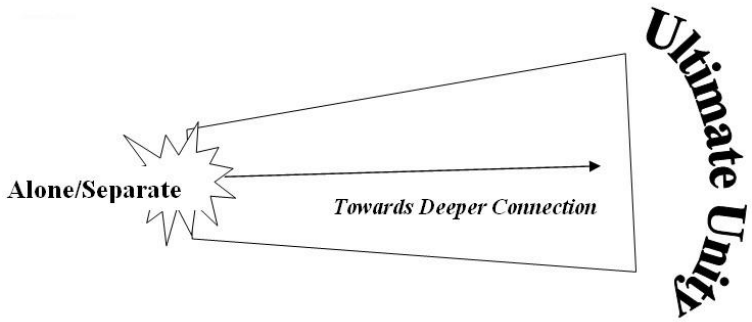

Figure 4. *A Relational Continuum*
Note: This reflection of human spirituality as a relational continuum is based on the work of de Souza (2012) and Fisher (2011).

Connectedness with Self

Connectedness with Self is where a relational definition begins, for our most authentic self is "the source of true power and authority in our lives is found" (Champagne, 2014). Conscious or pre-conscious, spirituality lies deep and mysteriously within each person revealing the uniqueness of each individual (de Souza, 2009b; Pichon, 2007; Tamira, Ford, &

Ryan, 2013). This internal personal nature of *being*, which can also be named the *core*, *essence*, or *the real you*, speaks to the innateness and constancy of spirituality as a constituent of humanity (Culliford, 2007; Moberg, 2010; Narayanasamy, 2007; Pargament, 2007). *Spirituality for me personally is something very deep on the inside of me* (Appendix G, Line 576). *...and then there's the other part of the person...a constant* (Appendix G, Line 242). This constant means that at a fundamental level each individual is in an intrapersonal relationship with him/herself: the self engages the Self (Pesut, 2003). Connectedness of self with Self is visually represented in Figure 5 as a single blade of a fan.

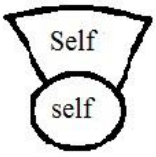

Figure 5. *The self in Connectedness with the Self*

This personal relationship reveals how an individual experiences the Self and how they see their place in the world, embracing notions of self-acceptance, identity, self-assessment, and self-talk (Pesut, 2003; Sacks, 2009). Who am I? is the first question humanity asks (Sacks, 2009): the ultimate question of self-identity (Frankl, 1992; Walter, 2002). The spiritual connectedness of self with Self is ...*something that makes the person the person* (Appendix G, Line 231); *makes me me* (Appendix G, Line 576-577).

Connectedness with Self is fluid, continually revealing and concealing (van Manen, 1997), joining and expressing, learning and growing, providing self-fulfilment, and development towards wholeness and ultimate unity (de Souza, 2011). It is a space of being where the present, past, and future all merge into the spiritual experience of life in the here-and-now (Carroll, 2001; Wilber, 2000). This is a feeling place: *the words of a song can make*

you cry, so it's about the inside (Appendix G, Line 94), and provides a sense of peacefulness through the creation of meaning (Chao et al., 2002; M. Holloway et al., 2011). *Being peaceful....Being at peace with who I am and my beliefs* (Appendix G, Line 487-488). *I don't think you can be connected properly with anybody else unless you're comfortable or connected with yourself* (Appendix G, Line 513).Connectedness with the Self is a welcoming space to unpack personal fears and joys (E Kelly, 2013). *My fears about me, which mightn't be real, mightn't be what anyone sees* (Appendix G, Line 95-96).

As a component of holistic care, participants described spirituality as the centre: *the centre of integration* (Appendix G, Line 436). *Inner, inside, what you're really like, the core of the person* (Appendix G, Line 91). *Spirituality is innate* (Appendix G, Line 240). *The inner, whatever it is* (Appendix G, Line 232). Connectedness with Self was the centre, where meaning, purpose and all that makes up a person can be incorporated and nurtured to create the whole. This essential nature is based on the *being*[11] of a person, rather than the *doing*. Located deep within a knowing place of intuition and internal wisdom, *being* shapes who the person is, inside and out, in all of a person's intricacy (Brewer, 2001; Heidegger, 2010). Even though the outer person, the *doing* seems to dominate how a person *is* in the world, this is an expression of the internal being where being the Self involves not striving, or achieving, but a form of waiting in time (Maslow, 1970). So, while *doing* is coping behaviour that comes out of an attempt to change the world, the expressive behaviour of *being* is neither about ends or means, having no, or little effect on the environment (Maslow, 1970).

Spirituality is also revealed and concealed through the seasons of dying (van Manen, 1997), which can bring a move along a continuum marked by physical decline, through the embrace of life, and on towards a wholeness of spirituality in ultimate unity (de Souza, 2009).

[11] *Being* as the fundamental characteristics of the self as explored by Martin Heidegger (2010). *Studies in Continental Thought: Truth and Being.* Bloomington, IN: Indiana University Press.

In these seasons spirituality can provide an energy that propels and motivates, inspiring and being inspired, providing expressions of meaning and spiritual growth.

> *There are times in our lives that we need to look at that spiritual side of who we are and what's feeding us, and what's going to nurture us through a phase in our life...* (Appendix G, Line 249-251).
>
> *I'm amazed at that energy. An awareness of what is in myself drives or encourages or influences other assets* (Appendix G, Line 265-266).

Within palliative care connectedness with the Self can be disturbed by a perceived *loss-of-self* brought on by changes to the physical body, changes to a person's identity, and the need to let go of a meaning and purpose of life that is now redundant and untenable (Kearsley, 2003; P. McGrath, 2002). *The physical body becomes strange and unexplored territory for the person who is dying* (Appendix G, Line 370). The reflection in the mirror has become a stranger and the ordinary of everyday life that has connected the patient to the *here and now* has vanished (P. McGrath, 2002). *The disconnection of self with Self is common in those diagnosed with a terminal illness...the patient, they are not what they were* (Appendix G, Line 600-602). While much of an individual's life focuses on the *doing* and achievements, as physical decline challenges the identity of a palliative patient and much of the familiar *doing* is no longer possible (Kearney & Weininger, 2012; Maslow, 1970), it is the *being*, the spirit, the fundamental characteristics of a person that persist (Taylor, 2000). The lived experience of some patients in palliative care, revealed to the researcher through praxis, presents the identity of Self as standing on persistently shifting sand where day by day, and sometimes minute by minute, the equilibrium seems to shift. *How does one rearrange a whole framework of one's meaning and purpose when the structure has become alien?* (Appendix G, Line 604-606).Within palliative care the task is to help facilitate the discovery of new meaning and new purpose alongside the acknowledgement of being to strengthen

connectedness with the Self (M. Holloway et al., 2011); a self that is quite familiar on the inside, while predominantly a stranger on the outside.

The delivery of holistic care does not commence with a focus on the needs of another, but rather on an appreciation of who the professional Self is as carer (E. Kelly, 2012c). It is not about knowing, but it is the *being* that provides the space for the patient to discover their own, innate spiritual answers (E Kelly, 2013). For the multidisciplinary staff working in palliative care, an understanding of, and reflection on, the self in connectedness with the Self can increase personal self-awareness of one's own philosophy, ethics, and dreams (Haugan et al., 2012). Research indicates that a balance between *being* and *doing*, while significant for some palliative care workers, is not accomplished all the time (Glass & Rose, 2006), yet this is an important component in the ability to self-care which can prevent praxis impairment and burnout while promoting worker wellness (Bradley, Whisenhunt, Adamson, & Kress, 2013). Hope, too, has been found to be a protective factor for community-based palliative care nurses to sustain themselves in the face of practice challenges (Penz & Duggleby, 2011). Exploration of what nourishes individual workers when caring for the dying brings an awareness of more self-care options. Meanwhile the provision of holistic care is enhanced as workers have an awareness of their own connectedness with Self, since they can then better understand how the patient experiences connectedness with the Self, and how this connectedness can be disrupted by diagnosis and decline.

Connectedness with Other

While spirituality reflects the inherent uniqueness of each person, at the same time it engenders a desire for unity, for community and for connection with Other (E. Kelly, 2012c; Laszlo, 2008; Pesut, 2003; Tacey, 2004), one of the characteristics that was revealed throughout conversations with the participants. *Spirituality is about my connectedness with others* (Appendix G, Line 589-590). *...the way that I live my life, care for my kids, lovemy*

family, look after my patients (Appendix G, Line 508). ...*more words rolled out around the table and opinion gained momentum* (Appendix G, Line 9-10). The self to Self connectedness within intrapersonal space ripples out from the personal into shared interpersonal space: a growing awareness of the Self as a relational being moving into relationship with Other (Pesut, 2003; Wilber, 2000). *An enriching experience for me personally* (Appendix G, Line 52-53). Established in the everyday of life, spirituality can no longer be seen purely as an internal, secluded personal characteristic, it flourishes within affiliation. *Another joined in...consensus built* (Appendix G, Line 33, 38). *Spirituality is about connection, but I think other connections rely on you being connected and at peace with yourself* (Appendix G, Line 490-491).

Currently within the science community there is movement from the long held scientific understanding of reality and individualism, toward a contemporary view from quantum physics of manifold interconnected realities: a philosophy that supports an intrinsic connectedness between humans (Laszlo, 2008). Within the field of neuroscience, research into mirror neurons indicates that humans have an ability to fully empathise with Other, mirroring their feelings (de Souza, 2014a; Rizzolatti & Fabbri-Destro, 2012). Study on the mirror mechanism within the brain has shown that a real sensation of the experience of Other is experienced by the observer (Rizzolatti & Fabbri-Destro, 2012). This connectivity is labelled relational consciousness by Hay and Nye (2006) who from their research with children and spirituality have described the desire to reach out and connect as a primal response. This human relational desire is an awareness that the Self and Other are both part of the whole (de Souza, 2014a; Fisher, 2011).

Connectedness with Other can bring acceptance, dignity, and respect for each unique individual, creating an atmosphere of tolerance where Other can enter and withdraw at will (Sulmasy, 2006). *The interplay backwards and forwards between carers and patients*

(Appendix G, Line 182). However, not all connections are equal, relationships can be messy and fickle as one human, revealed and concealed, interacts with the revelation and concealment of another (Pesut, 2003; van Manen, 1997). What is revealed, when one human is connected with another human, plays a significant part in creating the relational level these individuals may have with each other (Greene, Derlega, & Mathews, 2006). Self-revealing is a choice for openness against the maintenance of autonomy, and here a positive reaction from Other is likely to foster self-worth and identity (Greene et al., 2006). Whereas concealment could indicate multiple goals of the Self founded on a fear of rejection, belief that the Other cannot or will not be helpful, a potential loss of privacy, protecting the Other from possible hurt or the cost of sharing personal information (Greene et al., 2006): concealment opposes spiritual values of truth and truthfulness (Culliford, 2007). Consequently, along the relational continuum, connectedness with Other can flow through relationships that are intimate, all the way through to mere acquaintance, and sometimes even to the stranger when a bond of being in the same place at the same time draws fleeting connectedness. *In varying degrees of intensity (*connectedness*) ranges from the abiding with my husband and six children to the stranger I briefly encounter in the lift* (Appendix G, Line 590-591). The many diverse levels of relation all fit within the relational continuum of spiritual connectedness (de Souza, 2014a; Fisher, 2011; G. White, 2006). The continuum provides an uncomplicated approach for professionals to reflect on their own placement within relational connectedness.

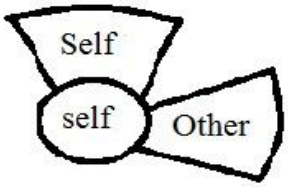

Figure 6. *The self in Connectedness with Other.*
Note: A visual representation of the connectedness continuum is presented as a fan with two blades

Connectedness with Other can also bestow a space where the Self can reflect on the Self-in-relation; a journey of discovery of the personal position within a communal space as life is lived and experienced. *There's a rich human conversation going on within myself...It is the endeavour of dual respect: self respect can lead to an understanding that recognises the Other is a Self, and of respect for that Other* (Appendix G, Line 379-381). Self-reflection and awareness rises as the Self embraces connectedness with Other and within interactions, personal thoughts and diverse wonderings can be explored and mirrored back (de Souza, 2014a; Ramachandran, 2011). This brings about a revolving conversation of spiritual interplay that has capacity for transcendence (van Manen, 1997). Peacefulness and acceptance in connectedness with the Self provide space for relational comfort and appreciation for Other which in turn can reflect back an appreciation for, and transcendence of, the Self (S. Nolan et al., 2011). *I think other connections rely on you being connected and at peace with yourself* (Appendix G, Line 490-491). However measuring oneself by comparison with others can bring intrapersonal disconnectedness (Pesut, 2003), a particularly poignant concern for the terminally ill requiring sensitivity by the multidisciplinary staff. This disengaged aspect of the self with Other is discussed further in the following section on disconnectedness.

Connectedness with Other within palliative care is a vulnerable space that requires nurturing (Seale, 1995). *The patient doesn't just get the illness, the family gets the illness* (Appendix G, Line 282-283). When a terminal diagnosis is confirmed this can have an effect on all of a patient's connections with Other.

> *This includes all the people associated, the patient, their family, loved ones and so on. There are big concerns rising as to what will life be like without this person? What they have shared together, what they've been to each other and now what they need to*

affirm. Dealing with the issues of parting from both the carer and the cared for (Appendix G, Line 402-405).

It is also acutely through the palliative journey of decline and dying that connectedness with Other provides great comfort. Physical decline can lead to a decrease in social engagement (resigning from work, leaving behind social roles and memberships), in a person's social circle (not attending clubs and hobbies, being unable to visit friends and family, not well enough for friends to visit), and even the most mundane of social events like grocery shopping or visits to the library (Sand & Strang, 2006). Dwindling social engagement is similarly an issue for the carers of the terminally ill patients as care burden increases (Haley, 2003).

The knowledge that all of humanity is connected may alleviate some of the fear of dying, which is thought of as the *ultimate dread* (Kearney & Weininger, 2012). Connectedness with Other can strengthen us in the face of dying alone, something which research has shown to threaten ideals of belonging to a caring community as well as to the carer's moral reputation (Seale, 1995), and further constructed by the media as akin to a *bad death* (Seale, 2004). *I think that alone* (being isolated) *is hard because we need each other* (Appendix G, Line 290). The fluidity of connectedness in spirituality enables the holding of hope and fear all at once. This paradox ensures a sacred space where one does not need to overwhelm the other, but both optimism and mourning can co-exist (E. Kelly, 2012c). *In terms of their connections, what they want to gather together, integrate, sift through, understand better, and bring all that together in a way that is meaningful for themselves* (Appendix G, Line 392-395).

Within community-based practice at BHCI connectedness with Other has a strong focus in providing spiritual support to each patient and their circle of connectedness with Other, be it partner, family, extended family, friends or colleagues. *How nurturing everybody*

is to the families, they treat the people like as if they're part of themselves, their own family kind of thing (Appendix G, Line 279-280). *The people dying, their family, loved ones and so on...What they have shared together, what they've been to each other* (Appendix G, Line 384-386). *Holistic care, which is spiritual care, is not just looking at one medical problem, but we look at how the medical problem impacts on the person's family and those around them....So it's a two-way connection thing* (Appendix G, Line 176-180). For the multidisciplinary staff, recognition of levels of connectedness provides three avenues for enhancement of palliative care:

- acknowledging the connectedness experienced by the patient with their carers brings a deeper level to holistic care;
- awareness of connectedness between the practitioner and the patient/carers assists the professional delivery of holistic practice;
- an increased self-awareness of connectedness for the professional with significant others in their own lives is a factor within self-care.

Acknowledgment of these three aspects of connectedness with Other embeds spiritual care within conscious and pre-conscious holistic practice.

As care needs increase, staff visits increase as required, often bringing a new and deep sense of connectedness for the patient and family with the professional carer. Gentle respect of what is revealed and what is concealed can bring an atmosphere of dignity, acceptance, and esteem, joining the speaker and the listener with compassion (Ellis & Lloyd-Williams, 2012; van Manen, 1997). This resonates with the organizational values of trust, respect, loyalty, skill, willingness, kindness, and honesty that are interlaced through each spiritual encounter indicating a spiritual foundation of connectedness with Other within the working ethos and environment (Ballarat Hospice Care Incorporated, 2013). It is these organizational values that propel a worker into connectedness with Other, that is, each new

patient and their supportive network. These values need to be emphasized as an element of best practice within training about spiritual care. Connectedness with Other, so important within the community-based practice of palliative care, radiates around connectedness with the world (Haugan et al., 2012).

Connectedness with the World

Connectedness with the world is a concept robustly presented in the literature seeking to define spirituality (de Souza, 2012; Ellis & Lloyd-Williams, 2012; Swinton et al., 2011), displaying spirituality as connectedness with the world as permeating through all of creation and creativity (Chao et al., 2002; Lovanio & Wallace, 2007; Sessanna, 2011). A third blade is added to the visual presentation of the connectedness continuum as a fan in Figure 7.

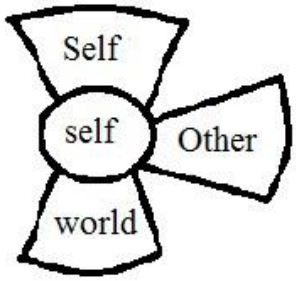

Figure 7. *The self in Connectedness with the World.*

However, connectedness with the world was not significantly identified by research participants as an element of the understanding or perception of spirituality at BHCI. Acknowledged by one participant, *...in the optimistic way I see the world and act within it, and then embracing that world back into myself* (Appendix G, Line 586).

Speaking of connectedness with place, Sacks (2009, p. 161) eloquently says, “The nation is where I live: it is in the landscape I inhabit, the language I speak, the culture that surrounds me and the society of which I am a part. It makes almost everything else in my life possible...” Connectedness with creation, for some a form of eco-spirituality, upholds the connectedness of human beings with the physical universe (Lincoln, 2000), a concept

especially important within indigenous cultures where the world is spoken of as my land or country and there is no intellectual notion of separation between humanity and the world (Harvey, 2012). This level of connectedness with place, pervasive within indigeneity is not commonly recognised within Western/modernist assumptions of personhood (Harvey, 2012). For the participants, some sense of an importance of connectedness with the world through place was highlighted when discussion arose around specific assets in the provision of community-based care, however this was not linked to spirituality and spiritual care.

> *You immediately come onto their turf, in their tower of strength. Whether that be out in the shed, or out in the horse paddock, or out in the garden, or even the clothes line. They're the places where he or she, or the family unit gains the greatest strength* (Appendix G, Line 298-301).

The connectedness of spirituality with creation found in the literature highlights the transformative qualities of creation and creativity (Corry, Mallett, Lewisa, & Abdel-Khalekc, 2013). A well-cited Swedish study of 953 town dwellers found a significant relationship between the use of parks and gardens and a lowering of stress levels (Grahna & Stigsdotter, 2003). Green spaces were classified as restorative environments. Similarly, a Danish study of 1,200 people supports the positive impact on stress by visiting parks and green areas (Nielsen & Hansen, 2007), and another study found five minutes spent within nature improved both self-esteem and mood (Pretty & Barton, 2010).

Characterization of connectedness with the world also includes that which is created, embracing such things as appreciating art, beauty, and the natural environment, creativity, gratitude, inspiration, music, and a sense of belonging or place (Chao et al., 2002; Lovanio & Wallace, 2007; Sessanna, 2011). *It also encompasses the planet, as I stand with others, or with myself, in wonder and marvel at the sunset, the perfumed rose bloom, or the constancy of the waves. Often it is within nature that my spiritual gets fed and blossoms; awed by*

wonder (Appendix G, Line 592-594). Frankl (1992, p. 115) argues, “The true meaning of life is to be discovered in the world,” where meaning is discovered through creating, experiencing or encountering, or through suffering. Creating, or enjoying the created, can take an individual out of and beyond the Self (Baggini, 2008; Haugan et al., 2012), allowing identification and communication of facets of the Self that often elude (Hartley, 2012), and forming a search for the authentic self or for the sacred (Mayo, 2009). This connectedness emerges from what some see as a harmonious orientation that favours creation (Berry, 2009; Lincoln, 2000; C. Smith, 2009). Connectedness with the created world and created things both reflect back to us knowledge of the Self (Bradley et al., 2013), while also reflecting an expression by which the Divine can be known (Ilia, Warner, & Wood, 2008).

Amongst the participants, the concept of connectedness with the world received only slight recognition in relation to place in the textual conversations and even less conversation occurred about connectedness with creation and creativity. This raises the question: Why have the participants put such little value on the inner resources that are bolstered by nature, creativity, and a sense of place, for the Self and self-care and within palliative care practice? Is it possible that this omission within the textual conversations was due to the strong focus of community-based palliative care being on the individual human patient and their carers, surrounded by the mystery of death so that the external material/physical world seems to be of little concern in a day filled with need. When patients and their support networks create a workload for staff that is at once intense and filled with crises, yet also fleeting and transitory, and waiting lists are compelling, the fostering of connectedness to place, to land, or to creativity provides a sizeable challenge to an already excessive workload (M. Holloway & Moss, 2010). The spiritual encounter of the multidisciplinary staff within community-based palliative care is all about the person, the patient and/or the carer.

> *So you treat them with dignity and respect, dealing with their need or referring them to someone else. We're all doing the same thing. Treating them with that respect and with that compassion you also help them on their spiritual journey* (Appendix G, Line 683-685).

Each encounter can engender a concentration on connectedness with Self and with Other; and while mystery and the beyond cannot be ignored in the dying process, the created world in all its glory can be. As a patient becomes house bound, and then bed/chair bound, the ability to engage with the natural environment is reduced to what can be seen out of a window, or to natural objects brought into the room (Hermann, 2001). Unless a love for nature, the outdoors, or the garden has been addressed specifically within conversation when a patient is in a stable condition, connectedness with the world is unlikely to be thought of as a priority in holistic practice, particularly as decline increases.

For the patient whose meaning has been strongly founded in connectedness with place, or such things as the garden, artistic pursuits, walking along the beach or beauty, this lack of priority from the staff leads to a deficiency in holistic care. Ignorance of the capacity to discover meaning through creation and creativity (Frankl, 1992) restricts the avenues for Self-reflection and self-care practices. Raising personal consciousness of connectedness to the natural world and creativity is something that could be included within an educative program to assist the multidisciplinary professionals identify this need within themselves firstly, and then within others. Connectedness with the world, as shown above, is often entwined with a connectedness with mystery or transcendence (Baggini, 2008; Corry et al., 2013).

Connectedness with Mystery and Transcendence

Collectively research participants understood spirituality to be associated with something impenetrable, incomprehensible, and unexplained: connectedness with mystery or

transcendence. *Spirituality is mystery* (Appendix G, Line 498). *Untouchable, unknowable...* (Appendix G, Line 13). Connectedness with mystery is an acknowledgement that as an individual there is something beyond, something larger than the Self and the seen universe; beyond the understanding and influence of the Self (Baggini, 2008; M. Holloway et al., 2011), *...this mystery provokes and enthuses me* (Appendix G, Line 581). This connectedness with mystery can bring with it a sense of reflection, appreciation, awe, hope, and wonder as this connectedness twists, turns, and evolves (Sessanna, 2011). The visual representation of connectedness with Self, Other, the world and mystery/religion is now complete in Figure 8 as a fan with four blades.

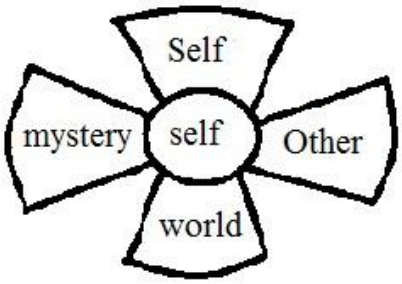

Figure 8. *The self in Connectedness with Mystery/Transcendence*.

Transcendence can be interpreted in a psychological sense where a wider humanist link with the human condition is the basis for pursuing meaning and purpose in an attempt to transcend suffering (Block, 2001; Kellehear, 2000; S. Nolan et al., 2011). *Makes me wonder...Spirituality makes me appreciate life. It makes me appreciate what I've got* (Appendix G, Line 495,502). Transcendence can also be understood in a spiritual and/or religious sense where an individual moves towards connectedness with the Transcendent, the Divine (Sheldrake, 2007; Sulmasy, 2006). *A passionate God-lover. It is within this relationship with something bigger than me that I experience nurture and nourishment of spirit* (Appendix G, Line 579-580). In exploring both of these ideas of transcendence, a humanist understanding is first surveyed.

Humanist transcendence moves creatively through expanding Self-knowledge into futuristic imagination, in an experience of connectedness with mystery. As the Self is transcended through the acknowledgement of fallibility and imperfection, it allows the view of Self to be widened (E. Kelly, 2012c). Transcendence expresses the idea that human beings can encounter themselves as more than just physical beings (S. Nolan et al., 2011). *An acceptance of that which is not only within us, but that without us that doesn't necessarily have an explanation* (Appendix G, Line 234-235). *This mystery provokes me and enthuses me. It is the centre of all my connections* (Appendix G, Line 581-582). Self-transcendence, being linked to spiritual connectedness, is described as extending the boundaries of Self, both inwardly and outwardly, in a way that the personal view of one's history and one's future enhance the here and now; something considered a useful coping mechanism (Haugan et al., 2012; Nygren et al., 2005). Manifestations of a high degree of connectedness to Self-transcendence include a sense of well-being, compassion, wisdom, receptivity, creativity, openness to life, self-worth, and respect for intuition (Haugan et al., 2012; Lundman et al., 2010; Nygren et al., 2005). *Those things that we can't explain...accepting of experiences like that* (Appendix G, Line 229-230). The immediacy of a terminal diagnosis initiates an urgency for situational transcendence where reflection on death, change, and suffering can be questioned leading to recognition of hope, meaning, and purpose (Kellehear, 2000), where transcendence can be strengthened (Emblen & Pesut, 2001), and the finding of meaning brings spiritual freedom (Frankl, 1992).

Turning now to religious transcendence, while belief in the Transcendent or Divine is not the core of religion, the majority of religions do uphold a transcendent reality that holds the power to bring about salvation (Hick, 2004; Sheldrake, 2007; Sulmasy, 2006). This generally immanent presence within the world and within humans can be expressed anywhere from the non-personal Absolute, a cosmic structure or process or ground of the universe,

Nirvana, Brahman, Dao, to a personal God (Armstrong, 2011; de Souza, 2012; Hick, 2004). For the religious person, understanding of life and worldview flows from a response to the transcendent, and aspects of human construct understood collectively, and then establish religious thought and habit considered to be required to encounter the transcendent (Hick, 2004). Recognized through the human outlook of a specific religious culture, with its idiosyncratic arrangement of "concepts, myths, historical exemplars and devotional or meditational techniques," the transcendent is a mysterious reality (Hick, 2004, p. 8). Regardless of the label given to transcendence it remains outside of human senses and understanding because it is literally transcendent (Armstrong, 2011). However, the positioning of this transcendent reality at the centre can release the Self from the burden of being their own centre and unearthing their own meaning and significance (Rohr & Feister, 2001). *Bridging the outer and inner is transcendent mystery providing an anchor wherever I find myself* (Appendix G, Line 588-589).

Death is a fundamental, mysterious journey transcending all that the human knows and surpassing all that is in the physical realm. *All the amazing stories we hear about the dying seeing and hearing their dead relatives...it just makes me wonder what else is out there and what happens when we die* (Appendix G, Line 493-495).Within the palliative journey, fraught with much that is unknown, it is here in particular that acceptance of and connectedness with mystery can bring the individual a sense of peace, transcending the need to know and control (Kellehear, 2000). *The bond I have with this mystery provokes and enthuses me* (Appendix G, Line 581). For the patient, the approach of death can assist spiritual growth, transcending of the Self, and often encouraging greater connectedness with the Divine (Schultz, Baddami, & Bar-Sela, 2011). For the carer, an equilibrium between sharing the care and performing the care for their dying loved one can bring a sense of self-transcendence for the carer (Milberg & Strang, 2007).

The facilitation of a reflective space for the staff to explore their own thoughts of dying, death, and the mystery of what lies beyond augments both holistic care for the patient and self-care for the professional (Glass & Rose, 2006). It is challenging to be faced with another's questions when one has not contemplated them oneself, and this potential confrontation leads to trepidation in other professionals around the provision of spiritual care (Brown, 2001). As an organization it would be helpful for BHCI to address this tension, which could be done through the development of staff awareness of personal connectedness to mystery and transcendence. This, alongside increased consciousness of a personal philosophy around dying, death, and beyond could assist staff in the confident provision of basic spiritual competency in holistic care that neither confronts or hurts them, or withholds from the patient and carer: this would be a move towards ultimate unity.

Ultimate Unity

Growing connectedness with Self, Other, the world, and mystery/transcendence, brings all these spiritual aspects of connectedness together toward the Whole (de Souza, 2012). There is now coherence in the use of the fan as a visual representation of connectedness highlighted in Figure 9. As the blades of the fan move faster, the edges blur and self becomes one with Other; Ultimate Unity. Self is now an element of the Whole which encompasses Other (de Souza, 2012), indicated by the full circle then perceived around the edges of the fan blades.

Figure 9. *Connectedness moving into Ultimate Unity.*

Moving out of separation, each connectedness builds on and builds up each other, integrating and blurring the boundaries towards Ultimate Unity (de Souza, 2009b). Spirituality is *the centre of integration, connection: in the sense of bringing together and creating a whole* (Appendix G, Line 435-437).

Summary of Spirituality as Connectedness and Relation

To summarise, the use of a relational characterization of spirituality as connectedness provides an easily understood and applicable, yet comprehensive, working definition of spirituality and spiritual care within palliative care. As becomes clear from the discussion, the four areas of connectedness intertwine and overlap and these layers can bring some clarity to the multidisciplinary staff about their own spirituality and self-care as well as a sense of competency around the provision of spiritual care. For the patient, the provision of spiritual care, based on spirituality as connectedness, begins where they are, allowing for *their* spiritual journey to begin with, impact, and guide all spiritual care. As the patient's agenda is a core value of community-based palliative care, spiritual care is located neatly within the style of holistic care offered at BHCI. Connectedness highlights the intrinsic dignity of each person and the inclusive nature of affiliation. With the shrinking lifeworld of the terminally ill patient increasing vulnerability of both patients and their carers, a focus on connectedness with Self, Other, the world, and mystery, moving towards ultimate unity, is a culturally appropriate and constructive place to offer spiritual care. Discovering and exploring strength and weakness in connectedness within the life of staff members can lead to flourishing holistic practice. As well, for the patient and carer, these strengths in connectedness and challenges of disconnectedness can highlight places where specialized spiritual support could be useful and effective.

Spiritual Despair – Disconnectedness

The second topic that emerged through the research was that of spiritual despair as disconnectedness, sometimes characterized as spiritual need, spiritual pain, or spiritual distress. With the positive side of spirituality being defined as connectedness, then the source and description of spiritual despair sits tidily within the experience of disconnectedness: a disconnectedness and dislocation with Self, with Other, with the world, and with mystery or transcendence (de Souza, 2012; Ellis & Lloyd-Williams, 2012; Liu & Robertson, 2011; Sheldrake, 2007). Figure 10 provides a visual representation of the effect of disconnectedness showing movement on the connectedness continuum away from Ultimate Unity and towards separateness.

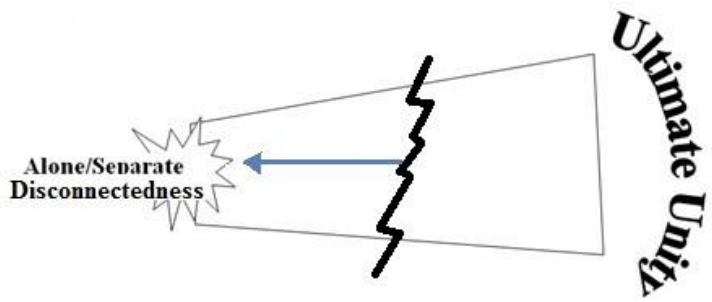

Figure 10. *Disconnectedness: moving from Ultimate Unity towards Separateness.*
Note: Disconnectedness in spirituality is based on the work of de Souza (2012).

Spiritual disconnectedness rises out of an experience of neediness within the human spirit (Mehta & Chan, 2008), and is considered to *exacerbate physical pain* (Appendix G, Line 18), something resonating with the literature (E. Kelly, 2012a).

Within the textual conversations participants initially identified spiritual distress as unexplainable and untreatable:

> *...the words spiritual pain makes me feel very very uneasy because to see someone in that pain without an ability to change it, and it's not about the physical, about the ungraspable, about the smoke, about the nebulous, about not being able to handle it, to heal it* (Appendix G, Line 339-342).

However the ambiguity around spiritual disconnectedness does not just operate around identification but also through expression as patients find themselves without words to articulate or define the experience of spiritual disconnectedness. *This restlessness...this unease...it's almost like you can't quite define it...like an itch you can't scratch...but you can't actually say you're itchy* (Appendix G, Line 337-338). *Spiritual pain manifests in that restlessness* (Appendix G, Line 332).

Within this research study, spiritual disconnectedness was generally identified as the patient being uncomfortable within himself/herself. *If I was to see a patient and they weren't sitting comfortably with themselves, I would see that as spiritual distress* (Appendix G, Line 119-120). However, other cues may also indicate a level of spiritual disconnectedness such as *a lack of control* (Appendix G, Line 328), *restlessness* (Appendix G, Line 334), *deep regret* (Appendix G, Line 26), and a lack of *meaning* (Appendix G, Line 34), views supported by the literature (E Kelly, 2013; P. McGrath, 2002).

For the sick the disruption of ordinary happenings in their season of life can be experienced as spiritual disconnectedness (P. McGrath, 2002), and for the dying there are additional concerns: *they're worried about end of life and where they're going* (Appendix G, Line 83-84). A referral to palliative care moves each patient and their carer into an unfamiliar landscape, which travels through a process of intentional disconnectedness and waning connectedness dictated to them by the disease. *Disconnectedness which illustrates the unfamiliar landscape of palliative care* (Appendix G, Line 600). Deliberate disconnectedness can occur as employment, and social and familial roles are relinquished, *put down* or taken from the patient (P. McGrath, 2002). *Dying people have to be freed of all the encumbrances in order to die. If spiritual care doesn't support this people can die struggling with things they just can't do or just can't put down or deal with* (Appendix G, Line 373-375). Weakness and decline often dictate the living of a shrinking life, where disconnectedness intensifies.

The layers of loss languish upon each other, potentially initiating many levels and states of disconnectedness. This deliberate disconnectedness as portrayed are emphasising the consequences of decline, rather than an open acceptance of death as identified earlier as 'learning to die' or 'giving oneself to death' (pp. 7) (M. Holloway et al., 2011; Koenig, 2002; Kubler-Ross, 1969/2011; Walter, 2002; J. White, 2004).

Spiritual disconnectedness is a highly personal and subjective matter and it is only within the individual life world of the patient that a personal experience of spiritual disconnectedness can be given words and measured (P. McGrath, 2002). In holistic care the mystery of spiritual pain is often not explored until other symptoms have been discounted. *When people are unsettled in themselves, and you've dealt with their physical pain or nausea and such, then I think of spiritual distress* (Appendix G, Line 524-526). This disconnectedness can encompass the Self, Other, the world, and mystery at varying points upon the relational continuum (de Souza, 2012; Ellis & Lloyd-Williams, 2012; E. Kelly, 2012b; Liu & Robertson, 2011). Given the above discussion, examining the possible impact of each of these elements of disconnection is an important part of this research study and is addressed next.

Disconnectedness with Self

Disconnectedness with Self can occur when intrapersonal expectations and ideals are not attained; when the Self is disappointed by oneself (P. McGrath, 2002).

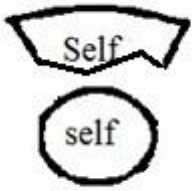

Figure 11. *The self in Disconnectedness with the Self.*
Note: Disconnectedness is represented by a separation between the self at centre and the *Self* blade of the fan.

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This can result in self-dislike or rejection of the Self and can be seen in neglect of Self, or heard in words of self-depreciation, fault-finding of the Self, and a verbal focus on weaknesses and mistakes (Fillion et al., 2006). An insult to connectedness with Self is the declaration, "*I don't want to be here*" (Appendix G, Line 323).

As each individual exists as a corporeal being in the world, that very existence is shaken when a terminal prognosis is made (Bishop, 2013; Sulmasy, 2006). The terminal body both reveals and conceals to the world concurrently, life, and approaching death (van Manen, 1997). Disease trajectory and decline can result in the patient experiencing a sense of dislocation, no longer feeling that they are *who* they once were, experiencing unfamiliarity with their own way of being in the world, physically, mentally, emotionally, and spiritually, and thereby resulting in a disconnection with Self (Fillion et al., 2006; E. Kelly, 2012b; P. McGrath, 2002). As physical decline gains momentum there can be a sense of being out of control of one's own life.

> *When they're not at ease with themself...spiralling out of control...where you can't get hold of what you need to get hold of in life; to seek out answers; to inspire healing. Just everything seems out of their grasp. An impression of disconnection... restlessness.* (Appendix G, Line 326,328-330,334).

Influenced by foreign emotions, in a body that no longer performs reliably, the Self in the mirror can seem strange and unfathomable (Kearney & Weininger, 2012; Krumwiede & Krumwiede, 2012). Neither the past, which cannot be changed, the present which can be distracted by a focus on dealing with *total pain*, nor the uncertainty of the future, provide comfortable spaces for the Self to reside (Appelin & Bertero, 2004; E. Kelly, 2012c). Disconnectedness with the Self is not unexpected yet it is the epitome of existential spiritual distress.

> *The disconnection of self with Self is common in those diagnosed with a terminal illness. Often as decline occurs for the patient they are not what they were, not wanting to go where the inevitable leads, and not wanting to be where they are in the present* (Appendix G, Line 600-603).

The existential questions of Who am I? Why am I here? What impact am I having on life? (Puchalski et al., 2009) become troubling when meaning and purpose are wrapped up in the life that was past and the Self is confronted with a life in the here-and-now that is foreign and disconnected (Frankl, 1992; Puchalski, 2002; Yan et al., 2010). *How does one rearrange a whole framework of one's meaning and purpose when the whole structure of Self has become alien?* (Appendix C line 604-606).

Disconnectedness with Self, and also with mystery/transcendence, may occur when there is a dissonance between objective religiosity, the dogma of the faith group, and the subjective religiosity of the individual. Guilt, shame, and fear can appear when the patient experiences feelings or thoughts that do not line up with their religious worldview.

Another form of disconnectedness happens when an individual connects to something that is not beneficial to their wellbeing (de Souza, 2012). This dark, shadowy side of connectedness can obstruct human flourishing (de Souza, 2012) and impede living life in the here-and-now. An example of this disconnectedness with the Self can occur when the patient is unable to accept a terminal illness prognosis, entering the fight to beat the disease and holding out for the notion of a cure (Wadford, 1994). This can make for a controlled atmosphere where words that discuss the dying journey and emotions such as anger, fear, or sadness are considered *negative* and are managed through suppression (Champagne, 2014; Cordova et al., 2003). This resistance makes for a wary atmosphere where *negative* words are attributed magical power to aggravate the disease. While *positive* and fighting words are ascribed the capacity to bring health and cure, this distorting of reality can lead to denial, and

disconnectedness with the Self. An Australian study into fostering hope in the terminally ill emphasized "the burden of and pressure to be positive and present a "fighting spirit"" proposing that an expression of a full range of both positive and negative thoughts, words, and feelings assisted coping and the nurturing of hope (Clayton, Butow, Arnold, & Tattersall, 2005, p. 1973). The denial of the severity of an illness can inhibit a peaceful dying process, "engendering the use of futile treatments and prohibiting patients and families from reconciling differences, organizing financial matters, completing advance directives, and saying goodbye" (Rousseau, 2003, p. 52). As Champagne (2014) states, "Naming reality is also a valuable way of gaining power over this reality."

Using the philosophy of Jung, the father of the shadow, de Souza (2012, p. 295), states:

> Jung felt that it was important for individuals to enter the darkness because it would allow them to discover what lay within. In other words they would rediscover a hidden part or parts of their personality without which they would not achieve wholeness.

Similarly, Collins (2007, p. 89) contends, "The shadow represents all of the rejected or unexplored feelings and inner tensions that fuel projections; however, without reflection or awareness the shadow becomes disowned." Wholeness, or ultimate unity, cannot be achieved when the individual clings to connections that are unhelpful and the shadow is denied. Yet the fluidity of connectedness in spirituality does enable the holding of hope and desire in one hand, while reality and fear nestle in the other hand, gently carrying both at once.

The acknowledgement and exploration of unhelpful connectedness and denial of the shadow are events that have not been identified within the palliative care and health literature. This is an area that requires further research.

The unexplored shadow side of connectedness also influences the care given by the multidisciplinary professional. For staff members, a hesitation about delving into the shadow hampers the ability to enter into healthy connectedness with Self and with Other, leading to a risk of projection from the professional onto the patient and carer (Collins, 2007). Conversely, appropriate therapeutic use of the self is enabled and sustained by the exploration of the shadow side (Collins, 2007).

For the carer, disconnectedness with Self can also occur as the informal caregiver role leads to the development of a modified Self through the challenges of living with, and caring for, a dying person (Carlander et al., 2011). In the crux of this unfamiliar and desperate landscape professional staff can be encouraged to help facilitate the discovery of new meaning and purpose, of hopefulness and connectedness with the strange new and ever evolving Self (Swinton & Pattison, 2010). For the professional carer, being aware of the personal, emotional cost for them of caring for the dying and working towards an expression and resolution of the feelings associated, can both have a positive effect on wellbeing (Sorensen & Iedema, 2009).

Disconnectedness with Other

Disconnectedness with Other is a loss of shelter against loneliness and isolation, that connectedness with Other typically supplies (Sand & Strang, 2006).

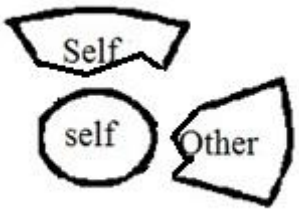

Figure 12 *The self in Disconnectedness with Other.*

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A change in the shape and pace of connectedness with Other may occur as a patient can no longer perform the roles that they were once capable of fulfilling within family, within employment and within the community (P. McGrath, 2002). Relationships with others can be taxed by the enormity of change; a constant reminder of the fragility of life and the size of the loss soon to be experienced. *They know they have to let go. They can't carry all they have cared for into death* (Appendix G, Line 372-373). It is not uncommon for connectedness to diminish as usual joint pursuits become unavailable and visual decline constantly reminds others of death (P. McGrath, 2002).

Disconnectedness through social isolation is a possible threat for both patients and caregivers (Haley, 2003; Sand & Strang, 2006). When a person experiences disconnectedness with Other it can result in conflict, fault-finding, and isolating behaviours and can include both individual and communal dislocation and societal withdrawal (P. McGrath, 2002). Each dying person holds a central place within their own relational web that will be irrevocably altered with their death, the ultimate disconnectedness with Other. The issues of parting are particularly poignant with the imagination at a loss to conceive the finality of non-existence for the patient and how the carer may move towards an altered, but ongoing existence (Sand & Strang, 2006).

> *There are big concerns rising as to what will life be like without this person. What they have shared together, what they've been to each other and now what they need to affirm. These and others are the issues of parting* (Appendix G, Line 403-405).

The multidisciplinary team need to be aware that as past relationships change and deteriorate, disconnectedness can also occur for the patient from those they perceive to be less skilled or more uncomfortable with the dying process. At the same time new links of connectedness are forged with the growing familiarity and dependency of patients on members of BHCI staff and other support services.

Disconnectedness with the World

> *Spiritual pain is an uneasiness; a not wanting to be where you are....In that point in time you want to be someplace else or be doing something else: you don't want to be where you are.* (Appendix G, Line 321-323)

Disconnectedness to the here-and-now and to one's place in the world can lead to a sense of global loneliness (P. McGrath, 2002). *Illustrating the unfamiliar landscape of palliative care* (Appendix G, Line 600).

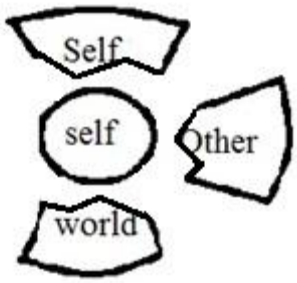


Figure 13. *The self in Disconnectedness with the World.*

The positive consequence of connectedness to the world and beauty is a solid part of attempts to define spirituality and its core values in the literature (Chao et al., 2002; de Souza, 2012; Fisher, 2011; Hack et al., 2010; G. White, 2006); it is also shown to be a core value within palliative care research (M. Holloway et al., 2011; Sessanna, 2011).

Connectedness with the world, the natural environment, and creativity become a conspicuous omission around spiritual need and spiritual care within the textual conversations. Literature, too, speaks sparsely of disconnectedness with the world.

In the initial development of the Spiritual Needs Inventory (SNI), Hermann (2001) found the experience of nature was one of six themes identified by hospice patients as a spiritual need which included being able to go outside, look outside or to have objects of nature within sight. The natural environment is well documented in the literature as providing

restorative experiences (Hansen-Ketchum, Marck, Reutter, & Halpenny, 2011; Kaplan, 1995), yet it was later discarded from the SNI after psychometric testing questioned whether it added to the internal consistency.

The omission of connectedness with the physical world within spirituality noted above leads to disconnectedness from the world not being identified within spiritual despair. While the appreciation of art and beauty, or being out amongst nature and engaging with the physical world is included as an aspect of spiritual stability within the literature (M. Holloway et al., 2011; Sessanna, 2011), the experience of disconnectedness with the world does not register as a part of spiritual distress. Yet when being creative, or working in the garden, or visits to the ocean or forests are facets of life that bring meaning and purpose, any disconnection from these will bring spiritual distress.

Acute disconnectedness with the world can occur for the terminally ill with their confinement to bed, where it is only possible to experience the created world in fragments such as nature brought indoors, floral arrangements, or well studied window views (Hermann, 2001). The capacity for pain that a patient can experience from disconnectedness with the world, nature, and beauty is an area the multidisciplinary staff need to be sensitive to, however further study in this area is needed.

Disconnectedness with Mystery and Transcendence

Disconnectedness with mystery can result in a reductionist notion that everything has an explanation, and given time answers for everything will be arrived at, hence that the universe is in the end just the sum of its parts (Bell, 2013). This represents a type of disconnect from reality: *It's kind of 'Oh well when this is fixed it will all be OK,' and I think that a lot of spiritual disease comes from that* (Appendix G, Line 324-325). Disconnectedness from mystery or transcendence can lead to a small, mundane, controlled world where there is little surprise, hope or change accessible.

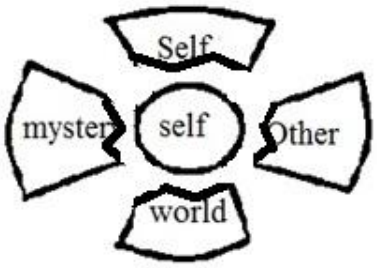


Figure 14. *The self in Disconnectedness Mystery/Transcendence.*

The literature indicates that this disconnectedness can lead to a loss of faith, the universal human attribute of meaning-making (Fowler, 1991), to a wilderness experience, an existential crisis (Penson et al., 2001), or a loss of anchorage (Yan et al., 2010). This state of crisis leads to a sense of vulnerability and decreases the facility of the patient to shield him/herself from feelings and ruminations about looming death (Sand & Strang, 2006).

Within palliative care disconnectedness from mystery is an irony as the patient is about to voyage into one of the biggest mysteries of humanity; the dying journey. Here, life can seem to be finely regulated by appointments, timetables for medication and repositioning, yet all the while the ultimate mystery, death, is known to be approaching at its own speed (S. D. Smith, 2009). *The feeling of a tightening of Lived Time* (Appendix G, Line 624-625). The moment of parting is a mystery of its own time: no matter the forewarning death often reveals itself more swiftly than has been contemplated (S. D. Smith, 2009).

Summary of Spiritual Disconnectedness

Spiritual disconnectedness can accompany the terminally ill in corporeal forms: lack of body control, restlessness, and particularly the desire to be in the world in a different body and a different space, and maybe even a different time. *Often as decline occurs for the patient they are not what they were, not wanting to go where the inevitable leads, and not wanting to be where they are in the present* (Appendix G, Line 601-603). Disconnectedness

encompasses a lack of meaning and purpose for the terminally ill (M. Holloway et al., 2011). Often confined to medical establishments and home, it becomes vital to reconstruct a new, and often a more flexible, sense of meaning and purpose that will necessarily be diminished to the new and declining boundaries of life (Hermann, 2001). Moving through lands of unfamiliarity and limitation raises a desire for the recognizable and as the body declines and disease restricts physical ability, reflection on the past and new meaning for the present become the focal point. Spiritual disconnectedness within palliative care cries out for appropriate spiritual care. *Someone who's not judging* (Appendix G, Line 35).

Disconnectedness shows itself to be a useful, expressive term when describing and defining spiritual pain and despair. Introducing the concept of disconnectedness to patients and carers enables them to identify and express subjective spiritual pain and helps create open inclusive language for discussion. For professional staff an awareness and acknowledgement of the sense and feeling of disconnectedness within their own lives can assist with a non-judgmental acceptance of the disconnectedness of those they care for (P. McGrath, 2002). The claim of the provision of holistic care can only be justified when the multidisciplinary team are adept at answering spiritual despair-disconnectedness in spiritually perceptive and competent ways (Mitchell, Bennett, & Manfrin-Ledet, 2006).

It needs to be noted that the concept of disconnectedness with the world was meagre within the literature, and the concepts of disconnectedness with the world and mystery/ transcendence were sparsely treated within the textual conversation as well. These are areas where education is required to assist the staff to be aware of the impact of disconnectedness with the world and to mystery or transcendence. Further research could assist in broadening the understanding of these concepts.

The provision of care to lift the spirit, or spiritual care, is often misconstrued as religious care (Fillion et al., 2006; M. Holloway et al., 2011; Swinton & Pattison, 2010). *I*

refer patients to spiritual care who say they have got religious beliefs. And I put it to them that they're worried about end of life and where they're going (Appendix G, Line 82-84). However, the literature and textual conversations point to two different avenues for caring for the human spirit: that of religious care where one's metanarrative and worldview is cast by institutional faith (E Kelly, 2013; Lee, 2002), and that of spiritual care where spirituality as connectedness is innate and inclusive of all humanity (Koenig, 2007; Pargament, 1997; Sulmasy, 2002). Therefore, this discussion now turns to the third research finding: the contrast of religious and spiritual care, a good versus good comparison.

Contrasting Religious Care and Spiritual Care

To this point in the interpretation of the research it has been useful to focus on the intersect of religious care and spiritual care, however there is a wide difference between the two in practice, and this differentiation that is now explored. While there is some overlapping of the two concepts, at the extremes religious care rises from the faith community and moves towards the individual, where an external treasury of wisdom and faith provides a worldview and metanarrative (E Kelly, 2013; Lee, 2002; S. A. Murray et al., 2004); whereas spiritual care begins with, and is drawn out of, the individual, and is seen as a personal, innate, inner core that moves internally and outward (Hill & Pargament, 2003; Peterman et al., 2002; Zinnbauer et al., 1997). Murata (2003), using the work of Emblem[12], teased the concepts of spiritual and religious care apart, identifying spiritual care as that associated with individual life values, connectedness with Other and the transcendent, while religious care involves a metanarrative of belief, ritual, and practice. These expressions of ideology could be useful ways to assist differentiation between the religious care and spiritual care in practice, education, and training.

[12]Julia Emblem (1992). Religion and spirituality defined according to current use in nursing literature. *Journal of Professional Nursing, 8*, 41-47.

There is a complexity in spiritual needs that defies strict demarcation: for some the human need is about connectedness with transcendence or the sacred within religion; for others the needs focus on connectedness with Self and Other and self-transcendence (Kellehear, 2000). So while agnostics and atheists may have spiritual needs (Bouma et al., 2011; Watson, 2009b), believers could have spiritual needs which may or may not include religious aspects (Baldacchino, 2008).

At BHCI spirituality sits separate from, but alongside, concepts of religion in its broadest sense. While participants agreed vocally that spirituality was not about religion, *Well it's not really to do with religion* (Appendix G, Line 8), in the shadows of the conversation, religion was clearly present. *Religion would come in as well...* (Appendix G, Line 92), *religion could be, but doesn't need to be part of it...* (Appendix G, Line 97). *I refer patients to spiritual care who say they have got religious beliefs* (Appendix G, Line 82-83).

While the literature is beginning to differentiate between religion and spirituality and their different foci of care (Baldacchino, 2008; Kellehear, 2000; Murata, 2003), participants were uncertain about definitions and differences. Accordingly, it is useful to begin the discussion on contrasting religious and spiritual care by looking at religious care.

Religious Care

Emerging from communities of faith, religion is defined as concerning three components: belief in and worship of a superhuman controlling power; a particular system of faith and worship; and a pursuit followed with great devotion (S. A. Murray et al., 2004). It is where the sacred and significance intersect (Pargament, 1997). Religion can create a community with a structure of belief and ritual that helps people find meaning and hope, and it depicts how each human fits within family, community, humanity, and transcendence (Pargament et al., 2000; Puchalski & O'Donnell, 2005). It gives a worldview that places

individual suffering inside the corporate human experience of despair and suffering (McSherry, 2005; Puchalski & O'Donnell, 2005), bringing meaning and purpose to affliction.

Within religious care it is the particular system of faith held by an individual, the religious label they choose to identify themselves with, that dictates the type of religious care offered. Religious care practices can include involvement in religious ritual; reading from sacred texts and religious writings; discussions about God, salvation, grace and notions of a final resting place of the soul; conventions of behaviour and diet; with all religions bringing to these a deep treasury of traditional wisdom (Kellehear, 2000; Puchalski & O'Donnell, 2005). *All major traditions have a deep well of human experience that has been greatly reflected upon, and there is much to be drawn from that well* (Appendix G, Line 439-441). In particular, the reciting of prayers is seen to put emphasis on restoration of individual morale, which can also be assisted by focussed discussion on unresolved religious questions, bringing many options for developing peace, hope, and religious transcendence for the dying (Kellehear, 2000; Pargament, 1997). *For some people their religious beliefs are important...it might impact on how comfortable they are about dying...they might believe something particularly and they have worries about that. Or it might actually put them at ease* (Appendix G, Line 537-539). Making use of a familiar or former religious support systems can include reconciliation, divine forgiveness, and divine strength in the hope of religious transcendence in the new struggle (Kellehear, 2000). Religious needs emerge from an individual's closeness to a cultural way of life, from current personal practice, or past socialization such as a religious upbringing, or past religious instruction, accompanied by a growing recognition of the relevance of religion in the current circumstance of suffering and dying (Kellehear, 2000). *How they're feeling about going towards God or whoever* (Appendix G, Line 106).

When a patient is referred to the spiritual support worker on religious grounds, it is essential that the multidisciplinary staff is made aware of any religious sensitivities the patient may hold (Nesbitt, 2012). Five of the major world religions that Australians are affiliated with are briefly detailed below in alphabetical order: Buddhism, Christian-Catholicism, Hinduism, Islam, Judaism (Australian Bureau of Statistics, 2006). Additionally Aboriginal and Torres Strait Islanders are incorporated, and these six accounts show some of the different rituals and religious behaviour that can be involved within religious care of the dying. As discussed in the review of the literature (see pp. 23) we know that Australia has become a society marked by Christianity, multifaith, and secularist aspects (Bouma et al., 2011, p. 4). To that purpose the multidisciplinary team need to be aware of the five major world religions Australians are affiliated with, as well as indigenous spirituality. These are discussed below highlighting differing worldviews of death and dying.

Aboriginal and Torres Strait Islander. As there is no common view held by Aboriginal and Torres Strait Islanders regarding spirituality, dying and death, it is essential that each patient is regarded in a personal way in consideration of their significant cultural issues (Austin Health, 2006; Gray, Hughes, & Klein, 2003). Fear and mistrust of institutions, sensitivities around dying and death, an upholding of cultural protocols around men's and women's business, and the communal nature of decision makes an impact on any spiritual discussion around death and dying (Austin Health, 2006). Cultural safety requires the multidisciplinary staff to reflect on the character of power in the offering of services to a marginal culture by a dominant one, as well as their own cultural background, all supporting positive acknowledgment of diversity (Austin Health, 2006; Gray et al., 2003). *Sorry time*, wailing and crying with the body are customary responses to death (Austin Health, 2006). These are all factors that require an empathetic and considered response. After death some

groups erect burial poles that contain symbols of the person who has died, and their family, while other groups use sand sculptures in burial rites (Goldburg et al., 2009).

Buddhism. The emphasis of Buddhism is on the attainment of enlightenment and developing an attitude that encourages letting go of life attachments (Baugher, 2008; Gregory, 2012; Puchalski & O'Donnell, 2005). The Buddhist eternal truths of annicca or impermanence, anatta, the self changes as conditions change, and duccha, life is filled with suffering brings strength to the dying journey (Goldburg et al., 2009; Gregory, 2012). Buddhists accept the concept of rebirth after death, believing the desires and attachments of a person are reincarnated in a new body as new desires and attachments (Goldburg et al., 2009). Therefore reincarnation identifies dying as a natural transition in life (Baugher, 2008). Care for the dying embraces kindness, presence, compassion, and concern to help motivate trust and confidence (Baugher, 2008; Gregory, 2012), as well as respect for the practice of meditation (Goldburg et al., 2009).

Christian. The three streams of Christianity, Orthodox, Protestant, and Roman Catholic believe in one triune God, being Father, Son and Holy Spirit (Bowker, 2003; Goldburg et al., 2009; A. E. McGrath, 2011). Those who identify with the Christian faith believe in resurrection founded on the death and resurrection of Jesus Christ (Goldburg et al., 2009; Pope Francis, 2013). This brings the encouragement that a person's life does not end with death, but is a transition to eternity (Pope Francis, 2013; Puchalski & O'Donnell, 2005). For the Catholic and Orthodox Christian solace can be gained through practices such as attendance at Mass, reciting the rosary, and the sacrament of anointing (Bowker, 2003), with icons being important to an Orthodox believer (Bowker, 2003). Hope can be found for the Protestant in reading and listening to scripture, prayer, and the Lord's Supper (Bowker, 2003; A. E. McGrath, 2011).

Hinduism. With a multifaceted blend of customary practices Hinduism has no separation between religion, culture and secular activity (Bhuvaneswar & Stern, 2013; Goldburg et al., 2009). While strict conventions govern intimate relationships, family obligations, education, work and diet, the central concept of duty brings observance, and a staunch loyalty to social roles and family over personal identity (Bhuvaneswar & Stern, 2013). Three main aspects of death for the Hindu include:

- reincarnation: cycles of birth, life and death mirroring the universe cycle of creation, destruction and recreation;
- karma: moral and cosmic consequences, the basis for the following rebirth and life;
- the indestructible divine or supreme being to which the soul is connected, and will return (Bhuvaneswar & Stern, 2013; Goldburg et al., 2009; Puchalski & O'Donnell, 2005; Thrane, 2010).

For the dying Hindu, active silence and minimal conversation can assist the quieting of the mind of the patient, preparing them for death (Bhuvaneswar & Stern, 2013).

Islam. Islam believes in the supremacy of Allah as the one true god, Muhammad as the godly prophet and the authority of the Qur'an (Goldburg et al., 2009; Puchalski & O'Donnell, 2005). The Five Pillars of Islam are the expression of faith for a Muslim: the creed, prayer five times a day, charity to the poor, fasting and pilgrimage (Goldburg et al., 2009). Acknowledgement of the importance of religious observance and rules of interpersonal behaviour (for example, gender segregation of health care professionals) throughout the provision of care are important within Islam (Sachedina, 2012). The community and family are intimately linked to the health and welfare of an individual, so open communication between patient, family, palliative care team and local imam can assist with an understanding of the local nature of Islamic communitarian ethics (Sachedina, 2012). When a Muslim is dying it is normal practice for those gathered to advise the dying person to

say: "La ilaha illa-Allah" (there is no God but Allah), lay them so that the direction of Mecca is on their right side, and recite from the Qur'an (Islamic Community of Northern California, 1993). After death the eyes of the deceased are closed and the body is covered with a piece of cloth (Islamic Community of Northern California, 1993; Puchalski & O'Donnell, 2005).

Judaism. For the followers of Judaism the Torah, or the Hebrew Bible, provides guidance for everyday life and is the source of all wisdom (Goldburg et al., 2009; Rivkah, 2010). Communal worship and prayer is encouraged and reinforced, often in the Synagogue, however prayer can also be performed alone (Goldburg et al., 2009). Judaism comprises a varied range of customs and traditions, with followers spanning from the unobservant and unaffiliated to devoutly observant Orthodox families (Goldburg et al., 2009; H. M. Ross, 1998). Particular religious observances held by a patient need to be ascertained by the multidisciplinary team: they could include dietary restrictions, treatment limits, specific rituals for handling the body of the ill and dying person (Puchalski & O'Donnell, 2005), while for traditional Jews quality of life is not an important factor (H. M. Ross, 1998). Applying the command "and you shall return it to him," Jews desire the palliative care team to restore to the patient what has been taken: such as peace of mind, or the sense of hope and meaning (Schultz et al., 2011). Through the palliative journey the Talmud details the organizing of one's personal affairs and reconciliation with the Creator through confession of sins, which can provide reassurance, and prayer; however it is required that imminent death not be revealed so as not to discourage to the patient (Cohn-Sherbok, 2012; Puchalski & O'Donnell, 2005).

Summary of religious care. These six small cameos of some religious thought, dogma, and ritual at the edges of life and death indicate that religious care needs to be highly specialised since it is founded on an exclusive worldview (E Kelly, 2013; Yan et al., 2010). These worldviews highlight the fact that religious needs require a response by those

specifically religiously qualified (Kellehear, 2000; Pesut et al., 2012). However, while religious affiliation or the taking of a spiritual history may provide an overview of a patient's objective religious worldview, this does not automatically mean in the subjective realm the patient observes or believes in all the dogma of that religion (Miner-Williams, 2006). The literature highlights weaknesses in many current spiritual history/spiritual assessment/spiritual screening measures that include: overlapping religiosity and spirituality (de Jager Meezenbroek et al., 2010; Kapuscinski & Masters, 2010; Koenig, 2007); not measuring the *current* state of a person's spirituality (Monod et al., 2011), and the creation of most measures within a social context of embedded Christian principles (Moberg, 2010). Using a spiritual history measure can help determine religious affiliation, however it does not indicate how observant a patient is as the individual often navigates their own religious belief (Miner-Williams, 2006). Therefore, religious care needs to acknowledge each individual journey to uncover the patient's personal way of living out their spirituality (Miner-Williams, 2006). Asking the simple question What is important to you? can open up a conversation about the individual patient's personal religious understanding and practice (Bhuvaneswar & Stern, 2013; E Kelly, 2013; Miner-Williams, 2006).

Research participants were quite happy to include religion within spiritual care. *I find it difficult to separate the concept of spirituality from religion* (Appendix G, Line 31). *I probably put a lot of it down to religion. A lot of patients I refer have got religious beliefs* (Appendix G, Line 101). The overlapping use of religion and spirituality is also echoed in the literature (de Souza, 2009; M. Holloway et al., 2011; Koenig, 2002). Nonetheless, patients who deliberately spoke of the importance of their religious beliefs were more readily referred to spiritual care. *I refer patients to spiritual care who say they have got religious beliefs* (Appendix G, Line 82-83). The textual conversation indicated the belief that any connection between spirituality and religion was tenuous, and entirely personal to the individual. *I see it*

more in the context of what we personally believe our life is all about (Appendix G, Line 31-32).

In the experience of the researcher in the position of spiritual support worker, when spirituality is aligned totally with religion, demarcation lines create exclusivity around spiritual care. Those who declare themselves to be religious are offered spiritual care, while spiritual support is disregarded or can even be considered unhelpful for people who have no religious affiliation. This ignores the many people who consider themselves decreasingly religious, and increasingly more spiritually aware (Marler & Hadaway, 2002), and the common phrase, "I am spiritual but not religious" (de Souza, 2009; Pesut et al., 2012) (see SBNR pp. 42). Something which also rose in the textual conversation: *Now people say they're spiritual but not religious, whereas you wouldn't have come across that in the past* (Appendix G, Line 478-479).

Referring only self-reported religious people for spiritual care also denies the innate human nature of spirituality(Culliford, 2007), and the need of humans to answer the big questions and to make meaning in life (Frankl, 1992). A further warning comes from Hartley (2012, p. 266): "where we might fail those people who we care for is when we leave them alone with their questions, helpless and afraid."

The palliative care literature suggests a contemporary move by chaplains and pastoral care away from a strictly religious provision of care to a more humanist spiritual support that encourages an individual search for meaning (Cobb, Dowrick, et al., 2012; M. Holloway et al., 2011). Humanism bases spiritual care on ethical responsiveness and responsibility, including such aspects of spirituality as reverence, love, humility in the presence of transcendence where transcendence encompasses the Other, Beauty, Goodness, and Truth (van Hooft, 2012). For this research study the concept of spirituality as connectedness with Self, Other, the world, and mystery has been accepted (de Souza, 2012; Ellis & Lloyd-

Williams, 2012; E. Kelly, 2012b; Liu & Robertson, 2011; Sheldrake, 2007), and this will be used as the foundation in the following discussion on spiritual care.

Spiritual Care

> *Dying people have to be freed of all the encumbrances in order to die. If spiritual care doesn't support this people can die struggling with things they just can't do or just can't put down or deal with* (Appendix G, Line 373-375).

Spiritual care has been characterized as any activity that can identify and enhance the connectedness a person experiences with Self, Other, the world and mystery/transcendence as sources of strength and meaning (de Jager Meezenbroek et al., 2010; de Souza, 2009b; Ellis & Lloyd-Williams, 2012; M. Holloway et al., 2011; Liu & Robertson, 2011). As each human being has a spiritual dimension, conscious or pre-conscious, whether directly spoken of or not, then there is a capacity for each individual to benefit from spiritual support (Pichon, 2007; Speck, 2005). National and international policies of palliative care affirm spiritual care as an integral component of holistic care (Palliative Care Australia, 2012; Palliative Care Victoria, 2006; World Health Organisation, 2005). This acknowledgement of the effect of a terminal illness on the biopsychosocial-spiritual aspects of each individual (Sulmasy, 2002), encourages spiritual care to infuse all elements of palliative care while recognising that spiritual need can be closely connected to physical symptoms and therefore requires equivalent focus (Carroll, 2001; Hodge, 2005; Lloyd-Williams & MacLeod, 2004). *Spiritual pain exacerbates physical pain* (Appendix G, Line 18).

Based in connectedness with Other, spiritual care is an expression of companionship that willingly enters into the often weak and vulnerable spaces of disconnectedness as sojourner and witness (de Souza, 2012; Ellis & Lloyd-Williams, 2012; E. Kelly, 2012c). *We need to give people an opportunity to sort out their inner turmoil* (Appendix G, Line 41-42). Often with disclosure there is an opportunity for movement to be made along the relational

continuum from the disconnectedness of separateness through connectedness towards ultimate unity (de Souza, 2009b, 2012). Spiritual care begins with the carer providing a haven: *a safe place within myself for sitting with the dying and those that care for them* (Appendix G, Line 564-565).

With the provision of spiritual care the patient is found to not be a naive child seeking answers but rather an intelligent person, very experienced in their own life, who has actively paved the way for this conversation with musings and mullings. *So we actually don't come...with blank slates as far as spirituality is concerned* (Appendix G, Line 210-211). *Helping people articulate for themselves what they are having difficulty articulating. Allow them to find their own words* (Appendix G, Line 460-461). The patient who actively wants to explore beliefs, meanings, and connections does not necessarily require an *expert* to come and problem solve, but rather someone who, while not afraid to be ignorant of another's personal world, can serve as respectful witness (E Kelly, 2013). *Making the most of now and appreciating it* (Appendix G, Line 504-505). Spiritual care does not approach with a schedule to *treat* the patient, but rather spiritual care arises from an ordinary interaction between two humans where spiritual care is the professional interest of one (Pesut et al., 2012). Care for the spirit is relational, allowing and enabling each person to be as they need to be at this time, rather than attempting to soften fury, calm distress, or provide answers to existential uncertainty (E. Kelly, 2012b). *Gather together what their life has been and affirm for themselves what they might need to affirm* (Appendix G, Line 395-396). Spiritual care is about focussed discussion rather than formal assessment (Ellis & Lloyd-Williams, 2012), someone to actively listen, genuinely respect, empathetically question. *Leaning forward...keeping eye contact...* (Appendix G, Line 354-355). *empathy...standing with people, alongside...* (Appendix G, Line 428-429). Somewhat like holding the torch while the companion changes the tyre, spiritual work is done by the patient, but cannot be

accomplished without the co-creation of sacred space, the torch light by which to work (E. Kelly, 2012c).

Spiritual care competencies. Spiritual care is *walking side by side with you...* (Appendix G, Line 36-37). ...*not about problem solving* (Appendix G, Line 39). Spiritual care is not problem solving because this present circumstance "needs to be lived through" (E. Kelly, 2012c), and the patient is the expert in their life. This places the core philosophy of spiritual care at odds with other professions within the multidisciplinary team where skills are used to bring an answer whether it be symptom control from the medical fraternity, financial resolution by the welfare worker, or taxiing to appointments by the volunteer co-ordinator. *Professions can have diverse worldviews...*(Appendix G, Line 417). ...*the medical analytic skills are particularly intellectual, rational skills, but the listening to a person requires more than the head, it requires the heart* (Appendix G, Line 410-412).

A position of refraining from problem solving and listening with the heart is supported by the spiritual care competency frameworks (Appendix F). Accordingly, an analysis of spiritual care competency-led models produced by the Marie Curie Centre, London, the NHS of Scotland, and the Psychosocial-spiritual special interest group, PCV, indicate four levels of spiritual care competency (M. Holloway et al., 2011; E. Kelly, 2012b; Marie Curie Cancer Care, 2003; Rumbold & Holmes, 2011):

- Level One: Person Centred Care as needed by all and provided by all;
- Level Two: Care Sensitive to the Spiritual Domain as needed by many and provided by many;
- Level Three: Care for Spiritual and Religious Issues as needed by some and provided by some;
- Level Four: Complex Spiritual and Religious Needs are needed by a few and provided by a few (Appendix F).

As shown within the literature (pg. 77), Level Two would be most appropriate for the multidisciplinary staff to operate competently in, that is Care Sensitive to the Spiritual Domain as needed by many and provided by many. Further, some staff operating at a Level Three competency, where basic spiritual and religious care can be provided, would enhance spiritual care within the organization. Healing for patients and carers, along with professional and personal growth for the multidisciplinary staff, originate from competency in spirituality and spiritual care (Mitchell et al., 2006). Educational components for the basic skills of these two levels unfold within the following reflections of spiritual care that came out of the textual conversations:

- identification of places of disconnectedness and providing presence within them;
- active listening;
- the big questions of life review;
- preparation for death.

Presence in places of disconnectedness. The encounter of peaceful presence, just being there, can provide a co-created sacred space where fears, misdeeds, and places of lost opportunity can be drawn out (Ellis & Lloyd-Williams, 2012; E. Kelly, 2012c). Those disconnected *would have, could have, should have* situations, where an individual imagines or wishes that the past was different, can be brought out into the open and approached with reflexivity (Ellis & Lloyd-Williams, 2012; E. Kelly, 2012c). *A vehicle to get rid of the skeletons in the closet...a cleaning of the soul...* (Appendix G, Line 14-15,36-37). *...walking side-by-side* (Appendix G, Line 36-37). (Appendix G, Line 161-162). Spiritual care is not passive, rather quite the reverse with immense action occurring as it sits quietly in stillness (E. Kelly, 2012c). *We need to be able to find the words to articulate what* (spirituality) *... so it doesn't come across as a passive thing, cos it's actually quite active* (Appendix G, Line 20-21).

Within palliative care the Lived Body of the dying is a foreign land for patient and carer alike (van Manen, 1997). *How does one rearrange a whole framework of one's meaning and purpose when the structure has become alien?* (Appendix G, Line 604-606). Decline, weakness, vulnerability, and signs of illness not only change the physical appearance and function of a person, but they can also disturb a person's sense of self and identity (Fillit & Butler, 2009; Romanoff & Thompson, 2006; Sulmasy, 2006). *The physical body becomes strange and unexplored territory for the person who is dying* **(**Appendix G, Line 370). This unfamiliar place can collude with the pressing time of a terminal prognosis, bringing a sense of crisis and dilemma. *They can't carry all they have cared for into death* **(**Appendix G, Line 372-373).

Within community-based palliative care, spiritual care for the carer occurs alongside that provided for the patient, sometimes concurrently and sometimes independently. The experience of living with, and caring for, the dying can profoundly challenge and ultimately modify a sense of Self (Carlander et al., 2011). *What life will be like without this person; what they have shared together; what they've been to each other...dealing with the issues of parting* (Appendix G, Line 403-405). Access to individually tailored emotional and spiritual support can help increase feelings of preparedness for care giving and the eventual death of the patient, significant in the process of connectedness in caring for a terminally ill loved one and the accompanying grief journey of bereavement (Ewing & Grande, 2013; Haley, 2003; A. Henriksson & Årestedt, 2013). For some carers this means having someone to talk to, while for others it can mean the organization of some time alone to provide some distance from the patient and immediate context (Redinbaugh et al., 2003). Spiritual support of the carer and acknowledging carers as partners in the process provides enhanced care for the patient (Candy, Holman, Leurent, Davis, & Jones, 2011).

Active listening. Spiritual care begins with genuine openness and an authentic approach of connectedness with Self to Other and their spirituality (E. Kelly, 2012c). *Cultivating a receptiveness...* (Appendix G, Line 427). *...an atmosphere of confidence and privacy* (Appendix G, Line 351-352). This highly personalised space is emphasised by acceptance, active listening, and an absence of judgement (E. Kelly, 2012c). *Listening is about being still, trying to quiet some of our own chatter to be able to hear* (Appendix G, Line 455-456). *Or they have to talk, it's something that is so important to them, it's their time to tell you what they need to* (Appendix G, Line 161-162). The co-creation of this space by patient and staff member, provides for the living text of Other to unhurriedly unfurl with dignity, respect and side-by-side journeying (Ellis & Lloyd-Williams, 2012; E. Kelly, 2012c). *Here I learned of the unique active strength of just being; and creating sacred space* (Appendix G, Line 565-566). This can be a nurturing space where the helplessness and hurt of disconnectedness can be recognised and held, and meaning in the *present* situation can begin to be explored (E. Kelly, 2012b).

Supportive non-judgmental presence carries significant spiritual and existential meaning, uniting through a spirit of compassion both the speaker and the listener (Ellis & Lloyd-Williams, 2012; Yan et al., 2010). *Gentle presence that lets people do their own work...* (Appendix G, Line 400). *...sit loosely with what I might think or believe, and allow the other person to tell me who they are* (Appendix G, Line 426). The expression of dual respect, respect for Self and respect for Other, provides witness, companionship, side-by-side presence, and stillness while the *expert*, the patient or carer themself, does their work (E. Kelly, 2012c). Dual respect signifies intentionally putting one's own beliefs aside and seeking to understand the phenomenological spiritual reality of Other (Hodge, 2005). *There's a rich human conversation going on within myself in terms of my own faith and beliefs. It is the endeavour of dual respect* (Appendix G, Line 379-380). Spiritual care draws out, supports

and encourages characteristics of human spirit such as awareness, compassion, connectedness, hope, love, perseverance, readiness, truth, wisdom and wonder (Bennet & Bennet, 2007; Culliford, 2009; de Souza, 2014a).

> *Spiritual care is about people feeling accepted for themselves, being listened to and received for themselves...being able to do...what they want to gather together, integrate, sift through, understand better...in a way that is meaningful for themselves* (Appendix G, Line 391-395).

The co-creating of a sacred space where a patient feels accepted and heard can give freedom to both affirm regrets and disconnectedness while also experiencing wonder in aspects that bring connectedness and meaning (de Souza, 2012; M. Holloway et al., 2011; Kellehear, 2000; E. Kelly, 2012b; Swinton et al., 2011). *Gentle presence...* (Appendix G, Line 400). ...*suspending judgment.* (Appendix G, Line 427). ... *accepting, warm, being non-intrusive* (Appendix G, Line 454). *Spiritual care is...about space and acceptance and sometimes it's just a matter of listening...we need to give people an opportunity to sort out their inner turmoil* (Appendix G, Line 39,41-42). Attentive deep listening and silence can bring consolation and encouragement (Yan et al., 2010), where the main contribution the hearer makes is to listen and give the space for patients to be themselves and talk about *their* heart (E. Kelly, 2012c). *Sit loosely with what I might think or believe allowing the other person to tell me who they are* (Appendix G, Line 426-427). Silence too is meaningful; it is the acceptance that while the worker cannot add words to describe or define the spiritual pain for the patient they will not desert them (Capretto, 2014). The conversational relation that can occur in short, but deep, connections at time of medical crisis has the potential to lead to a transcendence of the self (van Manen, 1997). Education of active and therapeutic listening could be useful to expand the basic skill set of the multidisciplinary staff.

Big questions of life review. Spiritual care is a space to explore what are considered big questions about personal meaning and purpose: Who am I? Why am I here? What is the meaning of Life, and of my life? Do I make an impact? (Frankl, 1992; Puchalski et al., 2009). Spiritual care ...*means the questions that you have about who you are, why you're here, what impact you've had in your life. What might be there after my life, or our patients' lives?* (Appendix G, Line 482-484). As life becomes constrained by terminal illness perspective on life can begin to move into reminiscing and these big questions also rise in past tense: Who was I? Why was I here? What impact did I have? Who will remember me? What does death and dying mean? *The existential questions of "Who am I?" and "Why am I here?" become troubling when meaning and purpose is wrapped up in the life that was past* (Appendix G, Line 606-607). ...*to be aware of the inner life, and the outer life, and the layers of interplay between them* (Appendix G, Line 568-569). Life review can assist in the acceptance of one's life as unique, releasing emotions and building a sense of meaning, creating a personal legacy, as well as a sense of preparing for death (Hack et al., 2010; Xiao, Kwong, Pang, & Mok, 2012). Life review can also improve quality of life and spiritual well-being (Xiao et al., 2012). *We need to give people an opportunity to sort out their inner turmoil* (Appendix G, Line 41). Spiritual care paradoxically stretches to simultaneously hold both hope and the sense of decline obvious in the physical body. *Holding the contradictory is a part of caring for the individual patient* (Appendix G, Line 628-629). Bringing the reality of an experience of connectedness with Other that can accommodate contradictory elements generously and without fear which allows for fluid expressions of meaning and purpose (M. Nolan & Mock, 2004).

I like to use the image of a lake. What we see on the surface is one thing, but what is

> *hidden in the depths is much more? Our words are surface things and underneath there are depths of meaning, significance, that words will never adequately describe* (Appendix G, Line 463-466).

Education for the multidisciplinary staff about using life review as a spiritual care intervention, the interdisciplinary skills required, and the need for clinical supervision when listening to patients' stories, would develop options for making meaning both for patients and carers, and also provide an option for staff self-care (Trueman & Parker, 2006).

Preparation for death. In palliative care the person-centred style of spiritual care can help with preparation for death (A. Henriksson & Årestedt, 2013). *Gather together the threads of their life in some way that they then can feel like 'I can put that down' or 'let that go'* (Appendix G, Line 397-398). The process of sorting out the physical and spiritual in the dying journey, confronts the patient with looming non-existence; the spiritual pain of ultimate disconnectedness and alienation (Kearney & Weininger, 2012). While the spiritual body is encased in a failing, declining physical body that holds all of life within it, this time can often be accompanied with growing spiritual strength (Kellehear, 2000).

> *Support bringing parts of the self together in ways that are hopefully constructive, creative...sometimes we can use art, we can use music, and we can use poetry to express something more of what is inside us* (Appendix G, Line 360-363).

Ira Byock (2004), a leading physician in the field of palliative care writes that in the process of sorting out there are four phrases that dying people often need to say before they die: "Please forgive me," "I forgive you," "Thank you," and "I love you." However, it is always personal choice: some choose to move towards ultimate unity through the spiritual endeavour of *learning to die* (M. Holloway et al., 2011; Koenig, 2002; Kubler-Ross, 1969/2011; Walter, 2002; J. White, 2004), a creative act of the spirit that enhances and builds up layers of connectedness with Self, Other, the created world, and mystery/transcendence.

At the same time as some others choose to inhabit their disconnectedness and hold onto regrets and hurts (Byock, 2004; de Souza, 2012; Liu & Robertson, 2011). Spiritual care involves the offering of neutral space where big questions can be contemplated.

Summary of Contrasting Religious Care and Spiritual Care

Through the dying journey and preparation for death, connectedness for the patient can be enhanced by the provision of authentic presence and companionship that helps co-create a sacred space where places of disconnectedness can be acknowledged, meaning explored, and life reviewed (de Souza, 2012; E. Kelly, 2012c; Puchalski et al., 2009). Spiritual care provides a space where issues of meaning and parting can be faced with non-judgmental presence, traditional wisdom, and care for the spirit that aligns with the organizational values: loyalty, trust, kindness, respect, honesty, willingness and skill (Ballarat Hospice Care Incorporated, 2013). For the most part, it is the nurses who are the brokers for spiritual support referrals so their identification of spirituality as important is crucial for timely referrals (Harrington, 2004; McSherry & Jamieson, 2011). The understanding of the effectiveness of stillness and active listening within basic spiritual care, alongside the need to restrain the desire to solve the problem or find the answer, needs to be included in educative programs for the multidisciplinary team (Ellis & Lloyd-Williams, 2012).

Effective spiritual care is equally about the spiritual wellness of each member of the multidisciplinary team and their individual ability to transcend the ordinariness and disconnectedness of everyday life (Kellehear, 2000). An educative component could provide a space where each team member is encouraged to explore their own sense of meaning, alongside the basic competency skills of levels one and two in spiritual support: active listening, responding, awareness, support, encouragement, respect, dignity, recognition of spiritual/religious needs, note writing and referral, and the importance of verbal and non-

verbal communication (M. Holloway et al., 2011; E. Kelly, 2012a; Marie Curie Cancer Care, 2003; Rumbold & Holmes, 2011).

All holistic care at BHCI is practised within the lives, homes, and contexts of the patient. The delivery of community-based palliative care was the third category that rose from the textual conversation. In order to explore this category, three different milieus have been identified:

- time;
- context of patient with their agenda, and carer;
- death as a societal taboo.

Community-Based Palliative Care

Community-based palliative care is experienced as connectedness with Other (de Souza, 2012; M. Holloway et al., 2011; E. Kelly, 2012b; Sheldrake, 2007). As an organization BHCI is a provider of community-based palliative care: there is no inpatient facility, all care is given within the home of the patient, or wherever they currently call *home*. Centred on holistic care, community-based care is by design comprehensive and integrated in nature, employing professionals from many disciplines in an attempt to address the concept of holistic care or total pain: care for the physical, psychological, social, and spiritual (Saunders, 2000; Sulmasy, 2002). Two valuable components of holistic care are the provision of care that is driven by patient need and agenda, and the capacity to be flexible in time and space (E. Kelly, 2012b). Community-based care enhances the notion of holistic care with care provided in the familiar patient space and context. *You put your notes in that say about your concerns for an individual situation and I don't gout to see anyone without reading those notes* (Appendix G, Line 171-174). Care also includes support and education for carers, family, and social networks, with the breaking of the societal taboo around death and dying by talking, behaving, and caring in ways that normalise the dying journey. Little research is

published under the theme of community-based palliative care, with even less on how spiritual care may be provided for those who choose to do much or all of the dying journey at home (Glass & Rose, 2006; M. Holloway et al., 2011). However, the meagre research that does exist indicates that patients receiving community-based palliative care report less unpleasant symptoms, greater control over treatment and life, higher quality of life, and fewer hospital admissions (Appelin & Bertero, 2004; Candy et al., 2011; Peters & Sellick, 2006).

Community-based palliative care goes hand-in-glove with the level one competency of spiritual care, where patient centred care is the goal (E. Kelly, 2012a; Rumbold & Holmes, 2011). Connectedness with Other flows through the connection between the worker and patient/carer, as well as supporting the connectedness of the patient and carer with each other and to family and friends, and connectedness with the world, and with mystery/transcendence (Appelin & Bertero, 2004; de Souza, 2012; E. Kelly, 2012c; Liu & Robertson, 2011). As stated previously, time, patient agenda, and breaking the societal taboo around death are basic understandings in the provision of community-based care.

Time

Time is an important component of any connectedness, and the capacity for flexibility around time within community-based care at BHCI is something talked of very positively by participants. *We've got that time: can allow that time for whatever they need* (Appendix G, Line 548). This is considered unusual in nursing circles, where insufficient time is acknowledged as a hindrance to the provision of holistic practice (Ronaldson, Hayes, Aggar, Green, & Carey, 2012).

Within palliative care time seems to speed up with enjoyment and crisis, while slowing down with boredom, anxiety and waiting (van Manen, 1997). Time becomes fluid as acknowledgement is made of the patient's and carer's need for support, or maybe for solitude. An intention to use and provide time as needed by the patient allows for short visits,

when need is small or families want space, to longer visits when needs are greater. *We are all incredibly lucky that we are allowed to take the time to deal with whatever comes up... and supports to refer back to find the right people to look after these people* (Appendix G, Line 151-154). This creates a flexible professional relationship that co-creates sacred space in the familiar context for the patient where time can build relationships while relationship gently gathers in time to make the most of it. *Time, respect and relationship...you have the time and opportunity to build these things, all within the patient's own space and under their direction.* (Appendix G, Line 608, 611-612).

The Context

We go into their home, we're in their surroundings, in their environment, so we follow them and what they want (Appendix G, Line 148-149). Community-based care occurs in the home, usually that of the patient, or where the patient presently calls *home. You immediately come onto their turf, in their tower of strength; whether that be out in the shed, or out in the horse paddock, or out in the garden, or even clothes line. They're the places where he or she, or the family unit gains the greatest strength* (Appendix G, Line 298-301).

Patient context. Staying at home, within one's community, can strengthen connectedness with life, friends and relatives, having memories and valuables close by and the continuance of some semblance of social life for as long as possible (Appelin & Bertero, 2004; S. A. Murray et al., 2004). Familiarity with this connectedness with Other can bring a sense of security and love to the dying which challenges the existential loneliness often experienced by the terminally ill (Appelin & Bertero, 2004; Sand & Strang, 2006).

The home environment can reveal much of the patient, especially what has become the *past* life, with pre-disease pictures of the patient sitting alongside tasks undone, all illustrating the changes and decline that have taken place. *When we enter their home and meet them in their context we get a broader picture of who they are* (Appendix G, Line 612-

613). *Looking at the broader picture of the person: body, mind and soul* (Appendix G, Line 181). It is in this here-and-now time that the memories of life blend with the vulnerable present, and concerns of the future, in conversations revolving around issues of connectedness and disconnectedness in parting. *There are big concerns rising as to what life will be like without this person, what they have shared together, what they've been to each other, and now what they need to affirm* (Appendix G, Line 403-405).

Patient agenda. With the capacity for the patient to set the agenda, there is a sense that they get to set the rules as goals of care originate from the patient and carer. *We might go in with a goal, but it's based on the patient's idea of that goal of care* (Appendix G, Line 306-307). *The recognition that it's more than treating the disease, we'll look after the symptoms and care, and keep you as comfortable as possible.* (Appendix G, Line 166-167). *Community care has sort of a much more personalised aspect* (Appendix G, Line 170). It is the holistic nature of care which can move professionals away from being task-oriented with a focus on the disease, to a broader picture where body, mind and spirit, as relationship and connectedness, are taken into account (E. Kelly, 2012c). *What hospice does is very much flexible and responsive to the situation, not task oriented. It's really person-centred* (Appendix G, Line 164-165). *Going to people's homes, on their ground, respecting what they want and working towards what they want and what the carers want.* (Appendix G, Line 544-545). *Community-based care is about patient control and patient space* (Appendix G, Line 155). However, patient and carer agenda are formed on ever changing ground (Carlander et al., 2011), and the very real threat of non-existence fundamentally disrupts connectedness with Self and Other (Redinbaugh et al., 2003), therefore worker response is required to be flexible, focusing on patient and carer need and individually tailoring care and support to suit. *We go into their home, we're in their surroundings... so who's in control? They are*

(Appendix G, Line 148,150). *Our 'to do' list is really guided at the patients' progress rate, set by the person...* (Appendix G, Line 307).

Family and carers. Community-based care can be inclusive of the patient, the carer, the extended family, and social support network (Redinbaugh et al., 2003). *It's not about a patient with a disease, but the family unit because the patient doesn't just get the illness; the family gets the illness* (Appendix G, Line 281-283). When a patient is cared for at home it is the family that do much of the caring, so supporting and encouraging their spirituality through connectedness with Self, Other, the world, and mystery /transcendence is an important part of community-based care (Candy et al., 2011; Carlander et al., 2011; de Souza, 2012; Liu & Robertson, 2011). So too is being mindful of creating a harmony for the carer between learning how to care, performing the care, and sharing the care with others, family, friends and professionals (Milberg & Strang, 2007). Empowerment through education for carers can be provided, in groups or on a one-to-one basis, about communication, patient care, symptom management, medication regimens and resource identification (Haley, 2003; Redinbaugh et al., 2003), and can enhance connectedness strengths helpful to adapt to the altered everyday life (Carlander et al., 2011). Community-based care is all about connectedness and teamwork between the carer, the patient, the community, and the multidisciplinary staff (Appelin & Bertero, 2004). The greater the communication between multidisciplinary staff and carers regarding options and resources, the safer the patient and the carer are likely to feel (Appelin & Bertero, 2004; Carlander et al., 2011). Providing a values based presence can also bring a sense of calm and connectedness ...*all is suddenly right cos together we've devised a way of dealing with it and you're not alone* **(**Appendix G, Line 289-290). Community-based care fosters patient and family satisfaction with dying and death care, supports and educates families to maintain home care for the patient, and typically decreases usage of general medical care (Candy et al., 2011; Haley, 2003). The interaction

between the patient, the context, and the impact of disease is an individual journey for each patient and their family, and this results in holistic care that is unique for this person's journey and context, and for the care team that walk alongside. *Individually tailored care too, and holistic* (Appendix G, Line 168). *I'm in an extraordinary privileged position here. I get to watch people's journeys and walk alongside* (Appendix G, Line 664-665).

Death as a Societal Taboo

The third milieu of community-based palliative care that arose from this research study is the breaking of the societal taboo around death and dying (Wong & Tomer, 2011). Humanity seems to be on a continuous quest to find meaning in life that bestows immortality, even while living in the spectre of unavoidable death (Rogers, 2011). Nevertheless, by its very nature and presence in society, community-based palliative care fleshes out words and actions to challenge the fear of ultimate disconnectedness, personal mortality, death. Acknowledgment of personal mortality through the meaningful reframing of death, and aligning it with one's worldview can bring opportunity to transcend the fear of death (Rogers, 2011), an ideal worked out in community-based palliative care.

> *In a western society it's become verboten: dying is something you do behind closed doors. (*With community-based care*) we're actually in there talking about it and facilitating it happening in the way that families and patients want it to happen. That's obviously very unique to patient care* (Appendix G, Line 314-318).

A preparedness for death through education, discussion and support is linked to lower levels of anxiety and increased levels of hope for the dying and their carers (A. Henriksson & Årestedt, 2013).

> *She declared he wasn't going to die at home, and he wanted to. She said she couldn't do it, and then, yes she could, and then, no she couldn't. And he wanted her to, and then he didn't and then - it was like this all the way. However the end result was that*

> *she was able to keep him at home up until the day he died. For me too, there was such a feeling of having aided her to do what she wanted to do but desperately felt she couldn't, and also what he wanted* (Appendix G, Line 666-673).

Community-based palliative care provides the patient and family with the option of staying at home, taking death out of the institutional environment of the hospital and assisting dying to be a journey made in familiar spaces (Redinbaugh et al., 2003). *We respect their choices. Develop relationship. It's not just about physical symptoms, if they've got emotional turmoil, being able to help them maybe sort some of that stuff out...so that they can die more settled.* (Appendix G, Line 545-548).

Summary of Community-Based Palliative Care

The uniqueness of community-based palliative care is shown to be built on flexible time, acknowledgement of the context and agenda of the patient and the carer, and professional practice that breaks the societal taboo of not speaking about death and dying, allowing it to happen naturally within the community. Community-based care delivered within the familiar context of the patient and carer, denotes it is *their* agenda that leads the way for truly person-centred care. Connectedness with Other is fostered between the multidisciplinary staff and the patient and carer through support, open communication, education, and flexible time provision. The participants showed that at BHCI the staff are very aware of their physical presence moving into the private context and physical presence of the patient and carer. ...*their turf; their towers of strength - the shed, the garden, or clothes line; meeting people on their own ground* **(**Appendix G, Line 298-304). There is a dual role here, one of an invited guest in someone's home and the other of professional engaged in a particular duty; movement within these two roles requires sensitivity and respect. *The endeavour of dual respect: self-respect can lead to an understanding that recognises the Other is a Self, and of respect for that Other* (Appendix G, Line 380-381). Reflecting this

research study back to the multidisciplinary staff will build awareness of the uniqueness of their role within palliative care and the community, bringing a deeper understanding of the positive contribution made by community-based care and an increase in job satisfaction (Pesut, 2002; Wasner, Longaker, Fegg, & Domenico Borasio, 2005). The foundation of person centred care being based on connectedness with Other enlightens the team on the place of spirituality and basic spiritual care within every day practice.

While the topic of community-based palliative care practice is not at first an obvious inclusion in a discussion of the understandings and perceptions of spirituality and spiritual care; the strength of response within the findings has led to its insertion. Spirituality defined as connectedness opened conversation into the uniqueness of community-based palliative care as practiced within BHCI, creating the possibility of a tangible empirical based understanding of what community-based care delivers for the participants, the multidisciplinary staff, and the organization. This is a topic that is scarce within the health and palliative care literature. Understanding and language will broaden the practice and discussion of spiritual care as a component of holistic care, and can be gained through education which was the final theme that emerged in the findings chapter: this is examined next.

Education

The desire and need for education regarding spirituality and spiritual care, and how it fits within multidisciplinary community-based palliative care practice was strongly presented within participant responses. *If you've had no training in it, and you've never had spirituality in your whole life, it's very hard to sort of bring it into conversation* **(**Appendix G, Line 81-82). *People never think about spirituality* (Appendix G, Line 76). *Some type of conversation would break the current silence* (Appendix G, Line 560-561). The need for evidence based education and practice is an opinion which is upheld in the literature (Cobb, Dowrick, et al.,

2012; Culliford, 2009; M. Holloway et al., 2011; Jenkins et al., 2009; Wasner et al., 2005). The European Spiritual Care in Palliative Care taskforce identified multidisciplinary education at all levels as a key strategic aim to improving the delivery of spiritual care to the dying (S. Nolan et al., 2011). Training in spiritual care for multidisciplinary professionals working in palliative care has been shown to have a positive effect on their compassion for Self and Other, increased satisfaction with work, and a reduction in work-related stress (Wasner et al., 2005). Similarly, further education for community palliative care nurses in the UK increased knowledge, confidence, and enhanced professional development (Hughes, Parker, Payne, Ingleton, & Noble, 2006). A shared spiritual language implies that spirituality will be categorized and understood similarly (Donmoyer, 2000). The worldviews of differing professions within holistic care can meet at the axis of fundamental respect for Self and Other, which brings a holistic sense to person-centred care (Pesut, 2003).

The lack of training in spiritual care reduces the skill level of holistic care at an organizational level, where skill is documented as an institutional value (Ballarat Hospice Care Incorporated, 2010). *But you do it (spiritual care) all the time and you do it beautifully. You just don't see it* (Appendix G, Line 140). It also decreases the spiritual capital held by the organization (Bennet & Bennet, 2007). Research participants showed that a lack of training coupled with the deficiency of a working language around spirituality at BHCI created a sense of incompetency and served to make spirituality an enigma, sentiments echoed in the literature (Cobb, Puchalski, et al., 2012; M. Holloway et al., 2011; Johnston Taylor, 2003). *If you've had no training in it... it's very hard to sort of bring it into conversation* **(**Appendix G, Line 81-82). *We're saying you do do spiritual care and you don't even know that you do* **(**Appendix G, Line 143-144**)**.

The aim of holistic care is for basic spiritual care to permeate all other dimensions of care for an individual patient, with the recognition that the social, psychological, spiritual,

and religious aspects are closely connected to physical symptoms and are of equal importance for care (Carroll, 2001; Lloyd-Williams & MacLeod, 2004). This aim can be helped by a common language and definition of spirituality as connectedness placed within orientation for new staff members and professional development education based on skills included in basic competency levels of spiritual care.

Common Language and Definition

We need to be able to find the words to articulate what it is so it doesn't come across as a passive thing, 'cos it's actually quite active (Appendix G, Line 20-21). *The group, having warmed to the subject, were developing their own lexicon and learning from it* (Appendix G, Line 99). The literature shows that a lack of understanding about contemporary perceptions of spirituality and spiritual care points to the need for knowledge and education to bring enhanced clarity for training and orientation in spiritual based palliative care practice (M. Holloway et al., 2011; Jenkins et al., 2009). Even in small, fairly homogenous groups of people, differences in words and language can be a cause of dissimilar meanings (Moberg, 2010). *We've all brought different ideas and language, or lack of language* (about spirituality), *into our positions in the organization* (Appendix G, Line 217-218).

The application of connectedness with Self, Other, the world, and mystery/ transcendence as a definition of spirituality alongside disconnectedness describing spiritual pain provides an easily articulated characterization of spirituality and spiritual care (de Souza, 2012; Fisher, 2011; E. Kelly, 2012b). *Some type of conversation would break the current silence, and help to bring together a language so spirituality can be discussed with some common understanding and meaning* (Appendix G, Line 560-562). Spirituality as connectedness on a relational continuum is a multidimensional description that is applicable to everyday experiences and therefore, fairly easy to teach for understanding in order to apply it to spiritual care (de Souza, 2009; Hawks, 2004).

Education for Orientation and Professional Development

The inclusion of spirituality in orientation and training is shown to embed spiritual practice within the organization which develops the provision of spiritual care (Jenkins et al., 2009). The lack of education regarding spiritual aspects within initial professional training, coupled with no organizational orientation or professional development regarding spirituality, have been shown to result in professionals feeling inadequate in their ability to talk about spirituality, or identify, assess, and deliver spiritual care (M. Holloway et al., 2011; Jenkins et al., 2009; McSherry, Gretton, Draper, & Watson, 2008). Organizational conversation and training about spirituality and spiritual care were identified as a priority for both current staff to break the silence and misunderstanding around spirituality, and also for new staff to understand and absorb the values ethos and spiritual atmosphere of BHCI. *Training new people coming into the organization is really important so they can understand and provide holistic care* (Appendix G, Line 42-43). Orientation education and professional development training about spirituality can provide empowerment for members of the multidisciplinary team in offering holistic care to meet spiritual care expectations at BHCI. The organizational values recognise skill both at initial employment and as enhancement through professional development within employment at BHCI (Ballarat Hospice Care Incorporated, 2013). These values, together with an understanding of spirituality as connectedness and spiritual pain as disconnectedness (de Souza, 2012; Ellis & Lloyd-Williams, 2012; Fisher, 2011), provide an unambiguous framework for spiritual care grounded in established theory, for the multidisciplinary team upon which to position their own specialized practice framework (M. Holloway et al., 2011). Connectedness with Self and a personal sense of worth, together with connectedness with Other, with the world, and with mystery/transcendence comes together to form the spiritual worldview of each individual (Fisher, 2011; Hawks, 2004). Investment in

the spiritual growth of the multidisciplinary staff ultimately increases the spiritual capital and skills base of the organization (Bennet & Bennet, 2007).

> *Professions can have diverse worldviews, but it is alright to talk about differences, because it is that fundamental respect for each other that brings a really holistic sense of the various disciplines working together, each contributing from their discipline with that wider and deeper awareness and respect. So you're a professional doing your work, but keeping your own humanity alive and a sense of the other person's humanity and profession there as well* (Appendix G, Line 417-422).

"Excellent practice both shapes and is shaped by context" (Benner & Sutphen, 2007, p. 107), and excellent holistic practice is preceded by a sense of skill and competency in spiritual care.

Competencies

Different approaches to competency frameworks of spiritual care proposed by various palliative care peak bodies and outlined in the literature (pp. 77) (Appendix F), highlight the requirements of multidisciplinary team members to be competent in the offering of person-centred care and practice in ways that are sensitive to the spiritual domain (M. Holloway et al., 2011; E. Kelly, 2012a; Marie Curie Cancer Care, 2003; Rumbold & Holmes, 2011). Proficiency in Level Two competency would embed spiritual care into the everyday practice of the multidisciplinary team providing home care (Jenkins et al., 2009). *I see a lot of patients struggling with it...I've struggled with it, and my colleagues have struggled with it because medically you're trained to deal with this side of the fence; the biomedical side.* (Appendix G, Line 16-18). Level Two of Spiritual Care is characterised as needed by many and provided by many (Rumbold & Holmes, 2011). It includes an awareness and identification of spiritual and religious needs, the use of a basic spirituality screening tool, empathetic communication skills (verbal and non-verbal), as well as an awareness of one's own spirituality (M. Holloway et al., 2011; E. Kelly, 2012a; Marie Curie Cancer Care, 2003; Rumbold & Holmes,

2011). At BHCI the dedicated spiritual support worker is responsible for most Level Three and Level Four competencies as defined above in spiritual care (pp. 76) (Appendix F). As Cobb (2012, p. 96), points out:

> The aim is not for each member of the team to develop comprehensive mastery of spiritual knowledge and skills, but for the team as a whole to extend and sustain their understanding, appreciation, and practice as compassionate, informed, and capable carers and healers.

When spirituality is understood as connectedness and spiritual distress as disconnectedness a rich and inclusive nature of spirituality is provided that brings an ideology of fundamental respect (de Souza, 2012; Fisher, 2011). Connectedness with Self involves the skills of increasing awareness of the Self through self-reflective practice, while also increasing Other awareness through empathy and listening, honing intuition, and the importance of presence. Therefore, the following areas need to be incorporated in education for practitioners in the move towards skill acquisition and competency:

- spirituality defined as connectedness, spiritual despair as disconnectedness;
- increased awareness of Self and self-reflection;
- increased awareness of Other with listening and empathy;
- honing intuition;
- presence.

Skills

The core topics of training identified within the literature were a robust definition of spirituality, reflective practice, emotional resilience, and listening and communication skills (Culliford, 2009; Ford et al., 2012; Lemmer, 2002; Pesut, 2002). Skills highlighted by participants included active or therapeutic listening, suspending judgment, stillness, embracing of the whole person, sitting loosely with one's own thoughts, intuition, increased

awareness of Self, increased awareness of Other, exploring hope, and reframing. *The multidisciplinary team need education around spiritual care, helping people to be sensitive to what's happening to them; to their spirit* (Appendix G, Line 446-447).

Definition. Any education of the multidisciplinary team must begin with a robust and stable definition of spirituality. This is achieved with the use of connectedness with Self, Other, the world, and mystery/transcendence (de Jager Meezenbroek et al., 2010; de Souza, 2012; Ellis & Lloyd-Williams, 2012; Fisher, 2011).

Self-reflective practice. One's worldview, beliefs, values, and attitudes make up both conscious and pre-conscious elements of professional character (Benner & Sutphen, 2007), and a well thought out worldview brings personal understanding of one's place and purpose in life (Hawks, 2004). *So for me they're all amazing stories that make me wonder what else is out there and what happens after we die* (Appendix G, Line 700-701). The consideration of one's own spirituality, beliefs, attitudes, and values is elemental in increasing compassion and recognition of the spiritual issues of Other (Greenstreet, 1999; Lemmer, 2002; Mitchell et al., 2006), providing an expansion of personal views enabling the exercise of one's own spirituality within the sphere of disparate beliefs and values (Pesut, 2002). *He can't not be here, can't just not cease like that. He must be somewhere* (Appendix G, Line 635-636). *I don't know, maybe there's something... but for me, all I care about is this life, whatever that life may be* (Appendix G, Line 645-646). *I remember going from 'oh no he can't die' to the next thing 'yes he can,' and he has, and that's OK* (Appendix G, Line 661-662).

Learning based on interpretation aims to discover and experience new understandings through drawing on one's own experience, life and world (Benner & Sutphen, 2007). *Staff are growing people, and they're learning people, and every engagement is a learning one* (Appendix G, Line 449-450). As spirituality is interpreted individually, uniquely, and personally, then education needs to assist the promotion of self-reflection on one's own

spirituality rather than the impressing of a particular worldview (Catanzaro & McMullen, 2001). It is a philosophy that continues into the provision of spiritual care for others is the focus on promoting the spirituality of the Other (McSherry et al., 2008). *Self-respect can lead to an understanding that recognises the Other is a Self, and of respect for that Other. Within that I have to be very careful that I don't intrude or impose on their Self* (Appendix G, Line 380-382).

An increased awareness of personal places of disconnectedness with Self, occurring through such things as grief, imperfection, shortcoming, pain, or suffering, can lead to an identification of the disconnectedness experienced by Other (de Souza, 2012; Mitchell et al., 2006). Similarly a rising consciousness of connectedness with Self, places of growth and strength can initiate a consideration of the importance of connectedness for others (Mitchell et al., 2006). The constructivist approach of this research study has been an appropriate foundation here where meaning exists within the Self and is confirmed through human communication and interaction (Canton, 2006). Reflection upon one's worldview and personal perspectives held on spirituality, death, and dying can bring transformative learning, increasing confidence and enhancing professional development (Barry & Gibbens, 2011; Canton, 2006). Connectedness with Other involves listening, empathy, building intuition, and provision of a still presence.

Other awareness. *Listening is actually quite a complex skill* (Appendix G, Line 451). *Listening to a person requires more than the head, it requires the heart...to hold that sense of the whole person* (Appendix G, Line 411-412,416). Taking the time to employ active listening skills such as open questioning, empathy, and silence can co-create spaces where patients and carers feel able to talk about hopes and fears (S. A. Murray et al., 2004). An investment in active listening also acknowledges that while the spoken word can be helpful in revealing something of spirituality, words themselves are never adequate but only convey a

vague idea (van Manen, 1997). *It's nurturing without getting involved, without taking it on or telling them...listening I suppose* (Appendix G, Line 284-285).

Listening through the heart can be woven through the practice of analytical and intellectual skills to provide and hold a sense of the whole person (Benner & Sutphen, 2007; S. A. Murray et al., 2004) ...*keeping your own humanity alive and a sense of the other person's humanity and their profession as well* (Appendix G, Line 421-422). The quietening of the voice of the staff member, internally and externally, cultivates receptiveness to the person (Baugher, 2008). *Listening is about being still, trying to quiet some of our own chatter to be able to hear* (Appendix G, Line 455-456). The multidisciplinary team walk alongside the patient who is already actively paving the road for *this* exceptional step of *their* journey with personal beliefs, meanings, and places of connectedness. *The emphasis is upon empathy, standing with people, alongside...I can't be everything you like and it's important that I continue to be me with integrity with my meeting with you, because I am more help to you if I have integrity* (Appendix G, Line 428-432). It is not about *knowing*, it is *being* that provides the space for the patient to discover their own, innate spiritual answers (E Kelly, 2013). We *need to be sensitive to* issues of parting *and need to be prepared to do something where it's indicated to. Or at least have some understanding of how we might at least not get in the way* (Appendix G, Line 407-409).

Intuition. *People need to cultivate those intuitive elements like hunches and ideas that seem to come out of nowhere* (Appendix G, Line 456-458). The appreciation and fostering of intuition and hunches, of both Self and Other, is a foundational aspect of spiritual care (Baugher, 2008; Murphy, 2009). *It's your gut when you say, "I didn't ask about death because it wasn't the right time." To me that's spirituality. It's that bit in you that actually knows that this is not the time, or this is the time* (Appendix G, Line 115-117). The sensitive, felt response of intuition within spiritual care grows out of waiting, wisdom, and experienced

practical knowledge (E. Kelly, 2012c), bringing an awareness of enhanced potential options (de Souza, 2006). *Getting a sense of something; thinking or feeling there's more here than I understand and I need to move carefully to allow that to come forward* (Appendix G, Line 458-459).

Presence.

> *In nature things are often drawn to stillness. If you're amongst horses that are very upset, if you stand very still they will gravitate towards you. There is a desire for stillness and clam, nature does it naturally, but I think our society has made everything so frenetic, so maybe when you're talking about what the staff do it's about that begetting calm* (Appendix G, Line 291-295).

Another component of spiritual care, that of *being* over *doing* in the co-creation of sacred space, has been identified as potentially challenging to professions involved in problem solving and operating with a tick box mentality (Baugher, 2008; E. Kelly, 2012b). While being a still, attentive presence can be challenging, it can be a significant gift to those being cared for (E. Kelly, 2012c). Again, working from the awareness of fundamental respect, an atmosphere is created where it is acknowledged that: *Staff are also growing people, and they're learning people, and every engagement is a learning one* (Appendix G, Line 449-450), (Mitchell et al., 2006).

Summary of Education

Participant responses aligned with the literature and acknowledged the need for education around spirituality to encourage the practice of spiritual care within holistic care for the terminally ill. Aspects of education required for orientation and professional development included skills in communication and listening, empathy, intuition, and an understanding of the value of presence. Even when armed with tools and skills to understand and provide spiritual care it is important to remember that this is co-creation, rather than expert problem solver and patient (E. Kelly, 2012a). Education brings a sense of competency

to the offer of holistic practice and can enhance resilience, self-care options, and job satisfaction.

To Summarise

This chapter has examined the five key themes that rose out of the textual conversations of this research study regarding the research question: What are the understandings and perceptions of spirituality held by multidisciplinary professionals involved in a community-based palliative care organization? They include:

- spirituality as connectedness and relation;
- spiritual despair-disconnectedness;
- contrasting religious care and spiritual care;
- community-based palliative care;
- the lack of a common language highlighting the need for education.

These themes address the fundamental characteristics of spirituality and spiritual care at BHCI which were brought to life in the findings. They present the understandings and perceptions of the multidisciplinary participants, in dialogue with current thought presented in the literature. The interpretation of the themes highlights several recommendations for the establishment of a multidisciplinary education program, for both orientation and professional development at BHCI, and also point to future research needed in the area.

The description of spirituality as connectedness with Self, Other, the world, and mystery/transcendence is a concept that is simple to understand and apply for holistic patient care and for worker self-care. Rarely static, spirituality ebbs and flows in movement, along a relational continuum, from separateness through connectedness towards ultimate unity. Connectedness with Self begins with intrinsic dignity and can bring new meaning and purpose through *being* rather than *doing*. For staff, an understanding of, and reflection, on self in connectedness with the Self can increase awareness of the values, philosophy, ethics,

and dreams held by the professional. As an important component in the ability to self-care, self-awareness can prevent burnout while promoting wellness. Holistic care is then based on appreciation of the Self as carer, rather than the need of Other.

Connectedness with Other is a primal response to reach out and connect throughout the relational continuum from acquaintance to intimate Other. It provides acceptance, respect, dignity, and an appreciation of one's unique life. Not all connections are equal; relationships can be messy and fickle as one human interacts with the revelation and concealment of another. Connectedness with Other is a vulnerable space within palliative care that requires nurturing. It can provide a place for diverse wonderings to be explored and mirrored back, while challenging the fear of dying alone. Staff recognition of levels of connectedness provides enhancement of palliative care: bringing a deeper level to holistic care. An increased self-awareness of connectedness for the professional with significant others in their own lives is a factor within self-care. The organizational values of trust, respect, loyalty, skill, willingness, kindness, and honesty bring further definition to connectedness and need to be emphasized as an element of best practice within spiritual care. Connectedness with the world encompasses place as a sense of belonging, in conjunction with creation, creativity, and beauty. Robustly presented in the literature, connectedness with the world was not significantly identified by research participants. Staff ignorance about the significance of connectedness with the world, and the ability to make meaning through creating, leads to a diminishing of holistic care, as well as self-care options. Connectedness with mystery/transcendence recognizes that there is something beyond the understanding and influence of the Self. This increases the ability to embrace reflection, awe, hope, and wonder. Psychological transcendence is an attempt to overcome suffering, while religious transcendence is movement towards the Transcendent or Divine. Death is fundamentally mysterious and exploration of one's own thoughts and philosophy of the mystery of death,

dying, and the mystery beyond is helpful for the palliative care staff. Moving out of separation each connectedness, Self, Other, the world, and mystery/transcendence, builds on, and builds up, each other. Integrating and blurring the boundaries towards Ultimate Unity, and the capacity for fully holistic practice.

Recognizing spiritual need and spiritual distress as disconnectedness is an easily accessible characterization of spiritual pain. For professional staff an awareness of disconnectedness within their own lives can assist with a non-judgmental acceptance of the disconnectedness of those they care for. Disconnectedness with Self occurs when one's very existence is shaken by a terminal illness and questions of meaning and purpose arise. It is marked by lack of body control, restlessness, and a lack of meaning and purpose for the terminally ill. The shadow side of connectedness shows itself when connecting to something not beneficial to wellbeing. This obstructs human flourishing and impedes living life in the here-and-now. For the staff, denial of the shadow hampers healthy connectedness and leads to a risk of projection from the professional onto the patient and carer. The acknowledgement of unhelpful connectedness and denial of the shadow are events that are not identified within the palliative care and health literature. Disconnectedness with Other brings social isolation as relationships are taxed by the enormity of change on the terminal journey. Disconnectedness with the world, through a sense of place, can lead to an impression of global loneliness, while it also impacts on meaning and purpose through a detachment with creation and creativity. The concept of disconnectedness with the world was scanty within the literature, and it and the concept of disconnectedness with mystery/ transcendence, were sparsely treated within the textual conversation. These are areas where education is required to assist the staff be aware of the impact of disconnectedness with the world and to mystery or transcendence. Further research could assist in broadening the understanding of these

concepts. Disconnectedness from mystery brings existential crisis, and a small mundane, controlled world revealing a decrease of hope or notions of change.

A comparison of religious and spiritual care found supposed overlapping moves towards unique concepts. Religious care acknowledges an external faith community identified by particular ritual, belief and practice, and a treasury of wisdom providing a worldview and metanarrative which provide specific ritual and practice. Staff need to be aware of religious sensitivities and religious care needs require specialised religious training. Spiritual care recognizes and enhances personal, internal values of connectedness, not by problem solving, but through providing presence within places of disconnectedness, active listening, exploring the big questions, and exploring preparedness for death. Effective spiritual care is equally about the spiritual wellbeing of the multidisciplinary team with the provision to explore connectedness, disconnectedness, and meaning.

Spirituality defined as connectedness opened conversation into the uniqueness of community-based palliative care as practiced within BHCI, creating the possibility of a tangible empirical based understanding of what community-based care delivers for the participants, the multidisciplinary staff, and the organization. This is a topic that is scarce within the health and palliative care literature. Community-based palliative care is founded on connectedness with Other and displays three main characteristics: time, the context of patient with their agenda and carer, and the breaking of the societal taboo of speaking about death. The staff is very aware of their physical presence moving into the private context and physical presence of the patient and carer. The dual role of an invited guest in someone's home, while also a professional engaged in a particular duty, requires sensitivity and respect. For the multidisciplinary team time becomes fluid as it is dictated by patient and carer need. Connectedness with Other and the world, as one's place of belonging, is strengthened for the patient and carer by the opportunity to carry out the dying journey in their own home.

Empowering and supporting the carers is an essential component of community-based care. Going into the home of the patient, onto their turf, encourages the realization of the goals of care held by the patient and carer: totally person centred care. The very nature and presence of community-based palliative care in society challenges the community silence and taboo as speaking of death can occur naturally in the home environment.

The need for education and training about spirituality is vital to encourage the practice of spiritual care within holistic care for the terminally ill. Aspects of education for orientation and professional development included skills in communication and listening, empathy, intuition, and an understanding of the value of presence. This is not the place to be an expert, or a problem solver, but rather to facilitate co-creation of sacred space. While many of the skills are not new per se, the research study set out to bring pre-conscious actions and behaviours into awareness, signifying their foundation within spirituality and spiritual care. Education brings a sense of competency to the practice of holistic care and can enhance self-care options along with job satisfaction.

Finally, a significant result from the process of immersion, interpretation, and reflection on the findings was the emergence and development of a spiritual screening tool called *Connecto*. The use of this easy-to-use measure will be described in the concluding chapter. This screening tool was introduced to the EO and multidisciplinary staff at BHCI who were enthusiastic in their acceptance of it, but it is yet to be trialled and implemented. In fact, the implementation and evaluation of *Connecto* will provide avenues for further research.

To conclude this chapter, the interpretation and reflections process through this research study explored the five key themes of:

- spirituality as connectedness;
- spiritual pain and despair as disconnectedness;

- the contrasting of religious and spiritual care;
- community-based palliative care;
- spiritual education.

Based upon these reflections the next and final chapter will outline the development and use of the spiritual screening tool *Connecto* and offer some recommendations for its application within patient assessment. Recommendations will also be offered for education and training in spirituality for professional development and orientation within community-based palliative care, along with proposals and suggestions for future research. These recommendations should encourage organizations to identify and invest in the spirituality of their multidisciplinary teams and will ultimately increase the spiritual capital of BHCI (Bennet & Bennet, 2007).

Chapter Seven: Conclusion and Recommendations of this Research Study

This research study set out to explore the research question: What are the understandings and perceptions of spirituality held by multidisciplinary professionals involved in a community-based palliative care organization? This final chapter brings this thesis to a close by presenting the results of the research study findings which includes the development of a spiritual screening tool, *Connecto*(Appendix H). However, to begin with, the research problem, context, and methodology is revisited, followed by a brief summary of the interpretation and reflection of the findings of this research study, and then finally, there are a number of recommendations for future practice and research that are proposed.

Community-based palliative care is established on the provision of comprehensive holistic care which is made up of physical, psychological, social, and spiritual needs. The multidisciplinary team is hampered in their provision of basic spiritual care by an inadequacy of language and education around spirituality and spiritual care. The goal of this research study was to capture the voices of the multidisciplinary team at Ballarat Hospice Care Incorporated (BHCI), in an effort to give shape and language to the perceptions and understandings of spirituality held by multidisciplinary professionals involved in a community-based palliative care organization. Utilizing the Social Research Design of Crotty (1998), this qualitative study was positioned within an epistemology of constructivism, making use of hermeneutic phenomenology as the interpretivist theoretical perspective. The case study methodology utilized the method of extended focus groups and semi-structured in-depth interviews to collect conversations from professionals of diverse disciplines. These conversations, recorded, immersed in, and documented through a hermeneutic phenomenological writing style, comprised the texts for interpretation in this research study. The lifeworld existentials (van Manen, 1997) of lived space, lived time, lived other, and lived body were used as guides to reflection and interpretation of the textual conversations. Figure

15 shows how the chosen research process of this research study fits within the social research design, leading to the formation of new knowledge, key themes, and *Connecto*.

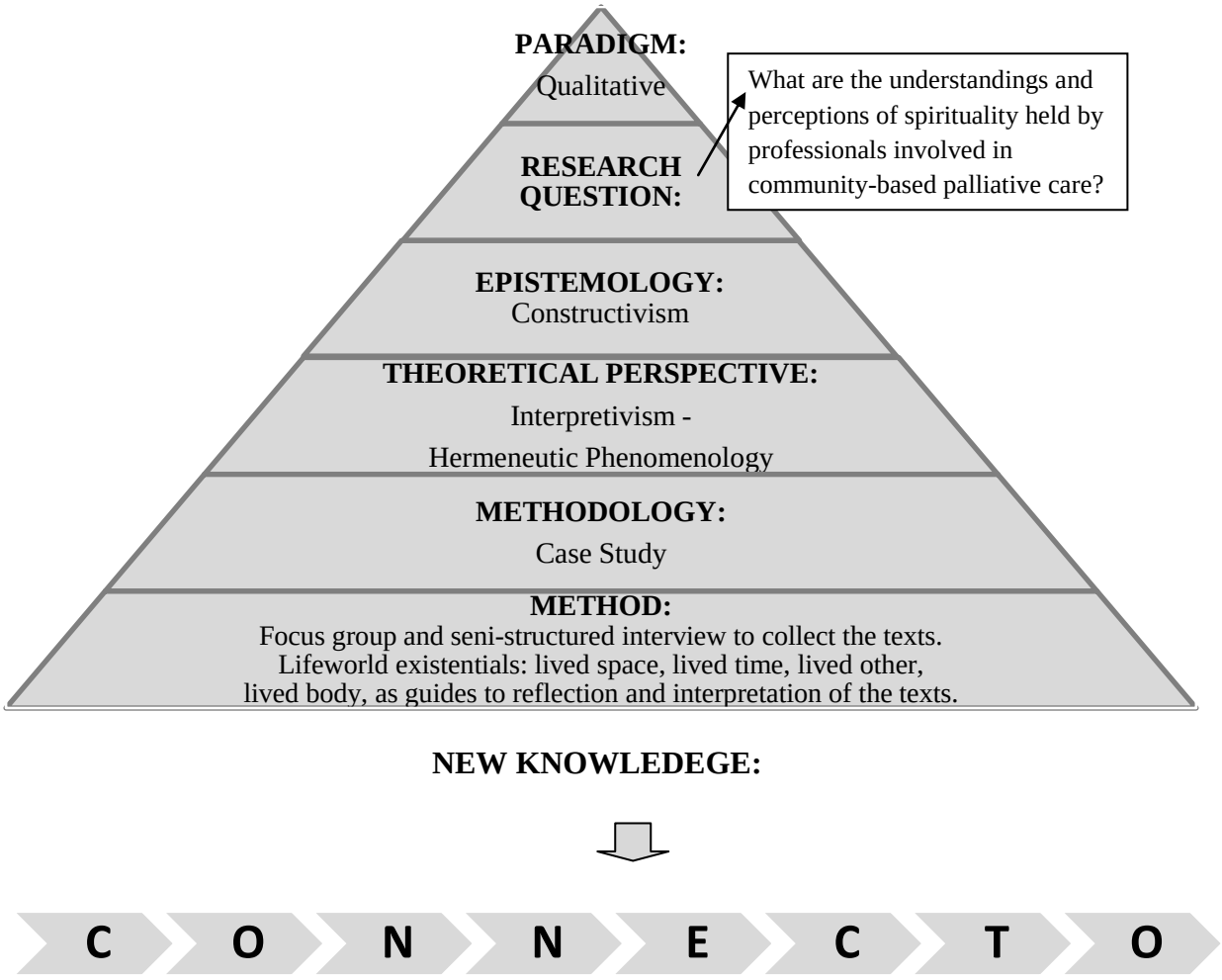


Figure 15. New Knowledge from the Social Research Design (Crotty, 1998).

Summary of the Interpretation of the Findings and Results of this Research Study

Through analysis and interpretation five key themes arose out of the textual conversations of this research study that were identified as addressing the fundamental characteristics of spirituality and spiritual care at BHCI. These represent a dialogue between the understandings and perceptions of spirituality held by the multidisciplinary participants, and current thought within the contemporary research literature around health, palliative care, and spirituality. These findings provided a lexicon of spirituality and spiritual care for BHCI

which placed spirituality within the framework of connectedness and spiritual pain as experiences of disconnectedness. The key themes of the discussion were:

- Spirituality as connectedness: Here, spirituality was acknowledged as connectedness with Self, Other, the world, and mystery/transcendence, moving towards ultimate unity, and providing a framework for exploring meaning and significance.
- Spiritual pain and despair as disconnectedness: Spiritual pain was characterized as disconnectedness from Self, Other, the world, and mystery/transcendence. Further, much of the dying journey highlights disconnectedness in these areas. Accordingly, within this framework the multidisciplinary team are provided with language to identify and express spirituality and spiritual need that transcends specific belief, as well as protective factors which nourish self-care and bring an increased awareness of one's own spirituality.
- The contrast between religious care and spiritual care: It is necessary for the multidisciplinary team to be aware of the contrast between these two. Religious care is founded in a faith community which provides the individual with an external treasury of wisdom, ritual, and worldview. Spiritual care, however, involves being an authentic presence, and helping to co-create a sacred space where meaning and life can be explored.
- Community-based palliative care: Community-based palliative care is unique within the health system, characterised by a flexibility of time negotiated by the patient, carer, and multidisciplinary professional. The context of the patient along with the agenda of the patient and carer is paramount to all goals of care. The provision of professional care *within* the community breaks the societal taboo that keeps dying and death hidden from public view.

- The need for spiritual education: There is a distinct need for education about spirituality and spiritual care which was highlighted by the lack of a common language and understanding held by the multidisciplinary team at BHCI.

  Skills required include:

  - identification of connectedness and disconnectedness as a framework for spirituality and spiritual care;
  - increased awareness of Self and self-reflection;
  - increased awareness of Other with listening and empathy;
  - honing intuition and presence.

These key findings provide a lexicon of spirituality and spiritual care for BHCI which places spirituality within the framework of connectedness and spiritual pain as disconnectedness. This brief summary of the discussion of the findings expounds the evidence-based foundation which led to the development of a screening tool, *Connecto* (Appendix H).

Recommendations for Future Practice and Research

This chapter has revisited the research problem and context, provided a brief summary of the interpretation and reflection of the findings, and mentioned the results of this research study, the development of a screening tool, *Connecto*. Finally, recommendations are proposed for future practice and research.

The findings of this research study identified the significant need for professional development of multidisciplinary teams working within community-based palliative care and have led to the following recommendations for future training and education through two streams:

- the practice of spiritual care within community-based palliative care;
- the use of spiritual care as self-care for the multidisciplinary professional.

The practice of spiritual care. The lexicon of the connectedness and disconnectedness framework of spirituality facilitates easy language for the discussion of spirituality, spiritual care, and a spiritual care referral. Education for practice needs to include the identification and understanding of:

- concepts of connectedness with Self, Other, the world, and mystery/transcendence;
- concepts of disconnectedness with Self, Other, the world, and mystery/transcendence;
- contrast between religious care and spiritual care;
- distinguishing features of community-based palliative care;
- basic spiritual care skills and competencies;
- the use of *Connecto* to embed spiritual screening within daily organizational practice.

Understanding these concepts of spiritual care increases and broadens the capacity of holistic practice.

Supporting self-care with spiritual care. Exploring personal connectedness and disconnectedness provides options for self-care for the multidisciplinary team members, creating:

- protective factors of *being* and hope, with an increased awareness of personal spirituality, ethics, philosophy, and values;
- self-care options with significant others;
- spaces of self-reflection through creation, creativity, and belonging;
- a space to reflect on dying, death, and beyond;
- self-reflection on connectedness/disconnectedness strengths through personal use of *Connecto*.

Familiarity with these concepts of spiritual care, and their support of self-care, can strengthen resilience, and increase job satisfaction. These recommendations relate to the significant need for education and training in spirituality and spiritual care which are to be presented as both

an organizational lexicon of spirituality and orientation, and professional development programs. A further recommendation is that the use of *Connecto* as an organizational screening tool could be used to address spiritual referral within palliative care.

Future spirituality research. Finally, further research is needed where the screening tool, *Connecto*, can be implemented, trialled, and evaluated for its effectiveness in enhancing the professional practice of multidisciplinary professionals who work in palliative care. Research into connectedness with creation and creativity, and the pain of disconnectedness from them, would be useful in exploring spiritual bonds between a person and the world, nature, beauty, and place.

In Conclusion

The inclusion of spirituality within holistic care has in the past been a health practice anomaly. However, the increasing recognition of spirituality as an important consideration in health practice has led to an increase in spiritual research in the field. This research study contributes definitively by providing one way of applying new knowledge to enhance both professional practice for the multidisciplinary team and the increase in options for self-care. The findings of this research study have been specific to the field of community-based palliative care, and in particular spirituality and spiritual care at BHCI. However, they can also be useful to professionals in other organizations, disciplines, and health fields as suggested (pp. 263). As *Connecto* is a simple tool that requires little time for training, and no particular background or previous experience, it can be quickly implemented into existing practice bringing immensely useful outcomes for anyone working within the caring professions (pp. 263). Given the increase of people desiring to die at home, the provision of community-based palliative care is an expanding necessity in our society. The provision of comprehensive holistic care within this service is only possible when spirituality and spiritual care are seen and supplied as an equal component alongside the physical, psychological, and

social aspects of the patient. This research study makes a valuable contribution to the improvement of the provision of spiritual care for terminally ill patients and their carers. Further, Connecto provides a simple spiritual screening tool that provides structure and policy to spiritual identification and referral. The education and training of multidisciplinary palliative care staff in terms of identifying spiritual strengths within patients and for themselves enhances care for the dying, and options of self-care for staff involved in such challenging employment.

Appendices

Appendix A Bracketing my Spirituality

When asked about my beliefs, I classify myself as a 'passionate God-lover.' My connectedness with the Christian, triune God brings meaning, purpose and motivation to everything I do in life. My first encounter with this Being was as a child, sitting in the sand dunes watching the surf pound the Victorian coastline. I experienced a sense of knowing there was something bigger than I, even bigger than the wave power; and it brought with it an awareness of safety, protection and acceptance. All at once I believed myself to be in relationship with God: God existed and wanted to be connected to me.

While my own experience was internal and definitive for me personally, I understand spirituality to corporately be an ambiguous idea, appearing to be defined in unique ways by each individual. Within those unique ways there can be similarities and differences, in language, experience and belief, but whether religious or not, I believe each human being to be naturally, intrinsically spiritually oriented. Moreover, I believe this naturally occurring, intrinsic spirituality is nourished by work and instruction to release inherent spiritual potential and growth.

My spiritual journey has become increasingly significant with the years. I have found so many seasons in life have not been conducive to reflection and contemplation; so found myself dipping briefly, then experiencing great spiritual thirst until the next quick dip. However, as living has loosened its demands on my time and energy, I have luxuriated in the space to think a thought without interruption. Here I have experienced the capacity to prioritise spirituality: thinking, reading, discussing, ritualizing, meditating, and application. As I have read more broadly and more academically throughout this study, my spirituality has become more accepting of difference.

While my spirituality embraces religious roots, I have no sense of owning *the* truth or believing my spirituality to be superior. I have no passion to evangelize or convince another of my beliefs and as such am able to listen and value another's description of spirituality. As my spirituality is of ultimate value to me, I presume that when the other talks about meaning in their own life, it is of ultimate value to them. This is a conversation to be entered into with respect and dignity.

As I take the stance that each person has an intrinsic spiritual component, then an indication of this is something I anticipate finding as stories are collected and analysed. Language and story may differ, but I think connection as impetus could be common. As different professions share perceptions and accounts of spirituality, the language used will add to a corporate understanding of how spirituality operates at BHCI.

Appendix B Ethics Approval for this Research Study

Appendix B-1

Ethics Approval: Ballarat Health Services and St John of God Health Care Human Research Ethics Committee

Ballarat Health Services
and St John of God Hospital Ballarat
Human Research Ethics Committee
Phone: 03 53204787
Email: researchethics@bhs.org.au

Dr Marian de Souza
Australian Catholic University
1200 Mair Street
Ballarat VIC 3350

30 October 2012

Dear Dr de Souza

Study title: An investigation of the perceptions and understandings of spirituality and spiritual support, held by professionals involved in community-based palliative care.
HREC Reference Number: HREC/12/BHSSJOG/98

Thank you for your response to the Committee's request for further information dated 28th October 2012. Your response was reviewed by the Ballarat Health Services and St John of God Hospital Ballarat HREC Secretary on 29th October 2012.

Decision
The application is approved on the basis of the information provided. This decision will be tabled for ratification by the Committee on 6th December 2012.

Approval
The approval is valid from 29th October 2012.

Approval is given in accordance with the research conforming to the *National Health and Medical Research Council Act 1992* and the *National Statement on Ethical Conduct in Human Research (2007)*.

Approved documents
Documents reviewed and approved were:

Document	*Version*	*Date*
Application		06 August 2012
Covering Letter		31 May 2012
Application	Signatures page	07 August 2012
Investigator CV: J Merran Fletcher		
Protocol: Group Research Protocol		
Application	Revised Version 26/09/2012	26 September 2012
Covering Letter	Revised	31 May 2012
Ballarat Hospice Approval		28 June 2012
Participant Information Sheet/Consent Form	Version 2	26 September 2012
Site Specific Consent Form	Version 2	26 September 2012
Victorian-Specific Module	Version 2	31 May 2012
Response to Request for Further Information: Revised application and documents		28 October 2012

The following conditions of approval apply:

Site-Specific Assessment (SSA)

SSA authorisation is required at all sites participating in the study. SSA must be authorised at a site before the research project can commence.

The completed Site-Specific Assessment Form and a copy of this ethics approval letter must be submitted to the Research Governance Officer for authorisation. This applies to each site participating in the research.

Correspondence to HREC

Please submit a signed original hardcopy marked attention to HREC Secretary along with electronic version to researchethics@bhs.org.au of the same. Quote the reference number from the title of this letter in all correspondence.

Protocol Amendments

Any changes to the protocol must be submitted to the HREC for approval and should be accompanied by a summary outlining the reasons for the change together with an indication of any ethical implications. Two copies of amended documents must be provided: one with the amended version number or date clearly stated in the footer and another clearly highlighting the amended text.

Reporting to HREC

The committee require that you provide notification of the:

1. Project commencement date,
2. Any local AE/SAE within 24 hours,
3. Annual progress reports,
4. Notification of conclusion of participant involvement,
5. Notification of study completion, and
6. Provide a copy of the final report and any publications arising from the project.

Please note, **an annual progress report is due October 2013** – continuing approval is subject to the timely submission of a satisfactory progress report. The progress report template can be downloaded from our webpage:
http://www.bhs.org.au/sites/default/files/finder/doc/ethics-committee/BHS_SJOG_HREC_Research_Progress_Report_form.doc

Publications

The Ballarat Health Services and St John of God Hospital Ballarat Human Research Ethics Committee, encourages the publication of results of the research in a discipline appropriate manner. Publications should provide evidence of the contribution that participants, researchers, funding sources and the organisations have made.

The HREC wishes you and your colleagues every success in your research.

Yours sincerely

Dr Susan Joy Shea
Secretary, Ballarat Health Services & St John of God Hospital Ballarat HREC

Ballarat Health Services
and St John of God Hospital Ballara
Human Research Ethics Committee
Phone: 03 53204787
Email: researchethics@bhs.org.au

Dr Marian de Souza
Australian Catholic University
Religious Education
1200 Mair Street
Ballarat VIC 3350

30st October 2012

Dear Dr de Souza

Study title: An investigation of the perceptions and understandings of spirituality

HREC Reference Number: HREC/12/ BHSSJOG/98
SSA Reference Number: SSA/12/BHSSJOG/99

Thank you for submitting a Site Specific Assessment Form for authorisation of the above project at

Ballarat Hospice Care **SSA/12/BHSSJOG/99**

I am pleased to inform you that authorisation has been granted for this project to be conducted at the above listed sites. Authorisation is given in accordance with the research conforming to the *National Health and Medical Research Council Act 1992* and the *National Statement on Ethical Conduct in Human Research (2007).*

Authorisation: The authorisation is valid from 30th October 2012.

Authorised documents

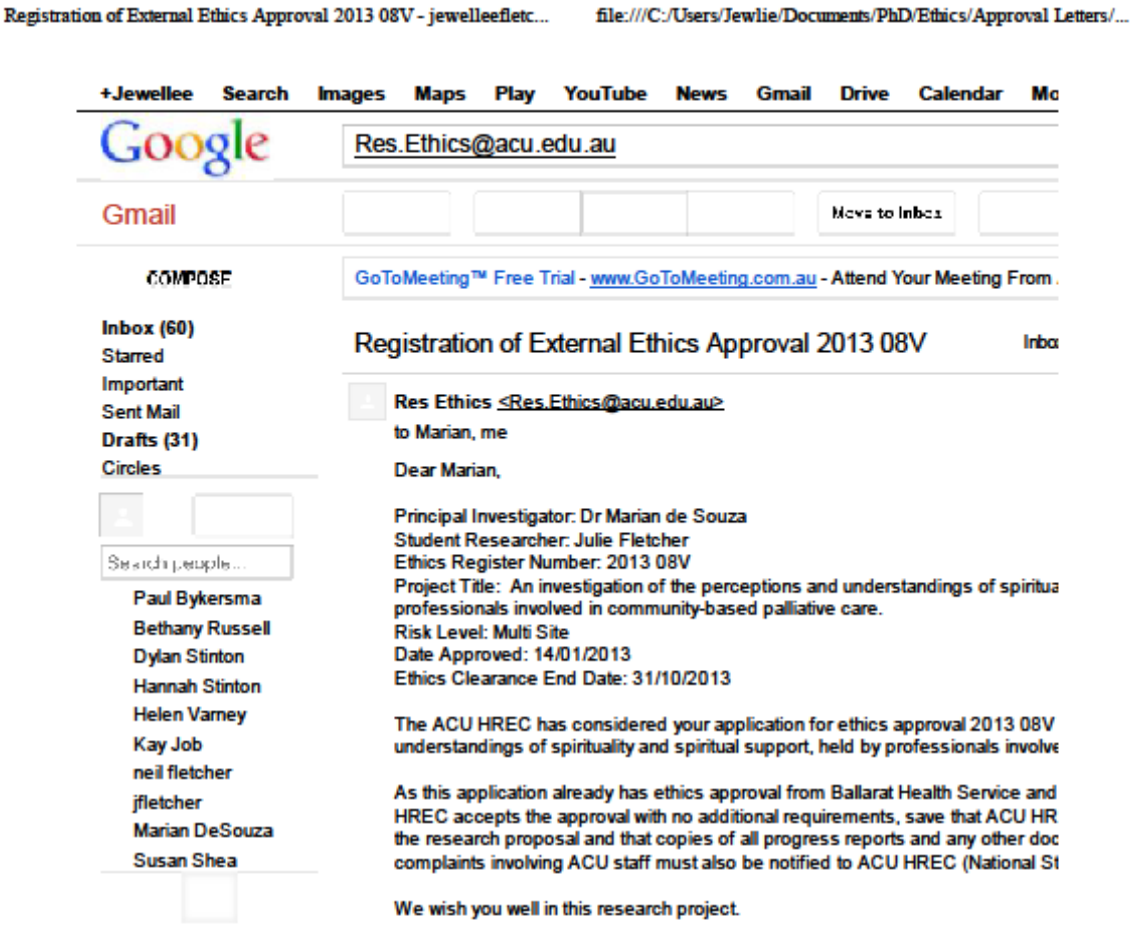
Document
Signed SSA Applications

Ballarat Health Services wishes you and your colleagues every success in your research.

Yours sincerely

Dr Susan Joy Shea
Secretary, Ballarat Health Services & St John of God Hospital Ballarat HREC
Ballarat Health Services Research Governance Officer

Appendix B-2 Ethics Approval Australian Catholic University HREC



Registration of External Ethics Approval 2013 08V - jewelleefletc... file:///C:/Users/Jewlie/Documents/PhD/Ethics/Approval Letters/...

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Kay Job
neil fletcher
jfletcher
Marian DeSouza
Susan Shea

Registration of External Ethics Approval 2013 08V Inbo

Res Ethics <Res.Ethics@acu.edu.au>
to Marian, me

Dear Marian,

Principal Investigator: Dr Marian de Souza
Student Researcher: Julie Fletcher
Ethics Register Number: 2013 08V
Project Title: An investigation of the perceptions and understandings of spiritua
professionals involved in community-based palliative care.
Risk Level: Multi Site
Date Approved: 14/01/2013
Ethics Clearance End Date: 31/10/2013

The ACU HREC has considered your application for ethics approval 2013 08V
understandings of spirituality and spiritual support, held by professionals involve

As this application already has ethics approval from Ballarat Health Service and
HREC accepts the approval with no additional requirements, save that ACU HR
the research proposal and that copies of all progress reports and any other doc
complaints involving ACU staff must also be notified to ACU HREC (National St

We wish you well in this research project.

1 of 1 15/11/2014 8:22 PM

Appendix B-3

Ethics Amendment Approval: Ballarat Health Services and St John of God Hospital Ballarat Human Research Ethics Committee, and Australian Catholic University Human Research Ethics Committee.

Ballarat Health Services
and St John of God Hospital Ballarat
Human Research Ethics Committee
Phone: 03 53204787
Email: researchethics@bhs.org.au

Dr Marian de Souza
Australian Catholic University
Religious Education
1200 Mair Street
Ballarat VIC 3350

11th September 2013

Dear Dr de Souza

Study title: An investigation of the perceptions and understandings of spirituality and spiritual support, held by professionals involved in community-based palliative care.

HREC Reference Number:	HREC/12/BHSSJOG/98
Amendment number:	HREC/12/BHSSJOG/98/AM01
Amendment date:	21st August 2013
Amendment details:	Spiritual Assessment Tool, Updated PICF Version 4

The Ballarat Health Services and St John of God Hospital Ballarat HREC Chair reviewed the above Amendment on 11th September 2013.

Decision

The HREC Chair approved the above Amendment on the basis of the information provided.

Approval

The approval is valid from 11th September 2013.

Approval is given in accordance with the research conforming to the ***National Health and Medical Research Council Act 1992*** and the ***National Statement on Ethical Conduct in Human Research (2007)***.

Approved documents

Documents reviewed and approved were:

Document	Version	Date
Covering Letter		19 August 2013
Notification of amendment		21 August 2013
Description of Connecto, spiritual assessment tool		
Response to Request for Further Information		11 September 2013
Patient/Participant Information Sheet and Consent Form	Version 4	11 September 2013

The following conditions of approval apply:

Protocol Amendments

Any changes to the protocol must be submitted to the HREC for approval and should be accompanied by a summary outlining the reasons for the change together with an indication of any ethical implications. Two copies of amended documents must be provided: one with the amended version number or date clearly stated in the footer and another clearly highlighting the amended text.

Reporting to HREC

The committee require that you provide notification of the:

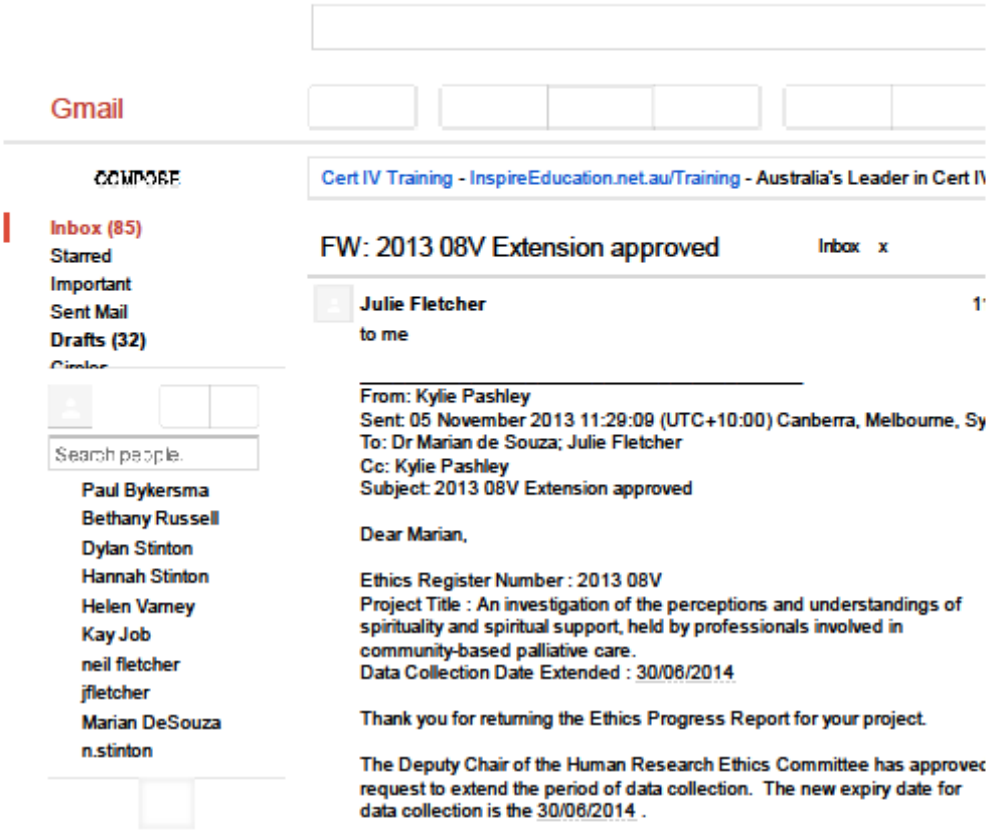
1. Project commencement date,
2. Any local AE/SAE within 24 hours,
3. Annual progress reports,
4. Notification of conclusion of participant involvement,
5. Notification of study completion, and
6. Provide a copy of the final report and any publications arising from the project.

Please quote the reference number from the title of this letter in all correspondence.

The HREC wishes you and your colleagues every success in your research.

Yours sincerely

Dr Susan Joy Shea
Secretary
Ballarat Health Services & St John of God Hospital Ballarat HREC



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jfletcher
Marian DeSouza
n.stinton

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FW: 2013 08V Extension approved Inbox x

Julie Fletcher 1

to me

From: Kylie Pashley
Sent: 05 November 2013 11:29:09 (UTC+10:00) Canberra, Melbourne, Sy
To: Dr Marian de Souza; Julie Fletcher
Cc: Kylie Pashley
Subject: 2013 08V Extension approved

Dear Marian,

Ethics Register Number : 2013 08V
Project Title : An investigation of the perceptions and understandings of spirituality and spiritual support, held by professionals involved in community-based palliative care.
Data Collection Date Extended : 30/06/2014

Thank you for returning the Ethics Progress Report for your project.

The Deputy Chair of the Human Research Ethics Committee has approvec request to extend the period of data collection. The new expiry date for data collection is the 30/06/2014 .

Appendix C Staff Address Disclosure Request

From: Julie Merran
Sent: Wednesday, 6 February 2013 11:56 AM
To: 'eo@ballarathospicecare.org.au'
Subject: Staff Address Disclosure

To: All

Sent: Wednesday, 6 February 2013 4:35PM

Subject: Staff Address Disclosure

Dear colleague,

My PhD research; *An investigation of the perceptions and understandings of spirituality and spiritual support, held by the multidisciplinary professionals involved in community-based palliative care* has been approved by the Ballarat Health Services and St John of God Hospital Ballarat Human Research Ethics Committee, and the Australian Catholic University.

The next requirement is to receive informed consent from all staff happy to be involved with the study. To ensure anonymity I would like to send the *Participation Information and Consent Form* to your home address, which BHCI will supply. You need only reply to this email if you wish hospice to not disclose your address.

Plan: 30/10/12 Ethics Approval Received

06/02/13 Email sent to staff re address disclosure

12/02/13 Post out Participation Information and Consent Form (PICF)

19/02/13 Return of PICF at BHCI staff day

Thanks in anticipation,

Julie Merran
Spiritual Support Worker
jmerran@ballarathospicecare.org.au

Appendix D Participant Information and Consent Form

Participant Information and Consent Form (PICF)

Full Project Title: An investigation of the perceptions and understandings of spirituality, and spiritual support, held by professionals involved in community-based palliative care.

Principal Researcher/Student Supervisor: Marian de Souza

Student: Julie Fletcher

1. Introduction

You are invited to take part in this research project. This letter has been sent to your mailing address, after your approaval was given to the Executive Officer for this to be disclosed. All staff and board members of Ballarat Hospice Care Inc. (BHCI) have been invited to participate. The research project aims to gain an understanding of spirituality within community-based palliative care.

This Participant Information and Consent Form tells you about the research project. It explains what is involved to help you decide if you want to take part.

Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Before deciding whether or not to take part, you might want to talk about it with a relative, friend or your local health worker.

Participation in this research is voluntary. If you don't wish to take part, you don't have to. If you decide you want to take part in the research project, you may be asked to sign the consent section. By signing it you are telling us that you:

- Understand what you have read;
- Consent to take part in the research project;
- Consent to be involved in the procedures described;
- Consent to the use of your personal and health information as described.

You will be given a copy of this Participant Information and Consent Form to keep.

2. What is the purpose of this research project?

The aim of this project is to collect stories and ideas of practice and perception at BHCI that encourage connection and spirituality, with the aim of creating useful common language around the understandings and provision of spiritual support within the organization. "Spirituality" has often been seen as meaning the same as "religion" but today there is more of a focus on the flourishing of the individual, and their connection with self, other, the world, and sometimes mystery. There is very little research into community-based palliative care, and even less into how spirituality operates within this context. BHCI gives me the opportunity to include all the professional disciplines and management, with that community focus. Invitations have been sent to all staff to be involved individually or in one of a few groups: staff focus groups and the Board of Management (along with the Executive Officer), in total less that 30 people. This is a non-funded research project where the results will be used by Julie Fletcher to obtain a PhD.

3. What does participation in this research project involve?

The research will involve a description of "Spirituality defined as Connection" followed by discussion of how this occurs within ordinary practice at BHCI. Stories of connection will be collected. This will involve a commitment of approximately 60 minutes and will be facilitated at the BHCI premises. The research project will be audio-taped, which will be destroyed after transcription has occurred. Results will be presented to BHCI, and available for all staff and board members. You will not be paid for your participation in this research.

4. What are the possible benefits?

Involvement in this research project will contribute to Spirituality being seen in broader and comprehensive ways, and will lead to more effective spiritual support for community-based patients.

5. What are the possible risk?

There is potential inconvenience for participants who would not normally be present at BHCI on the particular day. Confidentiality and anonymity will be kept by no identifiable label being attached to any of the transcripts. If you become upset or distressed as a result of your participation in the research, the researcher is able to arrange for counselling or other appropriate support. Any counselling or support will be provided by staff who are not members of the research team.

6. Do I have to take part in this research project?

Participating in any research project is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the project at a later stage. If you do consent to participate, you may only withdraw prior to the focus group beginning. Your decision whether to take part or not, or to take part and then withdraw, will not affect your relationship with the researchers or BHCI.

7. How will I be informed of the final results of this research project?

Results of this research project will be presented to BHCI, and available to all staff members. The results will also be the foundation of conference presentations and academic papers. Publishing of the results will occur by 30th June, 2014.

8. What will happen to information about me?

Transcriptions will not be labelled by name or profession, thereby making any statement non-identifiable. Audio-tapes will be destroyed, after transcription. Transcripts will be stored in a locked box at the home of the researcher, and destroyed after seven years. Stories and examples of spiritual support in work practice may be presented as a part of the research presentation, and may be used within further research. In this regard you are asked for extended consent for future related research.

9. Can I access information kept about me?

In accordance with relevant Australian and/or Victorian privacy and other relevant laws, you have the right to access the information collected and stored by the researchers about you. Please contact one of the researchers named at the end of this document if you would like to access your information.

In addition, in accordance with regulatory guidelines, the information collected in this research project will be kept for at least seven years. You must be aware that the information collected about you may at some point not be able to be identified once the identifying information has been removed when audio-tapes are fully transcribed. Access to information about you after this point will not be possible.

10. Is this research project approved?

The ethical aspects of this research project have been approved by the Human Research Ethics Committee of Ballarat Health Services and Australian Catholic University, and by the Board of Management at BHCI. This project will be carried out according to the *National Statement on Ethical Conduct in Human Research (2007)* produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies.

11. Consent

I have read, or have had this document read to me in a language that I understand, and I understand the purposes, procedures and risks of this research project as described within it.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project, as described.

I understand that I will be given a signed copy of this document to keep.

Participant's name (printed) …….

Signature Date

Declaration by researcher*: I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Researcher's name (printed) …….

Signature Date

Note: All parties signing the consent section must date their own signature.

1. Who can I contact?

The person you may need to contact will depend on the nature of your query. Therefore, please note the following:

For further information or appointments:

If you want any further information concerning this project or if you have any problems which may be related to your involvement in the project (for example, feelings of distress), you can contact the researcher, Julie Fletcher on 0419 465 963, or any of the following people:

Name: Dr Marian de Souza

Role: Principal Researcher/Supervisor

Telephone: 03 5336 5316

For complaints:

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact:

Name: Dr Susan Joy Shea

Position: Secretary, Ballarat Health Services, Research and Ethics

Address: PO Box 577, Drummond Street, Ballarat 3353 Phone: 03 5320 4787

Or

Position: Chair, HREC, C/- Research Services, Australian Catholic University,

Address: Melbourne Campus, Locked Bag 4115, Fitzroy 3065

Appendix E Question Lists

Appendix E-1 Proposed Questions.

Can you tell me something meaningful/important that happened to you, or that you have done, this week?

Have you had any training or teaching about spiritual care?

Do you feel confident to assess or assist patients and carers when they are in spiritual pain?

What might spiritual pain look like?

What does spiritual and spirituality mean to you?

What sort of words could be included in an explanation of spirituality?

Do you think spiritual care is important within community-based palliative care?

What might it look like in action?

What makes community-based palliative care unique?

What does spiritual support look like, sound like, feel like for those involved?

What sort of things help in spiritual support? What sorts of things make this difficult?

Can you tell me of a time when you have supported the spirituality of a patient, carer or workmate?

Have you helped a workmate debrief about work or personal issues and come to some understanding or meaning about the situation?

Can you see some spiritual aspects within this story?

Appendix E-2 Topic Guide and Questioning Route

Focus Group Outline:

Icebreaker

Confidence in supporting spiritual care within multi-disciplines at BHCI – 15 minutes

Have you had any training or teaching about spiritual care?

Do you feel confident to assess or assist patients and carers when they are in spiritual pain?

What might spiritual pain look like?

Unpacking and defining spirituality – 15 minutes

What does spiritual and spirituality mean to you?

What sort of words could be included in an explanation of spirituality?

Spirituality in community-based palliative care - 10 minutes

Do you think spiritual care is important within community-based palliative care?

What might it look like in action?

What makes community-based palliative care unique?

Stories of spiritual support – 20 minutes

Can you tell me the story of something spiritual that happened with a patient, a carer or a workmate?

What does spiritual support look like, sound like, feel like for those involved?

Ending questions – 10 minutes

Have other thoughts, definitions or stories been prompted for you?

Have we missed anything?

Probes: Can you tell me more?

Could you explain what you think in a deeper way?

Can you flesh that out with a bit more detail?

What does ‘not much’ mean? (Creswell, 2008)(Creswell, 2008)(Creswell, 2008)(Creswell, 2008)(Creswell, 2008)(Creswell, 2008)(Creswell, 2008)

Prompts: Have you supported a patient with family difficulties?

Have you ever had a patient who was angry with themself?

Have you ever performed a spiritual/religious ritual with a patient?

What sort of things help you this?

What sorts of things make this difficult?

Have you helped a workmate debrief about work or personal issues and come to some understanding or meaning about the situation?

Individual Interview Outline:

Icebreaker

Confidence in supporting spiritual care within personal profession at BHCI – 5 minutes

Have you had any training or teaching about spiritual care?
Do you feel confident to assess or assist patients and carers when they are in spiritual pain?
What sort of things help you this? What sorts of things make this difficult?

Unpacking and defining spirituality – 5 minutes

Can you tell me something meaningful/important that happened to you, or that you have done, this week?
What does spiritual and spirituality mean to you?
What sort of words could be included in an explanation of spirituality?

Presentation of making meaning out of "connection" stimulus – 5 minutes

Do you find "connection" helps in attempting to define and explain spirituality?

Spirituality in community-based palliative care - 10 minutes

Sticking with the "connection" definition of spirituality, why do you think spiritual care is important within community-based palliative care?
What might it look like in action?

Stories of spiritual support – 20 minutes

If we go back to the definition of spirituality as connection, and its four aspects, can you tell me when you have supported the spirituality of a patient, carer or workmate?
Can you see some spiritual aspects within this story?
Do they fit into our definition of 'making meaning through'?

Ending questions – 10 minutes

With all the different ideas we've had about spiritual care, have other thoughts, definitions or stories been prompted for you?
Have we missed anything?

Probes: Can you tell me more?
Could you explain what you think in a deeper way?
Can you flesh that out with a bit more detail?
What does 'not much' mean?

Prompts: Have you supported a patient with family difficulties?
Have you ever had a patient who was angry with themself?
Have you ever performed a spiritual/religious ritual with a patient?
Have you helped a workmate debrief about work or personal issues?

Appendix E-3 List of Questions Used

Questions – Focus Group One and Individual Interview One

- How would you describe spirituality and spiritual care?
- What do you see as the roles of spiritual care at Hospice?
- How do you see spirituality operating at Hospice?
- Do you have a vision for spiritual care?

Questions – Focus Group Two

- Have you ever had any training or teaching in spiritual care?
- What does the word spiritual or the concept of spirituality mean?
- What are some of the words that you would use to describe what you think spirituality means or feels like to you?
- What do you think is unique about community-based palliative care?

Questions – Focus Group Three

- Have you ever had any training or teaching in spiritual care?
- What does the word spiritual or the concept of spirituality mean?
- What are some of the words that you would use to describe what you think spirituality means or feels like to you?
- What do you think is unique about community-based palliative care?
- Can you tell me a story of something spiritual that happened with a patient, a carer or a workmate?

Question added to Individual Interview Two

- When you're with a patient what do you see that you would come away thinking that was spiritual distress? What sort of things might you label as spiritual distress? Spiritual need?

Appendix F Competency Framework for Spiritual Care

- **Level One.** Needed by all. Provided by all. Person centred care
- Understand all have spiritual needs
- Distinguish between spiritual and religious needs
- Unobtrusive screening, alert to issues without direct questioning
- Referral for spiritual support
- Basic skills: active listening, responding, awareness, support, encouragement, respect, dignity.
- **Level Two.** Needed by many. Provided by many. Sensitive to spiritual domain.
- Awareness of spiritual and religious needs, identification and response
- Basic screening may include questions about spiritual concerns
- Skills: recognition of spiritual and/or religious needs, responding, note writing and referral, importance of verbal/non verbal communication, awareness of own spirituality.
- **Level Three.** Needed by some. Provided by some. Care for spiritual/religious issues.
- Training to assess spiritual/religious need, existential questions and issues of personal identity
- Development of care plans responding to spiritual/religious/ethical issues in conversation with patient
- Pace directed by the patient
- Transparent silence
- Advanced Skills: specific training to spiritual/religious need, constructing and implementing care plans, empathy, hear spiritual dynamics in conversation, spiritual interventions - ritual, traditional text, prayer, meditation, confession, contemplation, story construction.
- **Level Four.** Needed by a few. Provided by a few. Complex spiritual/religious needs.
- Primarily responsible for spiritual and religious care of patients/carers/families
- Complex spiritual and religious needs
- Journeying with others, focussing on their needs, co-constructing meaning
- Liaise with external sources
- Resource for support/training/education of healthcare professionals (level 1-3)
- Reconcile personal spirituality with varied needs/beliefs of others.
- Higher Advanced Skills: accept and respond to complex referrals, companionship with deep
- listening, use in-depth spiritual history to identify assessment and treatment, create spiritual profile from spiritual history and patient needs/hopes/resources, conversation with patient regarding design of spiritual support plan

Marie Curie Cancer Care, (2003). *Spiritual and Religious Care Competencies for Specialist Palliative Care.* Accessed from www.mariecurie.org.uk, 15.09.13.

Rumbold, B. & Holmes, C. (2011) *Service practice in the 'level of need/competency' framework.* Consultation paper concerning spiritual care provision in Victorian palliative care services. Psychosocial-spiritual special interest group: Palliative Care Victoria.

Appendix G Textual Conversation Transcripts in Hermeneutic Phenomenological Style

Focus Group One

From Business Self to Intrapersonal Enrichment

The room bustled with efficiency and anticipation as the focus group began. While the introduction was spoken, wine, cheese, and biscuits were passed around, signalling the move into a different, unknown space. As the interview began with the question, "How do you describe spirituality?" the group relaxed back into their chairs to study their glasses and enjoy the silence. That is, all except one who leant forward intensely and began:

"Well it's not really to do with religion."

The silence again descended as people mused. As more words rolled out around the table and opinion gained momentum:

"meaning to living and dying";

"here and now";

"untouchable, unknowable, human";

"a vehicle to get rid of the skeletons in the closet";

"a cleansing of the soul";

"I see a lot of patients struggling with it...I've struggled with it, and my colleagues have struggled with it because medically you're trained to deal with this side of the fence; the biomedical side. But spiritual pain exacerbates physical pain."

Multiple voices and thoughts became stronger until another stated:

"We need to be able to find the words to articulate what it is so it doesn't come across as a passive thing 'cos it's actually quite active."

Through communal sharing the level of disclosure deepened to the vulnerable and honest, which was met by a respectful listening response. Stories of connectedness emerged as connection was occurring.

"I've had a couple of recent experiences where family members were apologising to me for not being more spiritual through their lives. Deep regret..."

A moment of silence acknowledged the spiritual pain of regret. While the conversation proceeded one participant held back, attentive, but silent. After listening and observing throughout the process, he cleared his throat and launched into a dialogue about the confronting experience of death and life meaning, and continued:

"I find it difficult to separate the concept of spirituality from religion. I see it more in the context of what we personally believe our life is all about."

Another joined in:

"Yes, meaning, that meaning of why we're actually here. Spiritual care is supporting. You've got someone who's not judging, but just supporting and helping you through to that stage that you need to be at peace...walking, side by side with you."

A consensus built:

"Spiritual care is not about problem solving, but about space and acceptance. And sometimes it's just a matter of listening, you may not agree, but just listen."

"I see spiritual care as pivotal in palliative care; we need to give people an opportunity to sort out their inner turmoil. Training new people coming into the organization is really important so they can understand and provide holistic care."

Met with nods and "mmms" of agreement all around the table, the researcher leant back in the chair with a sense of satisfaction. The words had flowed freely, bouncing off each other and swirling into accord. Closure required moving from the set interview questions to opening up the floor for participant agenda and the thank yous: "Is there anything else burning about spirituality that somebody would like to share?" Silence accompanied with

shuffling in the seat; the focus group momentum had shifted and preparation for leaving had begun. Breaking across these practises a hesitant voice spoke out:

> *"As a participant, tonight's been really insightful. I've really appreciated the honesty, the way people have shared. So it's been an enriching experience for me personally....it's been great for us as an organization too, and as a board to group share."*

The shuffling stopped as agreement noises were made, and a silence of harmony rose. This was the moment the group, as a whole, crested a new summit of connection and encounter, breathed in the view and then continued to pack. With the leaving, what had begun as an intellectual exercise now revealed a spirit of unity and a deeper purpose. Without knowing the words, a spiritual encounter had occurred.

Focus Group Two

A Lexicon of Spiritual Care

Beginning with the ice-breaker of previous training in spirituality and spiritual care fundamental Lived Time see-sawed through conversation as past and present toyed with the future. Have you ever had any training or teaching in spiritual care? "No" hesitantly rattled around the room as if for the first time spiritual care was seen requiring any training at all, and one previously missed out on. The accompanying silence was broken by one lone voice:

> *"In my course there would have been a very small component of spiritual care training; but minimal I'd say."*

Mumbles turned to a discussion of what may be identified as skills.

"Probably in my past employment, I've worked in welfare organizations before, so I probably had an understanding of helping people."

Moving on in an attempt to understand the perceived lack of spiritual training or societal discussion about spirituality the bald statement was made:

"People never think about spirituality."

"Yeah, people go through life, and as you get older you're looking more for what's inside you. But until you've got end of life, or a palliative diagnosis, it's when all that comes to the front."

A u-turn returned us to the beginning and the question of training:

"If you've had no training in it, and you've never had spirituality in your whole life, it's very hard to sort of bring it into conversation. I refer patients to spiritual care who say they have got religious beliefs. And I put it to them that they're worried about end of life and where they're going. You do need education on it – which we haven't."

For a time this put spirituality in the realm of religion, but this was a place it occupied shortly. When the group were asked to describe spirituality, the perceptions became broader and varied, and roamed around the room.

"I usually say feelings...I start with 'it's not religious, and its non-denominational..."

"Nobody else sees...It's about you and you alone."

"Intuition, or I just knew."

"Inner, inside, what you're really like, the core of the person."

"Yeah, you inside, right inside, you and you alone, which religion would come in as well."

"The words of a song can make you cry, so it's about the inside."

"The essence of me. The real you. My fears about me, which mightn't be real, mightn't be what anyone sees."

"Religion could be, but doesn't need to be a part of it. Each person makes their own decision about that don't they."

The group, having warmed to the subject, were developing their own lexicon and learning from it.

"I probably put a lot of it down to religion. A lot of patients I refer have got religious beliefs. I reckon they're afraid of dying and all that journey and what might come after. And that's, so when I think spiritual involvement straight away I go there. But I need to be brought back sometimes to the feelings they're having at the time. More so where they're going, and how's dying and all that sort of stuff. So I see spiritual with the end of life and how they're feeling about going towards God or whoever. But I'm hearing that I've got to keep bringing myself back to say we can be spiritual and have a lot of different thoughts and feelings that we need help on. And not necessarily have any religious beliefs.

Journeying back to a personal understanding of spirituality and spiritual pain:

"It's your gut too isn't it?"

"Yeah, it's my gut I'm going on, and your feelings."

"We talk often about the right time to ask someone "Where do you want to die?" or "Are you frightened of death?" There's ways to ask that question, and it's your gut when you say, "I didn't ask about death because it wasn't the right time." To me that's spirituality. It's that bit in you that actually knows that this is not the time, or this is the time."

The group moved further into the shadows of spiritual pain.

"If I was to see a patient and they weren't sitting comfortably with themselves I would see that as spiritual distress."

The concept of spiritual praxis entered the conversation as people clambered to identify its presence in others.

"People at the front desk are the gate keepers I think. You guys are the ones who determine how people see us." "Yes sometimes they're upset. You try to give them that calm feeling."

"Not being a nurse, sometimes they (the patients) unload to us because we're seen differently, they don't know us like they know the nurses who are there regularly, so it's someone to talk to that doesn't know anything about them. But they'll often unload at the front desk."

So you get the story because they haven't had opportunity to tell you the story before?

"That's right, to someone who doesn't know anything about them."

Another identification of spiritual practice is teased out further in the practice of peers indicating a longing for education:

"You're absolutely wrong there because when you put in a referral for the support team its very rarely practical stuff. It's, "this person was really upset, he's just got so many problems and he's so upset."

"Is that me? I've got the practical things that I refer to..."

"Where you operate out of is what's right and what feels, and that's why I'm saying you're wrong. You're trying to say, "I don't go there, I don't do that spiritual care thing," but you do it all the time and you do it beautifully. You just don't see it."

"No I don't. That's where the training needs to come in. You see that as spiritual from me?"

"Absolutely. But you know we're saying you do do spiritual care and you don't even know that you do, and you do it brilliantly."

The conversation petered out: cake plates were topped up with seconds and silence hung impatiently waiting to be chased away with the next question. What is unique about community-based palliative care? Immediately ideas filled the space.

"We go into their home, we're in their surroundings, in their environment, so we follow them and what they want."

"Who's in control when you go into the home? They are."

"Its: we're going to their space. We are all incredibly lucky that we are allowed to take the time."

"We've got the time to deal with whatever comes up, and supports to refer back to, to find the right people to look after these people."

So if community-based care is about patient control and patient space, are you saying it gives you time as well?

"You come out of there and it's been a complicated visit, but you've spent the time because they've wanted to share something. It's just totally their time."

"Yeah we've got time. We go to see one patient and we might think we'll be in and out and the whole thing will take maybe 40 minutes and when you go in there's some type of crisis and sorting it out may take 2 hours. Or they have to talk, it's something that is so important to them, it's their time to tell you what they need to."

You have flexibility?

"What hospice does is very much flexible and responsive to the situation, not task orientated. It's really person-centred."

"Yeah and the recognition that's its more than treating the disease, we'll look after the symptoms and care, and keep you as comfortable as possible."

"It's actually more individually tailored care too and holistic. We're not task oriented, and we've got the time to deal with whatever comes up and supports to refer back to. So community care has sort of a much more personalised aspect."

The relational nature within the disciplines of the community-based team was underscored:

"You put your notes in that say about your concerns for an individual situation and I don't go out to see anyone without reading those notes. Or we sit in the office and talk about it before hand."

The conversation stalled, and then hesitantly holism rouses:

"Holistic care, which includes spiritual care, is not just looking at one medical problem, but we look at how that medical problem impacts on the person's family and those around them. We also observe how those carers are relating to that person, or how the way they care for that person affects their medical condition. So it's a two way connection thing."

"Yeah, holism is looking at the broader picture of the person; body, mind and soul, and the interplay backwards and forwards between carers and patients."

As the conversation came to a halt and eyes studied the carpet Corporeality moved into the exercise of concealment. All were thanked for their participation and the interview was brought to a close with a sigh of relief flowing through the body language. With the ending of the focus group bodies repositioned, the atmosphere relaxed and further conversation flowed. The connectedness experienced within the group was something the participants actively continued and were slow to move away from. The participants straggled out again and the conversation continued between the observer and the researcher. It was discerned that

community based palliative care creates a multi-disciplinary community for the patient. A community coming in when the person can't go out.

Focus Group Three

Spirituality and Community-Based Care

Training. *Last minute cuppas were gathered as cake and cream were happily passed around and consumed. The ice-breaker, designed to not stray far from a "Yes or No" question broke all the ice and a rigorous discussion ensued.*

"When you talk of previous training, do you mean teaching, as in church, religion, that sort of teaching. The teaching that comes with a Catholic upbringing."

Immediately the researcher moved from passive to an active participant.

"No I hadn't I'd been thinking of that, I've been thinking about professional wise. But that's a really interesting point. Would you like to differentiate between those two?

All agreed with nods of the head, and the conversation continued.

"I figured that you're probably talking from a professional perspective but perhaps there is ground also, in being brought up with spirituality and whether that surrounds religion. I just want to clarify that I suppose. If it includes how we're brought up and what we're taught, because that is still teaching, whether we're children or adults studying it. Um I'd say that I have had some teaching with regards to spirituality through religion."

A position quickly concurred with, leading the researcher to ask: "So you're say we actually don't come into the job with blank slates as far as spirituality is concerned?"

"Exactly."

But a lonely voice disagreed.

"To me it was a blank slate because I didn't have any religious upbringing at all. Its not in the culture of my family. I picked up some understanding on-the-job through discussion with the spiritual care worker."

"So we've all brought different ideas and language, or lack of language, into our positions in the organization."

A moment was taken to reflect on the need for training and education about spirituality, then quickly the conversation turned back to religion, and whether it was affiliated with spirituality. Consensus again came quickly as religion was identified as an activity for the "child with family," but often left behind as adulthood was embraced.

"I think that as a child I went to church because I had to go to church, because they told me I had to go to church. So the way I feel about spirituality now is really not connected to religion."

Descriptions of spirituality. *With the sense that the topic of religion was resolved to satisfaction we turned to describing spirituality. Again, that sense of preparedness came to the fore and considered answers built on each other as everyone desired to contribute.*

"Having an acceptance of things, or letting life come to you. Those things that we can't explain...accepting of experiences like that."

"Something that makes the person the person. It's that inner thing that when you see somebody dead you say, "Ah they've gone." The inner whatever it is, the thing that makes us us."

"An acceptance of that which is not only within us, but that without us that doesn't necessarily have an explanation."

"It is tricky."

"A nebulous concept."

"It's kind of smoke, and you're trying to box the smoke, trying to round up the smoke."

Do you think spirituality is innate, is actually THE person?

"O yeah. It's a combination. You take on the image of your transport, the body, and then there's the other part of the person...the spirit, a constant."

"I see it as innate within us, but to a very small degree, and I think it's our life experience, circumstances and our phases of life that explore it, grow it, change it, influence it. Then it ends up wherever it goes in different sizes and quantities throughout our life journey."

Building on the idea of spirituality evolving the researcher asked, "Do you think the size is impacted by the attention we pay it?"

"Yes, I think there are times in our lives that we need to look at that spiritual side of who we are, what's feeding us, and what's going to nurture us, through a phase in our life. And then there's another time when it's less significant in our life."

The two-way interaction was emphasized:

"Yes, and I would add influence to your list, because the size of spirituality is dictated to by all these things, but it also influences all these things."

When asked about the word 'essence' screwed up faces filled the room. "It seems like vanilla essence...2 drips of flavour...that doesn't sit with me at all... doesn't work for me I'm afraid."

The momentum ran out of steam as a satisfied silence bubbled around the room. After a pause the question of definition was reapproached. The new direction received lots of attention.

"You could look at it from a scientific, or purely physics point of view. Part of us is made up of all these atoms and things, but there's also part of us that is made up of energy. It's a fact; you can't create or destroy energy you can only change."

"You can only change its form."

"Yes that's right, we use energy, we generate energy, we are energy."

"Yep, and I'm amazed at that energy. An awareness of what is in myself drives or encourages or influences other assets. I don't know what drives my relationships, or what is it within me that makes me cope with what I cope with."

Silence again, and then a commentary by a participant:

"It's interesting too, we sit here and talk about spirituality and your take on spirituality involves a belief that life doesn't end with death and your take on spirituality believes that it does. Spirituality is no less spiritual because of what you believe happens after death."

Community-based spiritual care. *The conversation turned to identifying the uniqueness of community-based palliative care. The values that cover the organization - trust, respect, loyalty, skill, willingness, kindness, honesty - were intertwined through conversation as it bounced around the room. Often encapsulated by the word "nurture," the values were wreathed in day-to-day praxis. Here too the primacy of care for the whole family was evident.*

"How nurturing everybody is to the families, they treat the people like as if they're part of themselves, their own family kind of thing."

"I think that's the key you've just hit. It's the family thing. It's not about a patient with a disease, but the family unit because the patient doesn't just get the illness, the family gets the illness."

"And it's nurturing without getting involved, without taking it on or telling them... listening I suppose."

The thought of presence and nurture is expanded with gusto, and stories.

"I notice it when I go out with someone that you go into the house and there's this kind of "we don't know what to do," by the time we leave there's a calm. It's kind of like all is suddenly right with the world cos we've devised a way of dealing with it and you're not alone. And I think that alone is hard because we need one another..."

"In nature things are often drawn to stillness. If you're amongst horses that are very upset, if you stand very still they will gravitate towards you. There is a desire for stillness and calm, nature does it naturally, but I think our society has made everything so frenetic, so maybe when you're talking about what the staff do it's about that begetting calm."

As the conversation slowed the question was rephrased and summarised: "Their turf, their rules?"

"The difference in community is because you immediately come onto their turf, in their tower of strength. Whether that be out in the shed, or out in the horse paddock, or out in the garden, or even clothes line. They're the places where he or she, or the family unit, gains the greatest strength. I think you lose a lot of that when you move into an inpatient setting."

"I agree. I think that's a beautiful example of one of the things that separates community palliative care is indeed that meeting people on their own ground."

"Yep, where they get to set some of the rules...or all of the rules."

"I think, we might go in with a goal, but it's based on the patients idea of that goal of care. Our 'to do' list is really guided at the patients progress rate, set by the person

and - if we don't check it all off or we check nothing off, or we check it all off it's not relevant, its how we leave that person, state of mind, how we leave that family, that's the big check off."

A break in the pace led to a repositioning of bodies, and second servings of cake, before the conversation gained momentum again and moved into the idea of death as a taboo within the community.

"For me it's what we're dealing with. Because particularly in a western society it's become verboten: dying is something you do behind closed doors. For me I see the differentiation in fact is that we're actually in there talking about it and facilitating it happening in the way that families and patients want it to happen. That's obviously very unique to patient care."

Spiritual distress was another topic that with little prompting flowed into animated conversation.

"Spiritual pain is an uneasiness; a not wanting to be where you are."

"In that point in time you want to be someplace else or be doing something else: you don't want to be where you are."

"It's kind of "Oh well when this is fixed it will all be OK," and I think that a lot of spiritual dis-ease comes from that."

"Yep, I think that's what it is. When they're not at ease with themself."

Vigorous nods and murmurs of agreement goad the conversation further.

"I think that it's a spiralling out of control. That lack of control where you can't get hold of what you need to get hold of in life, to seek out answers, to inspire healing. Just everything seems out of their grasp. An impression of disconnection."

"I agree with absolutely all of this and I think for people that are perhaps dying that spiritual pain manifests in that restlessness that comes often at the end of life and I remember thinking that about family as I watched them dying. They went through this phase of restlessness where they couldn't articulate what it was that they needed. That limbo: no-mans land. And when I think of spiritual pain it was the very first thing that came to my mind."

"This restlessness... this unease...it's almost like you can't quite define it."

"Yeah, like an itch you can't scratch...But you can't actually say you're itchy?

"And I think the words spiritual pain makes me feel very very uneasy because to see someone in that pain without an ability to change it, and it's not about the physical, it's the ungraspable, about the smoke, about the nebulous, about not being able to handle it, to heal it."

The accompanying silence allowed for furtive watch checking. Conscious that the allotted time was up, and work beckoned, bodies became restless and expectant eyes empty of words became impatient to be released.

Individual Interview One

Sitting Loosely with Thoughts and Beliefs

The room was small with a quiet reflective atmosphere. The comfortable chairs placed for counselling appointments, gave a sense of confidentiality and secrets shared. Peta came in with an air of gentle humility; a person who created an atmosphere of confidence and privacy on entering a room purely through character. Equally, a person with many years of experience providing spiritual care to vulnerable people, and now a member of the BHCI

governance board. As the first question was asked Peta leaned slightly forward, and keeping eye contact, quietly turned on the tap of his wisdom and experience.

> *"Spirituality involves the whole person, whatever their life experiences, what they learn, what they encounter, what they discover about themselves, almost anything they are able to draw together in forming themselves as a whole person."*

There was a pause, a regathering:

> *"And spiritual care endeavours to support bringing it together in ways that are hopefully constructive, creative. Offering possibilities that show respect for who they are. Sometimes we can use art, we can use music, and we can use poetry to express something more of what is inside us."*

Peta leant back and the far-off stare indicated an engagement with the Self and the perusal of many personal stories filed neatly in memory. Refocusing took a move to the dying patient and their carer.

> *"Those who are in the terminal phases of life, the person who is facing the end of life, I think spiritual care is important for all those people to deal with what may be unfinished."*

The physical body becomes strange and unexplored territory for the person who is dying. Speaking of this final journey Peta tentatively continued:

> *"There comes a point of not to care any longer, they know they have to let go. They can't carry all they have cared for into death. Dying people have to be freed of all the encumbrances in order to die. If spiritual care doesn't support this people can die struggling with things they just can't do or just can't put down or deal with."*

Once again distant memories drew attention back to other places and other times and the conversation paused, "I seem to have lost track. Where was I?" After a prompt Peta went on to speak of the place of personal faith.

> *"There's a rich human conversation going on within myself in terms of my own faith and beliefs. It is the endeavour of dual respect: self respect can lead to an understanding that recognises the Other is a Self, and of respect for that Other. Within that I have to be very careful that I don't intrude or impose on their Self."*

Peta sat forward with a confidential air and began speaking of relation in spiritual care.

> *"The carer, the friends, the family, they all have immense worries about the death, and how they will deal with all of life after this person has died. The patient who is doing a journey all on their own has questions about dying and death, and what may be after."*

Another space led to another prompt of reiteration and Peta shifted in the chair, indicating a change of topic was occurring. Continuing on relational thoughts, but moving now to the practice of spiritual care.

> *"Spiritual care is about people feeling accepted for themselves, being listened to and received for themselves. And in that process being able to do what they need to do in terms of their connections, what they want to gather together, integrate, sift through, understand better, and bring all that together in a way that is meaningful for themselves. Patients seek to gather together what their life has been and affirm for themselves what they might need to affirm. We help them to make sense of it and to make meaning. People gather together the threads of their life in some way that they then can feel like "I can put that down" or "I can let that go"."*

Taking some time to consider, Peta looked down, watching toes tapping on the carpet.

"Gentle presence that lets people do their own work, spiritual care becomes important to help people find their way through the difficulties of parting. This includes all the people associated, the patient, their family, loved ones, and so on. There are big concerns rising as to what life will be like without this person; what they have shared together; what they've been to each other, and what they need to affirm. Dealing with the issues of parting from both the carer and the cared for."

Shifting attention to the organization Peta explains:

"All of the people involved in hospice care need to be sensitive to that and need to be prepared to do something where it's indicated to. Or at least have some understanding of how they might at least not get in the way. Spiritual care needs to be practiced by all. The medical analytic skills are particularly intellectual, rational skills, but listening to a person requires more than the head, it also requires the heart."

Talking of the multi-disciplines Peta states:

"Medical, nurse, whatever, they've got a duty of care that they honour, they're good nurses, good doctors, and they must practice by their knowledge, their training, their expertise, in very specific ways, but it can be difficult to hold that sense of the whole person at the same time. Professions can have diverse worldviews, but it is alright to talk about differences, because it is that fundamental respect for each other that brings a really holistic sense of the various disciplines working together each contributing from their discipline with that wider and deeper awareness and respect. So you're a professional doing your work, but keeping your own humanity alive and a sense of the other person's humanity and profession there as well. It's important for

professional carers that they respect their own spirituality, open to being cared for, and can offer care to each other."

Returning to the understanding of spiritual practice Peta continues,

"I must sit loosely with what I might think or believe, allow the other person to tell me who they are. I am suspending judgment, and listening to words and silence of the person. The emphasis is upon empathy, we tend to make great strength of standing with people, alongside, and sometimes there is a need to stand over against: not only for my own sake, but for the sake of the other. But I can't be everything you like and it's important that I continue to be me with integrity with my meeting with you, because I am more help to you if I have integrity."

Having warmed up and finding the words now flowing freely, Peta returned to characterizing an understanding of spirituality.

"I'd define spirit as that centre of meaning and purpose of each individual. The centre of integration, connection; in the sense of bringing together and creating a whole. It doesn't have to be about religion. The very religious person is not necessarily a very spiritual person. However the Christian faith, Judaism, Islam, Eastern Religions, Hinduism, Buddhism, all these major traditions have a deep well of human experience that has been greatly reflected upon, and there is much to be drawn from that well."

As though the words had power when spoken, Peta's eyes glazed over and reflection began. The seconds slipped away while another world entered the room and I sat peacefully wondering whether to wait, or prompt a return. Reengagement came of its own accord as Peta reorganised body in the chair and began a different topic.

"The multidisciplinary team need education around spiritual care, helping people to be sensitive to what's happening to them; to their spirit. Assisting them to draw whatever meaning is there for them from particular events and find how they integrate that into themselves. Staff are also growing people, and they're learning people, and every engagement is a learning one. In that sense there's a lot of mutuality. Listening is actually quite a complex skill, but education in listening is absolutely primary, and by that I mean being able to sit loosely with what I perceive and giving space for the other person to be and explore who they are. It is about suspending judgment, being accepting, warm, being non-intrusive, and in a sense, being welcoming. Listening is about being still, trying to quiet some of our own chatter to be able to hear, and cultivating a receptiveness to the person. Also, people need to cultivate those intuitive elements like hunches and ideas that seem to come out of nowhere. Getting a sense of something; thinking or feeling there's more here than I understand and I need to move carefully to, if possible, allow that to come forward. I believe spiritual care is in fact helping people articulate for themselves what they are having difficulty articulating. Allow them to find their own words. But at the same time recognising that words are never adequate. And when we're talking about spirituality we're talking particularly about that I like to use the image of a lake. What we see on the surface is one thing, but what is hidden in the depths is much more? Our words are surface things and underneath there are depths of meaning, significance, that words will never adequately describe."

While the clock dictated the closing of the interview there was a sense that in this reflective time we too had only scratched the surface of meaning existing within this conversation of spirituality.

Individual Interview Two

Asking the 'Big' Questions

Ashley came into the room bringing an atmosphere of excited anticipation. With a self-professed interest in spirituality, Ashley had welcomed wholeheartedly the opportunity to discuss the topic of spirituality. Beginning with the ice-breaker, a question regarding previous education involving spirituality was asked:

> *"Just on my last day of uni we had a lecture on spirituality - about the change of pastoral care and the changing in beliefs. Now people might say they're spiritual but not religious, whereas you wouldn't have come across that in the past."*

Moving on to an understanding of spirituality, Ashley lent forward in the chair and passionately began:

> *"It doesn't mean religion. To me it means the questions that you have about who you are why you're here what impact you've had in your life? What might be there after my life, or our patients' lives? I believe they're still around."*

An understanding of the outworking of spirituality drew two main thoughts: peace and being comfortable with the Self.

> *"Being peaceful. It's based in communication with yourself and with others. Being at peace with who I am and my beliefs; feeling comfortable with what I believe."*

Sitting back and taking a moment to reflect, Ashley gathered thoughts.

> *"Connection. Spirituality is about connection, but I think other connections rely on you being connected and at peace with yourself. It can be described as core, or essence: it's what makes you you. But it doesn't stay static; it's obviously going to change, day to day, depending on what happens or is happening. All the amazing*

stories we hear about the dying seeing and hearing their dead relatives - it just makes me wonder what else is out there and what happens when we die."

"This is about mystery?"

"Oh yes. Now I can just be comfortable with anything really. Like I don't have to know all the answers. Sometimes it's "just because." Spirituality is mystery. Not worrying about big stuff, just chilling really."

Growing ever keener to contribute, Ashley eyeballed me intently and continued the train of thought.

"Spirituality makes me appreciate life. It makes me appreciate what I've got. Thankful for where I am I guess. Even though I've had lots of things go on in my life, I feel pretty thankful to be where I am, and what I've got. Making the most of now and appreciating it."

Moving from appreciation Ashley considered out aloud what acceptance might look like:

"It's not about denying those 'bad' things...they've had an impact on who I am now and the way that I live my life, care for my kids, love my family, look after my patients, how I work I think has impacted on who I am now and the way I live."

The conversation branched out towards the premise of using connectedness as an explanation of spirituality. Connectedness with Self was something immediately pounced on and toyed with.

"I don't think you can be connected properly with anybody else unless you're comfortable or connected with yourself. Central to that is communication with our Self – self-talk has a big impact on our life."

The idea of connectedness rippled out from the internal to playfully lap around exterior notions with the declaration of the importance of "being peaceful with yourself, with the world, and with whatever is beyond."

As ideas and thoughts came to a pause, Ashley lent forward, with a growing sense of competency, keen to hear the next question about spiritual distress.

> *"I think when you settle, and you're more peaceful in yourself, I guess you're open to more things, or open to more understanding, or believing in whatever. But obviously if there's lots of turmoil going on you just need to get through this. You think, 'I've just got to get through today,' or whatever it is. When people are unsettled in themselves, and you've dealt with their physical pain or nausea and such, then I think of spiritual distress."*

Contemplations of spiritual pain channelled their way towards death and dying, and the place spirituality can have in assisting reflection on questions of meaning.

> *"Before my mum was dying, and also then working here, I don't think that I really thought about spirituality too much. But for someone who's dying, they're going to have lots of questions. They're going to reflect on their life, they're going to worry about their family. We rarely get the big questions directly, particularly if there's other family present. They might avoid that, and it depends on the rapport you've got with them, whether they feel they can ask those sorts of things."*

Turning to look out the window and sit in personal reflection, Ashley was comfortably silent. After several moments a change of tack was indicated by a repositioning in the chair.

> *"For some people their religious beliefs are important...it might impact on how comfortable they are about dying - they might believe something particularly and they have worries about that. Or it might actually put them at ease."*

"So you see that sometimes spirituality or religion can bring a peace, and sometimes it can seem to harass?" "*Yep, but the person still dies in their own unique way."*

Another pause: another change of path, the everyday practice of palliative care in the community.

> *"Going to people's homes, on their ground, respecting what they want and working towards what they want and what the carers want. We respect their choices. Develop relationship. It's not just about physical symptoms, if they've got emotional turmoil, being able to help them maybe sort some of that stuff out, so that they can die more settled. We've got that time: can allow that time for whatever they need."*

There the conversation naturally ended, with a focus on the person centred approach of palliative care.

Individual Interview Three

The Missing Voice

Jewellee sits quietly, reflecting on the questions that have provided the skeleton for this body of work. Questions studiously poured over and employed to wield the conversation into shape are now the tip of the sword fast approaching. Time holds its breath as a starting place is found, then in fits and starts the second hand seems to move erratically around the clock face.

Setting off at the measured pace of the ticking clock; training in spirituality? "I think there is a great need for education here about spirituality. Some type of conversation would break the current silence, and help to bring together a language so spirituality can be discussed with some common understanding and meaning. I was fortunate within my professional training to do two practicum units based at BHCI. It was through the

accompanying supervision and feedback from assessment tasks that I began to carve out a safe place within myself for sitting with the dying and those that care for them. Here I learned of the unique active strength of just being, and creating sacred space. A journey that stretched every muscle of me; physical body, mind and spirit." Suddenly time started running ahead as descriptions of spirituality tick-tocked out in a hurry. "To be spiritual is to be aware of the inner life, and the outer life, and the layers of interplay between them. Spirituality brings a library of meaning and motivation to my life. If spirituality is about the core or quintessence of a person, then I believe it to be a part of being human. And whether attention is paid to it or not, spirituality still ebbs and flows like the tides: at times breaking high up on the shore and making itself known loudly and powerfully, while other times quietly dragging sand back off the beach at low tide." Discussion about what spirituality could be moved from the public towards the private sphere.

"Spirituality for me personally is something very deep on the inside of me that makes me, me, internally a connectedness with myself. This Self connection grows out of relationship with a mysterious, yet known, transcendent Being: I consider myself a passionate God-lover. It is within this relationship with something bigger than me that I experience nurture and nourishment of spirit. Whether labelled Transcendence or God is of no bearing, but the bond I have with this mystery provokes and enthuses me. It is the centre of all my connections and ripples out in and through my whole world. My spiritual experience is not based on something airy-fairy, but grounded in my experience of hopefulness and peace in both delightful and painful times." The fluidity of time brought a garnering of the private and the public. "Concurrently spirituality is socially established inspiring me in the optimistic way I see the world and act within it, and then embracing that world back into myself. My spirituality seesaws between the inner going out into the world and the influence of the world

coming towards me. Bridging the outer and inner is transcendent mystery providing an anchor wherever I find myself. The outer social foundation of spirituality is about my connectedness with others. In varying degrees of intensity, it ranges from the abiding with my husband and six children to the stranger I briefly encounter in the lift. It also encompasses the planet, as I stand with others, or with myself, in wonder and marvel at the sunset, the perfumed rose bloom, or the constancy of the waves. Often it is within nature that my spirituality gets fed and blossoms; awed by wonder."

With closed eyes Jewellee adjusted the clock, reflectively moving time back to memories of wonder. Lived Time, lingering, dallying, shuffling with the power of the past overtaking the now, sat silently. A reshuffling of the body indicated a correlating reshuffling of topics, with a deliberate, measured pace towards pain. "When I consider spirituality as displayed within connectedness, then the definition of spiritual distress effortlessly falls into disconnectedness which illustrates the unfamiliar landscape of palliative care. The disconnection of self with Self is common in those diagnosed with a terminal illness. Often as decline occurs for the patient they are not what they were, not wanting to go where the inevitable leads, and not wanting to be where they are in the present. Time waxes and wanes when neither the past, present or future can be considered as comfy or secure. How does one rearrange a whole framework of one's meaning and purpose when the structure has become alien? The existential questions of "Who am I?" and "Why am I here?" become troubling when meaning and purpose is wrapped up in the life that was past. I have encountered much stoicism on the face, as the spirit aches with great disconnective pain. It is only time, respect and relationship that might bring the mask down and draw this courage and strength into usefulness." Again time stalled in reflection, slowly regrouped and ideas moved on. "The beauty of community-based care is that you have the time and opportunity to build these

things, all within the patient's own space and under their direction. When we enter their home and meet them in their context we get a broader picture of who they are. This creates an effective springboard towards co-creating meaning and supporting connectedness." The running thoughts ceased and through the voice questions were silently satisfied; ruminating no longer the now beckoned to be filled with other spaces.

Stories

Story One

Moving into the community, Jo did an initial assessment on a particularly unwell lady. Her story held entwining of contradictory paths of meaning. The first path vehemently stated, "I will be cured, I will beat this cancer. Treatment is continuing and the goal is to get better." However this was enmeshed within a paradox conversation about the hope of attending her children's weddings, and the need to bring them forward: the feeling of a tightening of Lived Time. The contradictory thoughts in her mind sit parallel like a train track when spoken into the room; never meeting. Jo continued, "I talked and listened, I like that aspect, and I wrote the new wedding dates down. All the time assuring her that we did know and we did understand. Holding the contradictory is a part of caring for the individual patient."

Story Two

"A friend of mine was hit by a car and killed outright and I was on the same road. I remember seeing him lie in the road and his life was gone. There was no life in him, but it happened out in the bush, and I remember there was a soft rain falling and I remember standing there sort of looking up through the rain with that mesmerising effect and I thought "Where has he gone? He can't not be here, can't just not cease like that. He must be

somewhere." All the time I understood that knowing where he was was not going to bring him back.

Story Three

We were strongly assured that Charlie was not spiritual and didn't have time for mystery, yet shared this story with bewilderment.

"Both my partner and I had no belief in life after death, but when in hospital dying my partner had an experience of going off into a field and there was a dog and a buttercup. As I'm hearing about this...is it a vision...my dad stepped out to take a phone call from interstate. Dad returns and says the person on the phone had just seen my partner in a field with a dog and a buttercup. I don't know, maybe there's something..." the disorientation returned to assurance, "but for me, all I care about is this life, whatever that life may be, if there is one to me is not consequential because this one is the one that needs the energy."

Story Four

"I can actually remember my first patient that died, and I remember him well. He was a painter, I mean as in painting houses, and it wasn't so much him, but his daughter who lived interstate. Everybody was a bit wary of her, because she was on the phone "What's happening with my dad?" back and forwards and stuff like that and I was an intern at the time. I can remember when he died. I was on call that evening and I went in and the nurse says he's going down. So I just said "Now you just hold on there old buddy," and left him. I went away to see another patient and when I came back and he had died. And they all looked at me and said "Will you ring the daughter?" The daughter had come up to visit and we had talked, so I had a rapport with her, but I was only the intern, the person who had the very least power in the whole scene. It was a very strange feeling. Anyway, I did and it was amazing because she had been worried and I rang her and she was fine. She was really

grateful that I had rung her. But I remember him and I can still vividly see the whole thing. I remember going from "oh no he can't die" to the next thing "yes he can, and he has, and that's OK."

Story Five

Again in community-based care. "I often think I'm in an extraordinary privileged position here. I get to watch people's journeys and walk alongside. One client was in deep angst with having her father in her home. She declared he wasn't going to die at home, and he wanted to. She said she couldn't do it, and then, yes she could, and then, no she couldn't. And he wanted her to, and then he didn't and then - it was like this all the way. However the end result was that she was able to keep him at home up until the day he died. Satisfaction seems like the wrong word to me, but it was my experience when I learned of the circumstances of his death and how she had achieved what she really wanted to do. For me too, there was such a feeling of having aided her to do what she wanted to do but desperately felt she couldn't, and also what he wanted. And as I say, it feels wrong to use that word satisfaction, but when I got the news about how it had come about I thought, "That's great. Good on them." Wonderful and yeah a feeling of satisfaction.

Story Six

A revelation about receiving spiritual care during a visit to reception.

"From where I sit I see people come in, and you know they're shaking in their boots as they walk up the stairs. They don't want to come in, or are really emotional about coming in, for whatever reason, and then I see them walk out again with their head up, shoulders back and walking really firmly. Do you have a sense of that?"

"Yeah, I suppose. I can tell that they're upset."

"So you treat them with dignity and respect, dealing with their need or referring them to someone else. We're all doing the same thing. Treating them with that respect and with that compassion you also help them on their spiritual journey."

"Yeah, true. O I'll tell you about someone. I had a bit of contact with a patient's husband when he came in to pick up things, and quite a lot on the phone after she died; organising the equipment and that sort of thing. I could tell that he felt comfortable to tell me stuff, a connection. And when he came in last week I knew that was the last time I would see him. I felt sad. When he dropped in the last piece of equipment we just looked at each other and I thought, oh I could almost hug you, but I didn't."

Story Seven

I often turn my ears on when I hear of patients who are dying and the things they say. One lady who was dying at home said that her grandfather was around, but her husband said he was dead. While she was still able to communicate she was saying her grandfather was coming for her. You know that family that have died and are coming to escort them when their time is right. There's been stories in handover about a patient seeing relatives who have died, and I often wonder, "Is this patient going to die soon?"Another lady whose husband had died said she walked into the kitchen and she saw him. Had a vision of him: and it was him... So for me they're all amazing stories that make me wonder what else is out there and what happens after we die. I don't think we just die. So, I suppose I'm a collector of mystery stories. Yeah I hang on to them.

Appendix H Connecto Spiritual Screening Tool

Appendix H-1 Connecto Development.

Connecto (Appendix H-2) is the result of this research study, emerging through immersion in the textual conversations and being developed through engagement with the literature and the analysis of the findings. *Connecto* addresses the key themes that emerged from this research study in the following ways:

- Spirituality as connectedness, and spiritual pain and despair as disconnectedness.

  Connecto identifies elements of connectedness and highlights lack of connectedness, disconnectedness, which leads to spiritual pain and despair.

- The contrast of religious and spiritual care.

  Connecto is not derived from a particular religious tradition, but for the individual it transcends specific beliefs.

- Community-based palliative care.

  Connecto can be an effective tool in community-based palliative care as all members of the multidisciplinary team, regardless of personal philosophy, can use it within their professional practice.

- Spiritual education and training.

  Connecto provides a language for spirituality at BHCI, allowing for shared meaning and constructive spiritual referral.

While created specifically for the multidisciplinary professionals working in community-based palliative care at BHCI, *Connecto* has the potential to be used as a prompt within any context where people are cared for. The use of *Connecto* to screen for spirituality through strengths of connectedness and places of disconnectedness could include, but not be limited to, settings such as education, welfare, social work, inpatient health services, aged

care, and anywhere care is extended towards people. *Connecto* contains the capacity to support self-care for the multidisciplinary team member through an increase in self-awareness, awareness of Other, and the practice of presence. *Connecto* can also be used in personal reflection for anyone desiring to consider their own strengths in connectedness and personal areas of disconnectedness. *Connecto* is quick and easy to learn, requiring little training time, and yet the potential for great outcomes and depth of assessment is immense, only being limited by the reflection and imagination of the implementer.

A discussion of Connecto. Through the analysis and interpretation of this research study the outline for *Connecto* has been developed. *Connecto* does not measure spirituality as a whole but rather it identifies spiritual strengths and weaknesses through the framework of connectedness and disconnectedness. The structure has built on the qualities of a constructivist perspective which holds that meaning is constructed by individuals as they live and experience life in the world (see pp. 15). The theoretical framework recognizes spirituality to be understood as connectedness with Self, Other, the world, and mystery/transcendence, with capacity for integration in ultimate unity.

The inception of *Connecto* occurred in a true hermeneutic phenomenological moment while immersed in the interpretive process. *Connecto* rose from the life and professional experience of the researcher while immersed in the textual conversations of this research study in dialogue with existing theories discussed in the literature.

Connecto was initially shown to a fellow student, the EO at BHCI, and Ewen Kelly, Programme Director for Healthcare Chaplaincy and Spiritual Care in Scotland at a lecture given at LaTrobe University in Melbourne: all received the tool energetically. The profound simplicity of the tool was appreciated and encouraged. Ethics approval was amended for initial trials at BHCI (Appendix B-3), and approval sought from the BHCI Quality and

Improvement Committee in August, 2013, to trial *Connecto* within the organization. This being granted, *Connecto* was shown and explained to two members of staff who were highly experienced in performing initial patient assessment, and again the tool was well received. After refining the graphics and preparing the tool within an educative brochure and PowerPoint presentation *Connecto* was presented to a staff meeting at BHCI, in November, 2013. This is the hermeneutic phenomenological account of the introduction of *Connecto* to that staff meeting.

> *The lights in the room were dimmed. As an atmosphere of anticipation filled the room people moved in their chairs, leaning forward to find a prime position. Silence. A colourful DNA helix image flashed on to the projector screen. This symbol represented the melding together of BHCI values with what the academic literature had to say and importantly the research findings, their voice, the findings from the current research study. Together, interwoven and inseparable, these were shown to be the foundation of the spiritual screening tool "Connecto." An excited gasp went around the room and people leaned in more. The questioning thought, concealed and unspoken, implored the speaker for more information.*
>
> *Presentation slides illustrated the foundational question, "What is really important to you?" to nods and affirming noises dancing around the room. Still the eagerness for more impatiently waited. Next the "Connecto" diagram filled the screen and eyes grew wide as meaning-making absorbed all thoughts. Each component: Self, Other, the world, mystery, meaning and purpose, and religion were teased out, played with just long enough for familiarity to begin, then another became the focus. Marching through a short demonstration of the process and possible ways to use Connecto, the slides quickly came to an end and the feedback, sprinkled with questions, began:*

"That is so simple, it's brilliant."

Next further clarification began with a fear question:

"Might the parameters be too broad?

Was this the whisper of a medical professional desiring to have t's crossed, i's dotted and a tick list? The clash of professions rose then fell as reassurance was given that an intuitive referral was very useful.

"I particularly like the understanding of spiritual pain as disconnection. That makes spiritual care easily understood."

"Beautiful. Really beautiful."

"It's really great, so simple. I've worked in the States where spiritual care is so religion based and it excludes everyone who doesn't go to church. This is a breath of fresh air."

"There is nothing threatening about asking a patient, "What's really important to you?" For me or for them. And they won't wonder about what might be the "right" answer, or my agenda, it's just about them. I love it."

And the last question briefly held the air: "When can we start using it?" before animated chatter about usefulness filled the room and the lights came back on.

Having been well received and reverberating with the participants of this research study, *Connecto* is now moving towards initial trialling across the multidisciplinary team as the common organizational tool for spiritual screening.

Implications for Connecto Educators and Users.

The simplicity of *Connecto* results in instruction that is expeditious for both trainers and learners. Education focuses on three points:

- literature foundation of the connectedness framework for understanding spirituality;

- increasing appreciation of the patient context;
- reflection on story (both the told and untold) for identification of strengths of connectedness and places of disconnectedness.

Implementation, too, is speedy and easy to execute within existing practice, revealing rich information occurring throughout what would be the normal conversation between the professional and the patient or carer. *Connecto* is not prescriptive, nor does it address the provision of spiritual care, but rather it is a useful trigger to stimulate timely referrals to spiritual support. This indicates that the tool can be used by all staff members, regardless of training, beliefs, or values, providing a common language to recognize spirituality as connectedness and disconnectedness, for identification and referral purposes. It also results in the inclusion of all staff, requiring no-one to exclude themselves from using *Connecto*. While the conclusions are subjective to the multidisciplinary team member and a particular visit, as different staff members employ *Connecto* within existing practice with the same patient, a fuller, more objective picture arises through communication and consultation.

For the multidisciplinary staff, *Connecto* will assist in consideration of where spaces of connectedness occur which can indicate spiritual strength. Additionally, it will assist the staff to recognize disconnectedness which can highlight spiritual despair, and take into account the distinction between spiritual and religious care (Hodge, 2005). The use of *Connecto* then provides a common understanding and language, across the multidisciplinary team, for identification and referral to spiritual support.

For the patient and carer, *Connecto* will place their life experience and their agenda (*What is important to you?*) at the centre of spiritual screening, building on their stories of connectedness and disconnectedness (Hodge, 2005). *Connecto* will also assist in the building of spiritual meaning in their lived experiences as a professional providing patient care to the

dying. This simple screening tool provides a framework within which relevant language can assist those multidisciplinary professionals not spiritually trained to brings words to their ‘gut feeling’ that spiritual pain is present and impacting on the life of a patient and carer (Kapuscinski & Masters, 2010).

Connecto (Appendix H-2), is founded on the four elements of connectedness from the literature; self experiencing connectedness with Self, with Other, with the world, and with mystery/transcendence (“something bigger”) (de Souza, 2006). Religion can be a part of “something bigger” for those who seek transcendence through relationship with the Divine and/or a faith community. However, the term “God” was not used as the literature showed that for some it can impede their experience and identification of spirituality (pp. 29). It was noted that *Connecto* was more useful when it uses language that transcends specific beliefs (pp. 47,85,87). Attributes of spirituality from the literature support each element (Appendix H-4), stimulating thought about each element. This brings together a simple but elegant spiritual screening tool that transcends specific beliefs, while helping make sense and meaning of those difficult conversations about spirituality, spiritual care, and when to do a spiritual referral.

How to complete Connecto. *Connecto* begins with the simple, non-threatening question: *What is really important to you*? (Appendix H-3). Spiritual care is most useful for the patient when it begins with what is really important to them, this is a suggestion of where they experience connectedness and may find meaning and purpose (Hodge, 2005; E Kelly, 2013; Mount Vernon Cancer Network, 2007). Other formulations for this basic question can be utilized so members of the multidisciplinary team can choose a sentence that is comfortable with their personal language:

- *Before your illness what was important to you?*

- *What gets you out of bed in the morning?*
- *How do you make sense of what is happening to you?*
- *What gets you through hard times*?

These are all moving towards the patient's agenda, and they provide the capacity for leading to focussed discussion if desired, rather than a rigid formal assessment (Ellis & Lloyd-Williams, 2012).

The *Connecto* form gives an instantaneous symbolic visual representation of spiritual strengths and weaknesses to begin the process of "developing a coherent horizon of meaning" (Champagne, 2008). These strengths and places of disconnectedness provide an easy language of referral based on connectedness: i.e. "This patient is strongly connected to the world through his garden," as well as places of disconnectedness: i.e. "This patient questions whether their life has any meaning now they have a terminal prognosis."

The styling of the tool was dictated by the pages already included in a patient's medical folder. *Connecto* fits on the bottom half of the page that already contains the patient Geno gram, where lines are used to create a visual representation of family composition. *Connecto* can be used at the initial assessment of a patient or at any visit while the patient is on the program, and is also easily used to screen the carer for spiritual distress. *Connecto* can be reviewed at any time, through any conversation, encouraging the multidisciplinary staff, and patients to see spirituality as fluid and evolving rather than static (de Souza, 2006; Ellis & Lloyd-Williams, 2012). Any member of the multidisciplinary team can embed the use of *Connecto* within their own particular professional practice regardless of their own beliefs, values, and opinions (Benner & Sutphen, 2007; Pesut, 2003). Instead, it will depend on the individual personality and worldview of the staff to allow each to ultimately hear and perceive differing layers of story which, rather than being in competition with each other, will

add depth and breadth to the holistic story of connectedness and disconnectedness. As the conversation is directed by the patient's view of what is important to them, and allows their stories of connectedness to be a part of existing practice communication, it is the professional ethics of person-centred care and community-based practice that will guide the implementation of the tool.

Connecto can also be used personally by the multidisciplinary staff, with reflection on their own connectedness and disconnectedness, bringing deeper self awareness and also enhancing their professional development and self-care options (Barry & Gibbens, 2011; Canton, 2006).

The ways in which *Connecto* answers the requirements raised about spiritual measurement in the literature (pp. 87) are summarised below:

- *Connecto* is based on the theoretical framework of connectedness;
- *Connecto* transcends specific belief;
- *Connecto* was developed by a spiritual worker trained in interpretive traditions and disciplines of spirituality;
- *Connecto* uses information for screening that emerges through ordinary conversation found in the general population, requiring no awkward questions or specialised language;
- *Connecto* allows for the patient to identify meaning and purpose, and whether religion is a part of spirituality for them, providing a totally inclusive view of spirituality;
- *Connecto* is an inclusive tool exploring spiritual strengths, distress, and current spiritual state;
- *Connecto* is transferable across all contexts: home, outpatient, inpatient, coffee shop, or over the phone;

- *Connecto* can take place anywhere ordinary conversation occurs, making it easy to embed in routine practice.

While many spiritual assessment tools have been developed (see pp. 83-86) their focus has mainly been on employing a spiritual thermometer; however *Connecto* has the capacity to delve deeper into what people are thinking and feeling. It is the individual patient, and their particular current story, that rates the significance of spirituality (Bishop, 2013; Hodge, 2005; Monod et al., 2011; Palliative Care Australia, 2012), with a focus on *their* concerns and motivations (Culliford, 2007). *Connecto* is based on existing evidence based theory, using relevant common language (M. Holloway et al., 2011; Kapuscinski & Masters, 2010). As a spiritual screening tool *Connecto* traverses worldviews and theologies (Watson, 2009b). Spirituality and religion can be overlapped (Koenig, 2002), if that is the view of the patient, or can be considered separately (Baldacchino, 2008), and any specific belief or ritual is transcended (de Jager Meezenbroek et al., 2010).

Connecto does screen for spiritual distress (Koenig, 2007), and current spiritual state (Monod et al., 2011), and embedded within BHCI practice has the capacity to improve the provision of spiritual care (Jenkins et al., 2009), and increase the spiritual capital of BHCI (Bennet & Bennet, 2007). To conclude, the induction of *Connecto* as a common spiritual screening tool will represent an investment in the provision of comprehensive holistic care to patients and carers and it also has the potential to enhance the spiritual growth of the multidisciplinary staff and their options for self-care.

Appendix H-2 Connecto Form.

Connecto

"What is really important to you?"_____

Draw a line generating from ***The self***, outwards to the aspect(s) where you hear the patient experiences connectedness or disconnectedness.

Connectedness: ——————————

Disconnectedness: ——————//——————

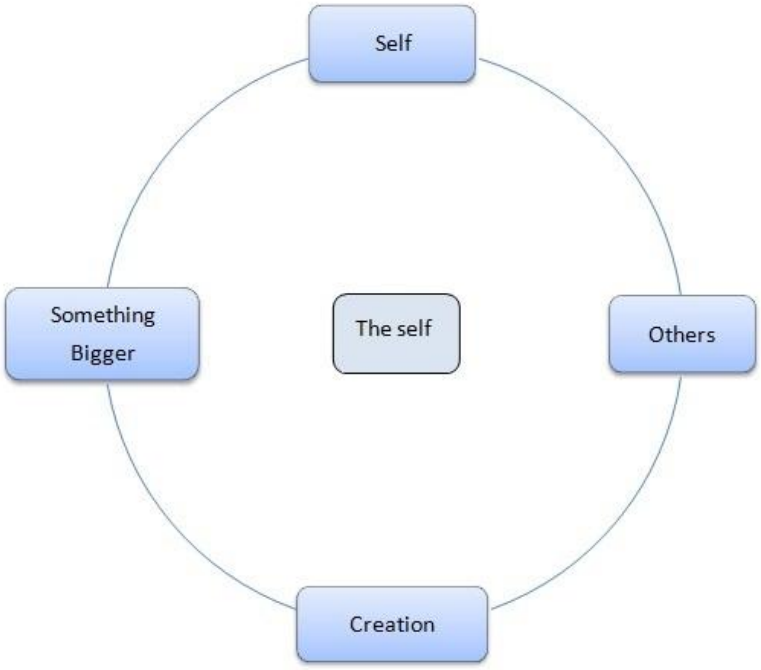

Figure 16: *Connecto Form.*

Appendix H-3 Filling out Connecto.

Filling out Connecto is similar to the filling out of a Genogram (B. Ross & Cobb, 1990), where lines connect people in relationship, and double crossed lines indicate a broken relationship.

- ask the introductory question: *What is important to you*?
- a line is drawn from the centre, *The self* towards different aspects identified as places of connectedness;
- a line is drawn with two lines marked across it to indicate places of disconnectedness.

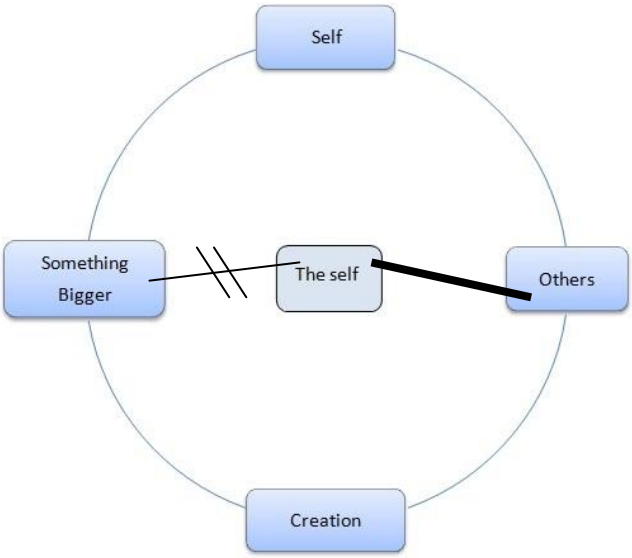

Figure 17. *Completed Connecto Form.*
Note: This figure indicates strong connectedness with Other, while disconnectedness with Religion is highlighted.

Filling out Connecto can happen after reflection on the conversation that has occurred through a home visit, or even in situ during the patient's storytelling. As places of connectedness and disconnectedness are identified, lines are drawn from *The self* at the centre, to the relevant element: Self, others, creation, something bigger. Just as filling out a Genogram is not an end in itself (B. Ross & Cobb, 1990), Connecto is a place to begin an exploration of connectedness.

Appendix H-4 Attributes supporting Connecto.

Attributes of connectedness from the literature have been collected to give some description to how the different domains of connectedness/disconnectedness might be defined by the patient.

Connectedness with Self
acceptance, comfortable, contentment, forgiveness of self, inner harmony, inner peace, serenity, inner strength, thankfulness, valuing, self-identity, self-knowledge.
Connectedness with Other
accepting others, caring, compassion, forgiveness of others, gratitude, harmony, helping, peace, respecting others, belonging, being valued, reconciliation.
Connectedness with Creation
appreciating, beauty, natural environment, gratitude, peaceful, respect, sense of belonging, wonder.
Connectedness with Something Bigger
awe, belonging, faithfulness, fulfilment, gratitude, hope, meaning and purpose, mystery, meditation, peace, reason to exist, sacredness, secular, transcendence. **Religious Attributes:** church, faith community, religion, religious leaders (clergy, pastors, pastoral care, priests, rabbis), rituals; divine, God, God's presence, Higher Being, Higher Power, reverence, sacred; afterlife, faith, heaven, holy, prayer, religious literature or scripture, worship (Chao et al., 2002; de Jager Meezenbroek et al., 2010; Sessanna, 2011).

Disconnectedness with Self
decreased confidence, despair, distress, fear, focus on weakness/mistakes, frustration, guilt, helplessness, exacerbated pain, restless, suppression of feelings, uncomfortable with self, Who am I? Why am I here?
Disconnectedness with Other
Alienation, conflict, fault finding, isolation, feeling unsupported, regret, separateness, vulnerability, withdrawal.
Disconnectedness with Creation
Global loneliness, missing outside/nature.
Disconnectedness with Something Bigger
Doubt, fear, loss of faith, lack of hope, inability to transcend the present, meaninglessness (Fillion et al., 2006; M. Holloway et al., 2011; P. McGrath, 2002; J. Murray, Wilson, T., Meredith, P., Mitchell, G., Hutch, R., 2007; Sand & Strang, 2006).

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