EXPLORING SPIRITUALITY
IN A NEW ZEALAND ONCOLOGY UNIT

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Dedication Page

This thesis is dedicated in loving memory of

Thomas William Downey

(November 11, 1976 – May 17, 2007)

&

Michael Hockersmith

(March 24, 1981 – December 28, 2010)

Until we meet again, Tommy my love and Mike my dear friend,

may God hold you two in the palm of His hand.

Abstract

Spirituality, as presented in this paper, is characterized as an individual's inherent need to find meaning and purpose in life, and as being the fabric that makes each person whole, (encompassing beliefs, values, attitudes, identity, and for some, religion). Further, it is argued that the ideas about spirituality as presented within are important and relevant in providing holistic care, especially in the context of oncology care.

A gap has been identified between research related to spirituality and spiritual care in hospital settings. *The New Zealand Cancer Control Strategy* aims to provide quality cancer care services through a holistic health care model with a person-centered approach which "recognizes a person's total well-being including their physical, emotional, spiritual, social and practical needs."[1] However, research conducted in New Zealand on the spiritual dimension, spiritual needs of patients with cancer, and spiritual care are absent from the cancer control section, which dictates areas of ongoing research. The purpose of this study is to explore and understand spirituality and spiritual care within a New Zealand hospital oncology setting by listening to the voices within those settings: patients, nurses, oncologists, and chaplains. The research questions addressed understandings and treatment of spiritual concerns in an oncology unit within a New Zealand public hospital. This study uses a qualitative approach which combined a literature review with in-depth interviews, totaling eight participants (patients n=3, doctors n=2, nurses n=2, chaplain n=1).

Although findings suggest that spirituality is understood in a variety of ways, common themes emerged, including: emphasis on relationships, holistic understandings (i.e. "who you are

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[1] Minister of Health, *The New Zealand Cancer Control Strategy*, (2003): 20, accessed 08 June 2009, http://www.moh.govt.nz/moh.nsf/0/3D7504AD140C7EF0CC256D88000E5A16/$File/CancerControlStrategy.pdf. Also it will be noted here that this thesis follows *The Chicago Manual of Style Online* 16th ed., (2010), accessed on 25 May 2011, http://www.chicagomanualofstyle.org/home.html.

as a person"), and the tendency to distinguish spirituality from religion. The evidence presented suggests that education in spiritual literacy is lacking, resulting in confusion and misunderstanding of the terms, which are factors that influence how spiritual care is delivered. This study concluded that spirituality is broadly understood by participants, it is an important component in holistic health care, and it may be valuable for medical staff to have an understanding of spirituality (as it is discussed in contemporary health care discourse) so that spiritual needs of patients with a diagnosis of cancer can be fully met in the context of holistic care.

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1 Introduction

1.1 Thesis Rationale

Approximately one in two men and one in three women will face cancer at some point in the course of their life.[2] Furthermore, death rates in New Zealand for some cancers are among the highest in the world.[3] Research suggests that spirituality is an important aspect in providing well-rounded medical care,[4] that it can be just "as important in many health initiatives as medication, hospitalization, or surgery,"[5] and that it is under researched.[6] The possible connection between spirituality and positive health outcomes is beginning to receive much attention by scholars and the need for more research is pertinent.[7]

The conceptual model for this thesis is grounded in a holistic understanding of health as stated in the *New Zealand Cancer Control Strategy*[8] and as articulated in Sulmasy's "biopsychosocial-spiritual model of illness"[9] and "patient-centered"[10] health care practices. In these models a person's total well-being including their physical, mental, social, and spiritual dimensions are recognized and considered to be important factors in health and illness.[11] Furthermore, the growing conceptual framework of health "as a process by which individuals maintain their sense of coherence and meaning in life in the face of changes in

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[2] Jerome Groopman, *How Doctors Think* (New York: Houghton Mifflin Company, 2007), 10.

[3] Minister of Health, *Cancer Control Strategy*, 9.

[4] Margaret Wills, "Connection, Action, and Hope: An Invitation to Reclaim the 'Spiritual' in Health Care," *Journal of Religion and Health*, 46:3 (2007): 423.

[5] David Aldridge, *Spirituality, Healing and Medicine: Return to the Silence* (London: Jessica Kingsley Publishers, Ltd., 2000), 9.

[6] Shane Sinclair, Jose Pereira, and Shelley Raffin, "A Thematic Review of the Spirituality Literature within Palliative Care," *Journal of Palliative Medicine* 9:2 (2006): 475.

[7] Carl E. Thoresen and Alex H. Harris, "Spirituality and Health: What's the Evidence and What's Needed?," *The Society of Behavioral Medicine* 24:1 (2002): 3-13.

[8] Minister of Health, *Cancer Control Strategy*, 20.

[9] Daniel Sulmasy, "The Biopsychosocial-Spiritual Model for the Care of Patients at the End of Life," *The Gerontologist* 42:3 (2002): 24-33.

[10] The Institute for Alternative Futures, *Patient-Centered Care 2015: Scenarios, Vision, Goals & Next Steps* (2004), accessed 25 May 2011, http://174.120.202.186/~pickerin/wp-content/uploads/2010/06/PCC-2015.pdf.

[11] Christina M. Puchalski and Betty Ferrell, *Making Health Care Whole: Integrating Spirituality into Patient Care* (West Conshohocken: Templeton Press, 2010), 55.

themselves such as illness"[12] permits this thesis to focus solely on the spiritual dimension; the dimension often charged with "meaning and purpose in life" responsibilities.[13]

The New Zealand Cancer Control Strategy suggests a need for increased research in all areas of cancer-related issues to identify and assess better methods of minimizing the impact of cancer in New Zealand.[14] The goal is to not only reduce the number of cancer diagnoses in New Zealand, but to improve the quality of life for those living with cancer and their family members by offering cancer care services, support and rehabilitation, and palliative care.[15] Within these services a spiritual dimension is recognized as a component of total well-being but how, and in what ways this is to be implemented into health care delivery is unclear.

1.2 Statement of Purpose

This thesis sought to explore spirituality and spiritual care in cancer care with the hope of gaining a better understanding of this area, which may in turn, impact and improve how holistic care is delivered in the future. More specifically, the purpose of this project was to employ qualitative methods to investigate the concepts of spirituality and spiritual care and how these terms are understood by individuals working in an oncology unit in New Zealand. This study used in-depth interviews as a means of collecting this prolific data. Participants included patients with a diagnosis of cancer, oncology medical staff (doctors and nurses), and one chaplain. The goals of this thesis are "explorative" and "descriptive."[16]

Central to this study were five key research questions:

- How do participants understand the term spirituality?

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[12] Christina M. Puchalski, "The Role of Spirituality in Health Care," *BUMC Proceedings* 14 (2001): 356.
[13] Patricia Fosarelli, "Fearfully Wonderfully Made: The Interconnectedness of Boyd-Mind-Spirit," *Journal of Religion and Health* 41:3 (2002): 213.
[14] Minister of Health, *Cancer Control Strategy*, 53.
[15] Ibid., 21.
[16] Margarete Sandelowski, "*Focus on Research Methods*: Whatever Happened to Qualitative Description?," *Research in Nursing & Health* 23 (2000): 334-340.

- What are the spiritual concerns of patients with a diagnosis of cancer?

- How do staff members and chaplains understand their role in addressing a patient's spiritual concerns?

- What are the role(s) of spirituality in a New Zealand public hospital's oncology unit?

- How can this research contribute to improving spiritual care in a New Zealand public hospital's oncology unit?

A literature review precedes the qualitative study and surveys three topics: spirituality, spirituality and health, and spirituality and cancer care. The themes generated from the literature review are then discussed with the findings presented in this qualitative study. The scope of the project is guided by the five research questions listed above.

1.3 Outline of Thesis

This thesis is organized in a linear fashion which presents the research topic, the purpose of this research, the literature review, the descriptive qualitative study, its methods and results, followed by a discussion section. It closes with a summary of the research findings and some suggestions for future research.

- Chapter one, is this introduction. The thesis topic, the rationale for undertaking this research project and the statement of purpose are presented. Also included here is the outline of the thesis.

- Chapter two is an in-depth literature review which surveys the following three areas of literature: spirituality in contemporary society, spirituality in health care, and spirituality in New Zealand cancer care.

- Chapter three presents the qualitative study which explored eight New Zealanders' understanding of spirituality, spiritual care and their roles in New Zealand cancer care. The methodology, methods, and results are discussed in detail.

- Chapter four details a discussion that combines the results from the study presented in Chapter three and the themes generated in the literature review.

- Chapter five concludes this thesis with an overview of important findings and recommendations for future research.

2 Literature Review

2.1 Search Strategy

Due to the cross-disciplinary nature of the study of spirituality in cancer care, this review surveyed information from the social sciences, medicine and health care, as well as government websites. Literature included in this review will focus on contemporary spirituality, spirituality and health care, and spirituality and cancer care. Relevant and reliable sources that focused on spirituality in these three discourses were prioritized.[17] It will be argued, as others have done before,[18] that spirituality and spiritual care are important components to administering and receiving holistic health care. Despite this view also being present in the *New Zealand Cancer Control Strategy,*[19] barriers still remain in research and clinical practice.

The selected literature was primarily drawn from peer-reviewed journals and academic books housed in the University of Otago's libraries. Electronic databases such as PUBMED, CINAHL, ATLAS, MEDLINE, TE PUNA, GOOGLE, and GOOGLE SCHOLAR were examined using keywords including: spirit$ and spiritual$ (truncated), spirituality, cancer care, well-being, holistic, patient-centered, health care, New Zealand and Māori.[20]

Literature was organized and analyzed based on important central themes; however, focus was given to those themes that fit within the scope of this project as articulated by the project's research questions and discussed in the Statement of Purpose.[21] The literature

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[17] Texts that were written in languages other than English were excluded due to my unfamiliarity with other languages; furthermore, religious scripture and lay books about spirituality were also excluded.

[18] Puchalski and Ferrell, *Making Health Care Whole*; Richard Egan, "Spirituality in New Zealand Hospice Care" (PhD diss., University of Otago, 2009), accessed on 30 May 2011, http://hdl.handle.net/10523/442; Barry Quinn, "Spirituality in Cancer Care," *Online Cancer Education Forum* (2008): 1-14, accessed on 17 Oct 2009, http://www.onlinecancereducationforum.com/detailed.asp?ref=47.

[19] Minister of Health, *Cancer Control Strategy*, 20.

[20] Abstracts were carefully read. Important articles were either filed electronically or a hard-copy was printed and filed. Sources and data were tracked manually in a hand-written log and then transferred to a computer.

[21] See *Introduction*, Section 1.2.

review section is organized and presented in a "funnel-like"[22] structure: the broad topic of spirituality in contemporary society will be surveyed, followed by spirituality in health care, and finally the concept of spirituality will be examined within this study's framework of New Zealand cancer care.

2.2 Spirituality in the 21st Century

This section contextualizes spirituality and observes central themes within the discourse. It is imperative to begin by addressing issues related to the definitions of spirituality. Next, spirituality will be placed in the contemporary social landscape. Finally, three dominant themes in spirituality discourse are highlighted: meaning and purpose, dynamic process or journey; and the centrality of relationships.

2.2.1 Definition Issues and Criticisms

The term spirituality has become what Schneider calls, "a contemporary conundrum."[23] It has been noted in nearly every study, article, and book examined here that spirituality evades definitions because it is difficult to measure due to its experiential nature,[24] blurs conceptual borders,[25] has a foot in many academic disciplines,[26] and because the term "suggests more than it defines."[27] Heelas observes that it is quite common for sociologists of religion to note early in their discussion of spirituality that the term's meaning is "'vague,' 'fuzzy,' 'obscure' or extremely 'ambiguous.'"[28] Hamberg adds the confounding variable, especially in its contemporary context where it has been 'unhinged' from religion, that the concept of spirituality is often used in "different ways" which produces multiple and

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[22] Egan, "Spirituality in New Zealand Hospice Care," 9.

[23] Sandra M. Schneider, "Religion vs. Spirituality: A Contemporary Conundrum," *Spiritus* 3 (2003): 163.

[24] Sinclair, Pereira, and Raffin, "A Thematic Review," 466.

[25] Brian J. Zinnbauer, Kenneth I. Pargament, and Allie B. Scott, "The Emerging Meanings of Religiousness and Spirituality: Problems and Prospects," *Journal of Personality* 67:6 (1999): 904.

[26] Schneider, "Religion vs. Spirituality," 163.

[27] Peter van der Veer, "Spirituality in Modern Society," in *Religion: Beyond a Concept*, ed. Hent de Vries (New York: Fordham University Press, 2008), 789-790.

[28] Paul Heelas, "Spiritualities of Life," in *The Oxford Handbook of The Sociology of Religion*, ed. Peter B. Clarke (Oxford: Oxford University Press, 2009), 758.

sometimes conflicting conceptual frameworks.[29] For example, King shows the adoption of spirituality as a central theme in contemporary ecological movements, women's movements, in education and even in discussions at the United Nations.[30] With the term's seemingly "amorphous" nature, one scholar even asks "Is it useful?"[31]

The use of the term spirituality in diverse social contexts is criticized by some scholars suggesting that it is "shallowly rooted, trivial, historically insubstantial, ephemeral, and socially, intellectually and existentially precarious." [32] Further criticisms charge contemporary spirituality with encouraging materialism and consumerism such that post-modern individuals "shop around…consum[ing] spiritualities on offer…to gather and to enhance [personal] sensation." [33] Roof describes the contemporary social landscape as "*pastiche*-style spirituality," [34] and "a spiritual marketplace." [35] Wilson suggests that spirituality in the capitalistic marketplace encourages narcissistic and individualistic behavior through "endors[ing] the hedonistic values of contemporary society as legitimate goals."[36] This latter perspective often stems from self-enhancement or self-development spiritual practices (i.e. mind-body-spirit practices such as yoga) which are sold by practitioners to clients for various fees.[37] Because spirituality can be easily commercialized and spiritual

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[29] Eva M. Hamberg, "Unchurched Spirituality," in *The Oxford Handbook of The Sociology of Religion*, ed. Peter B. Clarke (Oxford: Oxford University Press, 2009), 747.

[30] Ursula King, "Spirituality," in *A New Handbook of Living Religions*, ed. John R. Hinnells (Cambridge: Blackwell Publishers, Ltd., 1997), 678-679.

[31] Anna S. King, "Spirituality: Transformation and Metamorphosis," *Religion* 26:4 (1996): 347.

[32] Linda Woodhead, "Real Religion and Fuzzy Spirituality," in *Religions of Modernity: Relocating the Sacred to the Self and the Digital,* eds. Stef Aupers and Dick Houtman (Leiden: Koninklijke Brill, 2010), 33.

[33] Adam Possamaï, "Producing and Consuming New Age Spirituality: The Cultic Milieu and the Network Paradigm," in *Handbook of New Age,* eds. Daren Kemp and James R. Lewis (Leiden: Koninklijke Brill, 2007), 158.

[34] Wade Clark Roof, *A Generation of Seekers: The Spiritual Journey's of the Baby Boomer Generation* (New York: Harper Collins Publishers, 1993), 245.

[35] Wade Clark Roof, *A Spiritual Marketplace: Baby Boomers and the Remaking of American Religion* (Princeton: Princeton University Press, 1999).

[36] Bryan R. Wilson, *The Social Dimensions of Sectarianism: Sects and New Religious Movements in Contemporary Society* (New York: Oxford University Press, 1990), 288.

[37] Giselle Vincett and Linda Woodhead, "Spirituality," in *Religions in the Modern World: Traditions and Transformations* 2nd ed., eds. Linda Woodhead, Hiroko Kawanami, and Christopher Partridge (New York: Routledge, 2001), 325.

commodities or spiritual services often target the individual, it can be misconstrued and criticized as self-indulgent and shallow.[38]

When summarizing the spiritual milieu Bruce refers to it as *"diffuse religion"* whereby adherents to contemporary spirituality portray modest commitment, pay little attention to detail, lack a central authoritative person or scripture and as a result do not have any real community life or social impact.[39] Bruce concludes that spirituality in contemporary society "is vulnerable to being diluted and trivialized."[40] From the critics' perspective, this lack of consistency, cohesiveness and homogeneity regarding the eclectic and diverse peoples, places and things that make up contemporary spirituality, can lead one to conclude, there is little if any, "real scholarly purchase"[41] in the academic study of spirituality.

Advocates for the term, such as van der Veer, argue that spirituality "deserves scholarly attention" because of its diversity not in spite of it.[42] Woodhead agrees that the term spirituality is widely diffused with different meanings, contexts, and uses, especially in the context of everyday language; but so are other terms such as "race," "identity," and "class."[43] She concludes that "this does not in itself rule out their utility for scholarly analysis."[44] King concludes that "spirituality, however understood, is of considerable significance" [45] and whether right or wrong, it is likely that spirituality will continue to be of significance for many years to come.

2.2.2 Background: Spirituality's Break from Religion

Spirituality is a term central to understanding modern society.[46]

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[38] Ibid.

[39] Steve Bruce, *God is Dead: Secularization in the West* (Oxford: Blackwell Publishers Ltd., 2002), 91.

[40] Ibid.

[41] Woodhead, "Real Religion and Fuzzy Spirituality," 32.

[42] van der Veer, "Spirituality in Modern Society," 797.

[43] Woodhead, "Real Religion and Fuzzy Spirituality," 37.

[44] Ibid.

[45] Ursula King, "Spirituality," 679.

[46] van der Veer, "Spirituality in Modern Society," 790.

The word religion originates from the Latin root *religio* which implied "a bond between humanity and some greater-than-human power."[47] According to Hill and colleagues, the word spirituality stems from the Latin root *spiritus* meaning breath or life and was frequently cited in the Hebraic Old Testament as *ruach* and in the Greek New Testament as *pneuma,*[48] which suggests "it has a long history in theology and religious practice."[49] Traditionally, it was used to describe the experiential dimensions or spiritual sub-traditions within the world religions such as Sufism in Islam, Gnosticism in Christianity, and Kabbalah in Judaism.[50] It was bound to "'external' and 'transcendent' conceptions of the sacred" focusing on religious experience rather than doctrine.[51] Aupers and Houtman argue that "contemporary spirituality is characterized as a release from those [religious] ties."[52]

The rise of spirituality follows closely with observations that at the end of the nineteenth century, religion in western Europe, was described as being in a state of "decline or displacement" as articulated in the "sociological theory of secularization."[53] Although religion did not disappear per se, a sociocultural trend toward deinstitutionalization can be evidenced.[54] It is theorized that traditional religious institutions, over the last century, have lost some authority as the sole source of "indisputable meaning" as other sources, namely science, have offered alternative ways in understanding the world.[55] In other words, "the gradual transformation of a transcendent hierarchical order into a modern egalitarian

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[47] Peter C. Hill et al., "Conceptualizing Religion and Spirituality: Points of Commonality, Points of Departure," *Journal for the Theory of Social Behavior* 30:1 (2000): 56.

[48] Ibid., 57.

[49] Ursula King, "Spirituality," 667.

[50] Stef Aupers and Dick Houtman, "The Sacralization of the Self: Relocating the Sacred on the Ruins of Tradition," in *Religion: Beyond a Concept,* ed. Hent de Vries (New York: Fordham University Press, 2008), 798.

[51] Ibid.

[52] Ibid.

[53] van der Veer, "Spirituality in Modern Society," 790.

[54] Robert Wuthnow, *After Heaven: Spirituality in America Since the 1950s* (Berkeley: University of California Press, 1998), 11-14.

[55] Kenneth Pargament, "The Psychology of Religion *and* Spirituality? Yes and No," *The International Journal for the Psychology of Religion* 9:1 (1997): 7.

immanent order has displaced religion, while freeing a space for spirituality."[56] At the turn of the twentieth century, as nation states modernized, key characteristics such as equality, human rights, and individualization became dominant values in Western Europe and later America.[57] The term spirituality, it is suggested, became likened to these modernizing ideals.[58]

Vincett and Woodhead argue that contemporary spirituality emerged as a nineteenth century movement which arose as a "conscious reaction against existing forms of traditional religion."[59] From their understanding, spirituality "allies itself with some central dynamics of modern and late modern societies, including the affirmation of the unique value of the individual…"[60] Traditional religious institutions became associated "with external, dogmatic authority set over the individual"[61] and were seen as a barrier to an individual's desire to explore the sacred on their own terms.[62] For Vincett and Woodhead, spirituality had become a "preferred alternative" to religion because it was more "in tune with key modern values."[63] It is possible to suggest then, that when someone says, "I'm spiritual, but not religious," or "I'm spiritual and religious" they are highlighting the perceived dichotomy that religion, for some people, means traditional, authoritative, restrictive and organized institutions, and spirituality means personal, privatized and subjective experiences of the sacred.[64] Despite some scholars' objection to spirituality being defined in opposition to religion,[65] this distinction, more or less, "has persisted to the present day."[66]

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[56] van der Veer, "Spirituality in Modern Society," 790.
[57] Grace Davie and Linda Woodhead, "Secularization and Secularism," in *Religions in the Modern World: Traditions and Transformations* 2nd ed., eds. Linda Woodhead, Hiroko Kawanami, and Christopher Partridge (New York: Routledge: 2009), 529.
[58] Vincett and Woodhead, "Spirituality," 334.
[59] Ibid., 320.
[60] Ibid., 334.
[61] Ibid., 320.
[62] Ibid.
[63] Ibid.
[64] Ibid.
[65] Zinnbauer, Pargament, and Scott, "The Emerging Meanings of Religiousness and Spirituality," 902-906.

Rather than seeing spirituality in opposition with religion, some scholars contend that spirituality's break from religion arose naturally, due to various social instabilities. Wuthnow, focusing on the American landscape, highlights a sea of social calamities occurring in the U.S. and abroad in the second half of the twentieth century that contributed to the transformation of its citizens: from a society of "spiritual dwellers" into a society of "spiritual seekers."[67] Up until the 1950s in America, God inhabited a specific and defined space, a secure dwelling where instructions, rules to live by, meaning and purpose were freely bestowed upon the individual through history and tradition.[68] However, by the turn of the twenty-first century, social, economic, and environmental complexities increased and religious and social institutions alike, fell short in solving all of society's ills.[69] As a result, the individual "must work hard to figure out their own lives,"[70] lest they fall prey to a life without meaning, or what Frankl has termed, the "existential vacuum."[71]

The subjective turn inward,[72] characteristic of spirituality discourse, is often aligned within a deinstitutionalization framework as already mentioned above. Heelas has coined the term "Self-spirituality" to describe the spiritual diversity expressed in contemporary society.[73] He says, "Again and again, turning from practice to practice, from publication to publication, indeed, from country to country, one encounters the same (or very similar) *lingua franca.*"[74] The theme connecting the seemingly disparate and loosely defined spiritualities, according to Heelas, has to do with the individual's (and Earth's) temporal

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Zinnbauer et al., criticize the polarization of spirituality and religion. At the very heart, they contend that all religious institutions are heavily involved with spiritual matters, and furthermore, such matters fundamentally manifest in social contexts not individual ones. They argue that spiritual movements, touted for their "anti-institutional rhetoric" and focus on the individual, inevitably become institutionalized citing New Age groups and 12-Step communities as examples. To polarize the two terms, they feel will undermine the integrity of the discipline as a whole and distract scholars from more important research questions.

[66] Vincett and Woodhead, "Spirituality," 320.

[67] Wuthnow, *After Heaven,* 1-10.

[68] Ibid., 3-4.

[69] Ibid., 11.

[70] Ibid.

[71] Viktor E. Frankl, *The Unconscious God* (New York: Simon and Schuster, 1975), 90.

[72] Paul Heelas, *The New Age Movement* (Oxford: Blackwell Publishers Inc., 1996), 2.

[73] Heelas, *The New Age Movement*, 2.

[74] Ibid.

condition and ways to bring about their transformation.[75] Following this argument, Aupers and Houtman argue the "sacralization of the Self"[76] is the underlining and unifying tenet within the current eclectic spiritual milieu; contrary to Roof's "*pastiche*-style spirituality."[77] From a sociological perspective, Aupers, Houtman, and Wuthnow argue that with the decline of institutionalized religion, the deterioration of traditional moral values that were interlinked with religious authority, and a general mistrust of social organizations on the whole, individuals have nowhere else to turn except inward.[78] "Confronted with [ultimate] questions…only personal feelings and intuitions remain as touchstones for true meaning and real identity."[79] These theories suggest that the stability once ascribed to social institutions is giving way to perceptions that these are impermanent. As a result, each individual is now responsible for their own search to find stability, safety, and structure in the external world.

Trends of deinstitutionalization and its effects on individuals' belief systems shifting from authority in institutions to authority in the individual are not restricted to U.S. and Western European contexts. For example, in a 2007 study that investigated the "spirituality of young Australians," Mason and colleagues reported a decline in traditional spiritualities (e.g. traditional religions) but a growing trend for humanist spiritualities.[80] Representing 31% of the 1272 cases recruited for the study, humanist spiritualities for Generation Y Australians (age 13-29) places human reason and experience over religious or spiritual worldviews. Fundamental values for this group included: "the infinite worth of the human individual…the inviolability of personal freedom and autonomy…self-development and self-realisation."[81] They conclude that "their eclectic mix of worldviews and the cautious relativism of their

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[75] Ibid.
[76] Aupers and Houtman, "The Sacralization of the Self," 799-804.
[77] Roof, *A Generation of Seekers,* 245.
[78] Aupers and Houtman, "The Sacralization of the Self," 799-804.
[79] Ibid., 802.
[80] Michael Mason, Andrew Singleton, and Ruth Webber, "The Spirituality of Young Australians," *International Journal of Children's Spirituality*, 12:2 (August 2007): 149.
[81] Ibid., 151, 160.

values result from facing an uncertain world with only fragile support for their identity, beliefs and values."[82] This study supports Aupers and Houtman's theory that contemporary spirituality may have been relocated from "a Christian heaven to the deep layers of the self."[83]

In the context of deinstitutionalized societies, the individual has been charged with the responsibility of finding their own purpose and meaning in life, since meaning and purpose are no longer inherently prescribed by social roles, careers, and institutions- as these have come to be seen as impermanent and unstable. Thus, we can begin to see how contemporary spirituality has come to be viewed "as a self-authored search by individuals who are looking inward" [84] as Possamaï suggests or as Wuthnow describes it as "a vastly complex quest in which each person seeks in his or her own way."[85] In this all inclusive context spirituality can now be sought after in a variety of experiences including "nature, music, [and] art"[86] as well as in a person's relationships to others and/or a transcendent being.[87] It is argued then that every individual has a spirituality, even a self-proclaimed atheist, because everyone at some point in their life searches for personal meaning and value.[88] As a result, spirituality may be described as the integrative feature which weaves together the different aspects of an individual and their interactions with the external world in a meaningful way.[89]

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[82] Ibid., 161.
[83] Aupers and Houtman, "The Sacralization of the Self," 811.
[84] Adam Possamaï, *Sociology of Religion for Generations X and Y* (London: Equinox Publishing Ltd., 2009), 62.
[85] Wuthnow, *After Heaven*, 2.
[86] Christina M. Puchalski, *A Time for Listening and Caring: Spirituality and the Care of the Chronically Ill and Dying* (New York: Oxford University Press, 2006), 55.
[87] Ibid.
[88] Daniel P. Sulmasy, "The Healthcare Professional as Person: *The Spirituality of Providing Care at the End of Life*," in Christina Puchalski's, *A Time for Listening and Caring: Spirituality and the Care of the Chronically Ill and Dying* (New York: Oxford University Press, 2006), 104.
[89] John F. Hiatt, "Spirituality, Medicine, and Healing," *Southern Medical Journal* 79:6 (1986): 737.

2.2.3 Central Themes

Contemporary spirituality, it seems, uses and fills many niches successfully within contemporary society.[90] Three themes, albeit not the only themes in spirituality discourse, are discussed below. They are: the search for meaning and purpose in life, process of becoming or self-fulfillment, and the importance of loving relationships.

Meaning and Purpose

According to Frankl, spirituality and existentiality are synonymous.[91] At our most basic level, "man is striving to find, and fulfill, meaning and purpose in life" and this pursuit is what Frankl calls "the will to meaning."[92] It is a basic human need. However, this notion is not to be reduced to a narcissistic internal search to find oneself, but rather the search for meaning goes beyond the self, directed at fulfilling something, such as a loving relationship.[93] Frankl has termed this "constitutive characteristic…'self-transcendence'.[94] This is analogous to Galanter's description of spirituality as a "heightened sense of fulfillment."[95] This constituent buffers the misconception that spirituality involves an inner search and nothing more; quite the contrary, spirituality or existentiality involves connection or fulfillment to something greater than the self; a process that involves "going beyond the ego."[96] And as Bluck observes this search for fulfillment "is pursued in the secular world, as well as the sacred."[97] It is suggested here that on one level, spirituality functions as the part of the person concerned with searching for meaning and purpose in life.

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[90] Anna S. King, "Spirituality," 347.
[91] Frankl, *The Unconscious God*, 24.
[92] Ibid., 80.
[93] Ibid., 78.
[94] Ibid.
[95] Marc Galanter, *Spirituality and the Healthy Mind: Science, Therapy, and the Need for Personal Meaning* (New York: Oxford University Press, 2005), 14.
[96] Thoresen and Harris, "Spirituality and Health," 4.
[97] John Bluck, *Long White Cloud: In Search of a Kiwi Spirituality* (Christchurch: Hazard Press, 1998), 12.

Process and Journey

Spirituality is often described as a process, not clearly defined by a linear step-by-step progression but more so as a dynamic progression toward "some end point."[98] Emphasis is often placed on the inner, subjective world of the individual and bringing that into harmony with the external world.[99] Schneider says, "It is an ongoing and coherent approach to life as a consciously pursued and ongoing enterprise."[100] Mason et al. understand spirituality to be a "person's way of life" wherein their values and understandings of the world are expressed through lived practices and behaviors; the way in which you live, supports this notion of spirituality as active "process."[101] Wills notes this fluid component as well saying, "on the whole, the literature equates spirituality with seeking, striving, and forward movement."[102] There is also the notion that this process is one of self-improvement; that part of the journey includes bettering one's self, making positive advancements regarding the interior as well as the exterior of one's life.[103] There are many activities that are designed to enable, as much as possible, a transformation of the interior and external worlds including, but not limited to: tai-chi, reiki, reflexology, psycho-analysis, meditation, and yoga.[104]

The Centrality of Relationships

The centrality of relationships is a key theme in definitions of spirituality often because for some individuals, loving relationships can directly contribute to a person's sense of meaning and purpose.[105] For example, Dyson and colleagues in their literature review of spirituality's meanings found that relationships specifically between self, others, and God

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[98] Hiatt, "Spirituality, Medicine, and Healing," 737.
[99] Vincett and Woodhead, "Spirituality," 320.
[100] Schneider, "Religion vs. Spirituality," 167.
[101] Mason, Singleton, and Webber, "The Spirituality of Young Australians," 150.
[102] Wills, "Connection, Action, and Hope," 429.
[103] Heelas, "Spiritualities of Life," 759.
[104] Ibid.
[105] Frankl, *The Unconscious God,* 78.

were a central theme in the literature.[106] Vincett and Woodhead also recognized that language used in contemporary spirituality emphasizes holism and the "interconnectedness of things."[107] This suggests that the value placed on relationships and connections between the self, others (including one's environments) and perhaps a transcendent being could be one way of contextualizing spirituality.

2.2.4 Summary

In summary, spirituality has been critiqued by sociologists of religion for a number of reasons including "the precariousness of diffuse beliefs" resulting from its many uses across broad and diverse contexts.[108] Others argue that within this eclectic spiritual milieu there is unity in the tenet of "self-spirituality."[109] Motivated by social, economical, and environmental instability stemming from the deinstitutionalization of contemporary societies, the need for individuals to create and sustain personal meaning has become a fundamental characteristic of human existence in the twenty-first century.[110] The term spirituality is becoming more and more the label given to this process of individualized meaning-making, which is seen as a dynamic process and places deep value in relationships and connections to self, others, nature and for some, the transcendent.[111]

2.3 Spirituality and Health Care Discourse

This section opens with addressing the growing interest in spirituality and health care, and discusses potential reasons for this sudden rise. Following this, an overview of the spirituality and health care discourse is discussed, which includes issues of definition and criticisms. The third section highlights themes in the spirituality and health care discourse and

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[106] Jane Dyson, Mark Cobb, and Dawn Forman, "The Meaning of Spirituality: A Literature Review," *Journal of Advanced Nursing* 26 (1997): 1184.
[107] Vincett and Woodhead, "Spirituality," 320.
[108] Bruce, *God is Dead,* 90.
[109] Heelas, *The New Age Movement*, 2.
[110] Wuthnow, *After Heaven,* 2-18.
[111] Anna S. King, "Spirituality," 350-351.

expands upon two key areas: spirituality, meaning/purpose and its relationship to health and illness; and spirituality, beliefs, values and attitudes and their relationship to health and illness. The final section gives an overview of spiritual care.

2.3.1 Introduction

Scholarly interest in the topic of spirituality in health care has risen dramatically over the last few decades.[112] Forty years ago, respected databases MEDLINE and CINAHL generated 178 studies and one study respectively when searched with the truncated term "spiritual$."[113] Today, those numbers have grown fervently with MEDLINE producing almost 6,000 hits and CINAHL generating approximately 6,700 studies.[114] Koenig observes that since the explosion of scholarly research on the topic "at least three consensus conferences partially supported by the National Institutes of Health (NIH) [have been held] to review the research and come up with recommendations for methodological advances and future studies."[115] Reasons why this area has become such a "hot topic"[116] for scholars vary. However, it can be argued that the rise of interest in spirituality and health research parallels a wider trend in health care that focuses on expanding the concept of health.

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[112] Sinclair, Pereira, and Raffin, "A Thematic Review," 466.

[113] Ibid., 465.

[114] Sinclair, Pereira, and Raffin, "A Thematic Review," 465. Replicating Sinclair et al.'s search strategy, I conducted an updated keyword search for the term "spiritual$." As of 18 May 2011 the specific figures generated were: MEDLINE n=5836 and CINAHL n= 6729. This suggests that interest in exploring the topic of spirituality in health and illness continues to rise.

[115] Harold G. Koenig, *Medicine, Religion, and Health: Where Science and Spirituality Meet* (West Conshohocken: Templeton Foundation Press, 2008), 22.

[116] Thoresen and Harris, "Spirituality in Health," 3.

Since the late 1990s, government health strategies have been refocusing "health-care delivery in a way that will take into account the social dimensions of disease production."[117] Cassell argues that the impact of social factors including society, culture, community and family have a "profound and omnipotent" impact on the individual and their illness.[118] Such aspects are seen to make up the "social fabric of the patient" and these influences are expressed "within the concepts of language, knowledge and beliefs, habits and social rules that [ultimately] direct behaviors."[119] The ideological shift in medicine that a disease cannot be separated from the context of the whole person "takes more serious account of *all* these factors in defining illness and treatment."[120] Spirituality is included in this "wholeness approach" to medicine.[121] For example, Chio and colleagues conducted a study about the spiritual suffering of Taiwanese patients living with terminal cancer.[122] In Chinese culture, which is heavily influenced by Confucian thought, shame is brought about when an individual fails to fulfill certain roles and obligations such as filial piety, the obligation to care for one's parents in old age. They found spiritual suffering increased in patients who were overcome with guilt in being unable to fulfill duties of filial piety, as cancer would take away their life prematurely. In the same study, they found that those who held on to the Buddhist doctrine of karma (whereby many situations and happenings that occur in one's present life are consequences of actions from one's past lives) had a higher tendency to interpret their cancer diagnosis as a punishment for bad deeds done in past lives leading patients to inflict self-blame. They concluded that cultural factors play an important role in impacting and shaping an individual's cancer experience and developing culturally sensitive

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[117] Kevin Dew and Peter Davis, eds., *Health and Society in Aotearoa New Zealand* 2nd ed., (Melbourne: Oxford University Press, 2005), xxvi.

[118] Eric J. Cassell, *Doctoring: The Nature of Primary Care Medicine* (New York: Oxford University Press, 1997), 13.

[119] Cassell, *Doctoring*, 13-14.

[120] Peter R. Holmes, "Spirituality: Some Disciplinary Perspectives," in *A Sociology of Spirituality*, eds. Kieran Flanagan and Peter C. Jupp (Burlington: Ashgate Publishing Company, 2007), 29.

[121] Ibid.

[122] Chung-Ching Chio et al., "The Lived Experiences of Spiritual Suffering and the Healing Process Among Taiwanese Patients with Terminal Cancer," *Journal of Clinical Nursing*, 17 (2007): 735-743.

spiritual care approaches may help heal spiritual suffering of patients from different cultural backgrounds.[123] This study highlights two important facts. First, suffering went beyond the confines of physical suffering (directly related to the physical pain of having a cancer diagnosis), and recognized spiritual suffering as legitimate suffering. Second, the spiritual suffering was rooted in a cultural context which has been historically influenced by Buddhist and Confucian religious beliefs. Without, this knowledge of understanding an individual's "total pain"[124] interventions to alleviate only the physical pain may have fallen short at relieving concurrent stressors.

As the concept of health expands to include the biological, psychological, social, and spiritual aspects of a person,[125] studies such as Chio et al., support Cassel's observation which recognizes "all symptoms have causes, pathophysiology, *and meaning*."[126] Further, "as the health care market presses providers in a more holistic direction" this includes "attentiveness to patient spirituality."[127] It can be argued this shift to a more holistic approach to health care has cleared a space for the spiritual component to be examined as an important factor in health, illness, disease, and death.[128]

2.3.2 Overview of Spirituality and Health Care Discourse

The scientific model traditionally has focused on that which can be observed, reduced, measured and thus studied from an observer-observed perspective.[129] This has led to the physical dimension of an individual being privileged in the medical domain, resulting in the mental and social dimensions becoming secondary or subjective background features, and the

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[123] Ibid., 743.

[124] Cicely Saunders, "The Evolution of Palliative Care," *Patient Education and Counseling* 41 (2000): 10.

[125] Sulmasy, "The Biopsychosocial-Spiritual Model," 24-33.

[126] Cassell, *Doctoring*, 11 (my italics)..

[127] Stephen Post, Christina M. Puchalski, and David Larson, "Physicians and Patient Spirituality: Professional Boundaries, Competency, and Ethics," *Ann Intern Med* 132 (2000): 582.

[128] Sinclair, Pereira, and Raffin, "A Thematic Review," 466.

[129] Hiatt, "Spirituality, Medicine, and Healing," 736.

spiritual dimension nearly being forgotten.[130] However, this is beginning to change. In the U.S., more than 50 medical schools now offer courses on religion and spirituality, and many nursing programs offer training in these areas as well, especially as they relate to hospice care.[131] Moreover, in the U.K. "almost all health care practitioners would now claim to practice holistic health care…"[132] Holistic health care generally recognizes the complexity of a human being in that, they are a physical, social, emotional, mental, and spiritual being and that all of these play a role in health and illness. In the context of holistic care, spirituality is gaining widespread attention and is in need of serious consideration.[133] It is becoming increasingly recognized that a topic which weaves together issues pertaining to ultimate meaning, life, health, illness and death, as the topic of spirituality does, must have implications for medicine, "the discipline that deals with these issues."[134] For a comprehensive literature review of spirituality and health research see Koenig's *Handbook of Religion and Health,* which includes 1200 quantitative studies exploring the spiritual dimension as it relates to health and illness.[135]

2.3.3 Definition Issues

Like the sociological literature, the medical literature often suggests there is difficulty in defining spirituality.[136] And this is further complicated by the need for it to be acceptable to pre-existing scientific and evidence-based protocols. For example, Brady et al., suggest the problem for spirituality's rough transition into health care practice lies in the difficulty of

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[130] Ibid.
[131] Thoresen and Harris, "Spirituality and Health," 9.
[132] Derick T. Wade, "Holistic Health Care: What Is It, and How Can We Achieve It?," (lecture presented at the Nuffield Orthopaedic Centre's Annual General Meeting, Oxford, UK, September 17, 2009): 2, accessed on 13 June 2010, http://www.noc.nhs.uk/oce/research-education/documents/HolisticHealthCare09-11-15.pdf.
[133] Sinclair, Pereira, and Raffin, "A Thematic Review," 475.
[134] Fosarelli, "Fearfully Wonderfully Made," 213.
[135] Harold Koenig, Michael E. McCullough, and David B. Larson, *Handbook of Religion and Health* (New York: Oxford University Press, 2001).
[136] Marianne J. Brady et al., "A Case for Including Spirituality in Quality of Life Measurement in Oncology," *Psycho-oncology* 8 (1999): 417.

defining something whose nature is so "elusive."[137] Ramondetta and Sills find difficulty with new requirements expected of physicians to translate patients' "ideas about human spirituality into research protocol."[138]

In spirituality and health research, addressing issues regarding definitions of spirituality is readily cited. For example, Unruh, et al., compiled an exhaustive list of ninety-two definitions of spirituality from leading medical databases and professional journals in order to re-examine the appropriateness of spirituality being at the heart of the *Canadian Model of Occupational Performance*.[139] Sinclair et al., survey spirituality definitions from the perspective of authors who define it. He suggests three definitional categories that portray three different perspectives on spirituality. First, scholars describe the definition conceptually, understanding that spirituality is something to be experienced and thus escapes language and scientific quantification. [140] Second, scholars focus on conceptualizing spirituality based on commonalities by listing key characteristics and places emphasis on the term 'meaning' as in finding meaning and purpose within one's life. [141] Third, there are scholars who present a very finite and narrow definition that can either be quantified or used to eliminate those individuals whose spirituality does not fit within their operating framework.[142] Advocates for this final group are, for example, Koenig and Pargament, who firmly believe the definition of spirituality must maintain its connection to religion.[143] Dyson and colleagues conclude in their review of spirituality's meaning that there is a common

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[137] Ibid.

[138] M. Ramondetta and D. Sills, "Spirituality in Gynecological Oncology: A Review," *Int J Gynecol Cancer* 14 (2004): 185.

[139] Anita M. Unruh, Joan Versnel, and Natasha Kerr, "Spirituality Unplugged: A Review of Commonalities and Contentions, and a Resolution," *The Canadian Journal of Occupational Therapy* 69:1 (2002): 5, 16-19.

[140] Sinclair, Pereira, and Raffin, "A Thematic Review," 466-467.

[141] Ibid.

[142] Ibid.

[143] Koenig recognizes that spirituality's past was inextricably bound to religion as seen "in the patristic era and later spiritual thought derived from monastic life, the mendicants, the late Middle Ages, Luther, Ignatius, Teresa, and John of the Cross [and thus] to call something spiritual, it must have some connection to religion." Koenig, *Medicine, Religion, and Health,* 16-17.

tendency to link spirituality with religion.[144] However, such a finite and exclusivist definition could be rendered insufficient in medical practice wherein patients express and maintain a mosaic of beliefs and meaning-making schemas, which may, or may not, be connected to a theistic God. This is especially true in the context of New Zealand, where "less than 15 percent [of New Zealanders] are committed to any religious institution."[145] And thus Dyson and colleagues conclude the definition of spirituality "must be challenged and expanded."[146]

In the medical literature, it is generally agreed upon by scholars in literature on spirituality and health care that religion is understood as an organized faith institution, systematically represented by specific beliefs, rituals, communal worship, dietary and customary laws as found in the major world religions like Christianity, Judaism, Hinduism, Buddhism and so on.[147] Sinclair and colleagues conclude in their literature review of spirituality and palliative care that "the literature reflects an understanding of spirituality that is void of religion…"[148] Spirituality, in the medical literature, is often considered to be "broader in scope than religion."[149] Bradshaw describes spirituality's shift in meaning from "the human being in relationship to God" to a more general and inclusive "personal and psychological search for meaning."[150] Other scholars such as McCarthy,[151] Bluck,[152] and Nash and Stewart[153] suggest that spirituality is the universal matrix with which the human

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[144] Dyson, Cobb, and Forman, "The Meaning of Spirituality," 1184.
[145] Bluck, *Long White Cloud*, 11.
[146] Dyson, Cobb, and Forman, "The Meaning of Spirituality," 1184.
[147] Ramondetta and Sills, "Spirituality in Gynecological Oncology," 185; Sinclair, Pereira, and Raffin, "A Thematic Review," 467.
[148] Sinclair, Pereira, and Raffin, "A Thematic Review," 465.
[149] Mary Nash and Bruce Stewart eds., *Spirituality and Social Care: Contributing to Personal and Community Well-being* (New York: Jessica Kingsley Publishers, 2002), 15.
[150] Ann Bradshaw, "The Spiritual Dimension of Hospice: The Secularization of an Ideal," *Soc. Sci. Med.* 43:3 (1996): 415-416.
[151] Derek McCarthy, "Spirituality and Cultural Safety," in *Cultural Safety in Aotearoa New Zealand*, ed. Diane Wepa (North Shore: Pearson Education New Zealand, 2005), 172.
[152] Bluck, *Long White Cloud*, 12.
[153] Nash and Stewart, *Spirituality and Social Care*, 15.

condition exists; it is the very essence of our being. Due to its "inherent humanness,"[154] Olsen and colleagues argue that spirituality's utilization in medicine "should be understood as natural, rather than external and imposed."[155] These trends of distinguishing between spirituality from religion, understanding spirituality as something inherent to the human condition and that it is holistic (i.e. includes meaning and purpose in life, beliefs, values and relationships) mirror trends discussed above in the social scientific literature. Thus to speak of spirituality, spiritual care, the spiritual dimension, or the spiritual concerns of patients is to examine an individual's beliefs, values, meaning and purpose in life and relationships on a deeper level, and these may or may not include religion.

2.3.4 Themes in Spirituality and Medical Literature

There is a general assumption in the medical literature that spirituality is a positive construct.[156] It is often connected to ideas involving meaning and purpose, hope, relationships/connectedness, and beliefs and values.[157] Aldridge suggests that many of the terms associated with the spiritual such as "patience, grace, prayer, meditation, hope, forgiveness, and fellowship are as important in many health initiatives as medication, hospitalization or surgery."[158] It is generally thought that these spiritual elements help patients "to rise above the matters at hand"[159] so that even in the midst of suffering they can still maintain meaning, purpose, and hope; all factors that are considered important in quality of life measures.[160]

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[154] Michael Olson et al., "Mind, Body, and Spirit: Family Physicians' Beliefs, Attitudes, and Practices Regarding the Integration of Patient Spirituality into Medical Care," *Journal of Religion and Health* 45:2 (2006):245.
[155] Ibid.
[156] Sinclair, Pereira, and Raffin, "A Thematic Review," 475.
[157] Dyson, Cobb, and Forman, "The Meaning of Spirituality," 1184.
[158] Aldridge, *Spirituality, Healing and Medicine,* 9.
[159] Ibid.
[160] Brady et al., "A Case for Including Spirituality," 417-428.

Following this, much of the literature treats spirituality as "an instrument to be utilized in improving or maintaining health and quality of life."[161] Moreover, in medical discourse there exists a focus on "spirituality as it relates to the individual, namely the patient,"[162] as many studies' titles illustrate.[163] Larson and Larson observe that often spiritual factors are presented as being a positive resource for coping and gaining strength at times of illness and/or recovery from illness.[164] Likewise Puchalski who reviewed many studies conducted on patient illness and the effects of spirituality in health studies, observe that thematically-speaking the studies fall into three categories, namely mortality, coping, and recovery.[165] For example, in a U.S. study, Matsuyama and colleagues conducted focus groups with thirty-nine African American and Caucasian patients to explore perceptions and beliefs as related to cancer care.[166] They found that prayer, as a tool for coping, was discussed in six out of seven African American focus groups. Furthermore, these individuals reported that church, faith, and "church families" were important resources for coping, social support, and receiving information.[167] What this suggest is that the because the literature is heavily focused on the patient, it may be missing other important perspectives involved in the topic of spirituality and health-related issues most notably, medical professionals, family members, and chaplains.[168] This, according to Sinclair, is a gap in the research.[169]

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[161] Sinclair, Pereira, and Raffin, "A Thematic Review," 465.
[162] Ibid.
[163] Scott Murray et al., "Exploring the Spiritual Needs of People Dying of Lung Cancer or Heart Failure: A Prospective Qualitative Interview Study of Patients and their Carers," *Palliative Medicine* (2004): 39-45; Ingela Henoch and Ella Danielson, "Existential Concerns Among Patients with Cancer and Interventions to Meet Them: An Integrative Literature Review," *Psycho-Oncology* 18 (2009): 225-236; Brenda Cole and Kenneth Pargament, "Re-Creating Your Life: A Spiritual/Psychotherapeutic Intervention for People Diagnosed with Cancer," *Psycho-Oncology* 8 (1999): 395-407.
[164] David B. Larson and Susan S. Larson, "Spirituality's Potential Relevance to Physical and Emotional Health: A Brief Review of Quantitative Research," *Journal of Psychology and Theology* 31:1 (2003): 37.
[165] Puchalski, "The Role of Spirituality in Health Care," 353.
[166] Robin K. Matsuyama et al., "Cultural Perceptions in Cancer Care Among African-American and Caucasian Patients," *Journal of the National Medical Association* 99:10 (2007): 1116.
[167] Ibid.
[168] Olson et al., "Mind, Body, and Spirit," 235.
[169] Sinclair, Pereira, and Raffin, "A Thematic Review," 475.

Theme 1: Meaning and Purpose

Frankl writes that man is fundamentally characterized by his "search for meaning."[170] Puchalski and colleagues argue that "spirituality, which pertains to ultimate meaning and purpose in life, has clinical relevance."[171] This basic human need is of paramount importance when discussing health matters. Research conducted at the Department of Psychology, of the University of Brno, Czech Republic, reported that the 'will to meaning' is a "specific need not reducible to other needs."[172] More importantly, they found that when *frustrated,* there were serious health implications.[173] "In some cases, the frustration of the 'will to meaning' had a relevant role as an etiological factor in the origin of neurosis or of the suicidal attempt."[174] In other words, it is suggested that an individual who struggles to find meaning in life, may be more susceptible to physical or mental illness, or that disease progression may be exacerbated if individual meaning is impeded. Returning to the study of Taiwanese patients, their distress was heightened as a result of being unable to fulfill their role of filial piety, and this added frustration because they could not understand their life's purpose.[175]

On the other hand, where meaning and purpose in life are firmly established evidence suggests that this may help maintain an individual's sense of well-being in the midst of suffering and illness.[176] For example, in a U.S. study conducted by Brady et al., they found that 66% of people reporting intense fatigue, but also high levels of Meaning/Peace "reported themselves able to enjoy life 'very much' (the highest rating)."[177] Meanwhile, only 11% of individuals with intense fatigue, but low levels of Meaning/Peace were able to enjoy life at that same optimal level.[178] These studies suggest that considering the spiritual dimension as a

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[170] Frankl, *The Unconscious God,* 79.
[171] Post, Puchalski, and Larson, "Physicians and Patient Spirituality," 578.
[172] Frankl, *The Unconscious God*, 80.
[173] Ibid., 81.
[174] Ibid.
[175] Chio et al., "Spiritual Suffering Among Taiwanese Patients," 736.
[176] Brady et al., "A Case for Including Spirituality," 424.
[177] Ibid.
[178] Ibid.

separate domain reveals valuable information that may otherwise be overlooked or ignored if this dimension was to be grouped with other dimensions of a person such as the psychological dimension. [179] Furthermore, this study demonstrated that the spiritual dimension has an impact on an individual's sense of well-being, or their sense of ill-being and thus it should be considered independently, albeit alongside of, other dimensions in quality of life assessments.[180]

Theme 2: Beliefs, Values, Attitudes, and Identity

It is theorized that peoples' beliefs and values can play a role in health and illness. Pargament cites a growing body of evidence which suggests that "religious involvement and positive belief systems" are linked with "positive health measures, longer life expectancy, and higher quality of life indexes."[181] Furthermore, Lui argues that "a person's beliefs and their understanding and perception of their health and illness determine their response, their practice and the treatment and intervention they will undertake."[182] For example, Puchalski and colleagues revisit a study that investigated the deaths of a 172 children whose parents chose faith-healing over conventional medicine. After reviewing the medical records, it was concluded that most of the children would have lived had they been treated with standard medical care. Thus, they conclude spiritual beliefs can influence medical decision making.[183] Larson and Larson evidenced that the kind of beliefs (e.g. positive or negative) correlates strongly with health outcomes.[184] For example, they cite evidence that although religious coping did not lengthen the lives of acutely ill patients it "did enhance mental health status and social support."[185] On the other hand, in a two year study of hospitalized elderly patients,

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[179] Ibid., 423.
[180] Ibid., 419.
[181] Pargament, "The Psychology of Religion and Spirituality?," 10.
[182] David Lui, *Newsletter:* Issue 16, Mental Health Foundation of New Zealand (2009), accessed on 21 May 2011, http://www.mentalhealth.org.nz/newsletters/view/article/16/192/autumn-2009/.
[183] Post, Puchalski, and Larson, "Physicians and Patient Spirituality," 578.
[184] Larson and Larson, "Spirituality's Potential Relevance," 39.
[185] Ibid.

they found that those "who…felt alienated from or unloved by God or attributed their illness to the devil were associated with a 19% to 28% increase risk in dying."[186] These findings suggest that considering spiritual beliefs, attitudes, and values of patients is paramount in "fostering insightful health care."[187] Moreover, it has been shown here that these factors can influence medical decision-making, individual behaviors, and health-related factors.

2.3.5 Overview of Spiritual Care

Arguably, spiritual care and much of the present-day literature developed within the precincts of palliative care, and more specifically the Hospice Movement headed by Dame Cicely Saunders in the mid-1960s in the U.S.[188] Saunders said in 1963, "It is not possible to treat pain in isolation for we have to consider the whole person."[189] Hospice and palliative care principles articulated by Saunders, includes: recognizing "total pain" through symptom control, holistic care *via* a team of professionals, maximizing a patient's potential, and addressing their spiritual needs.[190] However, these principles are not only valuable in the final stages of a person's life, but are valuable when practiced in earlier stages of illness and care. Evidence for this can be found in a Scottish study conducted by Murray and colleagues that found spiritual distress was heightened not only during end stages of life, but also at diagnosis, when a patient finishes treatment, and disease progression.[191]

Other models of health care echo the 'whole person' approach to patient care. In 1977, Engel put forth the biopsychosocial model which, according to Sulmasy, positioned the patient directly within a matrix that included "the affective and other psychological states of that patient as a human person, as well as the significant interpersonal relationships that

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[186] Ibid., 40.
[187] Ibid., 38.
[188] Sinclair, Pereira, and Raffin, "A Thematic Review," 465; Saunders, "The Evolution of Palliative Care," 7-13.
[189] Cicely Saunders, "The Treatment of Intractable Pain in Terminal Cancer," *Proc R Soc Med* (1963): 195.
[190] Saunders, "The Evolution of Palliative Care," 10-11.
[191] Scott A. Murray et al., "Patterns of Social, Psychological, and Spiritual Decline Towards the End of Life in Lung Cancer and Heart Failure," *Journal of Pain and Symptom Management* 34:4 (2007): 398.

surround that person."[192] Twenty years later, Sulmasy added the spiritual component to this model recognizing that "a human being is a being in relationship- biologically, psychologically, sociologically, and transcendently."[193] According to Sulmasy, "Illness disrupts all of the dimensions of relationship" and thus only a biopsychosocial-spiritual model can provide true holistic care.[194] These models of care recognize the importance of providing more than just physical care to patients and seek to foster deep and meaningful connections between the doctor and patient.[195]

It is suggested that lack of understanding what spiritual care entails, lack of time, resources, and education, technology driven environments, fear of invading a patient's personal space and personal bias towards the topic are all contributing factors for the reported lack of spiritual care provided in hospitals.[196] Dyson et al. observe that the strong emphasis on the scientific model used in health care and the increased use of technology could be possible contributors to the lack of spiritual care in nursing.[197] However, this is beginning to change. Research and education stemming from the Hospice movement and palliative care have led to a wide scholarly interest in the topic of spirituality in health care as illustrated in Table One. Over the last twenty years, consensus panels have been formed to review the studies on spirituality's effects on health and illness.[198] Those reviewed in the panels found that the quality of studies have improved over the years, resulting in "volumes of specialty journals…and literature reviews" which evidence the clinical significance and importance of spirituality and health-related issues.[199] As studies improve and the body of evidence grows, medical schools are incorporating the research into their curriculums. For example, in the

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[192] Sulmasy, "The Biopsychosocial-Spiritual Model," 24.
[193] Ibid., 32.
[194] Ibid.
[195] Puchalski and Ferrell, *Making Health Care Whole,* 55.
[196] Quinn, "Spirituality in Cancer Care," 10-11.
[197] Dyson, Cobb, and Forman, "The Meaning of Spirituality," 1184.
[198] Post, Puchalski, and Larson, "Physicians and Patient Spirituality," 579.
[199] Ibid.

U.S. the number of medical schools offering courses on spirituality and health grew from 3 medical schools in 1992 to 75 (out of 125) medical schools in 2001.[200]

Not everyone is ready to accept spirituality's incorporation into medical practice. There are ethical considerations that arise when discussing spiritual care. Sloan et al., argue that simply because positive findings have been cited, for example, between church attendance and longevity in life; religious activities and their ability to provide comfort; and surveys that suggest patients' desire to have religious concerns addressed by their medical physician, these findings do not warrant an automatic integration of spiritual interests into medical practice.[201] Instead, they hypothesize that a prescription for religious activities may cause more distress if the person has become alienated from their religious tradition. Sloan et al., argue that religion is a private matter, and advice should not be given regarding such personal matters from an individual who is perceived to be an authoritative figure to an individual who is vulnerable due to illness. They conclude that because some studies show that patients want spiritual needs addressed this data should not be applied to all patients, settings, and times.[202] However, the examples Sloan et al. provide, such as a doctor prescribing attendance at religious services are also frowned upon in the same literature that support the integration of spirituality and medicine. For example, Mitchell and colleagues warn twice in their article about the importance of not imposing a prescriptive care approach to spiritual care in clinical practice.[203] Further, Puchalski adds that if a patient does not have

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[200] Puchalski, "The Role of Spirituality in Health Care," 356.
[201] Richard Sloan et al., "Should Physicians Prescribe Religious Activities?," *The New England Journal of Medicine* 342:25 (2000): 1, accessed on 15 May 2011, http://courses.washington.edu/bh518/Articles/ShouldPhysiciansPrescribe.pdf.
[202] Sloan et al., "Should Physicians Prescribe Religious Activities?," 2-6.
[203] Geoffrey Mitchell et al., "'Diagnosing' and 'Managing' Spiritual Distress in Palliative Care: Creating an Intellectual Framework for Spirituality Useable in Clinical Practice," *Australasian Medical Journal* 3:6 (2010): 364.

spiritual beliefs, a doctor or medical staff should not encourage them "to get" spiritual.[204]

This would be disrespectful and counterproductive.[205]

In order to respect professional boundaries while still fulfilling obligations of practicing holistic care, Mitchell and colleagues have purported a framework for translating spirituality into medical discourse.[206] By placing patients' spirituality-related concerns into a "diagnosing" and "managing" model, practitioners will be able to "identify what, within [the patient's] belief systems, could provide comfort."[207] According to this study, first, a safe environment needs to be created, centered on the patient, which encourages them to speak freely about their personal beliefs. This is called a "holding environment."[208] Second, the practitioner seeks to understand the level of importance such beliefs may have on the patient's life through a spiritual assessment or "diagnosis."[209] Other scholars have emphasized the value of spiritual assessments as well. For example, Post and colleagues paraphrasing Puchalski's FICA[210] questions suggest that medical practitioners introduce the dialogue with these four questions:

- Do you consider yourself spiritual or religious?
- How important are these beliefs to you, and do they influence how you care for yourself?
- Do you belong to a spiritual community?
- How might health care providers best address any needs in this area?[211]

This allows a patient to express his or her spirituality as they wish and in their own terms. From this perspective medical professionals invite patients to lead a discussion regarding the importance of their spirituality and how best to incorporate this into their treatment plan. To

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[204] Post, Puchalski, and Larson, "Physicians and Patient Spirituality," 580.
[205] Ibid.
[206] Mitchell et al., "'Diagnosing' and 'Managing' Spiritual Distress," 364.
[207] Ibid.
[208] Ibid.
[209] Ibid., 367.
[210] Puchalski, *A Time for Listening and Caring,* 238.
[211] Post, Puchalski, and Larson, "Physicians and Patient Spirituality," 580.

do otherwise would be unethical and may lead to, as Sloan, et al. point out, additional distress to the patient.[212]

2.4 Spirituality in New Zealand Cancer Care Discourse

It is reported that New Zealand health care professionals, receive little or no training regarding potential relationships between spiritual/religious factors and their effects on health and illness.[213] *The Guidance for Improving Supportive and Rehabilitative Care for Adults with Cancer in New Zealand* suggest reasons for this situation includes reluctance on the part of the professional to ask spiritually related questions, as the topic may be perceived to be private or health care professionals may feel they lack knowledge and are thus, incompetent to discuss the topic.[214] Lui also recognizes that "In the New Zealand health system and in medical circles, little is done to help care for a person's spirit."[215] The seemingly down-played role of the spiritual in New Zealand health care may stem from the fact that from a social perspective, "adherence to institutional religion is not predominantly strong in Aotearoa New Zealand."[216] And spirituality, according to Bluck, "is almost totally ignored by our media, carefully avoided in public by our politicians, [and] caricatured by our advertising industry…"[217] This information sheds light on reasons why spirituality is not a part of regular medical assessments.[218] However, in the context of holistic health care one should not assume, as Quinn rightly observes, that "just because someone does not have a religious affiliation does not mean "that they will have no spiritual needs."[219] Likewise, Liu wisely observes that "the notion of spiritual injury applies to all people, regardless of…their beliefs

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[212] Sloan et al., "Should Physicians Prescribe Religious Activities?," 25.
[213] Minister of Health, *Guidance for Improving Supportive and Rehabilitative Care for Adults with Cancer in New Zealand* (2008): 54, accessed on 08 June 2009, http://www.moh.govt.nz/moh.nsf/pagesmh/8346.
[214] Ibid.
[215] Lui, Mental Health Foundation of New Zealand.
[216] Bluck, *Long White Cloud*, 9.
[217] Ibid., 11.
[218] Lui, Mental Health Foundation of New Zealand.
[219] Quinn, "Spirituality in Cancer Care," Introduction.

about, and understanding of, spirituality…"[220] Thus, Mitchell and colleagues argue that spirituality functions as the medium with which a person makes sense of their current situation and it is the health care practitioners' responsibility to recognize this critical role of spirituality.[221]

It is important to understand that the nation of New Zealand, according to Geering, was born in "the Secular age," thus its social institutions reflect that paradigm.[222] However, with the "renaissance of Māori culture", matters of the spirit have been brought to the foreground.[223] With regards to health care, Durie observes that Māori health perspectives sought to "translate health into terms which were culturally significant, and to balance physical and biological approaches within cultural and sociological views." [224] Māori perspectives approach health and illness holistically. For example, the *whare tapa whā* model recognizes four components to an individual's health including: the spiritual side (*taha wairua),* thoughts and feelings (*taha hinengaro*), the physical side (*taha tinana*) and the family (*taha whānau).* [225] By the early 1990s, Māori perspectives on health had been significantly influential in developing new health policy as well as health services in which a space for the spiritual was seen as not only appropriate but necessary for Māori and Pākehā alike.[226]

Cancer is a life-threatening, life-altering disease and often times, an experience filled with fear and hardships. New Zealand has the highest death rate for some cancers compared with other OECD countries.[227] In 1998, 29% of all deaths in New Zealand were cancer-

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[220] Lui, Mental Health Foundation of New Zealand.
[221] Mitchell et al., "'Diagnosing' and 'Managing' Spiritual Distress," 364.
[222] Lloyd Geering, "New Zealand Enters the Secular Age," in *Religion in New Zealand* ed. Christopher Nichol and James Veitch (Wellington: Tertiary Christian Studies Programme, 1983), 165.
[223] Bluck, *Long White Cloud*, 9.
[224] Mason Durie, *Whaiora: Māori Health Development* 2nd ed. (Auckland: Oxford University Press, 1998), 76-77.
[225] Ibid., 69-70.
[226] Ibid., 77-78.
[227] Minister of Health, *New Zealand Cancer Control Strategy*, 11.

related.[228] For individuals already diagnosed with cancer, the *New Zealand Cancer Control Strategy* aims to provide quality cancer care services, support and rehabilitation, and palliative care services to all individuals, but how and in what way spirituality manifests itself within these caring services is yet to be clarified. Furthermore, the seventh principle in the *New Zealand Cancer Control Strategy* states that all agencies and individuals involved in implementing the strategy should "reflect a person-centered approach." This approach

> recognizes a person's total well-being including their physical, emotional, spiritual, social and practical needs within the context of family and whānau. For Māori this means recognizing and responding appropriately to a Māori holistic view of health. It also recognizes people's autonomy and dignity and their right to make informed choices.[229]

The term spiritual is recognized as a component of a person's total well-being and is acknowledged as such in five terms defined in the 'Glossary' section of the *Cancer Control Strategy*,[230] but it is absent in the 'Cancer Control Research' section which articulates the areas of ongoing research.[231] This suggests that there is a general recognition of the role of spirituality as a component to total well-being within oncology care but research is lacking in understanding the nature of this relationship.

Further studies suggest that "Despite the breadth of the current literature [spiritual/religious connections between health and disease] there is paucity of data regarding resident's first-hand accounts dealing with these issues in clinical practice."[232] In the context of New Zealand, this number is even smaller. [233] Reported data from health care professionals, chaplains, and patient's first-hand of spirituality and cancer care is minimal

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[228] Ibid.

[229] Ibid., 20.

[230] Ibid., 67-71. Other terms whose definitions included the term spiritual were: psycho-oncology, support and rehabilitation, palliative care, and cancer care services. This suggests that the spiritual dimension is recognized as an aspect of the whole person, but further clarification as to how this impacts health care delivery is needed.

[231] Ibid., 18.

[232] Olson et al., "Mind, Body, and Spirit," 235.

[233] Egan, "Spirituality in New Zealand Hospice Care," iii.

and the need for more research is pertinent.[234] The following qualitative study aims to add to

the discourse on spirituality in New Zealand cancer care.

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[234] Olson et al., "Mind, Body, and Spirit," 235.

3 Exploring Spirituality in a New Zealand Oncology Unit: A Qualitative Study

3.1 Introduction

The purpose of this research was to use qualitative methods to explore the understanding of spirituality and spiritual care within a hospital oncology setting. This was accomplished through in-depth interviewing of patients, nurses, oncologists, and one chaplain from the oncology sector of a New Zealand public hospital. Carr highlights one of the gaps in research stating that minimal spiritual care studies "have included…multiple perspectives in a single sample."[235] Thus, eight individuals were recruited to participate in this study: patients with a diagnosis of cancer n=3, oncologists n=2, nurses n=2, and chaplain n=1. When individuals share their stories, valuable feedback regarding the ability of systems to meet patient needs can be gleaned and provided to medical staff.[236] Moreover, this information can "contribute "to a more complete understanding of the phenomenon spiritual care."[237] At its core, this research is descriptive and explorative. It seeks to investigate understandings of spirituality and spiritual care for patients with cancer in New Zealand and the medical professionals who care for them.

All eight participants completed at least one in-depth interview. An open and semi-structured format for the interviews allowed a safe space to be created wherein subjective and personal information was gathered. The analysis followed a descriptive qualitative approach.[238] The interviews explored five main questions:

1. How is spirituality understood by each participant?
2. What are the spiritual concerns of patients with cancer and how do they express them?

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[235] Tracy Carr, "Mapping the Processes and Qualities of Spiritual Nursing Care," *Journal of Qualitative Health Research* 18:5 (2008): 686.

[236] Arthur W. Frank, *The Wounded Storyteller: Body, Illness, and Ethics* (Chicago: The University of Chicago Press, 1995).

[237] Carr, "Mapping the Processes," 686.

[238] Sandelowski, "Whatever Happened to Qualitative Description?," 334-340.

3. How do oncology staff members and chaplains understand their role in addressing patient's spiritual concerns in a hospital setting?
4. What role does spirituality have in an oncology unit in a New Zealand public hospital?
5. How can this research work to improve spiritual care in the oncology sector of New Zealand's public hospital?

3.2 Ethics

Ethical approvals from three committees were required prior to commencement: (1) the Lower South Regional Ethics Committee and (2) the department of Preventive and Social Medicine's Research Approval Committee and (3) the hospital's ethics board. The former committee's approval process covered a number of issues including the purpose and study design, the safety protocols for protecting potential participants, and social and ethnic issues. A 30-page ethical approval application was completed. This included general interview questions and the Consent Forms and Information Sheets which would later be disseminated to participants. Following the completion of the application a committee convened for a formal interview and approved the project.

The research team maintained awareness and sensitivity to the possibility that participants sharing their personal stories may generate a range of emotions. To provide emotional support the patients were informed that the chaplain and counselor were available to address any particular needs that may arise after the interviews. Furthermore, I upheld a warm, honest, and professional character when in contact with the participants.

3.3 Methods

3.3.1 Introduction

Qualitative methodology was the appropriate choice for conducting this research because the heart of the project called for an intimate understanding of the role of spirituality in cancer care as it is understood by the people involved, namely patients, oncologists, nurses, and chaplains. In-depth interviewing was a succinct way of gathering this high quality

data.[239] In the context of administering holistic health care with a patient-centered approach, Kendal et al., stresses the "need to use patient centred research methods that can capture the multidimensional nature of the illness experience and place this understanding within a familial and health service context."[240] Moreover, this qualitative research could enhance medical discourse in a way that statistical surveys cannot as the openness of the interviews permit participants to reflect deeply and speak freely about "what is meaningful and salient without being pigeon-holed into standardized categories."[241]

The methods utilized for this qualitative project followed a generic approach.[242] Caelli et al., observe that this approach has become quite common in qualitative research.[243] They define it "as that which is not guided by an explicit or established set of philosophic assumptions in the form of one of the known qualitative methodologies."[244] Sandelowski calls this "qualitative descriptive research" and it has as its goals to "comprehensively and accurately" detail the understandings of a specific event or phenomenon in "the everyday terms" of the individuals to which it is particularly salient.[245] Furthermore, it is argued that this approach is justified first, as a means for producing a valuable end-product which addresses specific answers to questions relevant to stakeholders; and second, such summaries may be important "entry points for further research."[246] The generic approach is an "eclectic but reasonable and well-considered combination of methods which includes: participant

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[239] Michael Quinn Patton, *How To Use Qualitative Methods in Evaluation* (London: Sage Publications, 1987), 11.
[240] Marilyn Kendall et al., "Use of Multiperspective Qualitative Interviews to Understand Patients and Carers' Beliefs, Experiences, and Needs," *BMJ* (2009), accessed on 29 May 2011, DOI: 10.1136/bmj.b4122.
[241] Patton, *How To Use Qualitative Methods*, 15.
[242] Kate Caelli, Lynne Ray, and Judy Mills, "'Clear as Mud': Toward Greater Clarity in Generic Qualitative Research," *International Journal of Qualitative Methods* 2:2 (2003): 3.
[243] Ibid., 2.
[244] Ibid., 4.
[245] Sandelowski, "Whatever Happened to Qualitative Description?," 339, 334.
[246] Ibid., 339.

recruitment, interviews, reflection on the interviews, transcription, and finally coding and analysis.[247] The following sections will discuss these phases in greater detail.

3.3.2 Site for Field Work and Participant Recruitment

Field work was conducted in a public hospital in New Zealand; chosen for its reputation as a teaching and research hospital and accessibility. Here, I developed a professional relationship with a specialist in the oncology unit,[248] who then acted as a liaison between myself, the hospital board, and possible patient and medical staff participants. Participant recruitment began initially with the key contact approaching patients with a diagnosis of cancer and medical colleagues in the workplace. In this initial conversation, he gave them a brief overview of the study as well as a copy of the Information Sheet. If the individual expressed interest and gave consent, their contact details were forwarded to me and I followed-up with a phone call.

3.3.3 Inclusion Criteria for Participants

Criteria for inclusion in the study was guided by the advice of Dr. Richard Egan, a specialist in spirituality and palliative care. Criteria for patient participation included: patients with a cancer diagnosis; fluency in English; non-Māori; over the age of 18; free of mental disabilities that inhibit cognitive functioning; and a willingness to speak openly and honestly about the topic. Similarly, criteria for medical staff and chaplain participation included: 7+ years of work experience in their respective fields, fluency in English; non-Māori; over the age of 18; free of mental disabilities that inhibit cognitive functioning; and a willingness to speak openly and honestly about the topic.

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[247] Ibid., 337.
[248] Hereafter referred to as 'key contact.'

3.3.4 Initial Contact and Participant Recruitment

The initial phone calls included an introduction and a brief overview of the study. It was imperative to emphasize the idea that spirituality means different things for different people and for some this might mean religion; while, for others it may be more about their values and beliefs; and still for others the term may be completely irrelevant. This conveyed the open nature of the topic for the interviews. After this brief overview, I asked them if they had any questions or concerns and whether or not they would be interested in having an initial interview. If they said yes, I described the content and format of the interviews and reminded them that the interviews would be recorded and transcribed, a follow-up interview may be conducted based on the first interview, that their anonymity would be preserved and that the findings would be published in my thesis. We then set up a time and place that was most convenient for the participants.

If the answer was no, perspective participants were thanked for their time. Despite my conscious effort of being warm, supportive, and caring two out of five patient participants decided not to participate in the first interview after our initial conversation stating the topic was too personal and the timing was particularly bad for them. (This is discussed further in the Results Sections.)

For oncology doctors and nurses, recruitment began again with the key contact. He disseminated the Information Sheets to his colleagues either personally or *via* their office mailboxes. Like patient participation, the names and contact information of the doctors and nurses who expressed interest in participating in the project were emailed directly to me. The same follow-up process used with patient participants was used with the doctors and nurses. After this introductory telephone conversation, a time and place for the initial interview was scheduled.

Chaplain recruitment was successful without the aid of the key contact. I approached the chaplain as she was passing from her office to the hospital wards. I introduced myself, and asked if this was an appropriate time to speak with her. She nodded and I introduced my research project and handed her a written abstract of the project to look over. After which, I asked if she would be interested in talking with me further about the topic. She said yes and we then set up a time and place that was convenient to do so.

3.3.5 Interviews

The interview process involved a number of steps including: determining interview time and location, introductions and formalities (i.e. signing Consent Form), the interview itself, and research journaling. Each phase is addressed in more detail below.

The locations for the interviews were dependent on the participants. For example, patient interviews generally took place at the individual's home, while hospital staff and chaplain interviews took place on site in either an empty hospital room or in their offices. The time was also determined by its convenience for participants.

Before the interviews began, short "ice-breaking" conversations took place. It was during this time, the Consent Form was read and details discussed such as there are no monetary gains and their identity will remain anonymous. After the Consent Form was signed, the formal interview began with an introductory question about their personal understanding of the term spirituality. All interviews were recorded using an Olympus Digital Voice Recorder that was placed on either the table or desk between myself and the interviewee.

Interviews were conducted in a semi-structured format and were guided by a list of typed questions (specific to patient, medical professional, or chaplain). However, due to the open-ended nature of many of the questions, often follow-up questions were not the

immediate 'next' question on the list. In this sense, participants guided the interviews and when I felt we had covered the topic, I then referred back to my list of questions.

All interviews began and ended the same way. To begin, a general overview of the term spirituality was presented and then participant were asked to describe their understanding of spirituality as it related to them in their life. At the end of all interviews, interviewees were given the opportunity to add any final thoughts or ask any questions they may have about me or the research. If an interview was particularly emotional, the participant was reminded that the chaplain and/or counsellor are available if they felt the need to discuss a personal issue in more depth.

After the interviews were completed, I reflected on the interview experience; journaling field notes about the atmosphere, or the thoughts and feelings that the interview invoked. Most of the interviews were very personal and a lot of the information recorded cannot be used here for numerous reasons including: certain details may threaten the anonymity of the participant or the conversation drifted too far from the research topic and as such the relevance of the data was diminished.

3.3.6 Transcribing the Interviews

All interviews were transcribed verbatim, from beginning to end. Free transcription software was downloaded from the internet to aid in the transcription process. The raw interview data has been stored on my personal lap top to maintain security and confidentiality for all participants. A back up of the interviews has been stored on my desktop which is in a secured office on campus. After the transcriptions were completed, I made two copies of each interview: a computer printout of the transcribed interview and a CD-copy of the audio-

recording. Both copies were then placed in an envelope and returned to the respective participants.[249]

3.3.7 Coding and Analysis

Before analysis could begin, I organized all of my raw data based around the central research questions asked in the interviews. Patton supports this initial organizing approach stating, "responses to interviews can be organized question by question."[250] By doing this, I began with a cross-case analytic approach: grouping together the participants' answers in conjunction to their respective questions.[251] This approach is justified because it was not uncommon to have multiple versions of the same question, or the same questions asked but in a slightly different order and the need to combine all the answers to a single location respective of the questions was pertinent. Thus, I created a Word Document that delineated the main and most important questions for the purpose of this study. I then went through each interview and either quoted or paraphrased the answer to that question from each respective interview. For example:

1. **Can you describe to me your understanding of spirituality?**
   A. Nurse Diane[252]- not personally understood as a religious term; not understood as taking time out for oneself; not really sure; [p.1]
   B. Nurse Anna- not really sure; not thought about daily, but periodically reflects on ultimate questions such as "Is there something greater out there? What actually happens to you when you die? Is there something out there or not?" [p.1]
   C. Dr. Angela- "So spirituality is not to me so much religious anymore but is more about the values and beliefs as you said that help to…make each person or do what you can contribute to making that person's life better as well." [p.1] It involves "being a good person or having values that will help to show to others that there is a meaning to what you can do to help them." [p.1]
   D. Dr. James- good set of attitudes and moral values as a normal way of living, not necessarily connected to any specific religion (including empathy, compassion for others, lack of violence…) [p.1]
   E. Patient Kyle…

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[249] Some participants (N=3) returned interviews with comments, corrections, additions and omissions; these were taken into account during the final write-up.
[250] Patton, *How To Use Qualitative Methods*, 439.
[251] Ibid., 440.
[252] All participant names in this thesis have been changed to preserve the anonymity of the individual; however, their title is correct.

F. Chaplain Marie…

After participants' answers were organized and compiled as they relate to their respective question, the answers were then coded. Cross-case analysis encouraged content analysis and eventually "core consistencies" were identified and called "themes."[253] The first meta-theme that emerged from the raw data is: understandings of spirituality.

Although qualitative studies arguably cannot be entirely objective due to the fact that data is analysed through the researcher's personal lenses,[254] this research sought to stay as close as possible to the organic data, and thereby maintaining its original meaning.[255] In other words, the data generated from the in-depth interviews such as individuals' concerns or personal understandings of terms, remain as such- their concerns and their understandings; "there is no mandate to re-present the data in any other terms but their own."[256] Hence, the data is not at a high risk for being subjectively manipulated to fit into pre-existing theories; it has remained as authentic as possible while maintaining the anonymity of the participants. Furthermore, the themes discussed in the Results section are not completely subjective either, they are often aligned with themes that emerged from the literature review and thus are grounded in the existing literary discourse. No computer analysis software was used for this section.

3.4 Results

3.4.1 Introduction

The findings have been organized into five meta-thematic sections which articulate the five research questions this study sought to explore. They are: (1) understandings of spirituality; (2) understandings of spiritual concerns; (3) spiritual care; (4) roles of spirituality in a cancer care unit in New Zealand; and (5) improving spiritual care in a New Zealand

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[253] Patton, *How To Use Qualitative Methods,* 453.
[254] Helen Aveyard, *Doing a Literature Review in Health and Social Care: A Practical Guide* (New York: Open University Press, 2007), 32.
[255] Sandelowski, "Whatever Happened to Qualitative Description?," 338.
[256] Ibid.

oncology unit. Short descriptions of participant demographics will be presented followed by a brief overview of the study's general reception by participants.

Participant Demographics and Their Reception of the Study

A general overview of demographics helps to inform of individuality of the eight participants. [257] The three men and five women ranged from 40-70 years of age. All participants were Caucasian and seven out of eight participants had been exposed to or participated in some form of Christianity at some point during their life (often in childhood). Three out of these seven participants stated that their early childhood involvement in Sunday school was a result of parent's desire to "fit in;" "save face," or simply because "it was what everyone did back then." One out of eight participants is currently an active Christian.[258] For the participants with a diagnosis of cancer, the cancer types included: prostate cancer (1), breast cancer (1), and non-Hodgkin's lymphoma (1). Each patient had been given a good prognosis at the time the interviews were conducted between November 2009 and June 2010.

General reception by all participants initially contacted was positive (including the two individuals who declined to participate in the interviews) as it was an expressed belief shared among them that the topic of spirituality in New Zealand cancer care was an important one and it should be explored in more depth. Furthermore, this belief was also expressed by some representatives seated on both ethical committees that approved this study.

A note regarding the individuals who decided not to participate. Two out of five patients initially recruited for the study declined to be interviewed. Reasons given for their reluctance included: feelings that the project was too personal, as one person said, "my beliefs are private and for me," that they felt uncertain about answering the questions adequately, and finally, that this was a particularly difficult time to offer such personal

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[257] Egan, "Spirituality in New Zealand Hospice Care," 146.
[258] In this thesis, the phrase active Christian describes an individual who attends Church regularly and participates regularly in Church-affiliated activities.

information as these issues were still being "figured out" by the participants. This latter quote called to mind a patient interviewee's statement about her reasons for participating in this study, which included the fact that she had already worked through these personal issues. This highlights the critical importance and the need for professionals to maintain a sensitive, open, and supportive environment for patients to work through issues that involve examining their existentiality.

3.4.2 Meta-Theme 1: Understandings of Spirituality

This sub-section details the findings that begin to answer the first research question. Three sub-themes emerged in the interview discourse regarding participants' understanding of the term, spirituality. They include: (1) understanding spirituality in a relational context (i.e. between self, others, nature, and for some, God); (2) describing spirituality as a holistic enterprise (i.e. "it is who you are as a person"); and (3) describing spirituality as something distinct or separate from religion. However, these categorizations should not detract from the raw and eclectically diverse views that were often participants' first response. The following quotes illustrate the broad continuum of perspectives which range from not knowing,

- *I still don't know for myself* (Diane, nurse);[259]

- *I don't know* (Anna, nurse);

to their life being entrenched by it,

- *It's as important or more important part of my life then physical or other parts of it and it enhances everything that I do* (Marie, chaplain);

to having no spirituality at all,

- *I don't have a thought of where I'm going at the end- you die. Your brain's dead, there is nothing.* (Mike, patient).

As the interviews progressed, discussions on the meaning of spirituality were expanded upon and are represented in the following three sub-themes.

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[259] As stated in Section 3.3.7 Coding and Analysis, all original names of participants have been changed to preserve their anonymity.

3.4.2.1 Sub-Theme 1: Relationships

The first of three sub-themes is that understandings of spirituality by participants often involved a relational quality characteristic by words such as "connection," "partnership," "belief in self," and "helping others." More specifically, findings reveal that participants' understanding of spirituality can be categorized as the relationship between self, others, nature, and for some a transcendent being or religion.

Spirituality as the Relationship Between Self and the Inner Self

Two participants contextualized spirituality as the relationship that one has with their inner self. For one nurse, this involved personal reflection and periodic inner contemplation about life's ultimate questions: "Is there something greater out there? What does actually happen to you when you die?" However, she notes that these questions are not a daily "battle" for her (Anna, nurse). Anna continues, "I suppose you swing sway one way or the other" which highlights an important feature of spirituality discourse which suggests that it is dynamic and fluctuates in importance based on one's current life events. More succinctly, Anna acknowledges in hindsight that for her personally these questions surfaced when she was diagnosed with cancer; however, after many years in remission, she says, "as your life becomes back to a more…normal routine" they are no longer pressing issues. While, Molly, a patient very clearly states that spirituality for her is understood as "belief in oneself…that's got nothing to do with God."

Spirituality as the Relationship Between Self and Others

Two doctors in this study understand spirituality as the relationship between themselves and others, namely in the doctor-patient relationship. For example, Angela, a doctor says spirituality is about "having values that will help to show to others that there is a meaning to what you can do to help them." James, another doctor, understands spirituality as one's "moral values" which he expands upon by saying "you know, empathy…consideration

for other people and understanding the impact that illnesses [can have] on them." Spirituality for these two individuals is about the encounter between their self as 'doctor' and other individuals, and how they can best be of service to their patients; or as Angela succinctly says, "spirituality is about…what you can contribute to making that person's life better." In other words, it is about creating meaningful relationships in the space and time that is permitted for doing so.

Spirituality as the Relationship Between Self and God/Transcendent Being/Religion

For one patient and the chaplain, spirituality was understood as a personal connection to God. For Kyle, a patient, spirituality was synonymous with religion and expressed through his active involvement with his Christian community. There was also a personal and private quality to Kyle's relationship with God saying, "It's a one-on-one thing, you talk to Him, and pray for my good health and generally other people" (Kyle, patient). The relationship is understood as being reciprocated as well for Kyle. While reflecting on the idea of God and his many serendipitous moments he says:

> was it coincidence or was it meant to be- I can't help thinking a lot of things like that were meant to be, now some Greater Power, call him God, call Him whatever you like must be- "interfering" is not a word in my life- in there pushing me in a direction…So someone's looking after me (Kyle, patient).

Marie, the chaplain, also understands spirituality through a Christian lens, but expands the context if the occasion calls for a broader, more inclusive understanding of spirituality. For her spirituality is, "knowing that you're a spiritual person, knowing that connection with God and knowing it at a depth where it does make a difference in your life, where it affects every aspect of your life" (Marie, chaplain). Marie understands her spirituality or her "connection with God" literally saying, "So when I go to a ward, if I'm a little concerned about visiting somebody, I'll take His hand…yeah, He's there, and I talk to Him and ask Him to lead me to who I am to see next" (Marie, chaplain).

For these two individuals, God is not confined to the realm of the Church. Both Kyle and Marie, speak of "feeling connected to God" when they are in the presence of nature as well. For Kyle, he feels this spiritual connection when he's working in his garden or on his farm "where he feels at one with nature." For Marie, the chaplain, the feeling of her spiritual connection with God often emerges when she's going for a walk on a beach or through the woods.

3.4.2.2 Sub-Theme 2: Holistic

Six out of eight participants understood spirituality holistically. For these participants spirituality acknowledges the 'wholeness' of a person. It is about "where you are at with yourself," or "who you are as a person." As one nurse describes it as a combination of spiritual and secular beliefs that "mold you to become- to have some spirituality" (Anna, nurse). Angela, a doctor, describes spirituality as "the values and beliefs…that help to make each person." This understanding suggests that spirituality functions as the intertwining feature of a person, uniting all the different aspects (i.e. beliefs, values, identity) resulting in "who you are as a person."

3.4.2.3 Sub-Theme 3: Spirituality Distinct from Religion

One participant perceived spirituality and religion to be one and the same; a second participant speaking from an objective, third person perspective described spirituality as a personal connection to God, and religion as the rules and regulations that govern or guide that connection to God. [260] The remaining participants revealed strong tendencies to separate spirituality from religion. Six out of eight participants expressed in various ways their desire to distinguish spirituality from religion. For example, Diane, a nurse, who initially did not know how to describe her understanding of spirituality said, "I don't think of it in a religious

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[260] However, it should be noted that this was not his personal spirituality, but his response when asked to define spirituality and religion. This patient did not believe in life-after-death, prayer, or any Christian-related dogmas. He stated adamantly that he was neither religious nor spiritual.

term that's for sure." Angela, a doctor, states that when she was younger, she understood spirituality as being connected to religion, attending church services and Sunday school, "but spirituality is not to me so much religious anymore…" Similarly, James, a doctor says spirituality includes "moral values…normal way of living…normal set of values…rather than any link to any specific religion." Marie, the chaplain, had a very open and inclusive understanding of spirituality. Although being rooted in a Christian perspective, spirituality for her runs deeper than religion. She says, "spirituality begins with a connection with God [and] by connection…I meant something personal not just traditional." Here she distinguishes between a personal connection with God and that of a religious or 'traditional' connection with God. Later in the interview, she explains that in circumstances where she cannot make a religious connection with a patient, she can always go beyond religion and make a spiritual connection.

3.4.2.4 Summary of Meta-Theme 1: Understandings of Spirituality

Spirituality was understood by participants in many ways. Generally, relationships are a central theme in understandings of spirituality. These are contextualized in relationships between self, others, nature and for some a transcendent being, God, or religion. Additionally, spirituality was often understood as being holistic. In other words, it was suggested by participants that spirituality is that part of the person that weaves all the individual parts into a whole. Finally, a majority of participants perceived spirituality as something separate from religion. Religion, for this group was pre-dominantly Christian and involved "going to Church," "believing in the Bible," "having Christian beliefs", and "things like that"; whereas, spirituality was seen as something that goes beyond religion and involves the entirety of a person, not simply their 'religious' beliefs/selves.

3.4.3 Meta-Theme 2: Spiritual Concerns

This section begins to address the second research question regarding understandings of spiritual concerns. It is divided into three sub-sections. First, the issue of whether or not patients want to discuss their spiritual needs with their doctors is examined. Second, the spiritual concerns (or existential concerns) that some patients experienced are reported. Let it be noted that what has been categorized as spiritual concerns may not be seen as such by the patients themselves as the term spiritual concerns in this study has been used synonymously with existential concerns. [261] The third and final sub-section reports how medical staff understand the term, spiritual concern.

3.4.3.1 Do Patients Want Their Spiritual Needs Addressed By Their Doctors?

This study revealed that all three patients said they see the value in having a doctor or nurse inquire into an individual's spiritual beliefs so as to ascertain their level of importance to that individual and how to best incorporate that information into their care. Two patients interviewed for this study admit that the conversation, if it were to happen, would not have made a difference to them personally or played a role in their treatment plan. This was due to one patient already having spiritual support from his church community and the other was a staunch nonbeliever. Nonetheless, while Mike acknowledges that a spiritual assessment may not have benefitted him personally, "For others I can say yes…absolutely. I think it's a valid question" (Mike, patient). More specifically, Kyle adds, "It may help some people who had come from Central Otago and had no back up in town or anything" (Kyle, patient).

3.4.3.2 Spiritual Concerns of Patients with a Diagnosis of Cancer

Spiritual concerns for patients in this study varied. For one patient, spiritual concerns were reported as being non-existent; for another patient, spiritual concerns included

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[261] Henoch and Danielson, "Existential Concerns Among Patients," 225.

loneliness and loss, and separation from religion; themes in the latter interview included inner spiritual work and the re-claiming of her health through inner strength; and for the third patient, his concerns were very much 'this-worldly' in that he was focused on reaching family-related milestones. These are discussed in more detail below.

No Spiritual Concerns

For Kyle, a patient who expressed a direct one-on-one relationship with and belief in God, and who also found positive support and feelings of self-fulfillment within his religious community, had no reported spiritual concerns. He specifically said he did not worry about such things, "Things fall into place, sometimes they fall out of place, but then they fall back into place" (Kyle, patient). Perhaps his sense of spiritual well-being was found in his belief that there was "someone guiding him in this way or that direction" and other times he felt "that there was someone looking out for him." This sense of divine safety and security combined with the very active family and social support he described could play a role in why he reported no spiritual concerns.

Isolation, Loss, and Loneliness

Spiritual concerns such as isolation, loss, and loneliness were expressed by another patient. One out of three patients handled multiple cancer diagnoses in the absence of close family support. This patient had not only multiple cancer experiences but many complications as a result of treatment, prescription medication, and the cancer itself. She reflects on the experience saying

> I think one of the hardest things that I found, really hard, is actually doing it by yourself, yeah, there's no one there to rub your back or say 'are you doing okay?' or you know, 'Tell me about it.' And you know, just to be there without even saying words, that's one of the hardest things.

Furthermore, she did not believe "that there was someone [transcendent being] out there." Inner strength, self-knowledge, self-reliability, intuition, self-evaluation, and being open and honest with herself were found to be key coping tools that carried her through cancer

treatments, surgeries, and the healing process. It was interesting to note that even though she was surrounded by friends, she reflects on this time saying, "I just seemed to be so alone." As a result, she engaged in spiritual work, often reflecting on experiences or mentally and emotionally preparing herself for upcoming surgeries or procedures. "I just take it one day at a time. Yeah. I allowed myself to go down. And realized I was going down, cause I had to go down to come back up." The idea of spiritual work was very much a part of this patient's discourse and could be a powerful resource of strength for other patients to tap into when family support is not readily available.

Disconnection with Religion

One participant expressed disconnection or dissociation with her religion. She reported being let down by her religious congregation by the lack of support its leaders offered her in her time of need. As a result, she says "Originally I had a belief in God. I don't believe that anymore…mainly through circumstance that whenever I needed spiritual or religious help, it's not been there…so I walked away from that." The question arises whether or not the patient would consider this a spiritual concern for herself, because later in the interview she says "religion was never a driving force in her life" and in another part she says she does not feel guilt or angst about her decision to withdraw from her religious community.

'This-world' Concerns

All three patients interviewed for this study expressed 'this-worldly' concerns including their need to "get all the right information" regarding their diagnosis for example, what is difference between Hodgkin's and non-Hodgkin's cancers; what is the value in the "watch and wait" approach; why are certain prescriptions and procedures being ordered instead of other prescriptions or procedures and so on. In addition to these concerns, one patient's concerns were very much "family oriented." He was very much focused on reaching

milestones such as important birthdays, graduations, and seeing his children mature into young adults.

3.4.3.3 Medical Understandings for the Term Spiritual Concerns

I think its [spiritual concerns] as probably varied as is human beings are (Diane, nurse).

It seemed asking medical professionals to describe their understanding of the term spiritual concerns was important as it was suspected that like the term spirituality, participants would have varying understandings of the term spiritual concerns. As such, it could be viewed as an incomplete analysis, to discuss how medical staff address patients' spiritual needs (the third meta-theme) without first discussing what they perceive patients' spiritual needs to be. Medical staff's ideas expressed about spiritual concerns fell into two categories: concerns related to loss of identity as a result of disfiguring surgery and patients asking the 'ultimate' or 'hard' questions. Each category is discussed in greater detail below.

Loss of Self/ Loss of Identity

One nurse thought the term spiritual concern(s) could include the crisis that may, for some, follow surgeries that alter body image such as the removal of breasts for patients with breast cancer. She speculates that spiritual concerns may arise from "the sort of de-sexing of them…their altered body image of who they are as a female…that sense of loss of self" (Diane, nurse). These concerns are exacerbated if the woman is of an age where she wants to have children and is no longer capable of doing so as a result of a particular surgery or invasive treatment that she underwent as a result of her cancer. Diane stresses that this is a big concern she readily sees on the cancer ward. She notes, that men also have disfiguring surgeries, but tend not to voice their feelings as much.

Questioning

The second nurse as well as the two doctors interviewed here described spiritual concerns in connection to certain questions being present in the patient's language. For example, James, a doctor with 25 years of experience, sees spiritual concerns to include the patient's attempt to grapple with understanding "why me"?

> Occasionally see people, 'I've lived clean all my life and I haven't smoked or drunk and had plenty of fresh air and plenty of fresh vegetables how can I get cancer?' And you know that was the underlying theme for the rest of their life, how could it happen to me? (John, doctor).

Similarly, Angela, a doctor with 17 years experience, believes it to be about the patient's need to find meaning or a reason for their diagnosis by asking "the why me sort of question and how can this happen to me and who made this happen? I think of those more as the spiritual concerns than anything else really" (Angela, doctor).

Anna approached this question from a personal stance saying "maybe for me…the Bible has got so much information in it…perhaps question…what is written in the Bible" (Anna, nurse). She also suggests spiritual concerns may involve contemplating life after death and grappling with the idea of whether or not the after place "maybe…is a better place then what the situation is that you're in at that point in time with your health" (Anna, nurse). As an afterthought, Anna suggests that perhaps doubt may be a spiritual concern as well "doubting that there is Something there" but then decides she would have to reflect further on that question.

3.4.3.4 Summary of Meta-Theme 2: Spiritual Concerns

In summary, this study found that two out of three patients interviewed said that an initial spiritual assessment would not have played a role in how their plan of care was designed; nonetheless, they perceived it to be a "valid" conversation and suggested that it may be valuable to other patients and their treatment plan. This study found that spiritual concerns were varied among patient participants and ranged from no concerns to concerns of

loneliness and maintaining inner-strength to family-related concerns. Finally, this study revealed that medical staff's understanding of spiritual concerns are generally seen as a process that involves patients asking the "hard" questions that involve challenging the diagnosis and searching for reasons why- why has this happened to me? This process can be intensified when patients are dealing with additional factors like altered body image or the inability to have children which not only affects them physically, but also mentally, emotionally, socially, and spiritually.

3.4.4 Meta-Theme 3: Spiritual Care

This section presents the findings that begin to address the third research question: how do medical staff and the chaplain understand their role in addressing patients' spiritual concerns? But first, how medical staff members as well as the chaplain understand the term, spiritual care is first addressed. Following this, how medical staff address spiritual concerns of patients is discussed.

3.4.4.1 Medical Understandings for the Term Spiritual Care

This study found that medical understandings for the term, spiritual care were varied. The answers ranged from giving a patient one's undivided attention to going beyond the day-to-day conversation to expressing difficulty with the terminology itself. These are explored below.

"Undivided Attention and Follow Through"

For Diane, spiritual care is about "giving someone your absolute, undivided attention and following through as best you can on anything that you know they might need" (Diane, nurse). James describes this as "a committed… partnership… hopefully listening and taking the other persons wishes into account" (James, doctor). This kind of spiritual care is very much on a practical level which Diane describes more succinctly as following through with

any of their needs be it pain management, or needing a family member or a religious representative to be phoned. Most importantly it involves being 100% present says one nurse. However, others see spiritual care as going beyond the physical to a "different level."

"Going to a Different Level"

For many of the medical staff interviewed, spiritual care involved going to a deeper level with a patient, beyond the physical realm.

> Spiritual care is probably to me, going to a different level to just an ordinary day-to-day conversation with a patient…you know it's not like 'oh how was your day today?' sort of thing, it's probably, you know, examining and going down a pathway of wherever that person wants to go (Anna, nurse).

Marie, a chaplain with fifteen years experience, describes spiritual care also as a patient-centered task of "meeting them [the patient] where they're at and whatever their beliefs are and honoring their life" (Marie, chaplain). Spiritual care as described here, remains an open activity, relative to and led by the patient. The key subtheme for spiritual care here, is moving beyond the physical level and perhaps one way of doing this as Anna suggests is "examining their emotional level and how they're coping with whatever it is that they are facing in that point in time" (Anna, nurse).

Difficulty with Terminology

"To my mind spiritual care particularly sounds religious and I would sort of not say that's something I'm involved in" (Angela, doctor). For her, the term suggests "a religious context and not necessarily what I tend to think of as holistic care which is sort of aspects of the whole of the patient's life and the effects of having a disorder that's having on that life…" (Angela, doctor). Angela prefers the term, 'holistic care' rather than spiritual care as the former encompasses ideas related to the 'whole' person, whereas spiritual care, in her mind, conjures up religious associations.

Although, not speaking about spiritual care specifically Diane also expresses difficulty with the terminology saying

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I guess for me- and I think to for patients is that the word 'spiritual' and looking after 'spiritual needs' is, the patients often don't know either so, that gets to be a really grey area. New Zealanders haven't been brought up like that, it might be in the next few generations we are more comfortable- but in the main, we're dealing a lot with the elderly who will either have or have not a religion, to actually have had them think about it themselves about it in a spiritual way, aside from a religious, I think that hasn't happened. It's the younger ones that tend to, because they've talked about it perhaps with whatever like yourself or even at school (Diane, nurse).

In summary, the four medical professionals understood spiritual care to include giving patients their undivided attention, following through with patient requests, and going to a deeper level with patients during their conversations. Two professionals had difficulty with the term spiritual care itself and the term, spiritual concerns.

3.4.4.2 Addressing Spiritual Concerns of Patients

This section details the study's findings that begin to answer the third research question which investigates how medical staff members and the chaplain understand their role in addressing a patient's spiritual concerns. Themes that emerged from the interviews include recognizing one's limitation in the area, and thus the value of teamwork; and despite the absence of clear and concise spiritual care protocols and guidelines there was an intuitive level of spiritual care being deployed which included: awareness and listening, communication and engaging patients in spiritual activities. These are examined in more detail below.

Recognizing Personal Limitations and the Value of Teamwork

The theme of working in a team was expressed unanimously by the four medical staff and the chaplain.

- *The doctors generally cover the physical side of things although some of them move into other areas as well depending on their own way of life. We* [chaplains] *care basically for the spiritual side of the person* (Marie, chaplain);
- *Depending on what their* [the patient] *crisis was about…I think I would also incorporate other people into helping them and depending on that individual good to find out what that best other support system would be actually* (Anna, nurse).
- *If someone is really distressed…I'll take them aside…and quite often they'll talk…or we have counselors…sometimes it's financial, in which case, you call in the social workers"* (Diane, nurse).

- *You don't really have time to dwell on those things* [spiritual/existential concerns] *but it's good that these other services and experts are available* (James, doctor).
- *It's about getting the right people involved...to act within the team not as a sole practitioner but within the team and get the counselors involved and get the nurses involved...speak to their GP at home and you know get some support at home* (Angela, doctor).

Motivation to utilize the strengths of other team members in addressing a patient's spiritual concern(s) often stems from the medical staff's acknowledgement of their personal limitations in the area. James understands this well saying, "I guess I'm aware of it [spiritual distress] but I don't attempt to delve into it too deeply because it's not something that I'm particularly good at" (James, doctor). Likewise, Anna adds

> I don't think I'm experienced enough I suppose or wise enough to know how to help someone in some spiritual, if it's some spiritual issue…if they're deeply religious…I don't know how I'd…be able to help them (Anna, nurse).

Anna goes on to say that in those instances her way of helping may be simply, finding the right person who is capable of addressing that particular patient's needs at that moment in time; "sort of like a middle person, I suppose" (Anna, nurse). Marie, one of the chaplains at the hospital, drives this issue home saying, "I wouldn't expect spiritual care to be carried out by someone who doesn't think about spirituality. I think that would be like me trying to do an operation!" (Marie, chaplain). In other words, some participants recognize that administering spiritual care involves specific tools which include adequate knowledge about spiritual issues. It is suggested that some of the medical staff interviewed for this thesis feel that they lack these tools or the capacity to address such issues knowingly.

Individual Tactics for Addressing Spiritual Concerns of Patients

Despite spiritual concerns collectively being addressed as a team enterprise, there are still individual roles that medical staff and the chaplain take on to accomplish this feat of caring for the whole person. As the plethora of spirituality-related definitions indicate, there is some ambiguity that surrounds the topic of spirituality in cancer care. Thus, no finite "plan of attack" or a "one size fits all" formula to addressing the spiritual needs of patients exists,

nor would it be accepted by everyone if it did exist. Succinctly put: "I guess that is where the individual spirituality…I mean, what might be for you, and I could do the very same thing to the next patient, and it would just, it would not hit the target" (Diane, nurse). However, medical staff and chaplains intuitively provide spiritual care to patients even if they do not see it as such. These included: awareness and listening, communication, and engaging patients in spiritual activities. These are elaborated below.

Being Aware and Listening

"It's about knowing that patient…and asking an open question" says Angela, a doctor. Although Angela does not rely on rigid quality of life assessment questionnaires, she has participated in many clinical trials where such assessments were used and that experience "probably does filter into to you, what the types of questions are…but in your own way, you know, 'how are you coping with this?, or how are you doing whatever?' and things like that" (Angela, doctor).

Open-ended questions are by nature, patient-centered questions that shift the power to the patient in terms of the extent to which they would like to discuss their needs. The other half to this equation then is listening to what the patient says, or as James suggests, "taking the other person's wishes into account…as much as possible," (James, doctor). Listening is highlighted as an important characteristic in addressing spiritual needs (or any needs a patient may have). Anna, a nurse says, "You'd more let them do the talking than yourself do the talking" (Anna, nurse). The chaplain confirms this saying, "Listening is a big part of what we do and when people share their fears, the fears not got quite such a hold on them" (Marie, chaplain).

Communication

Four out of five medical staff interviewed in this study, plus the chaplain, described their understanding of the term spiritual concerns to involve some kind of questioning on the

part of the patient; thus, addressing the spiritual concerns of patients is understood as addressing these questions as they arise. For Angela, this is about reassuring a patient that it is not their fault, that there is nothing they have done wrong, and that there is no way of understanding why one individual is diagnosed with cancer and another is not. "I think it's our role to discuss why its [a spiritual concern/existential crisis] come about and why they feel in such a way and hopefully try and give what feasible response there might be, but also to allow them to ask you questions as well" (Angela, doctor). This emphasis on two-way discussion is extremely important as Angela notes because it can facilitate an opportunity to clear up any misconceptions a patient may have "that then potentiates something…that can get totally out of hand" (Angela, doctor). The chaplain phrases this differently saying, "Again, it's a case of making a person think about what it is they are saying. If someone said, 'I think God is punishing me,' then for what? Why?" (Marie, Chaplain).

Engaging in Spiritual Activities

The interview with the chaplain was rich with examples of individuals in spiritual crisis and how she went about addressing these needs. One patient said to her, "I'm dying what do I do next?" while another said, "How do I get back to what I was taught as a child?" Often, she will listen to what they are saying very closely "because in it, they're putting their concerns and that's what they want prayer for…" Prayer then, becomes a very important activity in the chaplain-patient relationship: prayer to ease fears, prayer for healing (not miracles unless a patient specifically asks for that), and prayer to break the chain of family illness passed down through generations. Those are just a few examples of how prayer was requested by patients and/or used by the chaplain.

Also, the chaplain often performs blessings, either anointing the person specifically or performing a room blessing after a person has died. One patient visits her regularly and upon knocking on the door asks, "Can I have a cup of tea and a blessing?"

The chaplain also plays an important role in reconnecting people with their faith. Sometimes patients have asked her what churches have healing ministries or from a religious perspective, what happens when a person dies? Or how can I make a spiritual life with the time I have left? Marie, having fifteen years experience as a chaplain, often has discretionary time where she can sit, listen and explore these questions in depth with patients. Moreover this highlights an important role chaplains can fulfill when medical professionals are occupied in busy hospital wards.

3.4.4.3 Summary of Meta-Theme 3: Spiritual Care

The term spiritual care is understood in different ways and as a result, was generally seen as addressing personal issues (or questions) as they arise on an individual basis. Working from a team perspective which incorporates specialists from other areas and involves "getting the right people" together was a key theme in how the medical staff and the chaplain addressed patient's spiritual concerns. Although there is no concrete and universally accepted way of addressing spiritual concerns, an informal approach was evident in the staff interviews. The first step[262] involves paying attention, being aware and listening. Following this, doctors, nurses or chaplains may ask open-ended questions to probe more deeply and based on a patient's answer or the level of their distress, a medical staff member/chaplain may take the following actions: bring them to the quiet room, refer them to the counselor/chaplain/social worker, hold their hand, offer them tissues or a cup of tea, sit with them, pray, administer blessings or communion, read the Bible, make a phone call on their behalf and so on.

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[262] These steps may happen in the opposite order as well. And in some instances other steps may occur, for example, a doctor may get a telephone call from a patient's daughter, who is calling to inform the doctor that mother is not coping well, in which case the doctor may follow up in a different manner.

3.4.5 Meta-Theme 4: Roles of Spirituality in a New Zealand Oncology Unit

This section looks to address the fourth research question which sought to explore how relevant spirituality was to cancer care as it was perceived by doctors, nurses, patients and chaplains and in what way(s). This question was asked in two different ways: *how do you think spirituality or spiritual care plays a role within oncology care, if it does?* and *do you think that spirituality has a practical place in oncology care?* The former question was asked in the beginning of the interview and the latter towards the end.

3.4.5.1 Spirituality and the Element of Time

In this study, two doctors, two nurses and one chaplain agreed that spirituality, in their opinions, does play a role in oncology care. For three of them spirituality encompassed the element of time. Angela sees spirituality's role as a process of becoming at peace with one's diagnosis and the preparation involved in getting to that point of peace and acceptance. Spiritual care then, becomes part of the process in which the doctor or nurse can "enable as much as possible for them to be prepared for that event" (Angela, doctor).

James, a doctor, sees spirituality from a humanist perspective, which involved empathy, good morals and ethics, "normal set of attitudes, lack of violence and so on." Based on this definition he says spirituality plays a strong role in oncology care because "people come here scared out of their minds and you know they want a bit of positivity and a bit of reassurance hopefully and something to hang on to" (James, doctor). As a result, John continues hopefully, in time, "we would form a little bit of a partnership" (James, doctor).

Marie, the chaplain had a very specific understanding of spirituality's role in cancer care. For her, the role of spirituality was about using what time patients have left to make or rebuild "a spiritual life…if that means going out to the beach and watching the sunrise it's all part of it- it's just re-establishing that connection." In another part of the interview she

expands on the concept of making a spiritual life saying that it can include: reconnecting with church, reading the Bible after many years of it collecting dust on a shelf, healing a family relationship, writing down one's memoirs, taking communion and so on. "People chose to make changes as a result of the things that are happening to them" (Marie, chaplain).

On one level, these are some external things that an individual can do to "make a spiritual life" with their remaining time. On another level, there are internal things an individual can do to "make a spiritual life" which involve self-reflection. Marie says,

> I guess getting to ask questions about who God is, if God is, what difference is it going to make to you?...looking into the questions of spirituality if you've never spent time before and deciding whether it has a connection for you (Marie, chaplain).

Time, or an individual's "remaining time" is for the medical staff and chaplain, an important and key theme regarding spirituality's role in cancer care.

3.4.5.2 Spirituality in the Context of Holistic Care

A second notable theme that emerged regarding spirituality's role in cancer care is its seemingly inherent association to the psycho-social aspects of a person. When I asked James whether or not he thought spirituality had a practical place within oncology care he said, "If you're looking at the psycho-social aspect [then] definitely without a doubt" (James, doctor). Diane spoke of spirituality's role as surpassing the "task-oriented…physical thing" and addressing the "psycho-social part of it" (Diane, nurse). A few minutes later she adds, "I'm not afraid to talk about emotional questions" noting that it is often through those conversations that a patient's requests or concerns emerge.

3.4.5.3 Problems with Language and Ethical Concerns

Problems with terminology and the issues or dangers that can arise from conflicting conceptual understanding of the terms make up the third theme in this section. Participants did express some concerns with the shortcomings inherent in the language that surrounds spirituality.

- *I think there's a long way to go for health professionals to really know how to talk about it, I mean…'Is there anything I can do for your spiritual needs?' I mean it's not something, you don't say it like that* (Diane, nurse).

- *To my mind, spiritual care particularly sounds religious and I would sort of not say that's something I'm involved in* (Angela, doctor).

- *Patients don't refer to it as spiritual needs either* (Diane, nurse).

Being very clear about what is meant by spiritual concerns or spiritual care for example, is very important especially in the context of ethics. Doctors and nurses have their own spiritual beliefs which may or may not be congruent with those of the patient. Angela observes that, "difficulty can come from different peoples' perspective of spirituality" (Angela, doctor). She speaks of another doctor that she knows who is very religious and incorporates that openly into his/her practice. At times, this doctor will say to a patient:

> 'Do you want me to pray for you?' Which then puts a lot of difficulty cause that patient might think 'oh I must be dying cause they're gonna pray', and people's interpretation if they're not religious can be very, you know, concerning (Angela, doctor).

Angela is adamant about not pushing one's beliefs on to the patient. It must be on the patient's terms. This section highlights the value of having a conversation about this topic early on, being very clear about the patients stance towards and understanding of these terms, and how best to address spiritual care for each patient.

3.4.5.4 Summary of Meta-Theme 4: Roles of Spirituality in a New Zealand Oncology Unit

A general consensus shared by participants is that spirituality does play a role in a New Zealand cancer care unit. Specifically, spirituality and time were thought to play a critical role in a patient's ability to find peace and acceptance with their diagnosis and perhaps to re-discover a spiritual life or re-establish a connection with something greater than the self. While it was believed that spirituality has a role to play in the context of holistic

care, some saw potential for problems if professionals crossed ethical boundaries such as proselytizing or pushing their beliefs on to the patient.

3.4.6 Meta-Theme 5: Improving Spiritual Care

I think that this is such a potential field that's massive in terms of oncology and haematology (Angela, doctor).

The results in this section begin to address the final research question that investigates how spiritual care could be improved in the oncology sector of a New Zealand public hospital. This study revealed that all four medical professionals recognize their own limitations in addressing patients' spiritual concerns and admit that there are probably occasions where patients' spiritual concerns are not being fully addressed in the clinical setting. Two nurses and two doctors specifically state that they suspect some patients' spiritual needs are probably not being met. This may be due to a number of reasons including: lack of time, lack of resources, lack of training in the area, too busy on the ward, and at times, they simply do not having the energy or the skills to meet the given needs on that particular day. As one professional said, "it's like opening a can of worms sometimes" and often a clinical setting is not the proper place for such deep issues to be discussed. These finding suggest that more education on spiritual literacy and spiritual care may be of value in reducing the number of patients whose spiritual needs remain unmet.

3.4.7 Summary of Results

This section has reported the findings from eleven in-depth interviews that explored how eight participants' understood spirituality-related terminology; patients, medical professionals and a chaplain's perspectives on spiritual concerns and spiritual care. Additional findings report the thoughts related to the roles spirituality may play in oncology care and are used to explore how spiritual care may be improved.

Key themes indicate that spirituality means different things to different individuals; however, the role of relationships was a central feature in definitions of spirituality as well as the tendency to describe it in holistic terms. Furthermore, six out of eight participants distinguished spirituality from religion, wherein religion was often confined to activities such as going to Church and believing in the Bible.

Key themes regarding spiritual concerns or existential concerns were again varied. Although all three patients found value in the idea of discussing spiritual beliefs with the doctor, two out of three patients reported that this would not have been necessary for them personally. All three patients were concerned about "getting the right medical information." They wanted to know about their diagnosis, why certain procedures or medications were ordered for while others were not, and facts specific to their diagnosis. Spiritual concerns reported by patients included loneliness, isolation, and separation from religion/God. One patient was concerned about "remaining family time" and achieving certain milestones such as traveling or reaching their children's 21st birthday. And a third patient reported no spiritual concerns.

Central themes in addressing spiritual concerns were being aware, asking open-ended questions, listening, and working in a team. However, a key theme that emerged was the shortcomings of the language that surrounded spirituality, specifically the terms spiritual care and spiritual concerns. For some participants these terms were either too ambiguous or had religious connotations which were seen as problematic from their perspectives.

Central themes regarding spirituality's role in cancer care mainly focused on making what time a patient had left to be of value, which carried different meanings for each interviewee.

Finally, the central theme in the improvement of spiritual care section was that the medical professionals interviewed felt that perhaps spiritual needs of patients may be going

unmet. However, the three patients interviewed said their care could not have been improved and that the medical staff who cared for them were wonderful.

The overarching themes for the project are the individual component of spirituality, the dynamic ways spirituality-related terms are understood and incorporated into medical practice, and spirituality's pluralistic core, must be addressed in an open and respectful manner.

3.4.8 Limitations

This study excluded Māori participants, family members of patients with cancer, and patients with a terminal diagnosis. No doubt, these voices would have added richness in depth and value to this study's findings. Māori have made great contributions to the current medical models and perspectives on health;[263] however, due to my lack of knowledge of *tikanga* and *te reo*, Māori participants were not recruited. This exclusion originally was to be counter-balanced by conducting an interview with an individual who specializes in Māori understandings of health, sickness, death and spirituality. Unfortunately, due to lack of time, resources, and the accrual of sufficient data, this section was omitted and the information relating to Māori spirituality will be confined to the work discussed in the Literature Review and Discussion sections. For reasons already noted above, the study's scope could not include family members' perspective either. Another limitation to this study was the personal and private nature of the topic itself. There were many individuals who expressed anxiety about the personal nature of the topic or self-doubt in their ability to speak knowingly about the topic. As a result, this study could only include those individuals who were willing to talk openly and honestly about the topic.

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[263] Durie, *Whaiora,* 67.

4 Discussion

4.1 Introduction

The aim of this study is to explore and describe understandings of spirituality, spiritual concerns and spiritual care through studying the experiences of New Zealand patients with cancer and the professionals who care for them. Five initial research questions were asked:

- How do participants understand the term spirituality?

- What are the spiritual concerns of patients with a diagnosis of cancer?

- How do oncology professionals and chaplains address spiritual concerns of patients?

- What role does spirituality have in a New Zealand oncology ward?

- How can this research work to improve spiritual care in a New Zealand public hospital's oncology ward?

The following discussion is divided into five sections which address in order the five questions above.

4.2 Understanding the Term Spirituality

The first research question aimed to explore how individuals conceptualized the term spirituality either for themselves personally, or generally speaking. This study found that understandings of the terms spirituality, are varied, and are dependent on the individual. These results are consistent with previous studies. [264] However, despite individualistic differences in the interviews, commonalities did emerge. The study revealed that many participants thought of spirituality in a relational context (i.e. connection to self, others, or God); six out of eight participants distinguished spirituality from religion; and six out of eight participants also described spirituality as holistic in that it encompasses all of the attributes

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[264] Zinnbauer, Pargament, and Scott, "The Emerging Meanings of Religiousness and Spirituality," 893-897.

that makes a person whole (i.e. beliefs, values, morals). These are discussed in more detail below.

4.2.1 Relationships

Understanding that humans are relational beings situated in a nexus of meaningful relationships (i.e. biopsychosocial-spiritually speaking), can be seen as a fundamental characteristic in spirituality and health discourse.[265] Moreover, Sulmasy says that tending to the disruption of these relationships as a result of illness is the essence of true holistic care.[266] It was found that the term spirituality was understood by participants in one of three relational contexts: transcendent, humanist (including nature), and self. Specifically, spirituality was understood as the *relationship* between self and one of these three categories. When spirituality was contextualized by participants as the relationship between self and the transcendent, the relationship, in part, was described as a one-on-one relationship with a divine being who they called God. When viewed from a humanist perspective, spirituality was perceived to be the relationship between self and others (namely in the doctor-patient relationship) or between self and nature (as in deriving a sense of peace from a sunset). Finally, one participant viewed spirituality as "a sense of believing in oneself" (Molly, patient). For her, believing in herself meant generating "inner strength" or "spiritual strength." She said without it, she would not be here today. Thus, her inner resources of strength became a key coping strategy which carried her through many obstacles such as surgeries, adverse side effects from medication, and emotional pain.

These categorizations are consistent with findings in the literature. For example, in the literature review of spirituality's meanings by Dyson et al., they conclude that the "centrality of the relationships between self, others and 'God'" is a key theme in the discourse.[267] Ross

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[265] Sulmasy, "The Healthcare Professional as Person," 105.
[266] Ibid.
[267] Dyson, Cobb, and Forman, "The Meaning of Spirituality," 1183-1188.

recognizes this theme as well, although conceptualizes it differently in that she sees spirituality as having "vertical and horizontal elements."[268] In this schema, the individual's relationship with the divine/transcendent or their value system represents the vertical axis; the horizontal axis, which extends from the vertical, represents the individual's "lifestyle and relationships with self, others and environment."[269] Puchalski and Sulmasy define spirituality as one's relationship with the transcendent; however, for them the term transcendent is not limited to divine beings, but rather the transcendent can be found in any number of activities which bring about a sense of purpose and meaning such as work, music, art, science and so on.[270] Likewise, McKinlay, also sought to expand the concept of spirituality beyond the boundaries of religious institutions to include the relationship between self and God (whereby the definition of God was self-determined) and the relationship self and others.[271] Thus, exploring the importance of relationships with self (including one's value system), others, nature, and perhaps a divine being, may be utilized as a framework for practitioners and researchers when exploring the concept of spirituality.[272]

An inner strength and belief in oneself characterized one patient's spirituality. Molly, a patient, who although had a long history of Church involvement, felt abandoned by her church leaders and as a result abandoned her belief in God. She turned inward and depended on her "inner strength" to carry her through her cancer treatments. "I think people see spirituality in a religious sense rather than in a sense of believing in oneself, which is where I come from. I've got to believe that I can actually do it" (Molly, patient). This statement

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[268] L. Ross, "The Spiritual Dimension: Its Importance to Patients' Health, Well-Being and Quality of Life and Its Implications for Nursing Practice," *International Journal of Nursing Studies* 32:5 (1995): 458.

[269] Ibid.

[270] Puchalski, *A Time for Listening and Caring*, 55; Sulmasy, "The Health Care Professional as Person,"103-104.

[271] Elizabeth McKinlay, "Ageing, Spirituality, and the Nursing Role," in *Spirituality: The Heart of Nursing,* ed. S.M. Ronaldson (Melbourne: Ausmed Publications, 1997):101, cited in Susan Ronaldson's "Nursing- A Caring Spirituality," accessed on 26 May 2011, http://www.ciap.health.nsw.gov.au/hospolic/stvincents/stvin99/Sue.htm. Attempts were made to find the original source, and it was located at Canterbury Medical Library; however, due to the Christchurch earthquake in February 2011, the library remains closed.

[272] Dyson, Cobb, and Forman, "The Meaning of Spirituality," 1183.

exemplifies a contemporary understanding of spirituality or "self-spirituality"[273] as put forth by Aupers and Houtman. In their article, "The Sacralization of the Self," the individual, let down by society or their religion, turns inward where "personal feelings and intuitions remain as touchstones for true meaning and real identity." [274] From a medical perspective, understanding how a person copes and what resources he or she uses may be an important part of their treatment plan and in assessing how best to improve (if needed) these resources.[275]

4.2.2 Spirituality and Religion

The majority of participants distinguished spirituality from religion; however, there were two participants for which spirituality and religion were very much the same concepts or connected concepts. For Kyle, a patient, the two terms were synonymous. "They are one and the same, split them, you can't" (Kyle, patient). Similarly, a second patient said, "I would define spirituality as your beliefs in another place or another being, and how they guide you through your life; and I'd define religion as the rules and regulations that cover your connection with that spirituality" (Mike, patient). To situate spirituality in close proximity to religion is not uncommon as Pargament[276] and Sinclair and colleagues cite studies[277] wherein "many respondents…saw themselves as being both spiritual and religious."[278] According to Woodhead, it is studies like these that report no difference between spirituality and religious beliefs that contribute to the reputation of the term spirituality as being "fuzzy," "unclear," and "ambiguous."[279]

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[273] Heelas, *The New Age Movement*, 2.
[274] Aupers and Houtman, "The Sacralization of the Self," 804.
[275] Puchalski and Ferrell, *Making Health Care Whole,* 99-100.
[276] Pargament, "The Psychology of Religion *and* Spirituality?," 7-8.
[277] For example see, Penny Long Marler and Kirk Hadaway, "'Being Religious' or 'Being Spiritual' in America: A Zero-Sum Proposition? *Journal for the Scientific Study of Religion* 41:2 (2002): 289-300.
[278] Sinclair, Pereira, and Raffin, "A Thematic Review," 467.
[279] Woodhead, "Real Religion and Fuzzy Spirituality," 32.

It is important to understand that in the medical context, spirituality is not synonymous with religion.[280] This point becomes crucial as the trend for considering the importance of and caring for the spiritual dimension in health care increasingly becomes recognized in New Zealand health care strategies.[281] Geering writes in 1983, "The chief trend is the withdrawal of New Zealanders from active participation in any clearly recognizable religious group or institution."[282] Supporting this trend he cites an increase from 6.2% to 22.5% of the New Zealand population describing themselves as religiously unaffiliated during the years 1926-1976.[283] According to the 2006 New Zealand Census Reports, this number has grown to 34.7% of the population and consists primarily of Europeans and New Zealander ethnic groups.[284] The qualitative study herein presents findings which support these broader New Zealand trends and it highlights the importance of understanding spirituality and spiritual concerns of patients in a secular context- or in a "this-worldly context."[285] Although many religious people will also be spiritual (as evidenced in the patient Kyle's inability to separate the two ideas), a spiritual person may or may not be religious.[286] It is argued the existential search for meaning is a part of the human condition.[287] For many scholars this is the essence of spirituality and it can be sought after in a variety of contexts. The argument suggests then that all persons have a spirituality.[288] It is important to consider then, as Speck and colleagues observe, that simply because an individual does not have a

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[280] Sulmasy, "The Healthcare Professional as Person," 103.

[281] Minister of Health, *The New Zealand Cancer Control Strategy*, (2003); *Guidance for Improving Supportive and Rehabilitative care for Adults with Cancer in New Zealand* (2008); The Cancer Society of New Zealand, "Cancer and Spirituality," (2009), accessed on 25 May 2011, http://www.cancernz.org.nz/assets/files/IS_Cancer&Sprituality_12May2010(1).pdf.

[282] Geering, "New Zealand Enters the Secular Age," 173.

[283] Ibid.

[284] Statistics New Zealand, 2006 Census Data: Religious Affiliation, accessed 21 May 11, http://www.stats.govt.nz/Census/2006CensusHomePage/QuickStats/quickstats-about-a-subject/culture-and-identity/religious-affiliation.aspx.

[285] Geering, "New Zealand Enters the Secular Age," 164.

[286] Peter Speck, Irene Higginson, and Julia Addington-Hall, "Spiritual Needs in Health Care: May Be Distinct From Religious Ones and Are Integral to Palliative Care," *British Medical Journal* 329:7458 (Jul 2004): 123-124.

[287] Frankl, *The Unconscious God,* 79.

[288] Sulmasy, "The Healthcare Professional as Person," 104.

religious affiliation (as many New Zealanders do not) does not mean the he or she will not have spiritual concerns.[289]

There were strong tendencies by participants to separate spirituality from religion. Two doctors and two nurses deliberately described spirituality as something separate from religion. Likewise, Anna, a nurse said, "spirituality is perhaps where you are with yourself and…I suppose religion is some set sort of doctrine that's come and then there's all these different interpretations of it…" (Anna, nurse). The idea that spirituality is the more broad construct and that "religion is only one of many forms of spiritual expression"[290] is supported by this study's findings. Likewise Roof's research also found that the majority of its participants sought to distinguish between religion and spirituality.[291] Religion, for them, implied institutional life (i.e. attending religious services, observing religious holidays), while spirituality dealt with personal empowerment "and has to do with the deepest motivations of life."[292] Like the sociological and medical literature that understands spirituality (in part) as the more personal and subjective aspects that shape and form the person as a whole, so too were these themes echoed in this study's findings.

Two themes emerged in the language that participants used when discussing what distinguishes spirituality from religion: spirituality runs 'deeper' than religion, and spirituality is the essence of a person. Marie, the chaplain, believed spirituality and religion were connected; however, spirituality was something that went beyond religion. Reflecting on her own chaplaincy experience she says:

> being religious can simply be a formality and may never get passed the outer shell or reach the heart of a person. Spirituality…is knowing that you are a spiritual person…and knowing it at a depth that affects every aspect of your life" (Marie, chaplain).

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[289] Speck, Higginson, and Addington-Hall, "Spiritual Needs in Health Care," 123-124.
[290] Sinclair, Pereira, and Raffin, "A Thematic Review," 467.
[291] Roof, *A Generation of Seekers*, 76-77.
[292] Ibid.

With this understanding she recognizes that she may not make a religious connection with every patient; however, where they cannot connect on a religious level, they have an opportunity to connect on a deeper "spiritual" level. The chaplain's perspective mirrors trends in both social scientific and medical literature that describes spirituality as the more broad, more inclusive term, and religion it is suggested, as one of many pathways for spiritual expression.[293] To be clear, religion is generally understood as an organized faith institution, distinguishable from other religions, based on their specific beliefs, rituals, communal worship, dietary and customary laws, sacred scripture, and transcendent being(s) as found in the major world religions like Christianity, Judaism, Hinduism, Buddhism, and so on.[294]

4.2.3 Holism

The perspective that spirituality runs deeper than religion is further exemplified by participants when they use language that associates the term spirituality with the "essence of a person." For an example, one patient said religion is "the belief that God has been a person that has lived and people bow and scrape and do all these things to Him- to me that's all false. Spirituality is about the soul, about who you are as a person" (Molly, patient). Two doctors, two nurses, one chaplain and one patient expressed spirituality to be about the things (i.e. relationships, beliefs, attitudes, values) "that make each person" (Angela, doctor). Anna states this idea saying, "you can have maybe religious beliefs but then you can have a lot of other beliefs as well that mold you to become- to have some spirituality" (Anna, nurse). Bluck argues that spirituality involves the process of becoming a whole person.[295] Likewise, when arguing for a holistic approach to medicine Frankl writes:

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[293] Ibid.
[294] Sinclair, Pereira, and Raffin, "A Thematic Review," 467; Ramondetta and Sills, "Spirituality in Gynecological Oncology,"185.
[295] Bluck, *Long White Cloud*, 12.

> Body and psyche may form a unity- a psychosomatic unity- but this unity does not yet represent the wholeness of man…Wholeness in this context means the integration of somatic, psychic and spiritual aspects.[296]

Ten years after Frankl, while writing of the spiritual dimension, Hiatt says it serves as the "integrative function for the individual…bring[ing] the seemingly disparate parts of the personality and fragmented nature of experience together into a single whole."[297] These ideas have been found to be salient in 21st century New Zealand as six out of eight participants likened spirituality to the essence of a person, 'who they are as a person.' Moreover, for participants this holistic understanding of the person included their beliefs (religious or otherwise), values, and attitudes.

4.2.4 Summary

In summary, personalized definitions of spirituality vary considerably from one participant to the next; however, common themes can be found. It has been suggested in both religious studies literature and medical literature, and supported by this study's findings that spirituality, although dependent on the individual, involves deep and meaningful relationships and it also includes the inner matrix that makes a person whole (such as a well-developed belief and value system or whatever it is that makes a person feel whole and complete). Despite some religious studies scholars desire to keep spirituality and religion connected, (i.e. Pargament[298]), the majority of participants in this study distinguished religion from spirituality in that spirituality was seen as a broader, more inclusive concept that may or may not be connected to a particular religion.

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[296] Frankl, *The Unconscious God,* 28.
[297] Hiatt, "Spirituality, Medicine, and Healing," 737.
[298] For Pargament, Spirituality is defined as "a search for the sacred" and this is "the most central function of religion." Pargament, "The Psychology of Religion *and* Spirituality?," 12.

4.3 Spiritual Concerns

This section discusses the topic of spiritual concerns, from the perspectives of patient and medical provider, and the desire of patients to discuss spiritual concerns with providers. Next, the understanding of the term spiritual care is examined from the view of the medical provider and how in turn spiritual care is delivered in the medical system. Finally, the role of spiritual care and how it can be improved in the medical setting is reviewed.

4.3.1 Do Patients Want Their Spiritual Concerns Addressed by Their Doctors?

The medical literature suggests that patients want their spiritual concerns addressed by their doctors.[299] However, when asked whether or not they would prefer for their doctors to inquire about their spiritual needs or concerns, two out of three patients in this study said this would not be necessary for them personally; but, they also said that other patients may benefit from the conversation. The third patient did not answer in a 'yes or no' fashion, but instead felt that this was already happening in her care, albeit indirectly, through her doctor's patient-centered approaches to her medical care. "Now that's an interesting question," she says,

> Because I feel that I've actually taken over command of my own well-being at the hospital and I've been invited to do that particularly by [my doctor] who would ask me 'Now you tell me how you feel, and what do you think about this or [that] and I did comment to him when I saw him last time, I said, 'You're turning things around' (Molly, patient).

This patient has experienced a shift in her health care delivery from a biomedical focus to a holistic focus exemplified in the open-ended questions her doctor asked her, "Now you tell me how you feel?" and "What do you think about this?" Inviting the patient to take an active role in their health care plan is seen to be an encouraging factor that may enable a patient to

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[299] Gowri Anandarajah and Ellen Hight, "Spirituality and Medical Practice: Using the HOPE Questions as a Practical Tool for Spirituality Assessment," *American Family Physicians* 63:1 (2001): 81.

maximize their self-potential during times of illness. [300] Saunders says this "unique experience…may reveal hidden strengths, often to the surprise of…the patient."[301] This study has showed that inviting the patient to discuss their spiritual beliefs in an open conversation may be beneficial for some patients, by activating reservoirs of inner strength. Despite two out of three patient participants reporting that a spiritual assessment would not have been valuable for them, they did acknowledge it to be a valid procedure and shared the belief that for some individuals it would be valuable. Simply stated, a spiritual assessment would identify the patients who prefer that their spiritual concerns be cared for by incorporation into the health care plan.

Because each patient is different, Puchalski[302] and Anandarajah,[303] for example, have suggested including a spiritual assessment as part of the routine history assessment of each patient. Initially the dialogue would encourage the patient to share their spiritual or religious beliefs, thus taking the doctor-patient relationship to a deeper level; furthermore, the doctor may enlist a patient to use any positive inner resources (i.e. strength, healing, and acceptance) that may have arisen from this conversation.[304] In addition, this conversation could help to identify spiritual or religious beliefs/practices that may influence medical decision making, have a positive impact if incorporated in the treatment plan, or on the other hand, identify spiritual beliefs and practices that may complicate treatment plans.[305] Incorporating some tool for spiritual assessment may help to prepare, what Aldridge calls, "ecology of treatment"[306] so that proper professionals are identified to be of service if and when they are called to be present.

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[300] Saunders, "The Evolution of Palliative Care," 11.
[301] Ibid.
[302] Puchalski and Ferrell, *Making Health Care Whole*, 100.
[303] Anandarajah and Hight, "Spirituality and Medical Practice: Using the HOPE Questions," 81.
[304] Puchalski and Ferrell, *Making Health Care Whole*, 100.
[305] Ibid.
[306] Aldridge, *Spirituality, Healing and Medicine,* 11.

4.3.2 Spiritual Concerns of Patients with a Diagnosis of Cancer

Williams suggests that spiritual concerns (or the existential questions) often do not receive much attention in a healthy individual's day-to-day activities; however, these are "brought into acuity at the end of life."[307] This study has revealed that it is not only at the end of life when spiritual concerns (or existential concerns) are brought to the surface. Many studies, including this study, have shown that a diagnosis of cancer (even if it is not a terminal diagnosis) can generate a number of spiritual issues.[308] Further, because a cancer diagnosis is often associated with death,[309] high levels of fear, anxiety, uncertainty and a sense of loss are often experienced by many patients at the onset of diagnosis, throughout treatment and post-treatment and not only at the end of life.[310] Thus the "spiritual health spectrum"[311] that Williams created to thematically organize patients' spiritual health at the end of life can also be utilized for patients who are not in the terminal stages of illness. This spiritual health spectrum, which patients can move along, ranges from spiritual despair (i.e. alienation, loss of self, and dissonance) to spiritual work (i.e. forgiveness, self-exploration, and search for balance) to spiritual well-being (i.e. connection, self-actualization, and consonance).[312]

This study revealed that even though patient participants were not in the end of life, they also moved along points in this spectrum. For example, Kyle exemplified spiritual well-being by expressing an intimate and positive relationship with God, feelings of connection to life, nature, others, and self, satisfaction with his life's work, wholeness, and inner peace among other attributes. Molly's interview is an example of a patient moving between all three

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[307] Anna-Leila Williams, "Perspectives on Spirituality at the End of Life: A Meta-Summary," *Palliative and Supportive Care* 4 (2006): 416.

[308] Aygül Akyüz et al., "Living with Gynecologic Cancer: Experience of Women and Their Partners," *Journal of Nursing Scholarship* 40:3 (2008):243-245; André Samson and Barbara Zerter, "The Experience of Spirituality in the Psycho-social Adaption of Cancer Survivors," *The Journal of Pastoral Care & Counseling* 57:3 (2003): 340; Murray et al., "Patterns of Social, Psychological, and Spiritual Decline," 400.

[309] Quinn, "Spirituality in Cancer Care," Introduction.

[310] Murray et al., "Patterns of Social, Psychological, and Spiritual Decline," 400.

[311] Williams, "Perspectives on Spirituality at the End of Life," 415.

[312] Ibid.

stages. Her emphasis on inner strength, reassessing and re-evaluating life circumstances, self-exploration, forgiveness and search for balance are indicative to William's middle tier, appropriately named "Spiritual Work/Processing."[313] Molly, also spoke of times when she felt abandoned by her religious leaders, lonely, and frustrated portraying elements of spiritual despair. But these times were heavily laden with terminology characteristic of spiritual work as mentioned above which indicates her personal goal of working towards spiritual well-being rather than remaining "stuck" in feelings of spiritual despair. Finally, Molly's interview was punctuated with moments of spiritual well-being wherein she expressed appreciation for life and nature, feeling connected to deceased loved ones, and creativity. To improve end of life care, Williams concludes that, "researchers need to find effective interventions that help the terminally ill complete the work necessary for spiritual well-being."[314] However, based on findings within, it can be argued that expanding the concept of working towards spiritual well-being with all patients diagnosed with a serious illness could be beneficial.

4.3.3 Medical Perspectives of Spiritual Concerns of Patients

4.3.3.1 Issues Regarding the Term: Spiritual Concerns

This study revealed that three out of the four medical professionals interviewed had some issues with using words such as spiritual needs/concerns. For these three professionals the words were not "mainstream" enough; they would not ask a patient about their spiritual needs using those specific words. Likewise, it has been their experience that patients do not typically refer explicitly to "spiritual needs." Rather, what these professionals prefer is to ask psycho-social questions, or as one nurse referred to it as "the emotional questions," because it is presumed that the spiritual concerns of the patients will be built into the background or the conversational fabric of what a patient is saying. What these findings indicate is that medical

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[313] Ibid.
[314] Ibid., 416.

professionals' understandings of these words may play a role in how they deliver health care and in effect, how they may or may not address the spiritual needs of their patients. Furthermore, it highlights the difficulty in drawing a definitive line between the different dimensions of an individual. Frankl[315] and Brady[316] et al. suggest in their research that the spiritual dimension is a specific and unique dimension to that of the others, and to combine it with, for example, the emotional dimension, may result in specific needs being unintentionally overlooked and this may exacerbate the distress for a particular patient.[317] The value of education in spiritual literacy for medical professionals could help staff not only address personal issues they may have with terminology, and thus improving how they deliver holistic care to the individual; but also, illustrates the importance of considering the spiritual dimension as its own domain with unique needs that need to be met.[318]

4.3.3.2 Medical Understandings of the Term Spiritual Concerns

It was suggested by one nurse that there are probably as many understandings of the term spiritual concerns as there are people in the world. However, as with the term spirituality, this should not deter researchers from studying it, nor medical practitioners from considering it an important factor in comprehensive health care.[319] Ramondetta and Sills recall the White House Council of Aging, as early as 1971, felt it necessary to define spiritual concerns suggesting that it is "the human need to deal with sociocultural deprivation, anxieties, and fears, death and dying, personality integration, self-image, personal dignity, social alienation, and philosophy of life."[320] This study revealed that the four medical professionals interviewed perceived spiritual concerns of patients with cancer to be about asking the "hard questions" which involved coming to terms with their diagnosis, searching

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[315] Frankl, *The Unconscious God,* 80.
[316] Brady et al., "A Case for Including Spirituality," 419.
[317] Murray et al., "Patterns of Social, Psychological, and Spiritual Decline," 400.
[318] Brady et al., "A Case for Including Spirituality," 424.
[319] Woodhead, "Real Religion and Fuzzy Spirituality," 37.
[320] Ramondetta and Sills, "Spirituality in Gynecological Oncology," 185.

for a meaning in their illness, re-examining their beliefs (religious, spiritual or secular), and doubt. Spiritual concerns were also thought to include a loss of self or identity due to altered body image resulting from surgical treatment. These findings are consistent with other findings that suggest spiritual concerns involve "conflict and disharmony between [a patient's] positive belief systems and the reality of their current situation" and that this dissonance results in spiritual pain.[321] These findings are further supported by Quinn's observations that a cancer diagnosis can lead to many "changes in a person's life" which can result in a re-examining and re-evaluating of their "beliefs and values including what may be described as their spiritual needs."[322] Thus, a cancer diagnosis, which is often associated with a fear of dying prematurely, may undermine a person's pre-existing existential framework, thereby triggering spiritual distress.[323]

In this study, two doctors and one nurse reported that "people do…they do struggle with why is it me?" says Anna, a nurse. During the initial stages of diagnosis, Anna continues saying, "You probably examine things a lot more" especially at the onset of a cancer diagnosis. Reflecting on personal experiences, one of the medical professionals says that years ago, when she was diagnosed with cancer, questions that she faced included: "What is going to be of me, if I was not to be there?...Who am I?...What am I going to leave…as in memories?" She also shared that after making a full recovery and when her life returned to "normal" these deeper questions fell into the background.

On the other hand, one nurse reported that in her thirteen years of experience she has not received "too many 'why me's?'" (Diane, nurse). She hypothesizes that most likely it is the counselor who hears the "why me" question. It may be important to add here that the three patients interviewed reported not experiencing the 'why me' component so often cited

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[321] Chio et al., "Spiritual Suffering Among Taiwanese," 736.
[322] Quinn, "Spirituality in Cancer Care," 2.
[323] Henoch and Danielson, "Existential Concerns Among Patients with Cancer," 225.

in medical literature.[324] Essentially patients in this study understood their diagnosis as a series of uncontrollable circumstances that resulted in a cancer diagnosis, which ultimately could happen to anybody. Diane, reflecting on her nursing experience observe patients' tendency to mobilize and actively participate in their treatment plan. Rather than ask 'why me' patients, in her experience, are more often asking "What are the things I should be doing to keep myself well at the end of it?" This was supported with patient interviews that stated their number one desire was to follow through with treatment and carry on with their lives. In this vein, she has noticed "a lot of people wanting to use alternative therapies" because it is a way for patients to proactively "help themselves," by taking control of their health regime (Diane, nurse).

4.3.4 Summary

It is important to note that the term spiritual concerns in this study has been used synonymously with existential concerns and it has been argued here, as others have argued[325] that such concerns are inherent to the human condition. Post and colleagues have suggested the spiritual dimension is the part of a person concerned with purpose and meaning in life and this is important in the realm of clinical care.[326] Exploring a patient's spiritual concerns through open-ended discussions may prove useful in identifying which patients may view such issues as important components to their health care plan. More specifically, incorporating spiritual assessment questions may help not only to facilitate this dialogue but identify areas that can encourage patient engagement and self-actualization.

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[324] Quinn, "Spirituality in Cancer Care," 1.
[325] Henoch and Danielson, "Existential Concerns Among Patients with Cancer," 225.
[326] Post, Puchalski, and Larson, "Physicians and Patient Spirituality," 578.

4.4 Spiritual Care

4.4.1 Medical Understandings of the Term Spiritual Care

Spiritual care, as understood, by the medical professionals in this study included: undivided attention, follow through and going to a "different level" with a patient. This section details technical issues some medical staff had with the term spiritual care.

4.4.2 Delivering Spiritual Care: Addressing the Needs of Patients

This study showed that the four medical professionals' approaches in delivering spiritual care were not homogenous; however, there was an intuitive understanding in delivering spiritual care that was present in all the interviews. This is similar to Quinn's research wherein he observes that although the literature often describes the spiritual component as the neglected or ignored aspect in health care delivery, "the reality is that health care workers are often involved in supporting people with spiritual concerns even when they may not recognize this as such."[327] The term spiritual care was not used by these medical professionals to describe their way of caring; nonetheless, their actions of sitting and listening, asking open-ended questions, acting as a liaison between patient and another professional, handing a patient a tissue, or a cup of tea, and their attitudes of compassion, empathy, and kindness towards their patients is spiritual care as described in the literature.[328]

As noted, spiritual distress does not only transpire at the end of life. The findings from Murray et al., suggest that there are four predictable times when spiritual distress is heightened during the cancer experience including at diagnosis, finishing treatment, disease progression, and the terminal stage.[329] They conclude that recognizing these different trajectories early on in treatment through an open and honest conversation "may help patients

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[327] Quinn, "Spirituality in Cancer Care," Introduction.
[328] Puchalski, *A Time for Listening and Caring*, 39-40, 42, 44-46; Quinn, "Spirituality in Cancer Care," 11-12.
[329] Murray et al., "Patterns of Social, Psychological, and Spiritual Decline," 398.

in their search for meaning and prevent spiritual concerns amounting to disabling distress."[330]

Ramondetta and Sills also suggest that discussing issues related to what may be considered a potential spiritual concern for a patient at the onset of diagnosis "might help health care providers identify those individuals who need more help [coping with their cancer illness.]"[331] Together, these findings illustrate the value in having a firm understanding of what spiritual concerns may entail (e.g. searching for reasons why) and recognizing the four critical moments when these concerns are often elevated, which may prove to be a beneficial approach to addressing spiritual concerns. Furthermore, these different trajectories, as described by Murray and colleagues, may provide a template for professionals in working towards addressing the spiritual needs of their patients at the appropriate times during an illness experience.

4.5 Roles of Spirituality in a New Zealand Oncology Unit

This study revealed that participants understood spirituality's role in cancer care to involve the element of time. One doctor suggested that spirituality's role in cancer care becomes prominent in the context of a patient coming to terms with their diagnosis; an often difficult process that involves acceptance of their illness and finding peace in their current circumstance. Medical scholars describe this as a healing process, which is different from curing.[332] For example, Aldridge says to heal, not necessarily cure, means to come to a personal understanding and acceptance of one's suffering and to find "peace and reconciliation."[333] Marie, the chaplain called this process: "making a spiritual life." According to her, this involves using time to "re-establish that connection" be it healing broken relationships (with loved ones or with God), making positive changes in life, or spending time reflecting on spiritual questions. Hiatt supports these findings suggesting that

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[330] Ibid., 400.
[331] Ramondetta and Sills, "Spirituality in Gynecological Oncology," 186.
[332] Puchalski, "The Role of Spirituality in Health Care," 352.
[333] Aldridge, *Spirituality, Healing and Medicine,* 12.

chronic illness on the spiritual level provides an opportunity "for self-examination and initiation of changes that improve adaption and promote unity."[334] Further, he suggests severe illness can also be a powerful teaching tool, reminding patients of their mortality, and the "relativity of certain perception or life goals." [335] Thus, he concludes, patients can either "resist, submit to, or transcend suffering." [336] The latter involves acknowledging one's suffering head-on and then going beyond that point to "the part of the self that is not in pain and can still function and enjoy life."[337] Medical professionals' role in this process can be to act as the facilitator; to assist as much as possible the patient in moving along this "spiritual health spectrum" from spiritual despair to spiritual work to spiritual wellbeing.[338]

This study found medical professionals were hesitant about spirituality having a practical place within oncology care because the terminology associated with it (i.e. spiritual concerns or spiritual care) holds nuanced meanings for each individual and these may cause conflict. Furthermore, the language of spirituality and health care discourse for some participants were laden with religious connotations and this was a boundary they did not want to blur with their medical practice. This latter concern parallels Sloan et al.'s criticism of spirituality in health care;[339] but there is an important distinction that needs to be made between religious spirituality (which is what Sloan is criticizing) and spirituality which is broadly understood in medical literature. To cite Sulmasy's definition

> Spirituality refers to an individual's or group's relationship with the transcendent, however that may be construed. Spirituality is about the search for transcendent meaning. Most people express their spirituality in religious practice. Others express their spirituality exclusively in their relationships with nature, music, the arts, or a set of philosophical beliefs or relationships with friends or family.[340]

Although Sulmasy is writing in the U.S. context where religious affiliation is significantly higher than in New Zealand (where it is suggested that less than one in four New Zealanders

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[334] Hiatt, "Spirituality, Medicine, and Healing," 741.
[335] Ibid.
[336] Ibid.
[337] Ibid.
[338] Williams, "Perspectives on Spirituality at the End of Life," 415.
[339] Richard Sloan et al., "Should Physicians Prescribe Religious Activities?," 1913-1916.
[340] Sulmasy, "The Biopsychosocial-Spiritual Model," 25.

are religiously affiliated[341]), the latter half of the above definition seems to be more salient for individuals in this study. Spirituality is the broader term and religious spirituality (i.e. spiritual expression via a religious framework) is only one spiritual expression among many forms.[342] Current New Zealand trends suggest that as "religion becomes more and more privatized…the state [institutions]…become religiously neutral."[343] The medical professionals' desire to keep separate religious models and secular health care models exemplifies the depth of New Zealand's secular history. In order to progress forward in spirituality and health-related issues, clarity in definitional issues seems to be imperative; otherwise, patients' spiritual needs may be overlooked.[344]

4.6 Improving Spiritual Care

This study revealed that all four medical professionals recognize their own limitations in addressing patients' spiritual concerns and admit that there are probably occasions where patients' spiritual concerns are not being fully addressed in the clinical setting. Two nurses and two doctors specifically state that they suspect some patients' spiritual needs are probably not being met.

In spite of this, or perhaps because of this, medical professionals interviewed in this study rely on team work to provide optimum holistic care. This involves utilizing the strengths of other professionals in the hospital (or outside the hospital) such as counselors, social workers, chaplains, and so on, so that patients receive care that addresses all of their needs. Quinn supports professional team work recognizing that "each member of the health care team has an important part to play" [in] regards to addressing a patient's spiritual

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[341] Geering, "New Zealand Enters the Secular Age," 172.
[342] Puchalski and Ferrel, *Making Health Care Whole*, 24.
[343] Geering, "New Zealand Enters the Secular Age," 170.
[344] Dyson, Cobb, and Forman, "The Meaning of Spirituality," 1184.

concerns. [345] He concludes that this team responsibility should call physicians and nurses to be "even more alert to patients'…needs."[346]

Anandarajah says spiritual care "involves compassion, presence, listening and the encouragement of realistic hope and might not involve any discussion of God or religion."[347] This compassionate care is clearly present in the manner of care with which these four professionals practice; however, incorporating a spiritual assessment tool as part of the regular history assessment may be helpful in identifying more patients' spiritual needs, which it is thought by the medical staff may not be happening 100% of the time. Fosarelli's work reminds medical practitioners that "The healing art of medicine includes and goes beyond the science and takes into account what gives a person meaning: his or her loves, priorities, beliefs, fears, dreams, and questions." [348] This, it has been argued, is the essence of spirituality, and providing holistic care assumes that these important factors of the individual will be considered and addressed in their treatment plan.

The topic of spirituality and spiritual care in New Zealand health care is a newly emerging field of study. Egan, in 2009 conducted the first comprehensive national study of spirituality in New Zealand health services.[349] The study combined 24 in-depth interviews, with nationally disseminated surveys and an extensive literature review which together examined spirituality in end of life palliative care in New Zealand hospices. Egan's study concluded that the spiritual landscape of New Zealand was pluralistic and participants maintained a myriad of spiritual beliefs and understandings of spirituality. Further, spiritual care, was found to be inconsistent. On one side, it was exemplified in the empathetic, kind and compassionate nature of the staff; on the other side, spiritual care lacked structural

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[345] Quinn, "Spirituality in Cancer Care," Introduction.
[346] Ibid.
[347] Anandarajah and Hight, "Spirituality and Medical Practice: Using the HOPE Questions," 83.
[348] Patricia Fosarelli, "Medicine, Spirituality, and Patient Care," *The Journal of the American Medical Association* 300:7 (2008): 836.
[349] Egan, "Spirituality in New Zealand Hospice Care," ii.

consistency particularly relating to "spiritual assessments, staff support, training and policy."[350] The study herein supports Egan's findings and to reiterate a point he makes: these findings are not criticisms of the warm, kind, and wonderful staff interviewed "but a challenge to the whole organization."[351] This also echoes Puchalski's challenge that

> When a health care organization claims to embrace holistic care, which encompasses physical, mental, social, and spiritual care, it is making a moral commitment. The authenticity of organizational life will be judged in light of the expectations engendered by such a public commitment.[352]

Likewise, such institutional promises become even more salient in the context of Aotearoa New Zealand where government health strategies have sought to recognize, support, and protect Māori culture in light of the Treaty of Waitangi and bicultural approaches to health care policy and delivery.[353] These strategies seek to reflect and represent "New Zealand's dual heritage."[354] More specifically, bicultural approaches to health care services sought to expand the biomedical model of health and illness to include Māori perspectives. In doing so, the concept of health was redefined to include a "combination of social, cultural, economic, and political factors."[355] This includes cultural values and beliefs that, for Māori, taha wairua (the spiritual side) is generally considered to be imperative for health.[356] Thus, one cannot look at New Zealand health care without acknowledging how Māori participation in health services have revolutionized the New Zealand health care sectors and as a result, have redefined how health is perceived and understood.[357]

In summary, spiritual care is understood by the medical staff participants as giving patients their undivided attention and involves going to a different level *via* asking emotional questions that go beyond a patient's physical ailments. It was reported here that spiritual care, despite issues with the term itself, is delivered in a number of ways, as exemplified through

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[350] Ibid., iii.
[351] Ibid.
[352] Puchalski, *A Time for Listening and Caring,* 34.
[353] Durie, *Whaiora*, 85.
[354] Ibid., 119.
[355] Ibid., 94.
[356] Ibid., 70.
[357] Ibid., 87.

actions of compassion, empathy, and support. And finally, this section recognizes the importance of Māori contributions in expanding the concept of health from a biomedical model to a holistic model.

5 Conclusion

This thesis sought to explore and understand the role of spirituality in a New Zealand cancer care ward. A literature review supported this study and surveyed existing academic literature of three discourses: contemporary spirituality, spirituality in health care, and New Zealand cancer care. Contemporary spirituality was found to be pluralistic, dynamic, and discourse dependent. At its core, contemporary spirituality includes a subjective turn inwards, which partially is the result of a larger sociocultural trend towards deinstitutionalization characterized by a shift from institutional authority to individual authority. Themes in the social scientific literature purport that spirituality is deeply entwined with the individual's pursuit to find meaning and purpose in life; to find self-transcendence in this world through meaningful relationships with self, others, nature, or God, or in relationships with art, music, and science. Contemporary spirituality is often perceived to be the more broad term, consequently positioning religion(s) as one of the many forms of spirituality or spiritual expression.

Scholarly interest in the topic of spirituality and health care has witnessed a dramatic increase over the last twenty years in the U.S., over the last ten years in the U.K. and is recently becoming an important topic in New Zealand. In the context of holistic health care, which aims to meet the needs of the whole person, spirituality is clinically relevant and should be considered an important factor in health and illness. Much of the research in this area focused on patient spirituality and its effects on their health; thus, highlighting the need for more research that incorporates other important perspectives.

Māori perspectives have greatly influenced the expansion of heath concepts to include social, cultural, and spiritual aspects. Spirituality in New Zealand cancer care as a result is now recognized as an important component in government issued health strategies including the *New Zealand Cancer Control Strategy* (2003). This suggests it is not only an integral

component to Māori health, but to all New Zealanders who seek to maintain coherence, unity and purpose in the face of illness and disease, such as cancer. Research on the role of spirituality in New Zealand cancer care is minimal.

This study aimed to explore and understand this topic: first, by examining the literature and second, by interviewing the individuals who are involved in the cancer sector.

This qualitative study investigated the topic of spirituality in an oncology unit of a public hospital in New Zealand in order to gain a better understanding of what this means to health care professionals and the patients for whom they provide care. This study found that understandings of the terms involved in spirituality and health care varied, but commonalities did emerge. For some staff participants, the terms conveyed a religious undertone, which encouraged them to distance themselves from such topics. Interviewees thought the term spirituality included emphasis on relationships, holism, and six out of eight participants interviewed separated spirituality from religion. Medical staff perceived the spiritual concerns of patients to include difficult existential questions related to their illness. Thus, medical staff as well as the chaplain perceived spiritual care to involve responding to these questions and helping patients work out, as best they can, the answers to these questions or enabling them to find a sense of peace and acceptance with their illness. Spiritual concerns of patients ranged from reporting no spiritual concerns to family-related concerns to those of isolation and loneliness. Moreover, two patients reported that an initial spiritual assessment as part of a routine medical history would not have affected their treatment plan, but they add for other patients it may be important. Spirituality was perceived by participants to have an important role in cancer care, but in what ways and how it was important, varied among staff participants. Approaches to spiritual care varied among staff participants although themes such as teamwork, open communication, undivided attention and listening, emerged in the

interviews. Medical staff participants suspected that spiritual needs of some patients were probably not being met.

In New Zealand, a country that is becoming increasingly pluralistic, research on the topic of spirituality and health care, specifically cancer care is in its infancy. This study's findings demonstrated that spiritual concerns (or existential concerns) are not only triggered at the end of life but can be present at any time during the cancer experience. In addition, it may be argued that expanding the concept of working towards spiritual well-being as described in Williams' "spectrum of health" to all patients diagnosed with a serious illness could be beneficial.

Medical staff interviewed here expressed feelings that spiritual concerns of patients may be going unmet; therefore, education on spiritual literacy and spiritual care may prove valuable in reducing the number of patients whose spiritual concerns do go unmet. Furthermore, the value of education in spiritual literacy for medical professionals could help staff not only address personal biases they may have with the terminology, thus improving how they deliver holistic care to the individual; but also, it may validate the importance of considering the spiritual dimension as its own domain with unique needs that need to be met.

This study is based on a small sample size and focused on a single cancer ward. Furthermore, ethnic diversity among participants was minimal and key voices such as family members and caregivers were missing. To continue moving forward in the field of spirituality and health care these issues and those cited above, most notably, addressing issues of definitions and understandings of spirituality and spiritual care are in need of serious consideration. Thus, the grounds are fertile for further research to be conducted in New Zealand hospitals to improve upon these understandings of spirituality and spiritual care and their importance to health and illness.

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Appendices

A. Ethics Issues

University of Otago: This thesis was co-supervised by Richard Egan in association with the department of Preventive and Social Medicine. This department requires MA proposals to be passed through their Research Advisory Group. This group consisted of senior academics who reviewed the proposal for scientific rigor. I received a letter which approved the research project.

Lower South Regional Ethics Committee: I completed two drafts of the application form for this committee. This application process set the stage for the entire project. It called for detailed planning from Information Sheets, recruitment procedures, interview outlines to the final thesis write-up. In this process a Locality Assessment was included and permission granted from the hospital were participants were recruited.

Locality Assessments: A Locality Assessment was approved by the participating public hospital as required by the Lower South Regional Ethics Committee.

Confidentiality, Anonymity, Data Storage: All hard copies of interviews will be held in secure storage for the allotted time of ten years and then they will be destroyed as mandated by ethics requirements.

B. Information Sheets

Based on ethics guidelines, the information sheets followed a standard format; however, they differed slightly between groups (i.e. medical professional, patient or chaplain). A copy of the Participant Information Sheet for Patients is included below.

INFORMATION SHEET FOR PATIENT PARTICIPANTS
TITLE OF PROJECT: The Role of Spirituality in New Zealand Cancer Care

Thank you for showing an interest in this project. Please read this information sheet carefully before deciding whether or not to participate. If you decide to participate we thank you. 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 Project?

This project is being undertaken as part of the requirements of the Master of Arts in Religious Studies programme at the University of Otago.

The purpose of this study is to investigate, explore, and understand the role of spirituality in cancer care and more specifically, spiritual care in a public hospital oncology setting in New Zealand.

Research suggests that spirituality is an important aspect in providing well-rounded medical care, that it can be just as important as other medical procedures, and that it is under researched. By participating in the study you can contribute to broadening our understandings of the role of spirituality in cancer care and improving spiritual care for future patients with a diagnosis of cancer.

You have been invited to participate in this study because your experience as a patient with a diagnosis of cancer may provide deep insights regarding spiritual concerns and first-hand experiences of how they are addressed. The feedback provided, will, in turn, contribute to improving spiritual care for future patients with a diagnosis of cancer in New Zealand. You

have been approached to participate in this study because it is my understanding that your specialist has suggested the study to you.

What Will Participants Be Asked To Do?

Should you agree to take part in this project, you will be asked to take part in two, semi-structured interviews with the researcher (and an optional third meeting is possible if expansion or clarification is needed). The meetings will be conducted in English and at a time and location that is convenient for both researcher and participant.

The first interview, up to 30 minutes, will introduce you to the study and will provide an opportunity for questions and concerns to be addressed. If you agree to participate, you will be given the Consent Form to sign and the second interview will be set up.

The second meeting will consist of an in-depth interview and will last up to one hour. The interview is semi-structured in that I will have specific topics that I will want to address, but it is up to you how and in what way this will go. A third meeting is optional if either the patient or the researcher needs clarification or expansion on a particular topic that was addressed in a previous interview.

Potential Benefits and Risks

While this interview is not intended to be therapeutic, the benefits for participants in this study may include personal growth as the interviews will call for individuals to reflect on their lives; a copy of the interview which may be shared with family members (if your consent is given); and the opportunity to contribute to a study that may benefit future patients with a diagnosis of cancer by improving the spiritual care they receive during treatment.

The researcher is aware and sensitive to the fact that participants will be sharing their personal stories and at times, such experiences may generate a range of emotions on the part of the participant which may be positive, negative, or both. To help ease any potential stress, the researcher will provide a list of professional contacts and services to address any

particular concerns that may arise during the interview. The hospital chaplain is aware these interviews are happening and is available if needed. And if undue stress ensues the participant can withdraw from the study at any time without any consequence.

Can Participants Change their Mind and Withdraw from the Project?

Yes. You may withdraw from participation in the project at any time and without any disadvantage to yourself of any kind.

What Data or Information Will Be Collected and What Use Will Be Made of It?

Topics to be addressed during interviews include: your personal spiritual concerns and thoughts on spirituality; how you express these concerns; your experience with spiritual care; opinions on spiritual care; ways that you make sense of your diagnosis; coping methods used during your cancer experience; and suggestions of ways to improve spiritual care within a hospital oncology unit. The Lower South Regional Ethics Committee has sighted the broad scope of questions to be asked of participants.

For research purposes your interviews will be recorded and transcribed and a copy of the audio-recording and/or transcription will be offered to you. In addition to this, all participants will have the opportunity to review the transcript before final reporting to make corrections or omit portions they do not want included in the findings.

The results of the project will be published and made available in the University of Otago Library (Dunedin, New Zealand) but every attempt will be made to preserve your anonymity.

You are most welcome to request a copy of the results of the project should you wish.

The data collected will be securely stored in such a way that only those mentioned below will be able to gain access to it. At the end of the project any personal information will be destroyed immediately except that, as required by the University's research policy, any

raw data on which the results of the project depend will be retained in secure storage for ten years, after which it will be destroyed.

Reasonable precautions will be taken to protect and destroy data gathered by email. However, the security of electronically transmitted information cannot be guaranteed. Caution is advised in the electronic transmission of sensitive material.

What If Participants Have Any Questions?

If you have any questions about our project, either now or in the future, please feel free to contact either:

Lisa Knitter, MA student researcher   or   Erica Baffelli, Ph.D, Lecturer
Department of Religious Studies   Department of Religious Studies
Telephone: 03 479 8516   Telephone: 03 479 8516
Email: knili005@student.otago.ac.nz   Email: erica.baffelli@otago.ac.nz

Richard Egan, Research Fellow,
Department of Preventive and Social Medicine
Telephone: 03 479 7206
Email: richard.egan@otago.ac.nz

This study has been approved by the Lower South Regional Ethics Committee.

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: (03) 479 0265;
Freephone 0800 37 77 66;
Freefax 0800 2787 7678 (0800 2 SUPPORT) or
Email advocacy@hdc.org.nz

Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.

C. Consent Form for Participants

As mandated by ethics guidelines the consent form was read, clarified if necessary and then

signed by all participants. This process was consistent with each participant. A copy of the

Consent Form is below.

CONSENT FORM FOR PARTICIPANTS

PROJECT TITLE: The Role of Spirituality in New Zealand Cancer Care

I have read the Information Sheet concerning this project and understand what it is about. All my questions have been answered to my satisfaction. I understand that I am free to request further information at any stage.

I know that:-

1. My participation in the project is entirely voluntary;

2. I am free to withdraw from the project at any time without any disadvantage;

3. Personal identifying information (audio recording) will be destroyed at the conclusion of the project but any raw data on which the results of the project depend will be retained in secure storage for ten years, after which they will be destroyed;

4. I understand that this project involves an open-questioning technique. The general line of questioning includes topics related to spirituality- in the broadest sense of the term- and cancer care. In the event that the line of questioning develops in such a way that I feel hesitant or uncomfortable, I may decline to answer any particular question(s) and/or may withdraw from the project without any disadvantage of any kind.

5. I understand that there may be some risk involved due to the emotionality of the topic and that sensitive issues may arise; but I am aware of my right to decline to answer any question and that professional help is available to me if needed.

6. I understand there are no monetary or in-kind benefits from participating in this study.

7. The results of the project may be published and will be available in the University of Otago Library (Dunedin, New Zealand) but every attempt will be made to preserve my anonymity.

I agree to take part in this project.

....
       (Signature of participant)   (Date)

This study has been approved by the Lower South Regional Ethics Committee. If you have any concerns about the ethical conduct of the research you may contact the Committee Administrator by phone at 03 474 8562. Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.

Version No. 3
24 Aug 2009