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June 2008
‘Ko te Amorangi ki mua, ki te hapai o ki muri’
‘Place the things of the Spirit to the fore,
and all else shall follow behind’
(Payne, Tankersley, & McNaughton A (Ed), 2003, p. 85)
Abstract

Contemporary spirituality, characterized by ontic fragility like no other time in history, impacts on the death zeitgeist. Contemporary dying is often marked by pain, shame, anxiety, uncertainty and technological complexity, but can be a meaningful experience. The hospice approach leads the way by mandating spiritual care, and in doing so potentially transforms the dying process.

This study examined spiritual care in New Zealand end-of-life cancer care, primarily focused on hospices. The questions considered were: what does spirituality mean for those affected by terminal illness?; what are their spiritual needs?; what do Māori say about spirituality/spiritual care?; and how can spiritual care be improved? A mixed methods approach included an extensive literature review and two discrete studies. Study One involved 52 interviews (patients n=24, family members n=9, staff n=8, chaplains n=8, M_ori experts n=3). Study Two surveyed 78% of New Zealand's hospices (N=25, response rate 56%).

The findings show explicit spiritual care is inconsistent. Spirituality is understood broadly in the study samples. They had eclectic spiritual practices and beliefs, there were high spiritual needs, and structural issues need to be addressed to improve spiritual care. The majority had wide ranging beliefs in God and the afterlife, and many believed in paranormal events.

Spiritual needs were affirmed as a critical component of dying and care for those affected by terminal cancer, although up to a third did not want to be asked about them. Spiritual needs were seldom explicitly met by hospices, but the picture was complicated. The majority of patients and family members interviewed in Study One were not aware of and did not receive spiritual care from their hospice. This was confirmed by participants in Study Two: only 17% of patients and 14% of family members said they had received spiritual care from their hospice. However, the survey revealed that 77% of patients and 67% family had received spiritual care but mostly from their family members. Family members' spiritual needs and capacity to provide spiritual care was an important consideration that needs addressing. Approaches to spiritual care were widely canvassed and a range of approaches detailed.
Māori spiritual needs were thought to be reasonably attended to, but with some room for improvement. Staff spirituality was understood to be an important aspect in the continuum of care.

The most compelling evidence for unmet spiritual needs were structural gaps, particularly relating to the lack of spiritual assessment, staff support, training and policy. The role of spiritual care expert/chaplain was shown to be critical, with many challenges, not least whether their title is appropriate. A structural spiritual audit tool revealed room for improvement in all hospices surveyed. This is not a criticism of the compassionate individuals working in hospices, but a challenge for the whole organization.

Dying from terminal cancer is a time for potential spiritual growth, but an improved, more empowering and spiritually conducive hospice ‘space’ is needed. These seminal New Zealand findings are transferable beyond cancer to other end-of-life settings and add to the growing international evidence affirming the importance of spirituality at end-of-life.
Acknowledgements

At the heart of this thesis is the explicit aim to improve spiritual care for those dying in New Zealand. In the first instance, the thesis focused on those affected by terminal cancer, mostly in hospices. But I believe the findings have relevance for all those dying in New Zealand because of the profound generosity of those who contributed to this work. First and foremost I acknowledge and thank those who have died; at the time of writing this, 23 of the 24 patients interviewed have died. Without these people’s generosity of time and self this work would be empty. Secondly, their family members, whose spiritual needs are the least attended, I thank you for sharing your experience at what was for most an excruciatingly difficult time. Then to the other key informants, staff, chaplains/spiritual care givers, and Māori experts, thank you for your time and wisdom.

Behind this thesis was a process that only happened because of the good will of many staff in 25 hospices across the country. Chief among those who deserve thanks are the key contact people, often the nurse manager or similar person, who did days of work on site with recruitment, information and follow up.

Further regarding this thesis process are those who advised (cajoled, admonished and encouraged) me. To my supervisors, Professor Rod MacLeod, Dr Chrystal Jaye, Associate Professor Rob McGee and Dr Joanne Baxter; and advisor Associate Professor Peter Herbison, I sincerely thank you for your guidance. Also, I would like to thank two key people who helped with editing, Stuart Barson and Sandi Jull.

I would like to acknowledge and thank the organisations who have financially supported this work, particularly the Genesis Oncology Trust for their PhD scholarship, the Canterbury Westcoast Cancer Society for conference support, and the University of Otago Departments of General Practice and Preventive and Social Medicine for ongoing financial, office and administrative support. Further, I would like to thank Anita Fogerty, from the Department of General Practice, for help with the collation of the survey returns.
Writing this thesis was a major life event during which time I also got married, built a house, had a baby and experienced the death of a sister-like friend. To my wife, Sarah Dolby, you have no idea how your support has made this work possible. And to my son Benjamin, thanks for making me smile every day in your first eight months of life, which were the last eight months of this thesis.
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Glossary

Aotearoa — New Zealand (the land of the long white cloud)
aroha — love, to love*
atua — supernatural being
hapū — sub-tribe
haere mai — welcome, come here*
hauora — health
hinengaro — mind, emotion
huhua — be abundant, numerous*
hui — meeting
iwi — tribe
kai — food
kaiāwhina — helper, assistant*
karakia — incantation, charm, prayer
kaumatua — elder
kaupapa — subject, plan, scheme, proposal
kawa — Māori protocols
kāwanatanga — government*
kēhua — ghost — spirits*
kuia — female elder
mana — power, influence, prestige, authority
manaaki — to support, to take care of*
manuhiri — visitor, guest*
makutu — sorcery*****
marae — public area in front of a meeting house
mate — sick, dead
matakite — to see into the future, prophecy, prophet*
mate Māori — illness for which there is no obvious physical cause
matauranga — Māori knowledge****
mauri — spark of life****
mihi* — to greet or speech of greeting
noa — free from tapu, common, profane

oritetanga — equity****

Pākehā — person of European descent

Papa-tū-ā-nuku — Earth mother and wife of Rangi-nui*

rangitira — chief (male or female)*

Rangi-nui — atua of the sky and husband of Papa-tū-ā-nuku*

reo — language

rongoā — Māori treatments including herbal remedies

taha — side*

tangata whenua — people of the land, indigenous

tangihanga — funeral, rites for the dead*

tapu — sacred, off limits

te Āo Māori — the Māori world***

tihei mauri ora — sneeze of life, call to claim the right to speak*

tikanga — Māori customs and codes of behaviour

tino rangatiratanga — self determination*

tinana — body*

tipuna — ancestor*

waiata — song, chant*

wairua — spirit, spiritual

wairuatanga — spirituality ***

whakamoemiti — praise, thanks *

whakapai — to improve, bless*

whakapapa — genealogy

whakatauki — saying, proverb

whakawhetai — thanks, gratitude

whanaungatanga — family relationships or togetherness

whānau — family

whakapapa — genealogy*

whare — house, building

whare tapa whā — four-dimensional Māori perspective

whare wānanga — traditional Māori house of learning

whenua — land*

wheke — octopus*
Note, unless otherwise noted by an asterix (*), the definitions are sourced from (Jansen, Bacal, & Crengle, 2009).

* (Moorfield, 2005)
** (National Library of New Zealand Te Puna Mātauranga O Aotearoa, 2008)
*** (Ahuriri-Driscoll, et al., 2009)
**** (Martin, 2002)
***** (Mead, 2003)
1 Introduction

1.1 Statement of Purpose

The purpose of this study was to investigate and identify ways to improve spiritual care in New Zealand end-of-life cancer care, primarily focused in hospices. The study used mixed methods, combined with a literature review, to comment on the current spiritual care landscape in New Zealand's hospices. The primary participants were patients diagnosed with 'life-limiting', 'terminal' or 'end-stage' cancer. Other voices include family members, staff members, chaplains/spiritual caregivers, and Māori experts. This applied research has "exploratory" and "descriptive" goals (Hart, 1998, p. 44).

In the qualitative tradition, establishing a specific or detailed research question at the outset of the study is not always necessary. However, in this work, the following research question was developed: how effectively is the spiritual dimension of those affected by terminal cancer attended to in New Zealand’s hospices?

In the process of this research, a number of questions about New Zealand hospices have been considered:

- How is spirituality understood within this context?
- What are the current unmet spiritual needs of people affected by terminal cancer?
- How important is spirituality to people affected by terminal cancer?
- What is the place of spirituality for Māori?
- How can the spiritual needs of people with terminal cancer be improved?

---

1 The sample for the Studies herein are primarily New Zealand hospices, with the exception of one public hospital oncology unit in Study one. The term 'hospice' will be used for this thesis, but it includes palliative care.
This study is not an overview of religious approaches to end-of-life care\(^2\). Further, this work is not an enquiry into the spiritual needs of all people who are dying: for example, those who are dying from non-malignant disease are not the subject of this work.

This is a story of spirituality in a group of people with cancer and those who care for them. This is not ‘every-man’s’ story, but it is the intimate thoughts of many New Zealanders – from an amazing young Pacific Island woman whose husband married her knowing full well she was going to die in a few months; to a 55-year-old mother of a 16-year-old only son whose leaving was beyond despair; to a 75-year-old distinguished professional who, with full peace of mind, found meaning through a war artist who allowed him to make sense of three years of living with dying. Each of us will face death in a unique way, reflecting how we have lived up to that point. But we can learn from those who have gone before us. These stories – explored deeply through long conversations and broadly through hundreds of surveys – tell the story of spirituality and spiritual care as understood by those dying, or affected by dying, in New Zealand hospices between 2006 and 2008.

1.2 Structure & Hybrid Nature of Thesis

This thesis is ordered so the reader can clearly understand the purpose, literature, methodology, methods, voices of the participants, survey findings, discussion, and recommendations. There are a mixture of footnotes, quotes and sourced opinions, reflecting the hybrid nature of this academic thesis\(^3\). The structure is:

- Chapter One, this introduction, explains the topic, populations studied, reasons for the study, gives a brief description of the studies, and maps the thesis structure.

- Chapter Two reviews the literature on spirituality in contemporary society, health and hospice care and shows the need for this research in New Zealand.

\(^2\) For a good overview of this in New Zealand see Schwass, M. (2005). Last Words: Approaches to Death in New Zealand's Cultures and Faiths. Wellington, Bridget Williams Books and Funeral Directors Association of New Zealand

\(^3\) Where appropriate, the first person pronoun will be used so as to acknowledge the subjective nature of the work. Double speech marks are used for quoted words, single speech marks are used to highlight a word or phrase. Quotes are reported exactly as they were in the source. Where deletions are made from the source, this is shown by ellipsis (...). Quotes longer than three lines are indented and separate from the main text.
• Chapter Three details the methodology that underpins this research, naming the ontological, epistemological and theoretical positions of the author.

• Chapter Four details ‘Study One’, a qualitative investigation into the spirituality and spiritual care of those affected by cancer in seven hospices\(^4\) and one public hospital oncology out-patient clinic.

• Chapter Five details ‘Study Two’, a cross-sectional spirituality and spiritual care survey of 25 New Zealand hospices.

• Chapter Six reports on Māori voices regarding spiritual care at the end-of-life through the results of a brief literature review and four Māori interviews.

• Chapter Seven is a discussion and synthesis of the literature and Studies One and Two, and offers recommendations for improving spiritual care and future research. The appendices contain relevant data, such as tables and administration details of the studies.

1.3 Background

Hospices have recognized an integrated model of health since 1967; ‘total pain’ and ‘total care’ include physical, social, mental and spiritual dimensions (Saunders, 2000). Similarly, in New Zealand hospice care, an equivalent model is named in both English and Māori (Ministry of Health, 2001, p. 10). This context inspired this research – I was interested in spirituality in health and education. My Masters thesis examined spirituality in New Zealand

\(^4\) The population and research setting is important to name. In New Zealand, palliative care is delivered by hospices, hospitals and in primary care settings (such as General Practices); and palliative care is ‘needs led’ not disease specific. This research largely focuses on cancer patients in hospices; with the addition of one oncology out patient setting. In many cases hospice care is ‘five star’, best practice, exemplary care in the end-of-life healthcare continuum. Thus it is the most appropriate place to examine, explore and improve spiritual care before moving into other end-of-life settings. Further, the context of this study is in New Zealand, a multi-cultural country with four main ethnicities: Pakeha/European (67.6%), Māori (14.6%), Pacific Islanders (6.9%), and Asian (9.2%) (Statistics New Zealand Tatauranga Aotearoa, 2006). New Zealand is made up of a diverse range of religious and spiritual groupings.
state education and when I discovered hospice care actively promoted spiritual care I wanted to know how this was done in New Zealand.

Spirituality has significantly grown as a focus of research in the last two decades (Sinclair, Pereira, & Raffin, 2006). Stefanek suggests a 600% increase in peer reviewed publication between 1993 and 2003 (Stefanek, 2005, p. 450). Spirituality has been mandated to be ‘taught’ in New Zealand state schools since 2001 (Egan, 2000), over two thirds of US, and some Australian, medical schools teach courses in spirituality – and yet clarity about the what, why and how of spirituality and spiritual care is far from universally agreed upon. There has arguably been a re-emergence of spirituality, but there are still more questions than answers (MacKinlay, 2005) – and this may be the very nature of spirituality. Change is one of the defining features in today’s healthcare, patients and spiritual care (Cobb, 2007), particularly when demographics are considered (people are getting older\(^5\) and living longer; “modern medicine has increased the period of time over which a chronically ill patient dies” (Puchalski, 2006d, p. 7)). We are increasingly multicultural,\(^6\) epidemiologically there is change from communicable to chronic diseases dominating death, and the cost of technical medical interventions is skyrocketing. Sulmasy situates ‘patients’ in the marketplace: “Patients are consumers – amorphous blobs of undifferentiated medical preferences. Physicians are the providers” (Sulmasy, 2006, p. 102). Sulmasy suggests this economic model of healthcare is detrimentally affecting staff in a type of collective spiritual crisis. There is also an increasing population-focused policy approach that questions the dominant disease model, re-focusing on patient centered-ness, and asking what determines our health (Baum, 1998; Ministry of Health, 2000). Simultaneously, spirituality is being recognised in policy across many Western healthcare systems (Heelas, 2006, p. 18). Sulmasy calls this the “repersonalization” of medicine, helping to recognize it as a spiritual enterprise, despite two major barriers: the denial of death and the “economic reconstruction of medicine” (Sulmasy, 2006, p. 110).

\(^5\) The New Zealand Ministry of Social Development affirms this position regarding aging: “People aged 65 years and over are a growing proportion of our total population. By 2051, around 1.3 million of all New Zealanders (26%) will be 65 years and older and around one-quarter of these will be over 85 years.” (Ministry of Social Development, 2005, p. 3)

\(^6\) The New Zealand Ministry of Social Development affirms this position regarding ethnicity: “The ethnic mix of older people will change significantly. ... The older population is less ethnically diverse than the population aged under 65. ... The number of Māori aged 65 years and over is projected to nearly treble between 2001 and 2021, from 20,000 to 57,000. By 2021, they will account for 8% of all Māori, compared with 3% in 2001. ... At the 2001 Census, there were 7,600 older Pacific people. The number of older Pacific peoples doubled over the decade to 2001, and is projected to nearly treble between 2001 and 2021, from 9,000 to 25,000. ... The number of Asian people aged 65 years and over is projected to reach 55,000 by 2021, five times the 2001 population of 11,000 (Ministry of Social Development, 2005, p. 9).
A ‘fine line issue’ needs to be acknowledged in the academic study of spirituality. This concerns the nature of spirituality, which for some goes to the essence of being; care must be taken not to commodify, pathologise, medicalise or institutionalise spirituality. Art, poetry, music, song, these things must be acknowledged as critical points of entry and expression of the mystery that is personal spirituality for some people. Yet this study attempts to bring the biomedical world further along the 'biomedical ------ bio-psycho-social-spiritual' continuum, hence the need for scientific rigour in the research. But as Pargament says of religion, “Fears that science will remove the mystery from religion seriously overestimate the power of science.” (Pargament, 1997, p. 10). This too can be said of the study of spirituality – this is not an attempt to explain away the mystery inherent in spirituality, but rather to help understand the ground upon which this mystery sits, particularly for those near death.

Room for improvement in hospice spiritual care has been identified (Miller & Thoresen, 2003; Ministry of Health, 2001), hence the need for rigorous research. In order to take a whole person approach to cancer care, the New Zealand Cancer Control Strategy (2003) recommends an evidence-based approach to spiritual care. Internationally, medical research is beginning to acknowledge the relevance of spirituality and its relationship to wider health outcomes (Seeman, Dubin, & Seeman, 2003) (Scheurich, 2003) (Sloan, Bagiella, & Powell, 1999) (Powell, Shahabi, & Thoresen, 2003). New Zealand has a unique cultural mix, non-religious in the strictest sense (Gendall & Healey, 2009), yet according to Hornblow it still needs to develop “existential capacities across the life span” (Hornblow, 1999). Palliative care aims to assist in a ‘good death’ (Cobb, 2001). In many cases it does this competently, taking into consideration the spiritual needs of the patient and family (Ministry of Health, 2001; Walter, 1997). However a baseline understanding of spirituality and spiritual care in New Zealand hospices is needed to help inform and improve practice, hence the need for this research.
2 Literature Review

2.1 Literature Review Strategy

The following literature review shows the gaps and, therefore, need for the research detailed in Chapters Four, Five and Six. A wide range of literature has been canvassed to contextualise the 'spirituality discourse' generally and the 'spirituality and health discourse' specifically. A more detailed analysis of the literature on spirituality and hospice care discourse follows. The argument in this analysis is that spirituality needs serious consideration, as mandated in hospice care philosophy and services (Speck, Higginson, & Addington-Hall, 2004), but there remain gaps in research and practice.

The strategy for finding relevant literature has included consulting:

- Databases (key words included: spirit*, well-being, existential, palliative care, hospice care, end-of-life; databases included Medline, Web of Knowledge, Scopos, Google Scholar, Google and Te Puna);
- A wide range of books (sources included: New Zealand's libraries, particularly the University of Otago and the author's personal library);
- Government documents, strategies, policies and guidelines;
- Recommended texts and papers (for example from supervisors)
- Relevant PhD and Master theses

The reviewed literature does not include:

- Literature in languages other than English;
- Any comprehensive inclusion of 'sacred texts' (ie the Bible);
- Literature before 1985 (with significant exceptions, such as seminal texts like Varieties of Religious Experience, a Study of Human Nature (James, 1901 - 1902);
- Any comprehensive search of the lay spirituality literature (which has been burgeoning (Heelas, Woodhead, Seel, Bronislaw, & Tusting, 2005)).
Academic spirituality research traverses disciplines and schools of thought. Positively, this means it has not been captured by one discourse (Rumbold, 2002a). However, a major challenge to its cross disciplinary nature is a lack of consistency, most notably of concepts and definitions. This will be examined below, suffice it to say that conceptual positions are discourse dependent.

The structure of this literature review is ‘funnel-like’: the macro environment is traversed in the ‘spirituality in contemporary society’ section; then the place of spirituality in health/medicine is considered; spirituality is then contextualized within the study’s frame of hospice care.

2.1.1 Spirituality in Contemporary Society

It is a crucial fact of our present spiritual predicament that it is historical; that is, our understanding of ourselves and where we stand is partly defined by our sense of having come to where we are, of having overcome a previous condition (Taylor, 2007, p. 28).

This section contextualizes the study of spirituality in contemporary society. It includes a justification for this context, a discussion of past and present belief environments, a historically focused discussion of the place of death, and situates spirituality in our contemporary milieu.

2.1.1.1 Justification of Context

Within the academic study of spirituality it is important to present the context in which the research happens (Salander, 2006). An historical overview is inherently subjective, yet I believe justified in this case because spirituality is meaningless without a background, a whakapapa. ‘What does spirituality mean?’ is a question that can only be even partly understood when the historical context is considered.

7 Māori words, such as ‘whakapapa’ (ancestry) and ‘wairua’ (spirit), will be used throughout this thesis. There meaning will be clear from the context and/or will have transliterations in brackets. Further a glossary of Māori terms is provided above.

8 What follows can be criticised as a meta-narrative, an overview or overarching way of seeing history and how we have arrived at a place where spirituality is now studied within an academic context. A post-structural or post-modern reading suggests any attempt at overarching theorizing is futile, however this position has been challenged, and even considered “essential to our thinking” (Taylor, 2007, p. 573).

The primary issues related to the contemporary academic study of spirituality are to do with meaning: meaning of life itself and the meaning of ‘spirituality the concept’. To even begin to understand the first sense, one needs to contextualize the second.
2.1.1.2 Historical Context: The Belief Landscape

Secularity is a condition in which our experience of and search for fullness occurs: and this is something we all share, believers and unbelievers alike (Taylor, 2007, p. 19).

This section considers the historical strands of the contemporary spiritual landscape which, in the West, sits in a secular context. This is a complicated history, and this re-telling is partial and draws heavily on the work of the philosopher Charles Taylor. Taylor’s *A Secular Age* (2007) gives an account of what makes up the contemporary Western belief environment by an examination of belief, disenchantment, the nature of self, humanism and the tensions between belief and unbelief. Secularity is examined not as the division of Church and State, or the decline of religious practice, but more broadly as the “focus on the conditions of belief” (Taylor, 2007, p. 3). Taylor calls this the third sense of secularity: it is “a matter of the whole context of understanding in which our moral, spiritual or religious experience and search takes place (Taylor, 2007, p. 3). This ‘whole context’ needs to be considered in the spirituality research agenda and, perhaps more importantly, when dealing with dying people.

Spirituality until the middle of the 20th century was virtually synonymous with religion (Berry, 2005; Heelas, et al., 2005; Taylor, 2007; Ward, 2001); a multitude of positions have since developed. Taylor presents a secularization theory different to the mainstream. Typically, he suggests, mainstream theory uses a subtraction approach (Taylor, 2007) – society becomes more secular as religion is taken out of the picture (for various reasons). Taylor argues the process is much more complicated. Considering the evolution of belief, Taylor contrasts two positions, ‘belief’ and ‘unbelief’. Essentially there is a dichotomy between religious belief and a scientific belief (or ‘un-belief’ as Taylor calls it) (Bradshaw, 1994; Taylor, 2007). The religious position is broad, focusing on the transcendent and transformation (Taylor, 2007, p. 20 & 510). Taylor suggests since the middle of the 20th century the unbelief position has been the dominant unexamined default for Western society (Taylor, 2007, p. 424). Taylor usefully commandeers and expands on Weber’s idea of disenchantment (Gerth & Mills (Translator), 1958 [1946]), contrasting the religious or
enchanted worldview, with the disenchanted. The enchanted world is one that accepts as reality unseen forces, powers and beings, including spirits and God.9

Taylor persuasively argues that who we are as human beings is determined by which of the belief/unbelief positions we take. The unbelief position is hegemonic today, particularly among those in power, those in academia generally; all beliefs are challenged by its persuasiveness and pervasiveness. In the disenchanted world, the self becomes the “buffered self” as opposed to the “porous self” of the enchanted world (Taylor, 2007, p. 539). The buffered self is “essentially the self which is aware of the possibility of disengagement. … in relation to one’s whole surroundings, natural and social” (Taylor, 2007, p. 42). The nature of ‘self’, personhood, agency and so on have been explored elsewhere (Faull & Hills, 2006), but within the context of this research Taylor’s concept of the buffered self is relevant to spirituality and hospice care because if one accepts Taylor’s analysis, many of the people dying today in our New Zealand context will be ‘buffered’. Taylor goes on to assert that the disenchanted world is “without meaning” (Taylor, 2007, p. 680) and the contemporary state of collective meaninglessness is unique in history10 (Taylor, 2007). In times past, there may have been ennui, depression, or existential angst, but Taylor argues that at no time in history before the mid 20th century was meaning so assailed at such a societal level. It is because of the ‘whole population’ nature of this ‘problem’ that both this issue and thesis are set in a public health/health promotion context.

Arising out of this disenchanted world of the buffered self is the individualism and materialism that these authors argue are so pronounced in the modern condition (Bradshaw, 1994; Eckersley, 2004; Taylor, 2007). Without any external referents, individualism follows logically; the focus on ‘accumulation of possessions’ fills the void once inhabited by the transcendent. Taylor suggests that instead of meaning being situated outside of one’s self,

For the modern, buffered self, the possibility exists of taking a distance from, disengaging from everything outside the mind. My ultimate purposes are those which arise within me, the crucial meanings of things are those defined in my response to them (Taylor, 2007, p. 38).

9 This ontology is contrasted with the disenchanted position that sees the universe not as the divine cosmos, but as a mechanistic system bound by laws; a world that can be empirically named and understood solely via scientific investigation, logically and rationally (Bradshaw, 1994, p. 42; Taylor, 2007, p. 26&29).
10 See also (Eckersley, 2004, p. 2)
Thus the setting is created where individualism is inevitable when a transcendent view of reality is taken away, in almost solipsistic fashion; there are few if any ‘meaning markers’ outside of self.

The challenge of the buffered self in a scientifically focused world is that it does not always work that way in our experience. Taylor argues that for the first time in history the sense that ‘something is missing’ and even that life appears meaningless is widespread; he calls this spiritual instability the “predicament of the buffered self” and that the “ontic doubt about meaning itself is integral to the modern malaise” (Taylor, 2007, p. 302& 303). If, as Taylor argues, this ontic doubt is so widespread, it inevitably becomes an issue not just for the dying, but public health generally.

A counter-revolution against the disenchanted world and the buffered self, Taylor suggests, first began among the élites and artists of the Romantic period. In the 19th and 20th centuries humanism’s influence encompassed all levels of Western society (Taylor, 2007, p. 320). Churches did not empty en-masse before the 1960s, but ‘belief’ positions were increasingly challenged and changing. The romantic movement, at an ontological level, was reacting against the disenchanted world, where the buffered self sacrifices “spontaneity and creativity” and even “our feelings” (Taylor, 2007, p. 609).12

The contemporary spiritual environment is one that is marked primarily by plurality. Taylor suggests this period is evident from the mid-20th century – calling this the “age of authenticity” when spirituality or the focus on the sacred may not have declined but rather shifted further towards “self”13 (Taylor, 2007, p. 473). Taylor argues in the contemporary spiritual environment, with its inherent gap created by an immanent frame that allows for nothing meaningful beyond oneself, the human search continues. He points particularly to young people not satisfied with religion but still in search of “a more direct experience of the sacred, for greater immediacy, spontaneity, and spiritual depth” (Roof 1999 cited in Taylor, 2007, p. 506). Sourcing Roof (1999) and Heelas et al (2004), Taylor presents a contemporary

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11 Eckersley corroborates this position: “For most of our existence as a species, meaning was pretty much a social given” (Eckersley, 2004, p. 2).
12 Bradshaw (Bradshaw, 1994, p. 53) and Eckersley (Eckersley, 2004, p. 51) support Taylor’s analysis, albeit in different language.
13 Heelas et al base their whole thesis on Taylor’s earlier and connected idea of “the massive subjective turn of modern culture (Taylor 1991, p.26 cited in Heelas, et al., 2005, p. 2). The need to express such ‘authentic individualism’ became the focus, Taylor suggests, “as well as moral/spiritual and instrumental individualism, we now have a widespread “expressive” individualism” (Taylor, 2007, p.473).
spiritual landscape where many people are searching for wholeness, trying to find themselves. This ‘self-focus’ has been positively and negatively commented on, but it does not matter which approach is right,\textsuperscript{14} rather these thinkers agree that a historically unique spiritual landscape has developed\textsuperscript{15} radically influenced by scientific methods and knowledge, but which is left lacking something. It is in this context that death and dying become acutely challenged.

Taylor’s work gives a framework for seeing the place of spirituality and dying in the contemporary world. Like any meta-narrative, it is possible to find points of contention. For instance, Taylor states that “these are issues of universal human concern” (Taylor, 2007, p. 22). Universal positions on spirituality, where it is either assumed or asserted that each human has a spiritual domain, have been challenged (Schneiders, 1989). Taylor situates this universalist position with other philosophers who have done likewise. Taylor also notes in his “age of authenticity” thesis there were always some people on “a more genuine search for authenticity” (Taylor, 2007, p. 482). But Taylor is not alone in his analysis, others (Heelas, et al., 2005; Rumbold, 2002a) confirm this reading, particularly regarding the subjective turn focusing on self as authority. Rumbold warns that this “focus on consumption and self-direction may struggle in the face of death” (Rumbold, 2002a, p. 18) as many of these priorities fall away, thus Rumbold’s implied question of what is left, when that which helped to bolster ‘self’ – the material things, the internal compass – are paired away. Understanding more about death in our contemporary context may help answer such questions.

\textbf{2.2.2.1 Understanding Death}

Death has been our greatest question; community, religion and science our greatest responses to it; and dying the greatest test of both for each of us undergoing it (Kellehear, 2007, p. 65).

When one examines the life one has lived and struggles to accept that lived life, one is faced with a number of challenges and tasks of dying. .... The goal is to preserve the idea that there is still life to be lived, still time to become, so that one can die with a sense of peace, equanimity, and acceptance of the life one lived. The paradox of the end of life dynamic is that through acceptance of the life one has lived comes acceptance of death (Breitbart, 2008, p. 212).

\textsuperscript{14} Rumbold notes the stereotyping that all too often happens when talking about religion and spirituality. The “religious people are portrayed as unable to think for themselves, while non-religiously spiritual people are labelled self-indulgent or self-absorbed” (Rumbold, 2002a, p. 16).

\textsuperscript{15} See also (Bregman, 2006a)
Before commenting further on the context of contemporary spirituality, it is worth noting the place of death in this discourse. Throughout human history death has been a significant experience; it will continue to be so. This section will draw on Allan Kellehear’s extensive historical reading of death in his book *A Social History of Dying* (2007) and then consider death generally as a lens through which to examine belief, self and life. Kellehear considers the “patterns of dying throughout history” (Kellehear, 2007, p. 1), showing how we have arrived at our current ‘death zeitgeist’. The importance of this overview is to understand how and why we now ‘do death’ in the West.

Kellehear distinguishes three periods in which humans had or have a distinct understanding of dying. The first period goes back 12,000 years, when we lived for between 36 and 50 years (Kellehear, 2007, p. 19), and was a time when life and death were not seen as radically separate: death was an “otherworld journey” which started before one’s biological death and continued into the afterlife (Kellehear, 2007, p. 7 & 29). This first period was characterised by uncertainty. The second period — the ‘pastoral age’ — happened when we became farmers and early city dwellers. There was more preparation for death and the idea of the ‘good death’ developed. In the final period — the present cosmopolitan age — death is not good or well managed; it is shameful.

In the cosmopolitan age, death has moved from being “managed” to “shameful” (Kellehear, 2007, p. 218). Dementia prevalence is growing, physically painful deaths are likely (Steinhauser, et al., 2000) and degenerative diseases are the norm (Kellehear, 2007, pp. 203-208). Suicide, physician assisted death and euthanasia all become serious options in a context of dying with little dignity. Kellehear’s analysis of growing suicide rates is prescient,

> Not every old person is happy to be old, and to grow older still, so suicide is closely associated with modernity, prosperity and development with the highest rates exhibited by the elderly cited in affluent countries (Fuse 1997, Makinen 2002 in Kellehear, 2007, p. 201).

Kellehear describes the characteristics of a shameful contemporary death, calling it “terrifying” and “a rather shameful and embarrassing exit” ; he contends “most of us” will fall into this category (Kellehear, 2007, p. 212 &213). He suggests it is ‘timing of death’ that is the 21st century’s key challenge, for only the wealthy can afford a ‘good death’ and medicine cannot stop death, but does have a lot to do with when it happens (Kellehear, 2007, p. 236).
Kellehear argues one of the features of the literature on dying is an overemphasis on cancer, "a focus that inadvertently masks other major forms of dying today, especially aging and AIDS dying" (Kellehear, 2007, p. 4). This is an important point, for this study focuses on cancer. However I am very aware that many of the spiritual themes that arise below may be considered for other contemporary dying contexts.  

Death, it has been claimed above, offers a unique perspective on life. Byock suggests mortality has a didactic element, teaching us "that human life is inherently spiritual," whether or not a person has a religion (Byock, 2007, p. 437). How one approaches death is inherently linked to one's worldview, beliefs, one's spirituality in life (Cobb, 2003). This brings us back to contemporary spirituality, the place where we find ourselves dying; a place of fragile beliefs and less than ideal dying. Understanding contemporary spirituality may help to reclaim "death as a rite of passage as well as biological or medical event" (Hanks, Kaasa, & Robbins, 2004, p. 130).

2.1.1.3 Contemporary Spirituality

Spirituality has become an increasingly visible theme in the second half of the 20th century (Mahoney & Graci, 1999, p. 521). Western contemporary spirituality, evident and growing from approximately the middle of the 20th century onwards, happened within the "'disenchanted' world" (Cobb, 2001, p. 18), the cosmopolitan age, combining pre-modern (religious) and modern (science) worldviews into a postmodern dynamic (Rumbold, 2002a) marked by plurality, complexity and for many, confusion. Spirituality has become popularized (Rumbold, 2002b, p. xi; Schneiders, 1989), a "glow word" (Bregman, 2006a, p. 5), with everyone having a definition (MacKinlay, 2005). There are significant differences regarding perceptions and experiences of spirituality, not the least cultural and national. However the universalist position argues that to be human is to have a spiritual dimension; it is in this light that we proceed (Tanyi, 2002, p. 500).

16 A note about the 'death denying' culture. A common understanding, that Kellehear challenges, is that contemporary society is death denying, he argues, "we are not, and never have been, a death denying people" because the majority of people now and historically have always believed in an afterlife or "otherworld" (Kellehear, 2007, pp. 60–61). This does challenge Taylor’s assertion above that in the disenchanted world the majority do not believe in such ‘fantasies’ as the afterlife (and God) (Taylor, 2007). Perhaps it is the hegemonically powerful majority – the elite, the Academy – that do not believe. For instance in New Zealand, the majority do believe in life after death (Gendall & Healey, 2009; Gendall, 1999).

17 This position is shared by the majority of writers in the academic field of spirituality (Taylor, 2007), but it is important to note that the universal position is just that, a position, and not held by every one (Ardell, 1996).
Taylor, Heelas and others (Heelas, et al., 2005; Taylor, 2007), as explained above, situated contemporary spirituality within a historical context that was striking by the development of the ‘subjective turn’, in an ‘age of authenticity’ with a focus on self empowerment. Taylor argued that it was secularization, in his sense, meaning the “conditions of belief” (Taylor, 2007, p. 3) that led to the current spiritual topography. There are an array of additional determinants that contributed to the growth of contemporary spirituality, including globalization\(^{18}\) (King, 1996), indigenous spiritualities, human rights movements (King, 1996), feminism (Woodhead, 1993), psychology/therapy (King, 1996), religious plurality – particularly the influence of Eastern beliefs (Schneiders, 1989), lay contemporary spiritual literature (Heelas, et al., 2005), media (Bluck, 1998), new age movements/practices (Taylor, 2007, p. 512), recreational drugs, and the growth of mental illness (Rumbold, 2002a, p. 10). This list is provisional and not exhaustive, but aims to show the multi-factorial nature underlying contemporary spirituality. Contemporary spirituality includes all; it is eclectic and plural (Bluck, 1998; Moberg, 2002, p. 52); to the orthodox this is anathema, to many this is existentially confusing; to all it is a challenge (Moberg, 2002, p. 52).

Such spiritual plurality can only begin to be named with an array of qualifiers – religious, scientific, indigenous, secular, atheist, agnostic, feminist, black, gay, gaia-ian, new age, creation-centred, (Schneiders, 1989). Further it has significantly affected various sectors (some argue the whole of Western society (Bluck, 1998)) including the Academy, health, education; and appropriated for expedient conditioning by ‘the market’ (Clifton, 1999; Heelas, et al., 2005). Academically research and publication growth has gone for ‘barely noticeable’ (pre-1960) to a ‘noticeable blip’ (Moberg, 2002, p. 48), though this change amounts to exponential growth (particularly from the mid 1990s) (Sinclair, et al., 2006). In education, spirituality is mandated in curricula around the Western world (Egan, 2000). In health, spirituality is appearing with increasing regularity in policy, planning, curricula, journals, conferences and occasionally at the clinical or public health level (Sinclair, et al., 2006).

Of course there are significant, loud and powerful criticisms of this growth of spirituality. Conceptually it is challenged as not fitting into quantitative evidence based frameworks if

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\(^{18}\) Influenced by religions and the Academy, a significant site that contemporary spirituality has impacted upon is in various international, national, and sector specific policies. Health is the obvious example, and while expanded below, in New Zealand spirituality is named in the New Zealand Healthcare Strategy (Ministry of Health, 2000) and in Scotland the National Health Service mandates all their health services to consider spirituality (Murray, Kendall, Boyd, Worth, & Benton, 2004).
solely viewed from a positivist lens. I have consciously used a broad brush sweeping across
the contemporary spirituality landscape here, for below it is dissected further for more
argument and ideas from scholars across disciplines.

2.1.1.3.1 Academic Historical Links

Academic interest in contemporary spirituality, as Schneider noted, begrudgingly grew out
of theology and religious studies (Bregman, 2006a; King, 1996), then onto psychology, anthropology, sociology, history, education, health and others (Moberg, 2002). Even after
thirty years or more of research in this area, “there still seems to be more questions than
answers” (MacKinlay, 2005). Rumbold provocatively and insightfully calls this research area
“a countervailing discourse” (Rumbold, 2002b, p. x) to both religion and science. It is, he
suggests, a “shadow side of clinical science”, while paradoxically science helps facilitate the
growth of the spiritual discourse (Rumbold, 2002a, pp. 8-9).

Where, in the past, research on spirituality was considered a fringe activity, it has become a
recognised area of study. This is reflected in the growth of journals, conferences and books
dedicated to this area from the late 1980s (Schneiders, 1989, p. 677). The challenges of the
academic study of spirituality are many. Its ambiguity has been argued to be “unavoidable”
(Schneiders, 1989, p. 677), but as Bregman views it, “Clearly, lots of professionals and
researchers have sensed a need for some term or category to fill the niches which
“spirituality” now occupies” (Bregman, 2006a, p. 12). Sinclair (Sinclair, et al., 2006)
suggests a number of reasons for this growth, including recognition of the whole person, the
postmodern focus on self (de-centered authority) and subsequent focus on patient
centeredness; the place of qualitative methodologies and/or the limitations of the biomedical
focus; the growth of complementary and alternative medicines (CAM); and the holistic
influences of hospice and palliative care. Sinclair claims little evidence for most of these
suggestions. In light of Taylor’s belief framework above, it is fair to say that while Sinclair
may not have found ‘evidence’ for these reasons in his review of the palliative care literature,
the wider philosophical environment affirms his inclinations.

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19 Those writing about spirituality regularly give its etymological background, citing the Latin and Hebrew roots of the word ‘spirit’: from Hebrew – rua; Greek – pneuma; “which both signify wind or breath, a principle of vital activity” (Albanese, 1999, p. 308), see also (Bradshaw, 1994; Schneiders, 1989). Definition issues are discussed below; suffice it to say that these issues are ubiquitous in the literature (Sinclair, et al., 2006).
20 Spirituality research, historically, originated in psychological investigations, which started at the turn of the 20th century (Zinnbauer, Pargament, & Scott, 1999). (Chiu, Emblen, Van Hofwegen, Sawatzky, & Meyerhoff, 2004, p. 406)
From the religious studies/theological fields, Schneiders makes the case for the use of the term spirituality and its place as a discipline for study. She suggests spirituality is "interdisciplinary", "ecumenical, interreligious, and cross-cultural" and "a holistic discipline" (Schneiders, 1989, pp. 692 - 693), the parameters of which range from,

The psychological, bodily, historical, social, political, aesthetic, intellectual, and other dimensions of the human subject of spiritual experience are integral to that experience insofar as it is the subject matter of the discipline of spirituality (Schneiders, 1989, p. 693).

Psychology, particularly the 'psychology of religion' and 'transpersonal psychology', has long investigated religious and spiritual phenomena (James, 1902; Pargament, 1997; Wilber, 2000). A more detailed discussion of the relationship between spirituality and psychology is not within the remit of this work; suffice it to say that particularly before psychology became dominated by positivist scientific approaches, its gambit included the spiritual. Understandably sociologists likewise have had an interest in this area (Kellehear, 2007).

A significant and eclectic group of academics argue spirituality is at the heart of contemporary problems, from suicide and meaninglessness to individualism and materialism (Eckersley, 2004; Frankl, 1984; Hornblow, 1999; Swinton, 2001; Tacey, 2003; Taylor, 2007). This is the 'spiritual vacuum' or 'gap thesis' discussed above. It is argued that this 'gap' or ontic fragility is part of the postmodern condition.

Other religions have had a significant influence on Western thought. Another angle on the 'gap thesis' is Buddhist; this world was always empty – maya – or an illusion (Noss & Noss, 1994). Thus the 'gap' may be an opportunity for seeing the world 'as it is'. Likewise, for some Christians, the idea of emptiness may be an aspect of the spiritual journey. The so-called 'dark night of the soul' could be interpreted as a ubiquitous sense of meaninglessness. This perspective does not deny the 'gap' thesis, but like the holistic milieu response, offers a counter to what for some can be a black hole. Suicide is considered by many as the worst outcome of meaninglessness. Eckersley quoting Camus suggests that "suicide is a deeply existential act" and that "There is only one truly serious philosophical problem, and that is suicide. Judging whether life is, or not, worth living amounts to answering the fundamental question of philosophy" (Eckersley, 2004, p. 177). Sadly, some people, with terminal illness for example, believe their lives are not worth living: without affirming such a position, it is certainly imaginable. Eckersley's question about society generally could be asked about how
we care for our dying, "to what degree is suicide a social aberration, or an emblem" (Eckersley, 2004, p. 177).

2.1.1.3.2 Beliefs & Practice

People's contemporary spiritual beliefs, practices and experience have been usefully examined in Heelas et al's study of Kendal. Rumbold and Bregman suggest spirituality is doing the same job religion has in the past (Rumbold, 2002b, p. x). A significant aspect of contemporary spirituality is its influence across society. Some consider that pluralistic (post-modern) spirituality has entered or influenced all aspects of Western society (Bluck, 1998). It is normal everyday people reading the array of books on any and all aspects of spirituality available in our local book store. Many of us respond to the phone line astrologist, tarot reader or psychic – in 1999 $40 million was said to have been spent on such things in New Zealand (Clifton, 1999). Ward notes that Anzac Day, New Zealand’s day remembering those who died in wars overseas, is growing in popularity and "increasingly assuming a spiritual dimension" (Ward cited in Harvey, 2005).

A 1999 study asking US experts in the fields of death and spirituality studies about their definition of spirituality found, surprisingly, “Less than 30% of the death studies specialists were willing to say that a belief in God was an aspect of being spiritual, and this number dropped to almost 18 % among spiritual studies experts.” (Mahoney & Graci, 1999, p. 522).

This indicates that by the end of the 20th century, even in the US (with high Christian belief and church attendance rates), there was a strong swing away from including religious factors into definitions of spirituality. Like Bregman, Mahoney notes the increasing focus on the differences between spirituality and religion. One of Mahoney’s key points was “the meanings of spirituality are currently in flux” (Mahoney & Graci, 1999, p. 525).

2.1.1.3.3 Religious Spirituality

Before the middle of last century, spirituality referred almost solely to things religious. But out of the Christian religions spirituality developed and expanded to include religious and

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21 Heelas et al use Taylor’s work and contextualize it more specifically into the spirituality discourse. Taylor’s buffered self is an extension of his earlier concept of the ‘subjective turn’, which Heelas et al use in their book that examines whether or not the spiritual revolution thesis is right (Heelas, et al., 2005). They say it has happened culturally and in many fields, but not yet literally in religious or spiritual practice. This is relevant because if accepted, its impact on beliefs is critical. Heelas et al usefully highlight the focus of the market, education and medicine regarding ‘consumer-centred’, ‘pupil-centred’ and ‘patient-centred’ approaches being indicative of the subjective foci (Heelas, et al., 2005, p. 5). New Zealand’s spiritual landscape is not that dissimilar to the English town studied in Heelas et al’s work, thus relevant.
secular worldviews (King, 1996). While the ‘gap thesis’ has been discussed above, in the religious studies literature this was being recognised as far back as 1982 when Hansen (1982) "attributes the upsurge of interest in spirituality to the crisis of meaning generated by the events of the 1960s" (Hansen, 1982 cited in Schneiders, 1989, p. 676). The conceptual evolution of spirituality still encompasses the traditional, who understand and experience spirituality as equated with religion. Religion “is an expression of spiritual belief through a framework of rituals, codes, and practices; the sense of otherness or a power being a deity or supreme being” (Speck, et al., 2004, p. 124). Vandara gives an indicative definition of Christian spirituality which focuses on Jesus Christ and the Holy Spirit. (Vandara, 1989).

Thus, religious spirituality now is one of many spiritualities that exist alongside and overlap each other. This is not to undermine religious beliefs, nor is it forgetting the significant place Christianity has had in the West. Contemporary spirituality has affected contemporary religion in many ways, including:

- The place religion holds for many people, for example in New Zealand 55.6% still claim to be Christian (Statistics New Zealand Tatauranga Aotearoa, 2006);
- There has been a growth of non-practicing Christians (Taylor, 2007, p. 512), for example in New Zealand approximately 8–12% of the population attends Church regularly (Ward, 2001), but more than half the population call themselves Christian.
- The breakdown between religious groups (Taylor, 2007, p. 512). Exceptions do include the growth of fundamental extremists and ecumenical approaches.
- The rise in non-believers (Taylor, 2007, p. 512), from atheists, agnostics to those who claim 'no-religion'. For example in New Zealand this group has grown to 32.2% or 1.3 million people (Statistics New Zealand Tatauranga Aotearoa, 2006).
- The rise in the West of Eastern religious beliefs, partly due to immigration, but also combinations that include Christianity mixed with Buddhist beliefs (Taylor, 2007, p. 512).
- Belief in God is changing from the traditional personal God (Taylor, 2007, p. 512) to variations that include pantheistic and panentheistic beliefs.
- The radical changes that Christian denominations have made, for instance the Vatican II changes that included allowing Mass to be said in the vernacular; and the growth of charismatic and fundamentalist movements in and outside of mainstream churches.
In sum, Schneiders said contemporary spirituality, “can no longer be politely ignored either in a church which would prefer a less “emotional” approach to faith or in an academy which would guard its intellectual precincts from “subjectivism” (Schneiders, 1989, p. 676). Therefore from the middle of last century religions have recognised and to varying degrees responded to contemporary spirituality.

2.1.1.3.4 Criticisms

The concept, beliefs and practices of contemporary spirituality, in and outside of religions, have detractors. Because this concept is not captured by any school of thought, academic discipline or religion, it is expressed differently by each discourse. This is said to undermine any possibility of comparison or generalizability in research (Berry, 2005). Some scholars argue that spirituality has become meaningless as it tries to encompass too much (Burgess, 1996). This criticism often comes from religious studies academics, as does the position that laments the ahistorical nature of many of the definitions (Bregman, 2006a, p. 9), for example lacking any reference to religion or the transcendent.

Similarly, Burgess suggests, “some believe the current popularity of spirituality carries a shadow side”, citing Mitchell who argues that spirituality has become “a nebulous catch-all word referring to any kind of traffic between human beings” and some “ill defined world of the spirit” (Mitchell cited in Burgess, 1996, p. 26). This represents the view of some who fit into the religious spirituality label discussed above, which situates spirituality in the predominantly theistic definition.

The universalist claim, that all humans have a spirituality, even if they are atheists, has been criticised. Bregman glibly posits if we all have spirituality, “hospital chaplains can have care for everyone’s souls, not merely those of their own denomination or tradition” (Bregman, 2006a, p. 8). Bregman does not agree with this approach, but believes it is important to acknowledge a possible spirituality imperialism, “a kind of colonialism in the realm of ideas, and therefore ethically as well as intellectually unacceptable.” (Bregman, 2006a, p. 8). With its obvious Christian roots, some also find the use of the term, say for a Muslim spiritual experience, an imposition that potentially undermines their own religion (King, 1996).

Commodification of contemporary spirituality has also been criticised. Firstly, a spiritual seeker now has a choice in the “spiritual marketplace” (Heelas, et al., 2005, p. 1), able to pick and choose from an array of ‘tasty’ (and it is argued self-serving) beliefs (Davie, 1994). This
is seen as a shallow, expedient and even narcissistic approach to spirituality. Secondly, spirituality has been used by marketers to prey on the spiritually vacuous majority in Western societies (Bluck, 1998; Heelas, et al., 2005). Hill associates contemporary spirituality with capitalism and consumerism, as “capitalism now feeds on the enhancement and embellishment of the self” (Hill, M. cited in Clifton, 1999).

Feuerstein suggests three “erroneous notions about spirituality”: the conflation of spirituality and religion; a similar conflation with mysticism; and lastly reductionism, in this case reducing “spiritual phenomena to mere psychological or even neurological processes. ... [due to an] exaggerated scientific viewpoint” (Feuerstein, 1991, p. 200). Influenced by the Eastern religious thought, Feuerstein considers the spiritual search to be a profound obstacle, for it starts from the ego-personality premise, which he maintains must be transcended (Egan, 2000).

For some critics of contemporary spirituality, the term itself is too imprecise, so broadly used that it is meaningless. King suggests the debate may be pared down to the question, “is it useful?” (King, 1996, p. 347). This is the question, and whether one likes it or not, contemporary spirituality is here, from policy to (some) practice, democratized and challenging.

2.2.2.2.5 New Zealand context

Often considered a very secular country (Ellwood, 1993; Paulin, 2001, p. 6),22 New Zealand is a unique place on the edge of the world intellectually, culturally and spiritually. It is more appropriate to talk about spiritualities in New Zealand, rather than a New Zealand spirituality (Rumbold, 2005a), for while some generalization may be made, New Zealanders are increasingly diverse as a result of growing ethnic and religious diversity and demographic changes. Contemporary spirituality in New Zealand can be compared to other Western countries; while taking our unique qualities into account, it is fair to say Heelas et al’s conclusion that the “holistic milieu” (Heelas, et al., 2005) is seeping through most of British culture is also true here. Grimshaw says we have an “unacknowledged spirituality.” (Grimshaw cited in Harvey, 2005), while both Leibrich and Hornblow argue that the challenge regarding meaning is also true in New Zealand:

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22 New Zealand being broadly secular is a widely held position, but not universal. Stenhouse argues against it (Stenhouse, 2008, p. 79).
There is agonizing emptiness within our society that I think reflects a desperate need for meaning, relevance, something deeper in life. Some people say there is a spiritual renaissance (Leibrich, 2002, p. 156).

The most basic and urgent challenges facing New Zealand society are not economic. They are to do with our values - those activities which give meaning and purpose in our society, our social ecology, spirituality in the broadest sense (Hornblow, 1999).

New Zealand has a group of scholars from various disciplines who have written on things spiritual. Durie, Lineham, Leibrich, Geering, Stenhouse, and others come from a position distant from the centre (geographically, intellectually, experientially), one that permits unique contributions. Not least, and perhaps foremost, is the Māori perspective. While acknowledging heterogeneity, the New Zealand indigenous voice adds something unique that affects all New Zealanders and is partly responsible for the inclusion of 'spirituality' in policy: successive governments have been ethically impelled to consider Māori models of health and well-being: hauora (Ministry of Education, 1999), te whare tapa whā (Ministry of Health, 2000), te whēke (Pere, 1997), and te pae mahu tonga (Durie, 2004). Regarding New Zealand's indigenous culture, Māori or tangata whenua (the people of the land), have contributed to the spiritual discourse without peer and largely contributed to its renaissance. This area is expanded in Chapter Six below.

Academic spirituality research is still in its infancy in New Zealand. Many New Zealand scholars have come from the religious fraternity and these men and women have made significant contributions. Harvey, in a 2005 Weekend Herald newspaper article, quotes many contemporary New Zealand thinkers on spirituality. For instance, Lineham suggested, “Spirituality has replaced religion in our society; formal religion is now seen as a very negative force by many in our society, but spirituality is seen as a way for people to connect with something deeper” (Lineham cited in Harvey, 2005). Lineham’s position reflects an international perspective that sees spirituality as different from religion. Leibrich affirms this, suggesting, “Spirituality is an experience, not a religion. Spirituality is beyond doctrine, beyond cultural difference. It is something deep within our core” (Leibrich, 2002, p. 146).

23 Academic spirituality research in New Zealand may be partly judged by a search of Masters and PhDs from local universities. Such a search shows that there are 29 Masters and 7 PhD theses that include spirit* in their title. Since beginning this research, I have come in contact with a growing number of researchers doing postgraduate research on aspects of spirituality. At Otago University, for example, there were no completed PhDs concerned with spirituality before 1996, but as of 2008 there are PhDs or Masters being done on spirituality and: General Practice; Social Work; Palliative Care; Physical Education; Film; and Bioethics.
Geering, in the arena of what could be called secular spirituality and what he situates as post-Christian spirituality in an uncertain age, calls for a “global spirituality” (Geering, 1999, p. 159). Of New Zealand Geering accurately said, “New Zealand came to birth during the emergence of the Secular Age and the religious character of New Zealand has reflected the trends of that age” (Geering, 1983, p. 72). Geering suggests that there is “great reluctance on the part of the churches to acknowledge that we are entering a post-Christian age” (Geering, 1999, p. 6). However this position seems to have changed, as evidenced by the Presbyterian Church, with a number of discussion papers written exploring contemporary spirituality (Paulin, 2001; Ward, 2001) and the Bible Society of New Zealand commissioning research to better understand contemporary spirituality as it relates to Bible use (Opie, 2008).

Bluck makes a case for developing spirituality that is specifically ‘kiwi’, otherwise, he suggests, the “Coca Cola story” (materialistic individualism) will take over, Bluck thinks “the time is right for an exploration of kiwi spirituality”, but one that “has to be grounded in concrete realities rather than abstractions” (Bluck, 1998, pp. 104, 109, 111-112). Bluck’s “Coca Cola story” reference echoes Taylor’s analysis of the shallow spirituality led by materialism and individualism.

**New Zealand Beliefs and Religiosity**

Belief and participation in religious activities in New Zealand has always been relatively low, compared for instance to the United States (42% attendance weekly (Gallup Inc., 2008)). Depending on the survey, current weekly – monthly attendance is about 10% (Ward, 2001), though it may be closer to 20% (Webster, 2001) (Opie, 2008). Ward quotes early surveys and census figures to show that, until the end of the 20th century, there had not been much change: 1881 (20%), 1911 (20%), 1960 (20%), 2000 (10%) (Ward, 2001, p. 1). There has also been a notable growth of people, based on census figures, choosing the ‘no religion’ category, having increased in the census counts for the last 30 years (Paulin, 2001, p. 6). For example, the figure for people indicating ‘no religion’ in 2006 was 34.7% compared to 29.6% in 2001 (Statistics New Zealand Tatauranga Aotearoa, 2006).

In parallel with the ‘no religion’ figure, the ‘Christian’ figure has gone down over consecutive censes. Lineham suggests the figure is now below 50% when 2006 census data is analyzed (the raw data states 56.6% chose ‘Christian’) (Lineham cited in Opie, 2008, p. 9)). This is down from 60% in 2001. This was affirmed by a recent Bible Society survey, where a total of
46% of respondents called themselves Christian; notably, the percentages for older people where much higher: between 45–64 years (54%) and 65+ years (74%) (Opie, 2008, p. 10) (http://www.presbyterian.org.nz/1446.0.html).

Beliefs regarding what we now call spiritual issues (once called religious beliefs) have changed little, though in some cases have increased. Ward, based on the Massey ISSP survey (1991, 1998), notes that belief in God has increased from 29–31%, life after death from 56–60%, and regular prayer from 22–30% (International Social Survey Programme, 1991, 1998, cited in Ward, 2001, p. 6). The Social Values: A Report from the New Zealand Values Study 2005 (Rose, 2005) asked about the importance of religion and spirituality (n=2498). Sixty-one percent of respondents said that spirituality was ‘very’ or ‘rather’ important; 46% responded similarly for religion (Rose, 2005, p. 31).

A New Zealand qualitative study, funded by the Presbyterian Church, interviewed 40 non-Church attendees, including parents and children (Outside - Looking In; Researching the perceptions of non-churchgoers, 2003 February). While this was solely Auckland based, the key themes may be relevant for all of New Zealand:

1. People still believe that spirituality is important: there is something more to life than just existing.
2. Church attendance is not necessary to express your spirituality: spirituality is personal and inward.
3. Strongly negative perceptions of the Church prevent people from exploring their spirituality there.
4. The way the Church functions is at odds with people's modern lifestyle and the way they express their spirituality.
5. The Church needs to change the way it communicates and treats people if it is to be an attractive option for people on their spiritual journey (Outside - Looking In; Researching the perceptions of non-churchgoers, 2003 February, pp. 2-3).

This study concludes that “Spirituality is important” and “spirituality is defined as ‘something more’ to life than just existing: a greater purpose or meaning of some sort: a belief that one does not become ‘nothing’ on death” (Outside - Looking In; Researching the perceptions of non-churchgoers, 2003 February, p. 3). The researchers offered an interesting spiritual belief continuum ranging from “conventional” to “non-conventional”. At the conventional end, spirituality included believing but not belonging, while the non-conventional position avoided
any belief (Outside - Looking In; Researching the perceptions of non-churchgoers, 2003 February).

New Zealanders, like many Westerners, range across the continuum of religious and secular spiritualities. Lineham argues that “spirituality has new currency” (Lineham, 2005), but cannot be measured by traditional quantitative methods. The ‘Outside-Looking In’ study has shown the power of qualitative methods and is revealing regarding spirituality.

2.1.1.4 Definitions of Spirituality in the Healthcare Context?

The concept of spirituality is ubiquitous in the health literature (Sinclair, et al., 2006). How it is understood, as above, is dependent on one’s worldview. In summary, the worldview of the disenchanted sees ‘health’ biomedically or biopsychosocially; spirituality equates with religion which may be, in an atheistic way, acknowledged but rejected. A holistic (re-enchanted) worldview understands ‘health’ more broadly - biopsychosocial/spiritually or social-holistically; spirituality may be understood from a secular, religious or inclusive point of view.

With these worldviews in mind, definitions of spirituality in the healthcare literature can be understood in a useful taxonomy²⁴ (continuum or circular diagram):

1. Religious/transcendent
2. Behavioural/secular/humanist/existential
3. Contemporary inclusive/mixed/summative
4. Other (outside continuum)

More sophisticated categorizations are discussed below, as there are permutations within and across definitional categories, but what this one allows, particularly when considered diagrammatically, is a concise overview. Diagrammatically numbers 1–3 would be intersecting and number 4 to the side. Number 4, “Other” is included particularly for those who say they have no spirituality at all – which for many scholars in nonsensical as they would argue that everyone has some system of core belief, values and meaning.

²⁴ This model builds on Unruh’s, who suggests there are three approaches to the big questions in life: religious; sacred; and secular (Unruh, Versnel, & Kerr, 2002, p. 10).
There are very few definitions of spirituality in the healthcare literature that refer solely to religion. This is more a lay perception (especially in the US) among some populations that still equate spirituality with religion. Yet, apart from the minority of solely secular definitions, most contemporary definitions of spirituality do include religion as a possible aspect of spirituality.

While not common, there are some definitions that are solely behavioural, secular, humanist or existential – in the sense that they make no reference to religion. Some scholars suggest spirituality is “independent” of religion (Vance, Struzick, & Russell, 2007, p. 32) or completely devoid of religion (Barton, Grudzen, & Zielske, 2003; Geering, 2005; Lindridge, 2007).

The most common healthcare definition type is the contemporary inclusive/mixed/summative. This form is arguably the most commonly found (Berry, 2005), particularly in the palliative care literature, but also in most other health disciplines. A recent example from a UK review of spirituality and fertility is:

Spirituality refers to beliefs and practices that connect people with sacred and meaningful entities beyond themselves. These beliefs and practices often create a relationship with a supreme power, and gives meaning and purpose to life (Stuckey, 2001). Spirituality may be expressed religiously or humanistically, but within both contexts ‘personhood’ (including values and beliefs) and ‘relationships’ (with self, others and God) are the central concepts (Wright, 2002) (Roudsari, Allan, & Smith, 2007, p. 142).

Noteworthy in this definition is its mixed or “summative” (Unruh, et al., 2002, p. 7) nature. It includes nearly all the common spiritual descriptors above: beliefs, practices, connections, sacred meaning, transcendence, relationships, meaning and purpose, and values. Regarding God, the definition includes the term “God” and the less specific “supreme power”. It harks back to Dyson et al’s three relationships (self, others and God) (Dyson, Cobb, & Forman, 1997) and explicitly includes both religious and humanist approaches. It is different from many definitions only in its length (it is very long) and the inclusion of “personhood” as a “central concept”. In terms of categories, this definition is inclusive, with the exception of McGinn’s “historical-conceptual” approach, as it is not situated in a particular place, community or belief system. In terms of Rumbold’s ontological models, this definition fits into the social/holistic framework, though like many contemporary definitions, it barely mentions communal considerations – in this case the relationship with others is noted.

See also Kirkwood, 1994, (cited in Moberg, 2002, p. 49)
Further, the first sentence may not hold true for all spiritualities, for example Buddhism. Other examples of contemporary inclusive/mixed/summative definitions include MacKinlay (MacKinlay, 2005), Rumbold (Rumbold, 2005a), Tanyi (Tanyi, 2002, p. 506), Mattes (Mattes, 2005, p. 56) and Boero (Boero, et al., 2005).

Particularly relevant to New Zealand is one of the few definitions used in the health education, defining spirituality/te taha wairua as,

the values and beliefs that determine the way people live, the search for meaning and purpose in life, and personal identity and self-awareness (For some individuals and communities, spiritual well-being is linked to a particular religion; for others, it is not.) (Ministry of Education, 1999, p. 31)

This definition is from the 1999 Health and Physical Education Curriculum’s underlying concept of well-being/hauora. The curriculum writers defined well-being/hauora using Durie’s te whare tapa whā model of health (Durie, 1998b), which includes four cornerstones: physical (te taha tinana), mental and emotional (te taha hinenaro), social (te taha whanau) and spiritual (te taha wairua) dimensions. The te taha wairua definition does not explicitly name any communal or relational aspects, unless one is religious.

What is agreed in the literature is the lack of a universally agreed definition (Berry, 2005; Tanyi, 2002). The following considers some of the categorizations, commonalities, differences and critiques of the spirituality concept in contemporary health scholarship.

### 2.1.1.4.1 Categorization of definitions

Academic approaches to spirituality definitions sometimes draw upon various schema or theories to situate definitions in categories. These categorizations come from across disciplines and the scholar’s background seems to dictate the theoretical approach taken. Scholars who suggest schema or theories include: Schneiders definitions “from above...[and] from below” (Schneiders, 1989, p. 682); McGinn’s three categories (theological, anthropological and historical-contextual) (McGinn, 1993 cited in Moberg, 2002, p. 48); Ross’s two categories (vertical and horizontal) (Ross, 2006a, pp. 858-859); Moberg’s two

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26 Sourcing Principe’s (1982) historical survey of spirituality, Bergman suggests the “term is a recent invention. There is no historical use of it back before the 1980s to serve the multi-purpose roles of contemporary definitions” (Bregman, 2006a, p. 8). Principe’s analysis did not conceptualize spirituality outside a transcendent framework or one that was completely divorced from religion, this development appears to have come later in the 20th century (Bregman, 2006a, p. 9). Bregman (2006), Unruh (2002) and others find that since the 1980s there have been literally dozens of definitions (Unruh 2002 names 92), and Bergman’s analysis is that, “almost none of which seem to be concerned with social and historical contexts. Not only had the term “spirituality” become fuzzier rather than clearer over time, but the term had lost one of its moorings to its pre-1980s meaning” (Bregman, 2006a, p. 9).
categories (substantive and functional) (Moberg, 2002, p. 48); Berry’s definitional aspects (latency and multidimensionality) (Berry, 2005, p. 635); Sinclair et al’s three approaches (context driven, broad and ambiguous, concise and restrictive) (Sinclair, et al., 2006, p. 466); and McSherry offers a taxonomy, concluding there are two types of spirituality, the old referring to religious spirituality and the new “post-modern form” that is “subjective” (McSherry & Cash, 2004, p. 155).

Some hypothesize that spirituality is impossible to define or categorize and to do so is a theoretical position rather than examining the reality for people in healthcare. This position is held by McGrath who suggests that spirituality is “an essentially intangible subject” (Cawley 1997, White 2000 cited in McGrath, 2002b, p. 179). From a constructivist position that suggests all reality is contingent on subjective experience, one can understand how any universal definition would seem nonsensical.

2.1.1.4.2 Commonalities among Definitions

[T]here has been the move towards a more existential and eclectic notion of spirituality… . (Cobb, 2001, p. 126).

There are number of positions regarding the definition issue. The first argues there just is not enough semantic agreement across studies, disciplines and countries, therefore spirituality research will always be limited (Moreira-Almeida & Koenig, 2006). The alternative position suggests there are common elements in most of the definitions. For example, in Unruh’s review of the term, he argues “there is substantial agreement across authors from diverse professional backgrounds about what is meant by spirituality” (Unruh, et al., 2002, p. 9); also see review by (Chiu, et al., 2004). Therefore, while complex, research is valid, and if anything, more is needed regarding definitions (McGrath, 1999). There is a third position that simply agrees there is no consensus regarding the definition “due to its subjective and personal nature” (Tanyi, 2002, p. 501), but this does not mean it cannot be studied (Berry, 2005).

There are a range of review and exploratory articles considering definition issues in the health and spirituality literature field (Dyson, et al., 1997; Moberg, 2002, p. 50; Ross, 2006a, pp.

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27 This is arguably too simplistic, as Heelas et al note, the postmodern form of spirituality is not necessarily self-centred and materialistic (Heelas, et al., 2005) and scholars have argued for common elements/descriptors (Unruh, et al., 2002).
858-859). Often sourced, Unruh found 92 definitions which he categorized into seven themes:

1. relationship to God, a spiritual being, a higher power, or a reality greater than the self;
2. not of the self;
3. transcendence or connectedness unrelated to a belief in a higher being;
4. existential, not of the material world;
5. meaning and purpose in life;
6. life force of the person, integrating aspect of the person;

The other articles contain a broad array of descriptors for spirituality, including: meaning, connectedness/relatedness, hope, beliefs and expressions of spirituality (Dyson, et al., 1997); purpose, morality, community, compassion, forgiveness, peace, learning opportunities, charity (Mahoney & Graci, 1999); transcendence, unfolding mystery, higher power, and relationships (Tanyi, 2002); power/force/energy (Chiu, et al., 2004); core of being, religion, ultimate meaning, God (MacKinlay, 2005); love, belonging, giving, harmony/connectedness with others, nature and God, positivity, faith and belief (Ross, 2006a); quest for wholeness, and sense that there is more to life than the material (Cornah, 2006, p. 5).

In a British Medical Journal editorial, Speck noted an “increasing emphasis on spirituality as a factor contributing to wellbeing and coping strategies” (Speck, et al., 2004, p. 123). Speck then listed key words and phrases, and defined spirituality and religion:

• **Meaning**—making sense of life situations; deriving purpose from existence
• **Existential**—searching for personal meaning within one’s life, death, and concerns about freedom and isolation
• **Value**—cherished beliefs and standards of, for example, truth or thoughts
• **Transcendence**—appreciation of dimension beyond self; creative ability to rise above ‘here and now’ experience
• **Connecting**—relationships and communication with self, others, environment, higher power, the sacred
• **Becoming**—links to identity, personal growth, through reflection on life experience
• **Coping**—means of using or developing strategies in critical life events; achieving inner peace

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28 For the sake of brevity, I have just included the unique descriptors. Some of the authors had the same words, for example ‘meaning’ was common.
• **Spirituality**—the search for existential or ultimate meaning within a life experience, such as illness. (This belief usually refers to a power other than the self, which people may or may not describe as God, higher power, or forces within nature, and with which they communicate. The power helps the person to transcend the here and now, re-establish hope and the ability to cope.)

• **Religion**—is an expression of spiritual belief through a framework of rituals, codes, and practices; the sense of otherness or a power being a deity or supreme being

• **Philosophical**—relates to the same searching, but with a rejection of any influential power external to the self (Speck, et al., 2004, p. 124).

Speck et al’s summary is an example of how many scholars understand contemporary spirituality.

Finally, a very recent Canadian analysis of spirituality definitions in palliative care resulted in 71 articles and subsequent definitions (Vachon, Fillion, & Achille, 2009). These were categorized into 11 dimensions,

1. meaning and purpose in life,
2. self-transcendence,
3. transcendence with a higher being,
4. feelings of communion and mutuality,
5. beliefs and faith,
6. hope,
7. attitude toward death,
8. appreciation of life,
9. reflection upon fundamental values,
10. the developmental nature of spirituality, and
11. its conscious aspect (Vachon, et al., 2009, p. 53).

In terms of frequency, ‘meaning and purpose’ was the most common element in the definitions (Vachon, et al., 2009). Vachon then offered a definition derived from her analysis, suggesting spirituality is a “developmental and conscious process, characterized by two movements of transcendence; either deep within the self or beyond the self” (Vachon, et al., 2009, p. 56).
In summary, what is clear from this overview of definitions is that they have more in common than some authors in the literature suggest. The discussion thus far concerning the spirituality concept has by no means covered all definitions or even theoretical approaches, rather it has attempted to represent the literature fairly. The common elements will be further discussed in the spiritual needs section, as they are one in the same.

2.1.1.5 Spirituality Definition Summary

The issue of the definition of spirituality is conspicuous in this literature. There is some agreement, particularly about the relationship between religion and spirituality; they are different but connected concepts (Weaver, Pargament, Flannelly, & Oppenheimer, 2006, p. 210). The semantic variance across studies is criticized. Whatever the position, it seems schools of thought on this issue reflect as much about their ontology and methodological approaches as their particular descriptors chosen for their definition. Winslow expressed this well, suggesting that spirituality defines us (not that we define it) (Winslow, 2005). Therefore, arguably one’s worldview predicts definitional issues and subsequent research methods. If one comes from a broadly scientific, holistic and/or qualitative position, James’s comments about defining religion in his seminal *The Varieties of Religious Experience*, ring true today regarding defining spirituality,

The truth must at last be confronted that we are dealing with a field of experience where there is not a single conception that can be sharply drawn. The pretension, under such conditions, to be rigorously “scientific” or “exact” in our terms would only stamp us as lacking in understanding of our task (James, 1902, p. 45).

Further, Murray et al’s comment is indicative of this broad view, suggesting “Contemporary spirituality is eclectic and individualistic, situated on a sacred-secular continuum” (Murray, et al., 2004, p. 39). However, in a competitive funding and publishing environment, McGrath argues that when there is not a universal and comparable concept upon which to base research

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29 There are researchers and commentators from a variety of disciplines who do not believe the word spirituality is useful or challenge its universal applicability (Bregman, 2006a; Garces-Foley, 2006; McSherry & Cash, 2004; Moberg, 2002). For example, Bregman suggests that the word spirituality has become a “glow word” and argues “that the abundance of definitions hides a basic inner confusion.” and “its current “meaning” covers too much ground and fills too many roles for it to be truly coherent” (Bregman, 2006a). Bregman notes her position as a religious studies scholar, which to some degree situates her criticism. Each academic discourse that considers spirituality has a particular take on it and within religious studies it is often considered unuseful. Unruh makes the point that many parts of the secular definition, “such as meaning and purpose in life, can be readily discussed without the added layer of spirituality” (see also Kellehear, 2000; Unruh, et al., 2002, p. 10). Critics suggest definitions can be criticized for being too narrow, thereby of limited research value, or to broad thereby undermining an unique characteristics to be researched (Kellehear, 2000; McSherry & Cash, 2004; Moberg, 2002, p. 49).
and subsequent published papers, it is difficult to argue for research funding in the first place (McGrath, 2002b).

Various categorizations, commonalities and definitions of spirituality have been canvassed. The simple taxonomy at the start of this section has shown to be useful. The inclusive definition category, though not without its problems, is arguably the most common in the literature, particularly in the hospice care area. This is with some reason, as Cobb argues, “Spirituality contains a tension, therefore, in that it is expressed and experienced in distinct forms and traditions, whilst also being taken as a unifying, although pluralistic, concept which all people can be included equally” (Cobb, 2001, p. 24). For Cobb, this tension calls for an inclusive approach (Cobb, 2001).

The definitional issues are not insurmountable (Kellehear, 2000, p. 149) and it is important to have some “shared conceptual understanding” (Murray, et al., 2004, p. 39) in the field. A gold standard definition is unlikely (Berry, 2005), with measurement issues in spirituality research ongoing. McSherry argues there is a “growing acceptance within health care that such a definition [single authoritative] is not required in order to advance understanding and practice in this area” (McSherry, 2007, p. 3). In Moberg’s conclusion about definitions, he observes that “the ‘fickleness’ of academics’ inability to provide precise definitions has never prevented people from practicing it” (Moberg, 2002, p. 49).
2.1.2 Spirituality in Contemporary Society Summary

In summary, contemporary spirituality did not arise within a historical vacuum, but understanding it is no easy feat – it is complex, multi-dimensional, cross cultural, includes and is affected by old and new religions, and is dynamic. However it is not unusual that a concept is difficult to name and understand. The concept of ‘health’ has been called “the ‘mirage of health’ – a phantasmagoric state well worth pursuing but which tends to evaporate when attempts are made to achieve it or even to capture its essence” (Dubos, 1979 cited in Tones & Green, 2004, p. 1). This does not stop us using the ‘health’ concept, nor should complexity or semantic challenges shut down spirituality research (Moberg, 2002).

Contemporary spirituality has many positive sides. Eckersley calls these “countervailing” trends, which include environmentalism, feminism, and a growing consciousness of other people in the world and the spiritual side of life (Eckersley, 2004, p. 46). Science is also seen positively as the mediator between these worlds. Heelas et al had a positive reading also as they argued secularization was not incompatible with sacralisation, that society’s subjective turn did not automatically equate to selfish individualism. They noted that the spiritual revolution had happened at a cultural level allowing for a potentially holistic approach to add value to society (Heelas, et al., 2005).

The majority of scholars argue the negative aspects of contemporary spirituality do not outweigh the positives. However, there is a gap between positive holistic policy and operationalizing such policy. Further, a number of criticisms have been levelled at this broad approach to spirituality, which has the potential to be captured by the market, relativist religious positions or just end up being meaningless. Moreover, some of the research above suggests contemporary spirituality focuses on self, but this is challenged. Self-centred spirituality has been argued to be an inevitable consequence of the history of belief arriving at the buffered self living in a disenchanted world (Taylor, 2007). However, as a response to this world, a re-enchantment, a renewed approach to transcendence, has developed: one that may include God, but also other things that give ultimate meaning. Therefore, the term spirituality has a qualified affirmation from the literature. Will the use of the term and concept of spirituality work, is it helpful, particularly for people who are dying? Ultimately these are the questions that this research begins to answer. Rumbold suggests spirituality has
the potential to challenge authority (Rumbold, 2002a, p. 8). If Kellehear is even almost right regarding his shameful death thesis (Kellehear, 2007), contemporary dying needs challenging, for it is less than ideal.

For many people, particularly the young, spirituality is not top of one’s day-to-day priorities (Mason, Singleton, & Webber, 2007). However, arguably the consequences of a lack of spiritual well-being are part of the causal pathways in many people’s and societies’ contemporary dysfunctions, including mental illness (Frankl, 1984; Swinton, 2001), suicide (Eckersley, 2004), and meaninglessness (Eckersley, 2004; Rumbold, 2002a). This is the ‘gap thesis’, as perhaps there is a “collective uncertainty” in the West; (Brown, 1998, p. 1), people are “spiritually alienated” (Kohn, 2003, p. i) in the dominant pluralistic sea. These issues come into focus with imminent death. Spiritual care in this contemporary spiritual environment needs to take into consideration some of this context, for this will better allow for ‘spiritual space’ to be shared from an informed position.

2.2 The Spiritual and Health Discourses

Spirituality research in academic health discourses are many and varied,30 cross-disciplinary, and relatively recent (McGrath, 2003). Recalling the belief landscape detailed above, the history of research in this area has to some degree paralleled, influenced and been influenced by enchantment/disenchantment developments and holistic reactions. Much of the research before the mid-20th century focused solely on religion in theology and religious studies (with some in psychology). There was a Descartian influence that ghettoized religious research, until at least pre-1977 when Engel’s called for the biopsychosocial model to replace the biomedical focus (Rousseau, 2003, p. 54). Religion and spirituality were still seen as minor fields in health. Arguably it was not until the influence of the holistic milieu that research started to also recognise ‘spirituality studies’. By the 1990s, Berry suggests “evidence supporting the relationship between religion/spirituality and health had reached a level sufficient to draw the attention of researchers in many disciplines”; thus, in the US at least,
religion/spirituality moved from being a minor variable to a main variable in “federally funded studies” (Berry, 2005, p. 633)\(^{31}\) and there is now “a very large body of scientific research on spiritual–religious processes” (Boero, et al., 2005, p. 916).\(^{32}\)

Publications in this field, at least until 2000, were dominated by opinion-based papers (Chiu, et al., 2004), but also included a range of qualitative and quantitative studies. Quantitative studies are probably the dominant form, due to US funded and medically dominated research. Some have argued that hospice care has led the research, while others argue (not contradictorily) that spirituality in healthcare literature has been dominated by clinical perspectives\(^{33}\) (Rumbold, 2002b, p. x; Saunders, 2004). There are strong positions across the continuum, with the Sloan–Koenig debate at the centre (discussed below) of the clinical validity of religious care. The following review of the literature will first give a context in which to understand it, that is, a framework that helps to understand the research assumptions, methodologies, methods, outcomes and interpretations. Review articles related to spirituality and health are drawn upon to summarise this large and growing literature. Four themes (and various sub-themes) from the literature have been canvassed: lay discourse, spirituality and health issues; effects of spirituality on health; and critiques of spirituality research.

This is a research field that consciously works with and aims to improve care ‘on the ground’ (Schneiders, 1989). The vast majority of the published literature on spirituality and health comes out of the US, is quantitatively focused, and comes from a biomedical positivist tradition. As is common in this research tradition, seldom is the ontological or epistemological position made transparent. Ross notes about the nursing studies that “all of this research to date has been small in scale and is mainly exploratory and descriptive.” (Ross, 2006a, p. 860), but this is changing as this so-called “ignored dimension” (Murray, et al., 2004, p. 39) has had a 600% increase in publication rate from 1993-2003 (Stefanek, Green, & Hess, 2005, p. 450).

\(^{31}\) A growth in journals dedicated to R/S [religion/spirituality] developed from this period; Berry names nine journals. See Bradshaw (Bradshaw, 1994) for an interesting theological/historical overview of spirituality.

\(^{32}\) See also (Sinclair, et al., 2006)

\(^{33}\) Rumbold, a seasoned scholar in this field, argues that “It is clear,..., that spirituality as a concept offers ways of looking at the world that resist the stereotyping inherent in much professional practice and can restore some sense of agency to the person. (Rumbold, 2002a, pp. 18-19). This opinion is not indicative of the field, but the connection to practice is widespread.
2.2.1 Framework for Understanding Spirituality in Health

Rumbold offers a useful sociological analysis for understanding the place of spirituality in healthcare literature (Rumbold, 2007): there are three models in which spirituality is ‘understood’, including the biomedical, the biopsychosocial and the social. This model is used and developed to include the ‘holistic’ model.

In the biomedical model, health is the absence of disease; this disease is located in a body, not a person (McWinney, 1995). Spirituality is outside the purview of medical care. Spirituality is synonymous with religion, may be noted on entry into the healthcare system and attended to in a religiously orientated way via a denominational chaplain. While this stereotypes the biomedical model approach, Rumbold does name a perceived situation (Dyson, et al., 1997).

The biopsychosocial model, developed with the help of the WHO and Engel’s (Engel, 1977; World Health Organisation, 1947) challenge of healthcare’s biomedical focus. The biopsychosocial model does expand the view of health and starts to incorporate quality of life considerations. However, Rumbold argues strongly that in reality the focus is still clearly on biology or a scientifically dominated psychological approach. He notes this model does take into consideration spirituality and health, but frequently confounds spirituality with individual psychology. Spiritual assessment focuses on a person’s perceptions and beliefs, and the tools developed according to this model resemble psychological assessments. Patients’ answers to a series of standard questions contribute to an assessment of spiritual need. (Rumbold, 2007, p. 60).

In the biopsychosocial model health professionals still do all the care – often by nurses or an additional staff member. Rumbold has an implicit criticism in this model of care, for patients’ needs may be overridden with assessment methods focused on quantitative approaches.

A social model of health is Rumbold’s third and preferred approach, where spirituality “is usually treated as an aspect of culture” (Rumbold, 2007, p. 60). It situates spiritual care within the community as a determinant of health along side others such as occupation, class,

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34 Related to Rumbold’s biomedical model analysis, McGrath and others have contend that academic spirituality research and the subsequent discourses have been “marginalized” due to the dominant biomedical and biopsychosocial models of healthcare (McGrath, 2002, pp. 179; Dyson, 1997). See also Moberg who notes spirituality was thought, from a positivist point of view to be “merely a figment of folklore, myth, or the collective imagination” (Moberg, 2002, p. 48).
education, ethnicity and age. This is a public health/health promotion approach, focused on community development that sees spiritual care as the responsibility of the community or religious group rather than health professional. The social model situates ‘health’ and in this case, spirituality, not just in an individually focused and determined framework, but includes wider socio-environmental factors.

Rumbold’s social model could be expanded to incorporate what Heelas et al call the holistic milieu (Heelas, et al., 2005), so as to explicitly include holistic approaches. Rumbold may see this as artificial, but this third model could be profitably called, in the New Zealand context, te pae mahutonga, a Māori model of health (Durie, 1999; Durie, 2004).35

Rumbold does make two interesting observations about these models. Firstly, when spirituality is discussed in the context of the biopsychosocialspirtual model, as for example in Sulmasy (Sulmasy, 2002), Rumbold argues this amounts to no more than an ‘add-on’ to the biopsychosocial model (Rumbold, 2005b, 2007), with significant biological emphasis and paltry recognition of spirituality through a clinical, instrumental lens. Secondly, none of the models of health in the literature adequately articulate the reality for many people who, in Rumbold’s summary sub-title, see “health as an aspect of spirituality”, not the other way around (Rumbold, 2007, p. 61). Rumbold’s analysis is that spirituality has the capacity to “resist professional discourses that might otherwise overwhelm personal life” (Frank, 1995 cited in Rumbold, 2007, p. 61), thus spirituality enables the individual to maintain (or regain) autonomy. Therefore “a dilemma for spiritual care delivered within a biopsychosocial perspective” is that expert/healthcare professional-delivered spiritual care may be “counter-productive” to a person’s spiritual well-being (Rumbold, 2007, p. 61). While there are many critiques of spiritual care in health (Sloan, et al., 1999), Rumbold’s questions are unique and challenging.

Sulmasy’s analysis follows Rumbold’s, suggesting an “entire ‘movement’ has arisen promoting the integration of spirituality into medicine” (Sulmasy, 2002, p. 25). This movement has two camps:

35 The NZ Mental Health Foundation use Te Pae for their 2006 Strategic Plan. They describe it as follows: “Nga Manukura and Mana Whakahaere symbolise ways of working that match with the values of the Mental Health Foundation, namely Equity, Respect, Integrity, and Fairness, and with effective health promotion. Mauri Ora: Access to Te Ao Māori – Cultural Identity. Waiora: Environmental Protection – Social, Physical and Spiritual. Whaiora/Te Oranga: Participation in Society - Freedom from Discrimination. Toiora: Healthy Lifestyle and Choices (Mental Health Foundation of New Zealand, 2005).
1. One “discounts the reductivist, scientific model of medicine as “rational”, “Western”, “biased”, “narrow”, “chauvinistic”, and perhaps even toxic, seeking either to replace it or, at the very least, to complement it as a parallel universe of medical practice and discourse (Chopra, 2001; Myss, 1997; Weil, 1995).”

2. “The other camp thoroughly accepts the reductivist, scientific model, ..., appears to advocate the reduction of the spiritual to the scientific (Benson, Malhotra, Goldman, Jacobs & Hopkins, 1990...)” (Sulmasy, 2002, p. 25).

Sulmasy’s analysis could be said to lampoon and generalize the holistic approach of spirituality, but more accurately he does name a school of thought. The ‘second camp’ analysis fits into Rumbold’s biomedical or biopsychosocial model.

A pared down approach to these models is to see them along a continuum, from the biomedical to the biopsychosocialspiritual. Simplistically, the biomedical model, which has led to great advances for our physical health, treats the body like a machine, is reductionist and dualistic (mind-body). The biopsychosocialspiritual model is holistic, sees interconnections and integration between the dimensions and has elements in common with other models including: the ‘mind-body’, ‘mind-body-spirit’, Māori ‘te whare tapa whā’, Samoan ‘fono fale’ (Capstick, Norris, Sopoaga, & Tobata, 2009), and hospice’s ‘total care’.

How one understands health is significantly related to this framework. Baum suggests our “definitions of health structure the ways in which the world is viewed and how decisions are made.” (Baum, 1998). Similarly, whether or not spirituality affects health very much depends on how one defines both health and illness. For example, if, as Baldaccino asserts, health and illness need to be considered holistically, then spirituality inevitably affects and is affected by other health concerns (Baldacchino & Draper, 2001, p. 835).

Moberg, an US academic working in this field, writes on the measurement of spirituality (Moberg, 2002).

spirituality is an important contributor to physical, mental, and social well-being and that “care of the spirit” enhances it. ... Findings on its correlations with and contributions to other domains of human wellness are increasingly reported in literature of the social and behavioural sciences and the health-related professions (Moberg, 2002, p. 53).
Notable is the unqualified assertion that spirituality "enhances" other dimensions of health. This exemplifies a position now taken by many in the field — there is enough evidence to draw this conclusion. However, this is not universally held.

2.2.2 Review Articles

There has been a significant growth in review articles in spirituality and health since 1997. While not claiming complete coverage, I identified 62 published peer reviewed review articles related to health and spirituality. Of the 62 articles, from 1997-2000 (inclusive), there were three published; from 2001-2004, 28 published; and from 2005-2008, 31 published reviews.

In a US review article of trends in religion, spirituality and health from 1965-2000, Weaver et al’s conclusion may be emblematic:

Over the past 35 years, there has been a dramatic increase in the number of empirical studies that focus on the broad domain of religion, spirituality, and health. However, our analyses reveal that the resurgence of interest is almost entirely attributable to the attention devoted to the construct of spirituality (Weaver, et al., 2006, p. 211).

An analysis of the review articles shows hospice care is leading in this field (Rumbold, 2002a), closely followed by psychological and allied health. Nursing scholars and journals are also leaders in the field. This analysis is limited to subjective judgement and probable omission of existing review articles. That said, there are a large number of review articles in this relatively small field, which may indicate the newness of the field, still trying to justify itself within the publishing world and perhaps in the medical world. This is further evidenced by the number of journals with special issues devoted to religion/spirituality.

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36 See appendix B for a table with the 62 citations. Note one book is included, Koenig’s Handbook of Religion and Health, because of its ubiquity.


38 Is this a high number of review articles? It depends, not compared to cancer and QoL, which had “more than 500 review articles on the subject found in Medline between 1996 and 2006” (Moadel, Morgan, & Dutcher, 2007, p. 446).

39 Marks notes the following in the five years between 1999 – 2004: “These recent special issues include Journal of Health Psychology (vol. 4, no. 3), Journal of Men’s Studies (vol. 7, no. 1), Journal of Marital and Family Therapy (vol. 26, no. 2), Journal of Family Psychology (vol. 15, no. 4), two issues of Journal of Family Psychotherapy (vol. 13, nos. 1–4), Michigan Family Review (vol. 8, no. 1) and American Psychologist (vol. 58, no. 1)” (Marks, 2005, p. 173).
2.2.3 Lay Discourse (spiritual recovery)

Patients have identified a desire to have their spiritual needs addressed by various health professionals (Sinclair, et al., 2006, p. 479).

A notable aspect of spirituality research are the findings (and opinions) that there is a “client led recovery of spirituality” (Tacey, 2005) in healthcare (Parrott, 2004). A number of studies suggest patients want their spirituality addressed in medical contexts (D'Souza, 2002; McCord, et al., 2004; Murray, et al., 2004; Sinclair, et al., 2006). If this is true, perhaps this reflects the re-enchantment reaction discussed above; or in Rumbold’s terms, people coming from a social-holistic worldview are asking that their ‘whole’ self be considered in healthcare.

In a Scottish qualitative study, Murray et al interviewed 40 patients with terminal illness and carers over a year every three months, resulting in 149 interviews. Of the many findings, three sit in uneasy tension: the participants were reluctant to talk about spiritual issues; healthcare professionals “lack the necessary time and skills to uncover and address such issues”; and “Spiritual concerns were important for many patients … both early and later in the illness progression” (Murray, et al., 2004, p. 39). The tension is that patients seemed to want spiritual care, but the healthcare professionals do not have the capacity to meet this need.

In a US quantitative study, 921 participants were asked when it was appropriate for doctors to ask about spirituality; 83% wanted “physicians to ask about beliefs in at least some circumstances. The most acceptable scenarios for spiritual discussions were life-threatening illnesses (77%), serious medical conditions (74%), and loss of loved ones (70%)” (McCord, et al., 2004, p. 356). Further, the study found 91% of respondents had not had any enquiry about spirituality. The authors conclude the need for spiritual care increases with illness severity and suggest four predictors of those who want to talk about spirituality:

1. having beliefs that provide hope during times of illness,
2. having beliefs influencing a health care decision,
3. being 30 to 64 years of age, and
4. rating oneself as more spiritual (McCord, et al., 2004, p. 359).

40 Murray quotes a UK study that claims that 76% of people in Britain are aware of the spiritual dimension in their lives (Hay et al, 2000 cited in Murray, et al., 2004, p. 39).
In D'Souza's small quantitative study of Australians experiencing a psychiatric illness, 79 patients completed a six question survey asking about spiritual attitudes and needs. Eighty-two percent of these thought their therapist should be aware of their spiritual beliefs and needs. D'Souza contrasted this with a New Zealand finding that only 11% of patients had been asked about their spiritual needs (de Beer, 2000 cited in D'Souza, 2002). This gap between 11% of therapists asking about spirituality and the 82% of patients wanting it, D'Souza calls the “spirituality gap” (D'Souza, 2005).

There is still a need for more study to reach firm conclusions on lay perceptions of the need for spiritual care in healthcare (particularly in New Zealand). But there are arguments, philosophically and evidentially, that many people today, in appropriate circumstances, want spiritual care during illness.

2.2.4 Spirituality and Health Issues

2.2.4.1 Religion and Health

It appears that being religious is good for your health\(^4\) (Koenig, McCullough, & Larson, 2001). Vachon suggests the majority of research in this field considers religion and health, as opposed to the connected but broader concept of spirituality (Vachon, 2008, p. 219). The many studies about religion and health have mixed results, and polarized views on these. The majority of scholars from the US feel confident there is a positive correlation between religion and other health variables (Chatters, 2000). This is most obvious in Koenig’s book the *Handbook of Religion and Health* (Koenig, et al., 2001); his review article concluded “the vast majority of research completed to date indicates that religious beliefs and practices are associated with better mental and physical health” (Koenig, 2001, p. 333). Pargament affirms Koenig’s findings, concluding “positive methods of religious coping (e.g. seeking spiritual support, benevolent religious reappraisals) were associated with improvements in health." (Pargament, Koenig, Tarakeshwar, & Hahn, 2004, p. 713). In relation to cancer, it is surmised that, while religion may be protective, the mechanisms involved are not clear and

\(^4\) Prayer has been studied, and mostly shown not to work – but the ‘work’ in this context means some verifiable physical change – which comes from a narrow biomedical frame of reference. There are significant ethical issues regarding prescribing ‘religion’ and prayer with patients, but Koenig has suggested this would be beneficial in the right circumstances (Koenig, 2001, p. 321). This is controversial and challenged by Sloan et al (Sloan, et al., 2000) (see below for more discussion regarding spirituality and ethics). Religion is still a significant force in the world in developing countries, in some developed countries (particularly the US), and in most Western countries with increased immigration. It cannot be discounted in the contemporary spirituality discourse.
may have as much to do with the social and behavioural aspects related to religion, like positive lifestyle behaviours (Koenig, 2001). Not all studies have shown a positive association with religion. Pargament notes a number of negative religious coping methods, including "punishing God reappraisal, interpersonal religious discontent" which were "predictive of declines in health." (Pargament, et al., 2004, p. 713).

The relationship between spirituality and religion is, after definitional issues, one of the most common in the literature (McGrath, 2003; Sinclair, et al., 2006). The majority of scholars agree the two concepts are related but different (Sulmasy, 2002; Weaver, et al., 2006). Religion has existed longer as a concept; prior to the 1960s (or thereabouts), spirituality was within the religious ambit. After this period, spirituality increasingly gained independence and evolved semantically to the point that, for most scholars, religion is now a more formalized expression of spirituality. As Fisher notes, there are, however, variations on these interpretations.

Vachon suggests spirituality is often seen as more individually focused than religion and more about existential issues (Vachon, 2008). This is consistent with the Taylor/Heelas discussion above regarding the subjective turn in Western society. Traditionally, and still for many orthodox believers, spirituality includes a personal relationship with God within a religious structure, including worship, prayer and communal aspects.

Rumbold notes the "continuity between religion and spirituality in both content and function" (Rumbold, 2002a, p. 17), suggesting that religious language, resources and fundamental questions/needs are all part of contemporary spirituality. The difference between the two concepts became more pronounced in the late 1990s, but for many there was a "commonly held view" that they were the same (Dyson, et al., 1997, p. 1186), in the US at least. Demographics do determine conceptions of spirituality and religion: it may depend on the country (the US is more likely to conflate the two concepts); the culture (indigenous cultures tend to have a traditional and reclaimed view incorporating a broad view of spirituality); the age range (it appears older people conflate the concepts more readily); or conditioning (filial religious or spiritual practice influence one's position). Dyson does note the relationship needs to be addressed carefully in the clinical context, "It should not be assumed that spirituality is either synonymous, or coterminous, with religion, and it is suggested that to adopt this restrictive view is unhelpful in the provision of individualized care" (Dyson, et al., 1997, p. 1183).
Of interest is a major German and English systematic review of the literature on religious/spiritual beliefs on bereavement. Becker et al found that “only a fifth of the studies differentiated between religious beliefs and spiritual beliefs and addressed the issue of definition” (Becker, et al., 2007, p. 214). They concluded the “concepts of religion and spirituality are often not clear-cut, and defining the terms is difficult (Becker, et al., 2007, p. 214). This is an outlier position because most scholars suggest studies do address definition issues. However, the US tends to conflate religion and spirituality more readily; potentially more of the bereavement studies originate there.

One of the reasons many argue for the religious dominance of this research field is because of measurability. Religiosity is made up of the measurable components of religion: attendance, frequency, and commitment. Some scholars, notably Koenig et al, argue from a positivist quantitative point of view that only religion can be validly studied, as there are too many confounders and tautologies when researching spirituality (Moreira-Almeida & Koenig, 2006).

As noted above, religion is, in some cases, vilified in the spirituality and health literature (Mann, 2006). Leibrich exemplifies not vilification, but a criticism deemed appropriate by many,

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\text{Religion shapes our spiritual experiences because it is linked to culture, upbringing, a sense of history, but it is not the experience itself. ... It can actually create a barrier to sharing spirituality. Doctrine can also be a divider. An excuse for wars. Spirituality is a connector. A reason for peace (Leibrich, 2002, p. 146).}
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The problem with concepts of religion and spirituality is, from Berlinger’s point of view, “it is abundantly clear that the terms “spirituality” and “religion” are still frequently conflated, by researchers, clinicians, educators, and commentators, contributing to misunderstandings and frustrations on all sides” (Berlinger, 2004, pp. 687-688). This position is more representative of the US (McCord, et al., 2004) than research in this field from other countries, but, as the majority of research publications originate there, this opinion must be taken into account.

The universalist position that all humans are spiritual is often expressed colloquially in the “contemporary apophatic catchphrase, ‘I’m not religious, I’m spiritual’” (Berlinger, 2004, p. 681). Similarly, Heelas et al note that “increasing numbers of people now prefer to call themselves ‘spiritual’ rather than ‘religious’” (Heelas, et al., 2005, p. 1).
Of no doubt is that there is a “religious spirituality” (Berlinger, 2004, p. 691) discernable and lived by many.

2.2.4.2 Universalism

The vast majority of the spirituality and health literature recognises that spirituality is a universal human dimension and experience (Baldacchino & Draper, 2001; Moberg, 2002). Yawar says it is “a concept globally acknowledged” (Yawar, 2001, p. 529); Sinclair concludes saying “it is also a chord that can serve to bind humanity together.” (Sinclair, et al., 2006, p. 474); Tanyi calls it “an inherent component of being human, and is subjective, intangible, and multidimensional” (Tanyi, 2002, p. 500).

However, some argue that this universalism is a normative value judgement (Moberg, 2002, p. 49) and an “assumption” (Berry, 2005; McSherry & Cash, 2004). Berry distinguishes between universalistic and particular approaches to measurement: the former a “broad view of spirituality” relevant to all; the later measures particular aspects of spirituality relating to specific groups “of like-minded people” (Berry, 2005, p. 637). This is similar to the religiosity and spirituality measurement issues.

As an alternative to claiming every human being has a spirituality, Sulmasy’s qualification may be helpful: he suggests, “everyone who searches for ultimate or transcendent meaning can be said to have a spirituality” (Sulmasy, 2002, p. 25). This begs the question that if you do not ‘search’, do you not have a ‘spirituality’?

2.2.4.3 Spirituality – Culture, Ethnicity, Gender

This research does not focus on culture, ethnicity (other than Māori) or gender, however it would be arrogant to suggest that these issues do not affect spirituality. For instance, we know African-Americans (Johnson, Elbert-Avila, & Tulsky, 2005) and Pacific Island New Zealanders (Statistics New Zealand Tatauranga Aotearoa, 2006) are more religious, quantitatively, than their compatriots. In the UK, women go to church more often and attend holistic practitioners more often then men (Heelas, et al., 2005); William et al say the same is true in Australia (Williams & Sternthal, 2007).
While this study primarily focuses on Western\textsuperscript{42} spirituality and health discourse, it is naive not to be cognisant of non-Western angles. This is partly due to immigration and refugee communities in which many people may view health “complaints as having spiritual aetiologies” (WHOQOL-SRPB Group, 2006, p. 1487). Contemporary spiritual lay literature also suggests this connection (Chopra, 1990).

\subsection{2.2.4.4 Spirituality – Psychology relationship}

There is an implicit, occasionally explicit, difference of opinion (and probably worldview) between the biopsychosocial (Engel, 1977) and the biopsychosocial spiritual models (Sulmasy, 2002). Central to this are the differences and similarities of the psychological and spiritual dimensions.\textsuperscript{43} A framework to help understand the relationship(s) between these dimensions can be understood historically or ontologically.

Historically the relationship has been described as “at best, an ambivalent relationship” (Parks, 2005, p. xi), with a variety of key scholars expressing current positions on it (Unruh, et al., 2002, p. 10) (Emmons, 2006, p. 2; Jim, Purnell, Richardson, Golden-Kreutz, & Andersen, 2006, p. 1368; Macdonald & Friedman, 2002; Pargament, 1997; Wilber, 2000). Arguably there are three historical periods: the religious-psychological (James, 1902), the scientific-psychological\textsuperscript{44} (Krok, 2008) and the holistic-psychological (Moss & Dobson, 2006).\textsuperscript{45} There are overlaps and outliers, but the development moves from William James,

\textsuperscript{42} Culture and spirituality are inextricably connected. One could argue that they are synonymous, however this author would not. What is the relationship between spirituality and culture – which comes first – which is a subset of the other? These are critical questions. Braun’s definition is interesting: “Culture, in its broadest sense, refers to the worldviews, values, norms and behaviour guidelines shared by a group of individuals” (Brislin, 1993 cited in Braun, Pietsch, & Blanchette, 2000, p. 3). At least two aspects of this definition, ‘worldviews’ and ‘values’, have also been used in definitions of spirituality. Perhaps the answer to the questions first asked is, as always, it depends – on ontology and definitions. For instance, if one accepts broad definitions of these concepts and not only accepts but expects crossover between them, then there are no semantic problems. Braun et al.’s analysis of multi-culturalism and how the dominant US culture (including the health system) clashes with non-dominant cultures is relevant and has resonance for other countries (Braun, et al., 2000, p. 5).

\textsuperscript{43} For a sophisticated analysis of religious studies and psychological approaches to spirituality see (Bregman, 2006a).

\textsuperscript{44} The historical roots of spirituality and psychology are often pointed out as indicative of the differences. That is, psychology (if seen from the science-psychology view) has its roots in empiricism, the natural sciences, the objective study of the mind and behaviour, whereas spirituality’s roots are in religion, the non-verifiable, faith-based, and subjective-personal arena. Generalizing, spirituality accepts and even affirms that life is mysterious; the psychological argues the mysterious processes just have not been studied enough to be understood empirically.

In an interesting note that comments on the semantic changes in psychology and spirituality, Bregman suggests that if Kubler Ross was working today, she would be in the spiritual, not the psychological field, (Bregman, 2006a, p. 20).

\textsuperscript{45} Moss et al’s review article offers a very good overview of incorporating religion and spirituality into psychological care at end-of-life (Moss & Dobson, 2006). They explicitly adopt the biopsychosocial spiritual
who recognised religious/spiritual experiences as part of the human condition, to Krok and others, who understood spirituality to be a psychological phenomena, and then to the re-enchanted approach of the humanist or transpersonal psychologists (Wilber, 2000).

The ontological approach can be understood from Rumbold’s framework of biomedical, biopsychosocial, and social/holistic models — the spiritual-psychological debate is usefully qualified by this. Simply conceptualized, if biomedically understood, spirituality is outside any clinical frame of reference, and the psychological is tolerated. From the biopsychosocial point of view, spirituality is either seen as ‘mumbo-jumbo’ or can be incorporated by reframing the spiritual as part of the psychological domain. Lastly, in the social/holistic model, spirituality is understood as a distinct (or integrative) factor in humans. This has similarities to the historical approach, as the biomedical worldview is virtually synonymous with the scientific-psychological period.

Those who acknowledge spirituality positively inevitably come from a biopsychosocial/spiritual or social/holistic frame of reference. Then the two domains, spirituality and psychology, will be acknowledged as semi-permeable, but spirituality is distinguished by it’s ontology which may be cognisant and sympathetic to the metaphysical (Cobb, 2001).

For some, mental health is different from psychological health. There has been a burgeoning literature on spirituality and mental health (Swinton, 2001), and contemporary mental health definitions (outside of medical, psychological and psychiatric circles) often include spirituality46 (Lindridge, 2007). In short, within mental health, particularly among non-government organisations and service users, spirituality is being recognised and mandated in care.

In summary, spirituality and psychology have different historical roots and ontological bases. Spirituality has an integrative, relational, and transcendent foci; psychology has a biomedical model (indicative of the holistic-psychological period) and subsequently claim that to not attend to a patient’s spirituality is unethical, with the proviso that “should a psychologist choose to incorporate explicit aspects into the therapy process, it would be best for the patient and psychologist to have similar belief systems” (Moss & Dobson, 2006, p. 293). This is a debatable point, for some would argue that the universal nature of spirituality would allow for dominant commonalities to facilitate therapy.

46 For example, an Australian review used this definition: “Mental health is the embodiment of social, emotional and spiritual wellbeing. Mental health provides individuals with the vitality necessary for active living, to achieve goals and to interact with one another in ways that are respectful and just (VicHealth 2005b, p 7 cited in (Keleher & Armstrong, 2005, p. 13)).
/positivist/reductionist and cognitive foci. The two fields have a different interpretation and solution(s) to individual and societal dysfunction; for instance cognitive-behavioural therapy has been presented as cure-all for personal dysfunction, while a spiritual analysis may ask questions about personal meaning and purpose. Academically there is a gulf between them: in most textbooks of psychology, the spiritual is a minor subject or absent entirely (Carlson & Buskist, 1997).

2.2.4.5 The Numinous/Paranormal and Spirituality

In the mainstream spirituality and health literature there is a dearth of studies and very little written about the metaphysical, numinous or paranormal aspects of spirituality or spiritual experience (Baldacchino & Draper, 2001; Berry, 2005; Bregman, 2006a; Schneiders, 1989). Part of the challenge is that the metaphysical does not fit well into current paradigms (particularly biomedical, but the evidence also suggests the biopsychosocial and social/holistic views) (Bradshaw, 1994). In the palliative care literature, one of the few exceptions is Fountain’s article, where such experiences are defined as hallucinations, seen as a probable side effects of morphine (Fountain, 2001). A number of scholars who have canvassed this from a range of fields, including psychology and sociology (Betty, 2006; Kellehear, 2007; Macconville, 2006; Macdonald & Friedman, 2002, p. 111; Markides, 1994; Mason, et al., 2007; Wardell & Engebretson, 2006; Witte, van der Wal, & Steyn, 2008). US nurses are considering these issues clinically (see their manual Readiness for Enhanced Spiritual Well-being (Witte, et al., 2008)). A US study developed a “Taxonomy of Spiritual Experiences” essentially about mystical experiences (Wardell & Engebretson, 2006). Mason et al, in an excellent Australian mixed methods nationwide study (Mason, et al., 2007), found that 20% of all surveyed populations believed in various phenomena, that they named “alternative spiritual beliefs” (Mason, et al., 2007, p. 158).

From some scientific, quantitative or positivistic points of view, the metaphysical world is “not merely unknowable or irrelevant, but ... nonsensical...” (Bradshaw, 1994, p. 42). This is completely rational from a disenchanted point of view. Most of the papers cited in the section above come from a (re)-enchanted worldview that accepts unseen spirits as reality. What is ‘right’ and ‘true’ may not be the issue, but rather what is the reality for those involved and do such experiences help or hinder healing?
2.2.4.6 Spirituality and CAM

Complementary and alternative medicines and spirituality are under-researched (White & Verhoef, 2006). This is based on the position that many people use CAM to heal themselves: from Canada, White et al suggest “up to 25% of men with prostate cancer use spiritual or mind-body practices” (White & Verhoef, 2006, p. 117). Kaplar et al, in the US, suggest it is much higher: “According to the National Cancer Institute (2000), 83% of cancer patients surveyed reported using at least one form of CAM during their treatment” (Kaplar, Wachholtz, & O’Brien, 2004b, p. 40). CAM is a significant element in many people’s therapeutic arsenal (Heelas, 2006; Kaplar, et al., 2004b) and spirituality may be a bridge between mainstream medicine and CAM (Rumbold, 2002a, p. 8).

2.2.4.7 Spirituality and Aging

Spirituality and aging is an obvious area for research; many scholars have shown that in the latter part of life reflection and consideration of the big questions in life are more likely to occur (Vance, et al., 2007, p. 26).

Vance, in a review article, suggests,

Favorable outcomes have been attributed to religiosity and spirituality in older adults. Such outcomes include buffering older adults from difficult circumstances (e.g., poverty, health concerns) and improving their quality of life by providing meaning and purpose (Vance, et al., 2007, pp. 25-26).

Vance sources Heintz and Baruss (2001), who found older adults “scored higher in nearly all areas of spiritual expression.” When analysed, spirituality and religiosity were shown to be separate phenomena (Vance, et al., 2007, p. 26).

Residential care for the elderly is an increasing option for Western societies’ elders. The quality of life in these institutions is mixed at best (Kellehear, 2007) (Grudzen, 2003), but is also seen as a context for significant spiritual growth (Barton, et al., 2003).

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47 See Thompson et al, a UK group — the Association of Palliative Care CAM Task Group — for more information on outcome measures that are relevant for hospice/palliative care (Thompson, et al., 2008).
48 See this article for a full discussion of spirituality and aging issues.
2.2.4.8 Quality of life (QoL) research

It is suggested that SRPB [spiritual, religious, personal beliefs] should be more routinely addressed in assessment of QoL, as it can make a substantial difference in QoL particularly for those who report very poor health or are at the end of their life (WHOQOL-SRPB Group, 2006, p. 1486).

Quality of life (QoL) research is an area of research that has begun to take the spiritual dimension seriously, as a growing body of peer reviewed articles point to a positive and important relationship between spiritual beliefs and other domains of quality of life in health (O'Connell & Skevington, 2007, p. 77). QoL measurements previously focused on negative dimensions, thus spirituality/religion was often left out, to the detriment of some populations (O'Connell & Skevington, 2007).

The change to include spiritual and religious dimensions may be due to the policy development that focuses on the patient. Such ‘patient-centred’ paradigms increasingly include all dimensions of health and well-being. O'Connell and Skevington suggest there are challenges in QoL spirituality measurement. These include “a concern that spirituality and religion might overlap with other domains, particularly the measurement of psychological and social areas” (O'Connell & Skevington, 2007, p. 79). However they conclude suggesting a “case could be made for routinely addressing the spiritual needs of the general population, as an integral part of health screening,” (O'Connell & Skevington, 2007) and “Our results point to the conclusion that it is possible to assess spirituality and other existential issues connected with health” (O'Connell & Skevington, 2007, p. 84). They do note the relationships between domains still needs investigation, but that measurement is possible. Boero, in an Italian study of QoL, sources two studies that showed “non-spiritual groups reported significantly lower levels of QOL and life satisfaction than spiritual ones” (Riley et al., 1998 and WHOQOL Group, 2002 cited in Boero, et al., 2005, p. 916).

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49 Quality of life is a multi-dimensional concept that usually contains the physical, social and mental domains; with the spiritual domain increasingly being included (O'Connell & Skevington, 2007).

50 O'Connell and Skevington’s review article is an excellent overview. They situate spirituality in the WHO context, going back to the 1945 widely used definition which expanded health beyond the physical to include the mental and psychological. In 1983 the WHO considered the expansion of the definition of health to include spirituality. The debate on this process is a fascinating one and well documented in a United Nations report (Luedemann, 2005). While not changing the overall health definition in 1983, the following year “the spiritual dimension became part of WHO Member States’ strategies for health” (Boero, et al., 2005, p. 915). Spirituality was later included in the WHO palliative care definition (World Health Organisation, 2002) and more recently in the WHO QoL measurement tool (WHOQOL-SRPB Group, 2006).

51 See also (Boero, et al., 2005)
Adding weight to including the existential/spiritual facet in QoL measurement, a recent Canadian nursing study by Low and Molzahn, which considered predictors of QoL, “found that ... meaning in life directly and positively influenced QOL” (Low, 2007, p. 141). Further, Balboni et al, a US oncology team, quantitatively examined religion, spirituality and QoL. They sourced a range of studies and claim “Between 50% and 95% of cancer patients view R/S [religion/spirituality] as personally important” (Balboni, et al., 2007, p. 555). Their own study’s details included: n=230 people with advanced cancer, 63% response rate, US$25 compensation and measures included McGill QoL, Pargament’s Brief RCOPE, and questions on attendance and R/S support. The most interesting result was that religious and spiritual needs were important, but neither religious communities nor the medical system met these needs: “72% reported that their spiritual needs were supported minimally or not at all by the medical system” (Balboni, et al., 2007, p. 555). This was further complicated by the finding that religious and spiritual support (by religious communities and/or the medical system) was significantly associated with QoL. The results of this study need to be seen within their context, that is, a very religious Christian church-going community (compared to New Zealand for example). Even with this qualification, the results remain relevant.

Not all recent QoL studies that include spirituality have shown an association. Anita et al, in Canada, examined QoL in older adults (n=426). They used the WHOQOL-100 measurement tool and found “spirituality was not a significant factor contributing to QOL in this sample, and that the strongest predictors of overall QOL were social support and health satisfaction” (Anita, 2007, p. 32).

Naturally in this controversial field there have been detractors, most notably Moreira-Almeida & Koenig (Moreira-Almeida & Koenig, 2006). They challenged the WHOQOL-SRPB Group et al’s results, particularly related to mental health. Essentially their criticism suggested a tautology had been created by comparing spirituality items (like hopefulness and meaning and purpose in life) with psychological well-being (which arguably measures similar things). Moreira-Almeida & Koenig argue this is the case for a number of commonly used QoL measures that include spirituality (“such as the Spiritual Well-being Scale (SWBS) (Paloutzian & Ellison), Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being (FACIT-Sp) (Brady, Peterman, Fitchett, Mo, & Cella, 1999)” (Moreira-Almeida & Koenig, 2006, p. 844)):

These instruments include questions that tap psychological well-being, mental health, meaning and purpose in life and altruistic values that confound any findings where mental health is the outcome. Is it not surprising that
psychological health is correlated with psychological health? (Moreira-Almeida & Koenig, 2006, p. 844)

This is a criticism that needs to be carefully considered. What are the ontological frameworks of these two positions? Arguably, WHOQOL-SRPB Group et al come from a position that accepts the biopsychosocialspiritual model with some semi-permeability between dimensions — Rumbold’s social-holistic model. Moreira-Almeida & Koenig fit more into a biomedical model that acknowledges spiritual influences, but as far as research goes, requires that demarcation of variables is critical for true associations and comparability, therefore only religiosity (measurable items such as church attendance and prayer frequency) is measurable. There are issues with both positions. The former is attempting quantitative measurement of spirituality with variables that are possibly confounded with psychological health. The latter dictates a narrow research field for spirituality, which, in contemporary parlance, ends up only considering ‘religious spirituality’. Despite the criticisms, in many cases spirituality continues to be positively associated with QoL (Zavala, Maliski, Kwan, Fink, & Litwin, 2008).

2.2.5 Association of Spirituality on Health

2.2.5.1 General Comments

This section examines the following: general comments about measurement and assessment issues; qualitative studies; quantitative studies; mechanisms; method challenges; and mixed methods. Spiritual assessment at the clinical level will be considered in the next section, however Rumbold’s suggestion that it “must be a process, not merely an event” (Rumbold, 2007, p. 61) challenges the field. Before detailing particular studies, there are a number of general comments about the published studies.

2.2.5.1.1 Multi-disciplinary

Spirituality research, as it relates to health, is conducted in a number of disciplines, including philosophy (Taylor, 2007), medicine, nursing, psychology (Pargament, 1997), religious studies, social work, occupational therapy, religious gerontology (Emmons, 2006, p. 4) and chaplaincy (Wright, 2001). However these disciplines do not always work across boundaries, tending to publish in their own journals (Chochinov & Cann, 2005). There is also an ever growing publication list of books on popular spirituality (Mahoney & Graci, 1999).
2.2.5.1.2 Christian Bias and Religiosity Dominance

A number of scholars have noted the majority of participants in these spirituality/religiosity studies come from a Christian background (Becker, et al., 2007, p. 215; Cornah, 2006). This is especially the case in the US (Chochinov & Cann, 2005; WHOQOL-SRPB Group, 2006), which does challenge much of the work's relevance to places and peoples of other spiritualities (Moberg, 2002). Further, this bias is compounded as the researchers themselves tend towards Christian “ideological values” (Moberg, 2002, p. 50). This partly explains why up to the end of the 20th century the “vast majority of research today that talks about spirituality, ..., examines only religion” (Koenig, 1997, pp. 70–71 cited in Moberg, 2002, p. 48).

Berry (2005) reviews the research of religiosity and spirituality from the late 1800s to the end of the 1900s, including such authors as Durkheim, James, Starbuck, Frankl and Allport. Berry notes the early research reflected “Western and Judeo-Christian conceptual frameworks”, had “limited nomenclature”, the “supernatural was marginalized”, and viewed religious and spirituality research in a “reductionist, mechanistic, and materialistic” way (Berry, 2005, p. 631).

2.2.5.1.3 US Bias

There is an over representation of US studies in this field, reflecting the American cultural context (Chochinov & Cann, 2005; Moberg, 2002). Sinclair et al, sourcing Chiu’s review, suggest 79.5% of the studies were US-based and only 2.4% of non-Western origin (Chiu, 2004 cited in Sinclair, et al., 2006, p. 468). This bias has been partly attributed to the privately funded John Templeton Foundation, which finances research into spirituality, religiosity and health issues. Since 1975 the Foundation has helped fund approximately 35 US medical school courses on spirituality and health (Berlinger, 2004, p. 683).

Other Western countries with a growing spirituality research community/publishing record include the UK, Canada, Australia, Sweden, and Norway. In Asia, there is some research in this area out of Japan (Ando, Tsuda, & Morita, 2007; Kawa, et al., 2003; Murata & Morita, 2006) and Taiwan (Chochinov & Cann, 2005). Generally, most research in this field is Western-based with Caucasian subjects (WHOQOL-SRPB Group, 2006).

52 See also (Sulmasy, 2002)
The contrast with the US is ever present and in tension. Most of the research is from the US where the religiosity/spirituality distinction is not clear. Rousseau makes the point that the two concepts are commonly conflated (Rousseau, 2003) and McCord notes that the high profile researcher in this field, Koenig, uses spirituality and religion interchangeably, "believing that most Americans do not distinguish between these terms." (McCord, et al., 2004, p. 357). The tension is geographic, as the profile seems so different to, for instance, New Zealand, particularly in relation to religious character and church attendance. Tacey suggested 35% of Americans consider themselves 'born again', and, rather than the US, Australians and by extrapolation New Zealanders, are more appropriately aligned with Britain regarding religious/spiritual profiles.

### 2.2.5.1.4 Secular Bias

Unruh notes a "secularization of spirituality is apparent throughout the health literature" and that "there are significant objections to this secular trend" (Unruh, et al., 2002, p. 9). Sinclair affirms this, saying, "Spirituality is emerging largely as a concept void of religion" (Sinclair, et al., 2006, p. 464). Here is another interesting tension: the majority of the research and publication comes out of the most Christian/religious of the Western countries, yet the trend is to subtract religion from spirituality. This can partly be explained by the difference between definitions (and spiritual care) and the research, with the latter still more focused on religiosity.

### 2.2.5.1.5 Patients' Perspectives

There is some literature about the patients' perspective on spirituality in health, though it has been commented that this voice is lacking (Daaleman, Cobb, & Frey, 2001). Sulmasy, a medical doctor, affirms medicine's "countless therapeutic advances", but also argues medical science reduces "the person to a specimen" and "the reductivist, scientific model is inadequate to the real needs of patients who are persons"(Sulmasy, 2002, p. 25).

The patient-centred movement in medicine is a natural ally for and way into spiritual care. Similar to Saunders re-focus on the patient, Stewart et al suggests patient-centred medicine "includes the conventional biomedical approach" and goes beyond it "to include

53 In their review article, Williams et al name the significant religious trait of Americans: “Over 90% of American adults say that they pray and believe in God or a higher being, two-thirds are members of churches or synagogues, 40% attend religious services regularly, and a majority of patients would like medical providers to discuss the spiritual aspects of their illness. Moreover, 79% of US adults believe that spiritual faith can help people recover from illness, injury, or disease” (Miller, 2003, Nicole, 1996 cited in Williams & Stemthal, 2007, p. 47).
consideration of the patient as a person” (Stewart & Weston, 1995, p. xv). The patient-centred approach, which implies caring for the ‘whole’ patient as suggested by Heelas, logically ought to include the spiritual dimension (Heelas, 2006). As it happens, it often does not transfer into practice.

Heelas comments on the British National Health Service, claiming,

‘holism’ has come to be most readily, and widely, associated with the language of ‘mind–body–spirit’. [...] And it is this association which helps explain the growth of mind-body spirituality within the ‘sub’-culture of the NHS (Heelas, 2006, p. 14).

Spirituality, according to Heelas, became important due to the “patient-centred/holistic approach” and “the value attached to subjective well-being or quality of life.” and now has become an “essential component” of care (Heelas, 2006, p. 18). McSherry suggests this move has outpaced the public’s understanding of spirituality and there is a need to listen to lay voices more attentively (McSherry, 2007). However conceptualized, the importance of the patients’ perspective cannot be under-estimated and needs more research.

### 2.2.5.2 Measurement/Assessment Generally

There are strong opinions in various camps regarding the measurement of spirituality. These opinions range from, it’s impossible to measure it (Lederberg, 1999) to, just as other complex concepts are measureable, so to is spirituality (Vader, 2006). For example, McGrath, coming from a constructivist (perhaps postmodern) position, argues “Conceptually, spirituality cannot be understood as an independent entity to be measured and recorded” (McGrath, 2002b, p. 183), whereas Sulmasy suggests, with care, measurement is useful within a raft of approaches (Sulmasy, 2002). The following will consider qualitative and quantitative studies.

### 2.2.5.3 Qualitative Studies

Qualitative research may provide an important methodological approach in that it enables the assessment of subjective experience of illness embedded within its historical, cultural, social, and spiritual contexts. (Chochinov & Cann, 2005, p. 112)

Spirituality is often referred to as the “ignored dimension”, (originally “Dubbed by Soeken and Carson (1986)” (McGrath, 2002b, p. 179)) or the “forgotten factor” (Swinton, 2001). Similarly, qualitative spirituality research is relatively recent. However, it has grown in both
academic stature and frequency (Williams, 2006). Berry’s review of the “Methodological Pitfalls in the Study of Religiosity and Spirituality” focuses on quantitative research, however the author’s comment about qualitative methods are telling, “Qualitative methods can bring greater understanding and clarity of the RS [religion/spiritual] construct through careful investigation of the phenomena as it is experienced by various individuals” (Berry, 2005, p. 638).

Qualitative studies of spirituality are considered by some researchers to be the best or even only way to gather meaningful data (McGrath, 2002b). Chochinov’s comments above about qualitative research allowing for the capture of subjective experience are important when considering spirituality — a radically subjective experience (albeit with commonality across groups of people). Canadian nursing scholars, Sawatzky et al.’s, meta-analysis of spirituality and QoL (Sawatzky, Ratner, & Chiu, 2005) suggests much of the focus has been on “defining attributes and conceptualizations of spirituality” (Sawatzky, et al., 2005, p. 154). This is not surprising in a new field where semantic issues are still (and may continue to be) of primary concern to researchers.

Williams’ “meta-summary” of qualitative studies on spirituality at the end-of-life, a US based work, examined PubMed, Medline, PsycInfo, and CINAHL for spirituality and end-of-life. 11 articles were collected, “representing data from 217 adults” (Williams, 2006, p. 407) — in qualitative terms a significant number. Williams notes “most authors reported generic research designs (e.g. In-depth interviews) as opposed to grounded theory” (Williams, 2006, p. 413). While focusing on end-of-life care, this review’s findings are of interest: most studies were US based, followed by Australia, Finland, Scotland and Taiwan. Themes extracted across the studies included:

- spiritual despair (alienation, loss of self, dissonance),
- spiritual work (forgiveness, self-exploration, search for balance), and
- spiritual well-being (connection, self-actualization, consonance) (Williams, 2006, p. 407)

Concluding, Williams notes,

The findings from this meta-summary confirm the fundamental importance of spirituality at the end of life and highlight the shifts in spiritual health that are possible when a terminally ill person is able to do the necessary spiritual work. Existing end-of-life frameworks neglect spiritual work and consequently may be deficient in guiding research (Williams, 2006, p. 407).
There is a broad range of studies using qualitative methods to examine spirituality (Emblen & Halstead, 1993; Hermann, 2001; McGrath, 2002b, 2003; McSherry, 2006). Rather than full coverage of all spirituality and health qualitative studies, those reviewed above are representative. There is some disagreement among review article authors about the dominance of qualitative literature in this field, with Sinclair et al. (Sinclair, et al., 2006) and Williams (Williams, 2006) suggesting opposite positions. Okon, another review author, affirms Sinclair’s position about the relative lack of qualitative studies (Okon, 2005). Stefanek et al., in their review article, note the growth of qualitative studies, particularly in the nursing literature (Stefanek, et al., 2005).

Qualitative methods and studies have and will continue to make a significant contribution to the study of spirituality in health and end-of-life care.

2.2.5.3 Quantitative Measurement

Measurement is fundamental to scientific progress. The value of any subsequent research hinges on the ability to accurately measure relevant constructs. ... Measurement has proven to be a challenge in the area of spirituality and, therefore, instrument development remains a high priority for the future. (Emmons, 2006, p. 4)

Quantitative measurement is the backbone, the ‘evidence base’, of biomedicine. It is the dominant method (and methodology) in science and health, receives the most funding and the quantitative ‘hierarchy of evidence’ dictates the worth of studies. The quantitative spirituality and health field has a publication, sampling and ontological bias that is US, Christian, Caucasian, and biomedically dominated (Koenig, et al., 2001; Sinclair, et al., 2006). As many researchers know this, developments to balance the bias are underway, for example, to assess the broader concept of spirituality (Egbert, Mickley, & Coeling, 2004; Peterman, Fitchett, Brady, Hernandez, & Cell, 2002). This has happened because many are aware of societal change towards being ‘spiritual’ as opposed to ‘religious’ and/or the proliferation of non-Christian religious belief systems in the West (Peterman, et al., 2002). Importantly, quantitative methods can be used by those from a number of worldviews, including social-

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54 The quantitative dominance seems to be dependent on the health discipline. Cornah, in a UK review of mental health and spirituality notes these studies focus “almost exclusively on quantitative measures, which may not fully access the meaning spiritual activity has for the individual” (Cornah, 2006, p. 4). Alternatively, in the end-of-life field, William’s 2006 meta-summary notes the dominance of qualitative studies in the field to date (Williams, 2006). The probable reason for the quantitative dominance is that psychological studies, given credibility and funding within a hard science paradigm, dominate the US research on spirituality (Koenig, et al., 2001; Pargament, 1997), which in turn dominates spirituality publications internationally.
holistic (Sulmasy, 2002). Emmons’ position regarding measurement, noted above, is important, not in that more instruments are needed (in fact Rumbold argues for better use of existing measures rather than more (Rumbold, 2007)), but that measurement has been a challenge.

2.2.5.3.1 Quantitative Review Findings

Sinclair et al name relationships/associations positively correlated (pain, psoriasis, immune function, in vitro fertilization, social support, depression, QoL) with religion/spirituality (Sinclair, et al., 2006). Seeman et al’s US-based review concludes “available evidence is generally consistent with the hypothesis that religiosity/spirituality is linked to health related physiological processes—including cardiovascular, neuroendocrine, and immune function—although more solid evidence is needed” (Seeman, et al., 2003, p. 53). Seeman et al classify studies into: Judeo-Christian Religious Practices, Meditation Studies and meditation/relaxation interventions (mind/body studies). The authors name significant qualifications, including the dominant cross-sectional methods, selective sampling, and confounding issues.

From sociology, Moberg’s review article “Assessing and Measuring Spirituality: Confronting Dilemmas of Universal and Particular Evaluative Criteria” (Moberg, 2002) is an excellent US-based article. He notes, as early as 1979, sociologists were reporting theoretical, conceptual, qualitative and quantitative studies of spiritual well-being, albeit variously defined (Moberg, 2002, p. 54). Also, transpersonal psychology has dozens of measures that include or focus on spirituality. Moberg observed the increasing growth of measures and studies are hard to keep up, and names a range of instruments. Moberg notes key issues related to “the assessment of people’s spirituality” (quotes below are Moberg’s (Moberg, 2002)):

1. Investigating spirituality is very complicated, …, the spiritual side of human nature is extremely complex and multidimensional.

2. No research tool is perfect. Moberg notes the most widely used measure, SWB [spiritual well-being] scale, refers to God in 10 of its 20 questions, potentially alienating all those who do not believe in or understand the term as it is expressed.

56 Macdonald et al note there are “1,100 published studies examining the relation of spirituality and associated transpersonal constructs to psychological and physical functioning” (Macdonald & Friedman, 2002, p. 114). Their paper is an excellent overview of their field and quantitative measurement tools.
3. The indicators used to assess and measure spirituality are reflectors, accompaniments, or consequences of spiritual health, not the phenomenon itself.

4. The reification of measures, as if scale scores are the epistemically true phenomenon of spirituality rather than imperfect reflections, is similarly deceptive.

5. Reductionism is inescapable in all research on spirituality.

6. Just as feeling well physically can be an illusion, so also can feeling well spiritually.

7. Trying to satisfy everyone-in-general with universally applicable measures and evaluations may fully satisfy no one.

8. Universal measures of spirituality may oppress minorities.

9. Using only universalistic instruments to evaluate spirituality results in the loss of verified knowledge.

10. The most significant issues in assessment and research on spirituality center around validity (Moberg, 2002, pp. 53-56).

These ten points are each detailed and, combined with his "guidelines for research on spirituality", form one of the best summaries of important considerations on the spirituality and health field. Practically, Moberg argues that "The applied professions need evaluations of spirituality that are analogous to the physical and mental tests used for medical diagnoses and treatment" (Moberg, 2002, p. 47) and he argues against Koenig’s position that suggests only religiosity, not spirituality, can be validly researched,

the spiritual nature of humanity is just as amenable to empirical research as many other phenomena, such as attitudes, beliefs, self-conceptions, and feelings, that cannot be observed directly yet have become respected social and behavioral science topics (Moberg, 2002, p. 48).

Williams & Sternthala discuss the evidence and research directions of religion, spirituality and health (Williams & Sternthal, 2007). From its US perspective, what is limited about this article is it does not discuss or reference any qualitative studies. That said, what it does do, it does well — summarizes the quantitative research on religion and health. Williams & Sternthala note the positive association between religion and health found in the “over 1200 studies” examined in Koenig’s Handbook of Religion and Health (Koenig, et al., 2001).
“Religion-associated variables” have protective effects “for multiple mental health outcomes, including wellbeing, suicidal behaviour and substance misuse” and “associated with reduced anxiety” (Moreira-Almeida et al, 2006, Shreve-Neiger et al, 2004 cited in Williams & Sternthal, 2007). Sourcing widely, other conditions Williams & Sternthale positively associated with religion include: depression, alcohol and other drug misuse, smoking and sexual activity, immune system function, prayer, blood pressure, immune function, levels of stress hormone, cholesterol, religious attendance and mortality, and overall health outcomes; there is mixed data on spirituality and schizophrenia (Williams & Sternthal, 2007, pp. 47-48). The authors do qualify some of Koenig’s findings with more recent work (Williams & Sternthal, 2007, p. 48).

Williams & Sternthal, like many reviews, note the limitations of the quantitative studies, which include,

The scarcity of multidimensional, psychometrically tested measures of religion; few measures of spirituality; the widespread use of cross sectional data; potential confounding by omitted sociodemographic, social, and health variables; and a paucity of longitudinal studies (Williams & Sternthal, 2007, p. 48).

This overview of Williams & Sternthala shows the extent of the health conditions studied in relation to what they call spirituality and religion, but is essentially ‘religious spirituality’.

In their review of the concept of spirituality in the health sciences from 1990-2000, Canadian-based Chiu et al found 46 quantitative studies and 29 qualitative studies. They noted 31 instruments measuring spirituality, of which Paloutzian & Ellison’s (1982) Spiritual Wellbeing Scale (SWB) was the most popular (Chiu, et al., 2004, p. 415). Chiu et al name seven studies that used the SWB scale, each suggesting a significant correlation between spiritual well-being and various dimensions of health (Chiu, et al., 2004, p. 416). The review only goes to September 2000, but gives a good overview of measurement tools to then, including the Spiritual Orientation Inventory (SOI) (Elkins, Hedstrom, Hughes, Leaf, & Saunders, 1988) and the Spiritual Perspectives Scale (SPS) (Reed, 1987) (Chiu, et al., 2004, p. 417). From the literature, Chiu et al explain the definitions and corresponding measurements. For each of five definitional categories (existential, relational, transcendent, subjective, and expressive), they suggest a number of measurement tools.

Powell et al (Powell, et al., 2003) reported a levels-of-evidence approach rather than meta-analysis to examine the link between religion or spirituality and physical health. While testing
several hypotheses, they reported evidence is strongest and most consistent for a protective effect in healthy people, with a 25% reduction in risk of death after adjustment for established risk/protective factors (Stefanek, et al., 2005, p. 451).

Nursing scholars represent one of the largest groups publishing in this field. There are a number of reviews (Berry, 2005; Beuscher & Beck, 2008; Greenstreet, 1999; Kilpatrick, et al., 2005; Lin & Bauer-Wu, 2003; Ross, 2006b; Wong, Rew, & Slaikeu, 2006), many of which have been referred to already.57

2.2.5.3.2 Spirituality Measures

Dozen of instruments measure religiosity and spirituality58, and hundreds of instruments have one or two items. Below is an overview of a number of key measures referred to in the literature. The FACIT-sp instrument is more fully reviewed, as this measurement tool was chosen for Study 2.

INSPIRIT

An early US measurement of ‘spirituality’ is ‘The Index of Core Spiritual Experiences (INSPIRIT)’ (1991). This is “a seven-itemscale measuring the occurrence of experiences that convince a person God exists and evoke feelings of closeness with God, including the perception that God dwells within” (Kass, Friedman, Leserman, Zuttermeister, & Benson, 1991, p. 205). Kass et al examined the psychometric properties of this instrument: it showed a strong degree of internal reliability and concurrent validity (Kass, et al., 1991, p. 208). The study used self-reported measures of physical, psychological and religious orientation and tested for correlations with the INSPIRIT instrument. Positive relationships were found “between core spiritual experiences and health outcomes” (Kass, et al., 1991, p. 209). This tool reflects the context (US, Christian), with an assumption that God exists.

57 Ross’s review stands out as it is an overview of published nursing studies between 1983 and 2005. Ross notes that spiritual care has long been mandated in nursing care and there has been steep growth in this research in the US, UK and some studies from Europe. From her own collection and searching CINAL, Ross found 47 papers. The majority were qualitative and often in the oncology/hospice area. Ross notes the majority of studies are small, exploratory, descriptive, single centre, Judeo-Christian sampling, low response rates, and lack psychometrically tested instruments. Amongst other conclusions, Ross, sourcing Emblen & Halstead 1993 and McSherry et al. 2004, notes, “there seemed to be a mismatch between clinician and client/patient/carer perceptions of spirituality and desired spiritual care, which has implications for policy development and service delivery”(Ross, 2006a, p. 859). Further, Ross notes almost without exception these papers call for more and better spirituality education for nurses.

58 One of the earliest measurement tools for spiritual care was by Stool (1979) (Wright, 2001, p. 238).
Royal Free Interview for Religious and Spiritual Beliefs

King et al developed the ‘Royal Free Interview for Religious and Spiritual Beliefs’ in and for a diverse UK setting. It has been psychometrically tested, showing high reliability and concurrent validity. The instrument measures spiritual beliefs and practices (King, Speck, & Thomas, 1995). For an example of its use see (Walsh, King, Jones, Tookman, & Blizard, 2002, p. 1551).

Spiritual Well-being Scale

The Spiritual Well-Being scale (SWB) is a self-reported 20-itemscale with a religious and existential well-being subscale. It is one of the most commonly used scales, particularly in the US, despite some criticism. Douglas et al used a range of questionnaires, including the SWB and the SF36 (Douglas, Jimenez, Lin, & Frisman, 2008). Their findings affirm many of those in the field that lower spiritual well-being is associated with higher negative mental health (Douglas, et al., 2008, p. 349).

WHOQOL SRPB

The WHO has been developing validated quality of life (QoL) instruments since 1991 (WHOQOL-SRPB Group, 2006). This WHO QoL tool has recently added a spirituality section. WHOQOL-SRRB Group et al, a WHO working group, report on the usefulness (validity etc.) of the WHOQOL ‘Spirituality, Religion and Personal Beliefs’ (SRPB) tool, in a sample representing different cultures across 18 countries (n=5087) (WHOQOL-SRPB Group, 2006). The SRPB facets include:

• Spiritual strength
• Connectedness to a spiritual being or force
• Inner peace/serenity/harmony
• Meaning of life
• Hope & optimism
• Awe
• Faith
• Wholeness & integration.

For each facet there are four questions. For instance, for ‘Meaning of Life’, the first question is “To what extent do you find meaning in life?”, for which a 5-point Likert interval scale is

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59 Note, King et al have updated this instrument (King, et al., 2005).
60 See http://www.bath.ac.uk/whoqol/about.cfm for details.
used (WHOQOL-SRPB Group, 2006, p. 1489). This is a well-constructed, well-validated, cross-culturally developed and tested instrument, useful across a range of spiritual, religious and existential positions. WHOQOL-SRPB Group et al conclude, “The results showed that SRPB was highly correlated with all of the WHOQOL domains (p=0.01), although the strongest correlations were found with psychological and social domains and overall QoL” (WHOQOL-SRPB Group, 2006, p. 1486).

FACIT-Sp
The ‘Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being’ (Facit-Sp) is a “widely utilized” (Breitbart, 2002, p. 3) and “good” (Sulmasy, 2002, p. 28) measure of spiritual well-being in nine languages (Edmondson, 2008; Hills, Paice, Cameron, & Shott, 2005; O'Rourke, Tallman, & Altmaier, 2008; Szafarski, et al., 2006; Whitford, 2008). It was developed by a group who constructed the widely used and tested FACIT measures (40 questionnaires in 45 languages) of health related QoL, focused on chronic illness (see www.facit.org). The measure was developed with input from cancer patients, psychotherapists, and spiritual/religious experts “who were asked to describe the aspects of spirituality and/or faith that contributed to QOL” (Peterman, et al., 2002, p. 51). It was tested (reliability and validity were affirmed) (Peterman, et al., 2002). It was developed partly as a response to the widely used SWB scale, which was considered too Christian (Peterman, et al., 2002). Peterman et al’s paper demonstrates the FACIT-Sp is psychometrically sound and comparable with other spirituality/religiosity instruments (Peterman, et al., 2002).

A strength of this measure is it has been designed to work across cultures and spiritual beliefs, including atheists. It has two sub-scales: ‘faith’ and ‘meaning/peace’. Faith is not religion specific; in fact the two questions using the term state “I find strength in my faith or spiritual beliefs”. A five-point Likert scale gives options of “not at all” to “very much”, allowing respondents to deny faith or spiritual belief. The phrase “higher power (or God)” is used in one question; again this can be denied. Peterman et al respond to Koenig’s criticism regarding the meaning/peace subscale simply measures emotional well-being by referring to Brady et al and Cotton et al who show FACIT-sp is a significant predictor of QoL in cancer patients, even after controlling for demographics, disease characteristics and psychological adjustment (Brady, Peterman, Fitchett, Mo, & Cella, 1999; Cotton, Levine, Fitzpatrick, Dold, & Targ, 1999). Summing up, Peterman affirm that the FACIT-sp is a “brief, reliable and valid measure of spirituality” (Cotton, et al., 1999, p. 57). FACIT-sp is one of the few psychometrically tested instruments measuring aspects of spirituality/religion and health
designed specifically for research with people with chronic and/or life threatening illness. The instrument can easily be used by people without illness by changing a word in two items (Cotton, et al., 1999, p. 57).

A recent illustration of FACIT-sp is Whitford et al’s Australian study of cancer patients’ spiritual well-being (n=490/91.6% response rate). Whitford compared FACIT-sp scores with a Mental Adjustment to Cancer (MAC) scale. They found spiritual well-being positively associated with QoL and negatively with helplessness/hopelessness. They showed spiritual well-being was “a significant, unique contributor to QOL beyond the core domains of physical, social/family, and emotional wellbeing” (Whitford, 2008, p. 1121). Whitford et al concluded their results affirmed the “biopsychosocialspiritual model” and the need to assess spiritual well-being, but question the “clinical utility” of spiritual assessment (Whitford, 2008, p. 1121). Also using the FACIT-sp, Brady et al showed toleration of physical pain was higher for those who scored highly on the meaning sub-scale (Brady, et al., 1999). Breitbart et al (2000), utilizing the FACIT-sp, showed spiritual well-being to have a protective effect against depression, hopelessness and desire for hastened death among terminally ill cancer patients (Breitbart, 2002).

The FACIT-sp has been expanded into the ‘Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being-Expanded’ version. It was recognised that the first version “may not truly reflect all aspects of spiritual well-being” (Whitford, 2008, p. 1128). US-based Szaflarski et al used the extended version in an extensive study of spirituality and people with HIV/AIDS. They note the new version “showed good internal consistency reliability” (Szaflarski, et al., 2006, p. 30).

2.2.5.3.3 Negative Effects of Spirituality

Not all effects associated with spirituality and health are positive. A number of studies have shown negative aspects of spirituality, though these are mostly to do with ‘religious spirituality’. This may be because it is what is mostly measured, rather than there not being any negative aspects to the broader spirituality concept. Hills et al, in a US palliative care based study (n=31), examined spirituality and distress using a mixed methods approach that included a range of qualitative (e.g. FICA) and quantitative (e.g. Facit-sp) methods. They found that “Negative religious coping (i.e., statements regarding punishment or abandonment by God) was positively associated with distress, confusion, depression, and negatively associated with physical and emotional well-being, as well as quality of life” (Hills, et al., 62
2005, p. 782). These findings are indicative in the literature of negative coping related to religion. Hills et al recommend palliative care clinicians consider possible negative spiritual coping or spiritual distress in assessment.

In their review article, Williams & Sternthal (2007) highlight possible negative effects of religion. They contextualize it within the historical “hatred, aggression and prejudice” sometimes associated with religion (Williams & Sternthal, 2007, p. 48). They list possible negative effects: stress from religious participation, guilt from not conforming, meeting expectations, fear related to expectation (perhaps of the afterlife), use of faith healing, at the expense of medical treatment, extrinsic religious orientation and depression, and religious doubts and struggles (Williams & Sternthal, 2007, p. 48). As above, Williams & Sternthal is not an analysis of negative effects that may be related to spirituality per se, but to a particular area of spirituality, mostly associated with religion.

2.2.5.3.4 End-of-life Despair

McClain et al’s US-based study (McClain, Rosenfeld, & Breitbart, 2003) examined spirituality, depression and end-of-life despair in terminally ill patients (n=160). A variety of instruments were used, including Facit-sp, the Hamilton depression rating and the Beck hopelessness scale. Findings included “Significant correlations were seen between spiritual well-being and desire for hastened death (r = -0.51), hopelessness (r = -0.68), and suicidal ideation (r = -0.41)” and “spiritual well-being was the strongest predictor of each outcome variable and provided a unique significant contribution beyond that of depression and relevant covariates.” McClain et al concluded that spiritual well-being is “some protection” against despair for terminally ill patients (McClain, et al., 2003, p. 1603).

2.2.5.3.5 Bereavement

Walsh et al’s UK-based study examined the relationship between spirituality and bereavement. It was a prospective study, with three assessment points. The sample included 135 relatives and close friends of terminal patients. The measurement tools include: ‘The Royal Free interview for religious and spiritual beliefs’, ‘The core bereavement items scale’, and ‘The hospital anxiety and depression scale’. The authors concluded a more rapid and complete resolution of grief was more likely among those with stronger spiritual beliefs (Walsh, et al., 2002).
2.2.5.4 Mechanisms/Pathways

An important question in the spirituality and health literature is how does spirituality influence the various health outcomes claimed (Miller & Thoresen, 2003; Milstein, 2008)? That is, if it is accepted that spirituality is associated with an array of illnesses and conditions, what are the psychosocial and physiological pathways involved, or are there 'spiritual pathways'? Inherent in the first part of the question is the claim that perhaps it is just biopsychosocial effects, rather than any independent effect from the spiritual domain. Such questions come from a particular worldview. For instance, in his review article, Berry, sourcing George et al 2002, claims four mechanisms have been identified, including "health practices, social support, psychosocial resources, and sense of coherence (Berry, 2005, p. 639).

To examine the mechanisms and pathways of spirituality and other health outcomes, some scholars use existing models or develop their own (of which there is a lack (Berry, 2005)). Szaflarski et al draw on existing models and develop their own pathway to hypothesise and test spirituality and QoL outcomes.

Szaflarski et al’s model conceptualized spirituality and religion using two dimensions:

- distal ["individual behaviours (e.g., frequency of attendance at services, prayer, or mediation, etc.")], and
- proximal ["the functions of religion and spirituality for the individual (e.g., support, coping, meaning, etc.")]. (Szaflarski, et al., 2006, p. 29)

The authors hypothesized “that spirituality/religion would influence the feeling that life has improved either directly or via four mediating mechanisms: healthy lifestyle; social support; self-perception, or self-esteem; and, healthy beliefs" (Szaflarski, et al., 2006, p. 29). In summary, they concluded that half the effect of believing that life is better is directly influenced by religion/spirituality, while the “other half is indirect, mostly through healthy beliefs” (Szaflarski, et al., 2006, p. 34).

Cornah, in her mental health and spirituality review, suggests five mechanisms are discussed in the literature, including, coping styles, locus of control, social support and social networks, physiological mechanisms, and architecture and the built environment (Cornah, 2006, p. 2). Related more directly to religion and health, Williams & Sterntha’s (2007) review notes a number of pathways have been hypothesized, especially in studies on particular religious
groups. Such pathways include low or no alcohol and tobacco use, vegetarianism, and other positive lifestyle attributes (Williams & Sternthal, 2007, p. 48).

2.2.5.5 Key Critique of Spirituality Research

Depending on which article one is reading or which conference one is attending, the connection between spirituality and medicine is clinically proven, presumed, possible, debatable, unproven, unknowable, hazardous, or downright harmful (Berlinger, 2004, p. 686).

Critiques of spirituality and health research do not necessarily undermine findings, but rather challenge researchers to improve, test and expand the field. The qualitative critiques mirror the limitations of all qualitative work, particularly regarding generalizability. More frequent and critical are the challenges for the quantitative research. For instance, there is a significant lack of case-control, longitudinal and random control trials (Sinclair, et al., 2006). The critiques can be classified under interrelated categories: conceptual/philosophical issues and evidence issues.

2.2.5.5.1 Conceptual or philosophical issues

These issues relate to ontological critiques, reductionism and universality. The philosophical issues are ontological in nature, that is, the assumptions, the ideology, the view of health, the worldview that sits behind particular studies and measurement tools. Moberg questions the transparency of the ideology that underpins instruments, “ideologies so implicit, subtle, and held so unconsciously that their value base often is unacknowledged by researchers, clinicians, and educators” (Moberg, 2002, p. 55). In its broadest sense, this questions the researcher’s spirituality, and may be called an unidentified researcher bias, similar but different to the researcher bias that results from lack of reliability and validity testing (another criticism of some of the instruments (Ross, 2006a, p. 860)). The researcher’s ontology is seldom made clear.

Rumbold has a unique critique. He argues much of the research comes from a biomedical or biopsychosocial model that sees spirituality as an ‘add-on’, but still examined in a reductionist, mechanistic and predominantly positivist way. Rumbold also suggests “for  

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61 See also Herbert et al’s review of spirituality/religion and informal caregiver well-being: they examine the mechanism question focusing on “supportive social networks, …, coping resources, …, and positive emotions” (Hebert, Weinstein, Martire, & Schulz, 2006, p. 413)
many people health is an aspect of spirituality”, not the other way around (Rumbold, 2007, p. 61). The QoL approaches perhaps come close to responding to this critique.

One of Sinclair et al.’s review conclusions comes close to Rumbold’s thinking. Sinclair suggests the dominant individualistic approach “reduces spirituality to simply another tool in our treatment repertoire, having been stripped of its mystery by empiricism, to be administered to the dying patient by the skilled practitioner” (Sinclair, et al., 2006, p. 475). Sinclair argues that this approach is true of much of the nursing literature, where discussion of the “spiritual dimension” reflects “an underlying compartmentalization of the human make up” (Sinclair, et al., 2006, p. 479). Rumbold, Sinclair and perhaps Taylor (Taylor, 2007) are arguing the same thing; a solely scientific, materialistic and individualistic approach to spirituality is narrow, incomplete and potentially harmful, missing the integrative element.

The reductionist and universality issues are also conceptual, in that instruments are designed, sometimes with wide consultation (Peterman, et al., 2002), by nomination of particular items that represent or ‘measure’ spirituality (Moberg, 2002). Moberg notes that an “inescapable reductionism complicates all spirituality measurements” and “Scales intended to be universally valid have many deficiencies” (Moberg, 2002, p. 47). Macdonald et al, working in the transpersonal psychology field, respond thoughtfully to this issue, suggesting that “all conceptual modalities of knowing are inherently reductionist to some degree” (Macdonald & Friedman, 2002, pp. 104-105).

Regularly raised in reviews, one of Williams & Sternthal’s conclusions is “there is clearly a need for more careful conceptualisation and measurement of the religiousness/spirituality variable”, particularly the need to define and measure “spirituality as distinct from religion” (Williams & Sternthal, 2007, p. 49).

### 2.2.5.5.2 Evidence Issues

The evidence issues relate to the strength of the evidence, inappropriate conclusions, poor design, over-emphasis of religiosity, mechanisms and causation, and confounding and bias issues. Sloan et al have made the highest profile challenge in the medical journals to the value of the evidence. They suggest inappropriate conclusions have been made, particularly in regard to claiming there is enough evidence for religion to be attended to and affirmed in any way by clinicians (Sloan, et al., 2000). Sloan et al’s key concerns are “serious methodologic
flaws, conflicting findings, and data that lack clarity and specificity” (Sloan, et al., 2000, p. 1913).

The strength of the evidence is challenged on multiple fronts, most frequently on the lack of attention to confounding variables in study design, including socioeconomic status, behaviour differences, age, physical issues and social support (Berry, 2005). Sulmasy highlights the criticism of possible “confounding spiritual well-being with psychological well-being”. He responds by suggesting, “those who have made this criticism appear to have confounded for themselves the measurement of spiritual well-being and the measurement of religiosity” (Sherman et al., 2000 in (Sulmasy, 2002, p. 29)).

Much of this research is with patients who are unwell: response rates are low, for instance, in nursing studies, response rates “varying from 29% to 100%” are reported (Ross, 2006a, p. 860), therefore generalizability is questioned (Moberg, 2002). The bias issues relate to the Christian, US and religious foci of many of the studies (Chiu, et al., 2004; Sinclair, et al., 2006; Williams & Sternthal, 2007).

Further it is claimed inappropriate conclusions are drawn from studies not designed to measure spirituality, religion and health (Sloan, et al., 2000). Because of the cross sectional nature of many of the studies that are spirituality or religious specific, there is a lack of information on mechanisms and causation (Berry, 2005; Williams & Sternthal, 2007, p. 48). In his summary of mechanisms, Berry claims, “Given the pervasive social and personal nature of religion and spirituality, there are likely very few unmediated relationships between religious and spirituality factors and health” (Berry, 2005, p. 644). In an earlier study, a ‘levels of evidence’ review by Powell et al, the hypothesis linking religion or spirituality and cancer mortality was seen as inadequate (Powell, et al., 2003). The second cancer-relevant hypothesis (‘religion or spirituality slows the progression of cancer’) was rated as a ‘consistent failure’ (Stefanek, et al., 2005, p. 453).

A further challenge to the quantitative research of spirituality and religiosity is that it cannot be captured by ticking boxes and counting responses. Vance, however, makes a reasonable argument for self-reporting/self-rated spirituality (Vance, et al., 2007, p. 32). In many cases this is the approach taken in research.
2.2.5.6 Mixed Methods

There is a small, but growing, number of mixed method spirituality and health approaches (Hills, et al., 2005; Mason, et al., 2007). UK-based Becker et al.’s systematic review of spirituality/religion and bereavement, focusing on palliative care, argues that in this research field randomized control trials are not the gold standard. Becker et al and Moberg recommend “a multi-methodological approach combining quantitative and qualitative methods” (Becker, et al., 2007, p. 215). Moberg essentially calls for mixed methods: he posits the need to “Use a variety of research methods, both qualitative and quantitative, drawing upon many disciplines and professions” (Moberg, 2002, p. 57). Vance notes that “Qualitative investigation more easily and accurately reflects the elusive qualities of spirituality”, but also sources Strauss & Corbin (1990), who said “the findings of such qualitative approaches do not generalize well to the population at large. Therefore, other means of quantifying spirituality are required” (Vance, et al., 2007, p. 32). Inherent in the argument for mixed methods is this complexity issue: spirituality is not easily defined or captured, thus the more methods used in research the more likelihood of valid results.

2.2.6 Summary Spirituality & Health Discourse

Spirituality and health discourses have developed significantly with the advent of what Heelas et al call the “holistic milieu” (Heelas, et al., 2005). This is the period approximately since the 1960/70s when spirituality, evolving as something related to but different from religion, was seen to be a missing component in health discourses (Swinton, 2001). While it may be argued the dominant health paradigm still ignores spirituality, since this holistic milieu period many have recognised and researched health as more than just the physical dimension.

From the 1990s forward a growing body of research began to show positive relationships between religiosity and health outcomes (Berry, 2005). This led to a wider investigation of religion/spirituality and health outcomes. General comments were made about the multi-disciplinary approaches, the Christian, religiosity, US and secular dominance. It was noted that publications have grown significantly since the year 2000 and the patient perspective has, up until recently, often been overlooked. Qualitative methods and studies were canvassed and shown to have produced rich data that has grown understanding in the field. Quantitative methods and studies were discussed, with a range of instruments noted and a wide range of
associations found between spirituality/religion and other health outcomes. Many of these studies focused on religiosity, but include a growing group of spirituality and QoL research that mostly shows positive associations. Negative effects were also noted from some studies, particularly related to guilt and other religious issues. The mechanisms, or how spirituality works, in effecting other health outcome was noted to be an area that is seldom examined or understood. Further criticisms of these methods and studies were noted, with significant questions asked about quantitative design and generalizability of results. Mixed methods examining spirituality and health were argued to be an important development in the field, with a greater focus needed on patient and family member’s needs.

Clearly spirituality can be studied scientifically (Boero, et al., 2005, p. 916) and while the topic is broad and illusive, rigorous methods and qualified methodology can produce useful and significant results. This is important, as has been shown above, spirituality is clearly present in policy, guidelines, healthcare curricula, and needs based; therefore sound research is required to inform spiritual care.

2.3 Hospice Care and Spirituality

Spiritual needs may be paramount with some patients and are far more prevalent than is commonly recognized or addressed (Saunders, 2000, p. 11).

There is almost universal agreement that “Spiritual concerns are important to many patients, particularly at the end of life” (Sulmasy, 2002, p. 24) and hospice care unanimously mandates spiritual care62 (Doyle & Woodruff, 2004; Speck, et al., 2004; World Health Organisation, 2002). This section will bring together key issues that relate to hospice care and spirituality. These include a general introduction, spiritual needs (common spiritual issues) and care (assessment and interventions), comments about ‘who does it’ and ethical issues.

Hospice care research and publications often dominate and lead the spirituality and health literature. Sinclair suggests it is a “thriving field” (Sinclair, et al., 2006, p. 464). Many of the works cited above have been drawn from this literature, including (Barton, et al., 2003; Becker, et al., 2007; Byock, 2007; Chochinov, 2006; Clark, Have, & Janssens, 2002; Cobb, 2001; Cotter, 2007; Doyle, Hanks, Cherny, & Calman, 2004; Flannelly, Weaver, & Costa, 2001).

62 Randall & Downie are an exception. They make a distinction between intrinsic and extrinsic care, with the latter to do with psychosocial/spiritual concerns. They argue that palliative care ought to focus primarily on intrinsic issues (Randall, 1999).
2004; Hills, et al., 2005; Kellehear, 1999a). Spiritual concerns naturally arise in many people who have either a serious or terminal illness or have reached an age when death is more imminent (Hanks, et al., 2004; McGrath, 1999). It makes sense this field considers, researches and attends to spirituality more than other areas of healthcare (Byock, 2007; Cobb, 2001).

2.3.1 General Discussion

Palliative care services: ..., integrates [sic] physical (tinana), social (whānau), emotional (hinengaro) and spiritual (wairua) aspects of care to help the dying person and their family/whānau attain an acceptable quality of life (Ministry of Health, 2001, p. 10).

Hospice care aims to meet the needs of the whole person and their families, encompassing the physical, social, mental and spiritual dimensions (Ministry of Health, 2001; World Health Organisation, 2002). These international and national references show there is a clear mandate for hospice care to provide holistic care.63

With its roots in medieval Christian care for the dying, modern hospice care developed in the late 1960/70s, particularly inspired by Dame Cicely Saunders in England. St Christopher’s Hospice in London set the standard for a ‘good death’ in a medicalized age that Saunders believed had left the person out of the clinical context (Gracia, 2002; Sinclair, et al., 2006). Part of Saunders’ motivation personally and historically was Christian, thus religious concerns entered explicitly into the hospice agenda, and it often was (and still is) religious people who staffed and supported hospices (Rumbold, 2002a). According to Rumbold, the religious agenda was never proselytizing, but rather inherent in the values that underpinned a care ethos that attended to the whole person (Rumbold, 2002a). Saunders named this ‘total pain’ and then later ‘total care’, which included the physical, mental, social and spiritual

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63 Research in spirituality and palliative care is relatively recent and much of the published work, especially prior to 2000, has been anecdotal, philosophically or opinion based (Fry, 2000 cited in McGrath, 2002b, p. 179), leading to “the situation where notions of spirituality continue to be marginalised as unsubstantiated claims of ‘soft talk’ (McGrath, 1999 cited in McGrath, 2002b, p. 179). McGrath makes this claim by situating said ‘claims’ in the “prevailing privileged positivist, scientific discourse of modern Western healthcare” (McGrath, 2002b, p. 179). When looking at the whole body of the literature about spiritual care, McGrath is right from the point of view that the vast majority of reported studies and articles, especially early in the literature, spend considerable ‘column inches’ on justifying spirituality. What is clear is the importance attributed to spirituality in the hospice/palliative care context. In the Pallium Project, a European multi-country study of issues in palliative care (Janssens, et al., 2002) spirituality was found to have equal importance to other dimensions of health.
dimensions (Saunders, 2004). Chaplaincy was the original holder of the ‘spiritual care designation’, but the modern hospice movement (and palliative care) promotes a multi-disciplinary approach.

The hospice movement inspired a sub-speciality in medicine, palliative medicine, which went on to ‘mainstream’ palliative care processes, positively adding to the hospice vision, but also negatively undermining it through institutionalization, bureaucracy and medicalization (James & Field, 1992; Rumbold, 2002a). Breitbart suggests “Existential and spiritual issues are at the frontier of new clinical and research focus in palliative and supportive care of cancer patients” (Breitbart, 2002), however ‘spiritual issues at a frontier’ suggests there is something new about it in this context. This is perhaps indicative of palliative medicine as a medical sub-specialty that may have forgotten its roots in hospice philosophy where spiritual issues are foundational not new.

Rumbold warns mainstreaming hospice care potentially de-personalizes the spiritual care process. That is, if not done in a caring environment where such holistic approaches are understood and supported, patients who had not considered such issues before may be assailed by a ‘spiritual carer’ who has been told they must ask about such issues, potentially doing more harm than good. Thus Rumbold challenges the untrained or inexperienced ‘spiritual carer’, “Eliciting an implicit spirituality may well precipitate further chaos if that spirituality turns out to be inadequate in the face of suffering and death” (Rumbold, 2002a, p. 7).

Rumbold’s warning is salutary. The hospice mandated original vision remains at a policy level (Ministry of Health, 2001; World Health Organisation, 2002) and some pre-service medical and nursing training (Puchalski, 2006b), but often fails operationally (McSherry, 2007). For example, in New Zealand, one of the only surveys that asked about spiritual care suggested that only just over half (56%) of hospices (n=32) provided spiritual care (Ministry

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64 Compared to the Saunders model in the UK, the hospice movement developed differently in the US. One perspective is Garces-Foley’s, who argues partly due to the human potential movement and Kubler-Ross’s psychological model of death and dying (1969), “spiritual care was restricted to the narrow meaning of pastoral care provided by ordained clergy” (Garces-Foley, 2006, p. 124). Then into the 1980s and 1990s lack of funding inhibited spiritual care in hospices, with up to 40% of hospices not meeting the “Medicare standards for spiritual care” (Garces-Foley, 2006, p. 126). Garces-Foley, coming from an orthodox religious studies point of view, suggests in a context that laments the lack of religious approaches, much of the so called spiritual care could just be called existential or therapeutic (Garces-Foley, 2006).
of Health, 2001, p. 35). This ‘policy/operational’ split implies that Rumbold’s analysis of potential danger needs to be taken seriously.

Palliative care has developed and broadened to the point that it is argued “the principles of palliative care” should be applied to all patients with a “predictably fatal” illness “from the point of diagnosis” (MacDonald & Weijer, 2004, p. 76). Hospice care, hospices and the hospice philosophy are at the core of palliative care, and “spirituality is the vital dimension of hospice and palliative care that informs and energises at both an organisational and an individual level” (McGrath, 2002b, p. 188).

2.3.2 Spiritual Needs & Care

Part of the “work of dying” (Bregman, 2006a, p. 12) or the “task of dying” (Breitbart, 2008, p. 212) is to address spiritual concerns; there is evidence that when one becomes seriously ill, existential, religious and spiritual concerns come to the fore (la Cour, 2008). Up until such a crisis or event, for many people, little thought is given to the spiritual side of life, yet, only near the end of one’s life that a life path becomes more evident and an individual is able to embrace its full meaning. This historical and existential life path is the very core of each person’s spiritual legacy (Grudzen, 2003, p. 206).

Spiritual needs are critical and acknowledged in hospice care. It is recognized that if a patient is in physical or psychological pain (up to 50% or more of dying people in Western countries still experience significant physical pain at end-of-life (Elmqvist, Jordhøy, Bjordal, Kaasa, & Jannert, 2009)), spiritual needs may not even be able to be considered (Williams, 2006). Though it is also understood the relationship between the physical and spiritual can be two-way: either could affect the other (Doyle & Woodruff, 2004).

One of the unique aspects of hospice care is that the ‘unit of care’ is explicitly named as not just the patient, but also the family and carers (Field, Clark, Corner, & Davis, 2001; Ministry of Health, 2001). What this means is that all of these groups’ spiritual needs need to be assessed and nurtured. The literature is sparse on spiritual care for family and carers.

Chochinov makes the point that with all of these needs named and holistic approaches called for, one would think that such care happens as a matter of course; this is not always the case:
“there are aspects of end-of-life distress that are not routinely assessed, let alone effectively treated or managed” (Chochinov, 2006, p. 86). There is still work to be done in improving spiritual care at end-of-life.

Another of the unique aspects of hospice care is the attempt to keep patients at home, where they want to be, as long as possible (Chochinov, 2006). This priority is both a spiritual need and intervention; being at home allows ongoing relationships to develop, and meaning may be more easily found/maintained in this context (McGrath, 2003).

A fair question is how important are spiritual needs to those dying and those around them? Steinhauser et al’s study used a cross-sectional, stratified random national survey examining what patients, family members and healthcare practitioners (n=1462) thought were important factors at end-of-life. The results, across all three groups, for items rated as “important” (>70% response per item) included, “pain and symptom management, preparation for death, achieving a sense of completion, decisions about treatment preferences, and being treated as a “whole” person” (Steinhauser, et al., 2000, p. 2476). Four of the five items could be said to be spiritual in nature. While the study is US-based, the suggestion that 80% of end-of-life concerns are broadly related to spirituality, as discerned by all these populations, may be relevant across other countries. Breitbart affirms this, suggesting at the end-of-life “symptoms relating to psychological distress and existential concerns are even more prevalent than pain and other physical symptoms” (Breitbart, 2002, p. 272).65

Lin et al, concluding their “integrated review of the literature” state,

Patients with an enhanced sense of psycho-spiritual well-being are able to cope more effectively with the process of terminal illness and find meaning in the experience. …. The research indicated that health professionals can play an important role in enhancing psycho-spiritual well-being, but further research is needed to understand specific interventions that are effective and contribute to positive patient outcomes (Lin & Bauer-Wu, 2003, p. 69).

The spiritual needs of dying people are similar to those explained above. What we know is that people who experience serious or terminal illness are likely to have spiritual needs (McCord, et al., 2004). While it is impossible to take away pain of all kinds in the dying process (Cotter, 2007), there are significant opportunities to address spiritual needs.

65 See also (Janssens, et al., 2002)
2.3.3 Spiritual Care Provision

2.3.3.1 Spiritual Care Generally

Most clinicians and health care providers still give only cursory attention to the spiritual needs of their clients, patients, and staff, thereby depriving many people of the nearly always positive contributions of spiritual care to physical, mental, and emotional health and making it more likely that some will experience spiritual neglect or spiritual abuse (Moberg, 2002, p. 53).

The context for spiritual care is important. Frameworks for understanding health are noted above — biomedical, biopsychosocial, biopsychosocialspiritual and social/holistic models are suggested. If a biomedical approach is taken, then attending to the spiritual dimension in healthcare is a demarcation issue — it is not in the scope of practice. However, many ‘scopes of practice’ (for instance nursing and hospice care) are mandated to care for the whole person (McSherry, 2007; Sinclair, et al., 2006; Woll, Hinshaw, & Pawlik, 2008). If viewed through the social/holistic lens, Sulmasy’s edict holds true: “genuinely holistic health care must address the totality of the patient’s relational existence – physical, psychological, social and spiritual” (Sulmasy, 2002, p. 24). Technologically driven healthcare systems, whilst making great gains in physical health, risk forgetting the person behind the pathology (Boero, et al., 2005). Sulmasy calls the marrying of the “reductivist scientific truths” with “the larger truths about the patient as a human person” the “really enormous challenge healthcare faces today” (Sulmasy, 2002, p. 25).

Unsurprisingly, most scholars in the ‘spirituality and health’ field argue for the clinical relevance of spiritual care (Post, Puchalski, & Larson, 2000), with some caveats. However, as Moberg notes above, actual spiritual care is inconsistent at best, and in New Zealand perhaps only happens explicitly at home, in hospice care, private hospitals and some rest homes. In the wider context, and then specifically in the hospice care contexts, this section will consider spiritual care generally, who should provide spiritual care, spiritual needs, provision and assessment, interventions and ethical issues. Underlying this discussion is the position that spiritual care is an important consideration in healthcare, as mandated by the UK NHS (McSherry, 2007; National Institute for Clinical Excellence, 2004), the US Medical Association (Puchalski, 2006c), the WHO (World Health Organisation, 2002) and in palliative care (Ministry of Health, 2001; Palliative Care Australia, 2005).

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66 See also (Holmes, Rabow, & Dibble, 2006; Milstein, 2008; Ross, 2006b)
2.3.3.1.1 Defining Spiritual Care

Defining spiritual care is as elusive as defining spirituality. Murray et al suggest it is “helping people whose sense of meaning, purpose and worth is challenged by illness” (Murray, et al., 2004, p. 40). Spiritual care must also be about helping people with each of the aspects named in spirituality definitions: meaning and purpose are key, but also aspects like identity, values and beliefs, and relational issues are important. Manitoba’s Central Regional Health Authority mandates spiritual care for all health services; their definition of spiritual care is useful,

Spiritual care addresses the ultimate concerns of the whole person, encourages healing through the nurturing of spirituality within the context of the person’s beliefs and values as an interdependent component of holistic care (Regional Health Authority Central Manitoba, 2007, p. 2).

This definition sits clearly and explicitly in the holistic framework, though the criticisms about spirituality above could be made. In relation to the social-holistic framework, the obvious missing component is connections to the community. In Scotland, the National Health Service (NHS) developed guidelines for spiritual care and included definitions:

Religious care is given in the context of the shared religious beliefs, values, liturgies and lifestyle of a faith community

Spiritual care is usually given in a one-to-one relationship, is completely person centred and makes no assumptions about personal conviction or life orientation. (Working Group on Spiritual Care in the NHS, 2002, p. 6).

This definition, whilst broader than the Canadian version, is qualified with a range of principles including impartiality, accessibility, respect for beliefs and diversity/multiculturalism (Working Group on Spiritual Care in the NHS, 2002, pp. 7-8). These principles lay out a very broad mandate: ‘religion and spiritual care of all kinds’ is named. There are significant implications regarding training and capacity, both of which the document addresses.

The UK National Institute for Clinical Excellence (NICE) guidelines for Cancer Care define spiritual care as follows,

spiritual care should not be viewed solely in terms of the facilitation of appropriate ritual, which has implications for the assessment of spiritual needs.
The nature of support needed can range from an informal sharing of ideas about the ultimate purpose of existence to the provision of a formalised religious ritual. The appropriate means of meeting need will vary by location, resources and skills available. and the nature of needs assessed (National Institute for Clinical Excellence, 2004, p. 96).
As this definition suggests, one of the dominant themes in the literature is for patients’ spiritual needs to lead care, not healthcare professionals’ priorities. Part of the challenge is sharing a common language to explore spiritual issues (Leibrich, 2002, p. 157) (McGrath, 2002a). Rumbold calls for the creation of reflective spaces (Rumbold, 2005a) for spiritual care allowing time, creativity, ideas and issues to ferment in a variety of verbal and non-verbal registers.

Through extensive review and primary research, Ross suggests five factors that promote spiritual care in nursing:

1. nurses are aware of their own spirituality (e.g. beliefs, life experience)
2. good links exist with other professionals, (e.g. chaplains/clergy)
3. the environment is conducive (e.g. adequate staffing, time and/or resources)
4. nurses have been educated in spiritual care
5. patients are in a position to communicate their needs to staff (Ross, 2006a, p. 853).

Ross’s work refers to nursing, but is arguably relevant for all healthcare professionals, particularly in end-of-life care.

In a context where spiritually is inherently pluralistic, Rumbold argues that spiritual care “refuses to be conformed to a standardized or fact-file approach, even from those who maintain a connection with formal religion” (Rumbold, 2002a, p. 19). This discussion on spiritual care takes Rumbold’s statement seriously, suggesting as others have (Moberg, 2002), that a range of approaches bests serves spiritual care. Rumbold highlights this position as he questions clinically focused approaches to spiritual care that tend towards reductionism and individualism, “Far from exploring the range and complexity of human wholeness” (Rumbold, 2002a, p. 19). This challenge extends to the presumption that individuals make their own meaning in isolation, without reference to communal, social and, at times, religious constructs.

Spiritual care is generally broadly defined, and as expressed by the NHS, Ross and Rumbold, there is a growing consensus towards how spiritual care ought to happen. To do appropriate spiritual care, the needs of the recipients must be understood.
2.3.4 Spiritual Needs

In hospice care, the spiritual needs of the patient, family members (Ministry of Health, 2001) and in some cases, staff, are all mandated within the ‘unit of care’ (Palliative Care Australia, 2005). However, spiritual needs are often left off the agenda, for they are perceived to be difficult to attend to, measure\(^67\) and purchase.\(^68\) Further, who defines the ‘need’ is an important consideration\(^69\) — regarding spiritual needs, it depends on who the expert is and how they see the world/health. For instance, a biomedically focused atheist may suggest that spiritual need is purely associated with religious issues. If this is the case, in New Zealand, such need would only be relevant for the, at most, 20% of the population who attend church on any regular basis (Gendall, 1999). This, however, is not how spirituality is understood in some healthcare disciplines, most notably hospice care, and for some ethnicities, for example New Zealand Māori (Durie, 2008). Thus, accepting a social-holistic framework, what does the literature say about spiritual needs?

Murray quotes the US Institute of Medicine’s definition of spiritual need,

> the needs and expectations which humans have to find meaning, purpose and value in their life. Such needs can be specifically religious, but even people who have no religious faith or are not members of an organised religion have belief systems that give their lives meaning and purpose (Institute of Medicine. Approaching death; improving care at the end of life. Washington, DC: National Academy Press, 1997, cited in Murray, 2004 p 40).

The focus is typical of the contemporary spiritual discourse, which is, on meaning,\(^70\) purpose and values.

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67 The concept of need in health is not neutral. According to Tones et al, the growth in needs assessment developed with the growth of a consumerist approach to healthcare in the 1990s (Tones & Green, 2004). This market approach purchased health services that required defined and quantified ‘needs’ to be addressed in an efficient way within the increasingly squeezed public purse (Tones & Green, 2004). What this means is that how need is defined and therefore assessed is critical to the subsequent purchasing of services.

68 This has not stopped, for instance the UK NHS, from putting spiritual care into their guidelines, though clarity around purchasing such care, outside of the traditional chaplaincy approach, is far from clear. Likewise audit of such care is unusual, even in hospice care (Kernohan, Mary, Caroline, Barbara, & Felicity, 2007). These issues, particularly relevant for health economists, are seldom, if ever, canvassed in the spirituality and health literature. There is a gaping hole in the literature showing the economic efficacy, cost-benefit analysis or the “allocative efficiency” (Tones & Green, 2004, p. 145) of spiritual care.

69 Bradshaw’s (1972) analysis of needs begins to show the variety of positions possible: ‘normative need’ is expert defined; ‘felt need’ is defined by lay people, what it is they want; ‘expressed need’ includes how services are used by people; and ‘comparative need’ is defined by one area of services being compared to an equivalent area’s services (Bradshaw, 1972 cited in Hawe, Degeling, & Hall, 1992; Tones & Green, 2004).

70 A commonly cited US/Canadian study by Flannelly et al (Flannelly, Galek, Bucchino, & Vane, 2006) surveyed chaplains understanding of spiritual needs. The findings affirmed the definitional focus in the literature on ‘meaning and purpose’ (see also (Murray, et al., 2004)), for this, and ‘love and belonging’ were found to be daily issues for chaplains.
Generally the difficulty in assessing spiritual need harks back to the issues of definition and complexity of the concept (Flannelly, et al., 2006; McSherry, 2007). However, like the definition issue, there are commonalities among scholars and studies that suggest a range of spiritual needs. It is agreed that spiritual needs are unmet among the majority in healthcare (Hanson, et al., 2008). Palliative care leads much of this work (Milstein, 2008; Sinclair, et al., 2006), as Breitbart exemplifies, suggesting that spiritual needs of people with “advanced cancer” include “particular issues related to maintaining a sense of meaning, peace and hope (Breitbart, 2002, p. 10). Puchalski, also writing from a palliative care context, suggests “The inherent mystery of life triggers spiritual questions” and serious illness, death, stress and crisis can challenge the ground upon which life was thought to be meaningfully placed (Puchalski, 2006a, p. x). Cotter, while not romanticising dying, suggests it is a time for potential “spiritual transformation” (Cotter, 2007, p. 257). Unmet spiritual needs are a reality, even in the US, where these issues are mandated nationally. For example, Balboni et al found that of seriously ill cancer patients (n=230, 63% response rate) “72% reported that their spiritual needs were supported minimally or not at all by the medical system” (Balboni, et al., 2007, p. 555). Most studies affirm that patients have spiritual needs that often go unmet (Astrow, Wexler, Texeira, He, & Sulmasy, 2007; Cobb, 2003; Ross, 2006a). Further, studies show that when spiritual needs are met, QoL is higher (Astrow, et al., 2007; Balboni, et al., 2007).

Sinclair et al’s review of spirituality in healthcare and palliative care named spiritual needs as one of six key themes (Sinclair, et al., 2006). The authors noted almost all palliative care articles on spirituality included a focus on needs. Sinclair sources Murray et al (Murray, et al., 2004), Moadel et al (Moadel, et al., 1999) and Steinhauser et al (Steinhauser, et al., 2000) as key studies that named spiritual needs as follows:

- Murray et al.: “need for love, meaning, purpose, and transcendence”
- Moadel et al.: “the need to overcome fears (51%); hope (42%); meaning in life (40%); finding spiritual resources (39%); and someone to talk to about: finding peace (43%); meaning of life (28%), death and dying (25%).”
- Steinhauser et al.: “being mentally aware, making funeral arrangements, not being a burden, helping others, and coming to peace with God.” (Sinclair, et al., 2006, pp. 470-471).
Other needs noted included “self-realization” and “transcendence” (Sinclair, et al., 2006, p. 471). As noted above, these needs, apart from the funeral arrangement, parallel the definitional components of spirituality.

Australian Palliative Care Specialist Doug Bridge developed his own approach to explaining spiritual needs and priorities as seen in the following four diagrams.
FIGURE 2.1 Bridge’s Analysis
Bridge’s analysis does not fit all situations or ethnicities, but shows where one’s priorities might lie. It is of particular use when teaching students and/or families about the possible changes in people’s perceptions as they approach death.

In terms of the literature on spiritual needs, there is some consistency of named needs, but variation in priority. The following considers common spiritual issues named in the literature.

2.3.4.1 Common Spiritual Issues

Spiritual needs can be understood empirically, as suggested by the range of needs found from the studies mentioned above, or from inference based on how spirituality or spiritual well-being is understood. The literature discusses a range of common spiritual issues including: transcendence, meaning and purpose (existential issues), awareness, contribution, identity, beliefs and values, hope, connectedness/relationality, religious spiritual needs, suffering, spiritual distress/pain and spiritual blocks.

2.3.4.1.1 The Transcendent

There are various understandings of ‘the transcendent’: from the existential to the religious; from the simple belief that there is something greater than oneself; to the conscious attempt to contact spirits (Bregman, 2006a, p. 10).

From an illness perspective, Leibrich suggests transcendence means, “that although we are ill, we are not imprisoned by that experience but go beyond it. We transcend the illness and claim its power. Illness teaches us about being well” (Leibrich, 2002, p. 147). Leibrich makes the very important point that transcendence is possible within illness. True too for the dying process (and those involved), transcending the pain and suffering of dying can be a critical spiritual process.

Taylor suggests that transcendence has three aspects: a higher purpose; a higher being; and the after life (Taylor, 2007, p. 20). However, God (presumably Taylor’s ‘higher being’), an aspect of the transcendent as understood by most people, is seldom referred to in the palliative care literature definitions of spirituality. When ‘God’ is mentioned, there is usually a very broad implication for what or who ‘He’ may be. For instance, Dyson says “it is proposed that
the nature of 'God' may take many forms and, essentially, is whatever an individual takes to be of highest value in his/her life" (Dyson, et al., 1997, p. 1183).\(^{71}\)

Regarding the transcendent, Moreira-Almeida et al posit,

> there is general agreement that these constructs [religion and spirituality] are related to the search for the sacred or transcendent, which includes concepts of God, a higher power, the divine, and/or ultimate reality. (Moreira-Almeida & Koenig, 2006, p. 844).

While Moreira-Almeida and Koenig are probably right regarding this "general agreement",\(^{72}\) they do come from an American/Brazilian epidemiological and clinical perspective. It is debatable that all people who consider themselves spiritual are searching for "God, a higher power, the divine, and/or ultimate reality" (Moreira-Almeida & Koenig, 2006, p. 844).

In all Western countries, there are undoubtedly still people with religious spiritual needs. This was the dominant approach prior to the middle of last century, with sacraments ministered to the seriously ill. But religious spiritual needs clearly extend beyond the sacramental to the existential, though may be framed in religious language (Cobb, 2001). The literature clearly shows spiritual care demands much more than recording a patient's denomination (Wright, 2001). Further, Roudsari notes there are negative religious "coping patterns" that need to be assessed in spiritual care, including the illness as a punishment from God and anger towards God (Pargament, 2004 cited in Roudsari, et al., 2007).\(^{73}\)

### 2.3.4.1.2 Meaning and Purpose

One of the ubiquitous and arguably "ascendant ideas" in spirituality definitions is 'meaning and purpose' (Yawar, 2001) or the 'search for meaning' (Murray, et al., 2004) (Kellehear, 2000, p. 50) (Daaleman, et al., 2001; Dyson, et al., 1997, p. 1185). Much of this focus can be traced back to Frankl’s influential analysis in *Man’s Search for Meaning*\(^{74}\) (Frankl, 1984).

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\(^{71}\) See also (Fisher & Yarwood, 2008, p. 254)

\(^{72}\) Moreira-Almeida et al would probably agree with Moberg, who makes the point, “Unless spirituality has a transcendent reference point, only the politics of power (including the ideologies and purses that control research, publications, and professorships) will prescribe the values and set the operative standards that pragmatically define spiritual health and illness” (Moberg, 2002 cited in Berry, 2005, p. 638).

\(^{73}\) See also (Hills, et al., 2005)

\(^{74}\) A psychiatrist, Frankl experienced life in a German concentration camp, which is the background and inspiration behind his book – with its central therapeutic model called logotherapy: a "meaning-centred psychotherapy" which confronts and reorientates patients to the "meaning of his life" (Frankl, 1984, p. 120). It is not logotherapy that is recalled today, as much as his focus on the importance of meaning. Frankl’s motto for dealing with prisoners’ psychological issues came from Nietzsche “He who has a why to live for can bear with almost any how” (Nietzsche cited in Frankl, 1984, p. 97). This 'why' was a sense of meaning. Frankl thought
Another root of the meaning focus may be the ‘lack of meaning’, as discussed by Frankl, Taylor and others (see section 2.1.1 above). Frankl names the “experience of inner emptiness”, the “feeling of total and ultimate meaningless in their lives”, the “void within themselves”, all as the “existential vacuum” of which “so many patients complain today” (Frankl, 1984, p. 128). Frankl suggests “The existential vacuum is a widespread phenomenon of the 20th century” (Frankl, 1984, p. 128) because neither instincts nor traditions tell one what to do any more. This unique postmodern dilemma of meaninglessness then makes emphasis on the search for meaning in contemporary spiritual definitions understandable. In dealing with those who had lost hope, meaning and purpose, Frankl suggests “we had to teach the despairing men, that it did not really matter what we expected from life, but rather what life expected from us” and “Our answer must consist, not in talk and meditation, but right action and in right conduct” (Frankl, 1984, p. 98). The importance of meaning being generated outside of oneself and the personal responsibility to understand what one must give to life are not often highlighted when Frankl is cited. Lastly, in relation to Frankl, his often repeated concept, “suffering ceases to be suffering at the moment it finds a meaning” (Frankl, 1984, p. 135) or as Pulchalski paraphrases, “Man is not destroyed by suffering; he is destroyed by suffering without meaning” (Puchalski, 2001, p. 32), sums up the focus of meaning, particularly in serious illness in relation to spirituality.

Yick’s (2008) metasynthesis of qualitative studies on spirituality and domestic violence gives a definition of the ‘spiritual vacuum”; this was a theme four of the six studies examined noted as important. Yick suggests the spiritual vacuum is “where women lost a “part of their selves,” “their inner voice,” “their spiritual self,” “that deeper level within them,” their “spiritual core,” and their “connection with God, themselves, and others” (Yick, 2008, p. 1300). Yick goes onto to say that the spiritual vacuum “is not necessarily about losing faith in God or in a higher being; rather, it is literally an annihilation of the essence of who they were (Yick, 2008, p. 1300). Broadly considered, domestic violence is about the lack of health and well-being. Yick’s powerful analysis helps to illuminate the ‘spiritual vacuum’ problem, which is clearly a spiritual need.

That life was meaningful in a unique way for each person, and hardship “gives man the opportunity to grow spiritually beyond himself.” (Frankl, 1984, p. 93).

Taylor’s analysis argues that “in the enchanted world, the meaning exists already outside of us, prior to contact (Taylor, 2007, p. 34), where as the “disenchanted” world does indeed, seem a world without meaning.” (Taylor, 2007, p. 680).
Bregman notes that most foci on meaning and purpose are subjective and seldom refer to any "culturally-shaped external ideal" (Bregman, 2006a, p. 11). Bregman questions the unqualified nature of meaning and purpose in all these definitions (Bregman, 2006a, pp. 10-11). That is, if 'meaning' for a person is centred on a destructive, dysfunctional or immoral 'ultimate concern' what is the ethical way forward clinically? This is not a major challenge, but awareness of such opinions is important, especially in the ethical considerations about spiritual care.

It is in hospice care that many argue meaning becomes critical, as Baldacchino's comment echoes: "the person's whole sense of meaning may be jeopardized by the acute sudden onset of a life threatening illness,..." (Baldacchino, 2006, p. 887). Similarly, Murray observes "Many patients in their last year of life expressed spiritual needs in terms of seeking meaning and purpose in life" (Murray; et al., 2004, p. 44).

Whitford et al's quantitative study of Australian cancer patients showed meaning was more significant to QoL than faith (Whitford, 2008, p. 1124). Meaning\(^{76}\) and purpose are clearly fundamental issues to human flourishing and spirituality.

2.3.4.1.3 Existential

Existential concerns are fundamental to the human condition and the concept seems to be used interchangeably with spirituality. (Henoch & Danielson, 2009, p. 225)

'Existential', the word\(^{77}\) and/or concept, is part of many definitions of spirituality (Chiu, et al., 2004, p. 410). Cobb makes an interesting and debateable distinction between 'spiritual' and 'existential'. He suggests that while the 'existential' may allow for some transcendence, it is

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\(^{76}\) See also: Jim offers a definition of meaning, suggesting it is "a multi-faceted construct that has been conceptualized in diverse ways. It refers broadly to the value and purpose of life, important life goals, and for some, spirituality (Jim, et al., 2006, p. 1355). Many others refer or comment on meaning in relation to spirituality (Ando, Morita, Lee, & Okamoto, 2008; Boero, et al., 2005; Leibrich, 2002, p. 146; Mann, 2006, p. 119; Vachon, 2008, p. 218; Woll, et al., 2008).

\(^{77}\) The word actually refers to either "related to or affirming existence" or "existential philosophy" which suggested only empirically and experientially based knowledge is valid to create meaning in an essentially meaningless world. Therefore, in a sense, this concept is not used accurately by these definitions. However like many words and concepts, the semantic slide has evolved 'existential' into a concept that covers almost anything to do with serious meaning; as the popular term 'existential crisis' suggests a breakdown of meaning in one's life. It has been noted that its roots are very much empirically/experientially based and that some definitions use the term to include something 'beyond'. For example, Bregman is critical of the use of the 'existential' in many of the current definitions of spirituality. In Unruh's (2002) analysis of 92 definitions, one of the categories was 'existential' (Unruh, et al., 2002). Unruh classifies this definition as something beyond the mundane or everyday "not of this world" (Unruh, et al., 2002, p. 9). Bregman argues that this goes against the meanings that 'existential' had from its philosophical roots which were decidedly 'this worldly', making meaning from life (Bregman, 2006a, p. 10).
Therefore, there is an argument for inclusion of this into spirituality definitions.

2.3.4.1.6 Identity

Identity is another of the lesser known descriptors in spirituality definitions. It arises in discussions of personhood (Sulmasy, 2002) and McGrath found in a hospice qualitative study that “loss of self” (physical, identity, relational, and existential) was an issue (McGrath, 2003, p. 26). There are some definitions that use the term explicitly (Ministry of Education, 1999), however many more refer to one’s ‘essence’ (Geering, 2005; Vance, et al., 2007, p. 32; Yick, 2008) and ‘core’ (Bregman, 2006a; Daaleman, et al., 2001; Emmons, 2006; Leibrich, 2002; Wright, 2002). Perhaps identity is too broad a descriptor to include in a spirituality definition and partial synonyms like ‘core’ and ‘essence’ are more accurate and appropriate. If taken from a religious point of view, these later terms also come closer to ‘soul’ or ‘spirit’, which also fits into Unruh’s ‘life force’ category.

2.3.4.1.7 Beliefs and Values

The terms ‘beliefs’ and/or ‘values’ are occasionally used in contemporary spirituality definitions (Baldacchino & Draper, 2001; Krok, 2008; Ministry of Education, 1999; Ross, 2006a), though in other cases they are a product of spirituality (Doyle & Woodruff, 2004). ‘Beliefs’ is often used with a qualifier, such as spiritual or religious (O’Connell & Skevington, 2007). Sinclair makes the point that when spirituality tends towards more structured beliefs it moves closer to ‘religion’.

A New Zealand qualitative study of non-Church attendees found “Spirituality is linked to core values” (Outside - Looking In; Researching the perceptions of non-churchgoers, 2003 February, p. 3). Dyson identified, in his review of definitions, a theme “which enables people to have meaning and purpose – maybe related to ‘God’ or whatever is held as one’s ultimate priority” (Dyson, et al., 1997, p. 1186). This idea of ultimate priority or ultimate meaning is related to core beliefs and values. It seems sensible to qualify such terms as ‘meaning’, ‘beliefs’ and ‘values’ with terms like ‘ultimate’ or ‘core’; otherwise one could be talking about ‘believing the All Blacks will win’. The appeal of ultimate beliefs and values is in the secular context, as these can be referred to, understood, and developed, without reference to the transcendent. Some scholars have criticised the use of these concepts, suggesting they are psychological constructs rather than spiritual (see discussion below about spirituality and psychology).
2.3.4.1.8 **Hope & Forgiveness**

At the very centre of spiritual well-being is the word hope (Grudzen, 2003, p. 5).

"[T]he majority of studies relating to spirituality identify hope as a key component" (Breitbart, 2002; Dyson, et al., 1997, p. 1186; Emmons, 2006; Sinclair, et al., 2006). However this is another descriptor either left out in many more recent definitions or seen as related to spirituality (not part of its definition). For example, Emmons sees hope as part of spiritual experience (Emmons, 2006); Moadel and Sinclair include hope as an aspect or a theme of spirituality (Moadel, et al., 1999) (Sinclair, et al., 2006). Breitbart calls hope a spiritual need (Breitbart, 2002). Certainly, hope is associated — in the broadest sense — with spirituality. Meaning is shown to be critical to spirituality; the antithesis of hope is hopelessness or meaninglessness. Chochinov argues “that spiritual well-being may be a buffer against depression, hopelessness, and desire for death in patients with advanced cancer” (Chochinov & Cann, 2005, p. 197). MacLeod situates hope clearly when he says, “hope is central to the existence of each individual” and it is a “loss of control that threatens the existence of any future” (MacLeod, 2003, p. 127). This last opinion is particularly important for end-of-life care.

The related concept, forgiveness, can be a central issue at the end-of-life, and may be linked to guilt and remorse (Rousseau, 2003, p. 55). Such issues are directly related to hope, for it can be a form of hope to work through such issues individually and with one’s relationships.

2.3.4.1.9 **Connectedness/Relatedness**

Explicit reference to relationship, connectedness or relatedness is missing from some key definitions (Ministry of Education, 1999). Dyson quotes Hungelemann, calling relatedness the “the heart of spirituality” (Hungelemann et al, 1985 cited in Dyson, et al., 1997, p. 1186). Dyson’s whole analysis of spirituality is formed around relatedness to God, self and others (Dyson, et al., 1997). Similarly Rumbold, sourcing Laracey (1997), suggests spirituality involves relationship with:

- places/things (spatial)
- self (intra-personal)
- others (inter-personal)
- among people (corporate)
- transcendence (god, something there) (Rumbold, 2005a).

79 See also (Dyson, et al., 1997)
Chochinov suggests “the essence of spirituality is connectedness to something that imbues life with a sense of purpose or meaning” (Chochinov & Cann, 2005, p. 197). Relationship is the first of Unruh’s seven categories, there are a number of definitions that refer to it, and with good cause. This category crosses the vertical/horizontal lines, and goes to the centre of what many people believe makes life worth living: their relationships with partners, family, friends and the ‘other’.

2.3.4.1.10 Spiritual Distress/Pain

This literature makes reasonably frequent reference to spiritual distress (Boero, et al., 2005; Boston & Mount, 2006; Hills, et al., 2005; Kawa, et al., 2003; Lichtenthal, et al., 2008; Pronk, 2005), spiritual pain (Mako, Galek, & Poppito, 2006; McGrath, 2002a; McGrath, 2003; Murata, 2003) or spiritual blocks (Grudzen, 2003, p. 166). Spiritual distress is described, including “Feeling of loss of control appeared central to the spiritual distress” (Murray, et al., 2004, p. 42); Boero (like many) sources Frankl, suggesting that “spiritual distress results when life is not given meaning, so it is characterised by feelings of emptiness and despair (Frankl, 1959)” (Boero, et al., 2005, p. 916). McGrath considers the causes of spiritual pain, suggesting the core etiological factors for “spiritual pain” include a sense of diffuse emotional/existential/intellectual pain directly related to the meaninglessness created as the result of a break with the expected/normal network of relationships that function to connect one to life (McGrath, 2003, p. 24).

Chochinov notes spiritual pain has the potential to affect other dimensions of health: “physical (e.g., intractable pain), psychological (e.g., anxiety, depression, hopelessness), religious (e.g., crisis of faith), or social (e.g., disintegration of human relationships). (Chochinov & Cann, 2005, p. 107). In hospice care, ‘total pain’ (Clark, 1999) was one of the seminal concepts Saunders instigated in the modern hospice movement (Saunders, 2000). A key component to total pain was spiritual pain.

The most extensive ‘list’ in the hospice care literature naming spiritual and existential distress comes from Doyle & Woodruff in the online ‘International Association for Hospice and Palliative Care’s Manual of Palliative Care (Doyle & Woodruff, 2004). It includes the likelihood of spiritual questioning at end of life, suggests this may be a “source of clinical suffering”, and categorizes such suffering into past, present, future and religious issues (Doyle & Woodruff, 2004, pp. 2-3). Inherent in this list is a universalist position, however it is qualified by adding “existential” to spiritual. This is a way for those who claim ‘spiritual’ is
either a nonsense or anathema or not part of their experience to be included in this form of
distress that has shown to be a reality at life’s end (Murata, 2003, p. 15). Spiritual distress
and/or spiritual blocks may be related to any of the common spiritual issues named above. It
must also be noted such ‘experiences’ can be understood as spiritual opportunities; growth
and understanding may come out of the such experiences (Cotter, 2007). Chochinov suggests
“Acknowledging spiritual distress, in and of itself, can be interventional” (Chochinov &
Cann, 2005, p. 110).

2.3.4.1.11 Suffering

Suffering is a common aspect of spiritual pain and need, humans suffer as whole beings
(Cassell, 1991). A Japanese palliative care study developed a conceptual framework through
a nationwide consensus building process (Murata & Morita, 2006). The group defined
“psycho-existential suffering” as “pain caused by extinction of the being and the meaning of
the self” (Murata & Morita, 2006, p. 279). The authors suggest this type of suffering happens
when what is essential to being human is undermined. They included “loss of relationship ....,
loss of autonomy..., control future, continuity of self, and loss of temporality” (Murata &
Morita, 2006, p. 279). Two of the many interesting aspects to this framework stand out.
First, in a non-Christian country, the consensus panel, of which there were over 100 multi-
disciplinary peer reviewers, used the term ‘psycho-existential’ rather than spiritual. Secondly,
the focus is very much on self — with the exception of the inclusion of relationships — which
is tempered by self autonomy, control, continuity and one’s relationship to time. Other
Japanese studies (Hirai, Morita, & Kashiwagi, 2003) have further explored these concepts.

Kellehear’s often cited paper proposes a model of spiritual needs that encompasses three
dimensions: “the situational, the moral and biographical, and the religious” (Kellehear, 2000,
p. 149). There are a range of items under each of these dimensions. Under situational, for
example, purpose, hope, and meaning are included. Kellehear’s underpinning theory “is the
idea that human beings have a desire to transcend hardship and suffering” (Kellehear, 2000, p.
150), thereby making meaning out of that situation. Suffering is clearly central in this model.
Kellehear explicates the model for use in research and practice (Kellehear, 2000, p. 153).

In another often cited article, Sulmasy suggests spiritual issues are a natural part of dying and can be encompassed in the questions of “meaning, value and relationship” (Sulmasy, 2002, p. 26). These three areas Sulmasy equates to ‘dignity’, ‘hope’ and ‘forgiveness’ respectively, and each has a negative correlate: no meaning in life leaves “abject hopelessness”; life having no value, the “ultimate indignity”; or to die “alone and unforgiving” leaves one in “utter alienation” (Sulmasy, 2002, p. 26). Suffering then is the antithesis of meaning, value and relationship. This, however, is qualified by Frankl’s approach to suffering discussed above (section 2.4.2.1.1.2). Puchalski, working from a palliative care context, affirms this position, suggesting her patients handle suffering better when they have a sense of meaning, which, she suggests, is directly connected to their spirituality (Puchalski, 2006c).

Suffering, embracing pain and seeing redemptive opportunities are unfashionable ideas in a world that worships ‘youth’ and ‘health’, with pain of any kind abhorred. Yet “often it is just such an exceptionally difficult external situation which gives man the opportunity to grow spiritually beyond himself” (Frankl, 1984, p. 93).
Frankl continues “Existential frustration is neither pathological nor pathogenic”; taking such concerns out of the medical realm of disease (Frankl, 1984, p. 125). Acknowledging such suffering is important, but masking/ignoring/medicalizing it may be doing patients an injustice. Suffering is one of a patient’s primary issues when faced with serious or terminal illness (Wright, 2001). If the analyses above are accepted, existential suffering is certainly an aspect of spiritual care.

### 2.3.4.2 Patients’ needs

The spiritual needs of the ill have been canvassed above. Suffice it to say that, certainly from the US and arguably the Australian context, studies show a call from patients for their spiritual needs to be addressed by the healthcare system in some circumstances (Balboni, et al., 2007; D’Souza, 2005; Holmes, et al., 2006; McCord, et al., 2004; Sinclair, et al., 2006). Importantly, some patients (also family members and staff) do not want spiritual care (Cobb, 2003; Moss & Dobson, 2006; Rumbold, 2007), for this may be considered private, irrelevant to the healthcare setting or just inappropriate.

### 2.3.4.3 Family Members'/Carers' needs

Sinclair’s review shows a lack of studies examining the spiritual needs of patients’ family members (Sinclair, et al., 2006), yet this group are, after the patient, radically affected, particularly if their loved one has a serious or terminal illnesses (Lin & Tsao, 2004; Milstein, 2008). Milstein is one of the few scholars naming the need to take a spiritual history from the family, both to assess their needs and suggest spiritual care pathways, but also to assist them in spiritually caring for their family member (Milstein, 2008). Murray et al also note the “struggle” that carers have with “managing their own spiritual needs and knowing how to help a loved one in spiritual distress” (Murray, et al., 2004, p. 43).

Keeley, in a US qualitative study, examines the final conversations of the dying, focusing on family member experiences, and suggests the majority of these conversations have a spiritual component (Keeley, 2004). Keeley suggests the same spiritual work, as the patient, needs to be done by the family members, including finding meaning in the situation, coming to some understanding of death, and finding some transcendence after death (Keeley, 2004).
primary spiritual theme in Keeley’s interviews was validation — of beliefs, comfort, community (Keeley, 2004).

2.3.4.4 Staff needs

Professionals who specialize in dealing with death may be especially challenged to deepen their own explorations of spirituality (Mahoney & Graci, 1999, p. 522).

The spiritual care needs of healthcare professionals are a major theme primarily in the hospice literature (Sinclair, et al., 2006). Issues that arise include staff spirituality and care and their subsequent ability to care for patients: staff members’ spiritual familiarity, comfort and development may affect their ability to give spiritual care (Boero, et al., 2005; Joint Commission on Accreditation of Healthcare Organizations., 2005; Speck, 2004; Sulmasy, 2002; Vachon & Benor, 2003). Boston calls for “continuous reflective assessment” for palliative caregivers, meaning the institutional structuring of “informal and formal opportunities for personnel support.” (Boston & Mount, 2006, p. 24). Speck goes as far as saying “To be effective the carer must have personally engaged with the existential issues which arise” (Speck, 2004, p. 21), with significant consequences for recruitment and training. Cotter affirms Speck’s position, suggesting to be skilful, “compassionate companions” need to have dealt with their own death issues (Cotter, 2007). Saunders, perhaps the best source here, wrote staff “are impelled to develop a basic philosophy, part individual and part corporate.” and “gain enough freedom from their own anxieties to listen to another’s questions of distress” (Saunders, 2004, p. xix).80 In hospice care, support for spiritual carers is considered important (Speck, 2004) and education effective (Cobb, 2003; Holland, 2005; Ross, 2006a).

2.3.4.5 Community needs

Spiritual needs are almost exclusively examined from an individual perspective in the healthcare literature (Sinclair, et al., 2006). This issue is not obvious at first in a spiritual context that normally understands such issues individually. But spirituality, while manifesting individually, happens within a milieu of meaning creation and culture. Thus, for instance, Bever notes the importance of “community building” as a spiritual need (Bever, 2005). It

80 See also (Vachon & Benor, 2003)
includes “fellowship”, but further “promotes connection, belonging, and a sense of togetherness” (Bever, 2005, p. 155). Community spirituality issues need further study.

Spiritual needs are defined and explained above. Spiritual needs often go unattended in those that ought to receive such care. In palliative care, spiritual needs are widely understood and include not just the patient, but family members and staff needs. For spiritual care to be ‘successful’, clear understanding, assessment processes and interventions are critical.

### 2.3.5 Spiritual Care Provision/Assessment

This section compiles some of the key issues in, and ways the literature discusses, spiritual care provision/assessment. The majority of seriously ill patients are likely to want their spirituality attended to; however there is a proportion who will find this intrusive (Woll, et al., 2008). The primary approach suggested in the literature is ‘patient-led’ (Puchalski, 2006b). This section will consider some general issues, consider open and structured approaches to spiritual care, examine common spiritual interventions, timing issues and spiritual development.

Spiritual assessment is increasingly mandated in Western countries, the US and UK particularly (Joint Commission on Accreditation of Healthcare Organizations., 2005; McSherry, 2007). A major hospital accreditation body in the US requires, “organizations to include a spiritual assessment as part of the overall assessment of a patient to determine how the patient’s spiritual outlook can affect his or her care, treatment, and services” (McSherry, 2007).

Spiritual care, as with other areas of care, has processes that may be followed. At its most basic (and inadequate), spiritual care may be a simple question about religious denomination and need for a chaplain; more sophisticated approaches include spiritual histories, interventions and ongoing monitoring. The aim of spiritual care is to meet spiritual needs, but how these needs are assessed and addressed varies. Puchalski suggests the key practical elements of good spiritual care include,

- Practice of compassionate presence
- Patient-centred communication – Listening to patient’s fears, hopes, pain, dreams
• Attentiveness to all dimensions of the patient and patient’s family: body, mind, and spirit
• Obtaining a spiritual history
• Assessment of spiritual issues
• Spiritual Care Plan: Incorporation of spiritual practice as appropriate
• Chaplains and other spiritual care providers as members of the interdisciplinary healthcare team (Puchalski, 2006b, p. 232).

Puchalski gives this list for all healthcare professionals to adapt. She highlights ‘listening’ as the most important skill needed.

The clinical assessment of spiritual needs may take two distinctive forms: open-ended and structured (Okon, 2005). The structured approach is influenced by psychological assessments and some argue more appropriate for research (Whitford, 2008), using psychometrically tested instruments to assess the spiritual domain (Okon, 2005). The alternative approach is more closely aligned with a medical history, with open-ended enquiry.

2.3.5.1 Open-Ended

Spiritual assessment, as part of taking a patient’s history in an open-ended approach, ranges from the questions ‘to what extent are you at peace?’ (Steinhauser, et al., 2006, p. 101) and, “What role does spirituality or religion play in your life?” (Sulmasy, 2002, p. 30), to a range of questions about the importance of faith, religion, spirituality, life, meaning and purpose (Breitbart, 2002; Moberg, 2002; Okon, 2005, p. 400; Tanyi, 2002). A number of acronyms have been developed, suggesting a more structured approach, to assist clinicians. The most often cited is Puchalski et al’s “FICA” for “F - Faith and Beliefs, I - Importance, C – Community, A – Address/Action in Care” (Puchalski, 2006b, p. 238). The acronyms serve as reminders for clinicians, while taking a spiritual history, about what areas to cover and questions to ask. Other acronyms include,

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81 Moberg raised an interesting issue of the degree of spiritual maturity as part of the spiritual assessment and care process (Moberg, 2002). This is not explored widely in this literature and asks the question ‘can clinicians assess spiritual maturity’?
• “HOPE” (Anandarajah & Hight, 2001) “stands for H: sources of hope, O: role of organized religion, P: personal spirituality and practices, and E: effects on care and decision making.”


A spiritual assessment approach that splits such care off into another aspect along with social, mental and physical has been challenged as inappropriate (McGrath, 2003; Rumbold, 2002c). McGrath, discussing spiritual care in hospices, states, “It is not a matter of incorporating spirituality as one dimension in the plan of care, but rather understanding that for community-based hospices spirituality actually is expressed as the plan of care” (McGrath, 2003, p. 31).

This ‘integrated spiritual care approach’ makes sense when spirituality exists as an integral aspect of an institution and their care philosophy (like hospice). However, in other healthcare organisations this is not the case, therefore introducing spiritual care via history taking has its advantages. Puchalski notes within the spiritual history ambit referral to chaplains when needed is as important as referral to other ‘specialists’ (Puchalski, 2006d). This raises the question of spiritual care plans, which come from the spiritual history (Puchalski, 2006d).

### 2.3.5.1.1 Barriers to Spiritual Care

The literature highlights a range of barriers to spiritual care, including stigma, role issues, communication problems, environmental contexts, language issues, professional demarcation, capacity, training and knowledge.

Stigma associated with spiritual care or chaplains/spiritual carers is suggested by Hills et al as a barrier (Hills, et al., 2005). A related potential barrier to the open-ended approach that asks about spiritual or religious beliefs is understanding of what these concepts may be. Therefore, care needs to be taken regarding patient and family member understanding of the concept and care options.

From a nursing point of view, Narayanasamy & Owens name a range of barriers relevant for many healthcare professions, including “role ambiguity”, “lack of communication”, and
“environmental factors” (includes “lack of time and space, peace, quiet and privacy”) (Narayanasamy & Owens, 2000, p. 447). They noted infrastructural issues of a “lack of peer and management support, poor training and education and resources” as potentially unethical (Narayanasamy & Owens, 2000, p. 447). In a sense, all these issues are the problem/challenge of management rather than individual healthcare professionals.

Medical doctors outside of hospice care settings have traditionally not explicitly attended to spirituality. Acknowledging these issues for medical doctors is important, but they are also noticeably attitudinally based, with the exception of time and training. Lack of time and space are regularly noted as a barrier to spiritual care (Joint Commission on Accreditation of Healthcare Organizations., 2005; Milstein, 2008). These barriers are important, especially for clinicians, as they could block potential growth and healing of patients and family members, or cause further spiritual distress (Murray, et al., 2004).

2.3.5.1.2 Timing of Spiritual Care

Timing of spiritual care is an important consideration, potentially critical to healing and also a potential barrier. Murray et al note with terminal illness there are particular points on the illness trajectory that are critical for spiritual care, including the initial diagnosis, waiting to start treatment and after treatment ends (Murray, et al., 2004). Spiritual assessment, based on a UK study, mostly happens at the time of admission (Wright, 2001). This is not necessarily the best time; some argue a relationship needs to have developed for such deep issues to be broached (Rousseau, 2003).

Rumbold argues “spiritual care may be inappropriate, useless or even harmful” (Rumbold, 2007, p. 61) if done at the wrong time. Essentially, Rumbold is saying treatment concerns and physical recovery are such that time for reflection (induced by spiritual questions) may not be appropriate or helpful. Simple awareness of the possibility of spiritual care resources may be all that is needed.

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82 In the tradition of Erikson, Fowler, Piaget et al, there is a history of thought that considers the nature of how humans develop spiritually. Generally these are stage based models. For a full discussion see (Mattes, 2005). There is ‘evidence’ that as people grow older there are opportunities for spiritual development, for example, “The process of aging then contains such transformative elements by producing opportunities for deeper self awareness, connectedness with our individual life stories, and the giftedness of the unique individuals we have become” (Mattes, 2005, p. 58), and “The aging process by its very nature fosters a deepening personal spiritual development by drawing a person through the spiritual tasks of discovering, pondering, integrating, surrendering, growing, and companioning” (Mattes, 2005, p. 59). Mattes goes through each of these ‘tasks’ considering their process. Mattes’ article is thoughtful about aging and spiritual development, seeing aging positively as a time for integration.
2.3.5.1.3 New Zealand Hospice Care

Hospice care in New Zealand, like the rest of the world, has a “total care” mandate, including physical, mental, social and spiritual dimensions (Ministry of Health, 2001). The New Zealand Palliative Care Strategy (2001) uses Durie’s te whare tapa whā model, a Māori model with the same domains.

In 2008, the New Zealand Specialist Palliative Care Tier Two Service Specification noted under the Purchase Unit “Inpatient Care” and “Grief, loss and support” the need for assessment and palliation of spiritual needs and for a trained spiritual support person, in the context of a “interdisciplinary palliative care team” (Ministry of Health, 2008b, p. 22). These specifications highlight critical positions in spiritual care: assessment and care planning are needed, trained carers are important, and the interdisciplinary nature of the wider team is affirmed. These are widely held approaches in the literature; New Zealand-based professional competencies and guidelines for spiritual care have not been developed. As of 2008, the Ministry of Health was drafting guidelines for cancer supportive care (Ministry of Health, 2008a) which include, for the first time, spiritual care.83

The Psycho-Oncology Stock take 2006 (Surgenor, 2005) surveyed 112 service providers (n=134 returned surveys, 86% response rate) across New Zealand, many of which provided hospice care. The survey covered six sections, including ‘spiritual support services’. The survey “does not include arrangements to encourage access or refer patients/users to spiritual support provided by other organisations or cancer services (Surgenor, 2005, p. 19). That said, it is the most extensive survey of spiritual care provision in this field in New Zealand. The table below summarizes the regional data presented in the report (Surgenor, 2005, p. 19). Significantly, three-quarters of services are providing out-sourced spiritual support, while just under two-thirds are providing spiritual care from their own service. Just over half of the services have a ‘spiritual leader or advisor’ and 44.2% understand other personnel provide spiritual care. This implies there are not many chaplains or spiritual carers in these services and spiritual care is not seen as ‘everybody’s business’, as recommended by some scholars (Puchalski, 2006a).

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83 The Ministry of Health has consulted with me and have used my ‘working definition’ of spirituality (Ministry of Health, 2008a).
Table 2.1 New Zealand Psycho-Oncology Stocktake 2006 Spiritual Support Services

<table>
<thead>
<tr>
<th>Spiritual Support Service</th>
<th>Percentage endorsing availability across whole country</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pastoral care provisions</td>
<td>57.3</td>
</tr>
<tr>
<td>Spiritual care provisions</td>
<td>64.8</td>
</tr>
<tr>
<td>Existential interventions</td>
<td>39.1</td>
</tr>
<tr>
<td>Prayer</td>
<td>56.7</td>
</tr>
<tr>
<td>Facilitate rituals around death</td>
<td>64.8</td>
</tr>
<tr>
<td>Bereavement services</td>
<td>42.3</td>
</tr>
<tr>
<td>Other spiritual services and programmes</td>
<td>24</td>
</tr>
<tr>
<td>Facilitate access/refer to spiritual support to other organisations</td>
<td>75.8</td>
</tr>
<tr>
<td>Spiritual leader or advisor</td>
<td>54.6</td>
</tr>
<tr>
<td>Other personnel provide spiritual support services</td>
<td>44.2</td>
</tr>
</tbody>
</table>

While the overall psycho-oncology figures are less than impressive, when the data are examined by service category, hospice care spiritual care provision is significantly higher. The “Hospice Specialist Services [located in Auckland, Hamilton, Palmerston North, Wellington, Christchurch, Dunedin]” all reported between 87.5% and 100% for all of the spiritual support services examined, with the exception of “Other spiritual services and programmes” (28.6%) (Surgenor, 2005, p. 20). The figure of 100% ‘spiritual care provision’ is almost double the only other reported percentage of hospice spiritual care provision: the New Zealand Palliative Care Strategy (2001) figure of 56% (Ministry of Health, 2001, p. 35). The Strategy’s figures are from the Health Funding Authority 1999 “Data from hospice and hospital questionnaires” (Ministry of Health, 2001, p. 56) (the Strategy’s figures are based on 32 hospices, as opposed to six in the psycho-oncology survey).

Of further note from the psycho-oncology survey is that across all the ‘service categories’, which include specialist hospice care through to hospital and district health nurses, 70.2% of providers claimed spiritual care provision. The problem with such quantitative data is that they do not give any detail of what the spiritual care involves, but, nonetheless, these figures tell at least two stories. Firstly, a high proportion of cancer services across New Zealand provide what they understand as spiritual care. Secondly, almost 30% do not provide such care. The data on the hospice spiritual care provision are ambiguous, and the New Zealand
Palliative Care Strategy's figures could arguably be more accurate based on their greater number of hospices surveyed.

2.3.5.2 Spiritual Interventions

The literature suggests a wide range of spiritual care interventions. At one end, the simple but powerful tool of listening is recommended by many (Puchalski, 2006b), while more complex interventions such as psychotherapy are reported (Breitbart, 2002; Henoch & Danielson, 2009). Ethical issues are addressed below (Section 2.4.3.4), but it is worth noting that most authors qualify any approach with the need to be led by the patient, while not imposing any views, proselytizing or presuming that spiritual care is wanted (Okon, 2005; Rumbold, 2007).

Creating space, an environment, permission and time for a patient to “elicit the thoughts, memories and experiences that give coherence to a person’s life” (Rumbold, 2007, p. 61) is an influential view in the literature. Spiritual intervention is almost a misnomer, in that the intervention may be doing nothing but acknowledging spiritual issues, listening, ‘being with’. This could be at odds with the ‘doing’ and ‘fixing’ approach of much of healthcare (Randall, 1999).

Rumbold suggests a generic process that honours patients’ needs, while being explicit, structured and accountable. The process includes “identifying spiritual needs and resources in ways that,

- Respect patients’ perspectives and do not infringe privacy;
- Involve all members of the interdisciplinary team to the extent that they are able and willing to contribute;
- Permit clear documentation of needs, strategic responses to these needs, resources required, and outcomes;
- Integrate strategies into an overall care plan in ways that are readily understood by all members of the interdisciplinary team;
- Provide a shared framework for continuity of care between community agencies and inpatient services; and
- Provide a place for religious care but do not conflate spiritual issues with religious practice” (Rumbold, 2007, p. 61).
Rumbold suggests this process happens initially by an assessment/"screening process" that "maps significant relationships within the domain of spirituality"; he believes, "Collating these observations will produce a map of the significant connections that hold a person’s sense of self, community and purpose (Who am I? Who are we? Why are we here?)" (Rumbold, 2007, pp. 61-62).

This is an attempt at an integrative approach; Rumbold’s underlying concept is, in understanding a patient’s significant beliefs and life events, a spiritual picture or map may be ‘drawn’, gaps seen, and a spiritual care plan developed. The following considers the main specific interventions suggested in the literature.

2.3.5.2.1 Listening & Touch

One of the leading scholars in this field noted, based on his chaplain survey in hospitals and hospices, there is “strong evidence that patients require someone to ‘be there’ for them and someone to listen to them” (Wright, 2001, p. 238). Listening is a deceptively simple ‘intervention’; it is what questions one asks, how one listens and what one listens for that may make a difference. One of the above issues, forgiveness, is within the listening ambit. Breitbart suggests these fit under the ‘compassion’ rubric — including “hospitality, presence, and listening” — which he suggests is “an important element of all palliative care clinical interactions” (Breitbart, 2008, p. 211).

Appropriate touch is considered to be “of the most powerful healing modalities” (Grudzen, 2003, p. 29). Cultural and religious restrictions are important to be aware of here.

2.3.5.2.2 Life Review

Probably the most common spiritual intervention, after the spiritual care skills of listening and touch, is life review (sometimes called biography services) (Hermann, 2001; Milstein, 2008; Steinhauser, et al., 2008; Zielske, 2003). There is reasonable evidence that life review processes may be effective spirituality interventions, particularly for the seriously and terminally ill (Ando, et al., 2007; Bingley, et al., 2006). The review is a narrative that helps make sense of one’s life, one’s illness and is thereby therapeutic and empowering (Bingley, et al., 2006). Bingley et al note a ‘story’ helps create a sense of “continuity of self after death” (Bingley, et al., 2006, p. 194), presumably creating a sense of hope for those with ‘after-life anxiety’. One of the most widely published scholar on life review is Chochinov, who developed ‘dignity therapy’, a “therapeutic map” for those working with the dying using a series of questions to elicit their story (Chochinov, 2006, p. 94). The process includes...
recording, editing and returning the narrative to the patient. Chochinov evaluated this with 100 terminally ill patients and found very high levels of satisfaction (91%), heightened dignity (76%) and increased sense of meaning (67%) and purpose (68%) (Chochinov, 2006, pp. 99-100).

2.3.5.2.3 Spiritual Retreat/Therapeutic Groups

Spiritual interventions in groups are not new, but their efficacy has not been widely assessed. Kennedy et al showed an increased spiritual well-being from a two and a half day ‘retreat’ (Kennedy, et al., 2002, p. 64). While the focus included a number of interventions, spiritual tools were explored. A pre and post questionnaire, which used three questions about the importance of belief, spiritual coping and divine support, showed “78% reported increased spirituality after the retreat” (Kennedy, et al., 2002, p. 64).

Rousseau makes a strong argument for the effectiveness of group psychotherapeutic approaches for cancer (Rousseau, 2003). Breitbart suggests, for the terminally ill, an ambitious goal of psychotherapy “is to help patients come to a sense of acceptance of a life lived and thus, ultimately an acceptance of death (i.e., being able to face death with a sense of peace and equanimity)” (Breitbart, 2008, p. 211). Breitbart does question the possibility of this happening in every situation.

2.3.5.2.4 Meditation/Contemplation

Meditation and contemplation have been religious tools for millennia. Some healthcare scholars recommend these approaches for patients (Zielske, 2003). Baldacchino’s reviewed spiritual coping strategies and suggested the use of “meditation/contemplation whereby the individual connects with the inner self and acknowledges his/her strengths” (Reed, 1992 cited in Baldacchino & Draper, 2001, p. 838). Spirituality is naturally a reflective process (Cobb, 2003), thus meditation skills offer possible options, if appropriately developed.

2.3.5.2.5 Nature & Arts

The spiritually salutary effects of engaging with nature and the arts are widespread in the literature (Baldacchino & Draper, 2001; Zielske, 2003). Zielske suggests patients may paint

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84 Perhaps the best known intervention that uses contemporary spirituality as a focus is Alcoholics Anonymous. A key component to the AA programme is said to be spirituality, as Kennedy notes, AA uses spirituality explicitly to help change or improve physical and mental health (Kennedy, Abbott, & Rosenberg, 2002). The approach involves accepting the powerlessness of one’s own strength to control or change the addiction and then almost handing it over and asking for help from something outside of themselves, generically called ‘a higher power’.
to explore abstract ideas around mortality and consider popular culture media as an inroad for discussions regarding meaning (Zielske, 2003). Music therapy has an established tradition and has been shown to be useful (Horne-Thompson & Grocke, 2008). Literature has long been a consolatory medium and reading materials are recommended for patients (Hermann, 2001).

2.3.5.2.6 Space

There is a growing call for ‘space’ as a spiritual intervention (Rumbold, 2005a; Zielske, 2003). While this may seem inane, behind it is the quite sophisticated call for spirituality to be recognized and nurtured from the patient or family members’ agenda, hence the need for space. Space may be interpreted as opening up the issues in dialogue (Boston & Mount, 2006) or by creating a “healing space” (Milstein, 2008). Milstein suggests, “A healing space introduces multiple opportunities for meaning construction—a process of sense-making in the face of illness interruption—not apparent in a curing space” (Milstein, 2008, p. 2440). Another understanding of ‘space’ is as a spiritual experience (Leibrich, 2002).

2.3.5.2.7 Complementary and Alternative Medicine (CAM)

CAM is used widely in end-of-life care (Kaplar, Wachholtz, & O’Brien, 2004a, p. 40; Kozak, et al., 2009; Thompson, et al., 2008; White & Verhoef, 2006). Arguably, by the very ontological basis of CAM, all forms of it are spiritual intervention or therapy: CAM’s ontology is based on a holistic worldview (Heelas, et al., 2005), thereby explicitly acknowledging spirituality. There is a broad spectrum of CAM, including religious practices like prayer and rituals (White & Verhoef, 2006). Most authors include such practices as massage, music therapy, energy healing, aromatherapy, guided imagery, compassionate touch, acupuncture, pet therapy, meditation, art therapy, reflexology, and hypnotherapy and some Eastern religious therapies/techniques such as qi qong (Kozak, et al., 2009; White & Verhoef, 2006). A recent US phone survey of hospices (n=36) asked if CAM were available (Kozak, et al., 2009). 86% said yes, with over half offering massage (87%), music therapy (74%), and energy healing (65%) (Kozak, et al., 2009, p. 463).

2.3.5.2.8 Religious Spiritual Care

Religious spiritual care is the traditional and sometimes only spiritual care offered in health institutions. This usually refers to an ordained minister, often a chaplain, attending to the religious needs of patients. It has been suggested religious needs are easier to attend to (than say more complex existential needs) because there are obvious pathways and interventions (minister and sacraments) (McSherry & Cash, 2004). In an excellent overview of religious
approaches, Doyle & Woodruff name how religious faith can help the dying (Doyle & Woodruff, 2004). They suggest “most faiths are reassuring that biological death is not the end of life”, there is forgiveness, and this belief offers hope for both patients and those left behind (Doyle & Woodruff, 2004, p. 3). They note that religious beliefs can cause problems if miracles are expected or questions/prayers are unanswered.

2.3.5.2.9 Policy & Staff Training

As a spiritual intervention, policy is almost never referred to in the literature, with one or two exceptions (Zielske, 2003). Staff training is highlighted by many, especially nursing (Ross, 2006b). Sinclair notes research showing spiritual care training in palliative care impacts on compassion related to the dying, self, work satisfaction, stress and relationships (Sinclair, et al., 2006). Policy and training may be significant ‘up-stream’ spiritual interventions that are not widely recognised in the more individually/down-stream focused healthcare literature.

2.3.5.3 Who does it?

A major issue in spiritual care is who can, should and is able to provide spiritual care, as Milstein notes “There is no consensus as to which discipline should introduce the spiritual; …; however, the better choice may be dictated by the situation (Milstein, 2008, p. 2440). Traditionally chaplains have been the primary provider and this is still the case in many contexts (e.g. public hospitals in New Zealand). However, the literature reflects a move towards a more multi- or inter-disciplinary approach to spiritual care; this is particularly true for hospice/palliative care. Sinclair exemplifies this position, suggesting “chaplaincy should not own the sole rights to providing this care but, …, have an important role to educate, guide and equip other disciplines with the skill sets to engage in this care.” (Sinclair, et al., 2006, p. 479).

2.3.5.3.1 Multi/Inter-Disciplinary Approaches

In the US context, Puchalski argues whoever works with patients can help provide spiritual care (Puchalski, 2006c). In the UK context, Cobb affirms this position, arguing for an inter-disciplinary approach, including links with academics working in the field (Cobb, 2001). Thus, there is a strong theme in the literature that it is “everybody’s concern” (Speck, 2004, p. 23). There is a spiritual care leader (often the chaplain), but he or she is not always there at that ‘spiritual moment’ that needs to be addressed.
Does this mean the cleaner can provide spiritual care? - perhaps in some cases. The likely disciplines include: chaplain/spiritual carers, nurses, doctors, social workers, counsellors, occupational therapists, religious professionals, and other allied and complementary health professionals. This begs the question, are these professionals qualified, able and do they have the capacity to address the spiritual dimension of care?

The Scottish NHS affirms this inter-disciplinary approach and expands possible provision of spiritual care to include relatives and other patients (Working Group on Spiritual Care in the NHS, 2002, p. 7). This highlights the need for trained professionals, but indicates spiritual care may come from a number of professions and people connected to patients.

Speck, in his British Medical Journal editorial, suggests “many” healthcare professionals see spiritual care as “intrusive”; he speculates not only might this be because of the lack of clarity around “terms and concepts, but often it is the degree of personal challenge such conversations have for the caregiver themselves” (Speck, 2004, p. 124). Speck’s opinion challenges policy and guideline mandates, but perhaps more importantly calls for healthcare professional awareness and education.

The US “Joint Commission on Accreditation of Healthcare Organizations” assesses and accredits many healthcare organisations. Part of the accreditation process involves spiritual care. In their advice about spiritual care, they note staff “capable” of spiritual assessment and care “may come from varied backgrounds”; they suggest the following characteristics of a competent spiritual carer,

- A willingness and a desire to learn about how to conduct a spiritual assessment
- An understanding that there are many different spiritual and religious perspectives
- An ability to focus on spiritual issues with a patient without forcing one's own beliefs on him or her
- A comfort level with discussing spiritual issues
- A knowledge of appropriate responses to spiritual disclosures, including prayer, meditation, walks in quiet nature areas, and so forth (Joint Commission on Accreditation of Healthcare Organizations., 2005, p. 2).

This list raises many questions. It does however suggest it is not the profession but the person who is important when it comes to spiritual care; not everyone in every profession either can or should provide it, but rather there are ‘experts’ within each field. That said, this does not
imply there is no need for training or competency: all health professionals need some
cognisance of this area, thereby being minimally able to refer on to more competent staff
(Cobb, 2001). While demarcation issues, patient-centred approaches and related stress need
to be considered carefully in a multi-disciplinary team, these issues are surmountable (Ekedah &
Wengstrom, 2008).

2.3.5.3.2 Doctors
Medical doctors are potential spiritual carers. As above, if trained in the US, it is likely they
would have had to learn how to take a spiritual history, but this is not true of all Western
medical schools (New Zealand has no spirituality courses in the two universities that each
medicine). However, even in the US, very few doctors enquire about spiritual issues and only
10% take a spiritual history (Koenig, 2002, p. 2; McCord, et al., 2004).

Olson et al’s US qualitative study assessed “family physicians’ beliefs, attitudes, and practices
regarding the integration of patient spirituality into clinical care” (Olson, Sandor, Sierpina,
Vanderpool, & Dayao, 2006, p. 234). Using a “phenomenology and elements of grounded-
theory” approach, the researchers found,

There was an almost unanimous conviction among respondents that openness to
discussing spirituality contributes to better health and physician–patient
relationships and addressing spiritual issues requires sensitivity, patience,
tolerance for ambiguity, dealing with time constraints, and sensitivity to ones
“own spiritual place” (Olson, et al., 2006, p. 234).

Koenig, who recommends spirituality be attended to by doctors, does have some cautions. He
recommends a physician’s time in addressing medical problems is not undermined by
attending to the spiritual dimension, that this is “something done ‘in addition to’ addressing
medical issues and requires an extra commitment of time” (Koenig, 2001, p. 332).

In a review type article that considers how religion (and spirituality) affects surgical oncology
patients, mainly dealing with Islam, Christianity and Judaism, Woll et al challenge the
“objectivity and “distance”’ [that is] often stressed in medical schools” (Woll, et al., 2008, p.
3048). The authors argue this way of thinking is outdated, “it is now clear that approaching
the patient from multiple perspectives — biomedical, spiritual, sociological, and
philosophical — is a therapeutic imperative” (Woll, et al., 2008, pp. 3048-3049). Many
patients want this care in appropriate situations and will take the lead from their doctor, who
has much of the power in this context.
2.3.5.3.3 Nurses

The nursing literature on spirituality and health is one of the largest dealing with this subject (Carr, 2008; Emblen & Halstead, 1993; Greenstreet, 1999; Miner-Williams, 2006; Ross, 2006b). Bradshaw’s book, *Lighting the Lamp: the Spiritual Dimension of Nursing Care* (Bradshaw, 1994), is one of the few classic texts. It has a strong Christian bias, but deals with the area in a sophisticated historical, theological and clinical way. McSherry writes an equally fascinating book about spirituality in healthcare and nursing *The Meaning of Spirituality and Spiritual Care within Nursing and Health Care Practice* (McSherry, 2007). This is essentially McSherry’s PhD thesis — a qualitative examination of spirituality in the UK. Both authors note spiritual care is nationally and internationally mandated in nurses’ ethical codes, guidelines, training and competencies. They trace the history of spiritual care back to its Christian roots with Florence Nightingale and others.

The irony in this profession, as with most, is that while the mandate, competencies and some training exists, most nursing scholars argue (Ross, 2006a), as Reed does in her comment on a Danish Study, “On one hand, spiritual care is fundamental to nursing practice, whereas on the other hand, nurses continue to lack personal, practice, and empirical knowledge about the nursing science of spirituality” (Reed, 2008, p. 15).

UK based Narayanasamy & Owens did an excellent qualitative study of spiritual needs of patients by examining critical incidents. Amongst other ‘topic areas’, nurses were asked to describe a situation “which showed when and how respondents recognized that patients had spiritual needs” (Narayanasamy & Owens, 2000, p. 488). Questionnaires were used to collect the data (118 returned, 88% response rate). There were wide ranging themes and conclusions: spiritual needs were better met when religious background was shared or spiritual pain was obvious; personal belief systems influenced spiritual care; barriers were noted such as “role ambiguity”; and “The approach to spiritual care was apparently largely unsystematic and delivered haphazardly” (Narayanasamy & Owens, 2000, p. 454). Narayanasamy notes, of the spiritual care approaches named, the personal/cultural was the ideal, coming from a holistic patient-centred position, while the procedural was likely to miss people’s spiritual issues and the evangelical had obvious ethical problems.

2.3.5.3.4 Chaplains/Spiritual Carers

The role of health care chaplaincy has changed a great deal from being the sole providers of traditional religious ritual to one of being a resource to people...
undertaking this much wider search for meaning within the illness or dying process (Speck, 2004, p. 22).

Traditionally, spiritual care has been the realm of religious people, particularly nuns and chaplains (Norwood, 2006). The chaplain is a paid, well-qualified (usually ordained minister) and certified professional spiritual carer. There are, however, a number of issues related to this profession, including their role, title, denominational representation, capacity, and status.

The title is a controversial issue, as the context for spiritual care is no longer just a religious matter. Thus a religiously trained, named and often looking person may not be the most appropriate spiritual carer. There may be a distinction made between pastoral and spiritual care, with the former more religiously oriented (Garces-Foley, 2006). However this distinction is not clear across the board. Garces-Foley notes traditional spiritual care from an ordained chaplain was not only sacramental, but also existential in nature. She does note the defined nature of the ‘chaplain’ name, best understood as one who provides pastoral care outside a parish, “for example in a military unit”. (Garces-Foley, 2006, p. 121).

Related to the name issue is the denomination issue. Where once a Christian chaplain would be enough for the vast majority of patients in Western countries, the contemporary plurality of spirituality calls for a range of denominational options (Garces-Foley, 2006). The process for attending to denominations other than Christian is for the chaplain to refer on to appropriate religious leaders. However the dominance of chaplaincy by Christians is challenged (Williams, Wright, Cobb, & Shiels, 2004).

Perhaps more important, certainly for name and denominations issues, is the ‘role’ of the chaplain (Cobb, 2007). Cobb notes accurately, “Chaplains can no longer expect patients or their carers to understand who they are and they can rely much less on the social capital of religion” (Cobb, 2007, p. 7). Cobb writes from a UK context, but his observation is likely to be true in many secular Western contexts.

An issue for chaplains is capacity: the ability to meet the spiritual needs of all those he or she is mandated to care for in the healthcare setting, often extending to the spiritual care of staff, patients and their families (Williams, et al., 2004). The capacity to meet such expectations is

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85 There are some exceptions, for example a Roman Catholic priest and some other chaplains are not paid, nor are volunteer spiritual carers.
more often than not insufficient. In particular, if the spiritual needs of patients with serious illnesses (research shows they most likely to need or want it (McCord, et al., 2004)) are increasingly recognized, the capacity of spiritual carers will need to increase. Another approach may be for the spiritual carer/chaplain to help facilitate spiritual care through raising the awareness and capacity of the wider healthcare team.

Where the biomedical focus dominates, spiritual care may be relegated and marginalized (Norwood, 2006). While this is changing in the sense of guidelines and policy, the status of spiritual care in healthcare is arguably low. There is a call in the literature for further research and evaluation to show efficacy and need of chaplaincy services (Hills, et al., 2005). Similarly, the need to justify spiritual care is important in the ‘health purchasing’ environment (Ainsworth-Smith, 1998).

Chaplaincy is changing, as healthcare systems, patients and spiritual needs change (Heelas, 2006) (Cobb, 2007). Arguably, chaplains remain the “gold standard” (Mann, Galler, Williams, & Frost, 2004, p. 126) and a “key resource” for “spiritual/existential explorations by patients and staff”, but rather than being the only provider, they are perhaps better named as the lead provider of such care (Speck, 2004, p. 23).

2.3.5.3.5 Care Givers (family and friends)

Family members and friends are radically affected by a loved one’s diagnosis of cancer. Yet this population is one of the least researched; how well their spiritual well-being is attended to is not well known. There is some research suggesting this group provides the majority of spiritual care for family members with cancer (Hanson, et al., 2008).

In a widely read and sourced account of her cancer journey, UK journalist Picardie told her story in Observer newspaper articles and a subsequent book Before I Say Goodbye (Picardie, 1998). At the end of the book, her husband, Mark Seaton, writes the final poignant entry in the diary-style book,

Dying is nasty, ugly and painful; it’s so obvious, isn’t it?

You always imagine death as a sudden event.... ... But with a progressive disease like cancer, dying is a relentless attritional process of estrangement.

You want so much to do and say the right thing, but you are doomed to frustration, failure and regret. The only really ‘right thing’ would be to make that person you love well again, and this is the one great godlike task you cannot perform (Picardie, 1998, pp. 100, 103, 130).
Seaton's comments are a reminder of the terrible ordeal not only the person with cancer goes through, but his or her family and friends also endure. This perspective is important, for at times the 'cancer journey' may be romanticised (Kellehear, 2007).

A recent US quantitative study used a cross sectional survey (n=38 patients, 65 family members) to examine spiritual care satisfaction. The results were slightly surprising to the authors; 41% of spiritual care came from family and friends, 29% from healthcare providers and 17% from clergy. The most common spiritual care activity was “helping coping with illness” (87%), and the least common “intercessory prayer” (4%) (Hanson, et al., 2008, p. 907). Approximately half the participants were “very or somewhat satisfied with spiritual care” (Hanson, et al., 2008, p. 907). What is remarkable about this study is most of the spiritual care is provided by family and friends and up to half the participants did not receive adequate spiritual care.

A US based review article of quantitative studies examining the relationship between religion/spirituality and caregiver well-being (83 studies accepted, 37% published since 2000) noted “86% of studies found no or a mixed association ... between religion/spirituality and well-being” (Hebert, et al., 2006, p. 497). The authors put these surprising results, which they admit counter the positive association found in the wider field, down to the “multidimensionality of religion/spirituality and the diversity of well-being outcomes examined.” And like many quantitative researchers, they note the “frequent use of unrefined measures of religion/spirituality and of atheoretical approaches” in this field (Hebert, et al., 2006, p. 497). While no positive associations were clear, Hebert et al suggest a focus for future research: “What type of religion/spirituality has what effect, in what circumstances, via what mechanisms, and for whom?” (Hebert, et al., 2006, p. 515). This review reflects the difficulty quantitative studies have in this field generally and dominance of this method, with qualitative studies explicitly excluded.

While some studies have considered caregivers and family members, this is still an underserved population as seen in the published spirituality and health research.

Chaplains and professional spiritual carers still lead spiritual care in healthcare. However this situation is changing, challenging for chaplains, and challenging for other healthcare professionals with codes of practice calling for the spiritual dimension to be addressed. In
hospice and palliative care, inter/multi-disciplinary approaches to spiritual care are the norm, at least theoretically. In hospital and primary care, very little explicit spiritual care seems to be done outside of chaplaincy work. McSherry suggests there is possibly an undue expectation politically and in codes of practice of healthcare professionals to attend to the spirituality of patients (McSherry, 2007). If such care is to be done well, not in a compartmentalized and bureaucratized way, then issues of appropriate training, competencies and capacity will need to be addressed.

2.3.5.3 Spiritual care: ethical issues

Patients are invariably at a low ebb physically and many are elderly and frail; most have a multitude of physical and emotional and perhaps social and spiritual problems (Hanks, et al., 2004).

Ethical issues are a regular feature and concern of the spirituality and health literature (Tanyi, 2002). Two positions exist. One argues it is not ethical for healthcare professionals to ‘meddle’ with spirituality, therefore do not do it (Sloan, et al., 1999). The other, more common position, is it is ethical; in fact it is unethical not to address spiritual concerns in healthcare, therefore it must be done and done in an ethical way.

The ethics of spiritual care can by examined upstream including policy, professional codes of practice and competencies, and institutionally; midstream considering such issues as staff capacity, the physical environment and space; and downstream related to assessment and care plan processes.

Spiritual care has been taught in some US medical schools since the early 1990s and clear ethical guidelines have been developed. Two of these are worth noting. First, Puchalski argues it is unethical for healthcare professionals not to deal with spirituality for it “impacts clinical care in a variety of ways” including the possibility of beliefs affecting understandings of the illness and healthcare decisions, spiritual needs may be present, spirituality may help the patients cope with the illness, and spirituality is “integral to whole-patient care” (Puchalski, 2006b, p. 231). Puchalski goes on to list ethical and professional boundaries:

- Spiritual History: patient-centred
- Recognition of pastoral care professionals as experts
- Proselytizing is not acceptable in professional settings. Addressing spiritual issues should not be coercive.
• More in-depth spiritual counselling should be under the direction of chaplains and other spiritual leaders.

• Prayer with patients:
  o Not to be initiated by physicians or other healthcare providers unless there is no pastoral care available and the patient requests it or in circumstances where the physician/healthcare provider and patient have a long-standing relationship or share a similar belief system.
  o Physician/healthcare provider can stand in silence as patient prays in his/her tradition.
  o Referral to pastoral care for chaplain-led prayer (Puchalski, 2006b, p. 241).

This list is universal in application. The second approach comes from a US Professor of Ethics, Winslow, who suggested ethical boundaries for spiritual care include: understand each patient’s spirituality; follow patient’s wishes; do not impose spiritual care; understand one’s own spirituality; and proceed with integrity (Winslow, 2005). While similar to Puchalski, Winslow adds the importance of healthcare professionals understanding of their own spirituality. Okon, in his review article, has a similar ethical list, affirming the importance of the healthcare professional to “maintain one’s own integrity in regards one’s own religious beliefs and practices” (Okon, 2005, p. 406). Tanyi notes the importance of asking questions in a way that does not favour a particular spiritual point of view (Tanyi, 2002), and to do this those who ask the questions need to understand their own spiritual positions and have at least some understanding of other spiritual belief systems.

The most high profile ethical issues have been raised by Sloan et al (Sloan, et al., 2000), who have challenged the validity of raising particularly religious issues in the medical context. They suggest spiritual concerns are private matters, spirituality and science are incompatible and should not be broached in the healthcare setting. While a strongly held position by some, it is not the dominant one in the US where the debate is ongoing.

Competency and capacity are ethical issues Sloan et al raise, but also by others (Berlinger, 2004, p. 688). Kennedy asks if healthcare professionals have the expertise to adequately address the spiritual needs of patients (Kennedy, et al., 2002). Unruh uses an unethical example from a study examining occupational therapist’s attitude to spiritual care.

If any therapists are encouraging any spirituality (i.e., New Age, meditation, Moslem, Jehovah's Witness, Mormon, etc.) other than Christ, they are walking in Satanic Spirituality and the forces of evil are alive and well, being encouraged by

This shows the potential for harm when spiritual approaches clash. Berlinger raises a related ethical question: what if a patient’s ‘ultimate meaning’ is harmful to themselves or other people? For example, racist ideologies may be meaningful for some people; should such beliefs be understood, respected and accepted by clinicians (Berlinger, 2004, p. 688)?

How one proceeds with spiritual care, if at all, depends on worldviews and how much the evidence is seen as persuasive. Sloan’s critique is taken seriously by many researchers, for example Kennedy et al suggest that their intervention argues against Sloan’s position, in that spiritual care does work in the medical context (Kennedy, et al., 2002).

Doyle & Woodruff offer advice about handling spiritual issues in end-of-life care. They highlight “unreserved respect” of beliefs and practices before death and affirm any desires for rituals after death (Doyle & Woodruff, 2004, p. 4).

“Proceed with care” is a fair summary of ethical approaches in the literature. There is a majority opinion that spiritual needs ought to be addressed and that a patient-centred approach is best practice. What is absent from much of the ethical discussion are the up and midstream concerns of professional, institutional, environmental and capacity-driven issues.

2.3.5.4 Challenges for Spirituality in Palliative Care: Research, Policy, Provision

Related to ethical issues, spirituality in hospice research and care is not without its challenges (and detractors). Many of the criticisms discussed above (Section 2.2.5.5) can be levelled at spiritual care at end-of-life. What is different to the rest of healthcare is that in hospice care internationally there is universal agreement that spiritual needs exist and need to be attended to appropriately. However, McGrath and Rumbold note the challenges the mainstreaming of palliative care has had, particularly on the spiritual elements – sourcing James, McGrath notes, “in the twenty-first century, with the mainstreaming of palliative care, the challenge of protecting the spiritual vision and ideology is increasingly threatened by the encroachment of bureaucratization and routinisation” (James, 1992 cited in McGrath, 2002b, p. 178).
This issue is a clash of cultures, and as long as the hospice care culture is not completely subsumed by biomedically focused healthcare, the original hospice vision will hold strong.

Another key unresolved issue is measurement of spiritual well-being. Like the rest of the literature, there is no consensus on method or efficacy. However, as shown above, there is a growing body of research developing in this area. Taking a spiritual history is an agreed upon process — what this involves is not always clear, but there are commonalities (Koenig, 2002; Puchalski, 2006b). Further, there is agreement that some patients may not want spiritual care, but this needs appropriate assessment to discern such a position.

As noted above in the general section on spirituality and health, another challenge/criticism also present in hospice care is the perception that spirituality (in this field) is “largely as a concept void of religion”, often focused on ‘self’, lacking a communal connection and is compartmentalized (which contradicts the integral nature of spirituality as seen by some) (Sinclair, et al., 2006, p. 464). Garces-Foley refers to the new orthodoxy in hospice spiritual care which denigrates and marginalizes religious care. Sourcing Bradshaw (1996), Walter (2002) and McSherry (2002), Garces-Foley argues that the contemporary hospice approach to spiritual care “promotes a rigid dichotomy between these terms without regard for how religion and spirituality are understood by the general public or by scholars of religion” (Garces-Foley, 2006, p. 118), thus arguing that more people have a religious spirituality than is accepted or recognised. To some degree this is fair comment regarding the literature, but in reality in both the US and UK the vast majority of chaplains, the main spiritual carers in hospices, are still mainstream Christian ministers, so Garces-Foley’s criticism is not wholly warranted. Further, indications are that the majority of people, certainly in Britain, Australia, Canada and New Zealand, do not actively ‘practise’ religion, so a more secular approach would seem reasonable. Ideal spiritual care offers patient-led care, so if that patient is religious, then that ought to be the focus.

2.3.6 Summary: Hospice Care

The confrontation with death lays bare the spiritual core of the human condition (Byock, 2007, p. 438).

For most people at life’s end, part of the work of dying is spiritual, as Byock’s quote contends. It has been argued that up to half of a terminal patient’s concerns are spiritual. Williams reminds us that many people achieve a sense of spiritual well-being and their final
days are “recognized as an active, beautiful time of accelerated growth requiring courage, passion, and grace and offering the opportunity to be transformed” (Williams, 2006, p. 416). But she also notes for others it is a time of “despair and anguish”, filled with physical pain and exacerbated by spiritual pain – it is particularly for these people, that “researchers need to find effective interventions that help the terminally ill complete the work necessary for spiritual well-being” (Williams, 2006, p. 416). Williams’ position is indicative of the literature and affirms Saunders’ original vision to help the dying person “live until you die” (Saunders, 2000, p. 8). While some confusion seems to exist regarding hospice care’s brief, Chochinov suggests the original vision is coming back into focus (Chochinov, 2008). Doctors are not being asked to take on a “quasi-priestly role” (Berlinger, 2004, p. 688), but rather acknowledge spirituality as an important aspect of many people lives and the dying landscape.

The hospice care and spirituality section above has considered spiritual needs and care. Spiritual needs are widespread and while there is a clear understanding of this, consistency of care is lacking. Common spiritual issues were examined, with the literature naming a wide range from existential meaning and purpose to identity, beliefs, values hope and spiritual distress. Connectedness or relatedness were common issues and needs, and in one study with family members highlighted as preferred spiritual carers. Spiritual needs are not confined to patients, but it was shown include family members and staff.

Regarding spiritual care, there are two general approaches to assessment, with simple open questions or a formal survey approach, the latter being more suited to research, or done in conjunction with a spiritual history. In all cases patient-led approaches were affirmed with interventions ranging from uncomplicated to highly clinical and specialized. The creation of space, being with and listening, touch and experiencing the natural and artistic worlds were highlighted as spiritual approaches that all staff could be involved in. More specialized interventions included retreats, group therapy, meditation and religious rituals. Who does spiritual care was mostly agreed to be the role of all those involved in care, with the need for a specialist as important as any other specialist in medical care. Ethical spiritual care was highlighted as being critical, with proselytizing widely understood as a significant ethical error. As Sulmasy wrote, “At the end of life, the only healing possible may be spiritual” (Sulmasy, 2002, p. 30), thus it is important to understand and develop this foundational area of hospice care.
2.4 Why This Research is Needed

To move the field of palliative medicine forward so appropriate guidelines for spiritual care can be developed, it is critical that good research be conducted upon which to base spiritual care in an evidence-based model. It is only then that palliative medicine will be truly holistic, providing evidence-based care in all dimensions of the patient: biological, psychological, social, and spiritual (Puchalski, Kilpatrick, McCullough, & Larson, 2003, p. 7).

The literature reviewed above has affirmed the need for further research in the spirituality in hospice care area. The gaps identified may be classified under the following areas: contemporary spirituality, spirituality and health, and hospice spiritual care and needs. Regarding contemporary spirituality there is a need to understand this area more clearly within the context of an ever changing spiritual landscape, growing spiritual plurality, and increasing meaninglessness or a spiritual vacuum in the Western world. Understanding this vacuum has been argued to be a spiritual issue and relates to a good death, therefore important for New Zealand hospices.

Regarding spirituality and health, there has been no national research in New Zealand on this topic. Thus starting with hospice care is logical with its mandate to attend to all dimensions of health, including the spiritual. Further, internationally it has been argued above that there is a lay recovery and need for more attendance to spiritual care, with a particular gap in patient and carer perspectives.

This research aims to help map the spiritual care landscape in New Zealand hospices and understand our spiritual needs and care approaches at end-of-life for those affected by cancer. New Zealand has a unique cultural mix, secular in the non-practicing religious sense, yet still needing to develop existential capacities across the life span. New Zealand is committed to bi-cultural approaches with Māori and non-Māori that inform best multi-cultural practice. Thus it is important to understand spiritual care needs in this context. Further how the rest of the world approaches spiritual care needs to be understood so as to develop ethical approaches in New Zealand and avoid mistakes made by such countries as the UK, who are further along the spiritual care in healthcare path. It has also been argued that healthcare professionals are in crisis in the Western world and this crisis is spiritual in nature (Sulmasy, 2006). If this is the case, this needs to be understood in New Zealand and arguably improving spiritual care, which calls for the spiritual development of staff, will improve the sense of meaning and
purpose of these populations. This research is needed because extrapolating from international evidence, many New Zealanders may be dying in unnecessary spiritual pain. Perhaps the evident desire for physician assisted suicide affirms this need. Lastly, cancer is a significant and increasing cause of mortality, with long dying prognosis creating increased need, capacity and informed approaches to spiritual care. Contemporary dying is often shameful, lacking dignity and meaning. Attending to the spiritual dimension may help undermine shameful dying, with hospice leading, but needing to improve, the way forward. With these reasons in mind, the need for rigorous research, that combines the best of qualitative and quantitative methods, is needed to inform and improve holistic approaches to cancer care in hospices.
3 Methodology

So much depends on our perspective, and on the evidence on which we draw (Eckersley, 2004, p. 252).

3.1 Introduction

This chapter makes clear the ontology, epistemology, and cumulatively therefore, the methodology that underpins this research. Methodology is about the worldview and philosophical assumptions of the researcher and research, while method refers to the actual data collection processes. This research used mixed methods and what follows explains why.

3.2 Epistemological and Ontological Position of Author

It is important to locate the researcher’s lens so as to understand how these lenses might influence the research process because the researcher is the instrument (Yick, 2008, p. 1290).

The worldview, paradigm or philosophical underpinnings of the author inevitably influence the research and need to be situated from the outset (Hart, 1998), not so much as absolutes, but rather as starting points that acknowledge one’s worldview, way of seeing reality, the nature of reality, and how such reality may be named and understood (Tones & Green, 2004, p. 309). This is the spiritual ground, the landscape upon which beliefs, values, meaning and purpose are founded.

How one understands, studies and explains spirituality may be considered as much related to the individual researcher’s beliefs and worldview, as to his or her discipline, methods or subjects (Berry, 2005; Schneiders, 1989, p. 694).86 Thus a researcher’s values and beliefs, identity and level of awareness, part of which makes up one’s spiritual well-being (Ministry

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86 Schneiders makes the point that most academic research into spirituality is “participative” by nature, in that there is some personal interest, the desire to develop one’s own spirituality and “to foster the spiritual lives of others” (Schneiders, 1989, p. 695). This, Schneiders contends, does challenge the objectivity of such research. Qualitative methodology deals with this issue.
of Education, 1999), determine much of what he or she chooses to study, how it is studied and how it is presented (Moberg, 2002; Schneiders, 1989). As such, it is important, especially in the context of a study concerning spirituality, to name my position or lens (Salander, 2006).

Another approach to authorial awareness has been called ‘reflexivity’, which McSherry suggests enables “researchers to locate themselves within the research study” (McSherry, 2007, p. 170). This allows for bias that may influence the study to be transparent. Technically, bias is a quantitative term (Bhopal, 2002), but one may argue qualitative research recognises the inherent bias in all research — and once named attempts some level of objectivity by ‘bracketing’ one’s bias (McGrath, 2003). Further, noting such bias can be seen as an inevitable factor in the subjectivity involved in all research.

Regarding my own position, I believe there are truths, but many understandings of those truths, and I believe that there is a seen and unseen world — both of which can be understood, but neither is by most of us. I am increasingly convinced that there is a reciprocal positive relationship between spirituality and other health dimensions; one’s spirituality is affected by and affects one’s physical, social and mental states. Having said that, there are many issues, such as spiritual definitions, models, and research methodologies to address and incorporate, but these are challenges rather than incalculable problems. Epistemologically I sit between positivism and relativism/constructivism, what some call a pragmatic position (Creswell & Plano Clark, 2007, p. 22). Thus the world changes and people’s perception is contingent on their awareness, development, personality (and such things as culture and gender). The participants in this study made their experience of cancer meaningful in unique ways, thereby reflecting this constructionist position. Simultaneously, there were common themes, goals and obstacles that each of the participants discussed, thereby reflecting a position that there are universal aspects of ‘being’. Many of the participants talked about unseen forces and influences outside of their control and understanding. These trans-empirical or paranormal aspects of the study imply more about reality than the positivist paradigm acknowledges. Therefore, I acknowledge these realities for they are real for the participants. In sum, I believe, (1) that the world can be known through science, but not solely. The scientific approach is useful, but does not always tell the whole picture. Biomedicine is important, but arguably not the only way of looking at health. Further, (2) I believe the post-modern position that has questioned all certainty has its place, for it has allowed for different readings of texts (like the bible and science), situations and health conditions (McGrath, 1999). My position, therefore, is somewhere close to: a pragmatist epistemologically; an ontology that
accepts there is truth and different perspectives on truth; and a subsequent methodology that reflects (1) and (2), and therefore affirms mixed methods.

As a researcher, interviewer and author, my own spirituality has been challenged and enhanced by this project. Kellehear insightfully suggests, "The study of dying is like gazing into a reflecting pool" (Kellehear, 2007, p. 1), and I would add, the study of the spirituality of people who are dying has been like looking into this pool in all types of weather! This study worked 'on the ground' with dying people, of whom all but one at the time of writing have died. In light of this potentially stressful research situation, it was important to consider how I cared for my own spirituality (Harris, et al., 2008a). Thus through ongoing reflection, supervision (academic and what often amounted to therapeutic), good support from my family, by and large this experience was an affirmation of life and death.

3.2 Theory

[All research originates from some view of reality (Hart, 1998, p. 51).]

This section aims to show an awareness of the theories underpinning the methods and approaches used in the study. By the very nature of the topic — spirituality — a theoretical perspective is inherent in the work and explicitly named in the authorial position above. The theories underpinning this work are eclectic, including a holistic framework and integrative approach to medicine, and is influenced by health promotion theory (Tones & Green, 2004). This thesis is generally pragmatic, based on what Creswell calls a worldview of “pragmatism” (Creswell & Plano Clark, 2007, p. 22). Pragmatism is the central theory that underpins mixed methods as used in this research. The following situates spirituality within a holistic framework, then explains some theoretical background to qualitative and quantitative approaches, as used in this pragmatic approach.

Spirituality could be theoretically approached within the dominant psychological paradigm. That is, spirituality as part of various models (e.g. cognitive behavioural theory), thereby

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87 Patton suggests that pragmatism is an approach that can be devoid of theory, rather focusing simply on the question and real world situations (Patton, 2002, p. 136). Creswell develops pragmatism further as not just a real world approach but also as a theoretical approach (Creswell & Plano Clark, 2007).

88 US Professor of Psychology Robert A. Emmons notes that spirituality research needs to happen "while making non-reductive assumptions concerning the value of spiritual and religious phenomena. Non-reductive implies
suggesting that ‘the spiritual’ is a subset, a variant or synonym for aspects of or the totality of the psychological domain (Pargament, 1997, p. 11). Alternatively, and preferred by this author, is situating spirituality within models that acknowledge an inherent interconnectedness and semi-permeability of the dimensions of health and well-being, with spirituality sometimes seen as an integrating aspect, yet simultaneously acknowledging the side/taha/dimension/aspect of life called ‘spiritual’ as a valid discrete aspect to be considered, studied and nurtured (Moberg, 2002). Chochinov rightly says,

Despitethe artificiality of parsing spiritual or existential distress from physical and psychosocial concerns, doing so provides an opportunity to more fully explore the meaning of spiritual or existential “suffering” (Chochinov, 2006, p. 87).

Inevitably, by the use of words, categorizations, definitions, and measurement tools, there is going to be a reductive trend in the academic study of spirituality (Leibrich, 2002; Macdonald & Friedman, 2002). However, one can acknowledge the process that puts spirituality ‘under the microscope’ and simultaneously recall that it is part of a person’s and community’s whole being/experience.

Many indigenous cultures to this day see health as what has become known as ‘holistic’. Particularly relevant to this work are Māori and Pacific Island cultures that traditionally include holistic models of well-being (Durie, 1998a). Therefore, not a psychological paradigm, but a holistic paradigmatic approach underpins this study. This is consistent with the New Zealand Cancer Control Strategy (2003), which states “When someone develops cancer, its impact extends beyond the physical effects of the disease to include psychological, social, economic, sexual and spiritual consequences (Ministry of Health., 2003, p. 16).

Health, hauora and well-being are in many ways synonymous. Dame Cicely Saunders named the concept of ‘total pain’ (and therefore total care) early in the modern hospice revival, mandating physical, mental, social and spiritual needs to be attended in each dying person and their family (Saunders, 2004, p. xix). Vachon suggest wellness includes physical, mental, social and spiritual (Vachon, 2008). For a detailed discussion of well-being see (King, 2007). Of note in King’s paper is the glaring lack of attention to spiritual wellbeing and ironically Māori models of wellbeing. This is indicative of much of the wellbeing literature.

Moberg makes the point that “equally nebulous” aspects of human nature are examined in research:

Equally nebulous concepts that cannot be measured directly but for which epistemically assumed relationships with observable indicators have enabled the development of measuring instruments include anemia, anxiety, ego-strength, emotions, guilt, intelligence, motives, personality, prejudice, and temperament (Moberg, 2002, p. 48).

Of note, this approach is what Taylor (2007) and Heelas (2005) refer to as a particularly contemporary spiritual tactic. See Section 2.2.2 above for a further discussion of such issues.
Within the ‘cancer world’, that place where all those affected by cancer live or die, the mandated approach to care is holistic. This research focuses specifically on people affected by terminal cancer and consciously accepts the strategic approach and inherent ontological position named in the quote above from the Cancer Control Strategy.

Above, a pragmatic position was named in terms of an approach to knowledge. This sits on a continuum with positivism at one end and constructivism or relativism at the other. Positivism claims that “only what is empirical is real” (Bradshaw, 1994, p. 53) and/or can be known. Bradshaw and McGrath (McGrath, 1999) argue such an approach inhibits spirituality research, for which some aspects cannot be literally, and therefore figuratively, counted. Constructivism or relativism are positions that suggest reality is contingent and constructed individually and socially, therefore experienced differently by individuals and groups. Positivism\(^\text{92}\) claims hard science can measure and name all that exists.

Positivism is frequently used to stand for the epistemological assumption that empirical science based on principles of verificationism, objectivity, and reproducibility is the foundation of all genuine knowledge (Avis, 2003, p. 995).

This is contrasted with constructivism which claims not everything is quantifiable and testable, because there are “multiple social realities” for which only a “subjective, insider view” is possible to be known (Avis, 2003, p. 996).\(^\text{93}\) Hart explains these two positions as “realists and antirealists”, with the former primarily a positivist interpretation on truth in which the real world that can be understood through investigation (there are other realist positions (Patton, 2002)). The ‘antirealists’ “believe that the world exists, but its character and the ways we understand it are constructed and shaped by the language we use to describe it” (Hart, 1998, p. 85). Patton quotes Guba and Lincoln (1989), who suggest the constructivist position “as being ontologically relativist, epistemologically subjectivist, and methodologically hermeneutic and dialectic”\(^\text{94}\) (Patton, 2002, p. 98). Stereotypically, quantitative research has been associated with positivism, while constructivism often sits in the qualitative camp. This is extremely simplistic however, for methods from qualitative and quantitative approaches may be used under various worldviews/theoretical positions.

\(^{92}\) Avis makes the point that ‘positivism’ in this original form is no longer contemporary. He suggests it as “a coherent philosophy of science became defunct about 40 years ago, and with it perished the associated idea that empirical science could be a foundation for all factual knowledge” (Avis, 2003, p. 995).

\(^{93}\) See also (McGrath, 1999)

\(^{94}\) ‘Hermeneutic’ refers to the understanding that interpretation at any level in research is value-laden, and the ‘dialectic’ position acknowledges different worldviews and subsequent “contradictory ideas and contested arguments” (Creswell & Plano Clark, 2007, p. 27).
There are a number of positions along this theoretical continuum, with a centrist or “pragmatic epistemology” (Avis, 2003, p. 1003) favoured by this researcher. This position focuses “on the primary importance of the question asked rather than the methods, ..., it is pluralistic, ..., may combine inductive and deductive thinking” and is favoured by most mixed methods researchers (Creswell & Plano Clark, 2007, p. 23). Pragmatism recognises the validity of multiple worldviews, as opposed to what may be called an artificial dualism created by purist qualitative or quantitative theorists (Creswell & Plano Clark, 2007, p. 173). Thus ontologically “singular and multiple realities” are acknowledged (Creswell & Plano Clark, 2007, p. 24).

Regarding mixed methods, Creswell argues “that the use of quantitative and qualitative approaches in combination provides a better understanding of research problems than either approach alone” (Creswell & Plano Clark, 2007, p. 5). This allows for the weakness of each approach (qualitative subjectivity and quantitative lack of context (Creswell & Plano Clark, 2007)) to be strengthened by their combination. Creswell suggests there are four major mixed methods design types, including “triangulation”, “embedded”, “explanatory” and “exploratory” (Creswell & Plano Clark, 2007, p. 85). The research herein most closely resembles the ‘exploratory’ approach. The sequence of methods needs to be carefully considered. The exploratory design begins with qualitative, followed by quantitative methods, with the latter supporting the former in the analysis. Creswell argues that this exploratory approach is “best suited for exploring a phenomenon” and allows for ease of implementation via discrete phases. It does emphasise the qualitative, but by using the quantitative methods makes it more acceptable to “quantitative-bias audiences” (Creswell & Plano Clark, 2007, p. 78). This mixed methods methodology has been affirmed and/or used by a number of researchers in the palliative care/spirituality field (Denscombe, 1998; Field, et al., 2001; Harris, et al., 2008b; Kissane & Street, 2004; Lee & Sharpe, 2007; O’Cathain, 2009, p. 4).
3.3 Qualitative Methodology

Qualitative research is increasingly accepted as an important complementary methodology and method to quantitative work (McGrath, 2002b; Patton, 2002). This is especially true in particular areas and fields of research such as palliative care (Carlson & Morrison, 2008). Within a mixed method methodology, Study One draws upon qualitative methods with the aim of capturing the experiences and understandings of participants' spirituality and spiritual care. Qualitative research is an excellent approach to gather in-depth experience and hear the participants' voices. Field (Field, et al., 2001) and others (McGrath 1999; Kristajanson, 2004) argue that qualitative methods best suit the palliative care context, for a patient's intimate and subjective experience can be engaged with in the research context (Clark, 2001). Qualitative methods are well documented, have a sound theoretical framework and a developed 'tool kit' for which to approach research areas (Kristajanson & Coyle, 2004; Kvale, 2006; Patton, 2002). The place of the 'self', the researcher, is consciously and explicitly placed within this framework (Kristajanson & Coyle, 2004, p. 138). In the context of research on spirituality in palliative care, an area still in its research infancy, the qualitative approach is relevant and necessary.

In her “meta-summary” of qualitative studies on spirituality at the end-of-life, Williams notes "most authors reported generic research designs (e.g. In-depth interviews) as opposed to grounded theory" (Williams, 2006, p. 413). The research design for this thesis is generic, based on the pragmatist position expanded above. This had implications for the interview design, processes and analysis. Thus the methods described in the qualitative chapter stem from this position.

Verification (Thomas, 2006) and rigour (Hermann, 2001) are important concepts in qualitative research. Like the process, the steps for verification and rigour in the qualitative study have been eclectic and pragmatic. Practical steps, such as self-reflexivity (own role in design, data collection and analysis), field notes (in electronic and written journal form), triangulation, peer debriefing, and member checking (Thomas, 2006, p. 338), have been

95 Regarding the study of spirituality, McGrath claims that a positivist hegemony “that asserts that only what is observed actually exists” (Armstrong 1978 cited in McGrath, 2002b, p. 181) cannot cope with spirituality research “a nonquantifiable dimension, .... [that] does not fit comfortably or appropriately into such limited methodological thinking.” (McGrath, 2002b). McGrath's reasonably extreme position, arguing that spirituality can only be examined using qualitative methods, is at one end of the continuum, while others argue for a more moderate position that allows for combining methods (Kissane & Street, 2004).
employed to improve credibility (Kristajanson & Coyle, 2004) and trustworthiness (Lincoln and Guba (1985) cited in Hermann, 2001). Further, a transparent audit trail exists with processes documented or available for ethics processes, interview questions, ongoing reflection and analysis in field notes, electronic storage of interviews, transcriptions, computer analysis of transcripts with codes and quotes, and thematic development discussed in Chapter Four.

Transferability is “the extent to which the findings from a study might be applied to another situation” (Kristajanson & Coyle, 2004, p. 140). This is an important issue, contrasted to generalizability in quantitative studies, and said to be enhanced by the rigorous standards applied above. The present study is set within a defined context — however transferability of findings are argued. Transferability relates to the similarity between the two contexts (Lincoln and Guba 1985 cited in Patton, 2002). Dying from cancer may be argued to be a transferable context on some levels related to spirituality and spiritual care. Further, terminal illness generally may have scope for transferability.

3.4 Quantitative Methodology

The methodology of quantitative research, as the dominant research method in medical research, is well documented (Bhopal, 2002). In fact, seldom in quantitative studies is the methodology named or explained. Methodologically, it usually is based on a positivist or post-positivist position that understands the world as a singular three-dimensional reality open to objective empirical examination (Patton, 2002, p. 24). It aims for an objective approach to the problem and objective methods to avoid bias and confounding. There is a hierarchy of methods, with double blinded randomized control trials near at or near top. Data in quantitative research are generally numerical and subject to statistical analysis.

Understanding that palliative care, as a specialization in ‘modern medicine’ is relatively new, (Hanks, et al., 2004), it is no surprise that theoretical and ideological discussions about research methodology begin with a critique of the so-called biomedical scientific dominance (Field, et al., 2001; McGrath, 1999). Set within a positivist framework, such scientific

96 See also (Patton, 2002, p. 581ff)
research is criticized as “reductionist” and potentially misses the value and role of “human agency” (Field, et al., 2001, p. 4), where not everything “can be reduced to numbers” (Kristajanson & Coyle, 2004, p. 138). Vachon, rather than criticizing the biomedical, simply states “The traditional Western bio-medical model is grounded in the Cartesian and Newtonian paradigm, in which the mind, brain, and endocrine and immune systems are viewed principally as separate entities” (Vachon & Benor, 2003, p. 172). Much of the palliative care literature when considering the biomedical view, which underpins quantitative research, argues for a less ‘silod’ approach to the body and mind. Vachon goes on to argue that there is strong evidence for the mind/body connection (Vachon & Benor, 2003, p. 172).

McGrath, coming from a postmodern methodological position, suggests “The prevailing research culture operates on reductionist, physiological, epistemological assumptions in healthcare that perceives the body as a machine rather than as a spiritual or existential entity” (McGrath, 1999, p. 5). Regarding quantitative approaches, McGrath suggests “science is predicated on notions of measurable, empirical realism that asserts that only what is observable actually exists” (McGrath, 1999, p. 5), while qualitative approaches allow for the diversity, complexity and contingency that characterizes the postmodern analysis. McGrath’s position is that only qualitative research has the capacity to capture anything meaningful about spirituality in palliative care.

An alternative position is put by Harris, who suggests “quantitative techniques also play a role in seeking patients’ or carers’ views, and have been used to great effect more widely within palliative care research” (Harris, et al., 2008b, p. 384). Hart affirms this position, suggesting “the procedures of science can help us understand ... non-scientific based phenomena” (Hart, 1998, p. 85). It is this latter position that informs the use of quantitative methods in the mixed methods approaches, as is used in this study.

3.5 Health Promotion Theory

There is a natural synergy between spirituality and health promotion; like contemporary spirituality, health promotion has as its basis a holistic paradigm, is multidisciplinary and explicitly recognizes all dimensions of health (Baum, 1998; WHO, 2005). Further, the synergy is extended to hospice care, where many of the fundamental principles are the same.
This section briefly explains what health promotion is and how it is relevant to spirituality and hospice care.

Health promotion is a way of thinking and a profession, both with potential to add value in the hospice context. Health promotion is holistic, eclectic and aims to empower (Tones & Green, 2004) and enable (Raphael, 2000). Health promotion developed as a concept and profession in the latter half of the twentieth century, just as contemporary spirituality and the modern hospice movement did. Key milestones for health promotion were the Canadian Lalonde Report (Hancock, 1986; Lalonde, 1974), the WHO Declaration of Alma-Ata (WHO, 1978) and the Ottawa Charter (WHO Health and Welfare Canada Canadian Public Health Association, 1986). These events and documents marked new ways of thinking about health and health promotion, affirmed public collaboration, multi-sectoral approaches, a focus on inequalities, a broadening of the determinants of health, and ‘health for all’ (Stewart-Brown, 2006b).

With its roots in health education, health promotion came of age at its first international conference in Ottawa, Canada (WHO Health and Welfare Canada Canadian Public Health Association, 1986). The Ottawa Charter has been the foundation and ongoing ‘strategic manual’ for health promotion action. The Ottawa Charter defined health promotion as “the process of enabling people to increase control over, and to improve, their health” (WHO Health and Welfare Canada Canadian Public Health Association, 1986). Twenty years later, at a similar conference in Bangkok, the definition was expanded to state that health promotion included “a positive and inclusive concept of health as a determinant of the quality of life and encompassing mental and spiritual well-being” (WHO, 2005).

The Ottawa Charter names three strategies (enable, mediate and advocate) and five areas for actions, including building healthy public policy, creating supportive environments, strengthening community action, developing personal skills, and re-orientating health care services. These actions are usefully understood via the stream metaphor (McKinlay, 1993): upstream health promotion includes big picture issues and actions such as policy; downstream individuals are affected by what happens upstream, so downstream includes personal skills. Midstream we find environments, community action and health services.

There is a range of health promotion approaches, from up to downstream, focusing on individuals through to policy work that affects whole countries. It has been suggested there
are three main ways health promotion happens, each with a different emphasis and ideological background (O’Conner & Parker (1995) cited in Kellehear, 1999a, p. 10).

At its most basic, health promotion equates to prevention of ill health (Tones & Green, 2004). This includes the medical approaches of immunization and screening (Kellehear, 1999a). The second approach to health promotion is behaviourally focused and happens via particular lifestyle issues, such as tobacco control, physical activity and nutrition obesity intervention, harm reduction from alcohol and other drugs, and the promotion of safe sexual health practices. These approaches are largely biomedically focused, that is, focus on the “risk factor” or pathological problems and ways to counter them (Baum, 1998, p. 6). For this and the first approach, if they are too narrowly focused on individual lifestyle change, while not acknowledging the impact of environment, the possibility of victim blaming exists (Baum, 1998; Tones & Green, 2004).

Thirdly, further upstream health promotion approaches are “social-environmental” (Kellehear, 1999a), which happen at a policy level or are settings based. Such approaches include community consultation and health public policy. This socio-environmental view highlights the importance of social responsibility and the impact of determinants of health (outside the health sector) (Baum, 2008).

A moderate and eclectic approach, as favoured by this author, acknowledges the importance of a range of health promotion approaches. This recognizes the importance of health education, individual responsibility and choice, while also understanding that making ‘health choices easy choices’, for instance at a policy level, is socially responsible and positively impacts on health and inequality. A conducive environment makes individual empowerment more likely.

There are a range of health promotion methods including health education, social marketing, community development, advocacy, support/activist groups, coalition building, organisational development and policy development. Social marketing, via mass media, say for instance as a reaction to a ‘topic de jour’ like family violence, is often an instant and high profile (politically expedient) reaction to an issue. However, if such approaches begin and end with social marketing, their efficacy is limited and questionable (Tones & Green, 2004). The ideal health promotion approach draws upon a range of these methods in a multi-strategic approach, and is well planned, with good evidence via needs assessments and ongoing
evaluations. Some would say that effective health promotion must begin and end with the community, therefore one of the gold standard health promotion approaches happens in settings (Whitelaw, et al., 2001). These methods are explained as they could be usefully employed within the hospice context.

Unlike hospice care, health promotion has a more developed theoretical base. It draws heavily on behavioural psychology for models of behaviour change, community development and social marketing. In health promotion theory, ‘self efficacy’ is a significant concept when considering behaviour change. Resnick shows that spirituality is one of the factors that affects efficacy beliefs (Resnick, 2002). Health promotion theory, when used appropriately, can add significantly to the efficacy of interventions.

3.6 Summary

This chapter has briefly stated the methodological foundations of this thesis. I situated my own ontological and epistemological position within pragmatism — a theory and approach that is led by the research needs and draws eclectically from other theoretical positions — a ‘middle path’ approach between the extremes of positivism and constructivism. This authorial context justifies the use of mixed methods. As a growing theoretical and applied research area (Creswell & Plano Clark, 2007), this research takes an exploratory approach led by qualitative and supported by quantitative methods. Both approaches have rigorous designs that, when “numbers and narrative” (Creswell & Plano Clark, 2007, p. 175) are combined for analysis and discussion, allow for excellent breadth and depth investigation of phenomena.
4 Study One: Participants’ Voices

I think it’s important, but especially important in the situation I’m in. It would be very difficult if I didn’t have any sense of spirituality (Fran, 62, education, Ca)\(^{97}\)

It is such a diverse field that I think is daunting (Ewan, 68, finance, Ca)

The following chapter reports the process, results and some discussion of 52 in-depth interviews. The participants were people with terminal cancer, some of their family members, hospice and hospital staff, chaplains/spiritual carers, and Māori experts. All participant interviews focused on spirituality: what he or she thought it was, their beliefs about such things as life after death and God, and experiences and ideas about spiritual care. This chapter explains the methods used and presents the results under three meta-themes: spiritual definitions; spiritual beliefs and practice; and spiritual needs and care. This chapter excludes the Māori data as this is discussed in a discrete chapter below.

4.1 Introduction and Aim

4.1.1 Introduction

Using qualitative methods, Study One aimed to investigate and improve understanding and practices of spirituality in New Zealand palliative cancer care, primarily focused in hospices. To do this, 49 participants were interviewed across seven hospices and one hospital outpatient clinic.\(^{98}\) People with cancer were the primary participant group (n=24), followed by family members (n=9), staff (n=8), chaplains (n=8). The conceptual model for this investigation of spirituality involves the triangulation of Study One (Chapter Four), Study Two (Chapter Five) and the literature review (Chapter Two).

\(^{97}\) All interview extracts and hospice setting comments use created names and numbered hospices to maintain anonymity of participants and institutions. Pseudonyms are used, as in anthropology research, to acknowledge and honour the personal and subjective nature of the participants. When relevant, participant quotes have some demographic detail. Quotes are attributed to participants when some contexts may aid understanding. Attributions may include a pseudonym, age, area of work and people with cancer have a ‘Ca’, and family members ‘FM’, in brackets after the quote.

\(^{98}\) Of the eight sites recruited, one was a hospital oncology out-patients clinic. Unless specifically referred to, the following will just use the term hospice.
The interview process used open\textsuperscript{99} and semi-structured approaches producing novel and unique experiences and understandings of spirituality and care. The method of analysis is an interpretive and thematic approach. The interviews canvassed the following questions:

- How is spirituality understood?
- What are the current unmet spiritual needs of people affected by terminal cancer?
- How important is spirituality to people affected by terminal cancer?
- How can the spiritual needs of people with terminal cancer be improved?

Vitally, I would like to thank and honour all the participants, particularly those who experienced cancer as patients and family members. Interviewing these people in their homes, hospitals and hospices was one of the most privileged and unforgettable times of my life.

### 4.1.2 Ethics

The ethical issues in palliative care research seem obvious: dying people are vulnerable, and therefore need particular protection. However, this seemingly self-evident position leaves out the patient's agency, and in fact could be considered to undermine the patient in a patronizing fashion (Have & Clark, 2002, p. 211). There are significantly different points of view regarding palliative care ethics (Clark, et al., 2002; Randall, 1999).

This PhD study went through the contemporary ethics process, including:

- University of Otago (Preventive & Social Medicine Department Research Advisory Group)
- University of Otago’s “Research Consultation with Māori” process
- National Multi-regional Ethics Committee
- Hospice Ethics Committees (Hospice A, C, H)

\textsuperscript{99} The 'open' interview process (Kvale, 2006) involves initiating a broad open-ended question and letting the participant explore the subject. This contrasts with a structured approach of question and answers. For the pilot I started off with a semi-structured approach (source), aiming to cover certain topic areas with prepared questions and prompts. However I discovered/realized during analysis of a staff member interview recording that I, as the interviewer, might be stifling possible directions the participant may want to go. Therefore, I decided to begin subsequent interviews with an open approach and, if need be, move to the semi-structured approach. This was very effective as it allowed the articulate and extrovert participants to explore the topic freely, while, when needed, especially with participants who struggled with the topic, more direct questions enabled, in some cases, consideration of issues that had not previously been explored.
was most appropriate for the interview. I was not going to interview chaplains as it was initially thought their positions would be obviously religious and add nothing new. However, after an informal visit to a hospice chaplain\textsuperscript{101} and review of the literature, it was clear they have a significant position regarding spiritual care and to not include them would be an oversight.

Māori inclusion criteria included: age eighteen or above; fluent in English; knowledge and experience with some or all of the following: Māori death rituals, cancer and palliative care, that is, a tikanga based approach (Māori practices and values) which would include an understanding of tangihanga (Māori death ritual), whanau (family) issues and cancer issues for Māori. Potential Māori participants were chosen based on suggestions from Dr Joanne Baxter (Ngai Tahu Research Unit, University of Otago). The recruitment process was different for this group as they were not patients, so I contacted them by telephone, told them about the study and asked if they would like to participate, and if so emailed them the relevant information. All agreed and appropriate times were made for the interviews.

4.2.5 The Interview Process

4.2.5.1 Pre-interview Preparation

Interviewing someone, particularly a person with a terminal illness, needs to be well planned, with good preparation vital for a good interview. Beyond all the administrative concerns, there are professional (in the academic sense), technical, personal, moral and ethical considerations.

Professionally, I did not want to waste anyone’s time. Therefore, I needed to make the best use of the time available, conducting an interview that was safe and productive. I consciously considered my dress, my state of mind, timeliness, and made sure I had all the information about the person at hand (getting names right and whatever else I had gleaned prior to the

\textsuperscript{101} The thinking and decision about including chaplains is documented in my Research Journal (dated 5 July, 2006): I’m not feeling comfortable about excluding chaplains/spiritual carers. They are key players in spiritual care – in some ways the ‘specialists’. The idea of not including them was because we presume to know their position – but my reading hasn’t confirmed that (yet). That is, the vast majority of chaplains are priests or similarly linked to denominational religion. My experience so far (and stated in hospital chaplain literature) is that the chaplains approach spiritual care in what ‘xxx’, a spiritual carer from ‘xxx’, describes as faith neutral. Thus a person’s spiritual, religious or existential background and/or beliefs are all approached equally – spiritual care is offered to all. While talking to ‘xxx’ yesterday though, the religious approach does dominate with talk of sacraments etc. This may not be fair, for it is out of context. Chaplains: after talking with two chaplains in hospices that have been recruited, I now believe that to leave out chaplains would be to miss out on too much.
Raising Spiritual Awareness: McSherry raises ethical questions about opening up people’s spiritual awareness by interview, suggesting this could be exposing more than they can handle (McSherry, 2007). We considered this issue and made it very clear what the interview entailed and that a counsellor and/or chaplain/spiritual carer was available after the interview.

Ongoing Ethical Considerations: It must be noted that consideration of ethical aspects of the study was ongoing, particularly for Study One. During the interview process, ethical issues occasionally arose that were outside the protocols I had developed. For example, one participant told me in an interview that he had been told, without asking, by the hospice chaplain that he needed to repent for his sins. This created quite a dilemma, for I did not want to break confidentiality, realized that it could have been misunderstood (by either party), or could have been a case of unethical proselytising. As it happened, I had heard from a staff member in the same hospice that this chaplain had this ‘tendency’. After a phone call to my supervisor, I ended up telling the nurse manager the general tenor of the issue, without naming anyone, thereby bringing it to their awareness without breaking any confidences.

4.2 Methods

4.2.1. Introduction

Qualitative research is an excellent means of gathering in-depth experience and hearing the participants’ voices. Field (Field, et al., 2001) and others (Kristajanson & Coyle, 2004; McGrath, 1999) argue that qualitative methods best suit the palliative care context, for a patient’s “subjective experience is acknowledged and harnessed” (Clark, 2001).

This section notes key issues related to methods, including:

- Introduction
- Hospice choice and recruitment
- Key contacts
- Participant recruitment (information and consent documents)
- The interview process
4.2.2 Hospice Choice and Recruitment

This section justifies the choice and number of hospices across New Zealand and details the recruitment process for these hospices.

The choice of hospices was based on five considerations. A broad range of sites and approaches allows for appropriate coverage of the topic (Kissane & Street, 2004). A broad range of places, geographically, socio-economically and culturally was the ideal; just how far one researcher could cover these parameters was judged by the research team (student and supervisors). In the first instance, Professor Rod MacLeod was consulted due to his knowledge of hospices across New Zealand. Eight sites from the bottom of the South Island to the top of the North Island were chosen. The cultural spread of the hospice constituency was considered in the choices.

Recruitment of hospices involved initiating, developing and maintaining relationships. The process, partly dictated by the Ethics Committee, was initiated with phone contact with the CEO to introduce myself and the project. Followed by an email and 'snail mail' with a summary of the research and the 'Locality Assessment Form'. A further email went to the CEO and other key people (like Medical Director and Nurse Manager) with a summary of research, confirmation of ethics approval, and in some cases examples of the information sheet and consent form. This latter addition happened as some hospices wanted this information to go through their own ethics process. The key contact person was confirmed and appropriate times to visit the hospice for interviews organised. Finally the participant recruitment was done and interviews conducted.

4.2.3 Key Contacts

For each hospice it was important to have one person to deal with for the study. After confirmation with the relevant management, it was often the nurse manager (or equivalent) who became the key contact person (here after key contact). This person and relationship was
vital to the success of the study. I regularly called and emailed this person making sure they understood and were happy with the processes. Thus, this relationship between researcher and key contact was beneficial and ultimately productive. This model also set the process in place for Study Two (see Chapter Five).

4.2.4 Participant Recruitment and Information

In each hospice, the key contact person contacted the requested number of participants (patients, family members and staff) and gave or sent them the information sheet and consent form. I was then given the names and contact details for each person. Each potential participant was then telephoned by me, further questions answered and if at that stage the participant was still happy to be involved, the initial consent meeting was set up.

4.2.4.1 Inclusion Criteria for participation

For each of the populations there were specific criteria for participation, as set out below. Except for Māori, participants were chosen by the key contact or his or her staff. Inclusion criteria for patients were: terminal cancer diagnosis with less than one year prognosis; age eighteen or above; fluent in English and able to converse openly about the topic; free of cognitive dysfunction; and non-Māori.100 For family members criteria were: age eighteen or above; fluent in English; free of cognitive dysfunction; and non-Māori. Inclusion criteria for staff were: experienced staff member; some knowledge of spiritual care; and fluent in English. The staff member was chosen by the key contact. However the type of health professional was randomly chosen (see below).

Staff member choice was based on purposeful sampling — weighted towards nurses, as they are the largest health professional population (and do the majority of care) in these settings. Thus, of the eight sites, four participants were nurses, two doctors and two counsellors. The profession of the staff member interviewed at each hospice was randomly selected.

Chaplain/spiritual carer inclusion criteria were: one ‘official’ chaplain/spiritual carer from each site. If there was more than one, the key contact person made the decision about who

100After consultation, it was decided to exclude Māori patients and family members from the study because I did not have a background in tikanga (Māori values and practices), nor did I speak te reo (Māori language).
was most appropriate for the interview. I was not going to interview chaplains as it was initially thought their positions would be obviously religious and add nothing new. However, after an informal visit to a hospice chaplain and review of the literature, it was clear they have a significant position regarding spiritual care and to not include them would be an oversight.

Māori inclusion criteria included: age eighteen or above; fluent in English; knowledge and experience with some or all of the following: Māori death rituals, cancer and palliative care, that is, a tikanga based approach (Māori practices and values) which would include an understanding of tangihanga (Māori death ritual), whanau (family) issues and cancer issues for Māori. Potential Māori participants were chosen based on suggestions from Dr Joanne Baxter (Ngai Tahu Research Unit, University of Otago). The recruitment process was different for this group as they were not patients, so I contacted them by telephone, told them about the study and asked if they would like to participate, and if so emailed them the relevant information. All agreed and appropriate times were made for the interviews.

4.2.5 The Interview Process

4.2.5.1 Pre-interview Preparation

Interviewing someone, particularly a person with a terminal illness, needs to be well planned, with good preparation vital for a good interview. Beyond all the administrative concerns, there are professional (in the academic sense), technical, personal, moral and ethical considerations.

Professionally, I did not want to waste anyone’s time. Therefore, I needed to make the best use of the time available, conducting an interview that was safe and productive. I consciously considered my dress, my state of mind, timeliness, and made sure I had all the information about the person at hand (getting names right and whatever else I had gleaned prior to the

\[101\] The thinking and decision about including chaplains is documented in my Research Journal (dated 5 July, 2006): I’m not feeling comfortable about excluding chaplains/spiritual carers. They are key players in spiritual care – in some ways the ‘specialists’. The idea of not including them was because we presume to know their position – but my reading hasn’t confirmed that (yet). That is, the vast majority of chaplains are priests or similarly linked to denominational religion. My experience so far (and stated in hospital chaplain literature) is that the chaplains approach spiritual care in what ‘xxx’, a spiritual carer from ‘xxx’, describes as faith neutral. Thus a person’s spiritual, religious or existential background and/or beliefs are all approached equally – spiritual care is offered to all. While talking to ‘xxx’ yesterday though, the religious approach does dominate with talk of sacraments etc. This may not be fair, for it is out of context. Chaplains: after talking with two chaplains in hospices that have been recruited, I now believe that to leave out chaplains would be to miss out on too much.
interview). In some cases, I wore a name badge provided by the institution. Technically, good interviewing relies on particular skills. In preparation for these interviews, I had training from my supervisor, including practice and I examined trial interviews. Personally, I spent time before each interview ‘getting myself together’. Depending on the setting, this involved having a time of silent reflection and contemplation of what I was about to do. I felt this was important to prepare in such a way so as to honour the event.

Ethical and moral issues are discussed above, but specifically in relation to the interview occasion, I had asked to be invited into someone’s intimate space, therefore this needed to be taken very seriously. There were some issues of power. For example, some people saw me as the expert, in fact one patient sardonically asked if I was going to be the guru on spirituality. Awareness of these issues was critical, and my responses at all times were motivated by wanting to make the participant feel comfortable. While expediently wanting their attention and a ‘good interview’, I felt morally bound to make the interview an interesting and, if possible, productive occasion for the participant. I took seriously what I wrote in the information sheet that one of the potential benefits of the interview would be a better appreciation of the participant’s spirituality.

Finally, before each patient interview I endeavoured to call the person to check that they were ‘up to it’. This was based on the pilot, as in one case a patient participant was not ‘up to it’ and therefore it was decided to call all patient participants on the day of their interview.

4.2.5.2 Consent Meeting

The ‘consent meeting’ was the first face to face contact I had with participants. This was a critical time as finding participants was hard work, particularly for the key contact person, so I did not want to ‘lose them’. I made every effort to be hospitable, answer questions and allay any fears. This meeting tended to be no longer than twenty to thirty minutes. I would tell them something of the genesis of the project, something about myself and my background, and then explain the steps of the interview, transcription and write up processes. As the consent form shows, I asked the participant if they wanted to a copy of the transcript and/or a CD copy. I encouraged the participants to have a transcript as I also asked for their feedback on their interview.
4.2.5.3 The Interview

The interview is the central data collection method in Study One. More than data collection, the interview is a conversation, an interaction between two people discussing spirituality.

The interview happened wherever suited the participant. For patients and family members, the interviews took place mostly in their homes, with the exception of particularly ill people who were in the hospice. Staff members were interviewed in their workplace, during work time, at the discretion and generosity of their employer. Māori experts were interviewed wherever suited them, usually in their workplace. The exception was Dr Ngata, who was interviewed at Dunedin Airport (in characteristically humorous fashion, he said he would do the interview if I took him to the airport).

Particularly for patients, but in reality for all participants, the timing of the interview was critical. How he or she was feeling, what physical symptoms were affecting them, how the medication was balanced, the time of the day in relation to work and other commitments, all played a part in the interview outcomes. At the consent meeting, I attempted to find a time that met as many needs of the participant as possible.

In most cases the interview was at least the third time I had contacted the person and the second time I had seen them in person. I always considered the contributing factors to a good interview: dress, eye contact and so on. However, it seemed to me that the introduction, or the time before the tape goes on, was very important. At times, if it was appropriate, I took along some food. I always accepted a cup of tea and consciously made any family, geographic or conceptual connection with the participant. Lastly before recording, I reminded the participant about the anonymous nature of the interview, the aim, and some of what we hoped to achieve. This introduction took between five and fifteen minutes.

I usually started the interview noting the day, place and participant’s name, then I would remind the participant what the whole study was considering and at times I reminded them about the working definition of spirituality. However I found this was unnecessary, except for the occasional person who either had not read it on the information sheet and/or still had no idea what we were considering. A formal start did not always happen, particularly with staff and family members, as we may have started talking and I would stop our conversation mid-sentence to put on the recorder. Demographic information was usually asked early in the interview, though again this varied if the situation required a different approach.
As noted above, initially an ‘open format’ approach was employed for the majority of the interviews. Thus I used variations on the following question,

First I will ask a general question and then ask some specific questions later. What is it that you understand spirituality to be? (Deidre, 57, hospitality, Ca)

As noted by this direct quote, I asked an open question about spirituality and then depending on how the interview went from there, I would move into a more semi-structured approach with particular question zones to consider. However, with very articulate people I often did not look at my questions until well into the interview, as the conversation ranged over these topics and much more. The general areas that I wanted to cover included: participant’s understandings of spirituality; meaning and purpose in their life; comfort and hope; beliefs and values (God, afterlife, changes, worldview); identity (roles, changes); spiritual care (assessment, training); religion (perspectives, community); and any other comments.

In Appendix C3 there are copies of the interview schedule. The patient, family member and staff interviews had many similarities, but the Māori interview focus was different, looking more generically at how Māori spiritual needs were being met. However, it must be noted that these schedules were more important for the ethics committee rules than the actual interviews. While giving a guide, the qualitative interview situation often did not follow in such linear processes as is suggested by the schedules.

4.2.5.4 Research Journal

As soon as possible after the interview I wrote it up formally in my Research Journal. The write up was based on Crabtree & Miller’s 1999 systematic reflection about an interview (Crabtree & Miller, 1999). Below are the headings that were covered, plus my own additions, which included ‘spirituality definition/concept’, ‘initial themes’ and ‘narrative reflection’.
Table 4.1 Interview Systematic Reflection Framework

<table>
<thead>
<tr>
<th>Title: hospice, participant type</th>
<th>People present</th>
</tr>
</thead>
<tbody>
<tr>
<td>How I was feeling</td>
<td>Place</td>
</tr>
<tr>
<td>Name</td>
<td>Length of interview</td>
</tr>
<tr>
<td>DoB</td>
<td>Rate of speech</td>
</tr>
<tr>
<td>Address</td>
<td>No. / length of silences</td>
</tr>
<tr>
<td>Phone</td>
<td>Length of pre/post exchange</td>
</tr>
<tr>
<td>Email</td>
<td>Relative % of talking</td>
</tr>
<tr>
<td>Religion</td>
<td>Control / termination</td>
</tr>
<tr>
<td>Marital status</td>
<td>Tone</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>Physical health</td>
</tr>
<tr>
<td>Highest Qualification</td>
<td>Weather</td>
</tr>
<tr>
<td>Profession</td>
<td>Spirituality definition/concept</td>
</tr>
<tr>
<td>Time</td>
<td>Initial themes emerging</td>
</tr>
<tr>
<td></td>
<td>Narrative reflection</td>
</tr>
</tbody>
</table>

This systematic reflection has been a vital tool in this research. It created a formal process for ongoing analysis and self evaluation. The data from the journal entries was useful for later analysis, as is seen with the occasional use of journal quotes in this thesis.

4.2.5.5 Follow up

At the end of each interview, I highlighted the hospice staff who were available if the participant wanted to discuss any issues that had arisen from the interview. Further, with patients, I usually called them the next day to thank them for their participation and give them any information they might have asked about. For instance, one patient wanted me to check that she could talk with the chaplain about non-religious spiritual issues.

4.2.6 The Transcription Process

Transcription of interviews is an art and a skill. Funding allowed for external transcription services to be employed. There were over a hundred hours of interviews and subsequently thousands of pages of transcripts. Fortunately the transcriber was a colleague and researcher in end-of-life issues, therefore allowing for regular discussion and at times de-brief about the
interviews. The transcription protocols were kept simple: verbatim, exceptional pauses were noted, and strong emotions were noted (such as crying). This plain verbatim approach was considered reasonable as the interview was electronically available.

### 4.2.7 The Pilot Process

The pilot process for this study was an integral aspect in the appropriate development of working in the hospice context. The pilot went through the whole process from initial CEO contact to interviews, thereby trialling the research protocols including hospice communications, selection criteria, information and consent forms, interview schedules, interview techniques, and early analysis.

An evaluation of the interview process was done by the researcher, in consultation with the hospice staff and interview participants. Changes were made to the process, particularly regarding early and regular communication with hospice staff.

For me, an important conceptual realization was that the focus of the hospices is care of the dying, not research. So for instance, as recorded in my journal (20 July, 2006), when I as a researcher came to discuss progress or participant selection, "my world's focus [research] was a wee blip in her [nurse manager] busy day – she gladly gave me her time, but I needed to come back the next day to finalize the patient participants".

The selection process worked well for the pilot, but did vary in quality as the study progressed (see below for further discussion). As with any evaluation, not all recommendations were implemented. For example, regarding patient recruitment I was happy to have a person with any contact with the hospice, while it was recommended from the pilot key contact that we only ask those who had had three contact times with the hospice. This was a good idea, but not practical across the country.
4.2.8 Analysis Process

This section details how the interviews were analysed: pre-interview considerations; dialogic interviews (Kvale, 2006); immediate post-interview write up; cumulative analysis process; and computer assisted analysis.

The analysis process was cumulative and based on sound qualitative methods used in the study of patient spirituality (Daaleman, et al., 2001). Before the first interviews, I had begun analysis of the relevant literature. As the interview numbers increased, there were areas that were consistent and areas that needed to be explored in more depth. For example, with only one exception, family was a key factor in participants’ meaning and purpose in life. An underexplored area in the literature was the ‘fear factor’ that patient participants were feeling.

Dialogic interviews: while the interview was being conducted, there were often aspects raised by the conversation that we explored further. This reciprocal analysis was important as I believe and tried to convey that each person is the ‘expert’ on his or her own spirituality. Naturally, as I listened, I considered angles on their story so as to ask appropriate questions — this was led by the participant or intuition. Kvale’s term dialogic is used here to express the highly reflective and reciprocal nature of the interviews (Kvale, 2006). As described in detail above, I wrote up the interview as soon as possible. In terms of analysis, this allowed for immediate impressions, obvious themes and trends to be noted.

The process of analysis was cumulative over two years. This has allowed for deep reflection on the interviews, the literature and Study Two (see below). Thus, it is important to note that the analysis process was iterative, that is, constantly building on reflections from the interviews.

Themes were developed, via the literature, research questions and through ongoing analysis, comparison and examination of the codes. Codes were grouped together according to working themes based on the interview schedule and the research aims and objectives — a form of template organising style. The interviewing process also resulted in many unanticipated responses which were also coded and grouped together according to shared characteristics. Sometimes these fitted in with the working themes, sometimes resulting in a new sub-theme or themes. Some themes were obvious, while some sub-themes were more speculative. Themes were developed both from individual codes (for example, the ‘patient sp
definition') and from grouping codes with shared characteristics into overarching categories (sometimes called code families). Thematic demarcation is not absolute. Rather the lines between themes are more semi-permeable. For example, spiritual beliefs are obviously related to spiritual care and need.

Computer assisted analysis, using Atlas.ti (Version 5.2.21, Berlin, www.atlasti.com) was employed to help analyse the transcripts. Similar to NUDIST or INVIVO, but without any theory laden foci, Atlas.ti allows for minute coding of words, phrases or paragraphs, or what Daaleman call “independent meaningful units” (Daaleman, et al., 2001). There are four coding options: ‘open coding’, ‘coding in vivo’, ‘coding by list’ and ‘quick coding’. Analytical software can facilitate systematic and rigorous analysis, however is still dependent upon the analytical skills of the operator to utilise its full potential.

The coding process included a first pass with codes mostly drawn ‘in vivo’ or from the text. As the coding process matured, I developed a more consistent approach, with many common codes used across populations. Due to the technology available, the audio was available and usefully replayed during coding. The software was also used to analyse my Research Journal entries.

As a further level of analysis, the software allows for memos and notes. Thus, notes about quotes, codes or developing themes were made and saved with a code, thereby building up this higher level of analysis throughout the coding process.

Before writing up the discussion points via key themes, I felt the need to revisit the people through the interviews — the stories they told. Critically, for understanding the stories anew, I re-collated every Research Journal entry for the participants and went through each one, highlighting important points, making notes and if possible labelling the spiritual type I thought the story implied. I wrote up these stories and used them as a step preceding the results below.
4.3 Results

The following section details the descriptive results from the interviews: participant recruitment and demographics; and coding and thematic results.

4.3.1 Participant Recruitment and Demographics

The recruitment of participants relied heavily on key contacts. Generally, recruitment was reasonably successful, with the majority of people approached willing to participate. Those who did not want to be interviewed gave a range of reasons, including: being tired, sick or frail; having a strong religious belief that participating was not appropriate; or felt the interview may be too intrusive.

The demographic details\textsuperscript{102} illustrate rigour and provide clarity, not to suggest that these participants are ‘numbers’. Qualitative research does not aim to generalize from results in the quantitative sense of having a representative sample, margins of error, and reliability. That said, it is interesting to note some of the characteristics about the total participant group, just as one makes initial generalizations about someone they have just met based on gender, age, ethnicity, profession and so on. Thus, over the 52 people interviewed, it was an almost even split between men and women (24 men, 27 women); 88% of the participants were European/pākehā (45 pākehā, 4 Māori, 2 Samoan); the majority were married (73% married); the majority were affiliated to a Christian religion (59%), but there was also a large non-affiliated group (28%); for cancer patients, the dominant cancer types were lung (4) and bowel (4); almost half of the participants had some university qualifications (47%), and just over a quarter each had solely trade (26%) or secondary school (28%) qualifications. The demographic details are as accurate as possible, however there were a small number of participants who chose not to reveal some demographic data, for instance two patient participants did not give their age and some participants named more than one cancer type.

\textsuperscript{102} See Appendix C4 for demographic details.
4.3.2 Themes

The key results are reported in three meta-thematic sections: spiritual definitions, spiritual beliefs and practice, and spiritual needs and care. Meta-themes, themes and sub-themes were developed, via the literature, research questions and through ongoing analysis, comparison and examination of the codes.

4.3.3 Spiritual Definitions

*Spirituality has changed so much over the years* (hospice chaplain)

All participants were asked about spirituality generally and specifically regarding what it meant for them and how might they define spirituality. This section begins to address the research question of how spirituality is understood by those affected by cancer. Responses and definitions ranged from difficult to articulate,

- *I really struggle with the definition of the word* (Carl, 62, education, Ca),
- *I just have no idea* (Amanda, 59, hospitality, Ca),
- *never gave it a thought* (Frank, 75, photography, Ca);

...to the deeply considered,

- *a belief in myself to live a decent life and get as much enjoyment out of it as possible* (Mike, 73, agriculture, Ca).
- *how one looks at the world and oneself* (Henry, 76, finance, Ca)
- *it is the essence of who I am* (Abigail, 64, chaplain)
- *it extends to my whole being, relationships and where I am in this world* (Ida, 45, hospice nurse).
- *I think being spiritual is being a good Christian* (Aida, 65, hospitality, FM)

And the humorous/stereotypical,

- *A group of old ladies sitting around a table going knock, knock, knock on the underside of the table on the top and they are calling at spirits* (Frank, 75, photography, Ca).

A number of participants qualified their definitions with "it is very much an individual thing".
There were up to 16 codes within the definition responses. These have been grouped thematically into three areas: 'religious/transcendent', 'existential/humanist', and 'summative'. This is discussed below, combining the four populations. Another small set of responses was placed under the theme 'other': this included participants who had "no idea" about the definition.

4.3.3.1 Religious/transcendent Responses

Spiritual definitions from those with cancer were either explicitly named or implied (in two cases). There were 24 patient participants and of these 11 had a religious or transcendent understanding of spirituality, while the remaining 13 had what falls generally under an existential or humanist view. But this 'first pass' analysis was limited, as further investigation revealed further complexity. Three of the eight family members expressed the definition in religious terms, though only two of these participants were actively religious. Of the eight staff, two equated religion with spirituality, but only initially, as both of these expanded on the definition eclectically. All the chaplains/spiritual carers had broad inclusive definitions, with some articulating this in a well-considered structured way.

"Old Fashion Concept of Religion"

A number of participants equated spirituality with religion. Of the 11 people with cancer who at first reading named religion in their explanation of spirituality, five of these participants suggested that religion was their initial understanding of the term, but they also had a wider understanding, as suggested by the following quotes;

A\textsuperscript{103} Before you were asked to be part of this study, what is it that you understood spirituality was?

B Probably the old fashioned concept of religion as the stronger of any categories. Just a general feeling of living a good life. That's about it.

A I think that's fairly common too ....

B Because of my generation, I think as much as anything, I have had a strong background and upbringing in religious affairs, but I am not practicing any particular religion today as an adult but I am still influenced by all of the things that I was taught.

\textsuperscript{103} For this conversation and others below, 'A' is the interviewer, 'B' the participant.
Paul went on to express this spiritual and religious view of life, not as a part, but as the ‘core’ of life and way of living,

*It is actually a core if you like, it is the substance on which your life stands and as I have described I think to you before, it is a way of life, so it is not a dimension and this is where its not a way of life but just a kind of religious practice, ..., it is the substance on which your life stands.*

Paul did note that spirituality is not just the practice of religion.

Karen, a 52-year-old hospice nurse, said of spirituality, “I believe that the older person and including myself, identify it as religion and I believe that the younger person, probably 20 and under or maybe even 30s and under, doesn’t see it as that”.

A medical doctor felt very strongly about contemporary spirituality,

*I think we are satisfied with pseudo spirituality as a society. I don’t think we understand the true meaning of what it means to be spiritual beings. We seem to exalt too many – we exalt the environment and states of being and things rather than exalting the source of those and I think we are very short sighted as a society. That’s a reflection on our society not of hospice in New Zealand as the same but unless we rediscover those things then our society is going to deteriorate and what we are going to be satisfied with in palliative care is also going to drop, we would be happy to do the pseudo spiritual conversations and I think we are not going to be able to offer true peace (Ray, PC104 doctor).*

A sense of faith and hope was a strongly expressed and felt by those with a traditional view of spirituality — these people were often active church attendees. But even for those who equated spirituality with religion, they were also quite eclectic.

**Religion as One Expression of Spirituality**

*Religion is an organized way of expressing spirituality (Abigail, 64, chaplain)*

Adding to the relationship between religion and spirituality is the position that religion is one expression of spirituality. This idea was named by an older man with a banking background, who suggested spirituality is,

*how one looks at the world and oneself and I suppose no longer talking about one but talking about me, I only go to church very rarely but when I think of religion I think of it in terms of assisting my spirituality and understanding, just supporting it if you like. ...Anyway it is not necessarily religion etc, it is a broad thing and I*  

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104 “PC” refers to palliative care.
B  In fact the word, when I first saw the word spirituality on your piece of paper, it frightened me a little bit, only in the sense of now how do I define that, I am not quite sure.

A  That’s a good question.

B  Yes, I have a sense I suppose, of all the – much of my belief system might add up to something approaching spirituality but I don’t think I have got the wit to put all of that in to words (Andy, 74, law, Ca).

Andy was a very thoughtful and articulate man who was a judge for many years. His answer suggests an ambivalence or lack of clarity, perhaps about religion, but also about the concept of spirituality. While initially he equated it with religion, he went on later in the interview to suggest that “much of my belief system might add up to something approaching spirituality”.

Religion equals Spirituality

Those that associate spirituality exclusively with religion were represented by three or four participants. For example, a young Samoan woman with a strong church and faith background stated:

B  For me spirituality is –it is pretty hard to explain but it plays a big part in my life.

A  So it plays a big part in your life.

B  Yeah, it is a major part of my life, spirituality, I mean I know that I wouldn’t be here apart from my belief and my faith.

A  So the idea of belief and faith would be some of the key parts of spirituality for you.

B  Yeah, faith especially (Ramona, 32, finance, Ca).

Ramona went onto talk about the importance of her relationship with Jesus, and the support from the Pacific Island Church Minister and congregation.

From firmly within the Christian paradigm, a middle aged male artist names his spirituality as synonymous with religion — “It is fairly conventional. I am a Christian” — but then does qualify it:

I believe that religion or that spirituality being a reality is as real as the world, our sensory world and it should impact on our lives in the same way so that its not an activity that you do as well as playing golf or painting or playing guitar or going to church, having religion (Paul, 58, building, Ca).
don't really connect spirituality with formal religion, that's probably the best way of putting it. (Henry, 76, finance, Ca)

Cathy, a hospice counsellor, expressed it this way, “I think everybody is spiritual and religion is something that some people have on top of it”. While Winsome, a 58-year-old chaplain, said, “for myself basically spirituality links with God, but not for everybody and so we are still spiritual people whether we have that link with God or not”.

**Spirituality as the extra-ordinary**

Spirituality was considered by some participants to have a transcendent, mysterious, metaphysical, paranormal or even ‘spooky’ side. This may be within or outside the religious context. Some participants included the metaphysical into their definitions, but most did not. One approach was a cynical one, exemplified by Barry, an older man with a nursing background:

> See they talk about all these comets and these funny things running around the sky and all that sort of nonsense, so yes that’s what I thought it was all about but obviously it is something different but no that was the first thought and it came in to the religion side of it too (Barry, 72, medical, Ca).

Spiritualism, from one point of view, is actually an organized group of people with particular beliefs, often associated with the supernatural, mediumship and so on. However, as shown by this quote from Barry, there are some who may equate spirituality with spiritualism. Of note, while this participant was quite cynical, even belittling “séances and that sort of thing”, later in the interview, after some prompting from his wife, he told the story of a reoccurring experience of the supernatural. Frank stated simply “spirituality is life after death” (Frank, 75, photographer, Ca), implying a belief in something more than can be seen or proven.

A subset of the transcendent or metaphysical understanding of spirituality is that of the ineffable. Some participants said spirituality was about the unknown or non-physical aspects, exemplified by an older Christian man with cancer: spirituality is “just something other than what we can see or touch or handle that has some significance and force in life. More than that I couldn’t say” (John, 68, electrician, Ca).

Melissa, a 52-year-old chaplain, liked the inclusive working definition of spirituality in the interview information sheet, but said it also needed “a God factor or something larger or a higher power or however people kind of refer to something outside of themselves”, and she
also said of spirituality, “intuition and inspiration and the mysterious and the mystical come in to play in the interaction” (Melissa, 51, chaplain).

**Anti-religious Tendency**

* A lot of people don’t associate religion with spiritual. It is different (Deidre, 57, hospitality, Ca).

* The problem for me is that religions across the board have done a bad job (Phillip, 60, chaplain).

Participants mostly understood spirituality to be something other than religion, with a range of people explicitly saying that spirituality was not religion, for example: “[I] don’t believe in religion”, spirituality is “something beyond religion” and another person said that spirituality is not “organized religion” and is “beyond doctrine”. A middle-aged professional woman stated this clearly, “What it isn’t, is organized religion - with lots of doctrinal rules and is all about what you believe and you’re doing and doing what you’re told. I guess that’s what it ain’t, for me, anyway.” (Fran, 62, education, Ca).

**The Semantic Shift: from Religious to Spiritual**

* The distinction between spirituality and religion is very important (Phillip, 60, chaplain)

For many participants, ‘religion’ and ‘spirituality’ are related but different concepts, as one middle-aged woman with cancer who worked as a canteen assistant said insightfully: “A lot of people don’t associate religion with spiritual. It is a different”. This is further explained by another participant, a middle-aged professional man with cancer, who said “the immediate thought coming to mind is of a religious or faith type thing”, but Mike went on to say, “I certainly have no time for spirituality if it is associated with fundamental religion or religious beliefs, spiritualism [spirituality] for me is to have confidence and faith in my own ability to live the way I feel people should live” (Mike, 73, agriculture, Ca). Mike expresses the shift from understanding spirituality’s association with religion in the first and historical instance, but for him now it is redefined without any reference to religion. This semantic shift leads into another widely held understanding of contemporary spirituality — a humanist or existential approach.

105 Mike’s use of the term ‘spiritualism’ for spirituality is an interesting ‘mistake’, in that it shows something of the loose use of the terms such as spirit, spiritualism, and spirituality. This was not common in the sample.
4.3.3.2 Humanist/Existential Responses

After expressing what spirituality was not, often referring to religion, many participants then described it in humanist or existential terms. Key sub-themes included ‘beliefs’, ‘ethics’, ‘values’, ‘essence’, ‘core’, ‘well-being’, ‘identity’, ‘integration’, ‘relational’ and an ‘aesthetic’ approach.

Beliefs/Values/Ethics

Participants often used ‘beliefs’ in their articulation of what spirituality was for them, as two different participants with cancer simply stated: “it’s a belief thing” and “it’s what I believe in” and a hospice nurse likewise said “I believe it is a belief system.” More formally, Carl suggests, “I am going to build my comments as we go through this discussion basically on values and beliefs and as far as they are concerned, they will become the base of the idea of spirituality” (Carl, 62, education, Ca). Des said of spirituality, “it’s extremely primitive really, I think its personal and a belief and I think that everybody has it and if they are saying they haven’t they are stupid” (Kevin, 73, labourer, Ca). Oscar argued, “there is a spirituality and spirituality can either mean religion or some sort of belief system” (Oscar, 50, education, Ca).

Related to beliefs, many participants used the terms ‘values’ and/or ‘ethics’ in their definition. For example, Carol said it was a “a sort of an ethical code to live by” (Carol, 50, education, Ca).

Meaning and Purpose

‘Meaning and purpose’ were often used together in some participants’ definitions, particularly by chaplains/spiritual carers. For example, Damien said “spirituality, or the spirit is the thing that drives people to find purpose and meaning in their life. Religion is a formal set of beliefs that answer those sort of questions” (Damien, 55, spiritual carer). Abigail, another chaplain, suggested it “is really what gives meaning to people, meaning to their life, how they live their life”.

Core/essence/identity/well-being

Many participants referred to spirituality in terms of core, essence, identity or well-being. For example Fran said “It’s definitely to do with your sense of, sense of self, sense of where you are and who you are”. She went onto say,
If you think of spirituality around, you know, basically your well being and who you are and how you're facing this, the physical stuff can be pretty unpleasant but it's the core stuff that's in some ways the most painful, just coping with that and yet that's the bit that's not... (Fran, 62, education, Ca).

What Fran did not complete in this quote was her belief that the “core stuff” that is “in some ways the most painful” is not dealt with enough by the medical system.

Cathy, a hospice counsellor, said spirituality was “the essence of the person, their soul, their spirit, that thing that is hidden and only known to the person and to me it means something different to everybody” (Cathy, 56, hospice counsellor). Olivia, a hospice nurse, said “to me the spiritual is the centre” and Louise said, “spirituality really to me is about being – my inner well being” (Louise, 55, social services, Ca). Damien, a spiritual carer, situated spirituality in the well-being model “addressing those four corner stones, the physical, the psychological, the social and the spiritual”. Three other chaplains used “essential part” or “essence” in their definitions. After ‘beliefs’, these spirituality definition descriptors were the most commonly expressed.

Relational/integration/wholeness

Few participants named ‘relationships’ within their definitions, but some staff and chaplains/spiritual carers made a point to do so. Ida, a hospice nurse, expressed spirituality in relational terms, with people and the land. She said it was “who I am”,

But who I am in relationship to other people so not able to separate me from my surroundings and yet surroundings may be not just people, just me and the relationships, it is about the environment, it is about where you are, it is about having a sense of place, you know you mentioned before, that for me, is really important, that sense of place, is very much connected with who I am and where I have come from (Ida, 45, hospice nurse).

While not usually expressed or defined explicitly as ‘integration’, some participants suggested spirituality was about connecting and it was part of all things: Carol said “I think it is a way of life” (Carol, 50, education, Ca). Leon, a chaplain, said “it is those sort of models that separate spirituality out that I struggle with, ..., it is really important to me that your sense of spirituality moves – it doesn’t get compartmentalized, ..., it is that brings a sense of wholeness”.

In the summative responses below are other examples that include the relational and integrative aspects.
Aesthetic

Melissa, a chaplain, noted the importance of aesthetics to spirituality, as she said,

*the aesthetic sense is really important. As you look around here, you can see there is a bit of an emphasis on that and it is quite nice.*

While not often commented on, the aesthetic component of spirituality was critically important for David, a 71-year-old man with a background in law. Over the three years of his cancer journey, it was art that helped to make his life meaningful.

Mindfulness

Some participants used the term mindfulness in their definitions and explanations of spirituality. At times this was implied, as in the following quote that suggests the spirituality within the particular: “if they take particular trouble about the way the meal tray is set up or make sure that there are flowers in the room for somebody who hasn’t had any brought by visitors. I think that’s spirituality too” (hospice chaplain). Ida, a hospice nurse, talked a lot about “awareness and mindfulness” regarding spirituality and spiritual care.

Many participants named more than one aspect or domain in their definition of spirituality. The majority of people used these humanist or existential markers. Others included both religious and existential elements, explained below as summative responses.

4.3.3.3 Summative/Integrative Responses

*For me it is very broad* (Olivia, 55, hospice nurse).

Many of the respondents’ definitions did not fit neatly into a label, as can be seen by the number of quotes from the same people under different headings. Most participants’ definitions included a range of descriptors, drawing from the religious and existential; these definitions were categorized as summative, inclusive or interactive responses. A good example of this was the hospice nurse Ida, who had a very eclectic understanding and definition of spirituality that included much of the above, as well as,

*It has a content of faith for me, ... that whole faith around a belief in some sort of divine being, some sort of, call it God, call it who-ever, you know, for me it doesn’t really matter* (Ida, 45, hospice nurse).
Other staff, particularly chaplains/spiritual carers, had these broad definitions, for example Leon, a member of the pastoral care team, named three foci within the definition: meaning and purpose, wholeness/integration, and transcendent.

*I think you can approach it in three ways. Three ideas that sort of overlap, you know they are sort of I guess the lenses through which you look at the same thing, the dimension of human experience. The first is I think of it as a meaning and purpose in life, you know, I guess if you are asking someone what is life, or what has your life been about, what have you striven for, what have your values been, ... then slightly differently a second area for me would be a move in to thinking about that dimension of life that brings a sense of wholeness or integration, ... how does the whole of my life, my being, how does it hang together, what is the connective stuff, what brings balance, ... the third thing I think is transcendence, ... you can go out or you can look inward as well, in the sense of either what is beyond me or what is deep within me* (Leon, 52, chaplain).

Paul, another chaplain, suggests in a similar vein that spirituality “refers for me to the impulse that works in humans to harmonise deep factors of life” and this may include religious, existential or other things.

Damien, a 55-year-old spiritual carer, uses a definition of spirituality “[it] embraces the essence of what it means to be human. It is concerned with personhood, identity and meaning and purpose in life. The spirit holds together the physical, psychological and social dimension of life”.

Ray, a palliative care medical specialist, had a broad definition, and simultaneously he had a strongly conservative Christian position. Ray’s definition included,

*the core of our being. ... It’s who you really are. It is our belief, [we are] spiritual beings, that we need to be aware of something other than the physical. It is not our emotional state, it is to do with our hope, it is to do with our beliefs, our faith, it is to do with the priorities we choose ... an awareness of our fragility and our mortality is key to true spirituality, that we aren’t in control. We are not the masters of our own destiny and that there is someone beyond us that we need to rely on as opposed to a spirituality which says I can be in control of what is happening, I am one with the universe. I think the spirituality that as a Christian is one of humility rather than one of exaltation of self.*

Mellissa, another chaplain, gave me her considered definition in writing,

*Spirituality has to do with the values that we hold most dear, our sense of who we are and where we come from, our beliefs about why we are here - the meaning and purpose that we see in our work and our life - and our sense of connectedness to each other and the world around us. Spirituality can also have to do with aspects of our experience that are not easy to define or talk about, such things as intuition, inspiration, the mysterious and the mystical.*
Some participants clearly situated spirituality within religion, but the majority position defined it either in existential or summative terms.

4.3.3.4 Further Definitional Comments

Universalism
Many participants, particularly those working in hospices, suggested that all people have a spiritual dimension. Cathy, a hospice counsellor, exemplifies the universalist position when she said “in some people I would imagine it [spirituality] is quite underdeveloped or they haven’t labelled it or named it as such, but everybody has got it” (Cathy, 56, hospice counsellor).

Outlier Positions
There were some positions or comments regarding spirituality as a concept that did not fit into the categories above. For example, one hospice nurse said, “I think it is the wrong word. I think it is broad and it means a lot of different things to different people and until you actually get in to a conversation with some of our patients and have a good talk, you don’t actually know what it means”. Of the 52 interviews, only one person was explicitly antagonistic towards the use of the word.

Another outlier position was Sara’s definition, she said “I think at a very basic level, spirituality is in a sense always trying to climb back into the womb, but I think it is always trying to answer that need which is the basic need” (Sara, 55, counsellor).

4.3.4 Spiritual Practices and Beliefs

To address the research question “How is spirituality understood in the New Zealand hospice care context?” it was thought important to understand the spiritual beliefs and practices of this population. This involved asking a range of questions about participants’ spiritual activities, core beliefs, sources of meaning and changes that may have happened since being affected by cancer. The coding and subsequent sub-themes follow this pattern.
4.3.4.1 Spiritual and Religious Practices

All participants were asked about their spiritual or religious practice. Participants were asked about what helped to make life meaningful and bearable on a daily or weekly basis. Few participants attended church regularly, but many more had particular rituals that helped to enhance their spiritual well-being. Prayer and meditation were the most common traditional spiritual practices, but many people did have domestic rituals that helped to give daily life meaning. For example Barry, who had lived with cancer for 13 years, had two cups of tea each morning with his wife before they got out of bed to start the day. For Barry, his meaning in life was centred on this relationship with his wife, and this tea ritual — “that’s our daily ritual” — was one of the ways he kept it sacred (my interpretation). A number of participants had ‘rituals’ for comfort or meaning. For example, some family members said the following helped,

I usually just go down stairs in my sewing room and go in to the other dark room down there and sit down and have a little prayer and go in to my sewing room and sew away and then after that back up here again and I am all right.

A cup of tea and a cigarette and a walk around the garden

A glass of wine

Well once again I am going to go back to the power of prayer. My net friends, who I belong to a writing group on there and we used to talk every day... they all prayed for [husband] and so like there was this huge amount of people all over the world praying for..., I do believe that. Maybe I am re-finding my Christianity.

Yes, yeah, communicating on the computer. I talk to a lovely old couple in Tennessee every night.

Notably, creating a ‘sense of’ and ‘place of’ space to deal with being upset was a common theme underlying people’s responses.

Discussion about death itself did not happen very often with people with cancer or their family members, in fact in some cases when it came up the topic was explicitly shut down. There were those that said they hoped it would happen soon for the sake of their family member. The one exception was a daughter of man with cancer: Sara was a committed Buddhist who was “gently” talking about death with her father. In her words, “I want to feel that I can help father with that [dying] and that is the goal to be peaceful and to feel safe”.
4.3.4.2 Spiritual and Religious Beliefs

A range of spiritual beliefs were discussed with participants. Questions were asked about belief in God, the afterlife, the place of religion in their lives, and what gave them a sense of meaning and purpose in life. The place of the paranormal was not on the implicit or explicit interview schedule, but after three or four interviews it was raised by participants so many times that other participants were thereafter often asked about it.

4.3.4.2.1 God and the afterlife

The question of belief in God was explicitly asked. Mostly participants answered yes or no, but some of the more ‘philosophically inclined’ would say “it depends on how you interpret it”. Like the ‘God’ question, all participants were asked if they believed in the afterlife. Most did have some afterlife belief, which ranged from a traditional Christian heaven to reincarnation and post-death evolution and “it is a continuation on a different plane on a different level”. God was broadly understood by most people, with such things as “a higher being” and ‘universal super conscious’ named. There was a small minority of participants who believed there was neither God nor afterlife.

The Christian participants expressed a more traditional view of God via a personal relationship, implying a personified deity. There was one exception of a very theologically informed position: “God is uncreated and god is the ground of all being” and “Jesus is the incarnation and the Holy Spirit is what is given to us” (Paul, 58, building, Ca). Ramona’s (B) belief in the afterlife is expressed in the dialogue below with her mother (C) and myself (A):

    B I believe if you are faithful, in the afterlife you will get your reward.
    C Your reward in the afterlife.
    B Your reward is everlasting life with god
    C I don’t think I will get that because I have so many sins
    A Oh come on.
    B As long as you believe.
    A Yes, god forgives
    C I know that
Mia, an experienced hospice nurse, had a broadly religious position, “I do believe in a creator, I do believe in a God as such, yeah, I question some things in Christianity but I do have a very strong belief system in a spiritual presence”.

Agnostic positions were reasonably common, as exemplified by this family member commenting on the afterlife, “Well I rather hope so, I don’t know”. Andy expressed another agnostic position,

*It seems wishy washy to say it but I am agnostic, I don’t know, but I still say a prayer every thing, last thing going to bed. ... But I really don’t know whether there is this supreme being out there as we understand it or not, I just don’t know* (Andy, 74, law, Ca)

Andy’s actions of prayer imply that while he is not sure about God, prayer still has some meaning. Another self-confessed agnostic, Oscar said, “I think my afterlife is my children”.

There was quite a lot of ambivalence and confusion about these issues. Adam made it very clear early in the interview that he neither believed in God nor the afterlife, but then went on to say,

*I believe in spiritualism. .... We believe in spiritualism in so far as we have been communicated with, people have communicated with us, we haven’t communicating with them. We went to spiritualist church, it was run by the spiritualist church, one was a private individual, she conducted a meeting, she spoke to people in the afterlife and I am not admitting there is an afterlife but she spoke to people and she identified me quite clearly as a fellow with two brothers who were twins, one of whom was killed on a brand new motor bike because he was out riding his motor bike.*

Adam said his brothers had died and the medium had got it right. But obviously questions remained.

Barbara told the story of her grandson, “I bought Jacob an orange tree and it has got some oranges on too and he was saying, we were talking about that and I said when I die, you can talk to the orange tree and I will hear you” (Barbara, 69, domestic, Ca). Belief in the afterlife was common but not, by and large, conventional. There was a sense of belief ambiguity expressed by many participants, as Nel expressed, “I do believe there is something but just what...” (Nel, 70, manufacturing, FM).

Joan, a medical doctor, said “I can’t” believe in God or the afterlife, but went on to say, “I think there’s a lot more things that we don’t know about influencing kind of earth and humans
but I don’t think it is kind of the God in the biblical sense, and I don’t think I want to explain it, I don’t want to try to”.

Olivia, a hospice nurse, said she did not believe in a traditional God, but “I kind of believe in a maybe a goddess sort of person mother type influence” and about the afterlife she was not sure, but wonders “another part of me thinks there may be a return of the spirit”.

Staff participants had the widest range of beliefs about God and the afterlife. Many said ‘no’ to the question initially, but then went to explain their beliefs which like Olivia or Joan above were either agnostic or unconventional.

4.3.4.2.1 Religious Beliefs & Faith

Participants expressed a range of religious beliefs other than about God and the afterlife. Barbara said, “I have got a guardian angel and it is St Luke” (Barbara, 69, Ca). Questions were asked of God by family members, “I come up to church and I was a very strong person up at church but I kept asking that question, why me God, what have I done to deserve this and I have my only daughter and why this sickness” (Tai, 57, FM).

Ray, a palliative care specialist, had a very strong religious belief system, what may be called fundamentalist. He was very careful to say that he did not impose his beliefs on patients or other staff, rather his comfort with this spirituality allowed him to be comfortable raising spiritual issues with his patients. Ray worked at being present for each patient, literally saying a prayer as he walked into a new room so as to be fully mindful with someone new. For Ray, “nothing was an accident” and “science confirms creation”. As Ray saw it, the will of God led his work, family life and Church leadership roles.

Joan, a GP who worked in a hospice, suggested that most people “are somewhere in the middle” between strict religious beliefs and “people who have no interest in that”. Joan was suggesting that spiritual issues are important, but the extremes of belief are rare.

4.3.4.2.2 Meaning and Purpose

How one makes meaning in life is not always easy to express — “I don’t go around thinking about what does life mean” — so answering the question “what matters most?” often helped to facilitate this discussion. The vast majority of people answered “family” or a synonym thereof. A person with cancer exemplifies this, “Family has got to be the key thing, family is
what you live for”. Other responses about meaning and purpose to life from people with cancer included,

*It is just the mere purpose of being.*

*Trying to do the right thing at all times by both myself and others.*

*Yes that is now my sole purpose in life, to get my affairs in order*

*I think just being here*

*[Sport]: you get to know yourself and people very well through that sort of thing.*

*To do with other people. I believe that if there is any reason for me to be on this earth at all, it is in some way to either facilitate in some practical way, elevate people’s abilities to do things, or to feel good about themselves*

*There is a purpose to it all so there is both a personal purpose and sort of a cosmic purpose*

However, three people with cancer answered negatively, that is, life did not presently have meaning for them. Ewan’s answer to what was meaningful was evasive, “that’s a very difficult one” and “all those things that I have regarded as being certain, they are running out on me now” (Ewan, 68, finance, Ca). Another woman with cancer said, “I don’t know, sometimes I wonder why, why I have lived this life, why I am here, because I don’t really think I have contributed anything to life quite honestly” (Louise, 55, social services, Ca). However, after a prompt, Louise did recognize her kids give some meaning to her life. And Luke said, after some thought, “It hasn’t really [been meaningful], actually it hasn’t” (Luke, 58, construction, Ca).

Family members had a range of responses, mostly focused around looking after their sick partner or child, including,

*My main focus is I want to look after her right to the end, that’s my purpose in life at this stage.*

*The fact that I am here, that I am alive and that I can interact I think with other people and its other people actually give meaning to life more so than anything.*

*Washing, cooking, sewing (laughs)…Getting on with the work, or the jobs that have to be done.*

Staff were also asked about their meaning and purpose. For some, work was raised, “the nurses that work here, we don’t do it for the money because we don’t get anything like what the hospital nurses get. You work because this is the sort of job that you want to do” (Mia, 71,
hospice nurse). So “making a difference” in their work gave some staff meaning. Other staff remarks included,

*I think for me it is like that personal integrity, being truly yourself and for me that’s a thing that I am constantly mindful of and that whole self awareness about what I do* (Ida, 45, hospice nurse)

*the contact I have with family and friends. The work that I do* (Olivia, 55, hospice nurse)

*I believe God has asked me to be a leader and he has given me the skills that I need to be a leader ... both here in the hospice but also within the church structure* (Ray, PC doctor)

**Examined Life**

*We deny death and in doing so we deny ourselves the means of becoming, as it were, death fit, getting ready for the game* (Paul, 58, building, Ca)

Under the spiritual beliefs theme is ‘meaning and purpose’. Delving further, it was clear that some participants were particularly thoughtful — they had, and were living, ‘the examined life’. Exemplifying this is Henry, “Well to be honest I think I have thought about those things even before I was sick. I mean even as a kid I used to think about things, death if you like” (Henry, 76, finance, Ca). This reflective capacity was expressed by Luke, “I have made some horrendous mistakes in life and done things I shouldn’t have done”. In Luke’s case there was significant guilt in his life.

Oscar was a very articulate and thoughtful man who had actually put on his wall at home the four dimensions — physical-mental-social-spiritual — as a reminder to attend to each. His reflection of the ‘journey’ expresses this thoughtful nature and an insight into fear,

*I wouldn’t want to go on this journey again, but it is things that you sort of, you know thoughts you would never have had before or ways of looking at things that you wouldn’t have necessarily had unless you have gone through the fear of dying. And I think that in those first few months the fear is just overwhelming until you come to terms with it.*

Paul was another deep-thinking man who said that having time — an extended period of his illness/wellness — helped,

*Maybe if the initial prognosis had been correct and I had died within two months, I would have gone down feeling not so good about myself. Whereas now, you talked about a good death and I would hope that if this does come back and it does claim me that I would be able to do it that way. Whereas I don’t know what would have happened before but it has been a real benefit having had time to assess things.*
What about the unexamined life? Some participants clearly had not thought much past day-to-day living. Such questions as ‘the meaning of life’ were foreign and fruitless pursuits. Further, one family member said she had to deny the terminal nature of her mother’s illness, otherwise she felt she just could not cope,

*I just want to explain this because I knew - I’m just not very good at explaining about it because I rarely surface it because, I mean I don’t even think of Mum’s illness as terminal, I really don’t. It’s a complete. The only way I can keep it together really is to be quite in denial of it because it’s not only my connection with her, it’s [her daughter’s] connection with her.*

A hospice chaplain reiterated this unexamined position, “There is a lot of people out there who haven’t ever given it a lot of thought and the first time they often encounter it is when they come in here and they are confronted by a spiritual carer”.

**4.3.4.2.3 The Importance of Spirituality**

*You can drive yourself in to deep depression if you don’t have that spirituality*

(Oscar, 50, education, Ca)

The importance of spirituality was commented on by a number of participants from all populations. A 71-year-old staff member who had been a nurse for 49 years and had been working in palliative care for 17 years said, “I do think it is very important and I think it is important for us to recognize and for other people to recognize my spirituality”. A family member said, “I don’t think you would survive without it [spirituality]”. And when people with cancer were asked about its importance, many said “very” or in Fran’s case, “I think it’s important, but especially important in the situation I’m in. It would be very difficult if I didn’t have any sense of spirituality” (Fran, 62, education, Ca).

Staff often highlighted the importance of spirituality. Ida, a hospice nurse, notes that at their hospice “the spiritual aspect of care here I think is always considered to be paramount”, and further,

*I would say the whole spiritual aspect of care is a huge, a huge issue for people and it is funny, like when I go for the first assessment we talk about their physical needs and we talk about the whole spiritual and emotional needs and I say sometimes in my experience I find that these needs are sometimes greater than some of the physical needs and often people will respond to that and say oh for sure, yeah, you know so you know straight away where you are at* (Ida, 45, hospice nurse)

The recognition of the importance of spirituality was often understood as participants were affected by cancer, leading to an examination of life’s priorities.
4.3.4.2.4 Reprioritization

When we get a life threatening disease, we go through a metamorphosis (Ewan, 68, finance, Ca).

Spirituality seems not to be a static part of one’s life. Thus, when affected by cancer, not only does spirituality appear to become a priority, but potentially one’s spiritual beliefs change over the cancer journey. This appears to be the case not just for the person with cancer, but also those who care for that person: friends, family members and staff. For people with cancer, Paul suggests they enter “Cancer World”, a unique world with its own language and places, “it’s a world you enter and never come out of it”, a place that if you have not had cancer, you “can’t experience” (Paul, 58, building, Ca). Paul said ‘Cancer World’;

govern how you see the future, how you go about thinking and talking about the future and so in other words you enter a world which other people who haven’t got cancer or had cancer, can’t experience because they don’t, you have got to be – cross the border, you have to be in there.

Oscar, a deep-thinking man who understood science as critical to his spirituality, suggested that spirituality “is more to do with … the death part”.

Changes in beliefs due to cancer were called a “re prioritization” by one participant with cancer. Another said “I see the world entirely differently, I see the waste, I see so much waste”. This was reiterated by another who said “it has focused me quite a bit really on what is important in life”. Another person with cancer said, “I have to do a lot more thinking. And also, um, decide what’s important in your life”. Ewan noted,

when we get a life-threatening disease, we go through a metamorphosis and since I have had cancer and I have known it for around four years now, I have done an awful lot of reading, both about diet, about some religious matters, alternative therapies, supplementary therapies, and there are pitfalls in all of them (Ewan, 68, finance, Ca).

From a Christian point of view, Ramona said, “I think my belief has got stronger since my illness, because that is what I am trying to fully depend on, it is hard.” Ramona also said she had learnt from her illness, a position experienced by a number of participants. In her words, “I have learnt to appreciate every day that comes around, every blessing that I receive, I have learned to – even the bad things, learned to accept” (Ramona, 32, finance, Ca). Carl affirmed the learning from cancer when he said, “I have learnt quite a bit about myself”. Carol said, “I think you have to become stronger spiritually, definitely”, when considering the changes since cancer.
It seems cancer can potentially have positive side effects. As Grant said, he now has time to see the “things going on around you”, thus growing in awareness in his last months of life. Or as Fran said, “I guess I’m a lot more aware of being happy than I was”. This was reiterated by a daughter of an older man with cancer. She said of her father’s journey, in speaking to her father,

*I often think too father, even the fact that you have lived with this cancer now for seven years, the one positive thing I have seen for you is that you have had this time really reflect on your life ...it has been a fortunate time in a lot of ways* (Sarah, 40, medical).

Another change that was noted by some people with cancer was a natural altruism. Carl put it this way, “More than ever in my life I am interested now in the well being of other people, no matter who they are, whether they are well or unwell or whatever, it just concerns me” and “I have become a lot more accepting now” (Carl, 62, education, Ca).

An alternative position was expressed by Andy, who when asked about changes, said, “to my surprise, no, nothing has changed, and I have looked for change in that. I can honestly say in my self, no, nothing has changed” (Andy, 74, law, Ca).

Staff were aware of people with cancer reprioritizing their lives, but working in this context can be a reminder about what is important for staff also,

*It is much easier here to take a step back and look at the bigger picture and think why am I getting het up about this, it is not actually that important in the grand scheme of things so it is a very good way of making you reflect on what you are thinking or what you do. Again that’s probably part of the fact that you get a bit of time* (Joan, 29, doctor).

A hospice chaplain affirmed those above by saying, “When a person is dying they tend to push aside all the extra people and deal with things in a very close circle” (hospice chaplain).

### 4.3.4.2.5 Paranormal

The paranormal was not initially an area considered by the author. It is seldom seen in the literature and therefore was not on the interview schedule. However, after a number of interviews in which participants had told stories about their paranormal experiences, it was then incorporated into further interviews as a question. There were 23 coded events among patients (not 23 patients). Andy’s story is one of the most curious as he was a particularly formal ‘upstanding’ man, a former Judge who held “truth” as the highest value, and who one would not expect any fabrication. In Andy’s story, he died for six minutes, had an intense
visual experience and experienced remarkable peace; and then fully recovered without any complications.

A number of patients and family members talked about visiting mediums and/or the Spiritualist Church. They were convinced that they had had an authentic experience:

*My mother swears that she saw my father, about twice during the week before she died* (Deidre, 57, hospitality, Ca)

*Yes well we have one that follows us, it is attached to us somehow I have no idea how but every house we go in to there is always someone who walks down the passage regularly and the same here* (Amy, 66, medical, FM)

*I saw a vision the night my mother died, well, let’s put it this way. I had my father in hospital and I had my mother dying of cancer. I could not speak about cancer, I still find it difficult. I was 17 and mum called out and the angels came to get her but she didn’t actually die that night* (Aida, 65, hospitality, FM)

Other stories included seeing ghosts, dead family members visiting, seeing ‘auras’, miracle healing, seeing angels and near-death experiences. Of note, with only one exception, these experiences were all benign, leaving the person with a good feeling and often buoyed by the event. The negative experience was of a ghost that followed a participant wherever he went. He believed it to be one of the people he had shot in the war, it did not make him feel good and he was worried about meeting up with them when he died.

Staff and chaplain/spiritual carers had the most surprising (for this writer) reaction. For many of them, such events as described above were just ‘par for the course’ – “its not uncommon” among the dying. Phillip, a chaplain, used to think “the spooky stuff was bollocks”, but now describes it as “mysterious business”. In his hospice, as in many, they “bless rooms here automatically, but I had blessed one particular room that had a cold feeling and ‘something in it’. Also there was an apparition seen, a small boy, at night by some night nurses, and they blessed that away” (Phillip, 60, chaplain). Another chaplain noted, “The whole business of spirituality is recognizing that there is a dimension beyond the realm we live in so you have to make allowances for a spirit realm”, and told the story,

*The past fortnight there were two patients who have encountered spirits, one died, he was visited by his wife, and that gave him a lot of comfort. The other person, who I think, they saw a priest, it was a monk because the garb they described was a monk, a Franciscan monk, beside a patient’s bed, they woke up during the night and saw this monk sort of hovering around and the person died the following day but died in a place of peace and felt that this monk had ministered to them during the night* (Damien, 55, spiritual carer)
The blessing of rooms is literally about the unseen (and unexplainable), as a chaplain said, 

_the whole purpose of that is to cleanse it of any evil sort of influences that might be there and to hope the soul of the person who died sort of exit the environment so you know, there is the powers of principalities aspect which can be the negative, the scary ghosts, and there is the soul of the departed that you sort of help on the way so you address those needs by doing a blessing_ (George, 63, chaplain)

More than half the participants either had had these so-called paranormal experiences or believed in them.

### 4.3.4.3 Spirituality Compared to Psychology

Psychological and spiritual needs may be similar and/or intersect. Based on debates in the literature (Koenig, 2008; Pargament, 1997), it was thought of interest to ask participants for their understandings. With only one exception, a hospice nurse who said, “I think the psychological and spiritual is one and the same”, participants from all groups thought they were different, though many believed there were connections between the two dimensions. A hospice chaplain suggested “There is a thin boundary line there and there are areas and in fact you have to understand your limitations I guess that’s the thing and there are areas where a professional counsellor needs to be called on and I will do that”, making an important point about boundaries and referring patients on when necessary. A hospice nurse of 17 years experience said the psychological “is totally different to a spiritual belief system”, however she could not explain this clearly. However, she and another hospice nurse said the difference between these areas was particularly obvious at the “point of death”, as “it just seems very clear that the spirit has gone”. This later comment is referring to a ‘soul’ or ‘spirit’ concept. A palliative care specialist suggested that psychology “has a defined core about behaviour and the cognitive area; psychology doesn’t touch upon the existential/religious/god arenas”. Reiterating the inherent interconnectedness between these domains, a hospice chaplain noted, “I think spiritual care will most often involve the emotions on some level and if you don’t want your emotions involved, then you won’t want to go there”.

### 4.3.5 Spiritual Needs and Spiritual Care

*I am scared (Barbara, 69, domestic, Ca)*

*They call that “living the journey” and I though what a stupid euphemism but actually it is a journey* (Fran, 62, education, Ca)
This section will report spiritual needs and spiritual care results as expressed by the participants, which will help answer the research questions asked ‘how might spiritual needs be better understood and provided for in New Zealand’s hospice care?’

For the provision of appropriate spiritual care to happen, the needs of the individuals (patient, family members and staff) must be understood. To understand these issues, participants were asked about their own spiritual needs and care, what ideally would work, and in the case of the staff and chaplains, what were the current care provision processes? The sub-themes under the ‘spiritual needs’ theme include: awareness of spirituality, common spiritual issues, barriers and gaps, and changes in needs. The sub-themes under the ‘spiritual care’ theme include: provision of care (who does it and roles), the processes of spiritual care (how is it done, assessment, interventions, tools and resources, place, space, timing), training and policy issues. The final section will detail results about staff spiritual care.

Having terminal cancer is “is like a Damoclean sword that begins to hang over your head. How thick the cord that hangs the sword in each individual is different. My cord apparently is fairly slender but you are always aware it is there” (Paul, 58, building, Ca). Each person with a terminal diagnosis faces their mortality. Some ignore the impending end, but most attempt to come to terms with it. This is at the heart of spiritual needs and hence the need for spiritual care — help from someone on one’s final journey...

4.3.5.1 Spiritual Needs

There are not many people that have got it all together when they die (hospice nurse)

An important preface to ‘spiritual needs’ is the comment made by a number of participants that not everyone has a need to have their spirituality cared for by someone else. As a chaplain noted,

Some people really don’t have any need at all, they are quite comfortable, they are in a good space or they have got other people who come in and address their spiritual needs, or they have gone through that journey already and really they are just in a reflective mode (hospice chaplain)
Similarly, a hospice counsellor said, “I used to think that people that died in denial that they were dying, hadn’t done the work that would be helpful to do but in actual fact dying in denial isn’t a bad way to go”. These position are reminders that a ‘fundamentalist’ position that suggests everyone must die this way or that is neither useful nor does it reflect reality.

4.3.5.1.1 Awareness of Spirituality

Chaplains particularly noted the importance of the awareness of spirituality. This was commented on as a positive aspect among staff, “I think every nurse I have met here, and every doctor for that matter, has a sense, a spiritual awareness”. Spiritual awareness was noted as an important chaplain role, “Part of my role is to just keeping people’s awareness of that [spirituality] so that they can be aware or respond to that in a respectful way” (hospice chaplain). Further, a chaplain said he needed to be aware of the “sacredness of what is happening”, “give permission” to explore the spiritual dimension and create the “space” so that this can happen.

4.3.5.1.2 Common Spiritual Issues

A certainty is that people die as they have lived (Sara, 55, hospital counsellor)

Results reporting common spiritual issues come from two sources: the actual issues raised by people affected by cancer, and observations made by staff about common issues. These issues are ‘needs’ and opportunities for growth. Spiritual care may/can help facilitate such growth towards enhanced spiritual well-being. These issues/needs changed at different times in patients’ illnesses and this is commented on more fully below. Common spiritual needs included religious needs, existential needs (the (un)examined life), peace of mind (relationships, financial, hope, humour, identity, congruency) and blocks to peace of mind (spiritual pain, anger, fear, guilt, regret, worry, uncertainty, grief and despair). Many of these issues overlapped, but for ease of expression they are delineated.

Religious needs

Based on these interviews, it seems spiritual needs of a religious nature, except for the sacramental needs, are not that different from secular spiritual needs. For instance, Paul notes,

*I realized that’s the first thing that came to me, that that is a night sweat, it might be cancer, I might be going to die and I haven’t really been putting a high priority on my actual walk with God and now I might not have time to do so* (Paul, 58, building, Ca)
So while framed in ‘God’ language, essentially this need is about ‘putting things right’. Paul went on to say that he became much more serious about his relationship with God post-diagnosis.

Family member Campbell was angry with God, “He is being a bit of a bastard taking you earlier than you need to go though, I still haven’t forgiven Him, I have had words to Him but I haven’t forgiven Him yet”. Campbell expresses his need to reconcile what he sees as a premature death with God’s plan.

The need to ‘return to religion’, while part of the folklore for the dying, was not often mentioned by any participant group. Only two chaplains raised this issue, one suggesting that dying people “often return to … faith” and another saying “I do quite often get people who say it is too late. I have turned my back on God all these years; I can’t go running to Him for help now”. Naturally this chaplain went on to say he reassured such people that God was available at any time. Ray said he saw “atheists dying very peacefully” (Ray, doctor), but then went on to say this peace was due to “numbness”, not a “joyful peace” as he expects as a Christian.

**Existential needs**

*We have to be with people and sit with them, as they stare into the abyss… and not look away, not withdraw from them* (hospice chaplain)

Existential needs focus on making meaning within and along the cancer continuum. Staff and chaplains/spiritual carers suggested typical questions included ‘why me?’ A terminal diagnosis may induce an existential crisis or crisis of faith. Fran said of her cancer diagnosis, “I thought when I got cancer why me and then I think why not me?” Such understanding was not always the norm, as Joan, a GP in a hospice, noted, “I think a lot of people kind of ask the meaning of life type questions, sort of why me, why now”. Chaplains commented about these issues,

*Trying to attach some value to the life they have lived and trying to find some sense of the present and make sure that the issues we talk about, the loss, doesn’t mean that they are no longer functioning members of society* (hospice chaplain)

*Meaning, and identity, there is questions and reflections around those issues* (hospice chaplain)
I have experienced often with people, particularly with people who are unwell that they are searching often to find some meaning and maybe some reason and often there are a lot of questions as to why and why should they be the ones that are ill or stricken (hospice chaplain)

The existential issues chaplains refer to include one’s value in life with a debilitating illness, meaning and identity, and reasons for the situation happening.

**Peace of Mind issues**

‘Peace of mind’ was a term used by some participants summing up a primary need for those affected by cancer. Peace of mind was often hoped for rather than experienced, but most participants either considered it a goal or experienced it: Henry said, “I like the idea of peace of mind, I have it occasionally but most of the time I am thinking about something that is not particularly peaceful” (Henry, 76, finance, Ca). As with many of these needs and common spiritual issues, they are inter-related; for instance religious and existential issues feed into one’s ‘peace of mind’. For analysis and wider understanding purposes, these sub-themes are discussed individually.

Peace of mind appeared to be collaborative (it is affected by relationships), cumulative (it happens over time and depends on how much ‘peace of mind’ one starts the cancer illness with), and contingent (on other factors such as hope, identity and humour). Blocks to peace of mind create spiritual pain, which could come from a range of sources including religion, anger, fear, regret, worry and guilt. Inevitably there are connections with psychological processes/needs, and peace of mind may be synonymous with ‘getting one’s affairs in order’.

**Relational needs**

Many of the comments from participants regarding common spiritual needs and issues could come under the ‘getting one’s affairs on order’ rubric. While at first glance this seems to refer to financial issues, participants were more focused on relational issues and needs. As a chaplain suggested, spiritual questions include “what business do you still have to do that you haven’t completed?”.

The relational issue is expressed by a family member, “relationships, they are completely just turned upside down” and then other needs named included “if there is a tension within the family then obviously that impacts on the patient” (Joan, 29, doctor). One’s peace of mind is significantly impacted upon by how well one gets on with those ‘nearest and dearest’: as Joan
said, “that will have a huge impact on somebody’s health” (Joan, 29, doctor). Thus relational issues may become spiritual issues.

A hospice counsellor suggested “I see a lot where the patient accepts that they are dying better or more than the family”, which highlights a common sub-theme of family spiritual needs often being sublimated over the terminal phase.

**Spiritual stages/spiritual maturity**

A subtle sub-theme evident from some participants was spiritual maturity and its relationship to spiritual needs. This had a macro and micro element. At a macro level, a hospice chaplain noted, “it seemed to me that there was a big lack of something in people’s lives”, which was connected to a spiritual lack in society. A hospice nurse similarly said “it is spiritual care as a nation as well and we are all striving for finding some sense of meaning”. At a micro level, Fran, a woman with cancer, when talking about spiritual growth and her own journey dealing with feelings of anger, was asked if this was a universal process. She said “I guess it depends when you start from”, and then, “I think after the first diagnosis, I think everyone, no matter who they are or how spiritual they are, it’s fairly tough”. What is implied here is that everyone is in a different spiritual growth stage and therefore reacts differently when faced with a terminal diagnosis. A hospital counsellor suggested,

> people are refined by an illness like this, it is like making something out of a metal and putting it in the fire to finish it and people are – all my experience says, that a person becomes very refined self because so much falls away that just isn’t important any more and if they are inherently basically a person who is unhappy then they will become a refined version of being an unhappy person. If they inherently have the ability to be happy within themselves, then the fire of this illness process, makes them more than that (Sara, 55, hospital counsellor)

Sara also said “people die as they have lived”, which adds further weight to this idea of spiritual maturity and the importance in understanding patients’ (and family members’) needs in relation to it. A hospice nurse said almost the same thing, with an interesting addition, “people often die as they live... I can often tell when somebody comes in after a couple of days of getting to know the little bits about them how they will die. It is interesting, whether they are going to fight or be peaceful” (Karen, 52, hospice nurse). Mia, a hospice nurse, talked about people with “spiritual ease”, referring to those who had “done everything”, who “have died the best and I have nursed many that have died”. Signs of spiritual ease included having one’s funeral planned, things “tidied up”, and then “just quietly got on with dying”. Mia said this contrasted “somebody who hasn’t done any of that or doesn’t want to or has got a grudge of some sort, then they don’t die easily” (Mia, 71, hospice nurse).
Questions are raised here about spiritual care, spiritual pain and peace of mind at death. What is the value of ‘confronting’ one’s spiritual side when dying if it has never been considered before, particularly if it does not naturally arise?

Changes in Needs

I think you have to become stronger spiritually, definitely (Carol, 50, education, Ca)

Changes in spiritual beliefs have been commented on above. The other changes that are possible are regarding spiritual needs. Terminal cancer gradually pares down what one can do in life, so if one’s sense of meaning is based on something physical or mental that is taken away, an existential crisis may ensue. For example, Mike, a very ‘together’ man of 73 with cancer, broke down in tears when his driving licence was not renewed: “it is just something else that I have lost”, representing much more than the ability to drive.

Signs of changing spiritual needs may appear in dreams or as anxiety, as expressed by Luke,

A  What has changed?

B  A bit of animosity, a bit of unsureness, you know you sort of – I had a lot of bad dreams when I found out that I was going to die. ... You know this afterlife, I sort of had a premonition that I had an afterlife once before – I don’t know if it is a weird dream but I have had it too many times to accept it as just a weird dream if you know what I mean.

Paul, another man with cancer, implied the possibility of loss of self with physical changes, when he said “the word invalid can quickly change in to the word invalid because you are no longer able to take part in the world” (Paul, 58, building, Ca).

Hope

If you take somebody’s hope away then they have nothing left (Joan, 29, doctor)

Many participants named hope as a spiritual need and as a critical part of living with terminal cancer, as expressed confidently by Barbara: “I am not dying with cancer, I say I am living with cancer”. Often positivity was affirmed, with one person with cancer going as far as telling her children to ask all visitors to explicitly be positive in front of her. Hope of cure was only expressed by those in a hospital situation, which implied that even though their doctor had labelled them ‘terminal’, they had either not accepted or heard this prognosis.
Participants were asked what they found hope or comfort from. Answers ranged from focusing on the daily chores to prayer and medication, and particularly family and friends. Ramona said she has a “good cry” when down and this helps to then start her focusing on something positive, she also said “prayer plays a big part in my life”, so had a number of ‘tools’.

Hope was expressed as a either a legacy or belief in the afterlife. Expressed as a legacy, when asked about hope, Mike said “The fact that I have left behind two daughters and two sons and the various grandchildren and they are all good citizens” (Mike, 73, agriculture, Ca). Paul said his Christian beliefs gave him “a sense of hope that life doesn’t cease at the point of death” (Paul, 58, building, Ca).

Some participants expressed fatalism. For example, Adam said “I don’t have any specific hope or comfort. I just accept things as it is. There is nothing I can do about it, especially now, it is too late now to do anything about it.” (Adam, 68, electrical, Ca).

Oscar made the point about hope that it is important for the medical profession to remember to foster it,

the worst thing a doctor can do is to in anyway damage that hope and I think that’s what surgeons tend to do. .... If they can’t cure you, there is no cure whereas there are thousands of anecdotal examples of situations where that hasn’t occurred. ... hope is one thing I would never want to see taken away from anybody and I think that does happen far too often (Oscar, 50, education, Ca)

Staff members named hope within the spiritual needs conversation as one of the most important things to maintain for those dying. Comments included,

I think hope is a really big part of palliative care and I think there is nothing worse than saying to somebody there is nothing more that we can do and certainly that’s not what palliative care is about ... there is always something. I think keeping a little glimmer of hope even if you are kind of colluding with someone’s delusions about what might be happening is so important because if you take somebody’s hope away then they have nothing left (Joan, 29, doctor)

I spend a lot of time talking about hope because I think that without hope there is despair and there is always something to be hopeful for. ... Hope for another day, hope to see somebody come back from overseas, hope to not be in pain when you die, hope to be surrounded by your family. We must never take away hope (Cathy, 56, hospice counsellor)

I think hope is important really, and I think there is all sorts of hopes so that there mightn’t be much hope for a long and healthy life, but I think there is a lot of other hope for sorting relationships or rounding off sort of unfinished business or
In these quotes, hospice staff name a range of hopeful considerations, including “colluding with ... delusions”, seeing family members and dealing with a range of “unfinished business”.

**Identity**

‘Who am I?’ is a critical spiritual question related to the existential issues discussed above. A terminal cancer diagnosis may question one’s identity. Paul expressed an initial dissolution of self following his diagnosis. In his words, “I went through a cycle where I would drop right away to where I thought I am just useless, I am just – the self esteem is gone, I didn’t know who I was or what I represented, to a gradual re-growth to a position where I’m just – I feel okay about myself, you know” (Paul, 58, building, Ca). Alternatively Fran said, “I think I’m the same person but I’ve got rid of a lot of baggage”. Similarly when asked about his cancer affecting his identity Carl said, “Only to the extent that it has clarified it” (Carl, 62, education, Ca). Adam recognised his filial role had changed: “I am more of a husband now than I was, I think I am, I am a lot more grateful for what I have when I look around” (Adam, 68, electrical, Ca).

Grant understood that his role as a provider and ‘doer’ of things around the house and with cars had changed; his simple response had a sad undertone: “I was reasonably useful but I am afraid I am not now” (Grant, 72, mechanic, Ca). One’s identity with terminal cancer changes to some degree as one’s physical, psychological and social abilities fall away; this is problematic for some people. The examples below exemplify the ‘burden issue’, death’s immanent impact, sexual impotency and role reversal:

- *I often feel that I am asking a lot of people who look after me* (Deidre, 57, hospitality, Ca)
- *it affects your whole attitude towards your identity I think and I think* (Deidre, 57, hospitality, Ca)
- *What changes* (Deidre, 57, hospitality, Ca)
- *The mere fact that you are going to die* (Millie, 54, finance, Ca)
- *I think I have, I think I have gone forward as a husband even though I haven’t been able to do anything more as a husband in fact I have been able to do a lot less as a husband.* (Millie, 54, finance, Ca)
- *We swapped roles, we agreed to swap roles to make life easier didn’t we, I would work and he would cook and so we did that early on.* (Millie, 54, finance, Ca)
I have had to – all my sexuality taken away from me, that’s gone completely

B=(Adam, 68, electrical, Ca) C=(Adam’s wife)

Some staff working with dying patients also find their identity challenged: “I guess it makes you continually question who you are” (Joan, 29, doctor). A hospice nurse noted that people who work with the dying “have a fairly reasonable sense of who they are and why they want to do this”. Another hospice nurse said “being part of ‘hospice’ was a “journey of self discovery”. Identity, for many of those affected by cancer, was an important spiritual consideration.

Humour

Humour was a sub-theme that was revealed in the second or third listening of interviews. Particularly people with cancer, some staff, but not family members, showed a sort of black humour that seemed to help undermine the seriousness of the terminal context.

Congruency

An interesting, though not common observation by participants, was the need for congruency. Related to peace of mind, congruency is about living life as one would like to be living, rather than not meeting one’s own expectations. This is expressed in a Christian framework by Paul,

The word is congruency. I realized I wasn’t congruent with what God’s order for me was. I had slipped into a slight in-congruency of doing my own thing and bringing God in to the picture when it was convenient. I realized it should be the other way around, God should inform all our doings (Paul, 58, building, Ca)

Paul recognised this internal dissonance and that the time he had left was “a gift and we must use it as much as we can”.

Spiritual pain

Spiritual needs are expressed positively above, as strengths, with such issues as hope and identity. But each of these has a corollary or antithesis — those spiritual needs that are unfulfilled, or blocks to peace of mind. Again this is similar and related to existential and religious needs, but more finely examined. The blocks include religion, anger, fear, guilt, regret, worry, uncertainty, grief and despair.
Religious issues

Religious issues may cause spiritual pain. Ewan was deeply challenged by what might be called spiritual dissonance, as he said,

I find myself [with] a ladyfriend who is a Seventh Day Adventist and she wants me to share eternity with her and one of the first things that I strike is the 4th Commandment where you have to believe that God made heaven and earth, and not only did he make heaven and earth, he did it six thousand years ago (Ewan, 68, finance, Ca)

Ewan wanted to believe with his partner and see it as critical as her belief system implied both the possibility of everlasting life together but also everlasting damnation. The spiritual pain is caused by the dissonance between the Church’s position on creation and Ewan’s scientific understanding that the universe is much older, as he said “I find it extremely difficult to get past evolution”.

Ray, a palliative care medical specialist, said for those of faith an illness can create a crisis; some people ask “why is something bad happening to me?” or “Is it possible to be forgiven?”. Phillip, a hospice chaplain, highlighted the dangers of some “patients” or family with what he called “rah rah faith that says God can do this and their whole hanging out for a complete miraculous physical healing”. Phillip said, “sometimes it is egged on by their church and I have heard a pastor in here praying that kind of fervent prayer in a last minute sort of a situation. ... I actually think it robs people blind.” There is an obvious tension here between different spiritual positions. Another chaplain said how he was “appalled personally, at the number of people who think cancer is a punishment or at death they are going to face the big fellow and he is going to go smack smack”. Religious spirituality may be a significant burden.

Anger

Anger was not a common issue from any of the population groups, but for the one person with cancer who experienced it, anger was central to what he had to face as he was dying. In Luke’s words,

B  Anger is a bad one of mine.
A  Is it?
B  Yes, anger. .... I am very angry that I did this to myself. I don’t know why I am angry I did it to myself. I saw it kill my grandmother and my grandfather virtually, smoking. I am angry about a lot of things that I should have done
For Luke, at the time of the interview, anger was raw and not understood. What he did understand is that his anger stood in the way of his peace of mind. Forgiveness was what Luke was seeking and perhaps this anger was something blocking his capacity to forgive himself.

_Fear_

*A lot of them who know they are dying are frightened at the end of life* (hospice nurse)

Fear was a common experience felt by those with cancer, or as one participant said “Cancer is a pretty big frightener”. Barbara said simply, “I’m scared”, and Paul expresses lucidly “It terrifies me, the whole process. I remember when I was going to have this stem cell harvest and I just felt I was on the brink of an abyss. I felt I was about to fall in. I felt it was beyond my cope-ability” (Paul, 58, building, Ca).

Fear of death is central to the terminal experience. Barbara expressed this clearly, “one thing I dread is being on my own, I am not frightened to die, but I am frightened of dying, I don’t want to go through all this pain” (Barbara, 69, domestic, Ca). It seems part of the fear of terminal illness is the fear of dying, which ultimately happens alone “No matter how much your support system operates and I have got a good support system you do go through it alone” (Paul, 58, building, Ca).

Staff members were aware that fear of dying — regarding the act itself and the afterlife — were issues. A GP working in a hospice said “I think people are scared, they don’t know what happens, there is nobody in the family who can say don’t worry, I have cared for somebody else who was dying and this is normal”. A hospital counsellor affirmed this position: “There are two absolutes that remain in the process. One of them is the fear of pain, the function of pain, and the other is what is going to happen. And they are absolutes with every single patient”. This participant’s comment about “what is going to happen” was both about the process of death and life after death.

_Guilt and regret_

Guilt and regret were sub-themes that were not obvious at first, either doing or reading the interviews. However, after more analysis, it became clear that this was quite a common
experience. Luke expressed this position most strongly, saying “God I apologize for a lot of things I have done. I have never really hurt anybody, physically I never hurt anyone, mentally I have probably hurt a lot of people especially my own children” (Luke, 58, construction, Ca).

Family members experience guilt and regret. Campbell said “my only regret is you know you have all these plans and things that you would like to do in life, and milestones, that probably won’t happen the way I originally dreamed it would”. Another family member, this time a son-in-law who was the main care giver of his mother-in-law, said when asked about what he gained from the experience “I lose really, in many ways, because it steals my time, that time could be spent doing other things, but I do get something out of it because spiritually I get something out of it helping others”.

Staff member Ray said, “holding resentment is a spiritual block. Grief is a spiritual block. Not understanding why my child had to die, and carrying that with them, that’s a spiritual block” (Ray, 49, doctor). The spiritual carers/chaplains were very aware that guilt was a common issue at the end of life, noting some people came with a “guilt burden” that needed “absolution and forgiveness” or just to “get it off their chest”.

Worry

A lot of people worry about their family, their spouse, and spend a lot more time worrying about them than they do about themselves. That’s quite common (Ray, PC doctor)

Worry, anxiety, unease, being troubled and apprehension are all emotions, or spiritual distress markers, that were commonly expressed by those affected by cancer. Those with cancer often talked about worrying about their family, both as they went through the ‘hell’ of living with a person with cancer, but also the worry of how they would cope after their death, as a staff member summarises: “ultimately most people are worried about others”.

Grant said worry was enough to “kill you” and then he said,

B You go from why me, suicidal,

A Have you experienced that feeling.

B Yeah, I wound up in the wardrobe, [crying] this treatment, I have had enough of this, stopped up short, you are going to cause more bloody problems then it should do. An easy out for me, don’t do it, you know it is
Grant recognised his wife bore the “brunt of it”, while at the same time telling this harrowing story of near suicide. The “worry” is shown as more than emotion, rather part of an existential/spiritual crisis. The suicidal tendency was not uncommon as Luke expressed it,

Oh hell, I would never have made it, I would have put the barrel in my mouth long ago mate. If they had told me two weeks, I would have gone back home, go down the pisser, got into the piss, go home, I notice the key to my cabinet is missing....

... She has gone through hell with this. She has gone through worse than fucking I have got. I have got the disease and she is going through all the hell, you know (Luke, 58, construction, Ca)

Luke implies he would have killed himself without the help of his partner, who had taken the gun cabinet key. Also expressed poignantly, albeit colloquially, is Luke’s partner’s process.

Saying goodbye was expressed vividly by Fran as “the hardest bit, is actually just saying good-bye so that - made myself write them [letter to each of her family]. It’s the hardest thing I’ve ever done in my life” (Fran, 62, education, Ca). Farewells are understandably a major worry and arguably part of relational spiritual pain.

Living with cancer may happen over years, 13 years in one participant’s case. The constant anxiety, while simultaneously living one’s life, was an issue. While unrelated filially, Oscar (50, education, Ca) and Paula (37, social services, FM), expressed the same need to compartmentalize. That is, to deal with the stress of the cancer in their lives, it had to be “forced into compartments”, otherwise it would overwhelm them. Many people with cancer also felt the weight of “being a burden”, as one man said, “that’s one thing I don’t want to be”.

Oscar was aware of the burden he inevitably was for his wife: “the partner has to deal with most of the bad things as well if not physically, just mentally.... They are not getting any of the ups, .... like I do within those three or four days when you are well again. I look at ...... [wife] and I think her faith has suffered a bit” (Oscar, 50, education, Ca). This story suggests the worry and anxiety that comes with cancer may be a challenge to one’s spirituality and faith.
As Oscar and many other participants note, family members end up “sort of living off the sides” or constantly living with death being ever-present. One family member honestly said “I would look upon his passing as a blessing really, for him”. This was clearly not just ‘for him’, for this wife had gone through a long period of her own pain and suffering as the caregiver, sole earner and ‘man about the house’.

Family members experience pain from watching their loved ones in pain, as Campbell said of his wife, “The only thing I have trouble dealing with is the fact that I get upset when she is in pain and I get upset when she gets upset about the way she feels and the prognosis”.

Uncertainty

You have to come to terms with is the uncertainty, every day, every month...
(Fran, 62, education, Ca)

Uncertainty is a defining element in ‘cancer world’. As a staff member commented, “it is often that uncertainty, that uncertainty well what is tomorrow going to bring” that brings pain and anxiety — for some a spiritual challenge. Uncertainty about life after death was widespread. “What is going to happen to me when I die”, suggested Cathy, a hospice counsellor who had previously experienced cancer herself, was one of the most common spiritual issues. Cathy went on to say,

people with a strong faith there are no problems. They just know they are going to heaven or wherever they are going and that’s fine and in fact I think they have an easier time of it ... It is the people that haven’t had any belief at all and maybe not hooked in to their spiritual side to see the beauty in the world, who suddenly say oh my gosh, is that it and there can be a real crisis at that point which of course manifests in higher pain levels and all of the stuff why I get a referral in the first place.

Cathy suggests those with faith, a sense of certainty, believe they will be ok after death. It is, she suggests, “people that haven’t had any belief” who are more likely to have a spiritual crisis. Cathy expands on her crisis scenario, relating it to meaning,

people that can make meaning of their lives as they go along have an acceptance, a better acceptance of when the end is near than people who hibernate and haven’t really thought about it, who think I will always live until I am whatever, and kind of take life for granted and I think they have a – suddenly they are told they are dying and they have a huge crisis.

Cathy argues above that like those without faith or a belief in the afterlife, those who have not considered the meaning in their lives face a possible crisis with impending death. This position was similarly stated by Ray, a palliative care doctor, who said,
You see that sometimes in someone who has coasted and maybe someone who hasn’t had too many crises in their life, they come to the crisis of mortality and all their assumptions get challenged and you see a restlessness and a depression sometimes and symptoms get out of whack and stuff and I think that is an existential suffering. What they thought they were secure in, doesn’t seem so solid now.

Ray named this pain “existential suffering” as a critical area in spiritual care. Related to uncertainty, Mia, a hospice nurse, raised the issue of spiritual pain that manifests physically: “in your heart you know that it is because they are not at ease spiritually because there is something else going on”.

Grief and despair

Staff members suggested common spiritual issues were often related to grief and despair, for instance,

a lot of grief and despair about people leaving their children

lot of grief about leaving their partner, so it is about leaving... it is about leaving. will they be all right, so it is like sometimes it is about unresolved stuff, they haven’t seen someone or problems within their families

These issues of “unresolved stuff”, “leaving”, and ‘family problems not dealt with’, all relate to the broader theme of lack of peace of mind, or, more generally, aspects of spiritual pain. An experienced hospice nurse simply said common spiritual issues were “things undone”. This implies that ‘doing things up’ is what is needed to resolve spiritual issues — to do spiritual care, is it to help people ‘do things up’? Phillip named many of the spiritual issues that if unresolved cause pain, “a deep guilt. Fear, yeah, fear I think of various colours. Anger, residual anger and guilt, borne guilt that has never been well managed or dealt with within the person’s life. Piled or stacked up grief” (Phillip, 60, chaplain). Spiritual care has the possibility of helping those with this spiritual pain, which as one women with cancer said ‘is often much more painful than the physical stuff’, thus a priority for all in the process of a good death.

4.3.5.2 Spiritual Care

You can’t do effective palliative care without going to the spiritual realm. ...

Spirituality is not something that you can tuck in, it is learning to be comfortable with the uncomfortable (Ray, PC doctor)
It is just one of those things that you need to keep at the forefront of your mind and keep thinking about and be proactive about it, not trying to ignore it (Joan, 29, doctor).

The sub-themes under the ‘spiritual care’ meta-theme included: provision of care (who does it?, wants it? and roles), the processes of spiritual care (how is it done, assessment, interventions, tools and resources, place, space, timing), training and policy issues. Overall the vast majority of people who experience cancer are not aware of spiritual care, either being offered or received. This is despite almost all hospices and hospitals in New Zealand having spiritual carers/chaplains. This finding must be qualified by the fact that most of the people with cancer interviewed were not in-patients, however they were all terminal and connected with the hospice (n=21) or oncology out-patient department (n=3).

4.3.5.2.1 Provision of Spiritual Care

Who does it?

I am not the only spiritual care provider around here (hospice chaplain)

The question of ‘who provides spiritual care?’ is critical to understand so as to answer a number of the research questions, including ‘how are spiritual needs being met?’ and ‘what are the unmet needs?’

Staff

Traditionally the chaplain/spiritual carer is the primary provider of spiritual care, however based on these interviews, generally a multi or cross disciplinary approach was either experienced or recommended by staff and chaplains/spiritual carers. Staff members did vary in their understandings of what spiritual care was and their role in it. At one end of the spectrum was a counsellor who understood her role “to look at whatever their [patients] psychosocial/spiritual needs are”. While at the other end, a hospice nurse thought that “spiritual was the wrong word” and people had dealt with these issues before they arrived at hospice (there was one chaplain who also believed this position). By and large hospice staff named spiritual care as important and part of all of their roles, for instance a palliative care specialist said,

that’s I think what drew me to palliative care really. I was able to not deal just with the physical things. ... it lets you deal with the whole person, and lets you blend the knowledge, the scientific knowledge with an awareness of spiritual realities and that emotional and social stuff.
Staff had varying things to say about who does or ought to do spiritual care, reflecting a lack of consistent understanding about ‘who does what’ regarding spiritual care. Staff issues included demarcation issues, spiritual care provided from all staff including volunteers, and the importance of General Practitioners. For instance a hospice counsellor said,

\[I \text{ think you will find a lot of the doctors and a lot of the nurses would see that that is our role. They don’t see it as their role and they might say to you if I had more time I would like to explore that but I don’t have time, I am busy with my tasks and so by default, those conversations would come to us in our team.}\]

This comment challenges the notion of the multi-disciplinary spiritual care approach. This alternative position was expressed by a hospital chaplain who believed that other healthcare professionals expected her to “cover the spiritual side” and there was no “overlapping” of this role.

Alternatively, and at a different hospice, a nurse said,

\[we \text{ are very in to ‘ multidisciplinary’ and that is good, yeah, even the volunteers for instance, who run the day group. People who come to the day group once a week get a lot of spiritual ease without realizing it because the volunteers are there and they are loving them and they are caring for them and it is one to one and they have a nice meal and a glass of wine and somebody remembers their birthday.}\]

The multi-disciplinary approach to spiritual care is expressed very broadly in this comment and highlights the importance of the ‘small domestic things’ that can have or give meaning to one’s life.

A hospice chaplain, commenting about multi-disciplinary approaches, said “if the nurse feels confident enough to handle that, they will be the primary spiritual care giver and I will support them in the way of guidance or whatever resource. That doesn’t happen that often because a lot of the nurses will often default back to the spiritual carer”. While multi-disciplinary approaches are suggested in the theory as the best approach, there was some indication from staff that the chaplain/spiritual carer was the default spiritual care provider.

Commenting on her role in spiritual care, another hospice staff member suggested, “I am there as a signpost” (hospice nurse). This was an interesting image that suggested staff could create opportunities and give permission to people to explore, talk about it if needed, and be aware of spiritual issues, ideas and tools.
A GP who worked in a hospice notes the importance of connecting hospice and General Practitioners: “I think the GP is absolutely essential to a person’s care and a lot of people have been with their GP a long time and they trust them and have a good relationship with them and we really encourage GPs to come in here and see their patients and get involved”. The unasked question here was what role do GPs play in spiritual care? The important part in this context would be the “good relationship” which has been suggested by other participants as the basis for spiritual care.

Who does spiritual care is partly predicated by how one understands spirituality. This is expressed by a hospice chaplain who said “If you have the sense of spirituality is not compartmentalised but it is there in all of our lives and in everything we do here, then, implicitly, at some level, every engagement we have with a family or a patient has a spiritual dimension to it”. This is not a position held by all those associated with hospice and certainly not held by the hospital chaplain interviewed.

Chaplains/spiritual carers

I even have had a patient who considered me that bridge between death and life (hospice chaplain)

Chaplain/spiritual carers do spiritual care — that is their role, their job description. The eight chaplains/spiritual carers interviewed were asked about their role. All of these participants were either ordained ministers or religious sisters. Most of these participants started this answer referring to meeting the religious needs of patients and family members, in some cases directly or alternatively by putting them in touch with other ministers of religion. However this was not always the case, and all of them went on to say their role was to attend to the broader spiritual needs of all those associated with the hospice. In the case of the hospital, capacity was a major issue and this chaplain received a list of those who had ticked the religion box on the initial assessment form. They were prioritized according to denomination — the Catholics seen by the priest, others by the chaplain in the first instance. By and large, due to capacity restrictions, it was only these ‘religious’ people who were seen in the hospital setting.

Generic role comments included one chaplain calling himself “a translator”,

I see myself often as a translator because people are fishing around for the language to express this impulse, this burning or this passion even in some cases with some atheist people particularly. Some way of identifying what these things that have been buzzing around for years sometimes and have never been named.
Arguably, this translation is a critical role. Both here and from another participant there was an indication that spiritual literacy was generally low, therefore helping put words to feelings and thoughts was found to be useful.

As noted above, some chaplains/spiritual carers understood part of their role was to keep an awareness of spirituality/spiritual care. One chaplain said his role was about “recognizing, respecting, making space for, [and] facilitating spirituality” in the hospice. Phillip, a hospice chaplain, said his role had three facets: firstly to “discover” and then if desired, with a patient’s “faith community or religious connection”; secondly to attend to the needs of the people with “NRS (no religion stated)”; and thirdly the “education of myself, staff, and community”. Most of Phillip’s work, he said, was “one off one work with the NRSs”. This job description is reasonably indicative of all the chaplains interviewed, though each used different language. Phillip’s third role of education is related to encouraging the multidisciplinary approaches to spiritual care, which almost all chaplains/spiritual carers affirmed. Interestingly, one chaplain who came recently from a parish said he “had to ‘wrestle’ with the idea that others do spiritual care”, in that letting go of some of that work was not at first easy. There are demarcation and democratization issues implied.

Participants with cancer and family members

The few participants with cancer who were aware they had spiritual care often said their family members and friends provided it, usually in the form of prayer or support generally. Carl commented on the support he had received,

B I couldn’t ask for or expect anything like the wealth of generosity that has been forthcoming in terms of people trying their best to put me at ease ..., I couldn’t ask for more in terms of spiritual care.

A Via relationships?

B Yes that’s where it has come from and that’s what it amounts to. ...

A Have you been aware of any explicit spiritual care at the hospice?

B No, I find that there is there, a very genuine care, a concern for my welfare but all of them, every person I have met there has a line drawn, an imaginary line drawn that says I am not going to become attached to you (Carl, 62, education, Ca)

Carl’s comments show an awareness of spiritual support from friends and family, but note a lack of explicit spiritual support from the hospice.
Two people affected by cancer were aware of spiritual care from their hospice. John was aware of spiritual care in the form of religious discussions with staff: “I have noticed a great many of the people in the cancer field have in fact strong religious beliefs - the doctors and the nurses” (John, 68, electrician, Ca). The hospice John was in had a particularly large number (over 50%) of active practicing Christians. In another hospice, a family member’s comment about palliative care doctors humorously indicates holistic care, “you wouldn’t even need to have to go to med school to become a palliative care physician because of the fact that we have worked out what they do. When you go in for a consultation, the first thing they say is ‘how have you been’ you know, ‘how are you feeling’ (laughs)”. Apart from John, family member participants were not aware of any spiritual care from hospice or hospital services. This is an obvious gap.

4.3.5.2 Processes of Spiritual Care

If you have the sense of spirituality is not compartmentalised but it is there in all of our lives and in everything we do here, then, implicitly, at some level, every engagement we have with a family or a patient has a spiritual dimension to it (hospice chaplain)

This section reports results about the spiritual care process. The sub-themes include generally and specifically how spiritual care was provided or experienced; interventions (including tools and resources); time and timing issues; place and space issues; and staff spiritual care.

How is it done?

This section comments on participants’ experience and knowledge of how spiritual care was either experienced or provided. Many participants from all groups said it “is a fairly individual thing”, but then went on to make generalization based on their experience.

People with cancer and family members

This group largely were not aware of receiving spiritual care, with some expectations. However, participants were asked about what they thought an ideal spiritual care approach would be. People with cancer suggested the following: help with getting one’s affairs in order, being heard, relationship issues, and support from others who had experienced cancer. For example, four participants said,

people of course react differently but I suppose sympathy and support and talk, certainly not skirt around it ... one of the obvious things ... is getting your affairs
in order and if... someone can help with that... that would be a great support to them (Henry, 76, finance, Ca).

if I met somebody now who said look I have just seen my doctor and he has only given me three months to live, well the first thing I would say is, have you got any members of your family who you are not at ease with at the moment, the first thing see is I would put that right...and for the sake of those you are leaving behind make sure that all your things are in order (Mike, 73, agriculture, Ca)

I think support groups are incredibly important and I wish more people would realise it (Fran, 62, education, Ca)

it’s almost as if you have to have gone through something yourself in order to sit beside the person and say, I know what you are going through and I have got no answers either in terms of relieving the terrors (Paul, 58, building, Ca)

You need somebody who has had the disease and has a very positive attitude and someone who knows something about the situation (Oscar, 50, education, Ca)

These voices are important and highlight many issues; the priority of getting relationships “right”, the relevance of support from those who have experienced cancer, and the ubiquitous support and help with “getting affairs in order”.

Staff

Staff were asked about how they do spiritual care and what an ideal spiritual care plan would be. Most staff were quite explicit about their spiritual care.

A hospice nurse said spiritual care was important, but thought it happened at a subtle level,

I think some nurses wouldn’t call it spiritual care but I think it is what they give really and so I think it goes mainly unnoticed or unacknowledged and I think that is maybe quite appropriate as well, it is just part of who that person is with that patient or with that family really.

This subtle approach to spiritual care was reiterated by others, particularly the chaplains and a doctor who said “I think the rest of it is probably all done quite subtly just by observing people, picking up on things they have said in conversation”.

Another general comment about spiritual care situated it within a human-to-human relationship—“for me it is to do with meeting with the other person at some level”—which is reminiscent of the wounded healer approach.
Chaplains/spiritual carers

All eight chaplains were asked about how they did spiritual care — what was the process? General comments are reported in this section, with more specific formal assessment approaches below. An indicative comment was “A significant part of the ‘work of dying’ is dealing with spiritual issues”.

How is it done? Specifically: Spiritual Assessment

There isn’t a specific care plan for spirituality (hospice nurse).

Spiritual assessment was done and experienced by a number of participants.

Patient and Family Spiritual Assessment Experience

While not many participants with cancer had experienced spiritual care consciously, those who had referred to the chaplain. Almost all these experiences were helpful. For example Ramona said,

When I was in the hospice [the chaplain] used to visit every day and we used to talk about how things were and that was kind of different for me because normally in Auckland hospital, when I was in Auckland hospital, I didn’t see one priest when I was in there (Ramona, 32, finance, Ca).

Interestingly, Ramona was a very religious person and the same chaplain she was seeing noted that it was much easier to see and talk with people of faith, as there was a common language and shared beliefs.

Paul suggested spiritual care involved listening and touch: “listening is what I believe is what you need to do” and “I think touch is a very important thing” (Paul, 58, building, Ca). Fran believed more spiritual care was warranted: “I think there could be much more proactive [spiritual care] - and maybe from the clinicians a bit more about - in terms of asking how people really are” (Fran, 62, education, Ca).

Staff

Each staff member was asked about specific spiritual assessment. Some did not include the spiritual dimension in assessment, as one hospice nurse said, “It is not really addressed in the assessment unless they come up with it themselves”. When asked about her hospice spiritual care processes another nurse said “I don’t know much about it”. After some prompting, this latter person did fill out the ‘beliefs’ section on the initial assessment form. Another staff
member ironically said a spiritual care plan “would be a good idea”. Most were much more constructive and often made the point that “obviously there are the chaplains” and those “who come in from different faiths”.

Cathy, a hospice counsellor, had a four-fold or “four task” approach:

- There is having to accept all the symptoms and things that happen to you physically in your body. There is having to face the loss of living in this life and the transition of where do you go and what do you go to. There is the farewells and that sense of having to put everything in place to say your...[unfinished sentence]. And the fourth one is to make meaning of the life that you have lived.

Cathy had learnt this approach, but adapted it for her own practice. Cathy felt that spiritual care was mandated and explicitly part of her work with the dying. She expressed some frustration at the lack of explicitly spiritual care provided by the chaplain in her hospice. This was not an isolated position if this comment from a person with cancer is understood as similar: “the chaplains come around and they are wonderful and we talk about everything else about how I am feeling and this, that and the other, but nothing sort of, you know, spiritual health or anything”.

Joan, a GP working in a hospice, said spiritual care assessment should happen,

*the same way as any other sort of assessment, you know, you would need to sit and talk with the patient and family...* Having said that I think it is very difficult to do that in a structured way because it is not a structured thing and I think a lot of people might start running for the hills if you ask them you know.

This was qualified when Joan said a “multidisciplinary approach” and “just time to talk” is important and “I think it is very important to document significant conversations with people”. A hospice counsellor recommended a formal assessment with a range of questions that might include,

*What are people’s goals for themselves? What are they hoping to achieve. That would be under a spiritual assessment. What support do they have? What support do they wish to have if they don’t?*

Another doctor, a palliative care specialist, said,

*Like any other care plan, it is something that is done in association with the patient and family... involves trained staff...ongoing assessment...progressive expansion of their story...and people don’t open up to everyone and it is finding the right fit...where does that person get their support from and how can we help strengthen that support?... do they need to provide space?*
This suggests spiritual care assessment includes adequate consultation, staff capacity, assessment along the journey, meeting people’s needs with the right person, and providing appropriate space. This point about the “right fit” was also made by a hospice nurse: “it would depend on who the person was because some people prefer a woman, and some men prefer a man”.

Less formally, a hospice nurse suggested spiritual assessment was about “listening to a person’s feelings and their beliefs”. This was reiterated by another hospice nurse: “if I was a patient I would quite like to have opportunity to talk about what I believed in from here on in”, but she admitted that “it would be good to have it more formalized really, to remove it a bit from religion”. A third hospice nurse affirmed this position,

*For me, having the assessment there, you may as well throw it in the rubbish bin. For me it is like telling a story, you tell me your story, and within that story you will often glean where they are at spiritually anyway and sometimes if I don’t get anything I will just maybe target a few questions here and there...*

*I will talk about some of the factual things, like do you have a faith community, do you belong to any sort of structural religion or whatever in the past and often that will lead in to a conversation about where they are at.*

This raises the issue of how formal, informal, intuitive, and/or structured spiritual care should be.

In terms of literally writing up notes on spiritual care, most staff did not have a separate section or area in patient notes. There were a few exceptions, for example a hospice nurse said of the chaplain’s notes,

*there is a little box on our computer for the spiritual input and he will always write up and he will do his bit and so it is really good, it is on the computer and so the next day, I will go and I will think I wonder how [[chaplain] got on there and I will see it and he writes beautifully too, it is just, sums up the meeting in a few sentences.*

In another hospice a staff member said “there is a section called spiritual/emotional and you tick or circle yes or no and you might sort of elaborate on that”. In hospitals, generally all that would happen would be a single question about religious affiliation. This raises important issues of how spiritual care assessment outcomes are communicated over time and among a multi-disciplinary team. Other staff said that such things are discussed in the “multi-D team meeting”.

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Chaplains

Chaplains/spiritual carers gave some specific approaches to how they attended to people's spiritual needs (this connects to the role/job description above) and there were a range of ways it happens. Firstly, it depended on if and how the 'client' was referred. If a person or family members affected by cancer, or a staff member, was referred or asked to be seen, then there was an expectation and permission to move early on into spiritual issues. My impression from interviewing both chaplains/spiritual caregivers and other participant groups is that it was usually those with a current or past religious background that fitted into the group who wanted to see the chaplain/spiritual carer. Then there were those that were dropped in on—in most hospices the chaplain/spiritual carer had the 'run of the place'—thus unless here was a specific request not to do so, all in-patients could have a casual visit. Out-patients, who make up the majority of people affected by cancer, were visited mostly by referral (and spiritual care, if done by hospice staff, would likely come from community nursing staff). Regarding the 'drop-in' approach, it seemed that, in this case, spirituality or religion were often not mentioned until some relationship could be established.

There was some suggestion of a hierarchy of needs that were addressed. That is, religious needs were first considered and attended to by the chaplain/spiritual carer or referred onto another minister of religion.

The final 'need' addressed, and one that was on chaplain's agendas, but often not attended to, was staff spiritual care and education. Some chaplains/spiritual carers spent quite some time with staff and one or two did annual spiritual care seminars, but most did not.

Other specific approaches included different ways the people affected by cancer found out about spiritual care. This is a major issue as it can make the difference between receiving care or not. For instance, a chaplain said "they identify whether the individual has a faith or whether they have any spiritual needs, so that is the first thing, then they get a package that indicates that spiritual care is available".

A patient's story was named by a number of chaplains/spiritual carers as being the way to hear (assess) and care for the spiritual side. As one chaplain said, "The process would be—well first the story. I am always would be getting in to the narrative long before the other stuff". Many hospices now provide a biography service, which a hospice counsellor said was "one of the most meaningful things we do". The biography process is a reflective exercise.
looking back at one’s life. It is usually facilitated by trained staff or volunteers, written up and given to the patient and then their family as a legacy.

**Interventions**

After affirming the need for spiritual care, suggesting who does it, then making some general and specific comments about how it is done, for example regarding spiritual assessment, a range of interventions were suggested by participants. These are the tools and resources used in the spiritual care process.

A number of staff “cleanse” rooms after someone has died, and others named massage, teaching mediation and breathing techniques, and the use of “rescue remedy” [a homeopathic remedy to induce calmness] as spiritual interventions. A hospice nurse said “Probably talking mostly”, or from a palliative care specialist “time and attention”, affirming the ‘listening’ section above. Summing up, the same doctor said “Validation [of the person] is one of the strongest things that I can do with a person”.

As noted above, a hospice counsellor said that they had a ‘biography’ service which helped in the process of, “reflecting on your life and making meaning of your life, putting it in to a story form”, this she said was part of the “work of dying”.

**Chaplains**

*One of the things is, I pray hard* (hospice chaplain)

The chaplain’s tools include the traditional resources of the faith community such as the sacraments, rituals (including remembrance services), prayer and scripture. Then there are a wider range of spiritual tools including listening, making space and intuition.

For instance, regarding listening, a hospice chaplain said “the important thing about being there for people’s spiritual needs is to listen, not to tell them what they ought to be doing …Listening is the most important thing”.

The metaphorical and literal concept of space was mentioned by a number of chaplains, as exemplified here: “The important thing to me is recognizing the spiritual dimension as it is experienced, being respectful of it, making some space available where that can … about being in a space in the sense of permission. … So it is recognizing, respecting, making space
for, facilitating”. Literal space was discussed in terms of the spiritual centre of the hospice, which in most cases was the chapel or quiet room. These varied in quality, based on size, the way they were fitted out and ambience: at one end of the spectrum there was no space or an empty ‘patients room’ available, while other places had purpose-built spaces with views, space, shape and ambience consciously considered. Other space issues were for spiritual practices like prayer, yoga, meditation, rituals and the sacraments.

A ‘tool’ noted by more than one chaplain was intuition: “What does your gut say about what this person needs to talk about? What are you seeing in the person’s eyes? Are you seeing peace, or are you seeing uncertainty or anxiety, pain?” While less empirically verifiable, there was a strong sense from some chaplains/spiritual carers that this intuitive care was important.

Staff and chaplains/spiritual carers were asked about spiritual care resources. Understandably, people, the staff themselves, were named as a key resource, and then a range of answers including:

- books and some tapes
- art therapy and our music therapy.... ... aromatherapy
- rituals. ... Lighting of candles. When somebody dies, we put a butterfly on the door ... a bowl of floating flowers and candles that go in to the room and the family are encouraged to write messages of remembrance which are kept.
- We encourage [family] to do things with the body, to wash the body or to massage.
- We have a weekly candle lighting service where patients and families of the bereaved can come to... a chat.

These ‘resources’ or variations there of, were common across many hospices, but not mentioned in any of the hospital interviews.

**Time and Timing**

Time and timing were issues raised by many participants across the population groups. Some of those with cancer recognised that there were or would be more critical times in their cancer journey when spiritual issues would be dominant: “I think that the spirituality is important very early on and then if it comes up later” (Oscar, 50, education, Ca). Family members were
less capable of speaking well about this, but staff and chaplains/spiritual carers had a lot to say on the matter.

The tool (or “gift”) of time and ‘being with’ was mentioned regularly by chaplains/spiritual carers. For instance, one hospice chaplain said “just sitting beside them and holding their hand, you don’t even have to be talking - it gives them comfort” and another: “they have just asked for me to come and sit beside them and hold their hand as they die”. A GP working in a hospice noted this time issue by saying,

> we are fortunate in the hospice setting that we have more time to be able to assess things and find out about people and get to know them so there is not the urgency to do things right away unless people are in a lot of pain and they are dying and it is appropriate but a lot of people, they just need a bit of time and a bit of unravelling of what the problem is.

An important consideration for staff is “When is spiritual care appropriate?”. For, in the worst case scenario, potential harm could be done or a person could be put off by a spiritual carer, thereby closing the door to future care. A hospice nurse noted “very rarely would it come in at that first initial [meeting], because they have had a diagnosis and they are private people and then suddenly everybody, every man and his dog is coming in to their home”. Implied here is that part of the spiritual assessment is assessing the appropriate time to engage in these issues.

Related is the notion expressed by a few staff that spiritual assessment and care are not ‘one-offs’, but as a hospice nurse said, “because spiritual issues are totally evolving and changing and growing and messy”, they need regular attention.

Time is always an issues for health professionals, including chaplains/spiritual cares, thus they need to have some way of prioritizing people. Two chaplains made comments on their process to do this,

> I relied pretty heavily on the nurses and doctors to identify those who had spiritual pain so I could prioritize my rounds and my visits, so those with spiritual pain were always addressed first (hospice chaplain)

> The order would be those in spiritual pain. Those that had faith needs. Those that had sacramental needs, and then you have - like they wanted absolution, extreme unction, confession, ... , you arrange for the faith leaders of the other communities to come in ... . And then the last group would be those that just enjoy your presence ... the comfort, just sitting beside them and holding their hand, you don’t even have to be talking (hospice chaplain)
This later quote highlights the need to focus first on any person with spiritual pain, not prioritizing religious needs first, as was implied by another chaplain above.

### 4.3.5.2.3 Spiritual Care Training

We don’t have a lot of learnings around the spiritual aspect of care (hospice nurse)

If anything is going to improve spiritual care, [it] is people being able to pursue their own spiritual journeys (palliative care medical specialist)

The importance of having trained spiritual carers was made by a number of staff. If a multi-or inter-disciplinary approach is accepted as best practice, then this implies all staff need some level of training. In their interviews, staff and chaplains/spiritual carers were asked about professional development in spiritual care. Generally most staff had not had any, though there were some exceptions. Most staff thought it would be a good idea. Chaplains/spiritual carers saw spiritual care education as part of their role, but capacity seldom allowed for this to happen. As one chaplain said, “I haven’t seen any particular need to give any training”. The need for spiritual care training might be summed up in this hospice chaplain’s words: “Often I will come in and think ‘my God, this could have been picked up much earlier to the profit of the person’”.  

Staff who had formal spiritual care training had done it through their own post-graduate training or had attended in-service seminars. At a less formal or structured level, one staff member thought that her supervision and “learning from my colleagues” was a form of spiritual care training.

Regarding the need for spiritual care training, Ida, a hospice nurse, was quite vociferous in her comments. Ida argued that the “spiritual aspect” was central to palliative care – “right on in there”, yet there was a significant lack of training in this area. “Core skill days” were regularly and mandatorily attended by hospice staff, Ida said, but she went on to say that even though our “core skills” are equally about spiritual issues, spiritual training is not mandatory and seldom available. Ida argues that it ought to be mandatory and annual, and this would be particularly important for those who would not otherwise attend when such training was offered. In Ida’s words, “I would like to see something that is actually quite structured and part of the culture of the place, because otherwise people won’t go, they will say oh that’s airy fairy, I don’t need that. … It [structured spiritual care training] actually gives it credibility”.  

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An important point noted by many staff is the care and consideration that would need to go into the planning, content and process of spiritual care training. It was implied that it can neither be ‘rote learnt’ nor done in a ‘one-off session’. As a hospice nurse said, “it is not something that you can just all of a sudden, yep, I have done spirituality, I have got it”. It was suggested by the same hospice nurse that “you can’t sort of teach it in a way, but you can actually make yourself aware of your own spirituality, what is going on for me” and “I think that awareness and mindfulness of who you are is really important because straight away people know”. A palliative care medical specialist said, “I think having a spiritual foundation is essential, like I am quite comfortable talking with people about what they believe because I am quite comfortable with what I believe”. These positions suggest that part of spiritual care training would need to focus on the spirituality of the carers.

As a foil to this position however, a hospice nurse was wary of training that exposed too much of herself; she did not like ‘grief and loss training’ because she was asked to talk about her own feelings and experiences, in her words: “as long as they don’t get in to us and our own spirituality...because I think it is private you know and especially with a group [who you are working with]”. Contrasting the idea of not exploring one’s spirituality in training, when asked how such training might be done, a hospice nurse said “By sitting and talking about it probably and tapping into everybody’s own spiritual sense and what is important to them”. Therefore spiritual care training would need to be tailored carefully and targeted appropriately. Highlighting the importance of safety, in the words of the nurse who was weary of such training, “I would have to feel extremely safe to do it, extremely safe to do it”.

A palliative care medical specialist was very positive about having spiritual education/professional development as part of core competencies/skills for staff. Another hospice staff member said “I think anything pedantic would be completely inappropriate” which was qualified by saying such training would “have to be very wide, very exploratory” due to the “wide range of beliefs” of both healthcare professionals and people affected by cancer.

The other qualification that came up a number of times regarding spiritual care training was expressed by a hospice staff member: “it would be good as long as they didn’t bring the religion in to it, I get really ratty, I get really anti-religion and that’s only because of the way it was pushed down my throat”. This classic anti-religious sentiment is not uncommon and would be need to be acknowledged and attended to in any training.
4.3.5.2.4 Spirituality Infrastructural Issues

Staff were asked about the effect of infrastructural issues on spirituality and spiritual care. Coming from a health promotion position, which I did not express, except to one hospice staff member who had been a health promoter, the inquiry was aimed at understanding how the institutions’ policies, practices, and ethos affected and affects the spiritual care of those touched by cancer. Not many participants answered this question with anything of moment, however the few that did were important. The issues that arose included funding, training, recruitment, multi-/inter-disciplinary issues, medicalization, lack of chaplain’s capacity (paid hours), questioning who is being missed, and hospital spiritual care incapacity.

Medicalization was raised by two staff members. When asked if funding was an issue, a hospice chaplain said “Funding, yeah, funding is an issue with everything but it is not ‘the’ issue. I think more it is over-medicalization of the care.” This position was similarly noted by a hospice nurse manager who said there was a danger of medicalizing spirituality in a context where “doctors are still at that top of the hierarchy in palliative care”. Further, this participant highlighted the importance of the language used in hospice, which reflected or otherwise hospice values: for example, palliative care versus palliative medicine, spirituality versus religion and multi- versus inter-disciplinarity. In the first example, the nurse manager suggested that what they did in the hospice was not palliative medicine and “he gets angry when ‘they’ talk about it as though that’s what ‘they’ do”. Regarding the multi- versus inter-disciplinary difference, he said the former was more demarcated and the ‘inter’ implied “everyone shares roles”. Other spiritual infrastructural issues noted by this nurse manager included the need for staff to be comfortable, confident and aware, therefore spiritual education was critical. Further, he said “you need a champion for spirituality”, so as to be able to advocate for spirituality issues at management, education and clinical levels. Lastly, this nurse manager implied by his own analysis that a settings-based analysis of the ideology named and operationalised was warranted — that is, holistic care or total care is mandated, but is that the reality?

Lack of capacity by those who could do spiritual care (staff and chaplain/spiritual carers) was named as an issue. In a hospice this was an issue when a chaplain was asked about attending to the spirituality of staff: he said in quite a cynical tone “To a certain extent, [but] not in 16 hours a week”. The capacity issue was more of an issue in the hospital setting. All three participant groups from the hospital said that there was not enough time for or focus on spirituality/spiritual care. The hospital chaplain said that staff “just haven’t got enough time
to spend and listen” to spiritual issues, and the hospital counsellor believed she only just attended to the most critical of distressed cases. An interesting comment from a doctor in a hospice in this context was “we are just seeing the tip of the iceberg”.

The ethos of an institution is arguably part of the macro spiritual well-being of a place. Thus comments about the ethos were relevant to this study. By and large, they were very positive, as exemplified by this hospice nurse: “there is a definite feeling of love and caring here” and a palliative care medical specialist’s comment “It is the individual spiritual life of the different individuals in the team that gives this place its spirit. And we will guard that”.

Considering spirituality at an infrastructural level has implications for recruitment policies and practice. As one senior hospice staff member said, “you hire on attitude and belief and you train for skill. It’s having the perception and those core values are paramount because they have to mesh with the team …. You have to have the whole team to get that holistic assessment”. Similarly, a hospice nurse said of interviewing new staff “one of the questions I always ask, I always say to them every patient we have, every patient we look after is dying, how do you feel about looking after somebody who is dying and how do you manage your thoughts on your own death?”. If the candidate had not had experience with death, “had never done it” and did not adequately answered “what they spiritually did for themselves”, then she would veto the application.

There is a direct relationship between infrastructural issues and spirituality/spiritual care at a macro and micro level. Most of the issues named above are influenced by management decisions and board policies. For example, if spiritual care training is seen as an option add-on by management, it will never have status among staff.

**Hospital Spiritual Care**

Throughout the results above are comments from those affected by cancer within a District Health Board oncology department. This context is quite different from the seven hospice sites. For instance, a hospital counsellor makes the point,

*The entire philosophy the hospital works on is cure and I was asked – one of the consultants I met in the corridor not very long after I arrived, and they were talking about budget issues in the hospital as you do and he was saying with all due respect Sara, if you ask any patient what they would rather have, would they rather have another linear accelerator or a Sara ..., he said, they are going to say I want to be cured every time. And I said of course, everybody would want to be*
cured, of course that’s what they want. I said when you can’t cure a patient, when did a good death stop being part of medical care and he looked at me in shock (Sara, 55, hospital counsellor)

Sara highlights an infrastructural ethos or philosophical issue that not only suggests her work is possibly a waste of money, but undermines any holistic approach within this context. Sara did say hospital nurses were very good at referring because “they can’t take the burden of that themselves”.

Joan, a GP who worked in a hospice, commented on the hospital situation,

*I haven’t worked in a hospital for a few years, but when I first started, it just seemed that everyone just turned their back and it wasn’t – particularly I think in certain wards like the surgical wards, the surgeons weren’t interested in caring for somebody that they couldn’t do anything for... I think people find it very hard to make that decision that it is okay for somebody to die* (Joan, 29, doctor).

Like Sara’s comments, Joan implies a blind spot in hospitals to end-of-life care, and hence spiritual care. This has significant implications for spiritual care in this context.

### 4.3.5.2.5 Staff Spiritual Care

*I am much more spiritual now* (hospice counsellor)

The hospice ethos aims to include staff in the total care approach. Thus staff were asked about their own spiritual care needs and how they were attended/nurtured. Some staff said that in their pre-service training, while they did not explicitly consider their spiritual side, the focus on self-care was important. The obvious need for staff was dealing with the constant death, coming to terms with others’ deaths and the inherently spiritual work of coming to terms with their own mortality. A hospice nurse said this was an issue early in her career,

*when I first started working here I sometimes found it difficult, if I had been involved with a patient and the family and they died on my day off it felt not rounded off for me so I used to just have a wee ritual privately and sprinkle a bit of water and say goodbye to them.*

Thus issues of how a hospice (hospitals are not even close to this discourse) attends to the spiritual needs of staff and how staff look after their own spiritual needs is worth making explicit. At an institutional level, as discussed above, spiritual care training goes some way towards this aim, but it was suggested by a staff member that something like a “spiritual de-briefing” is needed. Supervision and de-briefing does happen in most hospices, but as another staff member said “not enough – and not explicitly about spiritual issues”.
Spiritual self-care was considered important by many staff participants. A hospice nurse suggested “mostly we do our spiritual growth and nurturing outside the place except we talk about difficulties to each other”. Spiritual care methods named by staff included “being outdoors, walking, composting, you know, earth based”, “music”, “art”, “meditation”, and consulting “with an inner guide”. Others mentioned the spiritual support they received from family and friends. One hospice had an active Christian staff — over half the staff across the disciplines — and they had instituted a weekly prayer session which the chaplain said “has defined the tone in this place and the peace that does exist here”.

An interesting comment about the ethos affecting de-briefing was from a hospice nurse who said “I think we are used to being nice and I think we could be more, in some circumstances, much more up front”; implying there was room for collegial constructive criticism.

As noted above, most chaplain/spiritual carers understood the spiritual care of staff to be within their mandate, but many did not have the time to meet this. An exception was a hospice counsellor who said she worked with staff “Whenever staff need it. Some days I might have a good half of my day is on staff related stuff. It is quite a big percentage”. There is an underlying question here about who staff go to and why — is there a barrier (other than capacity) to staff seeking spiritual support from chaplains/spiritual carers? It is likely that these issues are quite personnel dependent also.

4.3.5.2.6 Ethical Issues in Spiritual Care

Ethical issues regarding spiritual care were raised by a number of participants, including those with cancer and staff. The issues included conflations of religion and spirituality, ‘care of the soul’, and the use of religious approaches (proselytising) and prayer.

A misunderstanding regarding spiritual care is that it is about proselytising. This is exemplified in Barbara’s comments below,

A Well has anybody talked to you about spiritual issues.

B No, not really, no.

A Would you have liked to have them talked to you.

B Yes I would but um, I find that people who talk, like not you, but people who talk like that want you to believe what they believe and I always say to people I will respect your beliefs if you respect mine (Barbara, 69, domestic, Ca)
Paul said, “There is a suspicion of religious officials, people who come in, in their uniforms and I’m here to help you get some sort of spirituality” (Paul, 58, building, Ca). These comments, with many others, suggest care needs to be taken to articulate clearly to those who may want, need, or be recipients of spiritual care. They need to know that their priorities lead the care, as this hospice nurse asserts: “the central thing is what they believe”, not someone else’s spiritual or religious agendas. A related ethical issue is how much of oneself, one’s own beliefs, one talks about to people in care. A position articulated by a hospice nurse was “I don’t think my beliefs are particularly important” and this nurse went on to affirm, as above, the centrality of a patient’s beliefs.

The worst case scenario was described by a hospice nurse,

B We have had one or two that happened here [proselytising], you know because they were some particular religion and they get a short shift.

A Have you noticed that with staff or with patients.

B Mostly volunteers.

A Volunteers- okay.

B When I say mostly, probably in my time here, there has probably only been three or four but certainly people mainly of some religious belief that they have to go out...

This nurse had worked in hospices for 17 years and she was the only staff member to tell such a story. Another religious issue is the use of prayer with people affected by cancer. There were no occasions that chaplains/spiritual carers said they prayed with people, unless requested. As a chaplain said, “I will only pray with people if they ask me to”, and she went on to say, “I will think of you with kind thoughts and that to me is the same thing, if I feel it is not appropriate to use the word prayer”.

Another more subtle ethical issue that underpins spiritual care is the ethics of opening up spiritual ‘wounds’. Positively, and by general hospice consensus, the reflective process is almost inevitable with terminal diagnosis, therefore spiritual questions and issues naturally arise. Negatively, and not always considered, is that particularly if over-zealously pursued, spiritual ‘care’ could raise questions, issues and old ‘wounds’ that are unable to be resolved and therefore cause ongoing pain until death (and difficulty for other staff trying to deal with this situation). There were two examples from participants who referred to this later issue.
Firstly, a person with cancer said, when asked about more discussion about spirituality, “I don’t think so, I think that brings on more depression”. The other comment was from a hospice counsellor who said that sometimes people are better left to die in ignorance of things, for opening up issues may not help. Examples of positive experiences from spiritual care and reflection on spirituality were widespread from staff and chaplains/spiritual carers.

4.3.5.2.7 Reactions to Interview

An unexpected sub-theme, related to the ‘positive experiences’ just mentioned, was the ‘reactions to the interview’. This is relevant to spiritual care because some respondents said or implied things that impacted on their spirituality or spiritual care. People with cancer expressed a range of positive comments about their interviews, which may be, indirectly and unintentionally, taken as comments about spiritual care. For instance, reflecting at the end of the interview, Carl said, “honestly Richard, I have always struggled with the meaning of the word and it has certainly helped me to clarify it by talking with you... the interview did help me to find out what I have been believing and thinking about for most of my adult life”. This sentiment of creating a space for reflection was expressed by others: “since this came up it has made me think a lot about it” and “it has been really good that I have been given the opportunity to think about it”. The other unintended affect appeared to be therapeutic, as these comments suggest: “I feel absolutely uplifted by that interview” and “Talking to you of these things is like being able to have talked to the people I needed to talk to ... and that’s what is lacking”. After an interview, one of the hospice staff members said she “feels a lot lighter after the interview”.

Lastly, a family member called me up some months after the interview with her husband. She said “he was really at peace with himself in the last two weeks, and he had really enjoyed the interview”.

4.3.5.2.7 Barriers to Spiritual Care

While some people do not want spiritual care, there are others who do not receive it for a variety of reasons, what may be called barriers to spiritual care. Examples include infrastructural barriers, family issues, staff capacity, time/space/place issues and religious baggage.
Staff capacity

Regarding staff capacity to provide spiritual care, staff awareness was named by an experienced hospice nurse as a barrier for patients and staff,

*we in general as a staff don’t recognize the spiritual needs of fellow colleague and our patients. I mean I often think that sometimes when things go radically wrong and I think gosh, where did that come from and so I don’t think we do handle spiritual needs as well as we could. I don’t know how to do it any different* (Mia, 71, hospice nurse)

A hospice chaplain affirmed this sentiment: “one of the barriers here, I think our frontline staff, the PCCs [palliative care coordinators] bar two, three of them – there needs to be more work in actually picking up what I would classify as signifiers that there are some issues here”.

Related to awareness is the ideological framework out of which staff work. When asked whether funding was a barrier to spiritual care, a hospice chaplain noted the over medicalization. Only one participant raised this issue so explicitly, however a number of staff noted that despite the rhetoric, the focus of hospice care was on the physical.

Time/place/space

Barriers to spiritual care may be related to time and space. A number of chaplains noted the lack of time to be there for all those who needed it. All chaplains were paid, with one exception. The paid hours varied between 8 and 32.

The other issue about time with patients, as a hospice chaplain said,

*You have got small time to decide whether you trust a person, can work with them, whether you are going to allow them in to the intimate and difficult places in your life and whether that is going to make a difference.*

The barrier to spiritual care here is the fact that people associated with hospice as ‘out’ or ‘in-patients’ have less than twelve months to live. The in-patients are likely to have much less. Thus a spiritual carer does not have long to develop a ‘trusting therapeutic relationship’. The researcher’s experience as an interviewer was that dying people were extremely candid and open when approached appropriately. The other barrier named in the quote above is related to diagnosing the spiritual pain. This is a multi-disciplinary issue, as the spiritual carer cannot be everywhere, while a nurse or doctor will also have been working with that person in spiritual distress.
Religious Issues/Spiritual Carer’s Name

It appears religious issues may impose themselves negatively upon those in need of spiritual care. A hospice chaplain said “one of my more difficult pastoral coordination roles is to inform the priest that he is not wanted and that has created one or two difficulties”. Another chaplain said families “if they have got hang ups about religion, particularly, say, the Catholic ones, if they had been taught by a crabby nun or a priest .... [who] had beaten the hell out of them” can be a barrier to spiritual care being made available.

The issue of ‘religious baggage’ being an impediment to spiritual care was mentioned by most of the chaplains/spiritual carers. The issues included conflating spirituality and religion, anti-religious sentiment, and the name and image of the ‘chaplain’.

Chaplain comments regarding the conflation of spirituality and religion included,

You have to make [sure] pretty early in the piece the distinction between spiritual care and religious care.

A barrier can be where a person sort of confuses or thinks that spirituality is about religion and they are against religion because of some experience they have had in childhood or early adulthood.

There are people who tend to equate spirituality with religion and they say well I am not a religious person, I have no time for it, I have no faith but in fact when you start talking to them about the meaning of life, the purpose of the sort of life they have led and have them make sense of their life and make sense of their present predicament they find themselves in, that’s addressing their spiritual needs and they feel happier at the end of it without necessarily understanding what the process has been.

These three quotes, from three different chaplains, are important because people with spiritual needs could potentially miss out on care because of misunderstanding. The chaplain/spiritual carer name issue is another important consideration. Again, there were a range of comments from chaplains/spiritual carers,

In some cases it closes doors premature [the ‘chaplain’ term].

My title is not chaplain, it is pastoral care coordinator.

I think you both gain and lose by changing it.

We kept away from ‘chaplain’ as the key title, although it gets used, it is pastoral support coordinator.
Traditionally in New Zealand those who provided spiritual care in hospitals and hospices were generally called chaplains (along with the ministers who came in). However that traditional world was predominantly practicing Christian and no longer exists. As these quotes above suggest, hospice communities are beginning to think about what the role of spiritual carer should be called. The other issue that was commented on was the visual cues of this role. One spiritual carer (the term is used because that is what his title was, based on consultation with his hospice community) said he “doesn’t wear any of the ‘trappings of the cloth’, preferring rather to do as the nurses do and not wear a uniform”. This is another of those questions to be considered, probably best approached by each community as needs, beliefs and understanding will vary.

4.3.6 Summary of Study One: Participants’ Voices on Spirituality

This chapter has represented the voices of participants in this study. Everyone gave generously of their time and knowledge and I was acutely aware of time issues for patients, some of whom had only days to live. The ethical issues and methods sections above have explained in detail how we conducted this work, that is, with a reflective lens constantly examining processes, safety and insights. The results section provides a thematic narrative that shows how spirituality is understood, what the participants’ beliefs and needs were, and how participants understood the provision, processes and barriers to spiritual care.

Key themes include the ideas that spirituality is widely understood (pluralistic), different to religion (but complementary), and generally thought to be important. The overall definitional picture is one of inclusive and summative approaches dominating.

Spiritual beliefs and practices were canvassed to further deepen the investigation into how these populations understood their spirituality. The vast majority had no formal religious practice or attendance, yet very few people had no belief in God or the afterlife. Existential meaning was found primarily in family, though there were three participants who saw their life as meaningless. Some patients considered the time of their illness as a productive time of reflection and reprioritization. Surprisingly there were many stories of the paranormal — experiences that staff often understood to be normal.
Spiritual needs appear to be dependent on how one has lived up to the time of one’s diagnosis. Patients and family members’ identity is clearly challenged. Fear, anxiety, grief, despair, hope, guilt and the need for forgiveness, congruency, anger, and the search for peace of mind are common spiritual needs. These are likewise spiritual challenges and opportunities that spiritual care may help facilitate. Very few patients or family members were aware of receiving spiritual care from hospice or hospital staff — with the exceptions often being overtly religious. Some patients said they primarily received spiritual care from family and friends.

Not everyone wants spiritual care, but the staff and chaplains/spiritual carers who have worked with literally hundreds of people believe that most people have spiritual needs and want appropriate spiritual care. The “work of the dying” is mostly spiritual. Many staff and chaplains/spiritual carers said that an awareness of the importance of spirituality is a critical foundation, for which they then have an array of spiritual care tools to use. Spiritual care was ideally patient-led and often subtle. An inter- and/or multi-disciplinary approach was almost universally recommended. Ethical issues were clearly understood, with only one or two examples of inappropriate spiritual care (such as proselytising) mentioned across all participants. However, there were no consistent policies or practices for spiritual care.

Significant challenges were identified by participants. These included consistent spiritual assessment and care, staff attitudes and capacity, and infrastructural issues of policy, training, space and staff spiritual care. The hospital setting was the least likely to have multi-disciplinary spiritual care, with default to the chaplain likely. Addressing these issues will go a long way to improving spiritual care.

**4.3.7 Limitations**

Limitations are inevitable in one’s design, methods, analysis and findings. In the case of this study, the design included a random selection process in hospices. This is discussed above, suffice it to say, with hindsight this was not necessarily the best method. It mixed ‘methodologies’ in terms of trying to use a quantitative approach (randomisation) with a qualitative method. The methods generally were very good, in that the interviews were highly informative and participants honoured in the process. Communication with the settings could
perhaps have been more regular after the interview process. Analysis in qualitative work needs rigour and transparency and this could always be improved. The use of Atlas.ti was very helpful, particularly in creating coding lists and the quick availability of quotes for codes. While another researcher would inevitably see different things in the interview texts, it is asserted that based on the palliative care literature, the main themes have been discerned. Lastly, it is asserted that ‘truth and integrity’ have led the process as much as possible, with high levels of reflexivity, as is noted as qualitative research’s focus: “in qualitative studies the emphasis is not so much upon validity and reliability but on the truthfulness and integrity of the research findings” (McSherry, 2007, p. 102). The findings are discussed in Chapter Five.

The issue of “self-selection” in qualitative sampling has been noted as a concern (McGrath, 2003). As noted above, random sampling attempted to address this, however I now believe that purposive sampling until reasonable saturation is found is an equal, if not a preferable method. As the frequency of quotes above from some interviews suggests, not all interviews are ‘equal’ in terms of their utility.

Numbers for healthcare professionals other than nurses were very low, or in the case of some allied healthcare professionals, nil. Therefore, more focused research on discrete professional groups is warranted. In light of the medicalization argument made by some participants, an important place to start may be with medical doctors and specialists.

In terms of sites selected, the other obvious limitation is the sole hospital site. Saturation was not even close. These interviews, like the Māori interviews, gave a small insight into the context, but more research is necessary.
5 Study 2: Spirituality in Hospice Care Survey

5.1 Introduction

Informed by the interviews from Study One, the second arm of this research sought to further understand spirituality and spiritual care in New Zealand’s hospices with a national cross-sectional survey. The survey is the third information component collected to triangulate relevant data so as to give a broad and deep view of the topic. The quantitative study thus complements the larger qualitative study and therefore the reporting of Study Two below is more discursive than most quantitative work. This chapter tells another side to the spirituality in New Zealand hospices story and answers the questions about understandings of spirituality, unmet needs and spiritual care issues. These issues are grouped as two sets of results: patients and family members, and staff. There are three sections in each group based on spiritual definitions, beliefs and practices, and needs and care.

5.2 Aims

Study Two has the same broad aim as Study One: to investigate and identify ways to improve spiritual care in New Zealand end-of-life cancer care, primarily focused in hospices.

Study Two’s objective is: to provide a quantitative measure of spirituality and spiritual care in New Zealand hospices.

5.3 Methods

The methods section includes details of the measurement tools and survey development, the survey processes and data analysis.
5.3.1 Measures

The ‘Spirituality in NZ Hospice/Palliative Care Survey’ included the 23 item FACIT-spex, the ‘spiritual beliefs and care survey’; and a demographic section.

5.3.1.1 Survey Development

The survey development process included a literature search for a short validated spirituality survey and further items/questions were based on the wider literature, expert opinion and issues arising from Study One. The first section is not reported here. The ‘spiritual beliefs and care survey’ uses a mixture of five-point Likert scales. Section Three asks demographic questions based on the New Zealand 2006 Census.

5.3.1.1.1 The Survey

The Survey cover page had a range of required information and a short introduction. Filling out the survey was considered consent. Of note, the ‘Introduction’ reiterated that spirituality “means different things to different people” and included the working definition of spirituality:

Please note: ‘spirituality’ means different things to different people. In this study, spirituality includes beliefs, values, sense of meaning and purpose, identity, and for some people religion.

It was decided to include this definition to make clear from the outset that the survey was looking at more than religious issues, which may have excluded some participants. The survey took approximately ten minutes to complete. The survey structure is detailed in Table 5.1 below.

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106 For a copy of the survey document see Appendix D1.
107 Study Two reports on Sections Two and Three of the survey.
108 The expert opinion included my supervisors, an Otago Cancer Society focus group and it was piloted, allowing for feedback from the ‘real experts’, patients and family members.
109 The following questions in Section Two came from existing questionnaires, all the others were developed by the author (drafted, reviewed by supervisors, and trialled). Questions 2, 3: Dunedin Longitudinal Study, (Silva & Stanton, 1996). Questions 4, 11: Newsweek / Beliefnet Poll 2005 (Newsweek/Beliefnet, 2005). Questions 7, 8, 9: Qual-E QoL tool (Steinhauser, et al., 2004). Question 12: Based on the discussion aspects in (Macconville, 2006). Question 16, 17: (Model, et al., 1999).
110 The ‘Introduction’ was based on the introduction in the WHOQOL SRPB survey. (WHOQOL-SRPB Group, 2006)
111 Completion time was based on the introduction in the WHOQOL SRPB survey. (WHOQOL-SRPB Group, 2006)
### 5.3.1.1.2 Survey Structure:

#### Table 5.1 Survey Instrument Details

<table>
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<th>Instruments</th>
<th>Author/Year</th>
<th>Main Constructs</th>
<th>Validation Sample</th>
<th>Number of Items</th>
<th>Subscale, factors, or dimensions</th>
<th>Psycho-metric properties</th>
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<tr>
<td><strong>Section 1</strong></td>
<td>Functional Assessment of Chronic Illness Therapy – Spiritual Well-Being (FACIT-Sp-Ex)</td>
<td>Fitchett et al. (1996) and Peterman et al. (2002)</td>
<td>• meaning, • harmony, • peacefulness, • faith/spiritual related strength/confidence, • connection to God-higher power/others, • love, • forgiveness, thankfulness, • hope, beauty, compassion.</td>
<td>Adult cancer and other medical patients</td>
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<td><strong>Section 2</strong></td>
<td>Spiritual beliefs and care survey</td>
<td>PhD Researcher (Richard Egan) 2007</td>
<td>All Samples: • meaning • beliefs: religious/spiritual/changes in beliefs/God • religious attendance • spiritual activity • fear: death/family • regrets • spirituality definition • life after death • paranormal experiences • spiritual care: name/received/what • help with: fear/hope/meaning/spiritual resources • someone to talk: peace of mind/meaning/dying &amp; death • cultural need</td>
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<td>Expert review and piloted.</td>
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<tr>
<td><strong>Section 3</strong></td>
<td>Demographic survey</td>
<td>Drawn from New Zealand Census 2006</td>
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<td>NZ population</td>
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<td>n/a</td>
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5.3.1.1.3 Survey Pilot

The pilot hospice kindly agreed to be the site for developing the survey and survey management processes. The pilot was invaluable to test the survey management processes and clarified expectations for the national survey. The pilot had 10 participants who completed the draft survey. The participants wrote helpful comments and most were interviewed on the phone to understand more about the procedure. For example, one staff member commented, “are you asking if the hospice provides spiritual care for the staff?” for Question 19 in Section Two. Such feedback helped to clarify any question ambiguity that remained in the survey. Feedback from the staff member (key contact person) who conducted the survey helped to further develop such areas as participant inclusion criteria and recruitment time frames.

5.3.2 Participants and Procedures

This section details the procedures of the actual survey process: information sheet, hospice choice and recruitment, key contact person issues, participant selection and recruitment, response rate incentives, survey return and data entry processes, and data analysis.

The ‘Spirituality in NZ Hospice/Palliative Care Survey’ included two documents for each participant: an Information Sheet and the Survey.

The Information Sheet format followed national ethical guidelines, including: title, research name and details, date, introduction, research aims, voluntary nature of survey, potential benefits or harms, distribution of results comment, and supervisors’ names and contact details. Of note was the inclusion of a working definition of spirituality; a section that offered follow up care and a tear-off section at the end of the information sheet.

The Information Sheet section that offered follow up care read:

*The counsellor or chaplain at your hospice / palliative care service knows about this study and will be available to discuss any issues this survey may bring up.*
Based on the pilot study,\textsuperscript{112} we were aware that consideration of spiritual issues may raise issues for participants, therefore including this note about follow up care was crucial.

The tear-off section at the end of the Information Sheet read:

\begin{center}
\textit{Spirituality Survey}
\end{center}

\textit{To avoid receiving a follow-up request to complete this survey, when you have completed the survey please write your name in the space below and tear this section off and hand it to the liaison person in your hospice who distributed the questionnaire to you. (For some people, it may be easier to phone the liaison person.) Your name will not be passed on to the researcher – it is to assist the local liaison person to identify participants who have completed the survey and will therefore not be sent a reminder.}

Name:

The Information Sheet tear-off section was a technique to increase the response rates. It enabled participants to reply to the key contact person in the hospice care setting so no further reminder would be necessary when/if it was physically returned. Alternatively, participants phoned the key contact person confirming they had completed the survey. The key contact person then recorded the fact that the tear-off section had been returned on a ‘Reminder Template’ provided by the researcher.

\section*{5.3.2.1 Hospice Choice and Recruitment}

Twenty-five of New Zealand’s 32 hospices\textsuperscript{113} agreed to participate in the survey. There were a range of reasons the seven hospices did not participate, including staff stress, lack of staff, and key people not having the time. Each hospice CEO (or equivalent) was contacted by telephone to gauge initial interest and then emailed the following documents: a ‘Locality Assessment’ form; ‘Research Summary’; and letter confirming the discussion and details about the survey. Once confirmation of participation was granted, the key contact person was contacted to discuss further details of the survey and work out the best time for their site. The timeframe for the survey was to be October to December 2007, however there were approximately 30 surveys returned during January 2008.\textsuperscript{114}

\textsuperscript{112} Based on hospice staff reports to the researcher, there were two occasions in Study One of need for follow up.
\textsuperscript{113} This number is based on Hospice New Zealand’s 2007 database of hospices
\textsuperscript{114} The timing of the survey was consciously considered and it was decided that due to the cross-sectional nature of the study, there was no need for all surveys to be completed in the same time period.
Each hospice CEO nominated a key contact person to manage the survey at their site. As a critical component in the success (or otherwise) of the survey, she or he was contacted regularly via phone, email and in the case of the survey pack, via postal mail. The survey pack contained a large chocolate bar (as a gift of thanks) and the following documents:

- Survey Administration pack
- Survey Process
- Random number table for participant selection
- Reminder template
- Key contact person survey
- Information Sheets, Surveys and ‘stamped, self-addressed envelopes’ for Staff, Patients and Family Members
- Extra free post envelopes if there was a need to send out the surveys.

5.3.2.1.1 Survey Process

In the “Survey Administration” document for the key contact person, the survey process was summarized as follows:

In summary the process involves:

Participant selection (staff, patients, family members)

Asking participants to do survey, confirmation and writing names in the template.

Handing or sending out the surveys.

Reminder to those who haven’t returned the ‘survey slip’.

Fill out your ‘Key Contact Survey’ (please also do a survey yourself).

Note: could you please let your support staff know the survey is happening (whether counsellor, chaplain or the like). It’s unlikely, but some participants may want to discuss spiritual issues that the survey has raised for them.

The key contact person managed the onsite recruitment process. The researcher provided a “suggested approach to ask patients/family members”. Anonymity was ensured via the stamped addressed envelopes provided, which was sent directly to the researcher. Further, each key contact person filled out a questionnaire to determine extra information about the hospice care setting. This information included: name, site name, location, staff and patient numbers on date of recruitment, questions about the site’s spiritual care resources and facilities, and any comments about the survey process.
5.3.2.1.2 Sampling Considerations

The aim was for a confidence interval of 10% for categorical questions. That is, if the response to a particular question was 50%, then the 95% confidence interval would be between 45%-55%. Randomization was considered carefully in the design. The gold standard, which would have included random sampling by the researcher, however this was not feasible under the circumstance working with hospices. Therefore the pragmatic solution was to assess the probable number of patients in each setting and give the key contact person a random number list tailored for each setting. The key contact person used the random number list against his or her alphabetical list of patients. If the patient did not want to answer the survey, the next random numbered patient was asked. We were aiming for a sample size of 300 per population.

5.3.2.1.3 Survey Patient & Family Number

Table 5.2 below shows the number of patient surveys sent to each site based on the ‘sample size considerations’ and the October 2007 numbers above. The same numbers of surveys were sent for family members. This number of surveys was sent to each hospice to keep the analysis simple, therefore every participant had to be selected with approximately equal probabilities. Thus hospices were asked to recruit different numbers of participants based on their size.

115 In January 2007 initial estimates suggested that at any one time there were 2000 patients in hospice care settings. On 23 January, 2007, patient numbers were estimated as a ‘best guess’ after the researcher talked to the Ministry of Health, Hospice New Zealand and New Zealand’s only Professor of Palliative Care, Rod MacLeod. Of note, neither the Ministry nor Hospice New Zealand had accurate figures. In October 2007 estimates suggested there were approximately 2500 patients in the 25 hospices that had confirmed survey participation. This was the best guess of the key contacts, I asked them “on any given day how many patients do you have on your books?”.
Table 5.2 Number of surveys sent

<table>
<thead>
<tr>
<th>Hospice Patient Number Criteria</th>
<th>No of Surveys</th>
</tr>
</thead>
<tbody>
<tr>
<td>150 patients or more</td>
<td>18</td>
</tr>
<tr>
<td>120 patients or more</td>
<td>15</td>
</tr>
<tr>
<td>100 patients or more</td>
<td>12</td>
</tr>
<tr>
<td>70 patients or more</td>
<td>10</td>
</tr>
<tr>
<td>51 patients or more</td>
<td>7</td>
</tr>
<tr>
<td>50 patients or less</td>
<td>6</td>
</tr>
<tr>
<td>30 patients or less</td>
<td>5</td>
</tr>
</tbody>
</table>

Of the 25 hospices, 415 patient and 403 family member participant surveys were sent to the key contact people. There was a difference in patient and family numbers because some key contact people requested extra surveys for patients. Six hundred staff surveys were sent to key contact people. Staff numbers were based on the key contact person’s estimate of eligible staff (see below for criteria).

5.3.2.1.4 Participant inclusion Criteria

The inclusion criteria was based on advice from supervisors and amended after the pilot. Staff inclusion criteria were: paid clinical staff (plus all chaplains), nurses who work .5 FTE (full time equivalent) or more. Patient inclusion criteria were: terminal cancer diagnosis with less than one year prognosis; age eighteen or above; fluent in English (oral and written); free of cognitive dysfunction. And family member inclusion criteria were: age eighteen or above; fluent in English (oral and written); free of cognitive dysfunction.

5.3.2.1.5 Random Sampling

Random selection of patient and family member participants was attempted. A random number list was generated for each hospice. Key contacts estimated patient numbers and a random number list was generated based on that number. The key contact listed the patients alphabetically and then randomly chose participants based on the list. More random numbers were provided than participants required because there was a possibility the first random patient might say no or be ineligible. Accurate descriptions of the success or otherwise of this

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116 It was decided not to survey all staff. Therefore as the largest profession is nursing, many were excluded if they worked less than half time.
process was recorded by key contact people. The majority of settings were able to use the random process provided. Family members were recruited from the patient’s selected.

5.3.2.2 Response Rate Incentives/Staff Goodwill

This study was dependent on the goodwill of a range of health professionals across New Zealand’s hospices. Therefore it was critical to reciprocate this goodwill within the resources available. This had the secondary outcome of creating incentives to improve response rates. The reciprocation/incentive actions included a chocolate bar for each of the key contacts, and regular communication with them. There was an appeal to altruism at all levels of the study, including in key contact information and all participant information sheets. For example, the later document contained the sentence,

You may gain an increased awareness of your own spirituality and a sense that you are doing something that will help others in the future through improvements in spiritual care for staff, future patients and their families.

Finally, as an incentive action there was a tear-off section at the end of each information sheet for participants to send back once they had completed the survey.

5.3.2.3 Survey Return and Data Entry Processes

The surveys were returned via a self-addressed envelope to the University of Otago General Practice Department. In the Department, the survey numbers were logged into a database. The surveys then went to an independent data entry company where the data was double entered.

5.3.3 Statistical Analysis

Statistical analysis was significantly carried out by Associate Professor Peter Herbison (University of Otago, Preventive and Social Medicine Department) using the programme Stata (StataCorp LP, College Station, Texas, 2008). Descriptive statistics, including frequency tables and cross tabulations were produced. The percentages do not always add up to 100 and there are variations in denominator numbers due to missing values.

117 Thanks go to Anita Fogerty in the University of Otago Department of General Practice, for significant help with the collation of the survey returns.
5.3.4 Hospice Setting Spiritual Score

The ‘hospice setting spiritual score’ is based on an aggregate of survey questions that related to the whole hospice spiritual environment. While it is a subjective assessment based on the staff survey responses in each hospice combining eight items across the hospice does give some indication of an overall sense or climate of how ‘spirituality-nurturing’, or how attentive, a hospice is to spirituality. The score is made up of eight items, seven from the ‘spiritual beliefs and care survey’ in the staff survey and one from the key contact survey. A binary score for each item was developed and then summed to create the score. A higher value indicates a greater structural commitment to spirituality.

The Table 5.3 below shows the items used and other useful information.

Table 5.3 Hospice Setting Spirituality Score

<table>
<thead>
<tr>
<th>Survey Question</th>
<th>Measure</th>
<th>Range</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Key contact survey</td>
<td>Paid chaplain / spiritual carer</td>
<td>Yes / no</td>
<td>Based on key contact questionnaires</td>
</tr>
<tr>
<td>23.i</td>
<td>Chapel / quiet room available</td>
<td>Yes / no</td>
<td></td>
</tr>
<tr>
<td>19</td>
<td>Staff Spiritual Support</td>
<td>Yes / no</td>
<td></td>
</tr>
<tr>
<td>20</td>
<td>Spiritual Care Policy</td>
<td>Yes / no</td>
<td>Those who ticked “don’t know” were put into “no”</td>
</tr>
<tr>
<td>21</td>
<td>Spiritual Professional Development</td>
<td>Annual / no, occasionally</td>
<td></td>
</tr>
<tr>
<td>23</td>
<td>Spiritual Resources</td>
<td>4 or more of 10 options</td>
<td></td>
</tr>
<tr>
<td>24</td>
<td>Formal Spiritual Assessment</td>
<td>Always – Often / sometimes-never</td>
<td>That is Likert scale numbers 1-3 / 4-5</td>
</tr>
<tr>
<td>27</td>
<td>How important is spirituality in your hospice?</td>
<td>Extremely – moderately / not at all / a little bit</td>
<td>That is Likert scale numbers 5-3 / 1-2</td>
</tr>
</tbody>
</table>
5.4 Results

The survey results that follow include response rates, demographic details and key results from the ‘spiritual beliefs and care survey’. Informed by the research questions, the key results for the ‘spiritual beliefs and care survey’ are reported in two sections, the first reporting the patient and family results; the second the staff results. For both sections there are three result categories: spiritual definitions, spiritual beliefs and practices, and spiritual needs and care. The discussion about the results will follow in Chapter Seven. The story these data tell is about spirituality understandings, practices, beliefs, needs and care of hospice staff members (mostly nurses), patients and family members.

5.4.1 Response Rates

Response rates for the survey are reported in Table 5.4

<table>
<thead>
<tr>
<th></th>
<th>Survey No's sent by Researcher</th>
<th>Survey #s Given Out by Hospice Key Contact</th>
<th>Surveys Received by Researcher</th>
<th>Response Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Staff</td>
<td>600</td>
<td>550</td>
<td>364</td>
<td>66.16%</td>
</tr>
<tr>
<td>Patients</td>
<td>415</td>
<td>277</td>
<td>141</td>
<td>50.90%</td>
</tr>
<tr>
<td>Family Members</td>
<td>403</td>
<td>269</td>
<td>137</td>
<td>50.92%</td>
</tr>
<tr>
<td>Totals</td>
<td>1418</td>
<td>1096</td>
<td>642</td>
<td>58.57%</td>
</tr>
</tbody>
</table>

The researcher numbers (column two above) are higher than those sent out by the hospice key contact (column three above) for two reasons. First, the researcher sent out some extra surveys for patients as experience from Study One suggested that even after affirming participation in the study, some patients changed their minds. Second, as each hospice made their own decision on recruitment based on their capacity; many of the hospices did not attain the number of participants the researcher had initially expected. Further, there were 20 returned surveys without cover pages (and therefore no ‘survey number’) - these data were omitted from the hospice level analysis. Lastly, response rates for individual hospices varied, therefore this needs to be taken into consideration when considering discrete hospice scores.
5.4.2 Demographic Details

The demographic details of the surveyed samples are shown as tables in Appendix D2. As expected, the age of patients was reasonably high (mean 67 years, SD ±10 years). The staff mean was 51 years (SD ±9 years), with family member mean 60 years (SD ± 14 years). There was relative ethnic homogeneity across all samples (89% NZ/European, 4% Māori), which either suggests ethnicities other than NZ/European did not fill out the survey, or more likely other ethnicities are poorly represented in staff and patient numbers in New Zealand hospices.

The religious figures show a high Christian majority (71%), higher than 2006 Census figures for the whole population (57%). The denominational breakdown for Christian religion was: Anglican 27%, Catholic 18%, Presbyterian 22%, Methodist 4%, Ratana 0.2% and Other 30%. Regarding school qualifications, from the total surveyed population, 9% named the highest qualification option (Bursary or Scholarship).

The results are dominated by female responses, particularly for staff (male 11%, female 89%) and family members (male 30%, female 70%). However patient percentages show a reasonable gender balance (male 45%, female 55%). The nursing population dominates the staff response, thus this gender difference would be expected. The reason for the family member imbalance may be that it was the female family member that was more likely to fill out the survey. Table 5.5 shows the breakdown of professions for the returned staff surveys.
Table 5.5 Staff Professional Group Breakdown

<table>
<thead>
<tr>
<th></th>
<th>Number of Professions</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctor</td>
<td>28</td>
<td>7.7</td>
</tr>
<tr>
<td>Nurse</td>
<td>229</td>
<td>63.3</td>
</tr>
<tr>
<td>Chaplain</td>
<td>15</td>
<td>4.1</td>
</tr>
<tr>
<td>Counsellor / Social Worker</td>
<td>26</td>
<td>7.2</td>
</tr>
<tr>
<td>Health Care Assistant</td>
<td>9</td>
<td>2.5</td>
</tr>
<tr>
<td>Manger / Coordinator</td>
<td>7</td>
<td>1.9</td>
</tr>
<tr>
<td>Allied Health Professionals</td>
<td>11</td>
<td>3.0</td>
</tr>
<tr>
<td>Excluded</td>
<td>7</td>
<td>1.9</td>
</tr>
<tr>
<td>Prof Not Stated</td>
<td>27</td>
<td>7.5</td>
</tr>
<tr>
<td>Other</td>
<td>3</td>
<td>0.8</td>
</tr>
<tr>
<td>Total</td>
<td>362</td>
<td>100</td>
</tr>
</tbody>
</table>

As expected, nurses made up the greatest proportion of staff survey returns (63%), followed by doctors (8%) and social workers/counsellors (7%). Seventy-three percent of staff surveyed had worked in the setting for three years or more. Thirty percent of staff had worked for more than ten years in this setting, with only 12% having been employed for less than a year. A stable workforce is implied by these figures. Further, 64% of staff respondents worked half time or more, with 22% working full time.

5.4.3 Patient & Family Member Key Results: Spiritual Beliefs and Care Survey

5.4.3.1 Patient and Family Members: Spirituality Definition

This section reports the results of the spiritual definition question; the results are shown in Figure 5.1 below. Of note is that ‘meaning’, ‘purpose’, ‘beliefs’, ‘values’ and ‘faith’ were in the top five choices of both patients and family members. ‘Values’ was the most popular choice for patients and family members (51/52%). Four patients and four family members ticked the “meaningless” category – in other words, 97% of both samples surveyed thought spirituality was meaningful.

Some participants added written comments. For patients there were three comments which were: wanting the word “limited”; suggesting it was a “living thing in a person”, and that it
was about "the beauty and complexity of the natural world". Similarly there were two family member responses, one suggesting all descriptors "except religion" and the second comment simply stated "trinity".
FIGURE 5.1 Spiritual Definition Descriptors: Patients and Family Members
5.4.3.2 Patient and Family Members: Beliefs and Practices

This section reports the results of the questions about participants' spiritual and/or religious beliefs and practices (question numbers: 1-6, 11 & 12, 15, 26, 27). It was deemed important to understand such information as it helps tell the spirituality story of these samples.

In response to the question: “Do you feel life has meaning?”, eight patients and four family members reported that their life had “no” meaning – this equates to 6% and 3% respectively. As shown in the Figure 5.2 below, the results show that ‘family’ gives life meaning for both samples, more than any other option. ‘Family’, ‘friends’, ‘helping others’, ‘children’ and ‘life itself’ – are in the top five priorities that give life meaning. ‘Less than a quarter of patients or family members named work as giving life meaning.

![Figure 5.2 What Gives Life Meaning: Patients and Family Members](image)

Figure 5.3 below shows the percentages of how the respondents describe their current beliefs. Approximately a quarter (24% & 27%) of patients and family members have “no particular beliefs”, while only 10% of staff ticked this category. Patients responded as the most “religious” (17%), followed by family members (10%) and staff (5%). Staff were the most ‘spiritual’ (41%), followed by family members (26%) and patients (17%). Those who ticked “both” spiritual and religious varied between 31% and 42%. The ‘Other’ written responses were primarily religious or spiritual, just with more focused answers, such as ‘faith’, ‘Jesus’, ‘morals’, ‘pantheism’ and so on.
Religious attendance and spiritual activity were considered respectively. On average, about 22% of both samples attend a religious service weekly – this figure goes up to 27% when the monthly figure is added. Participation in weekly spiritual activity was on average, about 12% of both surveyed samples – this figure goes up to 19% when the monthly figure is added. Daily spiritual activity was 28%. Almost half (49%) the patients surveyed and just over a third of family members (36%) said their beliefs had changed since dealing with cancer issues.

The ‘belief in God’ results are shown in Figure 5.4 below. The figure shows the percentage of ‘no’, ‘don’t know’, and the nominated descriptors. Of note is that across the two samples approximately 70% believed in God, with “love” or “all loving” most often nominated as the descriptor for ‘God’. Further 13% of both samples answered ‘don’t know’ and 14% ticked ‘no God’.
The results of the question 'what happens after death?' show that over 70% of both samples believe there is something after death, with 73% of patients and 79% of family members answering one of these options: b (“the soul or spirit goes to another place”), c (“there is no heaven or hell, but the soul lives on...”) or d (“the soul is reincarnated”). Option b was almost three times more likely to be answered than the others. Reincarnation was the least favoured by both samples (3%).

The results asking about paranormal experiences are shown in Figure 5.5 below. Forty-four percent of family members and 50% of patients nominated no such experiences. Thus, in both samples between 50-56% of participants had experienced an unexplained phenomenon.
The results asking about the ‘name’ of the professional spiritual carer showed that for both samples 49% suggested that “it doesn’t matter” what the role is called. Almost 20% of patients and family members preferred ‘chaplain’.

### 5.4.3.2 Patient and Family Member Survey Samples: Spiritual Needs and Care

The spiritual needs of the two samples were assessed by Questions 7, 8, 9, 13, 14, 16, 17 and 25. These are reported below. The logic for the reporting begins with the question, “Ideally, would you like to have spiritual care?”, then “Have our received spiritual care?” and so on. These are critical data to answer the thesis question about unmet spiritual needs and developing the picture about spiritual care in New Zealand hospices.

The results of the question that asked about ideal spiritual care are shown in Figure 5.6 below. Of note, between 34% and 37% of patients and family members respectively did not want spiritual care. Family and friends were the most common choice for spiritual carer (patients 33%, family 39%), with a chaplain/minister the second most common choice (patients 31%, family 29%).

The denominator for all these results is the total respondents for each population; therefore, when examined by the denominator of those who wanted spiritual care and chose a carer option, the percentages are different. For example, with the total denominator figure, 33% of patients wanted spiritual care from family and friends. When this figure is divided by those that said yes, then it changes to 51%.

![Ideal Spiritual Carer](image)

**FIGURE 5.6 Ideal Spiritual Carer: Patients and Family Members**
Figure 5.7 below shows 23% of patients and 33% of family members had not received spiritual care, as they understood it. Friends and family were the most common spiritual carers (patients 38% and 45%; family 39% and 48% respectively). A chaplain/minister was the third highest option (patients 33%; family 24%). Like the question above, when the denominator changes to those who said yes, the percentages change, for example the patient ‘family/friends’ option moves from 45% compared to 58%.

![Received Spiritual Care](image)

**FIGURE 5.7 Those Who Have Received Spiritual Care: Patients and Family Members**

Participants were asked about wanting “help with” or “someone to talk to” regarding a range of spiritual needs. The results are shown in Figure 5.8 and Table 5.6 below.

![Help Needed](image)

**FIGURE 5.8 Spiritual Help Needed: Patients and Family Members**

Regarding fears, hope and meaning, of note, between 20–40% of all patients and 18–40% of all family members surveyed wanted some help with one of these options.
Table 5.6 Spiritual Help Needed II: Patients and Family Members

<table>
<thead>
<tr>
<th>Wanted help with:</th>
<th>Patients</th>
<th>Family</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overcoming fears</td>
<td>40%</td>
<td>41%</td>
</tr>
<tr>
<td>Finding hope</td>
<td>28%</td>
<td>23%</td>
</tr>
<tr>
<td>Finding meaning</td>
<td>30%</td>
<td>18%</td>
</tr>
<tr>
<td>Spiritual resources</td>
<td>21%</td>
<td>25%</td>
</tr>
<tr>
<td>Peace of mind</td>
<td>29%</td>
<td>29%</td>
</tr>
<tr>
<td>Meaning of life</td>
<td>24%</td>
<td>18%</td>
</tr>
<tr>
<td>Death &amp; dying</td>
<td>31%</td>
<td>27%</td>
</tr>
</tbody>
</table>

Of note regarding peace of mind, meaning in life and death & dying, between 23–31% of patients and 18-29% of family members surveyed wanted to talk to someone about these options.

The results of the question asking about fear of death show between 30%-41% of both samples had no fear of dying (patients 41%; family members 30%). These figures are similar to question 16. Conversely, 59%-70% of the samples surveyed had some fear, with the vast majority either ticking “a little bit” or “a moderate amount”. Regarding regrets in life, 51-63% of all respondents had some regrets. Just under half (49%) of the patients had no regrets. Like regrets, worry about family was an issue for most participants, with 66% of both samples having some worry about their family.

Regarding “unmet cultural need”, the results suggest there is little or no cultural needs being unmet, however this needs to be tempered with the homogeneous nature of the sample. The unmet cultural needs results were: 3% of patients; and 0% of family members.

5.4.4 Staff Key Results: Spiritual Beliefs and Care Survey

5.4.4.1 Staff: Spirituality Definition

This section reports the results of the spiritual definition question; the results are shown in Figure 5.9 below. Of note, like the results above, ‘meaning’, ‘purpose’, ‘beliefs’ and ‘values’ were in the top five choices of the staff; ‘awareness’ (60%) and ‘connectedness’ (59%) were
also chosen by a large percentage of staff. The top choice for staff was ‘meaning’ (74%). Further, less than one percent of staff members ticked the “meaningless” category.

Some participants added written comments. There were 18 comments from staff, of which four were religious and the other 14 were broad descriptors like “music”, “joy”, “paradox”, “life” and “wonder”.

![Spiritual Definition Descriptors](image)

**FIGURE 5.9 Spiritual Definition Descriptors: Staff**

### 5.4.4.2 Staff: Beliefs and Practices

This section reports the results of the questions about staff spiritual and/or religious beliefs and practices. In response to the question: “Do you feel life has meaning?”, two staff members reported that their life had “no” meaning – this equates to less than 1%. As shown in the Figure 5.10 below, the results show that ‘family’ gives life meaning more than any other option. Unlike patients and family members, ‘Work’ was in the staff top five priorities.
Figure 5.11 below shows that only 10% of staff ticked ‘no particular belief’ and just 5% considered themselves solely ‘religious’. Staff were the most ‘spiritual’ (41%) of the samples surveyed. Overall 90% of staff surveyed had a ‘set of beliefs’.

Religious attendance and spiritual activity were considered respectively. Twenty-three percent of staff attended weekly services, which went up to 30% when the monthly figure is added. Seventy-five percent of staff participated in spiritual activity, with 40% of this happening daily. Over half the staff surveyed (54%) said their beliefs had changed since dealing with cancer issues.
The ‘belief in God’ results are showed that 71% of staff believed in some form of God, with 15% stating there was no God and 14% did not know. Like patients and family members, “love” or “all loving” most often nominated as the descriptor for ‘God’.

Staff are the most likely to believe there is something after death, with 86% answering option b (“the soul or spirit goes to another place”), c (“there is no heaven or hell, but the soul lives on...”) or d (“the soul is reincarnated”). Staff were also the most likely to have had any paranormal experiences, with 64% nominating one of a number of unexplained phenomenon. Regarding the ‘name’ of the professional spiritual carer, 48% of staff did not care, 21% nominated spiritual carer or companion, and 12% nominated ‘chaplain’.

Staff were asked about the importance of spirituality from their point of view and from their hospice point of view. The results show the ‘importance of spiritual issues’ were considered “very” or “extremely” by 84% of the staff (based on their experience) and 60% of staff considered it “very” or “extremely” (based on how important it was for their workplace).

5.4.4.3 Staff: Spiritual Needs and Care

Staff spiritual needs, based on the same questions answered by patients and family members, are reported below. The results of the question that asked about ideal spiritual care show that 31% of staff did not want spiritual care. Family and friends (40%) were the most common choice for spiritual carer, with a chaplain/minister the second most common choice (30%). 26% of staff had not received spiritual care.

As shown in Figure 5.12, between 20-29% of staff said they needed help with ‘over coming fears’, ‘finding spiritual resources’, ‘finding peace of mind’, the ‘meaning of life’, and ‘death and dying’.
Regarding fears, hope and meaning, of note, all staff surveyed wanted some help with one of these options.

### 5.4.4.4 Results of Staff Only Questions

A number of questions asked about staff spirituality. Figure 5.13 below shows the results about staff spiritual care tools. The top two results were ‘listening’ and ‘appropriate’ touching, followed by ‘philosophical discussions’.
Ninety-six percent of staff respondents said they did not have spiritual support at their hospice or palliative care facility. While for staff professional development, Figure 5.14 below shows 35% of staff do not have spirituality professional development and 11% have it annually, while the rest have it “occasionally”.

![Spiritual Professional Development Offered?](image)

**FIGURE 5.14 Spiritual Professional Development: Staff**

Over 80% of the staff surveyed believed that patients’ spiritual needs were unlikely to be dealt with before they came into the hospice (i.e. answered “sometimes” or “never”).

Figure 5.15 below shows that 50% of sites surveyed had a spiritual care policy. However 34% of the respondents did not know if they had a policy or not, so the rate could be higher.
FIGURE 5.15 Spiritual Care Policy

Spiritual resources were understood to be very available in each hospice, with only 1% of respondents said they had ‘none’; the most common ‘tools’ noted were the ‘chapel/quiet room’ (78%) and ‘sacred books’ (77%).

Formal spiritual assessments, as shown in Figure 5.16, were performed by 41% of staff regularly (top three answers), which means that most of the time, 60% of staff do not do spiritual assessments.
FIGURE 5.16 Spiritual Assessment

5.4.5 Hospice Setting Spiritual Score

Figure 5.17 below show the score for each hospice surveyed.
The results for each item for the 25 hospices are: 19 had paid chaplains, 21 had a chapel/quiet room, 1 had adequate staff spiritual support, 20 had a spiritual care policy, 1 had adequate spiritual care professional development, 13 had four or more spiritual resources, 9 always or often did formal spiritual assessments, and all hospice staff thought spirituality was important.

The results of the spirituality score include five hospice care settings that do not have an inpatient option; therefore it is unreasonable to expect a chapel/quiet room (one of the eight criteria). Interestingly, of these five, two scored 4s, one 5, and two 6s. Therefore the other seven items are relevant for any site independent of size. The limitations are many, including the subjective nature of choosing how to weight each binary choice, but it is understood to be a ‘crude’ or ‘broad brush’ indictor which could be used simply for hospices/palliative care settings to assess or audit their own spiritual care development.

The setting spiritual scores show that all sites could improve overall spiritual care provisions based on these criteria. Just one hospice reached 7 out of 8, with the majority sitting on 4 or 5 out of eight (6 and 7 hospices respectively). The three most common items missing were “staff spiritual support”, “spiritual professional development” and “formal spiritual assessment”.

5.4.6 Strengths & Weaknesses

5.4.6.1 Response Rates

The response rates were 66% for staff, 51% for patients, 51% for family members and an overall rate of 59%. As noted above, there were a range of initiatives that went into improving the response rates. These response rates compare well to other studies done in palliative care (Jacoby, Lecouturier, Bradshaw, Lovel, & Eccles, 1999) and examining spirituality in healthcare (Baldacchino, 2006). A common problem in palliative care research is overestimating the number of patients who are available (Hanks, et al., 2004). In the United States, McCord et al asked consecutive patients in a Family Primary Healthcare setting to answer a short questionnaire about their health and spirituality; they achieved a 65% response rate (McCord, et al., 2004). Balboni et al, a United States oncology team, quantitatively examined spirituality/religion and QoL. Their study details included 230 people with advanced cancer, 63% response rate and they gave US$25 compensation (Balboni, et al., 2007, p. 555). A New Zealand cancer services stock take study, that used a
mail out method, noted they expected a “return-rate of 50-60% based on recent studies of health practitioners in New Zealand using a similar mail out design” (Jarvis et al., 2006 cited in Surgenor, 2005, p. 7). With this literature in mind, the response rate for this study was in line with previous research.

The hospice care context is difficult for quantitative research. As some researchers, like McGrath (McGrath, 1999) have suggested, qualitative methods are arguably the gold standard. This survey relied on key contacts at each site to administer the survey. Naturally neither their enthusiasm nor motivation was the same as the authors, and significant pressures came to bear. These included work load, lack of resources/staff, lack of understanding or confidence, some gate-keeping (arguably, as some nurses in teams thought that the survey would raise issues that were not then able to be dealt with), and power differential issues (one site thought that the nurse manager asking patients was not fair). Further, patients and family members are under a range of pressures (Lichtenthal, et al., 2008), not least for the patients their terminal context, but in this context the response rates are considered very reasonable.

5.4.6.2 Bias

Bias and confounding issues were considered in the survey design and analysis. The most obvious issue was sampling bias, that is, it is possible those who were more interested or opinionated chose to do the survey, therefore the sample cannot be said to be representative. The randomization process hoped to attend to this bias. However it did not work in all settings because the hospice key contact did not have the capacity to do so. Based on feedback from the key contact people, up to 7 of the 25 hospices did not use the randomization process. Therefore selection bias is acknowledged as likely in some cases.

5.4.7 Summary of Study Two Findings

The ‘Spirituality in NZ Hospice/Palliative Care Survey’ took place between October 2007 and February 2008.118 It was a self-reported, cross-sectional mail out survey of staff, patients and family members. It aimed to build on the prior qualitative study through a broad survey of spirituality issues. Two main sections are reported on in this thesis. The ‘spiritual beliefs and

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118 A broader discussion of Study Two will be done in Chapter Seven below. What follows includes discussion aspects that are not relevant to the wider discussion.
care survey’ was developed by the researcher, consisting of between 18 (patients) to 31 (staff) questions about definitions, beliefs and practice, and spiritual care needs and experiences. The final section asked about demographic characteristics.

After piloting the survey, 25 hospices were recruited. A key contact person at each site randomly selected patients/family members and recruited almost all staff members. The data was independently entered and Associate Professor Peter Herbison conducted the analysis using the programme Stata. The response rate across the three samples was 59%, with 642 returned surveys.

The demographic profile across all samples was reasonably homogeneous, with 89% European and 4% Māori. The patient mean age was 67. Females dominated staff and family member returns, but there was a closer split with patients. Across all samples 71% were Christian, 70% married and 9% had Bursary or Scholarship. Of the staff, 63% were nurses, 8% medical doctors and 7% counsellors or social workers. 73% of the staff had worked in this area for three or more years.

Results were reported in two sections: patients and family members, then staff. For each section there were three areas reported: spiritual definition, spiritual beliefs and practices, and spiritual needs and care. These sections explicate the thesis questions, as is discussed further in Chapter Seven. For all samples, approximately 1% stated spirituality was “meaningless”, and the top five descriptors for spirituality were “values”, “beliefs”, “meaning”, “purpose”, “awareness” and “faith”.

Spiritual beliefs and practices questions ranged from meaning in life to religious/spiritual activity. Nearly all samples believed life was meaningful, with family the greatest source of meaning for all groups. Approximately a quarter of patients and family members had no particular beliefs; patients were the most ‘religious’ and staff the most ‘spiritual’. Almost a third of all samples attended a monthly religious service and over half practiced a spiritual activity monthly. Belief in God was high, with “love” the most common descriptor for God. Over 90% of all samples believed in the afterlife and between 50-64% believed in some form of paranormal experience. Most participants did not care what the spiritual carer/chaplain was called. A large majority of staff believed spirituality was important in their setting, but only 60% believed their institution understood it as important.
‘Spiritual needs and care’ questions aimed to understand spiritual care preferences, needs and staff/hospice spiritual care capacity. Respondents were asked about actual and ideal spiritual care. ‘Ideally’, 34% of patients and 37% of family members did not want spiritual care. ‘Actually’, 23% of patients and 33% of family members did not receive spiritual care. For both ‘ideal’ and ‘actual’, for those who wanted spiritual care, their preferred provider was family and friends, and then a chaplain.

Regarding spiritual needs, 20-40% of patients wanted help, especially with “fear”, as 59% of patients said they had a fear of dying. Twenty-three to thirty-one percent of patients wanted someone to talk to, particularly about “death and dying” and “peace of mind”. Just over half of the patients had regrets (51%) and over two thirds worried about their families (65%).

Almost all staff (97%) had a range of patient spiritual care tools and resources, with the most popular tools being “listening” (97%) and “appropriate touch” (84%) and most popular resources the “chapel” (78%) and “sacred books” (77%). However there was a significant lack of staff understanding they had spiritual support, with 96% stating they had none. Most staff (89%) seldom had spiritual care professional development, most staff did not do a spiritual assessment of patients (60%), and only half of the staff respondents said their institution had a spiritual care policy.

A ‘setting spiritual score’ was developed by collating eight items that reflected an institution’s commitment to spiritual care. These ranged from a paid spiritual carer/chaplain to a spiritual care policy. All sites surveyed, based on this measurement, could improve their spiritual care. The highest score was 7 (out of 8), with most scoring 4 or 5.

The strengths of this survey included a reasonable response rate (overall 59%) and the range of questions about spirituality, spiritual needs and care. For example, for the first time we have an empirical sense of what spirituality means to a particular population, and likewise how many people in this situation might want spiritual care.
6 A Māori Voice: Spirituality & Hospice Care

'Ko te Amorangi ki mua, ki te hapai o ki muri'
'Place the things of the Spirit to the fore, and all else shall follow behind'\(^{119}\)
(Payne, et al., 2003, p. 85)

I dedicate this chapter to Dr Paratene Ngata, one of New Zealand’s foremost medical doctors and contributors to improving the health status of Māori. Dr Ngata contributed through his own General Practice on the east coast of the North Island amongst his iwi (tribe) Ngati Porou and by his contribution to helping the medical community understand te Ao Māori (the Māori world). Dr Ngata kindly agreed to be interviewed as an expert for this research. Then, in 2008, Dr Ngata himself was diagnosed with cancer and subsequently died in 2009. Dr Ngata told me that spirituality connects us to the past and the future, and death was another stage in life. I hope that this work will honour his connections. To Dr Ngata, he mihi atu tenei ki a koe, te tino rangatira mo te hauora Māori, and to his whānau, thank you for sharing him with us all.

The purpose of this chapter is to create a space for a Māori voice about the place of spirituality in hospice care in New Zealand, thereby beginning an exploration of the nature and importance of spirituality to Māori, as discussed by Māori, particularly as it relates to death and dying. Inherent in any discussion of spirituality in New Zealand are the contributions and aspirations of Māori; as a Pākehā (European New Zealander) I make no claim to speak on behalf of Māori.

Qualitative methods are best suited to meet this purpose, thereby allowing a Māori voice from existing experts and the literature. Three Māori experts in the field of health were interviewed. Māori participants were not hospice or palliative care patients or staff; they were purposefully recruited based on their expertise about te Ūro Māori (the Māori world), health and dying. Recruitment was based on the expert advice of Dr Joanne Baxter\(^{120}\). Of the three participants, two remain anonymous and the third is Dr Paratene Ngata. Of the other two, one is a senior health professional and academic, while the other is an experienced health

\(^{119}\)“This whakatauaki (proverb), ... comes from the East Coast tribes who are bound by common descent from the waka Takitimu” (Payne, et al., 2003, p. 85).

\(^{120}\) Dr Joanne Baxter is a senior lecturer, Hauora Māori, in the Department of Preventive and Social Medicine, Dunedin School of Medicine, University of Otago.
professional in a public hospital who deals with day to day care issues for Māori. The former shall be referred to as Peter and the latter Keriana. There are also some quotes from ‘Louise’, a Māori participant who had terminal cancer, who was mistakenly recruited by hospice staff and I thought it inappropriate to stop the interview once the participant had been asked, read the information and consent forms, and then agreed to a time and place.

The interview schedule focused not on the participants’ own spirituality, but rather their views about Māori end-of-life/hospice care such as current provision, needs, barriers and ideal approaches. Thus what follows reports on three sources of information: a review of literature that comments on Māori spirituality and dying, the expert interviews, and other interviews from Study One that commented on Māori concerns. A final discussion brings these together.

Lastly, in terms of introduction, I have positioned myself ontologically and epistemologically above (see Methodology Chapter Three). However, in summary, I approach research and the concept of health holistically. That is, I understand spirituality (te taha wairua/wairuatanga) to be a primary, inherent and integrative side to being human. The holistic models of te whare tapa whā (Durie, 1998b), te whēke (Pere, 1997) and fono fale (Capstick, et al., 2009) begin to express how spirituality sits within being human, but inevitably models, theory (and this work) reduce spirituality to less than it is. However, this approach is justified so as to understand and improve the spiritual care of those dying in New Zealand.

6.1 Literature Review

Te taha wairua is generally felt by Māori to be the most essential requirement for health (Durie, 1998b, p. 72)

The framing of the importance of te taha wairua/spirituality for Māori is examined in a number of contexts, including the Treaty of Waitangi (hereafter the Treaty) (Berghan, 2007), Māori models of health, and existing literature pertaining to te taha wairua. As expressed in Durie’s quote above, traditional and many contemporary Māori consider spirituality/te taha wairua to be key to good health and well-being/hauora (Durie, 1998b). A semi-permeability

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Note, I do not claim there is any homogeneity of ‘Māori spirituality’. However, like spiritualities generally, there are some things that can be said. Reid, a Māori scholar and medical doctor argues this well, “People ask: what’s the Māori way, or the Māori perspective or whatever. It’s plural, it’s diverse, it’s multiple, it’s flexible, it’s changeable. We must resist people trying to make us into museum exhibits of past behaviours. We are complex, changing, challenging and developing – as is our right” (Reid, 2005, p. 47).
exists between contemporary spirituality and Māori spirituality, for unlike religious spirituality, Māori spirituality as expressed by Durie and others, is inclusive, essential and fundamental, in their words:

Without a spiritual awareness and a mauri (spirit or vitality, sometimes called the life-force) an individual cannot be healthy…. (Durie, 1998b, p. 70)

Māori remained convinced that good health could not be gauged by simple measures such as weight, blood pressure, or visual acuity. Spiritual and emotional factors, though more difficult to measure, were equally important. (Durie, 1998b, p. 77)

Connection with the spiritual realm is a fundamental part of the Māori ethos. (Berghan, 2007, p. 20)

The Treaty (1840) is the founding document of New Zealand, a key part of our unwritten constitution. It details the relationship, rights and responsibilities between the Crown (now New Zealand Government) and Māori or tangata whenua (the people of the land) and was “largely ignored by successive governments” (Signal, et al., 2004, p. 222) until the mid-1970s. There are three ‘Articles’ of the Treaty: 1. kawanatanga (governance); 2. tino rangatiratanga (autonomy, self determination, continuation of property rights); 3. oritetanga or equity. These may be understood as three principles “partnership, participation, and active protection” (Waa, Holib, & Sponola, 1998, p. 2). The third principle, protection, is critical for Māori health as it mandates all necessary means be taken to ensure “Māori are able to enjoy an equitable health status compared to non-Māori” (Waa, et al., 1998, p. 3). In New Zealand, Māori do not have equitable health status, and by almost every indicator, from cancer rates to incarceration, they are affected disproportionately (Rochford, 2004; Signal, et al., 2004; Walker, et al., 2008). The importance of the Treaty cannot be underestimated in all New Zealand contexts, contemporary spirituality included. A case may be made that lack of attention to te taha wairua by the Crown has been causal in Māori ill-health and that this is a historical and contemporary example of not meeting Treaty commitments (Berghan, 2007).

To understand health ‘for and by’ Māori, it is important to understand te Āo Māori (the Māori worldview). In this context, Māori models of health allow for te taha wairua to be seen broadly. Mead\(^{122}\) contextualizes te taha wairua within tikanga (Māori “customary values and practices”), matauranga (“Māori knowledge”) and kawa (Māori protocol) (Mead, 2003). Mead further notes that each Māori child is born with spiritual attributes that include tapu

\(^{122}\) Mead goes into quite some detail regarding the “characteristics of wairua” and things that can damage wairua, which include “makutu (sorcery), ..., robbery, ..., drugs .... ” (Mead, 2003, p. 55).
(sacredness and associated with whakapapa or ancestry), mana ("prestige"), mauri ("spark of life") and hauora ("spirit of life, health, vigour") (Mead, 2003, pp. 363, 358). Similarly, Rochford notes that wairua is closely related and depends on whenua (land) and whakapapa/tipuna (ancestry and ancestors) (Rochford, 2004).

The ubiquitous (in policy and curricula) and best known Māori model is te whare tapa whā, as depicted in Figure 6.1 (the four cornerstones of health/four side of the house), which includes taha or sides: te taha tinana (physical); te taha hinengaro (mental and emotion); te taha whānau (social); and te taha wairua (spiritual) (Durie, 1998b; Rochford, 2004, p. 47). There are other models (for example Te Wheke, the octopus, with eight dimensions (Pere, 1997)), but the ‘tapa whā’ is the most often used and accessible model. The importance of situating te taha wairua in this holistic model is to note that the ‘taha’ are inherently connected and for Māori health (and by extension Pākehā) to be addressed appropriately, each ‘taha’ (side) of the ‘whare’ (house) needs consideration (Walker, et al., 2008).

(Ministry of Education, 1999, p. 31)

FIGURE 6.1 Te Whare Tapa Whā

Durie notes that “Underlying the whare tapa whā model is the consistent theme of integration” (Durie, 1998b, p. 73).
Contemporary spirituality and te taha wairua are not considered to be the same thing — but they are connected (Ministry of Education, 1999; Rochford, 2004). Dictionary definitions are always limited, but it is useful to see how ‘wairua’ is defined in the Te Aka Māori-English Dictionary:

Wairua: (noun) spirit, soul, quintessence - spirit of a person which exists beyond death. To some, the wairua resides in the heart or mind of someone while others believe it is part of the whole person and is not located at any particular part of the body. (Te Kohure Textbook (Ed. 2): 221-228 cited in Moorfield, 2005).

This is the first part of a long definition which refers to a range of te Ao Māori concepts (highlighting the need for understanding of this worldview (Ngata, 2005)). The key factor here is that wairua is named as the “spirit, soul, quintessence - spirit of a person which exists beyond death” (Moorfield, 2005), thus it is closer to the religious/transcendent idea of soul, as opposed to a secular ‘spirit of a person’. There is a distinction between ‘spirit’ and ‘spirituality’ that is seldom made in the academic literature — this seems to parallel ‘wairua’ and ‘te taha wairua’. Wairuatanga, another term for spirituality, is also used (Mead, 2003).

This said, it must be noted that wairua and te taha wairua are used interchangeably in much of the literature (Jansen, et al., 2009).

Spirituality becomes increasingly important near, at and after death (Durie, 1998b; Mead, 2003). Both Durie and Mead explain that the spirit stays around the body for some time after death (Mead, 2003, p. 58). Mead notes it is not uncommon for those near death to see and/or communicate with dead relatives: “There is a time before death when the wairua of the person is more able to commune with the wairua of the ancestors. Some report being visited by their relatives long-since dead” (Mead, 2003, pp. 148-149). While these processes and relationships may be difficult for Western science to understand, Shirres makes the point that the person dying becomes more tapu as he or she come closer to death (Shirres, 1997). Whether one accepts this or not, these processes may be important for those in hospice care, thus, at least, staff need to be cognizant of them.

According to Mead, the central importance of death is reflected in the tangihanga, the Māori ceremony of death (Mead, 2003, p. 133). Oppenheim has examined the tangihanga ritual in detail (Oppenheim, 1973), supporting the positions taken by Mead. Ngata affirms this position,

Illness, dying, death and grieving are a central part of Māori life. They are imbued with tapu (sanctity) and kawa (ceremony). The formal rituals and practices are elaborate, and the reo (language), karakia (invocations) and waiata
(chants and songs) are symbolic and poetic, encouraging emotions to be openly expressed (Ngata, 2005, p. 29).

Wairua, wairuatanga and te taha wairua, according to the literature discussed above, are central to Māori health and well-being. Further, the literature affirms the importance of an integrative view of health/hauora, with te taha wairua threaded throughout the weave of well-being.

6.2 Qualitative Results

The following reports thematically on the four Māori interviews. The three Māori experts’ interviews were analysed in a similar way to that explained above (see Chapter Four). There were 16 codes identified and used in the process. Two meta-themes were identified: a Māori worldview (te Āo Māori) and spiritual care at end of life. A Māori worldview encompassed the sub-themes of definitions, death/death rituals, cancer perceptions and transcendent experiences. Spiritual care included the sub-themes of ideal end-of-life care, Māori in hospices, cultural safety, barriers and the importance of spiritual care and structural issues. The final part of this section reports on non-Māori comments about things Māori in hospices, particularly by staff in relation to access and cultural appropriateness.

6.2.1 Māori Worldview

Rangi and Papa-tū-ā-nuku, those primeval parents and that is the Māori view and beyond that all the twinkling stars of the whetū rangitira, all the ancestors up there, in Rangimui’s domain, you know I think that’s a lovely – that’s my world view (Dr Ngata)

6.2.2 Definitions

Dr Ngata cogently situated spirituality within his Māori worldview, as he saw it “within the Māori world we have a very clear view”. Central to Dr Ngata’s view was connection, “one of the single most important words is about connecting and connecting generations, connecting families, … that connection between people”. Dr Ngata expressed an unambiguous certainty
about spirituality, “we know there is the spiritual stuff because the spiritual stuff is connected with the past and the future. That is the connecting bit and I am not too sure medicine is ready”.

Another of the Māori participants had a key role in a hospital. Keriana made the point that it was hard to make any generalizations about “Māori spirituality”, as “people may be from the same iwi, from the same hapu, but they still have different spiritual beliefs”.

Like Dr Ngata, Peter described spirituality in terms of relationship and integration, in his words, “I call it the communion, ..., communion in being able to commune with something and it might be immaterial, it might be an inanimate something or person”. This is not unique to Māori, but Māori have been able to “articulate ... and give it credence and credibility”. Thus Māori, Peter said, have been “less hesitant to talk about it [spirituality] and in talking about it freed it up for everybody”. This is an important observation as spirituality has been ‘freed up’ in New Zealand, particularly in health and education theory and strategies (Ministry of Health, 2000).

Peter noted the difference between spirituality and psychology: “I have tended to see it as one going in and one going out”, that is, “empirical and rational is the psychological background to explain things whereas I think intuitive and transformative is the spiritual way and transformative meaning transcending actually rather than transforming”. Peter’s observations here are insightful, as the debate about this relationship is far from clear in the literature. This behavioural and reductionist focus of psychology compared to the integrating and transcending focus of spirituality is notable.

6.2.3 Death/Death Rituals

Dr Ngata talked about the “inevitability” of death as a “stage of life”. There was an implication that for him, and he was generalizing about Māori, that there was an acceptance of death. This was further evidenced as Dr Ngata talked about “a readiness” that many Māori have for death. Louise, the Māori woman interviewed dying of cancer, noted she knew there was something seriously wrong with her. She held off going to the doctor for as long as possible. Dr Ngata also made some interesting comments about dying of cancer. He suggested there is a positive aspect,
that is the good thing about dying from cancer if there is such a good thing around that. You can prepare, and then you can ensure that things are – you still have some semblance of control at your end of stage life and make the appropriate arrangements and give the appropriate instructions or ake as we say.

Regarding arguments about what happens to the body of the deceased, Peter noted “without the argument means not being properly respected. If you don’t have an argument at your tangi about what will happen to you then nobody must care very much”. This is an important insight for mainstream health services (and media).

6.2.4 Transcendent Experiences from te Āo Māori

The ability of special intuition, prophecy, special sight or “matakite” was noted by all of the participants as a normal part of some Māori dying experiences. Dr Ngata suggested that “many people have ... a level of consciousness, ... So there is a readiness too. A readiness to see nanny [grandmother]”. He went on to say, “things like matakite and that, is part and parcel of that transition process that is talked about openly”. Louise had literally experienced seeing her dead “nanny” who “had made a place for me” and “My tipuna [ancestors] yeah, absolutely, they help me, they guide me”. Louise talked about the friendly spirits she would see in the hospice, who were mostly “the ones who love you”. Further, Louise said,

Sometimes ‘spiritual’ comes from the other side if you know what I mean, in the form of spirits. Yeah, see that to me is got a lot to do with spirituality, spirits, actual spirits and dealing with seeing these spirits or feeling these spirits because I don’t know, Māori, you get to a certain age and you start feeling things that you can’t explain and I don’t think you can explain spirituality really, can you?

Peter expressed an understanding of the spirit world, again as a natural part of many experiences of Māori. He did note that “The trouble with talking to scientists and doctors about it is they want to explain it”, yet it “is not based on empirical approaches and understanding” so difficult to rationalize. These insights about transcendent experiences including the paranormal, transpersonal or mystical sides of life, are important because these are people’s (and in this case many Māori) experience.
6.3 Spiritual Care

6.3.1 Spiritual Care Generally

The overwhelming theme regarding spiritual care from these participants was that it happened by or through whānau. Dr Ngata notes “spiritual care is provided by the family … and that is based around the family’s resources and the family’s belief systems”. This care may also come from a minister or elder who has family connections.

Peter noted the importance of spiritual care at end-of-life as it is not about curing a person, thus allowing “another dimension to come in or forces it even”, with the “ultimate end” being “healing”, “dying with dignity and without pain”.

Two of the participants talked about the “tone of voice” being critical as part of the “ingredients for spiritual care” (Dr Ngata). These ingredients also included “aroha”, “manaaki” and all of “the values”. Here Dr Ngata situates spiritual care within traditional Māori values.

Dr Ngata reiterated a number of times in the interview that the rituals of encounter and the tangihanga were “spiritual encounter[s]”; in his words,

\[
\text{we keep it [our spirit] well by creating a bit of time and space of a day or of a time or of an occasion, of an event where it is acknowledged when there is always an encounter between people, you know manuhiri visitors and manuhiri and tangata whenua or hau kainga or hei ka, there is always an opportunity in that ritual of encounter and that’s within the Māori world that’s how that spiritual dimension is acknowledged and maintained in my view, in the talk. tihei mauri ora , I breath it and it is life. E nga mana, e nga reo, all those who have gathered here, mihiatu, haere mai, nau mai, piki mai, welcome, welcome, welcome thrice. Kawea mai ngā āhuatanga bring with you, o koutou mate, your bereaved, your recent bereaved, ngā mate huhua, those who have just died, hei aha they join in join ours. Takoto mai kei konei, bring them here, hei aha kia tangi tahi so we can both grieve for those who have just passed on, ki tau wairua. Then we say those, so kia tuhono hono bring our bereaved together, no reira koutou ngā mate haere, farewell, he, go, kia ratou, to those who have gone before you.}
\]

This long quote is included to show the importance of Māori rituals of encounter, such as mihi and tangihanga, as a spiritual encounter. Dr Ngata has highlighted these rituals as occasions that create time and space for connections and relationships with people present and passed away, the place and whenua (land), and the unseen, to be acknowledged and fostered.
Reiterating Ngata’s position, Peter said of spiritual care “I think it is in the tone of the voice. I think it is more about the relationship”. Peter went on to say that spiritual care is “much more than instrumental language and technical advice”, but it is “about making a connection, ... . That’s the key to spiritual care and I don’t know that everyone has an ability to do it”.

Peter was asked whether this type of spiritual care, with a connection at its centre, was able to be taught. He thought it came down to empathy and while this could be encouraged and developed, whatever the case Peter did not “think that you could expect every hospice worker to be able to engage in some sort of spiritual relationship with every patient”. That is, there needed to be “a fit there” regarding the appropriate relationship for good spiritual care. Peter suggested “a good manager will be aware of that” and assign the appropriate person for the patient.

Regarding spiritual assessment, Peter suggested a person first needs to have had their basic needs met, “be free of pain, ... hunger, ... anxiety, that would create the prerequisites ... to have a sense of spiritual freedom..., or a sense of spiritual contentment”. Therefore a spiritual plan, Peter said, would initially be about “overcoming the barriers to spiritual contentment”, which includes,

being able to identify for that particular patient where the spiritual contentment is likely to lie with people, with a lot of people, with one or two people, with a particular bit of land. This cousin I was talking about who was dying, one of the reasons she came back here to die was that she wanted to go to a particular piece of land and that I think was.

Peter notes this contentment is again about connection and communion both with people and in this case the land.

Dr Ngata talked about the importance of te reo, waiata and karakia, saying they literally were therapeutic via “rongoā healing of the voice and healing of the language” which creates a “sense of calmness”. Also, Dr Ngata noted the importance of body language “particularly with the elderly people” when meeting someone dying or at a tangi. This is a time, Dr Ngata said, that “is not a rushed process, people need time to stop and reflect, to contemplate where they are at, and that’s part of that encounter”.
6.3.2 Ideal End-of-Life Care

Ideal end-of-life care for “most Māori”, Dr Ngata suggested, was “to have their end of life care provided at home”, where the “family manages the process” including the “spiritual care”. Dr Ngata talked about the importance of “control”, control of the processes around death and dying and control such that the family felt empowered. This came down to the very practical issue of space and time, thus allowing the family room to attend to these issues.

Peter highlighted “comfort” as the ideal goal in end-of-life care. This has two aspects Peter suggested, physical comfort and “human comfort” — “So the ideal place I think would be a place where those two sources of comfort could be combined together”.

6.3.3 Cultural Safety

The concept of cultural safety\textsuperscript{123} was raised by Peter. In the context of caring for Māori through hospice, Peter wondered whether “by Māori, for Māori” was the best or only approach. He suggested there were pros and cons, as “sometimes it is no better or no worse than any other provider”. What Peter did note is that “a Māori provider would have a better sense of cultural relevance and maybe able to relate that on an intuitive level, ..., it is a bit easier to touch the soul of the other person if you share the same background and culture”. Relevant to all ethnicities, Peter said regarding cultural safety “if you understand yourself, ..., your own culture and what you take for granted, ..., it will be easier for you to relate to other people”. This idea extended to the awareness that at times the carers may “not be tuning in”, thus need to refer on to someone who can. There is a sense of “spiritual safety” (Dr Ngata) within this cultural safety ambit. In this context, it is important to consider barriers for Māori end-of-life care.

\textsuperscript{123} Irihapeti Ramsden suggests “CULTURAL SAFETY is an outcome of nursing and midwifery education that enables safe service to be defined by those that receive the service” (Ramsden, 2002, p. Chapter 8). The concept of cultural safety is complex and has relevance across the health sector, with this definition not doing it/or Ramsden’s thesis justice, but begins to show what it is about.
6.3.4 Barriers to Spiritual Care

The primary barrier identified by Dr Ngata stems from his affirmation of healthcare organisations for becoming more “Māori friendly”. However, a barrier to Māori accessing services is not understanding the significance of key Māori rituals and values, for example the spiritual importance of the mihi. This may be understood as an extension of cultural safety, “spiritual safety is a good word to allow all that – that’s a good word so that whakapai [to improve, bless], whakamoemiti, whakawhetai [praise, thanks]” can happen. Dr Ngata said that barriers to be able to do this are “attitudinal” or “institutional ones, and they are often around space and time”. When asked about making spiritual care explicit, Dr Ngata thought this was important, so as to “create a space for it to happen, unless it is there it won’t happen, unless the space is there”. Secondly, Dr Ngata suggested “the health system has been driven by the needs of the doctor and the nurse” implying a re-focus on the needs of the patients and family members is called for. Keriana said, of the hospital, that the biggest barrier was the “non-availability of the chaplain”, referring to the Māori chaplain who was not always on call.

Peter suggested that presuming things about Māori patients can be a barrier. For instance, “the link a person has with their family, presuming that it is all good” may “create quite a bind for the patient”. Thus the importance of careful assessment is highlighted. Lastly, Peter suggested “go easy on the guidelines” as they have the potential to compartmentalize spirituality, which is the exact opposite of the holistic nature of spirituality.

The participants were asked how spiritual care could be improved at a structural level. As noted above, Peter cautioned the systemization of spiritual care. Dr Ngata said the growth and understanding of spirituality and spiritual care “will be incremental”. Regarding teaching it in medical schools, Dr Ngata thought it would happen eventually, “but they are struggling with what they are doing now” and “maybe it is not quite the time”. He compared introducing spiritual care to medical students with Māori health, which “has taken us what, 25 years”.

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6.4 Hospice Staff Comments

Of the other 48 non-Māori interviews, many of these participants made comments about Māori spirituality or the place of Māori in hospice care. Patients and family members mentioned this very little, with the exception of one patient who commented that Māori were more connected, more spiritual. In the interviews with staff and chaplains/spiritual carers, questions and comments where often raised about things Māori.

Chaplains raised a number of considerations about Māori. One chaplain noted the importance of “spirituality and spirit forces … in the Māori realm”. He said “their ancestors are around” and noted this was “less common” with Pākehā, “but increasingly they are taking an interest in their relatives who are beyond the veil”. Regarding trying to make the place welcome for Māori, another chaplain noted the staff “work hard at being culturally appropriate”. This latter hospice was the same one that Peter had had a very good experience of with his whānau.

A hospice nurse noted the importance of developing “connections … with Māori health providers”, taking time, developing respect and the basis for good communication (Ida, 45, hospice nurse). Ida made the important point that was commented on by Peter above that it is important not to assume anything. Her team had developed a “Māori health plan” and were in the process of appointing a kaumatua.

A number of hospices actively create space in their buildings for whānau to come and sleep over with their dying family member. There was a literal recognition from a palliative care specialist that “for Māori … their family is where they get a lot of their spiritual support from and they need their family around them”. Other hospices actively populate their walls/space with Māori motif and symbols.

Another palliative care specialist suggested Māori perspectives added to spiritual care in New Zealand and palliative care. He hoped that Māori will lead the way and that we have a huge opportunity in New Zealand to lead the world with spiritual care.
6.5 Discussion

Māori are quite comfortable around death (Chair, 2005, p. 41)

This chapter has aimed to appropriately record some Māori views about spirituality and hospice care. The discussion has extended beyond hospice to spirituality generally and death and dying processes and beliefs. From these interviews, there was a clear expression of the centrality of te taha wairua and its integration into te Āo Māori. Dr Ngata highlighted this position when he wrote to understand death in the Māori world, one needs to understand te Āo Māori; a worldview that implies an understanding and relationship with the animate and inanimate world, an interconnectedness and interdependence of all things (Ngata, 2005, pp. 29, 32). Reid and Keriana (interview participant) qualify this position noting that care needs to be taken not to homogenize all Māori into one group. Moreover, it has been argued that “practices surrounding death and dying [are], ..., important indicators of Māori health overall” (Reid cited in Schwass, 2005, p. 45).

The importance of te taha wairua was common among all the participants and in the literature. Durie has noted that te taha wairua was as “a ‘missing link’ in health services”(Durie et al, 1993 cited in Ahuriri-Driscoll, et al., 2009, p. 19). This is a salutary reminder for hospice care to keep in mind its spiritual care mandate; to do so will improve care for Māori. The participants expressed a broad understanding of te taha wairua, including the importance of connections and relationships with the past, present and future, with whānau alive and dead, and with the land and one’s marae. Rituals, such as tangihanga and mihi were highlighted as significant events that “embodied spirituality”. Further, spirituality was expressed as transformative, transcendent and an intuitive expression “seeking something beyond self”.

Understanding the importance of te Āo Māori, and the integrated nature of spirituality with and connected to land, whakapapa, tikanga, mauri, mana, tipuna and Atua, was expressed as an opportunity and potential barrier in hospice care. This worldview is an explicitly spiritual one that hospice can learn and be open to, but likewise lack of understanding does and could continue to create barriers for Māori (Reid, 2005).

Spiritual care was expressed by the participants as something beyond instrumental and institutional, focusing rather on relational and communion. Delivery of such care was noted as important, with “tone of voice” literally creating a connection or a barrier. Time and space for spiritual care were named as critical components, with most spiritual care happening
through whānau and ministers close to the whānau. Home, Dr Ngata noted, was the primary place of care and desired place of death.

Hospices, it was noted by Māori participants and some staff participants, are trying to “create a space for it to happen” (Dr Ngata interview) with Māori responsiveness plans, bringing kaumatua and kuia on board and extending links with Māori communities and health organisations. This was not consistent across the hospices where interviews took place. Barriers were identified by Dr Ngata and others as structural and attitudinal, with a need to improve cultural and spiritual safety to attract more Māori.

The New Zealand Palliative Care Strategy (2001) (NZPC Strategy) made some pertinent comments about Māori palliative care provision. One of its “priority objectives” is “to ensure accessible and appropriate services for Māori” (Ministry of Health, 2001, p. 5) and the NZPC Strategy requires local palliative care services to develop a plan with local Māori to make this happen. Further, the NZPC Strategy notes there is “a lack of awareness about palliative care services among Māori”, there are no Māori palliative care providers, there needs to be better coordination between Māori healthcare providers and palliative care providers, and palliative care providers need to “understand the whānau model of health and illness” (Ministry of Health, 2001, p. 46). Further, the Strategy acknowledged that there are “cultural barriers, in particular for Māori and Pacific people” to accessing palliative care (Ministry of Health, 2001, p. 4). These issues have been raised by the participants herein, thus continue to be issues, but some changes have been observed.

Māori die at home more than other ethnic groups in New Zealand (53% die at home compared to 31% Pākehā (Ministry of Health, 2001)). National statistics on Māori utilization of hospice services are lacking, but based on both the studies in this research, the NZPC Strategy and expert advice, Māori generally do not use hospice services as much as they could. There are exceptions, and Professor MacLeod suggests that Māori come to the hospice when they have heard of other whānau having a good experience. In his interview, Peter said his whānau had had a “wonderful experience” and a “remarkable fit” with their local hospice. On reflection, Peter suggested “it was a masterful blend of being around but not intrusive, to being caring but not intrusive and allowing things to happen but also being able to keep to some sort of routine”. Peter also commented on Māori use of hospice generally. He said

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124 Personal communication with Professor Rod MacLeod
“there was a sense then that Māori didn’t use the hospice very much. But I think that has changed”. This was, according to Peter, partly due to overcrowded Māori homes, where it may be “difficult to care for someone when you have got a lot of people around”.

Peter’s positive experience with hospice led to a reflection about the positive nature of time that hospice allowed: “The medical — conventional medical response often exacerbated anxiety rather than relieved it, so the management of anxiety as well as the management of pain is something the hospice does rather well”. When asked whether this was particular to Māori, Peter said that the need for spiritual care is a “universal experience”, but what is unique for Māori are some of the foci such as the need to connect with one’s marae and land.

Keriana said of Māori dying in hospitals that they almost all asked for some kind of religious minister for spiritual care. Dr Ngata reiterated Peter’s comments about the growing acceptability and accessibility of hospice for Māori. He said they are “becoming much more friendlier, Māori friendly”, with such things a “whānau room” and an openness to traditional healers, whereas “historically kaiawhina ... and healers, traditional healers only went in the middle of the night to take care of the pastoral needs”.

Regarding cancer death, Dr Ngata highlighted the positive side a cancer death process may afford, giving time to work things through with whānau and, secondly, the importance of retaining some control in this journey. This latter point is particularly important for hospices, for control is directly related to one’s ability to retain choice, dignity and a level of comfort.

Māori contributions have been significant to New Zealand’s understanding of both death and spirituality. The whakatauki (proverb) that started this chapter “Place the things of the Spirit to the fore...” expresses an overall theme that is extended by Dr Ngata’s call for space and time for this to happen with and for Māori and, by extension, for all. This final point is important, as what is good for Māori is usually good for all New Zealanders. Māori have helped to give “credence and credibility” (Peter interview) to spirituality and this debt needs to be acknowledged by hospices through more making “space and time” for Māori affected by terminal cancer.
7 General Discussion

7.1 Introduction

Internationally, spirituality in hospice care, where such care is mandated, is a “thriving research field” (Sinclair, et al., 2006, p. 464); remains controversial (McCord, et al., 2004); has multi-disciplinary academic influences; is not captured by any school, science or denomination; has cultural and geographical differences; is beginning to be taught in many health professionals’ pre/in-service training; and research on it is critically important to inform practice and policy. In New Zealand, this research is in its infancy and my research is the first nationwide study to examine spirituality in hospice care. McGrath suggested research into the “concept itself” is a “significant part of the task of exploring spirituality” (McGrath, 1999, p. 3); this thesis included this premise and aimed to examine how those affected by cancer in New Zealand hospices understand spirituality, asked if they thought it was important, considered unmet spiritual needs, asked if there are particular Māori spiritual issues, and ultimately considered how spiritual care might be improved in New Zealand hospice care. The following discussion is structured around these points, with the exception of most of the Māori component, which is discussed in Chapter Six above.

Contemporary spirituality is defined by eclecticism and plurality, thus has a wide canvas that encompasses the religious, ethnic and demographic heterogeneity that is modern Western countries. Further, it has been strongly argued (Taylor, 2007) that the modern democratized spiritual environment is characterized by an ontic fragility, of which hospice care must be cognisant. Hospice care aims to maintain or improve quality of life for those affected by terminal illness (Saunders, 2004), with religious and spiritual issues central to this mandate (Okon, 2005). Dying, it is argued widely, inevitably raises spiritual and existential issues (MacLeod, 2003; McCord, et al., 2004; Steinhauser, et al., 2000; Sulmasy, 2002)} and may be an opportunity for spiritual growth (Cobb, 2003); this is often true for patients, their families (Murray, et al., 2004) and hospice staff. Since the 1960s, there has been growing academic

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125 Hereafter, my thesis research shall be referred to as Study One, Study Two, the ‘Studies herein’ or the ‘present research’. Study One refers to the qualitative work, and Study Two the survey. Where percentages are quoted, unless stated, this refers to Study Two results.
and lay interest in these issues, partly due to growing spiritual distress and partly due to the postmodern environment in health and especially hospice care that has re-discovered the importance of spirituality. The idea of a contemporary “good enough death” (McNamara, 2004) must take into consideration this postmodern context, which also includes the growth of ‘the long dying’ due to the prevalence of non-communicable disease, especially cancer, constant changes and challenges in health care, and demographic changes (especially the ‘ageing and browning’ of New Zealanders). A summary of the key findings of this research are in the table below.

Table 7.1 Research Findings Highlights

<table>
<thead>
<tr>
<th>Research Finding Highlights</th>
<th>Study One</th>
<th>Study Two</th>
<th>Literature</th>
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<tbody>
<tr>
<td>Spirituality is broadly understood, universal and at times related to but different from religion</td>
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<tr>
<td>Spirituality is important in New Zealand hospice care</td>
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<td>Spirituality is more important for staff than institutions in New Zealand hospice care</td>
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<td>Formal religious attendance is higher than the total population (29% monthly)</td>
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<tr>
<td>Spiritual practice is high (50% monthly) compared to UK figures</td>
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<td>√</td>
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<tr>
<td>The majority believe in God (70%), the afterlife (79%) and many believe in paranormal events (50%+)</td>
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<td>Terminal cancer may be a time for spiritual growth</td>
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<td>A sense of meaning in life is very high, mostly focused on family</td>
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<tr>
<td>Terminal cancer often causes a reprioritization in life, reflecting a common spiritual/existential upheaval following diagnosis (for patient and family members)</td>
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<td>Spiritual concerns are a major focus of the ‘work of the dying’</td>
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<td>Spiritual needs are experienced by the majority of people affected by cancer, especially related to meaning, peace of mind, regret and fear</td>
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126 Survey questions may not have asked about the particular issues, so no tick is not a negation of the position.
Most people want spiritual care (two-thirds (67%) of all samples) &nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&nbsp;&n...
The samples studied in this research were reasonably consistent in their understanding of spirituality, in that, apart from one or two exceptions, spirituality was broadly defined, reflecting a plurality of approaches. The exceptions were “hardcore” religious people who could not conceive or believe that spirituality existed outside of a religious framework. There were a number of interview participants, patients and family members who had not really thought about this area and had no idea of a definition, but when explored further had deeply held values, beliefs and meaning in life. This phenomena, of the spiritually inarticulate, has also been found in other studies (Chochinov, 2006). Then there was the larger group of interview participants who were spiritually articulate, and increasingly so due to their illness or because of other’s illness. Their definitions of spirituality ranged from fundamentalist religious spirituality through to humanist/atheist and eclectic summative spiritualities. This section will discuss how these samples understood spirituality, how they rated its importance, and consider how this affirms or disagrees with the international literature.

How spirituality is understood in the New Zealand hospice context has been influenced by history, international developments and national influences. Historically, it was not until after the mid-20th century that spirituality began disentwining itself from religion; in Western countries the “secular age” developed, a time of spiritual plurality, existential fragility and widespread meaninglessness (Taylor, 2007). Spirituality had been missing in the health discourse until recently, but since the year 2000 publication growth has been exponential (Williams, 2006). As William James said of religion (and today he may have used the term spirituality), “we are dealing with a field of experience where there is not a single conception that can be sharply drawn” (James, 1902, p. 45). However, there is a clear semantic movement towards an eclectic and existential understanding of spirituality (Cobb, 2001). Hospice care was seminal and leads the way in health, literally recognizing the spiritual dimension with Saunders’s modern hospice movement from 1967 (Have & Clark, 2002).

In theory (Ministry of Health, 2001) and practice, spirituality is on the agenda in New Zealand hospice settings, due to both hospice philosophy and the credibility created by the importance of taha wairua/spirituality to Māori (Durie, 1998b). Internationally, spirituality is widely contested in the wider health field (Bregman, 2006b), but clearly on the agenda in hospice care (National Institute for Clinical Excellence, 2004).

127 This term “hardcore” was used by one of the young people interviewed with terminal cancer. She said of herself that she was a “hardcore Christian”. 

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7.2.1 Importance of Spirituality

One aim of this thesis was to examine the importance of spirituality for people affected by terminal cancer in New Zealand hospices. The unequivocal majority position was that spirituality was very important, particularly for those with terminal cancer. The literature affirms this position (Strang & Strang, 2002, p. 857; Williams, 2006; Wright, 2008). Steinhauser et al.'s qualitative study identified six components in a 'good death' for patients, family members and staff (Steinhauser, et al., 2000). Four of the six components ("preparation for death", "completion", "contributing to others" and "affirmation of the whole person" (Steinhauser, et al., 2000, p. 2476)) fall within the broad understanding of contemporary spirituality, thus further affirming the importance of spirituality in the end-of-life context.

7.2.2 Paradigm Clash

There is a possible paradigm clash regarding the 'spirituality importance' issue between the institutional and biomedical approach and the healthcare professionals and hospice philosophical approach. The former pays, at best, lip service (Rumbold, 2002a) or disdain (Randall, 1999) to spiritual care, while the hospice approach, and for most of the staff (certainly in the studies herein), spirituality is central to provision of care. Writing about chaplains in healthcare, Norwood examines this issue, suggesting chaplains are structurally and ideologically marginalized (Norwood, 2006). Structurally in the sense that their place in hospitals is marginal in terms of power and the existing hierarchy, ideologically in the sense that the biomedical perspective reigns in hospitals, a religious or spiritual approach is marginalized. Norwood suggests chaplains sit "somewhat precariously between competing paradigms of science and religion" (Norwood, 2006, p. 3). This is a useful analysis as it may be extrapolated to spiritual care generally. This paradigm clash was not particularly evident in the hospices in the studies herein. However, in the interview sample of hospital patients, staff members and chaplains, a disjunction was clearly evident between the primacy of spirituality for patients versus the lack of priority in hospital systems.
7.2.3 Religion

When the results of both Studies are considered, it is clear that spirituality as a concept was meaningful and useful in these samples, with less than 2% of all samples thinking that spirituality was meaningless. The majority of all samples said that spirituality did not include religion, or, more commonly, spirituality was something much more inclusive that may include religious beliefs. For instance, 78% of all samples surveyed excluded religion from their definition options. In the interviews, even those who said that spirituality equalled religion more often than not went on to qualify that this was their initial understanding, which had since expanded. There was an anti-religious theme through many of the interviews, which has been noted in other studies (Sinclair, et al., 2006). Further, Chiu notes that in the more recent definitions there were “fewer religious terms” and more focus on “self”, while “meaning and purpose” were less common and transcendence was becoming more common (Chiu, et al., 2004, p. 422). Many explanations are possible for Chiu’s observations and the New Zealand findings do not support the “meaning and purpose” proposition. Suffice it to say these positions are consistent with the common position that argues spirituality is becoming less religious.

7.2.4 Descriptors

Regarding the details of the spirituality definitions, Study Two revealed four descriptors for spirituality that between 50-60% of all samples affirmed: ‘values’, ‘beliefs’, ‘meaning’ and ‘purpose’. Then another four descriptors gained a 40-50% response: ‘faith’, ‘awareness’, ‘connectedness’ and ‘relationship’. The descriptor ‘God’ had a 39% response across the three samples. ‘Values’ was the most popular choice for patients and family members (51-52%), while ‘meaning’ was the top choice for staff (75%). A question that arises in the literature concerns the different understandings of spirituality that health professionals have to the public (McSherry, 2007, p. 184), and whether this is an issue for competent care. Staff do have a more homogeneous understanding of spirituality than patients/family members, thus there could be some dissonance. However, McSherry describes a situation where UK healthcare professionals have had significant spiritual care professional development (McSherry, 2007) and therefore are in a different semantic place than the UK public. This is not the case in New Zealand. McSherry believes this disconnect between professionals and public has potential for inappropriate care. In New Zealand there is no evidence of this as
eclectic approaches are common across a variety of people. Nevertheless, it may be a timely reminder prior to further professional development, which if it emphasises patient-led approaches, will ameliorate such concerns.

The quantitative results are consistent with the interviews and the literature — that is spirituality is both moving towards a more existential semantic state and an inclusive summative position (Chochinov, 2006; Sinclair, et al., 2006). Definitional discussions from the interviews were dominated by such descriptors as ‘essence’, ‘core’, ‘beliefs’, ‘values’, ‘meaning and purpose’, ‘mindfulness’ and ‘relational’. Differences across samples were most marked between spiritual carers (chaplains) and family members. Spiritual carers had a personal belief in God and were actively religious, but generally understood spirituality in the broadest terms, while family members were the most inarticulate of the samples. Patients were most likely to give humanist definitions, but mostly they too had inclusive concepts. An outlier addition to the spiritual concept was ‘contribution’, as was also identified in the literature (Zielske, 2003). A small number of patients and family members said that terminal illness have changed their whole life orientation towards an empathy and need to help others. This change, for one patient, was qualified within a “spiritual metamorphosis”, which named a common experience for many of those with terminal cancer.

7.2.5 Māori

The Māori experts, while taking care to note differences across iwi, hapu and whanau, said there was a range of understandings of spirituality, which for two experts focused on connections and communion. The literature noted the difference between wairua (as spirit or soul) and te taha wairua or wairuatanga (spirituality) (Mead, 2003), affirmed the connections approach and noted the place of land and rituals (e.g. the mihi and tangihanga) as central to taha wairua (Ngata, 2005).

7.2.6 Challenges/Criticisms

Challenges regarding the spirituality concept are widely canvassed in the spirituality and health literature (Koenig, 2008; Unruh, et al., 2002) and to a lesser degree in the palliative
care literature\textsuperscript{128} (Okon, 2005; Sinclair, et al., 2006). Within this research, some family members and patients found the concept difficult to articulate, rather than understand. One implication here is that if staff did not take time to clearly explain such concepts as spiritual or existential issues, some patients may have these needs missed and therefore unmet.

The most common criticism of spirituality is that it is too broad and therefore becomes meaningless (Sinclair, et al., 2006). However, this was shown to be a strength of the concept for hospices because it allows for the reality of pluralism, thus acknowledging an inclusive approach and the semantic reality. Many of the other criticisms related to cultural or religious impositions of spiritual meanings, for example proselytizing or assuming spiritual beliefs. These are serious ethical concerns which need to be dealt with by the provision of well trained and resourced staff, with a focus led by patient/family member need.

\textbf{7.2.7 Staff/Chaplains}

Staff and spiritual carers'/chaplains' understanding of spirituality was without exception inclusive. Further, among this population, and in the majority of other groups, there was a universalist approach that understood spirituality as part of the human condition. This reflects the international trend, but is not uncontested (Sinclair, et al., 2006). Many staff in this study and in the literature (Rumbold, 2002a) argue that spirituality is not just another ‘box to be ticked’. As one chaplain participant noted, “those sort of models that separate spirituality out, that, I struggle with”. This, the chaplain argued, suggested a spiritual dimension “at some level, [in] every engagement”. This understanding has many implications for spiritual care, as discussed below.

\textbf{7.2.8 Summary}

It is important to understand how the hospice samples in this research understood spirituality, as there is a lack of such research nationally and internationally (Daaleman, et al., 2001). The

\textsuperscript{128} Sinclair et al (Sinclair, et al., 2006) suggest that some scholars in the spirituality and health field are trying to rescue spirituality from religion, implying this is unwarranted and unjustified, is an implicit vilification of religion, and assumes all spirituality is positive. Garces-Foley, like Sinclair, writes about hospice care. She suggests hospice has vilified religion, suggesting, “Religion is caricatured as narrow, superficial, and divisive, while spirituality is extolled as expansive, meaningful, and inclusive (Garces-Foley, 2006, p. 127).
findings herein triangulate qualitative, quantitative and literature sources to give a clear view of how these samples understand spirituality. There are three general definitional categories: 1. a religious/transcendent approach; 2. a behavioural/sectarian/humanist/existential approach; and 3. a summative/integrative/inclusive approach. One can confidently say that the samples studied mostly have an inclusive understanding of spirituality, with primary descriptors including values, meaning, purpose, beliefs and often in relational and faith terms. Further, like equivalent countries (Australia (McGrath, 2002b), UK (Wright, 2008), US (Okon, 2005), Canada (Kuhl, 2005; Sinclair, et al., 2006)), this population mostly understands spirituality to perhaps include, but be something different to, religion. Significantly, in this study, 99% of participants understood spirituality to be meaningful; therefore a strong argument can be made for its utility. The average age of these participants was 56 years, which for some would imply the groups still understand spirituality to be more directly related to religion. This was not the case and such a trend is likely to develop further in the non-religious direction (Heelas, 2006; Mason, et al., 2007). With the above in mind, this thesis’s working definition, as stated in the information sheet, was a reasonable one:

*Please note: ‘spirituality’ means different things to different people. In this study, spirituality includes beliefs, values, sense of meaning and purpose, identity, and for some people religion.*

Obviously this is an integrative/summative definition, which has shown to be relevant and appropriate for the New Zealand context. A case may be made to add one or two descriptors to this definition, such as ‘connectedness’ and ‘awareness’. Spiritual definitions are widely contested in the international literature. However, the Studies here in and other reviews (Chiu, et al., 2004; Unruh, et al., 2002) affirm there is room for consensus, with plurality and inclusiveness being central to this position.

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129 In reality there may be a fourth category of “other” for those who do not fit into 1-3.

130 Based on the literature, the US is not consistent in this perspective. Koenig et al (Koenig, 2001) suggest that religion and spirituality are conflated, however much of the US palliative care literature (Puchalski, 2006d) affirms their difference.
7.3 What are the Current Unmet Spiritual Needs of People with Terminal Cancer in New Zealand Hospices?

To understand spiritual needs, first the concept of spirituality must be understood, as was explained in the last section. Secondly, spiritual beliefs and practices are important in this equation, as to understand the needs of a population one must explore something of what they think, believe and do (Tones & Green, 2004). Thus beliefs and practices are explicated below. Thirdly, in the Studies herein, participants were asked about literal spiritual needs. The literature and the findings from this research affirm the importance of spirituality in end-of-life cancer care (Doyle & Woodruff, 2004) and the desire for spiritual care increases as illness severity increases (McCord, et al., 2004). Just as spirituality is understood broadly, so too are spiritual needs. The literature names a range of spiritual needs, most of which were identified by those asked or surveyed in the present research, but like the literature (Moadel, et al., 1999; Rousseau, 2003), these needs were seldom met by hospice care. Patient spiritual needs have dominated the research (Doyle & Woodruff, 2004; Kellehear, 2000; Sinclair, et al., 2006), with some scholars noting the importance of examining (and attending to) the spiritual needs of family members (Lin & Bauer-Wu, 2003; Milstein, 2008) and staff (Joint Commission on Accreditation of Healthcare Organizations., 2005; Mahoney & Graci, 1999, p. 522); hence the importance of all the populations included in this research.

7.3.1 Spiritual Practices

Spiritual practices in these samples, as a component of need, were primarily broad in nature, rather than religious. For example, interview participants highlighted meditation, prayer and domestic rituals as spiritual practice that gave life meaning. For family members and patients, creating space and a place to be, reflect or get way to was important, particularly when upset. Space was an important literal and metaphorical theme across the qualitative study and some literature sources (Rumbold, 2005a; Zielske, 2003). Space literally allows for healing

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131 Spiritual needs intersect with physical, social and psychological needs (Doyle & Woodruff, 2004). For example, there is a whole area in the literature that considers the relationship between spiritual and psychological needs (Emmons, 2006; Pargament, 2007; Sulmasy, 2002). When taken holistically, as does hospice care, intersection and interaction between domains is self-evident. There is an argument that while spiritual needs affect and are affected by physical needs, the latter, especially as related to physical pain, need to be attended to before the former.
(Milstein, 2008); creating space in one’s mind, as the Buddhists recommend, may be considered a spiritual experience (Leibrich, 2002).

7.3.2 Spiritual Beliefs

To understand spiritual needs, spiritual beliefs were examined. In Study Two, patients responded as the most “religious”, followed by family members and staff. Ninety percent of staff ‘believe’ in something, while 76% of patients ‘believe’ in something (the options were none, other, religious, spiritual or ‘both’). What is important regarding unmet spiritual needs is that approximately a quarter of patients and family members have “no particular beliefs”, which could have implications for their spiritual development within the cancer journey. Spiritual beliefs regarding God, the afterlife and paranormal experiences were very high in both Studies, but the interviews showed that such beliefs were set outside a traditionally religious framework. This “belief without belonging” phenomena has been noted internationally as a growing feature of the belief landscape (Davie, 1994; Heelas, et al., 2005; Taylor, 2007). In light of these findings, the predominantly Christian approach from the ordained chaplain, as is the case in all hospices, is challenged (Heelas, et al., 2005; Mann, 2006; Williams, 2006).

7.3.3 Spiritual Needs

Regarding spiritual need, an important survey finding from Study Two was that up to a third of participants either do not have any spiritual needs\(^{132}\) or do not want them attended to by anyone. This confirms Cobb’s research (Cobb, 2003). Due to the cross sectional nature of the survey, it is difficult to delve into any causation or understanding of this finding. The interviews however add something here. For example, without exception, there were spiritual concerns from participants — those who had worked with the dying for years clearly articulated spiritual needs as a primary focus of the ‘work of the dying’. The spiritual concerns did however vary in complexity and intensity. For instance, at one end of the spectrum, staff and chaplain/spiritual carers were aware of their own spiritual needs and challenges associated with constant death in their work. At the other end of the spectrum, a

\(^{132}\) There was a suggestion by two staff members that a number of people come to the hospice with spiritual issues resolved. This question was then asked in the survey, for which over 80% of staff said that patient spiritual needs were not resolved by the time they came to hospice.
number of patients expressed their literal spiritual pain due to complex belief system issues, profound regret and existential angst, or through contemplation of the perceived inevitable extinguishment of self.

In a wide ranging review, Sinclair et al note staff named spiritual needs that “included maintaining meaning, control and/or dignity; addressing suffering/spiritual pain; reconciliation; listening, belonging and presence; patient’s concern about the future for self and family; and effects of religion, ..., and requests for a hastened death” (Sinclair, et al., 2006, pp. 470-471). Further, Murray et al note that “Carers were also challenged spiritually by suffering and had their own spiritual needs” (Murray, et al., 2004, p. 44). These needs have arisen in this thesis research, including the desire for death, which was expressed by a number of patients. With a few exceptions, how often spiritual needs are addressed in health settings is a question not often studied, with some evidence that suggests patients believe spirituality to be much more important than medical staff (Steinhauser, et al., 2000, p. 2482). Murata notes that loss of control and uncertainty are part of spiritual pain (Murata, 2003). Kernohan et al distinguished six spiritual needs: “to have the time to think; to have hope; to deal with unresolved issues; to prepare for death; to express true feelings without being judged; to speak of important relationships” (Kernohan, et al., 2007, p. 519). This snapshot of the literature about spiritual needs affirms the results of the Studies. That is, this research suggested spiritual needs focused on ‘peace of mind’ related to fear (59%), guilt, regrets (51%), completion, anxiety (uncertainty), hope and forgiveness. At least a third of patients surveyed in Study Two wanted someone to talk to about these issues, which was comparable to a similar needs assessment by Moadel et al (Moadel, et al., 1999). Meaning in life primarily came from family, and almost all were profoundly affected by cancer. Working with the dying, or dying, inevitably raised spiritual issues, and the reprioritization of life’s values, needs and foci was common.

Some family members believed looking after their own spirituality was important, it had grown as a result of the cancer experience and they believed they found meaning in helping as a caregiver. The desire for a good death for their dying family member was expressed by some, as was the worry about suffering at death. Family members’ needs are the least researched and are clinically unmet. What research there is positively correlates spiritual well-being with bereavement and grief resolution (Walsh, et al., 2002). These spiritual needs were not peripheral concerns, rather they were central needs that impacted or may impact on the well-being of participants.
7.3.4 Meaning

The Study One interviews, which allowed for depth and exploration, revealed a search for meaning within the cancer world, which the survey data did not identify. Meaning is a central theme in the palliative care literature (Bregman, 2006a; Doyle & Woodruff, 2004; Jim, et al., 2006; Murata, 2003); Murray et al note “Many patients in their last year of life expressed spiritual needs in terms of seeking meaning and purpose in life” (Murray, et al., 2004, p. 44). This was affirmed particularly in Study One, where three patients struggled with finding meaning in their lives. McGrath found that those with terminal illness had significant hardship, related to “sadness, frustration, and to some degree fear, rather than meaninglessness” (McGrath, 2003, p. 26). McGrath suggests these findings highlight the need to see spirituality holistically: “The data indicate that both survivors and hospice patients describe their spirituality in terms of meaning making and their connections with life, rather than with religion per se—a direction evident in the literature” (McGrath, 2003, p. 31). Rather than splitting spiritual care off as one aspect of the hospice approach, McGrath argues that for “community-based hospices spirituality actually is expressed as the plan of care” (McGrath, 2003, p. 31). Further, McGrath notes the lack of secular spiritual language available to express and discuss these issues. McGrath’s reflections are important in the New Zealand hospice context where spiritual care has room for improvement. If, as Tacey suggests, there is a “client led recovery of spirituality” in healthcare (Tacey, 2005), a case may be made that this is a response to the gap thesis, where meaninglessness is pandemic, and hospice care needs to be aware of this context. What was interesting in the present research, with a couple of significant expectations, was that the vast majority of participants understood life to be meaningful.

7.3.5 Religious/Transcendent Spiritual Needs

Religious spiritual needs appear to be the least ‘unmet’, for as one chaplain noted, those with a religious background share the same language and general beliefs as the chaplain, so they are easier to approach and work with. Further, there are a whole host of religious ministers that are connected to hospices, for example a Catholic priest will be on call at all times. Spiritual issues related to paranormal experiences, as was common in both Studies, may
become a need to be met if there is confusion, fear or anxiety related to these events. Based on the interviews, hospice staff, by and large, were quite comfortable with such experiences and thereby worked to comfort those who experienced them. The literature, however, is mostly silent on the metaphysical; Berry notes the supernatural has been marginalized in this literature (Berry, 2005).

7.3.6 We Die How We Live?

How one had lived one’s life up to one’s dying period/experience appears to dictate (or at least influence) how one will deal with the inevitable spiritual issues that arise. In the words of a hospital counsellor, “people die as they have lived”. This was affirmed by a number of hospice staff who suggested that for some people spiritual issues were raised for the first time when coming to hospice, thus such examination was new and, in some cases, fear inducing. Moberg alludes to an interesting component of spirituality — “spiritual maturity” (Moberg, 2002, p. 47). This warrants further examination as one argument suggests the more spiritually mature one is, the better the death they are likely to have. Therefore facilitating spiritual development facilitates a good death. The interviews revealed two general groups, those that fell into the belief ambiguity camp, compared to those who, through a thoroughly examined life, were clear about their beliefs. Related to this second group, some staff interviewed suggested those with strong religious faith and/or a considered system of belief, have an easier death.

Rumbold weighs in on this argument; he challenges the ethics of raising spiritual issues for those who have not considered them before and thereby creating unnecessary angst, much of which may not be able to be resolved before death. Rumbold asks the pertinent question, “whether end-of-life spiritual care can make up for rest-of-life neglect of spirituality” (Rumbold, 2002a, p. 19). Inherent in this question is another ethical question: in such a circumstance is it ethical to raise spirituality issues, as this may do more harm than good? This issue, like most of the ethical spiritual care issue, comes back to the need for such care to be patient-led and dealt with by well-trained carers.

133 There are a number of Western theories that consider or include spiritual development. Mostly these arise from religious studies, theology and psychology (this does not include the array of Eastern religious theories (eg. Ayurvedic) and complementary and alternative medicines (CAMs) (e.g. homeopathic)). Fowler’s ‘stages of faith’, Maslow’s ‘hierarchy of needs’, Jung’s psychotherapy model, and Erikson’s theory of psychosocial development, are probably the best known (Vance, et al., 2007).
7.3.7 Unmet Needs

Those affected by cancer, particularly patients, enter what one participant called “cancer world”. In this world, the interviewees and some scholars (Puchalski, 2006d; Rumbold, 2002a, p. 18) affirmed a reprioritization and reflection process. This can only be done by the individual, but there can be external and internal barriers to this process, that, if understood, can be ameliorated by external help. This is a general level spiritual need — acknowledging and creating space and time for those affected by cancer to reflect, as their lives have been ‘turned upside down’. One of the upstream unmet needs identified in this research is that hospices, while theoretically acknowledging spiritual needs, do not always consistently or explicitly attend to this area. The majority of patients and family members interviewed in Study One were not aware of and did not receive spiritual care from their hospice. This was affirmed by participants in Study Two; only 17% of patients and 14% of family members had received spiritual care from the hospice. What is revealing is that these samples had received spiritual care (patients 77%, family 67%), but it was mostly from their family members, friends or a religious minister.

There is a particular case regarding family member spiritual needs. The obvious focus of care is the person with terminal cancer, however, in its original and ongoing mandate, hospice aims to consider the needs of the family. Both Studies show high and unmet spiritual needs amongst family members. The interviews of family members and others suggested that often the spiritual needs of the family members were sublimated, “put on hold” and relationships were “turned upside down”. A hospice counsellor commented that “a lot” of patients accept the terminal diagnosis better than their family members. A patient said while he had some high points in this cancer journey, his wife had none. There was anger expressed by some family members, one in particular was furious with God for taking his wife before time. These needs were affirmed by Study Two, with, for example, family members having the highest reported needs regarding the need for help with peace of mind and overcoming fears. International literature suggests that family members are often overlooked in spiritual care studies, with a number of exceptions (Lin & Tsao, 2004; Milstein, 2008). Murray et al note the “struggle” that carers have with “managing their own spiritual needs and knowing how to help a loved one in spiritual distress” (Murray, et al., 2004, p. 43). Clearly the spiritual needs of family members are not well met and are under-researched.
Healthcare professionals’ spirituality was identified as an unmet need in all three sources. In the literature it is often commented on (though with little actual research evidence) (Sinclair, et al., 2006; Speck, 2004). In Study One there was a call for more spiritual care training and an acknowledgement that staff spiritual well-being was important. In Study Two there was a huge response from staff (98%) saying they did not have spiritual support at the their hospice. Most chaplains interviewed said their role included the spiritual support of staff, but time seldom allowed for this responsibility. Thus staff spiritual needs could be better attended to in hospices.

The most compelling evidence for unmet spiritual needs is the structural gaps that do not allow for the space needed by individuals to deal with these issues or for staff to help them. For example, of the staff surveyed from the 25 hospices (over 80% of New Zealand hospices), 60% did not do spiritual assessments, 98% did not receive spiritual support, 89% seldom received spiritual training and only 50% knew if they had a spiritual care policy. The challenge here is for hospice management to take the spiritual care mandate more seriously. Spiritual issues have been shown to be at least as important as physical concerns. Yet training, staffing and ultimately funding for spiritual care is infinitesimal compared to physical issues. For example, some hospices in New Zealand do not pay their chaplain, rather relying on their ‘Christian goodwill’. Further, the survey data were analysed to create a ‘spirituality setting score’ based on provision of a paid chaplain, quiet room/chapel, staff spiritual support, spiritual professional development, policy, resources, assessment and importance of spirituality. All hospices could do better based on these criteria and most were just average. This audit tool could be used as a simple approach to improving spiritual care at a structural level.

7.3.8 Summary

Spiritual issues naturally arise as part of the dying process (Sulmasy, 2002). Spiritual pain and distress comes from the breakdown, challenge to, or disintegration of one’s spiritual well-being — which is defined variously, but includes a sense of meaning and purpose, a considered system of values and beliefs, a sense of hope, identity and connectedness. For some this is situated within a religious context. Regarding spiritual pain, the literature most notably suggests this is a result of meaninglessness caused by terminal illness’ disruption of
everything (Boero, et al., 2005; McGrath, 2003; Murata, 2003). There are, however, a range of other causes (Doyle & Woodruff, 2004). The table below shows the relationship between spiritual well-being and spiritual distress.

**Table 7.2 Spiritual Issues as part of the Dying Process**

<table>
<thead>
<tr>
<th>Spirituality components</th>
<th>Spiritual distress</th>
</tr>
</thead>
<tbody>
<tr>
<td>Values, beliefs, hope</td>
<td>Valuelessness, normlessness, angst, fear</td>
</tr>
<tr>
<td>Meaning, purpose</td>
<td>Meaninglessness, ennui, hopelessness, despair</td>
</tr>
<tr>
<td>Awareness</td>
<td>Uncertainty, lack of awareness</td>
</tr>
<tr>
<td>Transcendence, religiosity</td>
<td>Self centered, religious pain/guilt</td>
</tr>
<tr>
<td>Identity, relationships, connectedness</td>
<td>Dissolution, disconnection, isolation, guilt</td>
</tr>
</tbody>
</table>

This table is simplistic — it suggests a binary relationship between these areas — whereas the reality is much more fluid. As noted above, such distress may be a sign of the growth and spiritual development that is necessary to become, as one patient said, “death fit”.

What is clear is that two thirds of patients and family members want spiritual care. There is reasonable evidence that these needs are not being met by hospice care. International literature argues that mostly spiritual needs are not being met (Astrow, et al., 2007; Balboni, et al., 2007, p. 555; Cobb, 2003; Moade1, et al., 1999; Ross, 2006a). However, Study Two found that most of those who wanted spiritual care received it. Who they want to provide such care was a surprise: the majority named family, then friends, followed by the minister/chaplain; staff were well down the list. This finding has quite radical implications, asking the question ‘how can hospice better equip family and friends to support their dying family members spiritually’. This is complicated by the complex spiritual needs of family members themselves, calling for significant leadership and some re-thinking of hospice spiritual care.

**7.4 What is the Place of Spirituality in End-of-Life Care for Māori?**

When discussing spirituality in New Zealand, Māori contributions, aspirations and needs cannot be ignored. This research combined with a focused literature review, aimed to give space for Māori expertise to voice its position. Dr Paratene Ngata inspired the thesis’
overarching theme of spiritual space as he called for "space and time" for spiritual care. Durie (Durie, 1998b), Mead (Mead, 2003) and others (Oppenheim, 1973) have highlighted the centrality of te taha wairua for Māori well-being and in death rituals/tangihanga. New Zealand hospices are working to improve accessibility for Māori and by re-focusing on spiritual care generally will thereby open the door wider for Māori.

7.5 How can the Spiritual Needs of People affected by Terminal Cancer in New Zealand Hospices be Improved?

You can't do effective palliative care without going to the spiritual realm
(Palliative care medical specialist, Study One)

The spiritual needs of those with terminal cancer care can be improved in New Zealand hospices by following their holistic/total care mandate. This section will bring together the relevant results from this research, and the literature on spiritual care to provide critique and direction. Spiritual care, like spirituality itself, does not have a universally agreed upon definition. However, this is not a hindrance, but rather indicative of a field that must be patient/needs led (Puchalski, 2006d). Thus, in summary, to improve spiritual care the wide canopy that is spirituality, spiritual needs and subsequent responses must be understood, arguably at individual caregiver and institutional levels. Simply speaking, spiritual care is doing, saying or allowing anything that assists a person’s, a family’s, a group’s or an institution’s spiritual well-being. This may range from creating space, to asking questions of meaning and purpose, to mutual exploration of hope. There are as many specific answers to what is the right spiritual care as there are people, but some generalizations can be made because we have some understanding of spiritual needs. This Canadian definition of spiritual care indicatively summarises those in the literature,

Spiritual care addresses the ultimate concerns of the whole person, encourages healing through the nurturing of spirituality within the context of the person’s beliefs and values as an interdependent component of holistic care (Regional Health Authority Central Manitoba, 2007, p. 2).

This Canadian approach was affirmed in this research, particularly by the spiritual carers. This holistic/whole person ideology reflects the integrative and inclusive definitions and approaches named within New Zealand hospices. Improvements to such care can be made by asserting and operationalizing these theoretical positions. The following discussion will be structured around the over-arching theme of 'spiritual space', which is relevant at the bedside
(downstream) and at the infrastructural level (upstream). The space theme was inspired by a number of the interviewee including Dr Ngata (Māori participant interview), and the literature (Leibrich, 2002) and Rumbold (Rumbold, 2007, p. 61). The stream metaphor (McKinlay, 1993) is useful as the downstream quality of spiritual care at the bedside is ultimately dependent on mid and upstream factors. A health promotion approach, as others have recommended in palliative care134 (Kellehear, 1999a), affirms the up/downstream approaches at policy, community, health services, environmental and skills levels. Spirituality needs 'space' at each of these levels, with awareness and understanding of spirituality being the primary vehicles to enable spiritual care improvements. This health promotion approach (WHO Health and Welfare Canada Canadian Public Health Association, 1986) will be employed to argue for approaches to help close the spiritual care dissonance (gap between theory and practice) evident in New Zealand hospices.

### 7.5.1 Upstream Issues

Spiritual space at an upstream level relates to hospice ethos, management, policy, recruitment and commitment to capacity (building) for spiritual care. The ethos of a hospice is the cumulative and collective culture made up of management attitudes and direction, staff input and community/patient influences. Management are critical in this process and a spiritually conducive ethos is one of the obvious areas of spiritual importance. Management can guide and promote a spiritually positive ethos through explicit support of spirituality in policy, thus giving power to those who do this work. A spiritual care policy, according to Study Two, was present in, at most, 50% of hospices. Supporting this, Narayanasamy & Owens note that infrastructural issues, such as a lack of “management support”, were barriers to spiritual care (Narayanasamy & Owens, 2000, p. 447). Further, a feature of spirituality in healthcare generally has been its inclusion in a growing number of policies, guidelines and curricula (Murray, et al., 2004). Murray notes the Scottish NHS organisations "are required to develop and implement spiritual care policies tailored to meet the needs of the local population" (Murray, et al., 2004, p. 39). This is a significant upstream issue for which health promotion has much to add value. Fleming notes "The discipline of Health Promotion can offer real potential in helping to bring about an appreciation of this spiritual dimension to the person

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134 Kellehear argues that health promotion has the potential to add a more “participatory” and structural analysis approach, including sound planning models and evaluatory frameworks, to palliative care (Kellehear, 1999a, p. 16).
and spirituality itself as a key determinant of health” (Fleming & Evans, 2008, p. 78).

McGrath argues that, to maintain a strong spiritual focus in hospice care, spirituality needs to be taken into consideration right from recruitment through to all aspects of the hospice ethos and organisation (McGrath, 2002b, p. 186). This is essentially a health promotion settings position, considering spirituality up and downstream. Sulmasy, also writing from a palliative care perspective, affirms the “ecological model of patient care”, which incorporates up and downstream perspectives (Sulmasy, 2002).

7.5.1.1 Recruitment

Recruitment is an upstream issue that is not often discussed in the literature but was raised by one experienced hospice nurse. She explicitly asked potential staff members how they looked after themselves spiritually and how they dealt with death. If they answered inadequately, showing no understanding of death, dying and spirituality, she would veto their employment. While under-researched, this is logically a critical issue, as appropriate staff, who ‘buy into’ the spiritual ethos of the place, are important to appropriate spiritual care. In all of these upstream issues, it is important that hospice management are aware of and understand the importance of spirituality.

7.5.1.2 Staffing and Professional Development

Management facilitation of staffing and supporting professional development are also upstream issues. A hospice nurse identified the lack of mandatory spiritual care professional a major barrier. She noted, in the context that at least half the patients’ concerns were spiritual, that nurses had mandatory training on physical skills, but little or no training about spirituality. The literature affirms the interviewee’s position, suggesting a lack of training affects healthcare professionals’ confidence, skill and thus ability to provide spiritual care (Dunn, Handley, & Dunkin, 2009, p. 19; McCord, et al., 2004; Narayanasamy & Owens, 2000). This is a significant gap in the New Zealand hospice professional development agenda. A comprehensive and consistent approach to spiritual care professional development would have a major impact on improving spiritual care for those affected by cancer.

135 Kellehear admonishes (appropriately) health promotion for ignoring the needs of those who live with chronic and terminal illness. He suggests that this ‘position’ is like that “old medical idea that the prospect of death disqualifies one from legitimate health care attention”; thus situated, Kellehear claims, not only chronic illness, but death and dying are public health issues (Kellehear, 1999b, p. 77).

136 One option to assist this process, as suggested by a chaplain interview in Study One, is to have the chaplain sit at the management table, thereby directly influencing policy and practice.
Staffing issues relate primarily to the spiritual care expert: the spiritual carer or chaplain. A least a quarter of Study Two hospices did not have a paid spiritual carer at the time of the survey. This may be a fiscal consideration and indicative of an institution's commitment to spiritual care. A further issue noted in the literature and in Study One hospital interviews was time available to invest in spiritual care (Dunn, et al., 2009, p. 19; McCord, et al., 2004; Narayanasamy & Owens, 2000). That is, if a healthcare professional's workload is such that they are just able to cope with the patient's physical needs, the 'doing to', it is unlikely there will be time for 'being with', which is the time for spiritual care.

7.5.1.3 Referral Options and Physical Environment

Two other upstream spiritual space issues that are partly dependent on management are clear referral processes/options, and a conducive physical environment. The referral process is a major issue as it starts upstream with policy on how spiritual issues are assessed and addressed, but is also a downstream issue with healthcare professionals acting as either facilitators or gatekeepers to appropriate spiritual care. These issues were discussed in the interviews; staff across all hospices grappled with it, but there were no consistent approaches. In the UK, Wright suggests a simple denominational question may be the extent of the spiritual history taken by many healthcare professionals (Wright, 2008). In the US, where spiritual care is widely mandated even in primary healthcare, there is little actual spiritual assessment and care done (McCord, et al., 2004). As suggested by a hospice nurse and the literature, a spirituality section in patient's notes and training on how to assess spirituality as a part of taking a patient's history are lacking (in most hospices) and important (Puchalski, 2006b). Also relevant to the referral process is the need for a range of spiritual experts, which include the in-house spiritual carer, but also various community spiritual experts, both religious and secular.

Regarding the physical environment, two of the 25 hospices surveyed in Study Two reported not having a chapel (sometimes called a quiet room). However, based on the seven hospices

137 The label or name of the spiritual carer is an important issue as some of the interview participants said they were unlikely to seek spiritual care from a chaplain as this role/name implied a religious approach. Study Two asked participants about the name, for which almost half of all groups did not care (49%), then spiritual carer/companion (19%), then chaplain (15%).
138 Or a lack of awareness of the importance of spiritual care, as was suggested by the survey gap between how 84% of staff thought spirituality was important, compared to their perception that only 60% of hospices thought it to be important.
visited in Study One, the quality of these spaces varies greatly, ranging from a purpose-built, well-resourced and aesthetically pleasing space to an empty ex-clinical room with a cross on the wall. One chaplain said that most of the spiritual care goes on at the bedside or in the home, so perhaps the ‘spiritual space needs’ extend to the whole hospice site. This was affirmed in the literature where lack of “peace, quiet and privacy” were identified as potential barriers to spiritual care (Narayanasamy & Owens, 2000, p. 447). Physical space, an upstream issue, for spiritual or religious care may need to be given consideration, including for rituals and ceremonies.

7.5.2 Midstream Issues

7.5.2.1 Community Relationships

Midstream measures correspond to the Ottawa Charter’s actions of “creating supportive environments” and “reorientating health services”. These are important concerns of hospice as it is the communities and health services that work with hospices and help fund them. In terms of creating supportive environments, there is some literature, led by Kellehear et al, regarding approaches to destigmatising hospices services generally (Kellehear, 1999a) and spiritual care services specifically (Hills, et al., 2005). Most New Zealand hospices have very good relationships with their communities, many employing fundraising/public relations experts. These relationships could be built on to advocate and educate the community in terms of what Kellehear calls death education (Kellehear & Connor, 2008), with the aim to address the death denying culture.

Regarding other health services, some New Zealand hospices currently work with primary health providers to educate and advocate for palliative care approaches. In one case, a chaplain interviewed talked about this process and the positive reception he received from General Practitioners as he discussed spiritual care of the dying. Growing these relationships with primary care will extend the hospice spiritual care ethos.

Each hospice has its own subjective ‘feel’ — that experience that one has in different homes — derived from the mix of people, the physical environment, and other less tangible factors. In my research journal I noted the ‘feeling’ of each of the hospices, not as an objective measure, but as a subjective view of ‘the place’. Like every house or marae, each hospice is different. One hospice was overwhelmingly multi-cultural in its feel, exemplified by Māori and Pacifica motifs in the hall ways. Another had a very ‘Christian’ feel to it, and upon examination over half the staff were ‘committed Christians’. The ‘feel’ of hospice, while difficult to quantify, is no less palpable than its architecture. Hospice logos are a further exemplification of the institution, with some including a cross. This issue is important because all hospices want to be welcoming places and arguably this can be consciously attended to and adjusted.
7.5.2.2 Spiritual Expert

A midstream-level issue is the spiritual expert in the hospice. While crossing into downstream issues, with much of his or her work at the bedside, the spiritual expert, as interviewed and evidenced in the literature (Cobb, 2007), has a range of midstream duties that include education of staff and the community, care for staff, input into policy and leading spiritual care for patients and family. This may involve direct contact or, as was often noted by hospice staff and chaplains, spiritual expertise was often offered and drawn upon by staff members.

Role clarity in the spiritual carer space was identified in the literature as a potential barrier to spiritual care, but only in the hospital interviews were there any demarcation issues highlighted. That is, the hospital chaplain said all spiritual issues were directed to her, while in the hospices staff mostly felt comfortable dealing with issues to a certain level, after which they would seek advice from the spiritual expert.

7.5.2.3 Spiritual Carers

There are a variety of spiritual carer roles in hospices. To improve spiritual care, these roles need to be clarified and better understood. Traditionally chaplains have provided spiritual care and therefore need to be considered regarding unmet spiritual needs. Chaplain-provided spiritual care is still the default option in many hospices, however Study One and the literature (Cobb, 2001) affirm multi- or inter-disciplinary approaches. Milstein suggests the situation and patient best dictates the choice of spiritual carer (Milstein, 2008) (see also Jenkins, 2002), while Puchalski argues that anyone who cares for the terminally ill should provide spiritual care (Puchalski, 2006a). The Scottish National Health Service agreed in 2002 to call those involved in such care spiritual caregivers, while also affirming that faith communities could give names as they saw fit (Working Group on Spiritual Care in the NHS, 2002). This is an important issue for some, though the Study Two survey revealed that over half of the participants did not care what such a role/person was called. Many of those interviewed, however, had quite strong views, with the majority view calling for an inclusive

Surprisingly, research by chaplains and on chaplaincy is not a major force in this literature. There are a number of chaplaincy-related journals, but publications in this area have not grown like the spirituality and health area generally (Weaver, Flannelly, & Oppenheimer, 2003). Key issues that do arise from this literature include reciprocity in spiritual care (Jenkins, 2002), the importance of the relationship with the patient (Jenkins, 2002) and those issues named above regarding role, name and referral issues.
term that reflected a spiritually inclusive approach. Whatever the name, the need for an expert spiritual caregiver has not changed. As Puchalski has noted, appropriate referral to spiritual care expertise is as important as referring to other specialists (Puchalski, 2006c). That said, there is a need for chaplaincy to change with the postmodern environment,¹⁴¹ one that is ostensibly secular, but shows signs of re-enchantment—the status of spirituality is growing and the subsequent need for spiritual care similarly growing. Where once chaplains where expected to give ‘the sacraments’ on most occasions (Emblen & Halstead, 1993), this has changed significantly to a broader brief (Norwood, 2006). Further, a significant issue is referrals to chaplains. Based on US studies, gate keeping for a variety of reasons appears common (Hills, et al., 2005; Norwood, 2006), thus Hills calls for more research exploring “patient/family barriers to accepting these referrals. Additionally, systems need to be developed to destigmatise consultation by expert spiritual care providers” (Hills, et al., 2005, p. 787). Gate keeping and stigma related to spiritual care were issues raised in the interviews. While not a major issue, a number of staff noted that some of their colleagues felt such care was ill-founded and inappropriate, thus made little or no attempt at highlighting spiritual care services in their hospice.

Study One included eight interviews with chaplains. The overall impression was that they were happy to lead spiritual care from a multi-disciplinary approach, as they knew they were not always available at the spiritually potent moments. Some noted that spiritual care was often subtle and not always made explicit with patients, none of them did formal assessment, and many talked about the importance of the relationship. Another hospice staff member criticised some chaplains for not being more explicit about spiritual care, as they were the only member of staff who had the obvious mandate to do such care and “opportunities were being missed”. This raises the issue of how direct a spiritual carer ought to be, which ideally is again patient-led.

The implicit versus explicit spiritual care issue is not widely examined in the literature. Study One results showed that both approaches existed. Some staff and patients believed spiritual care needed to be more explicit as needs were either being missed or unmet. The issue is that some spiritual care happens because of the hospice ethos and implicitly because of the caring

¹⁴¹ Mann comments on the status of chaplaincy in the contemporary era, suggesting that with the growth of the place of spiritual care in many professions, chaplains may be overlooked (Mann, 2006, p. 120). There is a constant call within the spirituality and healthcare literature for an exploration of appropriate spiritual language in a secular environment (McGrath, 2002a). Perhaps this lack of language is overstated, and these professionals — chaplains — can draw on a range of idioms and registers to attend to spiritual needs (Mann, et al., 2004).
The hospice ethos, without exception in Study One hospices, was one that clearly acknowledged and prioritized spirituality. Implicit spiritual care happens through staff naturally using key spiritual tools (identified in the literature and Study Two) of listening and touch. Therefore, while the vast majority of patients and family members were not aware of explicit spiritual care, they were, almost to a person, conscious and grateful of the excellent and caring service from the hospice. The question remains herein, ought spiritual care be made more explicit, or is the implicit often unacknowledged approach (by patients/family members) enough? Part of the answer to this question is commented on by unmet spiritual needs - of which there are many. Therefore, while the implicit approach may meet the spiritual needs of the majority, there is still a significant minority whose spiritual needs are not being met. This is because spiritual needs are not being appropriately assessed, addressed and a spiritual care plan incorporated into the overall care. This is especially true for family members, who were identified in both Studies as having the most unmet need and the spiritual carer of choice for the patient.

All hospice staff have the potential to be spiritual carers, therefore they need to be provided with the space, training and tools to be able to do so confidently. Barton suggest a raft of approaches to spiritual care “when there is no chaplain”, including: life review; art activities to display abstractions of life and death; rituals to celebrate death of residents and welcoming them; give staff permission to talk about spirituality; dedicated space for spirituality; make it part of intake assessment; in-service training; spiritual policy and guidelines; use existing staff with interest or expertise in spirituality; and use media (TV programs) as a way into talking about spiritual issues (Barton, et al., 2003, pp. 17-18). Both up and downstream, Barton’s list highlights many of the ways the Study participants also named.

7.5.2.4 Spirituality Education/Professional Development

The growth of spirituality and health research, with a belief (not always shown in the evidence) that this is primarily positive, has led to the introduction of pre-service and in-service education for many healthcare professionals. The US leads this trend, with spirituality courses in most of their medical schools. Puchalski led this, starting from 1991 when the George Washington University Medical School introduced the first course in a US medical school (Puchalski, 2006c, p. 23). Since that time, more that 60% of US medical schools have begun to offer spirituality courses (Booth, March 10 2008). As a result, the Association of American Medical Colleges (AAMC) has developed comprehensive “guidelines and learning
objectives for the courses” (Puchalski, 2006c, pp. 23-24). These guidelines are remarkable considering the controversy in the field. MacKinlay suggests there are two academic positions: one believes there is enough evidence for clinical practice to attend to spirituality (Puchalski, Koenig and others); the other position claims the evidence is weak, the studies are flawed and it is not the mandate of medical doctors, thus spirituality should be completely separate from healthcare (Sloan and colleagues). Obviously the former position has prevailed at US medical schools, however evidence suggests that it has not been taken up widely by clinicians (McCord, et al., 2004).

Guidelines on spirituality and health are not without controversy, as one of the Māori experts commented, “go easy on the guidelines”. Berlinger challenges the possible implication that all patients want spiritual care; she argues it could be “hazardous” for some (Berlinger, 2004, p. 692). Further, the AAMC “research data” guideline, Berlinger claims, is the most controversial as it appears to refer primarily to Koenig’s research, some of which has been challenged (by Sloan mostly) in the medical literature (Berlinger, 2004, p. 684).

Other healthcare professions are grappling with spirituality in their training, codes of ethics, practice and guidelines, for example, in nursing (McSherry, 2007), occupational therapy (Unruh, et al., 2002), social work (Hodge, 2003) and psychology (Emmons, 2006). Nursing particularly has a long history of religious and spiritual aspects considered in its training and practice (Bradshaw, 1994).

The call for spirituality education, pre- and in-service, seems like an obvious need because more and more national health services, guidelines and policy statements are requiring spirituality to be considered in general healthcare and hospice/palliative care (Joint Commission on Accreditation of Healthcare Organizations., 2005, p. 2; McSherry, 2007; Ministry of Health, 2000; Puchalski, 2006c).

Cobb makes a salient point about spiritual care. He argues that it “requires general and specific competencies”, as “it cannot be expected that people will naturally possess such ability because spirituality is a human trait” (Cobb, 2001, p. 114). Sinclair affirms this point in the palliative care domain, suggesting,

Recent research has demonstrated that spiritual care training for palliative care professionals produced significant and sustained improvements in compassion toward the dying; compassion toward oneself; attitude to one’s family;
satisfaction with work; reduction in work-related stress and in attitudes toward colleagues. (Sinclair, et al., 2006, p. 475)

The case for pre- and in-service training of spiritual care has been made by a number of staff interviewed in Study One. Many of the chaplains/spiritual carers interviewed understood professional development to be part of their mandate, but there was no consistency or regularity.

7.5.3 Downstream Issues

Downstream issues that could improve spiritual care relate to assessment, provision of spiritual care and ethical issues. How a healthcare professional, most often the nurse (Dunn, et al., 2009, p. 19), does spiritual care is influenced by three things: the infrastructural process and other mid/upstream issues; patient needs; and his or her own competency. It is widely understood in the literature and from those interviewed in Study One that patient/family needs lead care. What is also agreed is that the staff member’s own understanding of spirituality and therefore his or her comfort with it is critical to subsequent care (Puchalski, 2006d; Vachon & Benor, 2003). Regarding competency in spiritual care, while some people are more attuned to this than others, this can and often needs to be learned (Cobb, 2007), particularly the formal assessment processes and referral, timing and other options. Hospices in New Zealand currently provide some spiritual care, though this provision varies in quality and ideology. Fifty-nine percent of the staff surveyed in Study Two “sometimes” or “never” do formal spiritual assessments.

7.5.3.1 Assessment

Downstream, at the bedside, spiritual assessment is fundamental to appropriate hospice care and exemplifies making space for spirituality. Before one can appropriately meet spiritual needs, they must first be understood. Reasons cited by nurses for not conducting spiritual assessments include inadequate educational preparation in how to conduct a spiritual assessment, lack of time, being not seen as a role of the nurse, lack of spiritual assessment tools that provide thorough patient spiritual history, and confusion between spirituality and religiosity (Dunn, et al., 2009, p. 19; Wright, 2001). The Studies affirm Dunn’s analysis. There was no consistency of spiritual care approaches either formally or informally across the country. One hospice nurse talked about recently reviewing and renewing their assessment
process, for which the most time and argument was about the spiritual component. The literature (Joint Commission on Accreditation of Healthcare Organizations., 2005) and the interviews highlighted staff comfort with spirituality as being a critical issue. Spiritual assessments need to be more than denominational inquiry and there are very good tools for such investigation. An open-ended qualitative approach can take a structured form, with the aid of acronyms or by simply asking one or two key questions. Two of the most useful questions from the literature include asking “To what extent are you at peace” (Steinhauser, et al., 2006, p. 101) and, “What role does spirituality or religion play in your life” (Sulmasy, 2002, p. 30). A range of acronyms gives clinicians reminders about the spiritual areas to consider when taking a spiritual history. Puchalski developed the FICA approach, probably the most often sourced acronym, which reminds the clinician when doing a spiritual history to ask about faith and beliefs (F), the importance of spirituality or religion (I), the relevance of a spiritual or religious community (C), and the actions of a subsequent spiritual care plan (A) (Puchalski, 2006b, p. 238). Either the single question opening or the acronym reminder questions is a good start to developing a spiritual history process.

There are formal quantitative approaches that also help assess spiritual well-being (Moberg, 2002). These assessment instruments are primarily used in research; if used clinically they would only be useful in conjunction with a qualitative approach. Good examples of these instruments include the FACIT-sp (Peterman, et al., 2002) and the WHO QoL SRPB (Saxena S., 2002). A survey helps to identify issues and give a point of entry for further spiritual discussions. It is also worth noting that the Studies found the very raising of spiritual issues for discussion was in itself therapeutic.

Regarding measurement of such issues, Sulmasy’s asked “Can One Measure a Patient’s Relationship with the Transcendent?” (Sulmasy, 2002, p. 27). Sulmasy suggests the ‘God’ factor in spirituality “transcends the spatiotemporal limits on which empirical measurement depends” (Sulmasy, 2002, p. 27), thereby arguing that part of spirituality is immeasurable in a quantitative way. With this qualification, and acknowledging the limits spirituality/religious measurements have, Sulmasy concludes there is a place for them clinically and academically, with four categories open to assessment:

1. Religiosity, (strength of belief, prayer, worship practices, intrinsic/extrinsic);
2. Spiritual/religious coping and support, (spiritual language, attitudes, practices, sources);
3. Spiritual well-being, (spiritual state or level of spiritual distress regarding QoL)

7.5.3.2 Spiritual Care Provision

The importance of ongoing assessment and spiritual care planning and provision were highlighted by some staff members in Study One, noting that spiritual needs change along the cancer journey/progression towards death. Provision of care may take many approaches, staff from Study Two highlighted “listening” and “appropriate touch” as the most important spiritual tools, both of which were affirmed by the literature as key elements in spiritual care (Grudzen, 2003; Puchalski, 2006b; Wright, 2002). Listening seems such a simple ‘tool’, but all sources named it as a significant competency (my term) that is underestimated and not necessarily a common approach in a curative system.

To improve spiritual care, after appropriate assessment, staff having knowledge of common spiritual issues is important. These issues have been discussed above, but clearly an internal checklist for staff would be useful, including such issues as meaning, purpose, hope, fear, guilt, religious and paranormal matters and forgiveness. Further, discussing what a patient believed before his or her diagnosis may be of some benefit as these beliefs will inform how subsequent challenges are dealt with, as it has been noted that how one lives affects one’s dying. The Studies asked about change in beliefs and, in most cases, at the very least an examination, if not reprioritization, of beliefs ensued post-diagnosis. The potential spiritual/existential crisis that may follow diagnosis is important for hospice staff to be aware of.\textsuperscript{142}

A range of tools to assist spiritual care was identified from all sources. After the prioritized tools of listening and touch, philosophical discussions, ritual, and prayer were noted in Study Two as resources. Study One discussions revealed more options, with spiritual carers drawing on life review, art therapy, meditation, poetry, music, engaging with nature, complementary and alternative therapies, and non-religious and religious rituals. The spiritually unfinished business was often said to be, by Study One participants, relational, about guilt, forgiveness and worry about family. Then issues of self, identity, and fear were noteworthy. It was noted by a number Study One staff that, for many patients, coming to hospice was the first time anyone had raised spirituality issues and therefore the very act of

\textsuperscript{142} Hospice staff may not be involved with patients until well after diagnosis. This has implications for GPs and oncology units.
asking such questions created space and opportunity for growth. Rumbold’s spirituality mapping approach (Rumbold, 2007) (see below), with formal charted notes, would allow for an ongoing spiritual care plan to be assessed and addressed.

Patient-led spiritual care was an interesting idea raised by a number of patients in Study One. They suggested the best spiritual care might come from someone who had or was experiencing similar things — a ‘by cancer patient for cancer patient’ approach. How this might work would be context and personnel dependent, with ‘one-to-one’ and ‘group work’ options a possibility. The New Zealand Cancer Society’s “Living the Journey” group programme is often led by those who have survived cancer, so there is current provision that is ‘consumer led’.

Rumbold and others (Sinclair, et al., 2006) have noted the individualistic nature of much of the spiritual care discussed in the literature and provided in hospices. The authors note this potentially misses the communal aspects of spirituality, a reality for many people, as was expressed particularly, but not exclusively, by the Maori experts in the Study. Rumbold recommends a spiritual care approach that not only considers the patient’s individual needs, but maps the relationships in the community from which spiritual sustenance is drawn (Rumbold, 2007, p. 62). This is an important consideration as the primary spiritual caregivers in the study were family members and friends. The need to understand and build on this group’s capacity is critical for improving spiritual care.

Lastly, two thirds of all samples said they wanted spiritual care — a clear majority. With this in mind, an obvious corollary is to have spiritual care as the default option and ask, not if people want it, but rather if people do not want it. For example, as how one asks about spiritual care affects uptake, based on these findings an appropriate question might be: ‘Most people appreciate some spiritual care, how can we help you?’ While only a suggestion, the point is to make the environment for spiritual care accessible and easy for those who need it.

In summary, there are a wide range of spiritual care tools available based on needs, with a continuum from listening to in-depth spiritual intervention. Hospice staff, led by the spirituality expert, need to have a spiritual care ‘tool box’ full enough to address the plurality of possible concerns. Spiritual space, the capacity to offer a “supportive presence” (Rousseau, 2003, p. 55) of listening and ‘being with’ is critical. Staff need to understand what the spiritual concerns and signs of spiritual distress may be, and they need to know when their
limits of knowledge and expertise have been met (and therefore to refer on to the spiritual experts). Spiritual care plans will be unique to each individual and whanau/family, but may include life review, one-to-one work or group work. Some people affected by cancer will not want any spiritual care and hospice staff need to understand all the ethical issues.

7.5.3.3 Spiritual Care Ethics

The potential for spiritual abuse in hospice care is uncommon but not unheard of (Unruh, et al., 2002)(Study One staff interview). Spirituality for many people is to do with their essence, what matters most, so care must be taken with, what one chaplain in Study One named, as “sacred ground”. The basic ethical principle many of the staff interviewed and the literature highlighted is the imperative to be led by patient needs and not impose one’s own views. But there are some issues that need consideration. For instance, should a staff member pray with a patient? And how much of one’s own beliefs should staff share with patients? Starting at the general, before situational, ethical position, Puchalski and Winslow have developed ethical guidelines. A summary of these includes the need to take a spiritual history, recognise spiritual expertise, avoid coercion and proselytizing (Puchalski, 2006b, p. 241), and,

- Understand each patient’s spirituality,
- Follow patient’s wishes
- Do not impose spiritual care
- Understand one’s own spirituality
- Proceed with integrity (Winslow, 2005).

Winslow’s final guideline gives some direction regarding prayer, which is affirmed by Puchalski, that it should not be initiated by the clinician, one should not do anything that he or she is not comfortable with, and it is preferable to refer such prayer requests to chaplains or ministers. Regarding sharing beliefs, the foci is the patient (or family), as such this implies it is not the carer’s beliefs that are important. There is a position regarding a “wounded healer” type approach (Nouwen, 1972), where the carer is a fellow human without all the answers on a spiritual journey. However, this does not negate a position that suggests the carer’s beliefs should be mostly kept private, and that compassionate listening and space allows for the patient’s own journey to be explored.
7.5.4 Spiritual Care Challenges

There are many challenges and possible risks to spiritual care. If, as one of the Māori key informants said about spiritual care, “it’s all in the tone of voice”, then the possibility of ‘spiritual correctness’ and over-institutionalized or bureaucratized approaches could undermine the mandated vision.\(^{143}\) There is a strong argument for spiritual care to be the default position, with people needing to opt out of such care rather than the current opt in approach. A significant challenge before default spiritual care could ever be operationalised is the up-skilling of the workforce so as to avoid ‘tick box’ or formulaic approaches. Further, as the spiritual carer of choice for the majority of Study Two participants was family and friends, there is a significant challenge to up-skill them to meet such needs.

Further challenges due to demographic change will be about capacity to meet the needs of New Zealand’s ‘aging and browning’ population. As the older age group is growing, so the need for hospice care will inevitably grow, and Māori, Pacific Island and Asian populations are increasing, thus increasing the demand for culturally appropriate spiritual care. The infrastructure and evidence behind spiritual care are ongoing challenges. If one is not actively religious who are the spiritual caregivers that will be the ‘best fit’ for them? Currently the vast majority of hospice spiritual carers are called chaplains and this may inhibit access for the non-religious majority. Spiritual care in New Zealand needs more evidence to further justify and improve hospice care as our populations are unique, with particular spiritual needs. Lastly, if Taylor (Taylor, 2007) and others (Bluck, 1998; Heelas, et al., 2005; Hornblow, 1999; Tacey, 2003) are right, there is a pandemic of meaninglessness in the West. Thus, even before life becomes terminal, many people are lacking meaning and purpose in their lives. Meaninglessness was not a dominant theme in the samples studied, but future cohorts may exhibit this ‘condition’ and therefore be an important consideration for hospice care.

\(^{143}\) The NICE guidelines *Manual on Cancer Care* has a comprehensive approach for spiritual support services (National Institute for Clinical Excellence, 2004). This resource could be a model for other countries, such as New Zealand, that have not developed this process. The NICE spiritual care competencies reflect many of the contemporary and scholarly majority opinions and research positions found in the literature above. For instance spirituality is understood to be universal; the professional’s spirituality needs are noted; it is patient centred; and they work with and grow the capacity of the multi-disciplinary team. Thus, it is fair to conclude, that spirituality exists in many key policies and guidelines. Spirituality is recognized in New Zealand, but there are few, if any, ‘next step’ guidelines or competencies on how spiritual care should be operationalised.
7.5.4.1 Health Promoting Hospices

A significant challenge discussed above is how to improve spiritual care up, mid and downstream. A health promoting hospice approach would allow for a holistic, whole hospice, measurable process for such improvement.

Health promotion, hospice care and spirituality in healthcare have much in common. They all have been (re)developed in the latter half of the twentieth century. They all come from similar ontological and epistemological backgrounds, with holistic approaches explicitly named. Tones & Green argue that health promotion is “an a priori challenge to the focus on individualism that has, with justification, been vilified as victim-blaming” (Tones & Green, 2004, p. 3). This is a position that sits interestingly with contemporary spirituality. That is, the latter has been criticized for overly focusing on the ‘self’, to the exclusion of communal approaches (Heelas, et al., 2005; Sinclair, et al., 2006). Therefore, while health promotion can learn from hospice care’s insistence on the importance of spirituality (Kellehear, 1999a), there is a reciprocal learning opportunity, which, amongst other things, includes a collective, collaborative, socially responsible approach to health promotion that could be taken up in regard to spirituality in hospice care. Further, empowerment, a cornerstone value of health promotion, is important in hospice/palliative care; Cotter notes that end-of-life care is “seeking to empower individuals to discover truth and meaning in their own dying and death” (Cotter, 2007, p. 257). Lastly, the New Zealand Palliative Care Strategy recommended a “health promotion strategy” is developed for people and organisations at end of life (Ministry of Health, 2001, p. 23). A mandate clearly exists for health promoting hospices.

The settings health promotion approach has worked with communities in cities (Ashton, Gray, & Barnard, 1986), the workplace (Novak, Bullen, Howden-Chapman, & Thornley, 2007), universities (Dooris, 2001), schools (Stewart-Brown, 2006a), prisons (Tones & Green, 2004) and hospital and hospices (Kellehear, 1999a) to empower the community to build on their strengths and identify and improve on their weakness. The settings approach, inspired by WHO strategy “health for all” (Dooris, Dowding, Thompson, & Wynne, 1998) and the Ottawa Charter (WHO Health and Welfare Canada Canadian Public Health Association, 1986) stems from an ecological model that understands health to be influenced not solely by individual factors, but by wider environmental determinants. There is precedent for topic focused, settings-based approaches (Whitelaw, et al., 2001) that allow the issues to initially drive the health promotion approach. In this case, spirituality could be considered, examined and improved at the ethos/structural level, the community relationship level and the clinical
bedside level. The process involves management buy-in, establishing a health team made up of all populations involved to drive the settings-based approach, doing or outsourcing an evaluation of spirituality in all aspects of hospice, prioritizing areas for improvement, implementing changes/interventions, evaluation and continuing the process cyclically. As seen in Australia, health promoting hospices have significant potential (Kellehear, 1999a), but this process would especially improve spiritual care across the whole setting, from staff to patient to family spiritual well-being.

7.6 Limitations

The limitations of the discrete studies have been discussed in the relevant chapters above. There are a number of broader limitations to the discussion. Firstly, ideal circumstance would have allowed for Māori capacity in the research, thus allowing for a co-research approach. Secondly, there is a lack of attention to religious traditions and sacred literature, as was noted in the initial parameters of the study. Thirdly, complementary and alternative medical approaches have not been canvassed and these have much to add to the spirituality discourse at end of life. Fourth, the hospital interviews were revealing regarding patients and family members, but more because they were excellent participants, rather than the hospital setting. As a result, there has been no in-depth discussion of hospital spiritual care and this remains an area for further research. Lastly, the extent of the data from both studies was such that not all of it could be analysed and incorporated into this thesis. For example, the first section of the survey, the FACIT-sp-ex measure, was not included in the thesis. It is hoped later papers will cover this material.

In contacting all New Zealand hospice CEOs (or equivalents) I came across a number of research issues/limitations of note. For instance the following questions were raised. Are researchers clear enough about their reciprocal position with the participating organisations? Do researchers give feedback in a timely and appropriate manner? Regarding funding: do researchers include, in funding proposals, money for dissemination of results? Do researchers need to take care with a finite resource - hospices in New Zealand - and not over research this population? These questions arose from many discussions with hospice CEOs and particularly with one who “felt” over researched, “used”, and hence research fatigued.
7.7 Summary and Recommendations

This final discussion chapter has aimed to bring together relevant results of both the current research and the literature in order to comment on spirituality understandings, unmet spiritual needs and how spiritual care may be improved in New Zealand hospices. Spiritual space has been an overarching theme that has run through the discussion, from individual to institutional levels. Individually, spirituality is understood broadly by the majority of sources, with an inclusive approach dominant. This research has identified unmet spiritual needs by hospices as being likely to be high, with all three sources (Study One, Study Two and the literature) affirming this. However, there is significant will from New Zealand hospices to provide appropriate spiritual care and a range of issues and solutions in this regard have been discussed.

Studying spirituality artificially extracts it from 'the whole', thus I am aware that just as death is more than a biological event, spirituality is inherently connected, perhaps as an integrating factor, with all dimensions of self (including for some the 'Other' or God). This research happened within early 21st-century New Zealand, where changes in demographics, healthcare and the spiritual landscape have all affected hospice care. By its nature, contemporary spirituality is eclectic and marked by plurality; both characteristics have been affirmed in the study samples. The ontic fragility highlighted within this contemporary situation was not dominant, though was present in the Studies. Religious spirituality was expressed by very few participants, except that it was overwhelmingly dominant in chaplains. Māori contributions and aspirations were affirmed as critical to our New Zealand context. Paranormal experiences were found to be normal for many in hospices.

Spirituality must be seen as a part, or the centre, of a wider whole, whether named in a holistic or bio-psycho-social-spiritual model. What is clear from the data is that the dominant disenchanted world that eschews anything that cannot be seen and counted is not the reality for most people affected by cancer. The spiritual side or te taha wairua does not necessarily refer to the transcendent for all people in this study, but the dominant approach is an inclusive one that allows for individuals to decide for themselves. This is perhaps indicative of the democratization, lay recovery and re-enchantment of spirituality that many have named. Moreover, this affirms the foundation of hospice, its ethos and mandate to care for the whole
person (and family) till the moment of death, and through the grieving period for family members.

Spiritual despair may happen in the long dying that is terminal cancer. The challenge for hospice is to keep the awareness of spirituality at the forefront of care, understanding that inherent in the work of dying (for the majority) is facing one’s pared down being. A being that has only soul, spirit, essence left, and must be reconciled with the past, present, future, community and, for some, the transcendent or God. To do this work, patients and family members need spiritual space. It is argued above that this must be structurally, consciously, explicitly and carefully nurtured so as to empower at every step. Critical to this process are hospice staff, who need support, training and affirmation in this work.

The following recommendations are based on or extrapolated from the evidence above, are aspirational and are listed from up to downstream:

1. Provide evidence to prioritize funding at a national level for building spiritual care capacity up, mid and downstream within hospices.
2. Develop an inclusive working definition of spirituality for New Zealand hospices.
3. Facilitate structural spiritual audits in all hospices.
4. Develop spiritual care policies, guidelines, and competencies for pre and in-service training for New Zealand hospice care.
5. Implement pre-service spiritual care training courses for all healthcare professionals, particularly nurses and medical doctors.
6. Mandate annual and compulsory in-service spiritual care training as a component of hospice healthcare professionals’ maintenance of professional standards and continuing professional development.
7. Develop a health promoting hospice pilot in New Zealand, with a spirituality focus.
8. Grow the evidence base for spiritual care efficacy through tagged research funding.

144 Building on the palliative care service specifications, strategy and other cancer care guidelines.
10. Encourage a spiritual care process in every hospice, including a spiritual history/ongoing assessment, a spiritual care plan and formal notes, and tailored spiritual care/interventions.

11. Hospice chaplains consider changing their title so as to be inclusive for their community.

12. Spiritual care experts be paid and employed enough hours to do their job appropriately.

13. Adequate physical space be made available and appropriately fitted out for spiritual care.

14. Develop qualitative and quantitative spiritual assessment tools relevant for New Zealand hospices.

15. Develop a spiritual care resource to up-skill family and friends.

While there is no one definition of a good death (Steinhauser, et al., 2000), a “good enough death” (McNamara, 2004), for most people, demands spiritual concerns be addressed. No one can resolve these concerns for anyone else, but an environment can be made conducive, questions can be posited and literal and metaphorical space made available for such exploration. Cicely Saunders argued for a new “ars moriendi”, reincorporating the spiritual into care of the dying (Have & Clark, 2002). A key question underpinning this research is do we still, over four decades after Saunders’ first hospice, need a new ‘art of dying’? The answer is yes and no. No, in that hospices do not need a new art of dying, they just need to be regularly reminded of the art that is mandated. And yes, other institutions, such as hospitals, where hospice approaches are attempted via palliative care, need a reoriented philosophy of care and dying modelled on hospice.

New Zealand is unique in the world, on the edge geographically and metaphorically. We have the potential to lead spiritual care in a seminal way in the secular world. This research has added something unique to the hospice spiritual care literature, but I acknowledge the many New Zealanders who have thought and written about this topic, including Māori, academic and lay people. I am aware that on one memorable occasion from Study One, the interview was an inroad for the chaplain to work with a person who, by all staff accounts (and my interview confirmed), was full of anger and ‘spiritual pain’. Further, many of the participants expressed their gratitude for having the opportunity to discuss these issues and
how the interview itself had had an (unintended) therapeutic outcome. There were many tears from participants, times of silence and some awkward moments. Participants’ stories exploring spirituality were of pain and sorrow, anger, misdiagnosis, learning, growing, existential angst, family flourishing and diminishing and more, were all profoundly moving, and I was, and am, constantly amazed at the generosity and openness of these people. To all those who gave their time to this study, especially those who have passed away, I salute and thank you, and hope that this thesis has done justice to your generosity.
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Appendices

A. Ethics Issues

University of Otago: One of my supervisory departments (Preventive & Social Medicine) required PhD proposals to go through their Research Advisory Group. This was a group of senior academics who examined the proposal for scientific merit. I attended this meeting and discussed various issues. Subsequently, I received a formal letter which recommended changes. The primary change, which I agreed with, was to not attempt to correlate physical health with spiritual health. This was too big to do within this relatively small, individually driven, project.

National Multi-regional Ethics Committee: I did 25 drafts of the application form (appropriately called the “NAF-2005 vl”) for this committee. This process was before the pilot, as obviously ethics approval was needed to ‘test’ the interviews. The ethics application was an excellent exercise in minutiae, thereby planning the whole process from pilot to publication, and trying to consider all intended and unintended consequences. As noted above, the literature significantly informed ethical considerations.

Pilot Process: the pilot process was an opportunity to test the proposed processes; draft consent forms and information sheets; and interview schedule. This was very useful, as a number of changes were made in consultation with the staff and patients/family members. For instance the key contact questionnaire and communication processes were improved based on staff feedback.

Locality Assessments: as required by the National Multi-regional Ethics Committee, a Locality Assessment was negotiated with all the participating hospices for Stage One and Two.
Confidentiality, Anonymity, Data Storage: based on good practice and ethics requirements, electronic and hard copies of these interviews are held in secure storage. This will be held in storage for seven years then destroyed.
B. Review Articles on Spirituality & Health

Table B.1 Review Articles on Spirituality & Health

<table>
<thead>
<tr>
<th>Citation</th>
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### Table B.1 Review Articles on Spirituality & Health (Continued)

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### Table B.1 Review Articles on Spirituality & Health (Continued)

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There are a range of ‘titles’, which reflect the type of review article, these include thematic (Sinclair, et al., 2006)/systematic (Becker, et al., 2007)/integrative (Chiu, et al., 2004)/introductory (Culliford, 2002) and “Current status and methodological challenges” (Stefanek, et al., 2005). Larson (Larson, Larson, & Koenig, 2002) (Larson & Susan, 2003) is the only person to be the lead author on more than one review, however many of these scholars are named as second or third authors. Further there are a range of significant books published in this field and many of these review authors have also published books, including Koenig, Pargament, Puchalski, Ross, Heelas, Moberg and Stanworth.

Place of publication was the most remarkable attribute of these reviews. Of the 62, 41 (66%) articles were written by Americans (or US based scholars). Other countries included the UK with 14 articles (23%), Canada 6 articles (10%), and Germany and the Netherlands with 1 each. This affirms the widely held notion that the US leads research and publication in this field.

The health disciplines and journal types are represented broadly (see Table B.2 below). This is my subjective analysis; in the first instance I judged the ‘disciplines’ based on the author’s note in each article and this amount of information varied. Secondly, I combined some ‘disciplines’, such as ‘rehabilitation and aging’, ‘aging and HIV’ and ‘geriatrics’. In the ‘Journal Type’ there were some combinations, for instance ‘psycho-oncology’ was combined with ‘psychology’, and I chose to put ‘geriatric nursing’ in ‘geriatrics’, not nursing.

Perhaps more meaningful combination would be to combine ‘disciplines’ into the following:

**Table B.2 Review Articles by Discipline**

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<tr>
<th>Combined Disciplines</th>
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<td>19</td>
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<tr>
<td>(Palliative, Geriatric, Aging, Cancer, Death Studies)</td>
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</tr>
<tr>
<td>Allied Health</td>
<td>16</td>
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<tr>
<td>(Nursing, Occupational Health, Rehabilitation)</td>
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</tr>
<tr>
<td>Psychological</td>
<td>13</td>
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<tr>
<td>(Psychology, Adolescent Health, Health Comms, Mental Health, Adult Development)</td>
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<tr>
<td>Medical</td>
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Similarly, the Journal Types could be arranged as follows:

**Table B.3 Review Articles by Journal**

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<tr>
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<td><strong>Medical</strong></td>
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<tr>
<td>(Medicine, Psychiatry, Human Fertility, Medicine &amp; Philosophy, Pharmacotherapy, Medicine &amp; Rehabilitation, Gynaecology)</td>
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</tr>
<tr>
<td><strong>Religious</strong></td>
<td>7</td>
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<tr>
<td>(Religion &amp; Health, Pastoral Care, Religious Studies &amp; Aging, Psychology &amp; Theology, Spirituality &amp; Health)</td>
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<tr>
<td><strong>Social Science</strong></td>
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<td>Mental health</td>
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<td>Death Studies</td>
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<tr>
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<td>Quality of Life</td>
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<td>Health Comms</td>
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<td>Adult Development</td>
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<td>Chaplaincy</td>
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<td>Nursing</td>
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<td>Psychology</td>
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<tr>
<td>Religion &amp; Health</td>
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<tr>
<td>Cancer</td>
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<tr>
<td>Death &amp; Dying</td>
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<tr>
<td>Adolescent Health</td>
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<td>Geriatrics</td>
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<td>Occupational Therapy</td>
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<tr>
<td>Adult Development</td>
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</tr>
<tr>
<td>Medicine &amp; Rehab</td>
<td>1</td>
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<tr>
<td>Pharmacotherapy</td>
<td>1</td>
</tr>
<tr>
<td>Chronic Illness</td>
<td>1</td>
</tr>
<tr>
<td>Medicine &amp; Philosophy</td>
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</tr>
<tr>
<td>Spirituality &amp; Health</td>
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<tr>
<td>Psychiatry</td>
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<tr>
<td>Aging and Ment Health</td>
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<td>Human Fertility</td>
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<td>Gynaecology</td>
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<td>Psych &amp; Theology</td>
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<td>Rel Studies &amp; Aging</td>
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<tr>
<td>Pastoral Care</td>
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</table>
C. Study One

C.1 Information Sheets

Based on the ethics regulations, the information sheets followed the standard formula. The information sheets varied slightly between populations. The variations were based on the population’s needs, for example, headings changed.

Spirituality in end-of-life cancer care

Participant Information Sheet for Patients

Date: January, 2007

Introduction

My name is Richard Egan and I am working under supervision on a PhD. You are invited to take part in this project. Please read this information sheet carefully. You’ll have a reasonable time to consider whether to take part or not. If you decide not to take part there will be no disadvantage to you of any kind and we thank you for considering our request.
Please note: ‘spirituality’ means different things to different people. In this study, spirituality includes beliefs, values, sense of meaning and purpose, identity, and for some people religion.

What is the Aim of the Research?

This project is looking at ideas about spirituality in New Zealand palliative cancer care. We’d like to find out what patients, family members and staff think about spiritual care. To do this we are going to talk to people in selected hospices and an out-patients’ clinic. Later we’ll do a written survey of all the hospices in New Zealand.

Why were you chosen?

You were invited to take part because you’re receiving care from a hospice or out-patient clinic. You were identified as being eligible to participate in this project by the hospice or out-patient clinic staff.

How much of your time is involved?

There will be two separate meetings. The first meeting will take about half an hour where I will explain the research and answer your questions. The second meeting will be when we do the interview and this may take up to an hour.

Please note that taking part in this study is voluntary and that your refusal to participate or withdrawal from the study at any stage will not affect your continuing health care in any way. At any time during the interview session you can ask to stop and this will be done immediately.
What will the interview involve and where will it be?

In the interview I will have some questions that I’d like to ask, but you will also be able to talk about things that are important to you. I hope the interview will be like a conversation with you about spirituality. We can do the interview wherever you like – at your home, the hospital or hospice. You don’t have to answer all the questions, and you can stop the interview at any time.

In the interview we will talk about the following issues. If you agree to take part, I’d appreciate it if you could think about these issues before the interview.

- What is spirituality about?
- The ways spirituality might change during illness?
- Spiritual care for people who are dying.

With your permission I will tape record the interview.

What will happen after the interview?

Your interview will be typed up and you are welcome to have a copy of this transcription. If you would like, your family can also have a copy of the interview transcript or a CD copy. You are welcome to correct and make changes to your transcript before it is used in the project.

If you would like a copy of the results I can send you a short summary and the final report will be available from the University of Otago library. The findings from this project may be published but no one will be able to identify you personally in any publication. Your tapes and interview transcripts will be kept in a locked cabinet in the Department of General Practice and only I will have access to them. I will safeguard your information for the next 10 years and then it will be destroyed.
What are the potential benefits of this study?

I hope that you will benefit from participating in this project. You may gain an increased awareness of your own spirituality and a sense that you are doing something that will help others in the future through improvements in spiritual care for staff, future patients and their families. You will also have a record of the interview of some of your thoughts and feelings about spirituality.

What are the possible risks?

The interview may bring up some issues that you have not thought about before. This can be a positive thing. The counselor or chaplain at your hospice or out-patient clinic knows about this study and you can contact them if needed.

You may have a friend, family or whanau support to help you understand the risks and/or benefits of this study and any other explanation you may require.

If you have any queries or concerns about your rights as a participant in this study you may wish to contact a Health and Disability Services Consumer Advocate, telephone 0800 377 766.

What happens to the results of the study?

I expect to finish this project in 2008. The findings will be written up into a PhD thesis and the findings will also be published in academic journals and presented at conferences. A summary of the findings will be offered to participants and participating organisations. The findings may also be published in popular media such as magazines and newspapers.
If you require any further information, feel free to contact either me or one of my supervisors listed below.

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Auckland.
Ph. 09 486 1688

Associate Professor Rob McGee
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Dunedin School of Medical. Ph. 03 4797215

Yours sincerely

Richard Egan

Professor Rod MacLeod

This study has received ethical approval from the Multi-region Ethics Committee which reviews National and Multi regional studies. Further, the hospice CEO and the out-patients head of department have given permission for this study to be carried out.
C.1.1 Working Definition of Spirituality in the Information Sheet

Regarding the inclusion of definitions in research information, some argue that an “inductive” approach (Nordstrom, 2004) is most appropriate. That is, an approach that does not put words into the participants’ mouth by giving a definition. My position is that a working definition is needed because of the lack of epistemological and definitional clarity. It is presented as a ‘working definition’ and offered as one of many. The definition in all the information sheets was:

Please note: ‘spirituality’ means different things to different people. In this study, spirituality includes beliefs, values, sense of meaning and purpose, identity, and for some people religion.

C.1.2 Questions for participants to consider in the Information Sheet

In the information sheet there were three questions that asked the participants to begin thinking about this area. Combined with the spirituality definition, and any questions that were answered in the ‘consent meeting’, these prompt questions allowed the interviewee to consider spirituality before the interview.

In the interview we will talk about the following issues. If you agree to take part, I’d appreciate it if you could think about these issues before the interview.

What is spirituality about?
The ways spirituality might change during illness?
Spiritual care for people who are dying.

Changes to Information/Consent Forms: in a number of cases there were changes made, for instance, one patient asked that I changed the title “Spirituality in End-of-life Cancer Care” to “Spirituality in Cancer Care” due to the perceived morbid nature of the “end-of-life” phrase.

C.2 Consent Forms

As per the ethics committee guidelines and good practice, the consent form was read, understood and signed by all participants. There were no unusual variations in the consent process with participants.
Spirituality in cancer care

Consent Form for Participants

I have read and I understand the information sheet dated January 2007 for people taking part in this project on spirituality and palliative care in NZ. I have had the chance to have my questions about this project answered and I am satisfied with the answers I have been given.

I understand:

1. I have read the Information Sheet / have had the Information Sheet explained to me by ........................................;
2. I’ve had the chance to use family / whanau support or a friend to help me ask questions;
3. taking part in this study is my choice and I may withdraw from the study at any time and this will in no way affect my continuing health care;
4. I have had time to consider whether to take part;
5. that my participation in this study is confidential and that no material which could identify me will be used in any reports on this project;
6. my participation involves taking part in a tape recorded interview;
7. that the interview will be stopped if it appears harmful to me;
8. who to contact if I have any issues after the interview or about the study;
9. that if I’m unable to review my interview transcript it may still be used in the project.
10. I wish to receive a copy of the interview on CD and a transcript YES / NO
11. I wish for my next of kin to receive a copy of the interview YES / NO

   If yes, please write the appropriate postal address below:

   ..............................................................................................................

12. I wish to receive a summary copy of the results YES / NO

   It may be 3 years before the results are available.

I ____________________________ (full name) hereby agree to take part in this study.

Signature: ____________________________ Date: ____________
If you require any further information, feel free to contact either me or one of my supervisors listed below.

**Richard Egan**  
Departments of General Practice & Preventive and Social Medicine & Geography  
Dunedin School of Medicine  
University of Otago  
PO Box 913  
Dunedin  
Ph. 03 479 5766 / 0276819370  
egari989@student.otago.ac.nz

**Professor Rod MacLeod,**  
North Shore Hospice,  
PO Box 331129  
Takapuna,  
Auckland.  
Ph. 09 486 1688

**Dr Chrystal Jaye**  
Medical Anthropologist, Department of General Practice. Dunedin School of Medical.  
Ph. 03 4795767

**Associate Professor Rob McGee**  
Department of Preventive and Social Medicine  
Dunedin School of Medical. Ph. 03 4797215

**Dr Joanne Baxter**  
(Ngai Tahu Maori Health Research Unit)  
Department of Preventive and Social Medicine Dunedin School of Medical. Ph. 03 4797176

The researcher is available to answer any questions about this study. If you have any queries or concerns about your rights as a participant in this study you may wish to contact a Health and Disability Services Consumer Advocate, telephone 0800 377 766.
C.3 Interview Schedule

Below is the patient interview schedule. Essentially this was similar to the to other populations; with staff being asked more about their hospice. Māori interviews were quite different, for details see Māori Chapter.

Interview Schedule – Patient

Intro: affirm time ok; anonymity / confidentiality and consent

Note: I'll be taking a few notes and making some reference to this interview schedule – but you can talk about any aspects of spirituality that you like.

Start recording device

1. Thank you for participating ..........(name), on .......... (date)

2. Re-affirm aim and working definition:

   Spirituality means different things to different people. For this study, our working definition includes: your beliefs, values, sense of meaning and purpose in life, identity, and for some people, religion.

Demographic Info

Study ID:   Gender:   Name:

Address:

Email:

Diagnosis:

Religious preference:   Marital Status:
Ethnicity:  

Highest Qualification:

Highest household Qualification:

0) Open Question:

A) Definition – before you were asked to be part of this study – what was your understanding of spirituality? (definition?, important?, ‘what matters?’).

B) Meaning & Purpose – what gives your life meaning? (people, places, the past)
   - When you find yourself down or upset what do you find hope or comfort in?
   - do you do anything daily that gives life meaning? (spiritual practices, rituals – maybe gardening, special cup of tea, music)

C) Beliefs & Values – I imagine there may have been lots of changes since your diagnosis – has there been any change in your beliefs or values?
   - What about the way you see the world?
   - From what I’ve read, suffering and physical pain may be related to spirituality – what do you think?
   - Do you believe in God? The afterlife?

D) Identity – who you are, your essence, your sense of self is considered by some to be part of your spirituality – has your diagnosis affected your identity?
   - think about roles – as a man / women, at home or work – have these roles changed?
   - Has your awareness of your body changed?

E) Spiritual Care – how would you describe your spiritual care? (assessment?, care plan)
   - what would you like to have had (ideal spiritual care plan)

F) Religion – do you have a religious perspective / community. (how important?)
   - what about spiritual prayer or rituals?

G) Definition?? How would you define spirituality now?

H) Is there anything else about spirituality you would like to talk about?

Formal Finish (note the community coordinator is available)
C.4 Study One Demographics

Table C.1 Participant Demographic Information

<table>
<thead>
<tr>
<th>Demographics</th>
<th>Patients N = 24</th>
<th>Family Members N = 9</th>
<th>Staff N = 8</th>
<th>Chaplains N = 8</th>
<th>Māori Experts N = 3</th>
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D. Study Two

D.1 Information Sheet

Study Two information sheets varied slightly between patients, family members and staff.

Participant Information Sheet for Patients

Title of Project: Spirituality in Cancer Care

Researcher:
Richard Egan
Departments of General Practice & Preventive and Social Medicine
Dunedin School of Medicine
Ph. 03 479 5766 / 0276819370
Email: egari989@student.otago.ac.nz

Date: October 2007

Introduction
My name is Richard Egan and I am a PhD student in the Dunedin School of Medicine at the University of Otago. I would like to invite you to take part in this project by filling out the attached survey. Please read this information sheet carefully.

Please note: 'spirituality' means different things to different people. In this study, spirituality includes beliefs, values, sense of meaning and purpose, identity, and for some people religion.

If you decide not to take part there will be no disadvantage to you of any kind and we thank you for considering our request.
What is the Aim of the Research?

This project is looking at ideas about spirituality in New Zealand palliative cancer care. We’d like to find out what patients, family members and staff think about spiritual care. To do this we have talked to people in selected hospices and an out-patients’ clinic. Now we are conducting this survey of almost all the hospice / palliative care services in New Zealand.

Why were you chosen?

You were identified as being eligible to participate in this project by the hospice / palliative care service senior staff. **Please note that taking part in this study is voluntary. You may choose to not participate.**

What will the voluntary survey be about?

The attached survey asks about your understanding of spirituality, spiritual care and some information about you that will not identify you personally. All the information will be anonymous.

I would be grateful if you would complete the survey as soon as possible and either return it in the stamped addressed envelope or give it to the key contact person at the hospice / palliative care service. It will take approximately 10 minutes. You may choose to do the survey at your own pace over a couple of days.

What are the potential benefits of this study?

I hope that you will benefit from participating in this project. You may gain an increased awareness of your own spirituality and a sense that you are doing something that will help others in the future through improvements in spiritual care for staff, future patients and their families.

The counselor or chaplain at your hospice / palliative care service knows about this study and will be available to discuss any issues this survey may bring up.

If you have any queries or concerns about your rights as a participant in this study you may wish to contact a Health and Disability Services Consumer Advocate, telephone 0800 377 766
What happens to the results of the study?
I expect to finish this project in 2008. The findings will be written up into a PhD thesis and the findings will also be published in academic journals and presented at conferences. A summary of the findings will be offered to participating organisations. The findings may also be published in popular media such as magazines and newspapers.

If you require any further information, feel free to contact either me or one of my supervisors listed below.

Professor Rod MacLeod,
Department of General Practice & Primary Health Care. School of Population Health.
Tamaki Campus, Auckland. Ph. 09 373 7999

Associate Professor Rob McGee
Department of Preventive and Social Med,
Dunedin School of Medicine. Ph. 03 479 7215

Dr Chrystal Jaye
Medical Anthropologist, Department of General Practice. Dunedin School of Medicine. Ph. 03 479 5767

Dr Joanne Baxter Ngai Tahu Māori Health Research Unit, Dunedin School of Medicine.
Ph. 03 479 7176

Yours sincerely

Richard Egan Professor Rod MacLeod

---------------------------------------------------------------

Spirituality Survey

To avoid receiving a follow-up request to complete this survey, when you have completed the survey please write your name in the space below and tear this section off and hand it to the liaison person in your hospice who distributed the questionnaire to you. (For some people, it may be easier to phone the liaison person.) Your name will not be passed on to the researcher – it is to assist the local liaison person to identify participants who have completed the survey and will therefore not be sent a reminder.

Name:
D.1 Survey

Below is copy of the Staff survey. This has all the questions the patients and family members were asked, plus extra questions relevant only for staff.

Staff Participant Survey
Spirituality in NZ Hospice/Palliative Care Survey

Date: October 2007

Instructions

Thank you for agreeing to take part in this survey of spirituality and spiritual care in New Zealand Hospice/Palliative Care Services. The survey has three sections:

Section One: A survey of beliefs;

Section Two: Questions based on interviews with people in hospice care in New Zealand;

Section Three: Some background information about you.

There is room at the end for written comments. Once finished, please send back to Richard Egan via the accompanied stamped and addressed envelope OR hand it back to the contact person in the Hospice / Palliative Care Service.

If you misplace the return envelope, then please return to:

FREEPOST 112002
Richard Egan
Dunedin School of Medicine
Department of General Practice
Otago University
PO Box 913
Dunedin 9054
10 NC M01
Introduction

The following questions ask about beliefs, feelings and experiences. Spirituality means different things to different people. For this study, our working definition includes: one’s beliefs, values, sense of meaning and purpose in life, identity, and for some people, religion.

If you believe in a particular religion, such as Christianity, Judaism, Hinduism, Islam or Buddhism, you will probably answer the following questions with your religious beliefs in mind. You may believe that something higher and more powerful exists beyond the physical and material world; you may answer the following questions from that perspective. Alternatively, you may have no belief in a higher, spiritual entity, but you may have strong personal beliefs or followings, such as beliefs in a scientific theory, a personal way of life, a particular philosophy or a moral and ethical code. While some of these questions will use words such as spirituality, please answer them in terms of your own personal belief system, whether it be religious, spiritual or personal.

Section 1: Survey of Beliefs

Below is a list of statements that other people associated with cancer care have said are important. By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.

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<th></th>
<th>Not at all</th>
<th>A little bit</th>
<th>Some what</th>
<th>Quite a bit</th>
<th>Very much</th>
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<td>Sp1</td>
<td>I feel peaceful</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
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<tr>
<td>Sp2</td>
<td>I have a reason for living</td>
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<td>Sp3</td>
<td>My life has been productive</td>
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<td>2</td>
<td>3</td>
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<td>Sp4</td>
<td>I have trouble feeling peace of mind</td>
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<td>Sp5</td>
<td>I feel a sense of purpose in my life</td>
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<tr>
<td>Sp6</td>
<td>I am able to reach down deep into myself for comfort</td>
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<td>Sp7</td>
<td>I feel a sense of harmony within myself</td>
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<td>Sp8</td>
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<td>Sp9</td>
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<td>I find strength in my faith or spiritual beliefs</td>
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<td>Sp11</td>
<td>My experience of cancer care has strengthened my faith or spiritual beliefs</td>
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<td>Sp12</td>
<td>I know that whatever happens with cancer, things will be okay</td>
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<td>Sp13</td>
<td>I feel connected to a higher power (or God)</td>
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<td>I feel connected to other people</td>
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<td>Sp15</td>
<td>I feel loved</td>
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<td>Sp16</td>
<td>I feel love for others</td>
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<td>I am able to forgive others for any harm they have ever caused me</td>
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<td>Sp18</td>
<td>I feel forgiven for any harm I may have ever caused</td>
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<td>Throughout the course of my day, I feel a sense of thankfulness for my life</td>
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<td>Throughout the course of my day, I feel a sense of thankfulness for what others bring to my life</td>
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<td>Sp21</td>
<td>I feel hopeful</td>
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<td>I feel a sense of appreciation for the beauty of nature</td>
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<td>I feel compassion for others in the difficulties they are facing</td>
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Section 2

The following questions are based on interviews we did with patients, family members and staff in hospices and one out-patient’s clinic. There is no ‘right’ answer to these questions.

[Circle one]

1. Do you feel your life has meaning?
   a. NO
      (If No, then go to question 2)
   b. YES
      (If Yes, which of the following gives your life meaning?)

   [Circle one or more]
   
   i. Family
   ii. Helping others
   iii. Spiritual being
   iv. Work
   v. My religion
   vi. Building community
   vii. Friends
   viii. God
   ix. Life itself
   x. Meditation
   xi. Personal philosophy
   xii. Children
   xiii. Sport
   xiv. Other.......................

2. How would you best describe your current beliefs? [Circle one]
   a. I hold a set of religious beliefs
   b. I hold a set of spiritual beliefs
   c. My beliefs are both religious and spiritual
   d. No particular beliefs
   e. Other .......................  

3. About how often have you attended a religious service in the last year (excluding weddings, funerals and christenings)?

   [Circle one]
   1  2  3  4  5
   Seldom Or never  Every few months  Monthly  Weekly  Daily
4. How often do you participate in a spiritual activity (eg. meditation, tai chi, yoga, prayer etc.) not connected with a traditional church or house of worship, either alone or with others?

[Circle one]

1 2 3 4 5
Seldom Or never Every few months Monthly Weekly Daily

5. Have your beliefs changed since you have begun dealing with cancer issues? [Circle one]

a. NO
(If No, then go to question 6)

b. YES
(If Yes, how?) [Circle one or more]

i My beliefs have become stronger
ii I have questioned my beliefs
iii My beliefs have become weaker
iv Other.....................

6. Do you believe in God? [Circle one]

a. NO
(If No, then go to question 7)

b. DON’T KNOW
(If Don’t Know, then go to question 7)

c. YES
(If Yes, circle which words would begin to describe God)

i All knowing
ii All loving
iii All powerful
iv All that is
v The creator, but not creation
vi Universal consciousness
vii Love
viii A mystery
xi Other.....................
7. Thoughts of dying frighten me. [Circle one]


8. I have regrets about the way I have lived my life. [Circle one]


9. I worry that my family is not prepared to cope with the future. [Circle one]


10. Which of the following would you include in a definition of spirituality? [Circle one or more]

a. Meaning  k. Essence
b. Purpose  l. Life giving force
c. Beliefs  m. Balance
d. Values  n. Transcendent
e. Identity  o. Faith
f. Sense of awareness  p. Mystery
g. Religion  q. Inner core
h. God  r. It is meaningless
i. Connectedness  s. Other..............
j. Relationships

11. Which one of the following five statements best describes your views about what happens when someone dies? [Circle one]

a. It’s all over, there is no soul or spirit
b. The soul or spirit goes to another place
c. There is no heaven or hell, but the soul lives on in some kind of spiritual realm
d. The soul is reincarnated into another creature
e. Don’t know
12. Have you had any of the following experiences? [Circle one or more]

a. Experienced an unexplained phenomenon?
b. Seen a dead person, as a ghost?
c. Had a near death experience?
d. Had an unexplained vision?
e. None of the above?
f. Other? ..........................

13. Have you received spiritual care? [Circle one]

a. NO  
(If No, then go to question 14)

b. YES  
(If Yes, from whom)? [Please circle as many as apply]

i  Family
ii  Friends
iii  Hospital Chaplain / Councillor / Nurse / Doctor / Other ..............
iv  Hospice Chaplain / Councillor / Nurse / Doctor / Other ..............
v  District Nurse
vi  General Practitioner
vii  Minister / Priest / Rabbi / Imam
viii  Other .................

c. (If Yes, what did the spiritual care include)? [Please circle as many as apply]

i  Spiritual Counselling
ii  Spiritual Resources (Including Books, Bible, ...)
iii  Prayer From Others
iv  Prayer With Others
v  Listening
vi  Other ..............
14. Ideally, would you like to have spiritual care? [Circle one]

a. NO  
   (If No, then go to question 15)

b. YES  
   (If Yes, by whom)? [Circle one or more]
      i  Chaplain / Minister / Priest / Rabbi / Imam
      ii  Non-Denominational Spiritual Carer
      iii  Councillor
      iv  Nurse / Doctor
      v  Family / Friends
      vi  Other............

15. The most appropriate name for the key professional who does spiritual care is: [Circle one]

a. Chaplain
b. Spiritual Carer
c. Spiritual Companion
d. Pastoral Carer
e. Other .............
f. It Doesn’t Matter

16. I would like help with: [Circle one or more if appropriate]

a. Overcoming fears  
   Yes / No
b. Finding hope  
   Yes / No
c. Finding meaning in my life now  
   Yes / No
d. Finding spiritual resources  
   Yes / No

17. I would like to have someone to talk to about: [Circle one or more if appropriate]

a. Find peace of mind  
   Yes / No
b. The meaning of life  
   Yes / No
c. Dying and death  
   Yes / No
18. I have unmet cultural needs. [Circle one]
   a. NO
   b. YES
      (If Yes, what are they)?

19. Do you as a staff member have spiritual support at the Hospice / Palliative Care Services? [Circle one]
   a. NO
      (If No, then go to question 20)
   b. YES
      (If Yes, please briefly describe):

20. Is there a spiritual care policy which covers patients and / or staff at your Hospice / Palliative Care Service? [Circle one]
   a. YES
   b. NO
   c. DON'T KNOW
21. Does your Hospice / Palliative Care Service offer professional development in the spiritual care of patients? 

[Circle one]

a. NO (If NO, then go to question 22) 
b. YES (If Yes, then, circle one of the following: 

- Annually and compulsory 
- Annually and voluntary 
- Occasionally 
- Other ...................... 
- Provided by ..................... 

22. Are patient’s spiritual issues dealt with before they come into contact with Hospice/ Palliative Care Service staff? 

[Circle one] 

1 Always 2 Most of the time 3 Often 4 Sometimes 5 Never 

23. What spiritual resources are available at your hospice? [Circle one or more] 

a. None 
b. Poetry books 
c. Sacred books (Bible, Koran etc.) 
d. New age books 
e. Tapes 
f. Videos / Dvds 
g. Candles 
h. Incense 
i. Chapel / quiet room 
j. Religious symbols 
k. other ................. 

24. A formal spiritual assessment is done and written up in patient’s notes. 

[Circle one] 

1 Always 2 Most of the time 3 Often 4 Sometimes 5 Never
25. My spiritual care tools include: [Circle one or more]
   
a. Listening
b. Prayer
c. Rituals
d. Sacraments
e. Philosophical discussions
f. Talking about other things
g. Appropriate touching (eg. Holding a patient’s hand)
h. Small domestic / personal things
i. Other .............

26. In your experience, how important are spiritual issues for Hospice/ Palliative Care patients?
   [Circle one]
   
   1 2 3 4 5
Not at all A little bit Moderately Very Extremely

27. In this Hospice/ Palliative Care Service, how important is spirituality?
   [Circle one]
   
   1 2 3 4 5
Not at all A little bit Moderately Very Extremely

28. What is or was your most recent profession?

____________________________________________________________________

29. How much time do you work at the hospice / palliative care service? [Circle one]
   
a. Full time
b. Part time,
   (If part time, what is your closest percentage of full time?)
   i) 20% (1 day)   ii) 40% (2 days)
   iii) 50% (2.5 days)   iv) 60% (3 days)
   v) 80% (4 days)   vi) other .................
30. How long have you worked in specialised Hospice / Palliative care?

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>Less than 1 year</td>
<td>1 – 3 years</td>
<td>3 – 5 years</td>
<td>5 – 10 years</td>
<td>More than 10 years</td>
</tr>
</tbody>
</table>

31. Is there anything else you would like to say about spirituality and / or spiritual care in your hospice / palliative care service?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Note: the chaplain and councillor are aware this survey is happening. If you would like to talk about anything that this survey has raised for you, they will be happy to discuss anything further.

End of Section 2
Section 3: Background information about you.

The following questions collect some background information. These questions are taken from the Census and help us to understand the characteristics of the groups completing the survey.

[Please circle the appropriate option(s)]

1. Gender:  Male / Female

2. When were you born?  Day:.........Month:.............Year:...........

3. Which ethnic group do you belong to?
   a. New Zealand European
   b. Maori
   c. Samoan
   d. Cook Island Maori
   e. Tongan
   f. Niuean
   g. Chinese
   h. Indian
   i. Other, (such as Dutch, Japanese, Tokelauan). Please state_________________________.

4. Are you descended from a Maori (that is, did you have a Maori birth parent, grandparent or great-grandparent, etc?)
   a. YES
      If Yes, go to question 5)

   b. NO
      (If No, go to question 6)

   c. DON'T KNOW
      (If Don't know, go to question 6)
5. Do you know the name(s) of your iwi (tribe or tribes)?

   a. YES
      (If Yes, print the name(s) of your iwi (tribe or tribes)?

   b. NO
      (If Yes, print the name and home area, rohe or region of your iwi below:
      Iwi ________________________________

      Rohe (iwi area) ________________________________

6. What is your religion?

   a. No religion
   b. Christian
      (If you circled Christian, which of these, if any are you)?
      i. Anglican
      ii. Catholic
      iii. Presbyterian
      iv. Methodist
      v. Ratana
      vi. Ringatu
      vii. Other

6. Which of these statements is true about your legal marital / civil union status? [Circle one]

   a. I have never been legally married and I have never been legally joined in a civil union.
   b. I am divorced or my marriage has been dissolved.
   c. I am a widow / widower / bereaved civil union partner.
   d. I am permanently separated from my legal husband / wife / civil union partner.
   e. I am legally married.
   f. I am legally joined in a civil union.
8. What is your highest secondary school qualification?
   a. None
   b. NZ School Certificate in one or more subjects or
   c. National Certificate level 1 or
   d. NCEA level 1
   e. NZ Sixth Form Certificate in one or more subjects or
   f. NZ UE before 1986 in one or more subjects or
   g. NCEA level 2
   h. NZ Higher School Certificate or
   i. Higher Leaving Certificate or
   j. NZ University Bursary/Scholarship or
   k. National Certificate level 3 or
   l. NZ Scholarship level 4
   m. Other secondary school qualification gained in NZ.
   n. Please specify highest secondary school qualifications gained outside New Zealand:

..................................................................................................................................................
THANK YOU FOR YOUR HELP

We hope that one of the outcomes of this work will be the improvement of care for people in the future.

Sincerely

R. Egan

Richard Egan
D.2 Study Two demographics

FIGURE D.1 Demographic data by gender?

Table D.1 Demographic Data: Population, Gender

<table>
<thead>
<tr>
<th></th>
<th>Combined Pop No</th>
<th>Combined Pop %</th>
<th>Staff No</th>
<th>Staff %</th>
<th>Patient No.</th>
<th>Patient %</th>
<th>Family No.</th>
<th>Family %</th>
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<td>Population</td>
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<td>56.7</td>
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<td>21.96</td>
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<td></td>
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<td></td>
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<tr>
<td>Male</td>
<td>138</td>
<td>22.15</td>
<td>39</td>
<td>10.86</td>
<td>58</td>
<td>44.96</td>
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<td>Female</td>
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<td>77.85</td>
<td>320</td>
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<td>55.04</td>
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Table D.2 Demographic Data: Age

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<td>56.52</td>
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<td>66.98</td>
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<td>SD</td>
<td>12.37</td>
<td>8.99</td>
<td>10.24</td>
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<tr>
<td>N=</td>
<td>590</td>
<td>339</td>
<td>122</td>
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For the combined populations, the minimum age was 19 years and the maximum 89 years.

Table D.3 Demographic Data: Age and Gender

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<th>Age</th>
<th>Staff Male</th>
<th>Staff Female</th>
<th>Patient Male</th>
<th>Patient Female</th>
<th>Family Male</th>
<th>Family Female</th>
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<tbody>
<tr>
<td>Mean</td>
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<td>50.49</td>
<td>68.63</td>
<td>65.58</td>
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<td>SD</td>
<td>8.79</td>
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<td>8.88</td>
<td>11.23</td>
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<td>13.88</td>
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<tr>
<td>N=</td>
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<td>56</td>
<td>65</td>
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Table D.4 Demographic Data: Ethnicity, Religion, Marital Status and Qualifications

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<th>Combined Pop %</th>
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<th>Staff %</th>
<th>Patient No.</th>
<th>Patient %</th>
<th>Family No.</th>
<th>Family %</th>
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<td>89.24</td>
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<td>93.3</td>
<td>113</td>
<td>85.6</td>
<td>109</td>
<td>89.3</td>
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<td>Māori</td>
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<td>5.37</td>
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<td>1.3</td>
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<td>4.6</td>
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<th>Family No.</th>
<th>Family %</th>
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<td>0.7</td>
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<td>Hindu</td>
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<td>0.3</td>
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<table>
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<th>Combined Pop %</th>
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<th>Staff %</th>
<th>Patient No.</th>
<th>Patient %</th>
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<td>9.7</td>
<td>39</td>
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<tr>
<td>Highest Qualification</td>
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<td>25</td>
<td>19.5</td>
<td>34</td>
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<td>33.49 (8.94, 18.7, 0.16, 2.93, 2.76)</td>
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<td>25</td>
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360
E. Discussion

E.1 The Ottawa Charter, Hospices and Spirituality

At the heart of health promotion is the Ottawa Charter; therefore it is worth going through the five strategies to see how they line up with hospice/palliative care and spirituality:

Table E.1 Ottawa Charter, Hospices and Spirituality

<table>
<thead>
<tr>
<th>Ottawa Charter Action</th>
<th>Relevance to Hospice Care</th>
<th>Relevance to Spirituality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Building healthy public policy</td>
<td>Policies that affect death and dying are numerous. This action consciously adds a lens on policy making that affects palliative care. “Identify obstacles to health and to develop policies to remove them so that making ‘healthy choices’ will be an easier task for everyone” (Kellehear, 1999a, p. 11)</td>
<td>Spirituality is now found in policies around the world. Thus it needs to be further recognised in all health policy, thus giving it ‘teeth’ for a variety of approaches to be operationalised.</td>
</tr>
<tr>
<td>Creating supportive environments</td>
<td>The physical, social, spiritual and mental environments all affect one’s dying and understanding of death. This action is about helping to facilitate such environments that make healthy choices the easy choices. “Make all environments – work, leisure, and health care settings – conducive to health. More specifically, the term ‘environment’ here might apply to cultural, situational, physical, temporal, and life experiences” (Kellehear, 1999a, p. 11)</td>
<td>Baum argues that environments need to be created for people to realize their full potential (Baum, 1998). For this to happen, all dimensions of human potential must be included and therefore advocacy is needed for environments that allow for spiritual well-being in a range of settings (schools, workplaces and hospices).</td>
</tr>
<tr>
<td>Strengthening community action</td>
<td>Enhancing existing strengths and resources within the community to deal with death and dying. This action is about encouraging participation, collaboration and consultation on ways that people die in communities. “Emphasise that health care should be participatory. Professional work must be work with, rather than on, others” (Kellehear, 1999a, p. 12)</td>
<td>Enable communities to name their own identities, beliefs, spiritual and religion positions and needs.</td>
</tr>
<tr>
<td>Developing personal skills</td>
<td>Empowering and enabling people (staff, patients and family members) to take control within their dying situation through education, information and skill development. “Information and education about health”(Kellehear, 1999a, p. 12)</td>
<td>Healthy choices need to be comprehensive, therefore include spiritual skills and development of spiritual protective factors</td>
</tr>
<tr>
<td>Re-orientating health care services</td>
<td>Broadening healthcare services views to include holistic understanding, approaches and care is a key action. Many health services interact with hospice/palliative care, thus they can share in the holistic understanding as professed by both health promotion and hospice/palliative care.</td>
<td>Show evidence, advocate for holistic / person centred approaches – follows that spirituality needs to be addressed. Challenge / compliment medical model. Develop set of spirituality indicators – for individuals and populations.</td>
</tr>
</tbody>
</table>

"The values of participation, mediation, advocacy, and enabling should not be confined to health professionals and the health sector" but all sectors (Kellehear, 1999a, p. 12)