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Spirituality and Spiritual Changes
in People Living with Dying

A thesis

submitted in fulfilment

of the requirements for the degree

of

Masters of Arts in Psychology

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by

Deidre du Toit



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Abstract

This study investigated spirituality and the spiritual changes people living with dying may experience. The study was based on a phenomenological perspective where the centrality of the participant's personal worldview and experiences was highlighted. Data was gathered through open and semi-structured interviews with three participant groups: health care professionals working in palliative care and hospices, people who had experienced a serious or life-limiting health condition, and the caregivers of terminally ill patients. Interviews were recorded and transcribed verbatim. A thematic analysis approach was used to analyse the data. The findings showed a diversity of spiritual understandings and suggested that participants understood neither religion nor spirituality in exactly the same manner. The analysis revealed that some participants used religion to describe their understandings of spirituality. Some participants regarded the terms 'spiritual' and 'religious' as synonymous while for others the terms were conceptually independent. Participants used a variety of definitions to describe spirituality. These primarily involved regarding spirituality as a belief in a God or a higher being, or as a relationship with or connection to a God or higher being. Participants also viewed spirituality either in terms of the human spirit or soul and its continued existence into an afterlife, or in terms of mysterious events and the paranormal. Findings further revealed that many people living with dying described periods of gradual spiritual growth, or sudden and unexpected spiritual transformation: however, not all people reported spiritual changes. These findings imply that people may have a dominant spiritual perspective through which they understand experiences. Identification of these perspectives in clinical settings

may make it possible to tailor spiritual support resources according to individual spiritual perspectives. However, further exploration of the different spiritual perspectives is suggested as different groups may have different spiritual needs.

Acknowledgements

I would like to express my sincere gratitude to the participants of this study. I appreciate your generosity and willingness to share your stories with me. I hope my analysis of your stories reflected their unique nature.

I wish to convey my deep thanks to my research supervisors. Dr Neville Robertson, your input, advice and thoughtful comments during this study has been invaluable. Dr Tess Moeke-Maxwell, our conversations helped me to see things from a different perspective, you drew my attention to ideas I might otherwise have overlooked.

Last but definitely not least I would like to extend my warmest thanks to my family. Stephen, Dominique and Donovan, for travelling this journey with me and always believing I could do it. To my mum, Marilyn, and sisters, Adele and Karene, thank you for your ongoing interest and encouragement.

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Chapter 1: Introduction

All people live with the knowledge that they are eventually going to die.

However, to live with a life-threatening illness involves, among other things, dealing with the unavoidable finitude of life (Faber, Egnew, & Faber, 2004).

During the progression of an illness the patient and their family members are challenged to continue daily life while confronting the unpredictability of life and death (Carol, 1985). For all those involved this may be a period in which spirituality becomes increasingly important (Grant et al., 2004; Kernohan, Waldron, McAfee, Cochrane, & Hasson, 2007; Okon, 2005). Patients and family members are frequently just as distressed by spiritual matters as by physical pain, which can impact on various dimensions of patient care and well-being, including treatment decisions, emotional distress and depression (Grant et al., 2004).

However, research aimed at examining individual in-depth experiences of spirituality and spiritual changes at the end of life is lacking.

Spirituality can be a source of peace and stability. However, it is not a fixed state and can act as a powerful source of change (Pargament, 2006). Significant stress and trauma, such as awareness of one's death, illness and healing, mystical experiences and near-death experiences can be antecedents to spiritual change or transformation (Cotton et al., 2006; Ironson, Stuetzle, & Fletcher, 2006; Lancaster & Palframan, 2009; Lutz, Kremer, & Ironson, 2011; Rambo, 1993; Samuelson, Fromme, & Thomas, 2011; Shaw, Joseph, & Lindley, 2005). Little attention has been paid to the specific domain of spiritual change. In fact, contemporary scholars specifically encourage research into the understanding of changing spirituality and spiritual needs (Benore & Park, 2004; Murray et al., 2007;

O'Rourke, Tallman, & Altmaier, 2008). Expanding knowledge and awareness of possible spiritual routes may help to anticipate times when patients and families experience greater spiritual distress during illness. For example, within the New Zealand palliative care setting, both patients and relatives have been found to experience spiritual and or existential turmoil after initial cancer diagnoses (Egan, 2009). Grant et al. (2004) call for proactive ways to prevent or reduce spiritual distress at the end of life. Expanding knowledge and awareness of the spiritual changes people living with dying may experience, as well as understanding the mechanisms that cause and intensify spiritual change, is necessary to the delivery of effective end-of-life care.

The introduction of spiritual health care to the palliative care setting in New Zealand is in its infancy (Egan, 2009). As part of an integrated support approach, those affected by life-threatening illness in New Zealand are offered spiritual holistic care to promote hope and well-being (Ministry of Health, 2001).

However, the spiritual needs of people receiving treatment and care in cancer services frequently go unmet (Ministry of Health, 2008). The following factors may be contributing to this. Firstly, insufficient resources such as spiritual care policies, guidelines, assessment tools and funding for spiritual care experts are available. Secondly, communication factors may contribute to these needs being unmet. In 2008, the Ministry of Health reported that some patients are unaware of spiritual help that may be available, patients do not know who they can call on for spiritual help, and health care providers may not know how to access professionals who provide spiritual care. Thirdly, health care professionals may be hesitant to request spiritual support services or to talk openly about spiritual matters to patients (Ministry of Health, 2008).

Statement of Purpose

The broad aim of this thesis was to investigate spirituality and spiritual changes in people living with dying. This qualitative study explores the spirituality of the 'living with dying' experiences of patients through the eyes of their health care professionals and their caregivers. Spirituality is also explored from the vantage point of people who have experienced life-threatening illnesses.

Although it is widely recognised that spiritual transformations happen and that they can have extreme consequences, there have been few scientific studies conducted within this area. A further aim of this study was to explore the spiritual changes that people living with dying may experience. More specifically, the current study seeks to fill a gap in existing knowledge by investigating the possible causes and consequences of spiritual changes in people living with dying and what these changes mean to them.

Phenomenology

Given the importance of spirituality to individuals during times of stressful life events and while facing death, it is essential to understand what spirituality means to a diverse group of New Zealanders. This study takes a phenomenological perspective where the centrality of the participant's personal worldview and experiences is highlighted (Starks & Trinidad, 2007). By allowing participants to express their own views on spirituality, the researcher's awareness of the lived experiences of the participants will increase. In this way the voices of participants can be heard while common features may be captured (Moran, 2000; Starks & Trinidad, 2007). Phenomenological studies seek to understand the meaning and commonalities of an experience, as it is lived (Laverly, 2003). From a

phenomenological point of view, participants are regarded as the expert on their own spirituality, and therefore, any way in which they express their spirituality is valid (Lavery, 2003; Moran, 2000; Starks & Trinidad, 2007; Wilson, 2010).

A person's perception of spirituality can fundamentally depend on their worldview (Moran, 2000; Wilson, 2010). A religious person may be more likely to experience their spirituality as intimately attached to God, whereas a person with no religious affiliation may perhaps experience spirituality through nature. However, most individuals tend to have their own subjective as well as objective understandings and interpretations of the world. For example, two Pentecostal Christians may have different ways of cultivating their relationship with God. Subjective views of the participant can be identified by letting their voices be heard (Moran, 2000; Wilson, 2010).

Position of the researcher

The act of research is subjective and value laden and it is becoming common practice for researchers to shed light on their role in their research and their personal motivation for embarking on the study (Patton, 2002). As is increasingly recognised by qualitative researchers, I was not detached from the research but closely involved with the participants and the analysis of data. I took on the role of the learner, not the expert and regarded each participant as the expert on their own spirituality. However, I did not enter this study as a *tabula rasa*; my worldview, my previous experiences and current knowledge on the subject came into the research with me. How I studied, analysed and presented spirituality was related to my worldview and how I understand the nature of reality. In the following section I will discuss what sparked my interest in this topic and

comment on my personal and academic understanding of what spirituality is in order to explain my own position, which may have influenced the study. I will also make explicit the twin roles I occupied during this study, firstly as a researcher and secondly as a hospice volunteer.

I have always been interested in human behaviour, particularly in the psychology of religion. Nobel Laureate ethologist (behavioural biologist) Niko Tinbergen argued that in order to fully understand any behaviour, four questions about that behaviour should be asked: these questions are referred to as the four questions of Tinbergen (1963):

1. Evolution: What is the behaviour's phylogeny (evolutionary history)?
2. Ontogeny: What is the development of the behaviour over the life span of an individual?
3. Causation: What are the causes of this behaviour?
4. Survival Value: Is the behaviour an adaptation? Does it have any specific survival value?

Causation and ontogeny are proximate mechanisms; what the behaviour is composed of. Survival value and evolution are ultimate mechanisms; the purpose of the behaviour. Tinbergen's questions act for me as a conceptual lens through which I view my interest in human behaviour as well as this study.

My interest in this topic arose while attending a course on Death and Dying presented by Professor Glynn Owens at the University of Auckland. Professor Rod McLeod presented a guest lecture, introducing Hospice New Zealand. During the lecture he pointed to the importance of spirituality in lives of people with serious illness and those facing death. He introduced an analysis by Australian

palliative care specialist, Doug Bridge, which shows the changing priorities, particularly the increased importance of spirituality, for those approaching death. Figures 1, 2 and 3 illustrate these shifting dynamics. However, Bridge (2009) points out that the view of doctors during the course of a patient's illness remains mainly focused on medical issues (Figure 4).

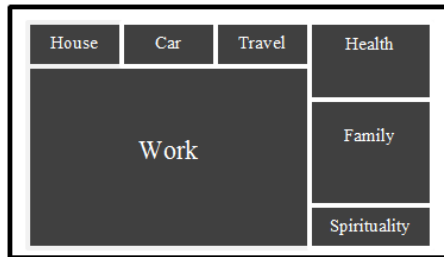


Figure 1. The healthy person's world

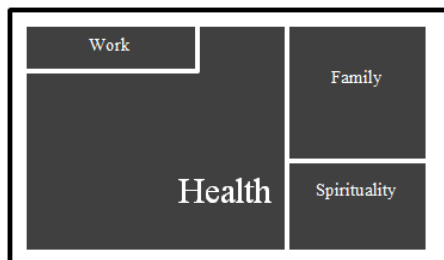


Figure 2. The sick person's world

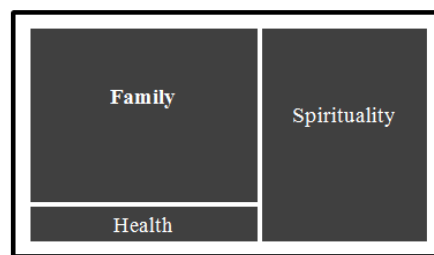


Figure 3. The dying person's world

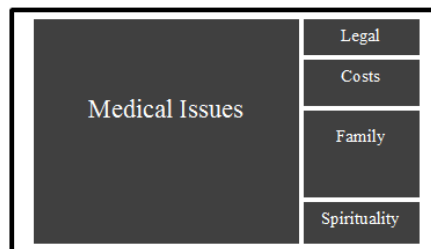


Figure 4. Doctor's view of a dying patient.

Immediately a multitude of questions came to mind. I started wondering why and when these changes in spirituality started to occur. Was it because of a fear of death, of non-existence? The uncertainty of what follows death? Were the changes in priorities and spirituality even fear-based at all? Then followed the next line of thought; what exactly changes for these people? Do they become more religious? Do they develop an interest in Eastern philosophies? What is spirituality?

At that time I felt too uncomfortable to ask what the word 'spirituality' referred to during the lecture, as I thought that I might be the only person in the lecture who was unable to fully articulate the term. My initial response to the word 'spirituality' was to relate it to Western religion and Eastern philosophies like Buddhism and Taoism. The notion of spirituality brought to mind images of monks mediating in temples and shamans reaching altered states of consciousness to interact with the spirit world. After researching spirituality and spiritual changes within the health care sector, I learned that the word 'spirituality' is indeed vague and fuzzy and difficult to pin down. Research into spiritual changes, which were not directly related to religion, religious conversion or de-conversion, was sparse. Professor Owens gave me the encouragement I needed to attempt this study.

During this study I have occupied twin roles: that of the researcher and also of a hospice volunteer. As a hospice volunteer I provide family support for the families of dying patients. I also work in the in-patient unit where I assist with lunch and afternoon teas. I take patients for walks when appropriate and sit with patients who are lonely, anxious, and fearful or those who might like company. I

attend and participate in hospice volunteer training sessions on a regular basis. I have found myself to be an observer but also a participant in the experience of people living with dying.

I am not religious. I do not believe in the existence of deities or that we will ever be able to answer the question as to whether deities or higher powers exist or not. I believe in the 'here and now' and make an effort to fill my life with meaningful relationships and activities. Although I am not religious and do not call myself spiritual, I accept that unseen realities are very real and meaningful for others who have such beliefs. The interviews with participants made me deeply appreciate how each person's constructed reality is real and true to them.

Outline of Thesis

This chapter outlined the thesis topic and the rationale for undertaking this study. It provided a brief description of phenomenology, the philosophical viewpoint from which the study was conducted, and presented the aims of this study.

Following this introduction, Chapter 2 presents a review of the literature relevant to this study. This chapter consists of three sections: a) an assessment of spirituality in the health care context with particular reference to palliative care; b) spiritual changes and transformation; and c) spirituality and religion in a New Zealand. In Chapter 3 I describe the methodology used in the present study and important ethical issues. In chapter 4 I outline the findings and analysis of this study. Lastly, in Chapter 5 I conclude the thesis with a discussion of the implication of the findings of this study, the limitations of the study and I suggest avenues for future research.

This study presents an opportunity to examine religious and spiritual phenomena and to explore the nature of spiritual changes as experienced by participants. This may not be an easy task. As Rambo (1993) suggests, it is “difficult to understand, predict, and control that which is generally invisible to the outsider, mysterious and sacred to the insider.”

Chapter 2: Literature Review

Investigating Spirituality

Spirituality in the health care sector is recognised as an essential part of delivering holistic care and meeting the spiritual needs of patients (Dyson, Cobb, & Forman, 1997). Until now the spiritual dimension of human life has remained poorly defined. Defining such a complex and subjective phenomena is “not a simple task” (Coyle, 2008, p. 1) and definitions are vague and fuzzy (Kaut, 2002; Zinnbauer et al., 1997).

Over the past 20 years, research on spirituality in the health care context has questioned whether holistic care can be provided properly without a clear definition of what spirituality is. As far back as 1997, Dyson and colleagues stated that “the assessment and meeting of those needs is impeded by inadequate definitions and conceptual frameworks” (Dyson et al., 1997, p.1183). Years later, scholars are still concerned about the vagueness of the definition: “The confusion surrounding the definition of spirituality challenges the delivery of spiritual care and by the same token that of holistic palliative care” (Vachon, Fillion, & Achille, 2009, p.53). To deliver proper spiritual care, especially in the context of dying, there needs to be a closer look at what spirituality means, not only from the philosophical viewpoint of researchers or medical professionals, but also from patients’ and family viewpoints (Kaut, 2002). Knitter (2010) pointed out that these key voices are currently also overlooked in New Zealand health care research.

Why is spirituality difficult to define?

Spirituality has been studied from a variety of disciplinary perspectives including nursing, medicine, psychology, anthropology, sociology and psychology. It is also a common topic in palliative care literature. Consensus on a definition of spirituality still eludes researchers because of the influence of the diversities of worldviews and different intellectual traditions from which spirituality is studied, leaving the definition open to various interpretations – intellectual, cultural and religious – resulting in a cacophony of definitions (Salander, 2006; Speck, 2005; Westerink, 2012). Contemporary spirituality has become a “chameleon - changing colour depending on the foliage within which it sits” (Sheldrake, 2010, p. 367).

One of the main obstacles to defining spirituality is its relationship with religion (Dyson et al., 1997; Sinclair, Pereira, & Raffin, 2006). The term ‘religion’ has stayed relatively stable over the past decades. Religion is generally associated with organised systems, beliefs, worship, and rituals to establish relationships with a god or gods (Koenig, 2008; Sinclair et al., 2006). On the other hand, the concept of spirituality is evolving and has changed considerably over the past few decades (Koenig, 2012). Smith and Denton (2005) described these changes

the very idea and language of ‘spirituality,’ originally grounded in the self-disciplining faith practices of religious believers, including ascetics and monks, then becomes detached from its moorings in historical religious traditions and is redefined in terms of subjective self-fulfilment (p.175).

Accordingly, Hufford and Bucklin (2006) argue that the technical redefinition of the term spirituality through academic discourses causes lexical complications, misunderstandings and stigmatisation of the term as the lay person understands it.

The relationship between religion and spirituality

The nature of the relationship between spirituality and religion is difficult to pin down (La Cour & Hvidt, 2010; Sinclair et al., 2006; Swinton, 2012). Typically, researchers agree that religion and spirituality are interconnected concepts, but not necessarily synonymous. In the health care literature a limited number of studies focus solely on spirituality. Many studies focus on religion as a form of spirituality, especially research conducted in the USA (Dyson et al., 1997; Swinton, 2012). There is irregularity in the use of the two terms; religion and spirituality are often used interchangeably or synonymously (Balboni et al., 2011). However, using these terms interchangeably may disguise the notion that different levels of religious faith and spirituality may exist. To add to the complexity, some authors differ on which concept is the broader one, religion or spirituality. Breibart (2007) stated that spirituality encompasses religion; therefore spirituality is the greater concept. Others argue religion is the greater concept and that any concept of the spirit or existential questioning originated inherently from religion. Some authors distinguish between spirituality and religion when introducing the concepts: however, a “religious undertone” (Salander, 2012, p. 19) is evident in many articles. The inconsistency in the use of the two terms may suggest a similarity in the defining features of each.

In contrast to the studies mentioned above, where religion is seen as a part of spirituality or where spirituality includes religion but does not expand beyond it, there is also a growing trend of separation between the two concepts (Swinton, 2012; Tanyi, 2002). With the reduced influence of Christianity within Western societies and the evolution of new forms of religion and spirituality, a shift in the spiritual discourse is increasingly noticeable, which is also evident within

palliative care discourses (Cobb, Dowrick, & Lloyd-Williams, 2012; Egan, 2009). Religion, in this context, is characterised within the strong confinements of organised religious institutions. A contemporary phenomenon is that people tend to move away from the confinements of organisational religious institutions to attain their spiritual ideals. People are increasingly describing themselves as 'spiritual but not religious' (Marler & Hadaway, 2002; Saucier & Skrzypińska, 2006). Sinclair and colleagues asserted that certain scholars in the field of spirituality within healthcare are apparently attempting to set spirituality free from religious restraints (Sinclair et al., 2006). Contemporary literature in the spirituality-religion-health inquiry defines spirituality in a very broad and inclusive manner. Common spiritual descriptors include beliefs, connections, transcendence, relationships, meaning and purpose, and values (Egan, et al., 2011; Tanyi, 2002; Vachon et al., 2009, p. 21). The main focus of spirituality in contemporary clinical settings is on subjective forms of belief, meaning and purpose, which leans towards a more existential philosophy (Cobb et al., 2012).

The existential search for meaning can be explored through the religious, secular and spiritual domains (La Cour & Hvidt, 2010). Therefore, one cannot assume that only spiritual people make meaning and find purpose in life (Koenig, 2008). While an existential search seems to be one of the main characteristics of spirituality, existentialism itself is not the same as spirituality (Hill, et al., 2000). It seems that increasingly researchers are starting to conflate the terms spirituality and existentialism (Krikorian, Limonero, & Maté, 2012; Ross & Austin, 2013). Salander (2006) argued that existential questions of meaning are being placed in the spirituality discourse where they are not appropriate and do not belong.

Although research and literature that address spirituality in a health care context continue to contribute to the already established wealth of information in this area, the opposing content of research, as discussed above, may be counterproductive to the field (La Cour & Hivdt, 2010). When these different traditions oppose or disregard each other, possibilities to for understanding spirituality from people's subjective experiences and multi-layered existences may be reduced (La Cour, Ausker, & Hivdt, 2012).

The Sacred

A number of researchers suggest that what distinguishes spirituality from other existential quests is its connection to, or orientation toward, the sacred (Cobb et al., 2012; Hill et al., 2000; Koenig, 2012). These researchers offer a more explicit definition, placing the sacred or the divine at the core of spirituality. Hill and colleagues stated that "when the term 'spirituality' is invoked to describe ideologies or lifestyles that do not invoke notions of the sacred in one way or another, they are not spiritualities at all, just strongly held ideologies or highly elaborated lifestyles" (Hill et al., 2000, p. 64). As an example, Hill and colleagues used vegetarianism. Some people may be vegetarian because they are against cruelty to animals, or they may focus on health benefits associated with vegetarianism. In such cases vegetarianism is an ideology. However, some practitioners understand their vegetarianism in connection to the sacred: for example, some may feel that it is not necessary to take the life of any creatures for food. For such people vegetarianism is an extension of their spiritual practices. Then it is appropriate to refer to vegetarianism as spiritual.

Spirituality can also be perceived as "a search for the sacred" (Paragment, 2006, p. 12). Koenig (2012) is of the same opinion and stated that a distinction can be

made between spirituality and all other things since spirituality has a connection to that which is sacred. The sacred includes that which is holy “concepts of God, the divine, and the transcendent,” but it is not limited to notions of higher powers (Pargament, 2006, p. 12). A study conducted by Zinnbauer and colleagues reflects these viewpoints. In their study, 346 participants scripted their own definitions of religiousness and spirituality (Zinnbauer, Pargament, & Scott, 1999). For the sample as a whole, religiousness and spirituality were defined in significantly different ways, while the nature of the sacred was generally described similarly. Religion was associated with organisations, in particular organised rituals and behaviours relating to religious organisations. Participants also described religiousness as a personal belief in and commitment to a God or Higher Power, while spirituality was described in terms of a personal connection sensed with a higher power. Participants described the nature of the sacred as the traditional Christian concept of God, a transcendent being or nature. The addition of a sacred element into descriptions of spirituality is beneficial, because it indicates that spirituality can occur inside and outside of organised religion.

The Immaterial and Supernatural

An apparent uneasiness seems to exist among academic scholars with regard to the immaterial and supernatural connotations associated with the term spirituality (Hufford & Bucklin, 2006). Spiritual practices that are not exclusively in the domain of God are generally absent from the spiritual and health research literature. For example, spiritual healing techniques are rarely discussed in academic journals. One such Japanese spiritual healing practice is Reiki. The word Rei means ‘God's Wisdom or the Higher Power’ and Ki is the ‘life force energy’. So Reiki is essentially ‘spiritually guided life force energy’ (Rand, 2011).

Therefore the universal energy that is available can be channelled by healers to the benefit of their clients (Bishop, Barlow, Walker, McDermott, & Lewith, 2010). Bishop and colleagues conducted a qualitative study investigating the effects of Reiki treatments on cancer patients. Participants felt that after receiving Reiki treatments they could cope better with illness symptoms, without changes in the symptoms themselves. Participants reported sleeping better, as well as having more energy to perform valued activities. They reported positive changes in self-efficacy, relationships, and overall well-being. The findings of this study indicate that spiritual healing methods may have positive outcomes for cancer patients. A small number of people with serious health conditions such as cancer make use of spiritual healing practices to complement modern medical therapies.

Recently, Vaccarino, Kavan and Gendall (2011) from Massey University in Auckland surveyed 1027 New Zealanders, representative of a wide spectrum of society. They aimed to get a better understanding of New Zealanders' religious and spiritual beliefs, practices and experiences. The survey was based on the International Social Survey Programme questionnaire. They found that 39 % of their respondents believed in spiritual healing while 44% believed in religious miracles. Additionally, their research showed that spiritual beliefs are associated with experiential encounters (Vaccarino et al., 2011). The experiences and beliefs described indicate a more complex, "social world of the spirit" (Hufford & Bucklin, 2006, p. 31) than is currently addressed in contemporary literature. It suggests that belief in an unseen spiritual world is an important part of the domain of spirituality and is often overlooked by contemporary scholars.

Spiritual measures

Instruments used to measure spirituality in health care have come under heavy criticism from various scholars who suggest that spirituality is often measured and defined as positive psychological states and existential quests (Koenig, 2012; Moreira & Koenig, 2006). Measurement of the concept of spirituality presents some problems. One example is the Functional Assessment of Chronic Illness – Spiritual Well-Being Scale (FACIT-SP) (Peterman, Fitchett, Brady, Hernandez, & Cella, 2002). This tool is used widely in quantitative studies as a measure of spirituality. It contains statements such as: ‘I know whatever happens in my illness things will be okay,’ ‘I feel peaceful’ and ‘I have a reason for living.’ Koenig (2008) notes that it is not surprising that spirituality, measured in this way, will correlate with good mental health. Casey (2011) concurs and considers these statements to be measures of positive psychological states. Hence any study utilising these measures will find a strong positive relationship between spirituality and positive psychological states.

Koenig (2008) also heavily critiqued the conflation of spirituality and existential well-being. The Spiritual Well-Being Scale consists of 20 items, 10 of which assess existential well-being and 10 of which assess religious well-being. However, these scales make use of general psychological well-being constructs, posing questions such as ‘I feel that life is a positive experience’ and ‘I feel that life is full of conflict and unhappiness’ (reverse scored) (Koenig, 2008). Some researchers are questioning the way in which the use of positive psychological states and existential quests are considered spiritual measures (Casey, 2011; Paley, 2008; Salander, 2006). Positive states and quests may equally well be the cause or effect of spirituality (Koenig, 2008).

Universality of Spirituality

The concept of spirituality in health care has been critiqued as being without parameters, which risks losing the core meaning of the word (Casey, 2011; Moreira-Almeida & Koenig 2006; Salander, 2012). Broad definitions of the concept imply that spirituality is an inclusive concept, not linked to any religion or denomination. By utilising wide-ranging definitions, “organisational needs within health care” (Walter, 2002, p. 134) may be simplified. Because of the wide-ranging definitions, it is acceptable for a non-religious person to provide spiritual care to the religious, or for staff of a particular religion to provide spiritual care to a patient with another religion. However, in doing so the term spirituality may be

transformed into a sort of giant conceptual sponge, absorbing an extravagant and seemingly boundless range of matters from humanism, personal well-being, Jungianism, Buddhism, ecology, art and poetry, contemplation of nature, hope, politics, work environment connectedness, and many more” (Paley, 2008, p. 5).

Spirituality in health care is has often been “universalised” (Paley, 2008, p. 5) and is understood as something everyone possesses and experiences. Many researchers claim that all humans have spiritual needs, even though they may not recognise them per se (Narayanasamy, 1999; Reed, 1992). The concept of spirituality is subjected to a “stretch dynamic” (Paley, 2008, p. 5) and is being over-extended, until it exists in all individuals. This kind of ‘stretching’ is noticeable in statements such as:

If spirituality is defined only synonymously with religion and a belief in God, then several persons, namely the atheists, agnostics, humanists and hedonists, would be excluded from the possibility of using spiritual coping mechanisms. Therefore, spirituality applies to both believers and non-believers (Baldacchino & Draper, 2001, p. 835).

Some researchers dispute the universal nature of spirituality and argue against the assumption often taken in palliative care literature, that everyone possesses a “spiritual dimension” (Walter, 2002, p. 2). The idea of spirituality as a universal concept is especially opposed in modern secular countries like those in Scandinavia, where only a small minority of people call themselves spiritual (La Cour et al., 2012; Salander, 2012). Surveys conducted in England (King et al., 2006) and Australia (Hilbers, Haynes, & Kivikko, 2010) also found that not all people consider themselves to be spiritual. The following distinct groups were discernible:

1. Religious but not spiritual
2. Spiritual but not religious
3. Spiritual and religious
4. Not spiritual and not religious

In New Zealand the same groupings were recognised (refer to Figure 5). The Massey International Social Survey Programme (Vaccarino et al., 2011) revealed:

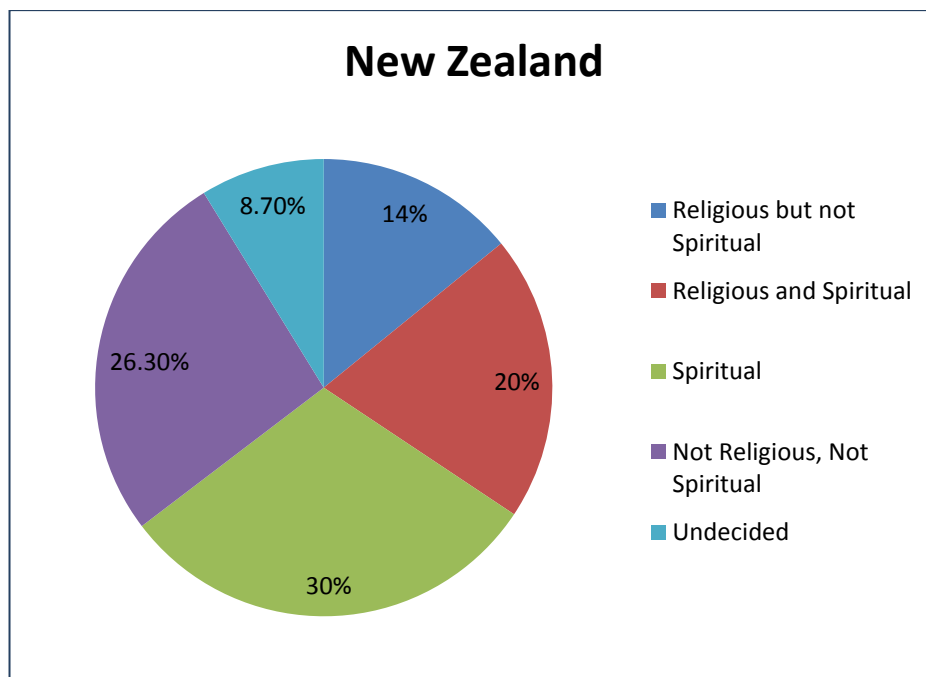


Figure 5. Religious and spiritual self-description of a New Zealand sample based on the Massey International Survey Programme

King and colleagues (2006) suggest that the group ‘not spiritual and not religious’ is currently not being studied in empirical research projects and should be studied as a distinct group. Such proposed studies would enable researchers to make comparisons between different categories of beliefs regarding spirituality. For example, the harm and benefits of religion and spirituality in all groups could be studied in order to understand more about spirituality.

This literature review and other studies (La Cour et al., 2012; Mc Sherry, Cash, & Ross, 2004) suggest that the concept of spirituality in health care may not be universally recognised. Studies from Scandinavia (Ingelhart, 2009), Australia (Hilbers et al., 2013) and New Zealand (Vaccarino et al., 2011) suggest that not all people consider themselves to be religious or spiritual therefore spirituality cannot be seen as a universal phenomenon that is shared by all individuals (La Cour et al., 2012; Linderman, Blomqvist, & Tadaka, 2012; Salander, 2006).

Spiritual changes and transformation

As mentioned in the introduction, spirituality is often defined as a source of peace and stability; “a force of conservation” (Pargament, 2006, p. 16). However, spirituality can also be a powerful source of change (Pargament, 2006).

Historically, much of the attention psychology gave to the association between the sacred and deep-seated human change was focused on religious change (Pargament, 2006). The topic fell out of favour as scientists became critical of radical religious transformation. However, in recent years scholars have reignited interest in religious transformation through conversion, and in the broader concept of spiritual transformation (Pargament, 2006).

Similarly to spirituality, spiritual transformation is a wide-ranging concept studied from multi-disciplinary approaches. Spiritual transformation has been defined in a number of ways. Some definitions focus strongly on changes in religious beliefs, attitudes and behaviours (Schwartz, 2000). The term religious conversion is often used interchangeably with spiritual transformation. In a religious context spiritual transformation typically occurs within three areas: (1) as an intensified devotion within the same religious structure; (2) a change from no religious commitment to a devout religious life; or (3) a change from one religion to another (Schwartz, 2000).

Pargament (2006) defines spiritual transformation in a much broader, culturally non-specific fashion as “a fundamental change in the place of the sacred or the character of the sacred in the life of the individual” (p.18). For example, in the archetypal religious conversion situation the place of the sacred in the life of an individual may change from a self-centred to a God-centred position. Religious conversion can also apply to another religious denomination or a completely

different religion. Spiritual change may also occur away from religion, to a more “universal concern” (Pargament, 2006, p.18). The character of the sacred in the life of the individual may, for example, change from a punitive to a loving God. Similarly, Hill (2001) also focused spiritual change on the sacred but oriented more towards meaning making as a motivation for spiritual transformation “the process of change within the self, frequently accompanied by strong feeling toward an identity with something sacred through which meaning is discovered” (p.89).

Contemporary researchers agree that spiritual transformation is not the consequence of a single cause. This study will follow contemporary researchers such as Lutz, Kremer, and Ironson (2011) who indicated that spiritual transformation is associated with dramatic changes in spiritual beliefs along with major changes in behaviours, self-view, and attitudes.

Spiritual growth and spiritual decline

Tedeschi and Calhoun (2004) criticised the focus that psychology and medical literature place on traumatic events that result in negative psychological or physical complications. The positive psychology movement sparked interest in well-being and resiliency, creating a shift of focus to positive personal growth after stressful or traumatic events, known as post-traumatic growth (Joseph, Linley, & Harris, 2005; Linley & Joseph 2004; Seligman & Csikszentmihlyi, 2000).

Spiritual change has been identified as one domain of post-traumatic growth (Tedeschi & Calhoun, 1996). Accordingly, spiritual transformation consists of two elements; positive changes known as spiritual growth and negative changes

known as spiritual decline (Tedeschi & Calhoun, 1996). Spiritual growth following a diverse range of traumatic events has been widely reported. For example, many cancer patients experience spiritual growth and enriched spiritual lives throughout their cancer journeys (Cordova, Cunningham, Carlason, & Andrykowski, 2001).

Literature on spiritual transformation seems to focus largely on spiritual growth. However, spiritual changes are not always positive. Spiritual decline represents a departure from one's widely held spiritual worldview, sense of self, behaviours and beliefs.

A New Zealand study conducted by Sibley and Bulbulia (2011) in the wake of recent earthquakes in New Zealand compared the growth and decline of religious faith over a two year period between people affected by the earthquakes and those not affected. The study showed that people who did not have faith before the earthquakes and who were affected by the earthquakes were more likely to increase their faith or accept faith (start believing) compared to the rest of New Zealand. Additionally, people who lost their faith reported lower levels of well-being than the rest of the population who were affected by the earthquake.

During times of traumatic and stressful life experiences not all people necessarily report undergoing spiritual changes. Spiritual transformation was recently explored in a group of individuals who had experienced traditional spiritual healing. Participants reported different levels of spiritual change, from spiritual decline, to no spiritual change, medium to moderate spiritual changes and profound spiritual changes. Spiritual changes reported in this study were mainly behavioural changes such as bible reading, prayer and meditation. However,

some participants reported changes in mood and feelings of belongingness in the context of a spiritual realm (Mehl-Madrona, Mainguy, & Valenti, 2013).

Scholars have called for more research into post-traumatic changes involving religion and spirituality (O'Rourke et al., 2008). Ironson et al. (2006) indicated a specific need to investigate decreases in spirituality to establish possible relationships between spiritual decline and biological matters. The present study responds to this by exploring spiritual changes within the context of death and dying.

Spirituality and Religion in New Zealand

Given that this study was undertaken in New Zealand and considering the ongoing cultural transmission and interrelationships that exist between Māori and Non-Māori cultures it is important to acknowledge some historical matters, particularly the colonisation of Māori, which influenced the spiritual landscape of New Zealand greatly.

Before European settlement in New Zealand the ontology of Māori held that there was a connection between the spiritual world and the natural world. Wairua – spirituality as defined by Māori worldviews - is conceptualised as a “fundamental factor for Māori that knows no boundaries” (Valentine, 2009). Spirituality permeates all that Māori do and it affects all facets of life. The spiritual dimension is understood by Māori to be “one’s capacity for faith and wider communion and acknowledges that health is related to unseen and unspoken energies” (Durie 1998, p. 69). Valentine (2009) found that interpretation of the term wairua fell into four categories: “descriptions, experiences, beliefs and Māori world views” (p. 131). Valentine (2009) further described that Wairua exists within and between

Māori, the elements and their environments. Wairua is a necessary aspect of life and being. Wairua enables a person to relate to themselves, others and their environment. Wairua is connected to Māori people's ability to understand and know the world (Valentine, 2009). This highlights the span and complexity of Māori spirituality and how it completely embraces Māori life and culture.

In the 19th century, European (mostly British) missionaries arrived in New Zealand. They intended to convert Māori to Christianity and to introduce what they perceived as a more civilised, western way of life. Even though many Māori converted to Christianity during the early years of colonisation they did not simply abandon their traditional spiritual beliefs. Māori accepted elements of Christianity into their existing world-view. They merged seemingly contradictory essential Māori expressions and values with the Christian gospel, allowing a more inclusive perspective. Many Māori joined mainstream Christian churches. Christianity continues to be important for many Māori today. In the 2006 census 57.2 per cent of Māori identified with the Christian religion (Statistics New Zealand, 2006).

Cultural background influences understandings of health and well-being (McNeill et al., 2010). In contrast to western definitions where health is usually seen as the absence of illness (Capstick, Norris, Sopoaga, & Tobata, 2009), Māori perceive health from a unique perspective of interconnections (Durie, 1998; Ministry of Health, 1997; Shaw, Tyacke, Sherrard, Hikuroa, & Corbett, 2010). Spirituality has long been recognised by Māori as an integral component of an individual's being and an essential part of good health and well-being, "without a spiritual awareness and a mauri (spirit or vitality, sometimes called the life-force) an individual cannot be healthy" (Durie, 1998, p. 70). The most often-utilised Māori model of

health used to explain this holistic approach is Te Whare Tapa Whā (Durie, 1998). In this model, health is metaphorically represented by a four-sided house. Te Whare Tapa Whā includes four sides (taha); tahawairua (spiritual), tahahinengaro (emotional and mental), tahatinana (physical), and tahawhānau (social). A characteristic of this model is that the taha (sides) are connected and each taha delivers support and strength for the others. In order to address Māori health, each taha is equally important for overall well-being. If one wall is weak or out of balance the house loses its equilibrium (Durie, 1998; Ministry of Health, 2002). Such an imbalance can cause a disturbance in the connections between the walls and result in illness, the opposite of well-being (Durie, 1998; Ministry of Health, 2002). Connectedness is very important in the Māori world view because a deceased person's spirit remains in the space between the physical world and the spirit world (Durie, 1998). Māori typically experience the spiritual presence not only of their recently deceased loved ones, but also of their ancestors, enabling them to develop a sense of connection with the past. In addition, history is a central factor to Māori culture and is a way to find understanding of the present by looking back into the past (Moon, 2003).

Furthermore, for Māori, palliative care usually is a sacred encounter (Campbell, 2011). Even though the word 'palliative' may be novel, the concept of palliative care has been part of Māori culture for many generations. "To Māori the word palliative means aroha, awhiri, manaaki, awhina and karakia. These are values we have been taught as we were growing up and this still is an essential part of our make-up" (Campbell, 2011, p.19).

Spirituality and religion in contemporary New Zealand

New Zealand is becoming more secularised (Vaccarino et al., 2011) and classical secularisation theory posits that due to growing modernisation, religion has become unbelievable and questionable for many people, resulting in the decline of religious practices and membership of religious organisations (Graham, 1992; Ward, 2004). Even though secularisation refers to the exit of religion from structured institutions, it does not necessarily imply the end of belief (Heelas, 2006; Ward, 2004). Beliefs change and religious beliefs appear to be evolving rather than dissolving (Webster, 2001). Within societies in the Western World it seems that Christian views are slowly moving away from conventional Christian practices (Heelas, 2006). There seems to be a veering from a need for an authority from without, or ‘church without’, to a more intrinsic authority from within the person, the ‘god within’ (Heelas, 1996; Heelas, 2006; Schnell, 2012).

Identifying as a Christian in New Zealand appears to be declining; New Zealand census data from 1991-2006 showed a steady decline in Christianity and other religious practices in New Zealand, while the ‘Other Religion’ and ‘No Religion’ categories have shown a reasonable growth (Statistics New Zealand, 2006). These interpretations are based on the 2006 New Zealand census and may be obscured by changes made to the census forms. The ‘other’ and ‘no’ religion options were only recently added to the census forms.

A significant body of literature indicates that there is evidence of a spiritual evolution; new forms of religion and spirituality that are more personal and less formal (Cobb, et al., 2012; Coyle, 2008). This spiritual evolution can be observed with the emergence of more Pentecostal churches, where the authority rests on personal conviction of events and the Holy Spirit rather than on tradition.

In New Zealand there is growth evident in Evangelic, Pentecostal and Fundamentalist Christianity as well as within Māori Christianity. New forms of Christianity in New Zealand are reflected by the increase of mega and micro-churches (Lineham, 2003).

Mega-churches are mostly Pentecostal, which is also the fastest growing Christian denomination in New Zealand since the 1980's. The Pentecostal religious movement relates to any "Christian denomination that emphasises the workings of the Holy Spirit, interprets the Bible literally, and adopts an informal demonstrative approach to religious worship" (Merriam-Webster Dictionary, n/d). A well-known example of a mega-church is the Destiny Church which appeals to many city-dwelling Māori (Lineham, 2003).

Micro-churches, in contrast, are relatively unstructured, intimate groups of individuals who meet on a regular basis to build friendships, share meals and have meaningful conversations and discussions, in a relaxed atmosphere. This allows members of a micro-church to experience freedom to function as an autonomous community, sometimes within a larger church community (Knox Waitara, n/d).

In Māori Christianity a renewal of interest has been experienced specifically in the Ringatu and Ratana churches due to the attraction of new-agers with indigenous spiritualities (Vaccarino et al., 2011). Māori spirituality is also increasingly noticeable in New Zealand with prayers and rituals displayed in community and national events (Vaccarino et al., 2011).

In addition there also appears to be a growing trend toward Eastern religions and New Age spiritual groups in New Zealand (Vaccarino et al., 2011). There is an

explosion of Hindu, Buddhist, Muslim, Jewish and Sikh identification evident in New Zealand.

The Massey International Survey Programme (Vacarino et al., 2011) mentioned before, revealed that although there seems to be a general decline in the practice of traditional religion in New Zealand, religious and spiritual beliefs are still important to many New Zealanders. The results of the survey indicated that:

- 37.8 % of the respondents believed in a personal God
- 45.2% of the respondents had found their own personal approach of connecting with God without religious observance
- 39% of the respondents encountered a spiritual experience of something larger than themselves
- 57% of respondents believed in the afterlife
- 39% believed in horoscopes according to star signs
- 38 % believed that fortune tellers can foretell the future.

These results suggest that many New Zealanders acknowledge that there is more to existence than the material world. As Ward (2004) states, New Zealand is not a culture of unbelief.

Spirituality in the New Zealand Healthcare Context

As part of an integrated support approach, people in New Zealand who are affected by life threatening illness are offered spiritual holistic care to promote hope and well-being (Ministry of Health, 2001). The importance of spirituality is signposted in various health-related organisations (such as Hospice) and in government strategies to support end-of-life care (Ministry of Health, 2001). However, research on spirituality in New Zealand health care context is in its

infancy (Egan, 2009). The Ministry of Health (2008) has recommended that professional awareness of the spiritual needs of people affected by cancer should be raised. To address spirituality and the spiritual needs of patients with terminal cancer in hospices in New Zealand, Egan (2009) conducted a mixed methods study. He conducted 52 interviews followed by a quantitative survey based on the findings of the interviews. Egan's research highlighted the importance of spirituality to patients with terminal cancer, a finding that is echoed throughout health care literature. In addition, his study demonstrated that the understanding of spirituality in the New Zealand hospice milieu was diverse. These various understandings were thematically grouped into three definitional categories:

Firstly, religious responses: a few participants conflated the concepts of religion and spirituality. They had a sense of faith which was clearly communicated within their strictly religious worldviews. Other participants saw religion as a manifestation of spirituality. In addition, some participants believed spirituality was about the unknown, a non-physical aspect the "mysterious, metaphysical and paranormal or even 'spooky'" (Egan et al., 2011, p. 10). This extra-ordinary aspect of spirituality was mentioned by religious and non-religious participants. Other participants appeared to have anti-religious inclinations and specified that spirituality was a completely different concept to religion.

Secondly, humanist or existential responses: within this category participants associated spirituality with concepts such as beliefs, ethics, values, essence, core well-being, identity, integration, and aesthetics.

Thirdly, summative responses: Many participants offered a variety of religious and existential expressions to define spirituality that did not match a specific category. These were regarded as the summative responses. A very descriptive

example to illustrate such a wide-ranging understanding of spirituality was provided by Damion, a spiritual carer.

[it] embraces the essence of what it means to be human. It is concerned with personhood, identity and meaning and purpose in life. The spirit holds together the physical, psychological and social dimension of life (Egan et al., 2011, p.12).

Egan indicated that most participants held broad understandings of spirituality, as exemplified in Damion's quote. In general, the main spiritual descriptors used by his participants were "values, meaning, purpose, beliefs and often in relational and faith terms" (Egan et al., 2011, p. 17). Taking these categories into account Egan offered a summative working definition of spirituality to delineate the contours of the spiritual discourse in New Zealand:

Spirituality means different things to different people. It may include (a search for): one's ultimate beliefs and values; a sense of meaning and purpose in life; a sense of connectedness; identity and awareness; and for some people, religion. It may be understood at an individual or population level (Egan et al., 2011, p. 17).

Egan's research, the first of its kind in New Zealand, made a substantial contribution to the spiritual care literature. The present study aims to add to the New Zealand knowledge base of spirituality in the health care context by giving patients and caregivers a voice.

Despite an abundance of quantitative literature concerning spirituality in the health sector, qualitative studies still remain uncommon. The voices of people who are living with life-limiting illnesses and their caregivers within the spirituality and health care context are generally absent and qualitative research in this area is lacking. Within grief literature Pilkington (1993) argued that it is through understanding grief that service providers can effectively support the

bereaved. Hence, within palliative care, to ensure patients, caregivers and the bereaved are provided appropriate spiritual care and support, it is also imperative that spirituality is clearly understood. It is therefore important to keep in mind the uniqueness of the diverse views people have about spirituality, religion and the association between them. The many meanings attributed to the term spirituality and the different ways people consider themselves to be spiritual need to be recognised (Zinnbauer et al., 1999). McSherry and Cash (2004) stated that we should accept that the word spirituality has different meanings. It is therefore important to ask people what they think about spirituality, which this study will address.

Chapter 3: Method

The broad aim of this study was to investigate spirituality and the spiritual changes people living with dying may experience, using qualitative research methods. Data was gathered through in-depth interviews across health services sectors and included: health care professionals who worked in the field of death and dying; caregivers who cared for their loved ones during a life-threatening illness; and people who had personally experienced a serious health condition. Following one of the principles suggested by Carr (2008), this study used a multiple perspective approach within a single study. This approach has only been used in a small number of studies investigating spirituality, however, there is huge potential to gain a “more complete understanding of the phenomenon” (Carr, 2008, p. 686) by using this approach.

Qualitative Research

Qualitative research is a group of techniques used to collect and analyse data where researchers strive to learn more about “*how* the social world is interpreted, understood, experienced, produced and constituted” (Mason, 2002, p.2). The goal of qualitative research is the development of ideas, theories and concepts which expand our understanding of social phenomena as they occur in their natural settings (Pope & Mayes, 1995). Qualitative methods use “words rather than numbers to describe findings” (Owens & Payne, 1999, p. 148) while drawing attention to experiences, understandings and meanings through the eyes of the participants (Silverman, 2011; Steinhauser & Barroso, 2009). Qualitative

researchers explore relatively unknown phenomena that are challenging to express in a quantitative manner (Steinhauser & Barroso, 2009).

Researchers have employed qualitative research in a wide range of areas related to death and dying. For example, in her book, *On Death and Dying*, Kubler-Ross (1997) employed qualitative research to explore the experiences of dying patients. This resulted in her five-stage model of coping with death, which included the stages of denial, anger, bargaining, depression and acceptance. Spirituality has successfully been studied qualitatively in the health care context to explore topics such as the spiritual needs of cancer patients (Grant et al., 2004) and spiritual changes in patients suffering from HIV (Cotton et al., 2006). Murray et al. (2007) used qualitative research techniques to capture a comprehensive understanding of illness experiences in patients with heart failure and lung cancer. They identified and compared social, psychological and spiritual changes within and between their two participant groups (Murray et al., 2007).

Sensitive and complex topics such as spirituality, especially in palliative care settings, are best studied via qualitative research because of its emphasis on the understanding of meaning (Seale, 2001; Patton, 2002). Discovering or finding a single truth about death and dying, and for that matter spirituality, would be a “hopeless task” (Owens and Payne, 1999, p. 157). The best researchers can do is find ways to understand the subjective understandings of people and the social meanings of events related to death and dying. In studies relating to death and dying, finding ways to support the dying patient and caregivers are of greater value than trying to find the presumed *truth* about the dying process (Owens &

Payne, 1999). Qualitative research clearly emphasises meaning and this made it most appropriate to this study.

Participants

Because of the exploratory nature of this study, three different groups of participants were included to gain information from a wide range of backgrounds and perspectives. The first group consisted of health care professionals in the area of Palliative Care and hospice; counsellors (2), nurses (2) and volunteer workers (3). The second group consisted of individuals who had personally experienced a life-threatening illness (3). The third group consisted of caregivers to family members or loved ones who suffered from a serious or life-threatening illness (3). The study involved participants from one hospice.

The experience and observations of health care professionals were important to this study since health care professionals have knowledge of a range of patients from various backgrounds within palliative care. As a result, it is highly likely that they may have noticed themes emerging in different patients and families. People who had experienced a serious health condition were interviewed to gain a first-hand understanding of their spirituality and any spiritual changes they may have encountered.

The third group, the caregivers, who were not initially included in this research study, were subsequently included following the suggestion of a participant to include further perspectives of spiritual changes experienced by the family members of those who were dying and those who took care of them. Caregivers were not professional health care workers, but had had “very intense” experiences through having cared for dying family members. A review of literature suggested

a lack of studies investigating caregivers' personal spirituality and needs. As a result this new group was added to the study and additional ethical approval for the inclusion of this group was gained. Exploring the caregivers' stories provided a valuable perspective not only into the spirituality of the dying person, but also into the spirituality and unmet needs of caregivers.

Recruitment and Access to Participants

Participants were accessed through more than one recruitment and sampling method to keep a sampling bias to a minimum (Stroebe, Stroebe, & Schut, 2003). Criterion sampling, where specific factors are utilised to identify participants (Patton, 2002), was the first sampling method used. Inclusion criteria for the three participant groups were as follows: health care professionals - experienced staff members with some knowledge of spiritual care; participants who had personally experienced serious health issues - to have suffered from a life-threatening health condition; caregivers - being a caregiver to a person suffering a serious health condition. The study was inclusive of participants over the age of 18 who were free from cognitive dysfunction and included people with diverse gender and sexual orientations, ethnic and religious backgrounds. Although inclusive of Māori, no Māori participants self-selected to be involved in the study.

Three recruitment methods were employed. Firstly, health care workers were recruited through my supervisor, Tess Moeke-Maxwell's palliative care contacts. Secondly, hospice volunteer workers were recruited through a hospice volunteers coordinator. She emailed a diverse group of volunteer workers with background and information related to the current study. Letters of invitation (Appendix A) and information sheets (Appendix B) were included in initial emails. Those interested contacted me directly. Lastly, participants who had experienced a

serious or life-threatening health condition, and caregivers, were recruited through social networking and snowball sampling. Snowball sampling, where participants provided information on gaining access to additional participants (Patton, 2002; Streeon, Cooke, & Campbell, 2004), was very effective in accessing additional previously hidden participants (Miller & Brewer, 2003).

Participant Demographics

Thirteen individuals were recruited to participate in this research study. Several participants shared their individual stories from multiple perspectives. For example, some participants were both counsellor and patient; retired nurse and hospice volunteer worker, or patient and volunteer worker. Therefore the number of perspectives (17), are greater than the number of participants (13). Medium-sized samples such as this allow in-depth information to be retrieved (Patton, 2002).

All participants recruited were women, with ages ranging between 41 and 76. In terms of ethnicity, seven participants identified as New Zealanders, three as Dutch, two as South African and one as Scottish. Several participants were Christian within the following specific denominations: Catholic (2), Pentecostal (2), Presbyterian (2), and Latter Day Saints (2). One participant was a Messianic Jew. The remaining participants did not affiliate themselves to any religious organisation.

Interviews

The method for data generation was in-depth, semi-structured, one-on-one interviews. Semi-structured interviews were viewed as discussions (Mason,

2002) or “conversations with a purpose” (Burgess, 1984, p. 102) because of the informal style used during these interviews.

Semi-structured interviews are meaningful in exploratory studies as they give awareness into participant perceptions, experiences, views, understanding, knowledge and interpretations (Mathieson, 1999; Mason, 2002). In health psychology semi-structured interviews are regularly utilised to explore the transition from health to illness in patients, including, for example, changes in relationships before and during an illness (Mathieson, 1999).

Preparation

Preparation for an interview played a major part in the outcome of an interview and required rigorous and thorough planning (Mason, 2002). Consideration was given to personal, technical and especially ethical and moral issues (Egan, 2009).

Because of the sensitive nature of the content and since “the researcher intruded into the private sphere or delved into some deeply personal experience” (Lee & Renzetti, 1990, p. 513), I revisited moral and ethical issues constantly throughout this research study (before, during and after interviews). What each individual regarded as private and personal was unique, not only cross-culturally, but also between individuals. Conversely a particular topic may not have been regarded as highly personal but it may still have been emotionally charged (Lee & Renzetti, 1990). The study also touches on what most participants deem sacred and all information was treated with the greatest respect and care.

The Interview

Prior to the interviews I emailed potential participants a copy of the information sheet (Appendix A) and the consent form (Appendix B), which facilitated informed consent and allowed all potential participants to study the merits of the proposed study in their own time (Parkes & Prigerson, 2013).

Interviews were conducted at a location convenient to both the participant and me. Interviews were generally held at the participant's home while two interviews took place at my house and two more interviews were conducted at the University of Waikato.

At the beginning of the interview, I provided background information about myself and any additional information deemed necessary about the study. At this time I also provided hard copies of the information sheet and consent forms to help participants familiarise themselves with the interview expectations, structure and content. Potential participants had the opportunity to ask any questions regarding the project, informed consent and confidentiality issues. Once the individual agreed to participate, informed consent was obtained.

I recorded the interviews digitally, with the permission of the participants.

Interviews lasted from 45 minutes up to 2 hours. During the interviews I listened intently, made notes of the non-verbal language and avoided giving my opinion unless the participant asked for it.

I used an open-ended approach to data collection; questions were flexible and individualised answers were encouraged (Mathieson, 1999). To be able to capture the participant's viewpoint I created a general interview guide (Appendix E) as

suggested by Lofland (1974), and I did not ask the questions in any particular order. In addition, I provided the participants with plenty of time to share their stories and experiences in their own words. This allowed for in-depth information on what participants perceived as important (McCracken, 1990). I asked additional questions, tailored to participant's stories, to explore interesting themes relevant to the research study. Although I reminded the participants that there was no right or wrong answer and that they did not have to follow strict question guidelines, some participants preferred to be asked questions and often asked if "we are on track." During these interviews I followed the interview guide more closely. While I did not use a formal structure during the interviews, interviews generally included introductory questions, more specific questions and some closing questions as suggested by Suzuki (2002).

I asked introductory questions to put the participant more at ease and to create an environment where participants felt safe and comfortable. During this phase of the interview I asked the participants to share more about themselves, where they grew up and how they ended up working in the area of palliative care or why they had chosen to become a volunteer. Interestingly, most participants introduced religious and spiritual histories during this 'getting to know each other' phase of the interview.

Following that I asked specific questions about spirituality - for example: "*what is your definition of spirituality?*" During the course of the study, I conducted interviewing and analysis simultaneously with the aim of exploring emerging themes in subsequent interviews. For example, during the first two interviews

both participants commented that spirituality was a decision an individual makes. This theme was then explored further in all the other interviews.

During the interviews I aimed to learn more about what the participant's definition of spirituality was and according to that definition, I asked questions about their spiritual experiences, in particular whether they had experienced any changes in their spirituality or observed any spiritual changes in patients or family members they cared for.

The interviews ended with closing questions where the participant had the opportunity to reflect on the interview and raise any other issues that they considered important but had not been covered during the interview. I shared key findings with those participants who were interested.

Reflective Diary

Immediately after the interview I reflected on the interview, firstly by recording initial thoughts about the interview digitally, making notes and documenting findings in a research journal. In addition, I recorded and answered the following questions, suggested by Silverman (2011), in a reflective diary:

- Where did the interview occur?
- Under what conditions?
- How did the participant react to the questions?
- How well did you ask the questions?
- How was the rapport?
- Did you find out what you wanted to?
- If not, what was the problem?

- What emerged out of the interview?
- Did it go okay?

Transcription

I transcribed the interviews, verbatim, noting emotional responses, tone of voice and pauses. To check accuracy I read each transcript while at the same time listening to the related recording and immediately correcting mistakes. Following this, formal analysis of the data began.

Analysis

The overall aim of the analysis was to deliver a rich thematic explanation of the complete data set. Thematic analysis was used to discover, analyse and report themes in the data (Braun and Clark, 2006). One of the benefits of using thematic analysis is that it is reasonably manageable and straightforward (Braun & Clark, 2006). Additionally, it can provide the groundwork for the development and improvement of skills in the beginner researcher (Braun & Clarke, 2006).

Important considerations when doing a thematic analysis include:

- inductive versus deductive thematic analysis
- a rich description of the entire data set versus a detailed account of one particular aspect
- the level at which themes will be analysed; latent or semantic (Braun & Clark, 2006). These matters are discussed in more detail below.

Thematic analysis can be inductive (linked to the data), or deductive, which is theory driven. This study was built on principles from the inductive approach.

Data was collected purposefully for this study and the focus was on the participants' own experiences. Some of the themes that were identified did not reflect on any of the research questions. As recommended by Braun and Clark (2006), I tried not to look for themes dominant in current spirituality discourse during the analysis. However, initial codes originated not only from participants' responses but also from my existing understanding and theoretical knowledge. Based on this, I cannot claim that the themes identified during the analysis emerged totally from the data alone.

Furthermore, this analysis took a semantic approach. The themes were identified from the "explicit or surface meanings of the data" (Braun & Clarke, 2006, p. 84). This stands in contrast to analyses at the latent level, where the researcher identifies a deeper meaning to what the participants expressed in order to ascertain underlying philosophies or ideas. Because this study was concerned with the participants' personal and extremely private experiences and views on spirituality, I decided to analyse at the semantic level and not to "put words into the mouths" of the participants, read too much or too little into what they shared and thereby influence the outcome of the study. Using a semantic approach, themes are identified within the surface meaning of the data. I did not analyse further than what the participants contributed. This however does not mean the analysis was only at a descriptive level where data is merely organised to point out and summarise patterns (Braun & Clark, 2006). With the semantic approach one's analysis goes further than the descriptive level. There is an effort to speculate over the broader meanings and effects of the patterns.

Formal analysis, guided by the work of Braun and Clark, (2006) began by reading and re-reading each transcript carefully while interesting and seemingly important features in the data were highlighted. Interview data was coded line by line.

Initial codes, which described the main idea of the line or segment, were identified by making notes in the margins of the transcript.

Next, initial codes were recorded on index cards as suggested by Rennie, Phillips, and Quarto (1999). The index cards were then arranged into more abstract groups depending on the meaning and content of the code. The common meaning that glued initial codes into a unit was defined and constituted a basic theme.

Initial codes were not restricted to one group but were allocated to different groups if justified. This process was completed for each individual transcript; after a while no new categories emerged from the data, known as saturation (Chenitz & Swanson, 1986; Strauss & Corbin, 1998). When saturation was reached, themes were compared within each transcript and between transcripts in the data set.

Some basic themes appeared to have many links to other basic themes. Others did not have many links and these were then collapsed into existing themes. Basic themes were then categorised and further abstracted into broader themes.

Particularly valuable during this analysis was the use of initial and developed thematic maps as suggested by Braun and Clark (2006).

Ethical Considerations

To maintain ethical standards the research design and methods used in this study were approved by the Psychology and Research Ethics Committee of the School of Psychology, Waikato University. Ethical guidelines were based upon the New Zealand Psychological Society Code of Ethics.

The purpose and value of this research, description of the study design, safety issues for both the participants and researcher, and social and cultural issues were covered in the ethical application. Of particular importance were cultural and social issues, minimising harm and discomfort, informed consent and privacy and confidentiality, which are discussed below.

Cultural and Social Issues

The cultural and social backgrounds of participants in this study varied significantly. I respected the cultural and religious knowledge, values and practices of all participants while having an awareness of my own cultural values, beliefs and practices. I also reflected on how my personal biases (as discussed in the introductory chapter) might impact on others and the outcome of the interviews.

Minimising Discomfort and Harm

This study is inherently sensitive and the subject of spirituality and dying may potentially be disturbing to some people. Talking about sensitive and personal experiences may possibly be upsetting to some participants and may highlight issues they have not thought of in a long time or even never thought of before. Having a support person present during the course of the interview was encouraged. Contact numbers for loss and grief support organisations (Appendix D) were provided at the end of each interview in case participants needed to talk about issues discussed during the interviews. Participants were contacted via phone or email after their interviews to thank them for their participation and to find out how they were. Murray et al. (2009) found that patients and family members were able and willing to talk about death, dying and other sensitive

matters. In fact, patients reported that they found it easier to talk to a researcher rather than a medical professional about sensitive matters. Blinderman and Cherny (2005) reported palliative care patients may in fact benefit from the experience and they enjoyed the opportunity to discuss existential and death-related issues.

Informed Consent

Participation was on a voluntary basis. Clear information about the nature of the research study was provided. In addition, participants had ample time to consider whether they wanted to participate in the study or not. A letter of information (Appendix A) and consent forms (Appendix B) were provided to participants via email prior to their interviews. At the beginning of each interview, procedures related to the research were discussed. This included the aims, transcription procedure, the way information might be used in future and the participant's right to withdraw at any time. Informed consent was obtained after the participant understood all facets of the research and was still willing to participate.

Privacy and Confidentiality

Privacy and confidentiality of all participants was protected throughout the research process. As suggested by Kaiser (2009) I took great care to collect, analyse and report data without compromising the identities of the participants. During data collection, assurances of confidentiality were given verbally and via statements related to confidentiality on information sheets and consent forms. Transcripts and digital copies of the interviews were kept in a secure file on my personal computer. An additional set of copies was secured on a USB drive and is

locked away in a cabinet my house. No one other than I has access to the information that is linked to participant's names.

All personal identifiers were removed to generate a clean data set that contained no information which could potentially identify participants (Kaiser, 2009).

Names of participants, people and places mentioned during the interview were replaced with pseudonyms. All participants had the opportunity to choose their own pseudonym.

Even after changes in names and places have been made, a unique combination of characteristics can still be used to recognise a participant, especially if the participant has lived through unique life events (Kaiser, 2009). Therefore, I scrutinised examples and quotations used in the write-up of the findings to ensure participants could not be identified through deductive disclosure.

Summary

This chapter reviewed the aims of the research; identified the research methods used to collect and analyse the data; provided information on participant recruitment and demographics; and emphasised the ethical considerations concerning interviewing participants in the context of living with dying. The qualitative research paradigm was deemed the most appropriate way to gather data for the current study. The following two chapters outline the research findings, which are then discussed in relation to the existing body of knowledge. These chapters are followed by the concluding chapter, (Chapter 5).

Chapter 4: Findings

In Chapter 4 I explore participants' understanding of spirituality and how spirituality changes for some people while living with dying. This chapter is divided into five sections. In the first section I restate the importance of the relationship between spirituality and religion as mentioned in the literature review. I introduce key findings of this study and present the Diversity of Spirituality Model I have created to demonstrate the variety of understandings of spirituality. In the second section I discuss the concept of spirituality as synonymous with religion. In the third section I examine spirituality and religion as distinct concepts. In the fourth section I look at how participants related their spiritual experiences to Māori spirituality. Lastly, I discuss the importance of spirituality and religion in the lives of people living with dying.

Introduction

To gain a clear understanding of the term 'spirituality' in the context of living with dying, participants were asked what they understood spirituality to mean. No information about spirituality was provided prior to participants being interviewed. Analysis showed a major theme that emerged from the data analysis was that of religion. During our conversations about spirituality all participants reflected on religion. In fact, religion was the first issue most participants brought up when starting to discuss spirituality, which suggested that they drew on religion as a baseline from where spirituality could be described. It is true that all participants were brought up in a Judaeo-Christian background, therefore approaching spirituality from a religious context might not be surprising.

However, to understand spirituality in such close relation to religion is not uncommon (Pargament, 1999; Sinclair et al., 2006; Zinnbauer & Pargament, 2005).

Following the participants' dialogues, I drew on religion as a point from which to launch this discussion. As mentioned in the literature review, the relationship between spirituality and religion is hard to pin down. Some authors emphasise a single spiritual perspective, giving the impression that a particular spiritual viewpoint is superior to other perspectives. For example, some claim that religion encompasses spirituality. They argue that the concept of spirituality was historically derived from religious traditions (Hall, Koenig, & Meador, 2004) and that spirituality is shaped by religious experience and a relationship with a God (Taylor, 2003). Any notion of the spirit or existential questioning thus originates inherently from religion. In contrast, authors like Breibart (2007) maintain that spirituality encompasses religion and that "religion is only one of the many forms of spirituality" (Sinclair et al., p. 467). There is also a growing tendency to separate the two concepts (Swinton, 2012). Tanyi (2002) called for a distinction between the two concepts, arguing that "humans' search for meaning and purpose in life may be lost due to adherence to religious practices and beliefs" (p. 502). However, the polarisation of these two concepts may create an impression of 'bad religion' and 'good spirituality' which should be avoided (Pargament, 1999; Zinnbauer et al., 1999). Although some have begun to separate the concept of spirituality from that of religion, Pargament and Mahoney (2002) view spirituality as the most central function of religion—to facilitate the search for the sacred. In addition, many scholars define spirituality as meaning, purpose, values, beliefs, hope, emotion, connectedness, and existential philosophy. In terms of

relationships it may apply to a relationship with the self, others or the environment and, for some, a transcendent being (Egan, et al., 2011; Tanyi, 2002; Vachon et al., 2009). The use of such broad definitions of spirituality means that the concept of spirituality may be

transformed into a sort of giant conceptual sponge, absorbing an extravagant and seemingly boundless range of matters from humanism, personal well-being, Jungianism, Buddhism, ecology, art and poetry, contemplation of nature, hope, politics, work environment connectedness, and many more” (Paley 2008, p.5).

Salander (2006) poses the question “Who needs the concept of ‘spirituality’?” He states that spirituality as it is defined in health care settings is a redundant concept because it refers to positive psychological traits and existential questions of meaning and purpose which can be addressed by psychologists.

Opposing perspectives in studies such as those discussed above may be counterproductive to the field of spirituality in the healthcare setting (La Cour & Hivdt, 2010). When these different traditions oppose or disregard each other, possibilities for understanding spirituality from people’s subjective experiences and multi-layered existences may be reduced (La Cour, et al., 2012). As advised by Zinnbauer et al. (1997) it is important for researchers and clinicians to recognise the different ways people refer to spirituality.

The diversity of academic viewpoints mentioned above was represented by the spiritual perspectives participants reported in this study. The findings of this study revealed that in relation to religion, spirituality was understood by some participants as synonymous with religion, while others saw it as distinct from religion. In cases where spirituality was understood as being synonymous with religion, two broad spiritual perspectives emerged. The first spiritual perspective

was that of participants who applied a theistic dialogue to describe spirituality.

These participants belonged to religious organisations, practiced religion actively and understood spirituality within the clear borders of religious organisations.

The second spiritual perspective was that of participants who applied a non-theistic dialogue to describe spirituality. These participants did not consider themselves to be religious. They did not belong to any religious organisations and were not active in any religious or spiritual activities.

In cases where spirituality was understood as being distinct from religion, two more perspectives were identified. The first was that of participants who applied a theistic dialogue to describe spirituality. These participants were religious; they belonged to religious organisations, without active involvement. Such ‘spiritual and religious’ participants understood spirituality and religion to be interdependent yet complementary concepts. Lastly, using largely non-theistic dialogue to describe spirituality were the spiritual but not religious participants. They understood spirituality and religion as two distinct terms.

From the interview analysis, I identified four broad spiritual perspectives which I labelled, following Berghuijs, Pieper, & Bakker (2013), Hilbers et al. (2013) and Vaccarino et al. (2011), as ‘religious/spiritual’, ‘religious and spiritual’, ‘spiritual but not religious’, and ‘not religious or spiritual.’ Participants with a ‘religious/spiritual’ perspective make no distinction between their religion and spirituality. I chose the label ‘religious/spiritual’ because from this particular perspective ‘religion’ and ‘spirituality’ are very closely entwined.

Each participant’s spiritual perspective was important and relevant in their lives, so each perspective should be considered as equally significant in research and clinical settings. These spiritual perspectives also share many characteristic and

are inherently overlapping. For example, most participants had a belief in a God. Despite an overlap in the participants' personal understanding of the concept, the idea of God was not the same for each perspective. Some religious participants had a very specific view of a Christian god. For example, Hilda referred to God as a "glorified person" while other religious participants also believed in the Christian God but their understanding was much broader.

I created the Diversity of Spirituality Model (refer to Figure 6) to illustrate the uniqueness of each perspective but also to highlight the variety of understandings. It is important to keep in mind that this is a model of the different spiritual perspectives. The aim of this model is not to categorise or stereotype people, "but to provide a map of the terrain within which people think and act" (Walter, 2002, p.8).



Figure 6. Diversity of Spirituality Model

The present study in the New Zealand context identified another theme - Māori spirituality. Many participants, irrespective of their own spiritual perspective, spoke about how Māori spirituality impacted on their own spiritual beliefs.

Within each of the spiritual perspectives identified in this study, participants variably described spirituality:

- as a belief in a God or a higher being;
- as a relationship with or connection to a God or Higher Being;
- in terms of the human spirit or soul and its continued existence into an afterlife and,
- in terms of mysterious events and the paranormal.

Each spiritual perspective with its corresponding descriptors is explored in detail in this chapter. In the following section I discuss, under the *spirituality synonymous with religion* theme, the ‘not spiritual or religious,’ and ‘spiritual/religious’ perspectives. After that, under the *spirituality not synonymous with religion* theme, I discuss the ‘spiritual and religious’, and ‘spiritual but not religious,’ perspectives respectively. Next, I discuss ‘Māori Spirituality.’

It is important to note that there was an extensive overlap in the content of the perspectives and the corresponding descriptors participants used to define spirituality. Even though these spiritual perspectives and descriptors are dealt with separately in this chapter, they were for the most part interconnected and most participants had more than one understanding of spirituality. The order in which they are represented is simply for the sake of convenience and does not imply priority of any theme above that of another.

Any spiritual changes participants reported and experienced are incorporated within the findings of the different perspectives because the way participants understood spirituality influenced the spiritual changes they underwent, and conversely, spiritual changes some participants experienced influenced the way they understood and spoke about spirituality.

Spirituality synonymous with religion

Not spiritual or religious

Jeanette (caregiver) and Lydia (patient) were mostly ambivalent about the concept of spirituality and displayed uncertainty about the existence of God and the afterlife. They did not report practicing religion, nor did they appear particularly interested in any form of spirituality. They largely equated spirituality and religion.

Like many other participants in this study, Jeanette contradicted herself and changed perspectives about spirituality quite easily. She said, “I don’t have any religion and spirituality. I can’t say that I have lots of feelings [about spirituality].” She also appeared to evaluate the apparent advantages and disadvantages that spirituality may hold, somehow calculating and comparing benefits and costs. In one way she thought that spirituality may have some benefits. For example, she said, “I’m not above going to some fortune-teller or seer or wise person, a more spiritual person to see what they think [about the afterlife]. I’m not dismissing, I’m not dismissive of spirituality.” However, a drawback would be that she did not want to be “one of those people who never believes any of that stuff and then only use it when they need it.” She seemed to

use this balancing act to decide whether she wanted to interact with spiritual activities or not.

Lydia, who was in remission from colon cancer at the time of our interview, expressed her doubts about spirituality but was not troubled by it; she simply stated that she did not know what the term spiritual meant. Berghuijs et al. (2013) set out to find out what it means to be spiritual and what it means to be religious in the Netherlands. Similar to the present study they reported that many of their participants did not know what the term spirituality meant. These authors argue this could signify three different things: a) that these participants really did not know what spirituality was, b) they did not have the ability to translate their feelings into words, or c) they wanted to avoid talking about it (Berghuijs et al., 2013).

Concept of God

When these participants spoke of a god they referred to the culturally dominant Christian idea of God. Lydia was undecided about whether she believed in God or not. She said, “One way I do, and the other side, I’m not so sure. I think about these things, but I don’t know. I don’t know and can’t really say.” Jeanette and her husband Grant, who joined our conversation, agreed that they needed more evidence on the existence of God. Jeanette said, “I don’t know if that makes us very smug or self-satisfied, I just need a bit of convincing to believe and I haven’t had that yet.” Jeanette and Lydia’s comments revealed scepticism about the existence of God. Their worldviews seemed to be constructed without the assumption that God exists. However, both gave the impression of being, to some extent, open to spiritual or even religious ideas.

The Spirit and the Afterlife

Grant suffered a serious heart attack and believed he was going to die. He explained his feelings of ambiguity on the afterlife, “I thought about how it will affect the people when I’m gone. But that is the sort of it, I don’t really think, a part of me doesn’t really think there is anything after life.”

Lydia expressed similar uncertainty. However, she did not dismiss the idea of an afterlife completely. She said:

I would like to believe it, but if there is any that is another thing too. I think you better make the most of it here and try to be kind to other people, enjoy yourself and what comes afterwards, might be a bonus. But I don’t know.

Jeanette rejected the traditional Christian view of heaven and hell. She believed that heaven and hell are here, on earth. She said:

Heaven and hell is here on earth and we can make our life hell, and all the people around us, we can make their lives hell too if we want to. Or we can, well, to me this is heaven.

For Jeanette, who lost her son, Jesse, in an accident, the afterlife was about hope. She commented that at the time of Jesse’s accident she did not receive any “spiritual messages” from him. “You know, people say [you might smell] diesel smells, but I had nothing like that.” However, when Jesse died in hospital, a few days after the accident, Jeanette had a very powerful feeling “that Mum was out there, trimming some dahlias. Dead-heading dahlias. (Laughs). And looking and saying ‘Oh, here is Jesse’ and her and Dad were together.” Jeanette felt Jesse was in the presence of his loving grandparents, which gave her the reassurance that he was in an unconditionally loving environment. The image of dead dahlias Jeanette sensed was interesting. Firstly, Jeanette was a keen gardener who used gardening

imagery throughout her interview to describe important events in her life.

Secondly, her son Jesse died of a massive brain injury. The process of dead-heading flowers revitalises a plant and promotes new and improved growth, which may signify the hope Jeanette held for the restored and continued existence of Jesse. Jeanette hoped physical death was not the end of her son's existence. She commented on the possibility of an afterlife:

I don't think it [death] is just the end. I think that Jesse, the essence of Jesse, is out there. But I don't know whether it is only while people who, you know, his loved ones are around. I don't know, I'm not sure. But I like to think, but what mother wouldn't? What mother would not like to think that he is there, out there in the stratosphere? It is a wish. Spirituality is a wish...you so want it to be true. If you think of someone and you didn't enjoy their company or someone, like, like my mother in law, (laughs) I never think of her in a spiritual way, whether she is out there or not. You only cling to the ones that you love.

Jeanette's comments highlighted the idea that the afterlife may be limited to memories of the deceased being held by those who remain behind. The afterlife, therefore, is fundamentally social in nature. In line with her thinking, Hodge (2011) argued that humans have social reasoning processing capabilities that allow them to imagine another individual and to be affected by that individual in their absence. Humans imagine absent others in an embodied state and not as disembodied minds, since social interaction would then be unlikely. When thinking of someone in their absence, one imagines that person being at another place, doing something. Because humans understand death as an absence, we tend to think about deceased loved ones similarly to a living but absent person. Hodge (2011) reasoned that the 'somewhere' for a deceased individual is the afterlife where the deceased individuals are continuing their social responsibilities (Boyer, 2001). Belief in an afterlife may not be a personal attempt to achieve an everlasting life, but a place where one imagines loved ones in an ongoing

existence; busy doing something, somewhere (Boyer, 2001). As Jeanette pointed out, those individuals who inhabit the afterlife are those who mattered to her. We imagine their continued existence in the afterlife in a way which allows for lasting social exchange (Hodge, 2011). We continue to think about deceased loved ones and, consequently, they continue to affect our thoughts, emotions and behaviours (Hodge, 2011).

Talking about death and dying

Jeanette cared for her friend, Dorothy, who died of liver cancer. Jeanette reported that Dorothy was not a spiritual or religious person. She reportedly did not believe in God or that an afterlife existed. Jeanette hoped to discuss issues surrounding the existence of an afterlife with Dorothy but found it hard to start a conversation.

Jeanette said:

It is very hard for people to do that [talk about death]. I said to Dorothy once, 'What do you think is going to happen?' And she said 'what do you mean?' I said 'when you die' and she said 'well I'm going to die.' She wasn't snappish, but she didn't like that question. But I was wondering if she had an expectation, you know, of an afterlife.

It seemed that Jeanette, as the caregiver, wanted to talk about an afterlife more than Dorothy did. Dorothy seemed to be more focused on finishing off projects that were important to her before she got too weak to complete them. She also wanted to be sure all her loved ones would be well looked after once she died.

Talking of death in Western societies has become increasingly difficult (Campione, 2004). A contributing factor may be the fading of religious discourse (Campione, 2004).

Spiritual changes

Lydia said she did not experience any spiritual changes during her illness. She indicated that during her illness she didn't want to talk about spirituality. In fact, she was upset when the oncologist talked about God during a consultation, so much so that Lydia decided to see a different oncologist. She said:

I had a bit of an awful time when we started with the chemo. The doctor, the oncologist, was not the right person for me I think. She started straight away, about God and God looks after you. And that was, I was not really happy with that.

Lydia's experience with the oncologist highlighted the importance of spiritual assessment and screening. If the oncologist had been informed of Lydia's point of view of not wanting to discuss religious or spiritual matters, she may have avoided talking about God, which could have prevented Lydia experiencing additional strain during her illness. Such negative experiences with health care professionals, as described by Lydia, may enhance feelings of uncertainty and distrust towards the health care professional and impact negatively on treatment outcomes (Seibaek, Hounsgaard, & Hvidt, 2013).

I asked Lydia if at any stage during her illness she wanted to talk about spiritual matters and she answered:

No. I think when you really feel that you are going to die; I think then you will go into that a bit more. But for me it is just, at the moment I put it away because I am not going to die, not from this illness.

Later in our interview Lydia stated, "There are people who are really into spirituality. But I always think you have to be in a situation where you get 'that thing.' I did not get that yet." She seemed to suggest that a particular event may be

a turning point towards spirituality or religion. She implied that she has not yet reached that crossroads but that it might someday transpire. This may have important clinical implications: Lydia's narrative pointed out that not all people may need or want spiritual care. However, spiritual beliefs and feelings may change and a need to discuss spirituality may emerge at a certain time during an illness.

On the other hand health care professionals reported that some of their 'not spiritual and not religious' patients underwent spiritual changes. Estelle (counsellor) told the story of a young agnostic man who held no afterlife beliefs. When he came closer to death and after a discussion about what might happen after death with two Māori "blokes," he started to feel anxious that there might be an afterlife and that he had missed out thinking about how to reach it. He started rejecting his previously firmly-held belief that there was no afterlife. Estelle said this young man needed assurance and he wanted to know how to walk his new path. She said:

He wanted help to know what to do in order to move into an afterlife. Thinking that possibly there is an afterlife. And he hasn't thought about it before now. And so he suddenly started having conversations about what the afterlife might look like, how he want to prepare for that and how he might want to prepare his family for that. And he made decisions with his family about having him, once he has died, in an open casket in his home so that the family could speak to him and spend time with him and allow his spirit a comfortable journey into the next life.

Maria (nurse) told a story of a patient who "did not have any belief in God, just in science." When he came closer to death, he became extremely anxious. He asked Maria to pray for him because "It is unbearable. Death is tormenting me. Death is eating me alive." After her prayers he calmed down and died shortly after. These two examples may indicate that once people realise they are going to die, they

could experience changes of their spiritual beliefs that might be quite distressing. It therefore seems important that health care professionals and caregivers know that spiritual changes may sometimes occur and that they may result in varying degrees of distress.

Discussion

The findings of the current study indicated that not all people confronted with a life-limiting illness may want to talk about spirituality. Previous research shows that many patients express the need to talk about existential issues, such as the meaning of life (Josephson & Peteet, 2007; O'Connell & Skevington, 2005). For example, Lydia talked at length about her family and how they fill her life with meaning. She also indicated that she contemplates life and often asked existential questions, especially after being diagnosed with cancer. She said:

We always ask the questions. Did I do something wrong? Did I eat things that I shouldn't? Did I live a bit, not the right way? But, I can't really find anything from all those questions. But I have always considered my life to be a good thing, knowing that gives me happiness and peace.

Strieb and Klein (2013) cautioned against interpreting being mindful of existential issues as necessarily spiritually relevant. There are people with a worldview that excludes religion and/or spiritual interests from their lives (Koenig, 2008; Pargament, 1999). Not identifying as religious or spiritual does not mean an individual is somehow uninformed, or ignorant, "perhaps lacking in an essential aspect of human make-up" (Walter, 2002). It is a personal and distinctive belief that should be valued just as any religious and/or spiritual perspective (D'Andrea & Sprenger, 2007). Holistic care should be person-centred to incorporate any worldview (Seibaek et al., 2013).

An important deduction from these findings is that many people who deny a belief in supernatural power and are “averse to the idea of supernatural deities tend to believe in reincarnation and life after death” (Schnell & Keenan, 2013, p.115). Just like Jeannette, Schnell and Keenan’s participants expressed a “wish” for the beyond. A yearning for the continuation of the existence of deceased loved ones in the hereafter. Even though some ‘not religious or spiritual’ people may not want to talk about religious topics such as God, discussions about the afterlife may be an important part of holistic care for ‘not religious and spiritual’ caregivers or people living with a life-limiting illness.

Findings revealed that not all participants or people observed by my participants, identified as being spiritual. These findings stand in contrast to the notion that spirituality is a universal concept (Egan et al., 2011; Miller & Thoresen, 2003; Narayanasamy, 1999; Tanyi, 2002) but are supported by survey data from Finland (Linderman, Blomqvist, & Takada, 2012), Australia (Hilbers et al., 2013) and New Zealand (Vaccarino et al., 2011) indicating that not all people consider themselves to be religious or spiritual. Belzen (2009) argues that one cannot make assumptions about human nature, as “it arises from being embedded in culture” (p. 214). Therefore, the only assumption that one can make is that a person may *become* spiritual or not. Spirituality is not a phenomenon that is shared by all individuals (La Cour et al., 2012; Linderman et al., 2012; Salander, 2006).

Religious/Spiritual

Maria (nurse), Rose (nurse), Mattie (hospice volunteer and caregiver), Hilda (caregiver), Sophia (caregiver) and Anne (patient) all of whom identified as religious, did not distinguish between the concepts of religion and spirituality. They used the terms spirituality and religion interchangeably and their

conversations about spirituality were strongly grounded within their religious beliefs. For example, Maria simply said, “My spirituality is my Christian belief.” Anne, Mattie, Hilda and Sophia similarly equated the term spirituality with their Christian religious traditions. For example, Sophia said, “For me spirituality is my religion. Just by saying, like many people do, ‘I believe in something larger than ourselves’, is not spirituality. Spirituality is religion.” For Sophia spirituality seemed to be an exact and specific concept, within a strictly religious context. She was opposed to an unclear, vague and wide-ranging interpretation of the concept.

Their understanding of spirituality was centred on God, their relationship with God and the belief that the human spirit continues to live in an afterlife after the death of the physical body. These religious participants’ understanding of spirituality is closely related to the concept that Richards and Bergin (2004) labelled a theistic spiritual world view. The central assumptions of a theistic perspective are the belief that “God exists, humans beings are creations of God and there are unseen spiritual processes by which the link between God and humanity is maintained” (Bergin, 1980. p. 88).

In her study to determine how people talk about spirituality in everyday life, Ammerman (2013) identified a distinct theistic form of dialogue many people used to describe spirituality. Ammerman (2013) reported that for these participants there was practically an absence of spiritual language that moved beyond theism. She also noted that events in the natural world and in the souls of these participants had clear religious meaning and did not depend on any broader, general spiritual language.

Maria, Rose, Mattie, Hilda, Sophia and Anne were all from a Christian background. However, for them, being spiritual did not necessarily imply being

Christian; the term spirituality included all religions. They also pointed out that all religions should be respected. For example, Maria commented that she did not have great knowledge of “other spiritualities” as she did of her own, but she respected other people’s spiritual beliefs. She explained, “I have seen other spiritualities and their rituals throughout my career, and one respects that. Especially when people are dying.” Sophia showed a similar respect for others’ spiritual beliefs and thought that “spirituality is a relationship with someone who is in control of everything. For me it is God. For others it may be Buddha and that’s okay. I respect that.” The openness participants described towards other religions have also been described by Strieb, Dinter and Soderblom (2008).

The findings further indicated that these participants did not refer to spirituality in any broader terms than religious dialogues. I asked Anne for her opinion about the general notion that spirituality may be a broader concept to religion and she replied, “I don’t think so. That question is starting to get quite academic. So, without going into all that, to me, spirituality and religion is the same, in the sense that it is a belief in God.” Here Anne touched on an important point; she seemed to suggest that academics’ and probably health care professionals’ conceptualisation of spirituality may differ from lay understandings. This idea was also brought up by Rose, a hospice nurse, who said that introducing the topic of spirituality to family members was often quite challenging because family members were usually not very forthcoming when talking about spirituality:

Rose: Sometimes we have to introduce the idea that time is short, you know, and we go through all the things we can do to help them with physical pain and emotional things. I’ll push in the thing that, as part of hospice philosophy there is a spiritual component, but several families say ‘no, we don’t have anything to do with church or we don’t go to church or anything like that or ‘we used to be Catholic but we are not now’.

Interviewer: Does that happen often? That family members think you talk about religion when you mention the spiritual support they can receive from Hospice?

Rose: Generally, yes. Mostly they would say something like 'we don't go to church'.

It appeared that the reluctance of family members may be born from the idea that Rose meant 'religion' when she spoke about 'spirituality.' These results suggested that some patients, family members and caregivers might often parallel spirituality with religion and that the dominant spiritual discourse within the contemporary health care sector may be different to that of those people. Patients and their families often used markedly different language to define spirituality than did health care providers (Duggleby, 2000; Mc Sherry, Mc Sherry, & Watson, 2012). However, in contrast to these findings were those of Egan (2009) who found that many New Zealanders with cancer used similar language to define and describe spirituality as did health care providers.

Concepts of God

Several participants mentioned that a belief in God is fundamental to being spiritual. For example, Mattie said:

Knowing there is a God who has this great plan we are all involved in - that is spirituality...one of my hospice patrons that I cared for quite length of time, her husband, well, they both had no aspect of spirituality. They didn't believe in God or anything like that. They had no comprehension of anything more to life.

These participants each had a specific set of ideas about God's qualities and how he interacted with and felt about humans, and naturally, how humans ought to interact with God. These participants thought that God was above all else benevolent. They ascribed various positive traits to God, like "almighty" (Maria), "wise" (Sophia), "caring" (Hilda) and "compassionate" (Mattie). God was

perceived as a superior being. For example, Hilda thought of God as a “glorified person” whom she referred to as ‘Heavenly Father,’ who loved humans unconditionally.

To these participants, God was removed from the material world, but nevertheless involved in it. As exemplified in Mattie’s quote in the previous paragraph, they all believed that whatever happened to them was God’s will. They saw the challenges of this life as an opportunity for personal and spiritual growth. Sophia said God mercifully allows people to enter a journey of spiritual and personal growth.

Throughout the journey a person may get closer to God (spiritual growth) but also endeavour to become a better person (personal growth). For example, she said:

It is a process where one learns and grows, every day. You fall and get up. Repeatedly. Don’t misunderstand me, it is not a habit, it is something you strive towards. The Buddhist may strive to become more like Buddha himself. Personally, one of the things I strive for is to inherit the everlasting life.

Anne, who was in remission from breast cancer at the time of our interview, described similar views. She felt there was a higher purpose for her illness - an opportunity to grow spiritually.

‘Religious/spiritual’ participants were religious people who equated the terms religion and spirituality. They mainly used a theistic dialogue for talking about spirituality. For them spirituality centred on God and practices to develop one’s relationship with God. This is consistent with the findings of Schultz et al. (2008) who conducted a study on the role of spirituality in coping with cancer in African American cancer patients (Schultz et al., 2008). They found that participants defined spirituality as synonymous with religion, as a relationship with God and with afterlife notions. Other research in the area of spirituality in the health care

setting reports similar findings, in relation to such a theistic discourse, to the present study. For example, in their Australian qualitative study to examine the lived experience of spirituality as perceived by palliative care patients and their caregivers, Penman, Oliver and Harrington (2012) found that many of their participants did not distinguish between religion and spirituality and that the most common descriptor to explain spirituality and spiritual experiences was a belief in God. Lowry (2012) conducted a study on the meaning of spirituality to older adults in various states of health and found that all participants referenced God or Christ as the source of their spirituality (Lowry 2012, p. 358). Lowry (2012) and Penman et al. (2012) attributed the centrality of God in the discussions of spirituality to the age, gender and cultural background of participants in their respective studies. In these studies, similar to the present study, participants were mainly white, mature, female and from Judaeo-Christian backgrounds, similar to the demographics of participants in the present study. However, these findings were consistent with studies conducted in non-Christian countries. For example, in a study of Iranian cancer patients it was found that, from a Muslim perspective, there existed no difference between the concepts of religion and spirituality (Rahnama, Khoshknab, Maddah, & Ahmadi, 2012). Similar to religious participants who equated religion and spirituality in this study, they used such terms as "relationship with God" to define spirituality. A central theme was that participants emphasised faith and trust in God, and relied on God during time of illness, trusting God to do what was right for them. A study of the lived experience of Lebanese oncology patients receiving palliative care reported patients were very dependent on God for help and support (Doumit, Huiker, & Kelly, 2007).

Spirituality - A way of life

Those religious participants who equated religion and spirituality were all church-going; they were actively involved in formal religious traditions. They attended church services, Bible study groups and were active in prayer groups where they prayed for those in need, especially the sick. Sophia said:

My religion Christianity, the spirituality you are talking about, can be shared with others through activities such as shared Bible reading and prayers. But there is also a personal relationship with God wherein I am fully immersed, where I feel the presence of God and the Holy Spirit and share my feelings and emotions with God, privately.

Sophia seemed to suggest that within religion there are two types of spiritual experiences; one is that of a social and public expression of religion within family and church environments; an involvement and contribution within a religious community. On the other hand there seemed to be a more private experience that she considers to be very individual: an intimacy with God. This individual personal experience falls completely out of the public domain. Sophia believed the private and individual relationship she experienced with God was also experienced by other religious people and is a part of the spiritual and personal growth people experience while practicing their religion. Even though she made a distinction between a public and private spiritual understanding, both experiences occupied the religious sphere. Both of these dimensions, the outward social and the personal more inward, were spiritually meaningful to her.

Rose also talked about her relationship with God on an intimate level, which involved prayers, “not as formal as I used to when I went to Sunday school, it is now much more personal. It is like conversations I have; yeah I talk personally with God...like praying, thinking, and talking to God.”

Maria and Sophia mentioned that their personal relationships with God were continuous experiences and were not restricted to “Sundays or when one needs God.” Sophia described how her dying mother received comfort and strength from her religion, however it was not something:

...fanatical, like people who only need God in times of trouble, she always had God, Jesus and the Holy Spirit in her life. She lived her life through them. Because... how can one separate what you do for God and what you do for yourself or others?

Hilda stated that spirituality to her is way of life, which cannot be compartmentalised to Sundays only, “spirituality is lived, it is part of our lives. It is not just a Sunday thing or something you turn on when you need it.” Hilda said caring for her sick husband was a spiritual act because “that is what Jesus would have done.” She modelled Jesus’s behaviour in her daily life.

The Spirit and the Afterlife

In addition to understanding spirituality as a belief and a relationship with God, the concept of spirituality was strongly associated with the human spirit or soul, as exemplified by the following quote by Hilda:

Spirituality? Well, it is all to do with the spirit, isn't it? Because we have physical bodies and we have spiritual bodies, you know. And the spiritual part of our lives, the spiritual body, that is what spirituality is all about. You know, death is not the end of life, it is just the end of this part of life.

Hilda said taking care for her dying husband was a spiritual act because “there is a body that needs help, but there is still the person, the spiritual person, the real person that is still in that body. That doesn’t change and that is the real person.”

Hilda seemed to view the spiritual body and physical body as two separate entities. This suggests that the spiritual body, the person’s real identity, still remains intact after death. As a concept the ‘spiritual body’ Hilda referred to

seemed to describe the idea of the Apostle Paul in the New Testament. He described the resurrection of the body after death as spiritual. In contrast to the physical body, the spiritual body was immortal and lived in heaven, with God. Maria believed the human spirit was the object of 'spirituality.' She framed her thinking within her Christian belief system. She said:

The word spirituality was derived from what word? The word 'spirit.' So, spirituality is about the soul or spirit. Jesus was a human being, on earth, like all of us and now he exists as a spiritual being with the Father, so shall us who believe in Him.

For Maria the importance of Jesus being resurrected seemed to be at the basis of her faith. It explained how it is possible for the spirit or spiritual body to continue living and gives hope for a better life after this. It seemed that the continued existence after physical death implied there is an ongoing existence of the 'self' (as in the case of Jesus), in a non-material form. Durkheim (1995) reasoned that the belief in a soul or spirit is functional as it explains the continuity of life after death.

In accordance with Christian principles these participants believed that death was not the end of existence, but a continuation of the human spirit into an afterlife. Religious doctrines provided them with the knowledge of how to attain everlasting life. For example Mattie, an active member of the Church of the Latter Day Saints, explained that her belief in the afterlife was formed by the interpretation and understanding of the Holy Scriptures of her religion. Mattie believed that this life is preparation to meet God in the next life. She explained that a strong understanding of the scriptures "takes us to a place where we know there is more to life, there is an eternal existence and that it [death] is not the end of everything, it is the end of this part of life." Likewise Maria, an active member

of the Pentecostal church, found her beliefs in an afterlife centred on Christian teachings. She quoted the Bible - John 14:2, to explain her understanding that heaven “is the dwelling place of God and that Jesus promised to prepare it for true Christians.”

Sophia cared for her mother who died of breast cancer. Sophia’s mother believed that religion and spirituality ensured an everlasting life with God in heaven, which gave her hope. Sophia said, “Mum was sad because she had to leave all of us behind. But she knew where she was going and that gave her peace.” Her mother found courage and was at peace with her illness.

Spiritual Changes

In the following section I discuss spiritual changes that participants and those observed by my participants experienced. In this study three participants Anne, Gemma and Jo reported experiences of personal spiritual change. O’Hagan (1986) said that there are different ways of knowing. She made a distinction between personal (first-hand) knowledge and distant (objective knowledge) and argued that a deeper understanding of any experience may be possible if the first-hand lived experience is taken into account. Therefore I devote a section to each of these three participant’s first-hand experiences. Anne’s story of spiritual change follows immediately after this brief outline, while Gemma and Jo’s experiences are reported under the ‘spiritual but not religious’ perspective.

Anne’s Journey of Spiritual Growth

Anne, who was in remission from breast cancer at the time of our interview, described similar views. She felt there was a higher purpose for her illness - an opportunity to grow spiritually.

Anne explained that she reconnected with her childhood religion “just before” she was diagnosed with breast cancer. She indicated that the reconnection to her faith in the months leading up to being diagnosed with breast cancer was more than mere coincidence, but the involvement of God. The reconnection to her faith put her in a place during her illness where she “was just a lot more aware of where it [the cancer]” fitted into her life. Anne used religion to interpret her illness. During the course of her illness she had come to see that God had a plan for her life. Her cancer was God’s way to make her stop in order to become a better person “or some other purpose I don’t know about yet...and that is comforting.” She accepted her illness within this bigger picture of God’s plan for her life. She commented, “Things happen for a reason and that is my journey and that is what is supposed to be happening and I don’t really get too upset about that.” She came to a sense of understanding and her suffering and feelings of powerlessness were greatly reduced. It appeared that this process of religious meaning-making gave her a sense of harmony in her life - it was meant to be.

Anne underwent a gradual spiritual change during the course of her illness. She reported that her relationship with God steadily went to a deeper level than before. She started to pray more often, which gave her a sense of peace and calmness. Her prayers were not aimed at requesting a cure for her illness but for strength and courage to be able to cope with her situation. Anne read the Bible more often than before her illness and surrounded herself with Christian music and books and believed these activities brought her closer to God. She attended church more often, where she found social support from fellow worshipers. She also found spiritual support in the form of intercessory prayers. She commented, “I was in

need and I was feeling that I needed that help.” She found regular prayer and going to church “comforting, really comforting.”

She still seemed to feel vulnerable at times, understandably so, because of the uncertainties that go hand in hand with a cancer diagnosis. Even now, in remission, she quantified her uncertainty, “They said to me so you are given an 85 per cent chance in 10 years’ time to be fine, based on the statistics that they got, so that is sort of my diagnosis and history.” But, to Anne, religion is an anchor: she knew God was there to “keep everything steady and on an even keel.” This knowledge provided her with a sense of security during her unsettled, unpredictable and volatile cancer experiences. Knowing God was there for her was “sort of a quite comfort, a quite peace... Yeah, I felt quite safe.”

Research suggests that a shared or collaborative style of coping between a person and God empowers individuals (Pargament & Park, 1995). In similar vein, the religious tools Anne had at her disposal seemed to empower her to find inner strength, especially at night. She described several vivid dreams of the devil trying to get hold of her. She explained:

I had dreams that were quite strong, that I still remember clearly of what I assumed to be the devil trying to grab hold of me. And me trying to fight it off saying, ‘no, no!’ I was fighting it away, you know, I said ‘I am strong and I have got stronger.’ I remember feeling very scared when I woke up, scared, terrified but stronger.”

Because she felt safe and very close to God she believed she could resist the devil, which may possibly be a representation of her cancer, because she said “now I have more tools and get more tools to try and fight back.” Previous research showed that for many patients suffering from life-threatening illnesses, fear of death is more severe at night (Grant et al., 2004).

From Anne's narrative there seemed to be two constructs she talked about. The first was that of God and the personal relationship between God and herself. It seemed that Anne found solace in her renewed relationship with God, which provided her with a sense of belonging, peace and security. There was a desire and active engagement to build a stronger and deeper relationship with God. It helped her to create order in a world that had been disjointed by her cancer diagnosis.

The second construct, religion, provided her with a set of pre-existing religious rituals, behaviours and beliefs. In other words the "religious tools" she mentioned were offered by established religious frameworks. She found meaning and purpose in her illness and events surrounding her illness within these existing religious structures. Her relationship with God and the pre-existing rituals, beliefs and behaviours provided her with a way to find meaning and purpose. Similar to Anne's story, Gall and Cornblat (2000); Levine, Yoo, Aviv, Ewing, and Au (2007) and Swinton, Bian, Ingram, and Heys (2011) in their respective studies of women with cancer reported that many of their participants attributed their illness to the will of God. The women very often found acceptance of their illness and gained meaning and purpose through the belief that their illness was part of a bigger plan God had for their lives. A prominent theme in Levine's study was that women found comfort in knowing God was there for them and taking care of them. Moreover, Park and Cohen (1993) said that when people attributed illness to a benevolent God they tended to make positive reinterpretations of the illness (Park & Cohen, 1993). A strong relationship with a caring and loving God have been associated with a greater sense of control in times of uncertainty and overwhelming situations, like life-threatening illness (Pargament, 1997).

Spiritual changes observed by health care professionals and caregivers

Anne's story was one of gradual spiritual growth throughout her illness journey. Likewise, some caregivers reported that their dying loved ones became more focused on their spiritual lives as their illnesses progressed. They appeared to have focused on their personal relationship with God and at the same time, were actively involved in a more social expression of their spirituality. Participants reported that even when their dying loved ones were bedridden they were still praying, reading the Bible and talking about God with others. This demonstrated their devotion to God. They continued to be faithful to God regardless of their deteriorating health. This expression of dedication to God and subsequent deepening of the relationship between God and dying loved ones was also illustrated in the literature (Ironson et al., 2011).

Sophia's mother used to read meaningful Bible scriptures to her family members and prayed with them on a regular basis. However, she also "spent much more time with God, in prayer. Yes and much more time with her Bible". There seemed to be an increase in frequency and depth of prayer in these individuals. Holt and colleagues (2009) and Lancaster and Palframan (2009) reported more frequent praying in cancer patients in their respective studies. In contrast Denney, Aten, and Leavell (2011) found changes in the quality and depth of prayers but not the frequency of prayers in patients with HIV/Aids.

Health care professionals in this study reported some experiences of their patients. They referred to spirituality as a dynamic process, evolving through time. They frequently expressed illness metaphorically - as a journey. When patients get diagnosed and go through treatment they face an "uphill journey" or "death is still a long way off." Even though the patients fight an "uphill battle" they still feel the

illness is being contained and is relatively under control and that “death is still far on the horizon.” Health care professionals in this study observed a certain point in their patients’ journeys where they become aware they were going to die. It is at this point where they “recognise the spiralling was beginning” or that the “illness is taking them over.” These metaphors indicate that the illness is not under the patient’s or medical staff’s control anymore. Losing this sense of control over their future and relationships may cause them considerable anxiety and distress.

When health care professionals described experiences of their patients there was not always sufficient detail available to determine which perspective the particular person would hold when talking about spirituality. Therefore in the following section I discuss spiritual changes that health care professionals reported in their religious patients. It is important to keep in mind that these patients could primarily have had a ‘spiritual/religious’ or ‘spiritual and religious’ perspective and of course as described in the previous section, spiritual beliefs may change.

Estelle, a counsellor, reported that many patients who had left their childhood religion behind purposefully brought religion back into their lives at some point during the palliative stage of their illness, most often when the patients had recognised they were going to die. It seemed that if religion was part of a person’s childhood experiences, it was possible for them to revisit those beliefs when they found themselves engaging with, or suffering from, a life-limiting illness.

Consistent with post traumatic literature (Tedeschi & Calhoun, 1996) this study found spiritual changes for ‘religious/spiritual’ and ‘spiritual and religious’ people included spiritual growth. They engaged increasingly with the religious and spiritual resources available to them from before their illness. These people spoke of a meaningful deepening of their religious faith which gave them strength,

courage and comfort to deal with life-threatening illness and face death, which was also reported by Kristeller and Hummel (2006). Most 'religious/spiritual' and 'spiritual and religious' participants reported a gradual process of deepening of their own faith or that of their loved ones which provided an increased sense of comfort and strength.

Spiritual decline is associated with being less spiritual and less religious (Cole, Hopkins, Tisak, Steel, & Carr, 2008). Rose, Maria and Estelle reported that some of their religious patients contemplated turning away from religion and questioned their faith and the love of God. They experienced "painful secondary loss" Walter (2002, p. 8) - they felt were losing their faith as well as their lives. These incidents often occurred in times of intensified physical pain. Similar findings were also reported by Murray et al., (2007). For example, Estelle shared the experiences of a man, who, during his illness suddenly said:

I fooled myself, I fooled myself, living with this Christian belief all these years, and now it is obvious to me that there is no God, and I've got no meaning in my life. I'm going to ditch it all.

It seemed that these patients tended to increase the distance between themselves and God and their religion for only brief periods of time. These reflections at the end of life resulted in significant distress to the patients and it appeared that physical suffering could lead to questioning one's belief system. After counselling sessions or discussions with hospice nurses these patients usually redirected their beliefs in a religious direction once more. It is therefore difficult to conclude if these moments of doubt and tumbling faith reported in this study could be called spiritual decline. As mentioned in the literature review, spiritual decline is not often studied or reported, which may be due to the current emphasis on the

positive side of spirituality such as connectedness, appreciation of life and peacefulness (McSherry & Cash, 2004). Future studies may be warranted to explore associations between spiritual and physical pain.

There seemed to be a stronger focus on the non-physical aspects of the self during this time of spiritual growth. In accord with previous research (Maynard, Gorsuch, & Bjorck, 2001) this study pointed out that a relationship with God may be a very important part of a person's spiritual journey of living with dying. It also seemed that religious rituals, beliefs and behaviours complemented or supplemented the deepening of the significant relationship with God and vice versa.

Discussion

Religion

The present study suggests that even though New Zealand is a secular country and church attendances have decreased, not all people have turned away from or are hostile to religion. Many people may find comfort, meaning and purpose in life through the familiar rituals, knowledge and social support that religion offers. The notion that spirituality is becoming less and less religious in New Zealand (Egan, 2009) cannot be fully supported.

Studies have shown that many people experience religion and prayer as an essential part of healing, health and medicine (Kaut, 2002 ; McCaffrey, Eisenberg, Legedza, Davis, & Phillips, 2004). A major way in which religion shaped my participants' experience of death and dying was that it facilitated coping in such adverse situations by providing participants with a framework through which they could understand the world. Religion offers beliefs, practices, rituals, history and sacred writings which provide support, purpose and direction in the lives of

religious people (Kaut, 2002; Purnell, Andersen, & Wilmot, 2009; Walter, 2002).

When faced with serious or life-threatening illness, a large majority of people want to be at peace with God, which can be facilitated by religion and religious activities (Steinhauser et al., 2006). Jacobsen, Luckhaupt, Delaney and Tsevat (2006) found a strong positive association between the perceived severity of illness and religious comfort. Furthermore, Wink and Scott (2005) primed thoughts of death under experimental conditions and found that religious beliefs and practices buffered against the fear of death.

Furthermore, religion provided a source of social support. Organised religion provided a sense of group identity through a network of supportive individuals. Hilda, Mattie, Maria and Sophia were involved in various spiritual activities and drew strength from the knowledge that they had social support provided by members of their religious communities.

Many participants in this study experienced life through a religious or spiritual lens. To them religion and spirituality were not merely a set of beliefs, values or rituals to be used in difficult times. Religion and spirituality offered a way of life “to be sought, experienced, fostered, and sustained consistently” (Hill & Pargament, 2003 p. 68). Religious patients and caregivers have social spiritual support from religious communities. However, since religion and/or spirituality are an integral part of their lives they still may want to talk to health care professionals about these issues.

Spiritual changes

Spiritual change may often be triggered by a stressful or traumatic event such a life-threatening illness (Vachon et al., 2009). Potential conditions for spiritual changes to occur consist of, but are not restricted to, suffering and distress (Grof

& Grof, 1992; Grof & Grof 1989; Taylor (2012). Rambo (1983) noted that negative affect, anxiety, guilt, sadness, uncertainty and turmoil can precede spiritual transformations, which was also shown in this study. Trajectories of spiritual distress during life-threatening illnesses have been described during four key transitions; at diagnosis, discharge after treatment, disease progression and the terminal stage (Murray et al., 2007). For participants and patients in this study, spiritual changes seemed to transpire when the disease had progressed to such an extent that the patient became fully aware that they were going to die. Closer to the end of life some people observed by my participants experienced spiritual changes that involved modifications to their spiritual perspectives. These changes at the end of life have in some cases resulted in significant distress to the patients. Physical suffering can lead to questioning one's belief system and is not a luxury, but an important aspect to support the patient as they face living with dying (Seibaek et al., 2013). These results suggest that it is of great importance to identify patients who have changes in spiritual beliefs or experience spiritual doubt, and find ways to restore their sense of well-being.

Spirituality and religion as distinct concepts

In the previous section I examined the perspectives of religious participants (religious/spiritual) and non-religious participants who made no distinction between 'religion' and 'spirituality.' In the following section I explore the perspectives of participants who understood 'religion' and 'spirituality' as distinct concepts. Firstly, I discuss the 'religious and spiritual' perspective. That is the perspective of religious participant who differentiate between the two terms. Secondly, I discuss the perspective of non-religious participants who self-identified as spiritual, the 'spiritual but not religious' perspective.

Spiritual and religious

Grace (caregiver), Laura (caregiver) and Judy (hospice volunteer), all of whom are religious, made a distinction between the terms ‘spirituality’ and ‘religion.’ They did not distinguish the two concepts but thought there was a supporting and collaborative relationship between spirituality and religion. They understood spirituality as a broader concept than religion. Spirituality, to them, was about a connection to God, about the continuation of the human spirit into an afterlife and about the mysterious and unexplained. They were knowledgeable and comfortable talking about concepts relating to religion. Nevertheless they perceived spirituality as experiences both inside and outside the borders of religious traditions. As discussed in the literature review, this separation of the two terms is widespread (eg., Dyson, et al., 1997; Sheldon, 2000). These findings also fit with the understandings of Marler and Hadaway (2002) and Zinnbauer, Pargament and Scott (1999).

What is spirituality?

These participants were quite comfortable defining the concept of religion but found it challenging to pin down what exactly is meant by the term ‘spirituality.’ It seemed that language was generally not capable of conveying their understanding of spirituality. They often used stories to express their opinions, perceptions and experiences related to spirituality during our discussions.

Grace and Laura said religion was about specific beliefs and external practices in structured organisations. Further, Judy said that religion provided people with instruction about morality, “Religion is teaching us to do what is right. It is your teachings, it’s words. This is how I see it, you got the Words and it gives you your do’s and don’ts.” In contrast to religion, spirituality was difficult for Judy to put

into words but she did narrate events she considered spiritual. She recalled experiencing spirituality as a young girl going to church. She used to sit in the front pew in church, where the light of the sun shone through leadlight windows:

Because that is where I thought the rays of God's love are shining through...and that is spirituality you know, it's alive, it's light, it's warmth, it's love, you feel surrounded by warmth and love. You've got to have that spiritual connection with God.

It seemed that Judy believed practicing her religion and going to church provided her with opportunities for a connection to God, which she understood to be spiritual. Later during our interview Judy also described spirituality as the love between a grandmother and grandchildren “which gives one a warm and fuzzy feeling, you know, you love them without judgement.” One dimension of Judy’s understanding of spirituality may be about acceptance and unconditional love. It seemed that the loving feeling between Judy and her grandchildren, whom she loved and accepted unconditionally, and the love and warmth she felt from God, seemed to be comparable. Judy was the only participant in this study who talked about love as being spiritual; however, this concept is mentioned throughout literature.

Another religious participant, Laura, thought the concept of religion was “connected to the church. Something church people made up...statements and beliefs” while for her, spirituality went beyond specific beliefs, behaviours or rituals: it also involved a connection to God. She explained that people cannot see or touch God; however, we can feel and hear God through a spiritual connection. Laura is Jewish and keeps the Sabbath on a weekly basis, as intended by her religion. She found the experience to be very spiritual,

Yeah, sometimes especially keeping the Sabbath...it is spirituality as well; you just get a little taste of the peace. She believed a connection with God could be established through silence and prayer, we can have spiritual contact with God if we are still. And praying, for me, that is praying.

These participants explained their understandings of spirituality within a religious context. Therefore the illustrated examples and quotes were all within that context. While they recounted their stories of religion these participants emphasised their personal feelings of connectedness with God, which for them appeared to be somehow different from traditional religion. Spirituality, to these participants, appeared to be something deeper, a profound experience of a personal connection with God that they found in religion. For Judy and Laura, establishing such a spiritual connection with God was done through conscious and specific actions related to their different religious traditions. Going to church, observing the Sabbath and being still, created a space they moved into, which gave them the opportunity to leave the everyday behind and concentrate their thoughts on God, thus establishing the spiritual connection. ‘Religious/spiritual’ participants in the previous section experienced spirituality as a way of life. There did not seem to be a disconnect between their understanding of God and their active quest to live accordingly. In contrast, the ‘religious and spiritual’ participants in this section spoke of specific moments of connection with God as spiritual and usually not as an ongoing relationship with God. This subtle point of difference is reflected in the conceptualisation of spirituality and religion offered by Marler and Hadaway (2002) that spirituality is about a connection between the individual and a larger, supernatural reality, while religion is the expression of that connection; “organised or institutionalised spirituality” (p. 295).

Grace, a 42-year-old Catholic, attended church on a regular basis, but not as often as she wanted to. She thought spirituality represented something stable and constant within all religions. She also believed that spirituality could be separated from religion and that people could be spiritual without practicing a specific religion.

There is religion and there is spirituality. And I think, all religions have an element of spirituality in it. But spirituality does not have to be about religion. I haven't heard people say there are different spiritualities.

Her understanding indicated that spirituality surpasses the margins of religion. This understanding was situated in direct opposition to the understanding of participants in the previous section who equated spirituality and religion and spoke of “different spiritualities.” In addition, Grace also thought deep spiritual conversations with people outside religion are possible and enriching because of the parallels that exist between their personal understandings of spirituality. She talked about her friendship with Jo, a participant to this study who we will meet in the next section. Jo self-identified as spiritual but not religious. Grace said, “You know, I can talk to her [Jo] about these things [spiritual things] because I know she is spiritual. She is not religious but she is spiritual, definitely spiritual.” Both of them believed in the existence of an afterlife and that certain unexplained events in daily life could be somehow related to a spiritual realm. It seemed that the boundaries between the linguistics and perceptions of Grace’s religion and Jo’s spirituality faded when they focused on similarities between their worldviews. Researchers have repeatedly expressed a level of disapproval that the term “spirituality” is fuzzy and vague, to the extent that it is rendered meaningless (Kaut, 2002; Zinnbauer et al., 1997). However, it is precisely this vagueness that permitted communication between Grace and Jo. Grace’s understanding echoed

the words of Swinton and Pattison (2010) that “it is in fact the vagueness of the concept that is its strength and value” (p. 226).

God, the Spirit and the Afterlife

During conversations about spirituality, participants seemed to put a great deal of emphasis on some form of afterlife. For example, Grace said “spirituality is about believing there is more than death.” For her the afterlife is heaven, but she also considered the notion of an afterlife to be a personal belief. She said, “there are many theories out there.” Similar to Grace, Rose also mentioned the afterlife as a theory. Rose a palliative care nurse, experienced a change in her beliefs about the afterlife while working with dying patients. She explained that her afterlife beliefs used to be grounded in the teachings of her Catholic religion throughout her childhood and young adult life. However, she felt that these beliefs were merely cognitively established and explained that “it was sort of like a belief in my head, you know, head stuff. I’ve had that kind of theory I guess.” While working as a nurse at a hospice, she witnessed many dying patients having death-bed visions or approaching-death experiences. Death-bed visions refer to the phenomenon when people nearing death see or communicate with deceased family members, friends or religious figures (Brayne, Farnham, & Fenwick et al., 2006; Brayne, Lovelace, & Fenwick, 2008). In other words, they see and communicate with spirits that exist in the afterlife. Rose explained that while being with patients nearing death one often observed:

Changes in their consciousness...patients look around in the room or specifically look in one side of the room. And it is as if, you know, if they can see someone or something. Some people begin talking to someone.

Rose explained that witnessing this phenomenon, firsthand, verified and strengthened her afterlife beliefs. “Now that I’ve seen it in so many cases I believe there is definitely something there, you know, after death.” Additionally, she found confirmation of her beliefs in the writings of other hospice nurses, who like herself, witnessed patients having death-bed visions and as a consequence believe that life after death exists. Her personal experience of spirituality as opposed to theoretical religion validated Rose’s beliefs in an afterlife. Rose’s experience pointed to spirituality as an experiential phenomenon, as proposed by Zinnbauer et al. (1997). Such significant events have been found to raise the awareness of a spiritual dimension in many palliative care workers.

Death-specific beliefs such as afterlife beliefs seemed to be important to participants in order to cope and deal with illness or death of their loved ones. It seemed that caregivers wanted to talk about the afterlife, more than patients seemed to. Caregivers focussed their spiritual conversations to a great extent on the afterlife, while patients seemed to focus on using their spiritual and/or religious tools to find comfort and strength to cope with their illness. For example, Grace, who cared for her dying father, emphasised that she wanted to talk about spirituality, particularly the afterlife, specifically when her father’s illness was getting worse. She tried to start conversations with her father about what might happen to a person after death, but she found it hard to broach the subject with him, especially because he was not a particularly spiritual person. On the other hand, he needed to know his family would be able to cope after his death. Therefore he engaged in conversations about everyday practicalities: for example, farming methods and taxation. He wanted to be sure his family would be all right when he died.

Grace said that in general she found it difficult to start conversations about spirituality, especially with people who did not share the same beliefs or who are not open to open to the subject “I cannot talk about spirituality to just anyone: not everyone is open to it and not everyone believes, you have to be on the same line. ‘Cause it is not a topic everybody is comfy with.” Therefore she was not “able to talk to my dad. But was able to talk to my mum. My mum is very spiritual, religious yes, a spiritual person and I was able...we were able to share.” These words suggested that it was easier for Grace to talk about spirituality to someone who shared the same spiritual beliefs. However, she also found it necessary to discuss the afterlife with her dying father. Grace asked her father just before he died, if he would visit her, in spirit, after his death, and he answered that he would. Her father’s headstone comprised of two stalks of wheat with birds sitting on them. After her father’s death she often noticed birds playing outside her house and on a particular day:

There was a little Fantail, and it was pooping on my car. Sitting on the antenna and I was thinking ‘little bugger’ (laughs) then I thought of him (Dad), and he came back several days in a row. He was pooping on the car, making a point.

The fantail symbolised Grace’s sense that her father’s spirit was in fact still around, in everyday life, which gave her a sense of connection to him, peace and comfort. The playfulness of the fantail may further suggest to her that her father was happy and at peace in the afterlife.

The findings of this study showed that beliefs in an afterlife were important for helping some participants cope with living with dying. Caregivers found it very distressing to watch their loved ones suffer. Hilda commented, “Watching someone’s suffering is hard work. It is very hard work and sometimes you think

you would rather be in that situation yourself.” The belief that a loved one’s suffering would end and that they would move on to a better place provided caregivers with hope. Death seemed to imply a new and better life especially when a dying person was suffering a lot physically. For example, Laura felt comforted and reassured by the belief that when her parents died they would be united with God, at which point there would be no more suffering, “tears, suffering and sadness.” Expanding on this Laura said she felt at peace because “he [her father] was going to see my mother again so it was good, nothing scary about it. If you believe that there is a God and you believe what the Bible says, there is nothing to be worried about.” Death-specific beliefs are important psychological phenomena and a critical functional component of how the bereaved cope with death (Benore & Park, 2004; Stroebe, Gregen, Gregen & Stroebe, 1992).

Furthermore, the findings of this study indicated that afterlife beliefs seemed to reduce fear of death and promote readiness for dying in some patients. Laura indicated that his belief in the afterlife gave her father a certain readiness to die. Laura’s mother had died three months before her father did and when her father was dying he called on her not to worry about him because he was ready to die; he was going ‘home’ to Laura’s mother. Hood and Morris (1983) also reported that the belief in a continued existence in an afterlife may help some people confront the certainty of death. This finding was also reported by McClain-Jacobson and colleagues (2004).

God and going to Church

The ‘religious/spiritual’ participants in the previous section were actively involved in their various denominations. The ‘religious and spiritual’ participants

did not attend church often or ‘as much as I used to’ (Judy), or ‘whenever I have time I go’ (Grace). Images and concepts of God were far broader in this ‘spiritual and religious’ perspective than in the previous section. Participants in general did not describe God’s characteristics as the ‘religious/spiritual’ participants in the previous section did. Neither did they talk about God’s actions and intentions or their relationship with God. For example, when I asked Grace whether she held a specific image or concept of God, she explained her understanding of God as follows:

Within the Catholic faith you have all these saints so you can pray to this saint and to that saint. Yeah, I sort of wondered about that, sort of it is a very personal thing...some people are very much drawn to mother Mary, for some people it is God, some people say Jesus. I think, I leave that sort of floating in the air. For me, there doesn't have to be a specific perfect answer that God is this or that. It doesn't matter for me. But you can always come to him with anything, good and bad. I think it is real, it is not a fantasy, but yeah, he is everywhere.

The ‘spiritual and religious’ participants seemed to express a certain tension between their religion and their own principles. Grace described the friction she sensed in regard to the Catholic Church she belonged to. She said, “there is a priest, he was going on about gay people, and that spoils it. It is people that spoil certain religions, it is the people factor.” This type of criticism of religious belief and practice is quite common among those who call themselves spiritual, but also among those who are actively religious (Hollywood, 2010). At the same time Grace also seemed to have the need to justify her affiliation to the Catholic Church. She described what it was she needed and obtained from her faith. Catholicism gave her time for quiet reflection which “can be very healing.” To her the Catholic Church “is a bit different based on time for yourself. It is more old-

fashioned religion. Some of the modern ones are so hands in the air.” Church provided rituals and time for quiet reflection that she found soothing and healing.

The mystery

Grace, Judy and Laura spoke of mysterious and unexplained events, angels, mediums and ghosts and understood these events as spiritual. In contrast to ‘religious/spiritual’ participants who made sense of unexplainable events by attributing causation to God, the ‘spiritual and religious’ participants did not offer explanations: nor did they claim that it was God or specific supernatural forces that caused these events. Instead they simply referred to them as spiritual. To illustrate the difference, Rose (nurse) a ‘religious/spiritual’ participant introduced in the previous section, described a series of events that occurred when she wanted to go abroad to care for her dying uncle. There were many variables that could have prevented her from going. However, she explained that everything “fell into place. I could not have done it on my own, God helped me. That was spiritual; it was very spiritual how things turned out.” Grace reported similar experiences and believed unexplained coincidences and seemingly unrelated events that occurred resulting in a meaningful outcome were fundamentally spiritual in nature. However, she did not offer an explanation that God was steering these events; in fact, she offered no explanation and did not seem to be troubled that she could not find an explanation. She said, “Spirituality can be really right here, on earth, you come across things, things happen and you think. ‘Why was that?’ you know, ‘what was that?’ It’s the mystery, its spirituality, the mystery.” Ammerman (2013) also reported such “a layer of mystery alongside everyday visible reality” (p. 276) as part of her participants’ understanding and experience of spirituality.

These mysterious stories were commonly narrated in the latter part of the interviews or at times when the interview was finished and the recorder was switched off. Jeanette even asked permission to tell her story. This indicated that although people understood mysterious and supernatural events as meaningful and as part of their spirituality they did not always feel comfortable talking about them. A reason for the discomfort could be because in general, people view the “metaphysical world as unknowable, irrelevant and nonsensical” (Bradshaw, 1994, p. 42).

Judy told a story of visiting a medium. However, she wove the story of the medium and her mother with twists and turns through other stories until she came to a point, just before the end of the interview, where she concluded the story of the medium. Judy experienced complicated grief that was not mitigated by her religious institution. She wanted to make sense of her mother’s death, who died when Judy was a teenager. Judy’s mother was diagnosed with cancer; however after telling Judy she was going to get better, she died unexpectedly. Judy described the unanticipated death of her mother as “shocking and frustrating”. She recalled her mother was going to perform a dedicated Bible reading in church on World Prayer Day but, “she bloody well died before that happened. And it left us frustrated. It shocked everybody. She just went out with a [click her fingers]. Frustrated and frustration!”

Part of her frustration caused through her mother’s death was the anger she felt towards her mother. Judy thought her mother knew that she was going to die, but she kept it from Judy, possibly to spare her distress. For many years Judy felt unsettled about her mother’s actions. She tried to find some kind of meaning; however, she found no answers. She said:

A lot of us ask the why. Why? I most certainly did. If God is a God of love, why is my mother so sick? And then they say there is reason for that. The ministers [say that]. But that is not good enough. And you should be able to go to Google (laughs) to get the answer, but it don't work that way. Now I don't know if she really, really believed that [she was getting better] and if she was just saying that so I won't worry, because only two weeks later she was gone. So I don't know, but I won't say directly to her 'oh mum you lied to me' but she...I don't know what she did.

Hence after many years of questioning and seeking she turned to alternative spiritual avenues for answers. Judy decided to visit a medium, whom she believed was able communicate with her mother's spirit in the afterlife because "spirituality helps you in bad moments, and it may give answers, you know." Her words reflected the constant need for understanding of the situation but most probably also of herself. For Judy the experience with the medium was constructive. She did not give Judy a specific message from her mother, however, she said "your mum is behind you and she loves you so much. She is glowing." The knowledge that her mother loved her was encouraging and reassuring. It gave her the comfort she was not able to find before. She found a new perspective surrounding her mother's death, to not waste energy on things one cannot really understand and know. It also reflects on Judy's understanding of spirituality as unconditional love, that she was seeking from God in moments of silence and which she gave to her grandchildren.

Through their narratives it seemed that some participants felt reluctant to talk about spirituality and spiritual experiences out of concern that the value of their meaningful spiritual beliefs and experiences might be demeaned. For example, while caring for her dying father Laura witnessed the presence of three angels. On a particular morning she entered her father's bedroom and saw three angels in the bedroom with him. She recounted her experience:

His face was turned towards the door. And there were three angels. Two standing and one sitting on the bed. I don't recall their faces but they were all white, and they were just there waiting with him. My dad looked at me, he had a look on his face as if to say 'ah, you will understand, Laura' and I acknowledged 'yes, yes, Dad I understand, it is time for you to go. Dad it is good.' And that is when he went. The angels took him.

Laura was consoled by the presence of the angels, because her father “had the comfort of those three angels and he knew where he was going. He was going to see my mother again so it was good.” Laura tried to share this profound experience with her sisters. However, they laughed at her experience and she struggled with the feeling of being disregarded by her sisters. Laura agonised with their impression that this experience could be explained away as imagination on her part. She said, “I haven't told many people because when I told my sisters they just looked at me and said 'oh, you're crazy'. Yeah, they say he passed away in his sleep...hmmm, yeah but I saw them.” Her sister's reaction, she felt, invalidated her experience. She consequently kept her experience private and reflected only on it in moments of solitude. This isolation stemmed from the fact that her experience was not socially and culturally recognised.

Not much is written about the metaphysical or the paranormal in relation to spirituality in the health and palliative care context. However, within the area of personality psychology, spirituality has been associated with beliefs in precognition, psychics, miracles, astrological powers, and ghosts (Saucier & Skrzypinska, 2006). To the participants, the importance of their experiences did not lie in the truth or the confirmation of the experience, but in the meaning the experience had for that person.

Discussion

Findings suggest that spirituality according to the ‘spiritual and religious’ participants is a broader concept than religion. It was about a connection to God, life after death and the mysterious side of life: that which cannot always be explained by reason. Gall, Malette and Guirguis-Younger (2011) explored the definition of spirituality and religiousness from perspectives of 234 participants from several nationalities, including French Canadians, English Canadians, Americans, and Europeans, along with participants from Asia, Australia, New Zealand, Africa, and Israel. They found that those participants who were affiliated to religious organisations and identified as spiritual also (like Laura, Grace and Judy) defined spirituality in terms of specific references to experiencing a connection with God and they used their religious structures as a pathway to experiencing the connection. Similar to the present study, further spiritual descriptors in Gall’s study were the afterlife and the unexplained or paranormal events.

There seemed to be a fuzzy boundary between the perspectives of ‘religious/spiritual’ and ‘spiritual and religious’ participants. Both these perspectives were theistically oriented. It was difficult to pinpoint exactly what differentiated these groups from each other except linguistics. A subtle point of difference that came up was that ‘religious and spiritual’ participants called the personal connection to God ‘spiritual’ while ‘religious/spiritual’ participants spoke of a personal relationship with God, as the core of their religion (spirituality).

Of all the perspectives identified in this study the ‘spiritual and religious’ perspectives seemed to be the most complex. Participants who reflected the

‘spiritual and religious,’ perspectives ventured effortlessly between theistic and extra-theistic perspectives. They did not seem to have trouble placing themselves within any of those perspectives, even within the same story.

Berghuijs et al. (2013) set out to find out what it means to be spiritual and what it means to be religious in the Netherlands. They found being ‘spiritual and religious’ was not characterised by a single orientation, but was signified many different understandings, making it less easy to interpret. These authors concluded that one should take into consideration the possibility that the ‘spiritual and religious’ category or perspective consists of different smaller groups. It appears that the ‘spiritual and religious’ ought not to be considered a homogenous group. Similar to this study Berghuijs et al. (2013) found that people who held a ‘spiritual and religious’ perspective seemed to fuse an attraction to traditional religious beliefs and behaviours with an attraction to ‘new spirituality’ that is, “new age ideology; healing, crystals, alternative treatments energies and astrology” (La Cour et al., 2012).

Findings revealed that these participants experienced religious belonging in varying degrees and that not all religious individuals relate to their different religions in the same way. “Just because someone admits to a religious adherence this does not necessarily mean that their commitment is keen and knowledgeable” (Pattison, 2013, p.27). Therefore, one cannot assume that all religious people will have similar spiritual needs. Pargament (2001) noted individuals who incorporated a religious and/or spiritual dimension into their lives and who held the role of a higher power as significant in their lives might benefit from religious and spiritual care more than individuals who did not cultivate a spiritual dimension in their lives. In 2001, Pargament found that more religious individuals

received more benefit from religious coping than less religious people. Less religious individuals may have difficulty drawing on spiritual coping resources, or may, as Jeanette commented, be characterised by feelings of desperation.

Spiritual but not Religious

In the previous sections it was highlighted that many participants talked of spirituality as inseparable from religion or felt that these two concepts were interdependent. These perspectives were also reflected in previous research. On the other hand, people are increasingly calling themselves ‘spiritual but not religious’ (eg., Hollywood, 2010; Marler & Haddway, 2002; Schnell, 2012). Similarly, in this study Gemma (counsellor and patient), Jo (hospice volunteer) and Estelle (counsellor) identified as being spiritual but did not belong to religious organisations. Neither did they participate in any religious activities. These participants, similar to the religious participants mentioned earlier, were familiar with the language of spirituality. However they used a completely different language themselves.

‘Spiritual but not religious’ participants conveyed a clear-cut difference between spirituality and religion. Their spiritual understandings and interpretations were anchored in their own experiences. They were brought up in Christian backgrounds. However, Jo and Gemma both underwent significant, unexpected spiritual transformations, which will be discussed shortly. Estelle has been involved in many different faith traditions and cultural experiences. Their various experiences had a significant impact on how these participants perceived spirituality. This finding is reflected in the findings of Berghuijs et al. (2013) who found that people who self-identify as spiritual but not religious were more likely

to have experienced spiritual transformation than people who self-identify as religious.

All three 'spiritual but not religious' participants relocated their understandings of spirituality beyond religious structures they were brought up with. Spirituality, to them, was about the "inner self" (Estelle). They experienced spirituality as "something that is larger than ourselves" (Gemma) and "being connected with everything" (Jo). La Cour et al. (2012) reported the same conceptualisation of spirituality in people they called "believers, but not religious" (p.74). These authors linked an inner striving that was not religious, a "vague striving for the essence of existence" (p. 74) to being 'spiritual but not religious'. These findings are confirmed by Barker (2010) and Zinnbauer et al. (1997).

Comparable to the 'religious/spiritual' participants in this study who understood that their lives were part of God's overall plan, 'spiritual but not religious' participants talked about being part of something bigger than themselves. In contrast to the 'religious/spiritual' participants they did not define spirituality as a belief in God or the worship of Gods. Neither did they assign any descriptions of any specific God. What these participants were describing seemed similar to what Ammerman (2013) called an extra-theistic discourse. In their study they identified spirituality, similar to what Jo, Gemma and Estelle described which is not attached to religion or dependent on any God but is about the inner self and personal experiences beyond the ordinary (p.268).

Jo, Gemma and Estelle were inclined to detach themselves from traditional forms of worship and, as mentioned before, saw a particularly strong contrast between spirituality and religion. To them religion was something fixed and organised, on an outward and social level:

For me spirituality is a connection with something that is larger than ourselves. It is not, I suppose, I make a distinction between man-made religion and spirituality. Man-made religion is what man has decided what is actually going on...But to me it is actually something that is very fundamental to who I am.

Although Jo and Gemma disagreed with traditional forms of religion they did not have any anti-religious attitudes; neither did they take a stand against religion, as reported by Egan (2009) and Keller et al., (2103) respectively. For example, Jo commented, “I think there are some people who need to go to a church or a communal place where they can say their prayers together.” Although they reported a difference of opinion with traditional Christian beliefs, they also revealed a disagreement with scientific rationalism, For example, Gemma said:

It is really nice to have someone to talk to about spirituality. I was talking to a friend recently who is going through a tough time but she has a way of thinking spiritually and I was talking to her at that level that was really invigorating for me because I have forgotten and when I am talking to palliative care patients that is often present, so that's maybe why I like that field. That is probably why I like that field, to me that is real conversations. I think that we as westerners we have really poo-pooed it all for the scientific model and it has been to our detriment.

Houtman and Aupers (2007) also reported this trend in what they called post-Christian spirituality where traditional Christian beliefs are replaced by spiritual worldviews. Furthermore, the authors believe post-Christian spirituality is an authentic way of knowledge acquisition and can be compared to finding knowledge through religion or science.

As mentioned earlier, Gemma and Jo both experienced sudden spiritual changes that influenced the way they perceived spirituality. Their respective spiritual experiences left them with altered opinions about spirituality, in relation to various aspects of themselves and the world in general. They reported changes in

their behaviour and personalities. They seemed to have a richer understanding and awareness of themselves and the world after their spiritual experiences. As a result of her spiritual experience Gemma adopted a fresh perspective on her illness, and her focus shifted from herself to the ones she might leave behind if she died of cancer. She also mentioned that in her counselling practise many palliative care patients reach that point of focusing on leaving their loved ones behind intact.

Gemma's journey of spiritual transformation

Gemma experienced sudden and unexpected spiritual transformation during her cancer journey. Before her spiritual experience, Gemma's faith rested on Christian beliefs which she described as "wishy washy." Her experience of her mother's cancer journey caused extreme anxiety for what lay ahead for her "I watched my mum's bones crumble, she had broken her spine, she had broken her hip, she had been in a lot of pain...I sort of thought that was my path, that was the way I was going." After she received news from her doctor that her cancer had spread and it was time for her to "get her affairs in order," Gemma experienced an unexpected and "fundamental spiritual shift." On a particular day, Gemma's husband was driving her to have a MRI done to confirm the doctor's opinion. She described her feelings of despair and hopelessness on that trip. "I cried out, and said someone has to come and help me because I am completely at the end of my tether. People say you fall on your knees, well, I was below my knees." A stretch of their journey required driving past a large river. The weather and river reflected her feelings of desolation: "It was pouring with rain; the river was like this mud soup stuff. Really ghastly, really, really no good." It seemed like she was at some level, experiencing an "existential aloneness" (Swinton et al., 2011. p. 646) where other

people could only see fractions of her pain. She also recognised these feelings in her husband. She said: “Peter was in some other land as you would be when your partner is going through something like this.” It was during this time of extreme anguish and suffering that she experienced a “spiritual shift” through which her emotional and spiritual turmoil lifted. She said:

And I just kind of went ‘Ah this is it, kind of; check me out right now. This is it.’ And then I had a profound shift of having this flood of peace coming over me...It is quite extraordinary. I don’t know what happened there, I don’t know if it is significant in Māori or whatever, I just had this bgwoo [demonstrations with hands like a blast] that happened to me there and I was going ‘what on earth was that?’ I had no idea, no idea. And then I thought there is something a lot more that I don’t understand and I don’t have to understand.

Even though Gemma did not understand the nature of her spiritual experience it left her with a sense of peace and contentment that rendered her more capable to cope with her illness and the complications surrounding it. She did not need an explanation about what happened to her or why it happened, “it was not about is this real or not, it was not about finding scientific evidence. I had the experience and that was that.”

After this extra ordinary spiritual experience Gemma’s spiritual journey was mostly self-directed. She became very interested in spirituality, from her own “personal viewpoint not from anybody else’s.” She started to read widely from a range of spiritual literature. She explored alternative healing modalities (for example, Reiki) and she began meditating on a regular basis. She also made an effort to spend more time in nature where she found peace and a sense of healing. She discovered different things about herself, she explained “I can write with my left hand, I can write poetry, all sorts of stuff that I never known I had. It is creative and it is fun.” She experienced an intensified perception; she noticed

smells and raindrops in a way she had not noticed before and noted “You know, you just kind of wake up.” Gemma’s main spiritual practice in a time of crisis during her illness was prayer, which she understood to be internal conversations. Prayers provided her with strength. Gemma’s experience also changed the way she thought about her own death; she started to believe strongly in the afterlife and being reunited with her loved ones. She thought that even if the afterlife is not real and whichever form it takes, the belief itself created a sense of strength and comfort:

I suppose when I die, I’m not really frightened of it. It brings tears to my eyes, but I am not frightened of it. And there will be lots of people to welcome me so, I think that’s pretty cool. And whether that is a shadow of my imagination, I don’t know, I don’t really care, I don’t know if it is right or wrong. I don’t really care if it is right or wrong. I really don’t. It strengthens me. It strengthens me.

Jo’s spiritual transformation

Jo reported having a near-death experience after a traffic accident. Despite remarkable similarities between the near-death experiences of individuals, no two accounts are identical (Moody, 1975). Jo said she was “surrounded by this beautiful light, but I was also floating in a dark area. I don’t know how you can describe that is light and darkness at the same time as well?”

Understandably, her worldview changed. In her nursing work, her approach to patient care changed; she was more mindful of her patient’s needs: physical, emotional and spiritual. Her way of being with a dying patient was different to what it used to be and she noticed the difference between herself and other people:

When people died others were more apprehensive, more you know, ‘That person is dying, stay out of the room.’ And I went there and I had a feeling, you know, dying is not the worst thing that can happen to you.

Joe's perception of God changed, she explained:

I think that it [the near death experience] changed a whole lot of my thinking because (sigh), I can't describe it (sigh) because all of a sudden you know there is more than just us human beings walking on two legs on this earth plane. And God is not the person they say in church sitting on a throne with Jesus sitting on his right hand side and what have you. It doesn't work that way, because it is not like that. I believe there is a... God energy but it is not the God that lots of people believe in, you know, the shape of a person. I think it is in all of us...and maybe our energy goes back to this God energy and I started thinking about reincarnation and I think that is a very plausible something as well.

Near-death experiences are not common human experience; people find it difficult to express their feelings about it (Moody, 1975). Jo found it difficult to talk to others about her experiences but at the same time this did not trouble her as she did not feel the need to convince them of her experience. Soon after her near-death experience, Jo reported having clairvoyant experiences, which she described as difficult and that the experiences were always in favour of others as she felt obliged to help them.

Estelle's journey

Estelle gave an articulate account of her understanding of spirituality. She considered the spiritual aspects of her work and her background. She grew up in a strongly Catholic environment; however she was always open to other religious traditions and philosophies such as Buddhism, which all provided Estelle with various spiritual approaches to interpret the world. She believed religion provided countless ways to find meaning and purpose in life. However, she refrained from committing herself to a specific religious organisation or even a set of views, as she wanted to remain open to experience other traditions and beliefs. It seemed that Estelle suggested that religion in general may confine people to a specific

way of thinking. It is important for Estelle as a counsellor not to send a message of rigidity but one of openness to the diverse worldviews of her patients. She appeared to suggest that any health care provider may be spiritually supportive if they do not compartmentalise themselves into a specific set of religious or spiritual beliefs. To her spirituality was about “the inner essence” of her life. The ‘inner essence’ may be a vague reference to the spirit or soul and this may reflect her tendency to use a fluid spiritual discourse. Estelle also emphasised that spirituality and religiousness were not only related concepts but complementary to each other. Her spiritual beliefs seemed to be syncretic in nature, a fusion of different belief systems.

Concepts of God

A distinctive feature of ‘spiritual but not religious’ participants was their view of God. Phrases used to describe some kind of God were vague like “something bigger than us” “something within each person,” not giving a name or form to their conception of ‘god’. They said that God was within each person instead of something or someone “out there,” an energy rather than a personal God with whom one can enter into a relationship. This concept of God seemed to be much more abstract than the concept of the Christian God religious participants talked about. For Gemma the image she had of God was not attached to some sort of persona. She had a holistic view of God which incorporated all life “Do I have a deity? No, not really. Do I have some sort of...? No, me, I have a feeling that I see God in things; [God] could be a lake. Could be that there is no wind today.” Jo believed that humans and ‘God’ are made of the same energy or substance as the universe. She said:

I believe there is a God Energy but, it is not the God that lots of people believe in, you know? In the shape of a person. I think the energy is in all of us, in everything.

Jo spoke of spirituality as the interconnectedness of all of life. She believed that there are a lot of people who don't need religion in their lives. "people who also have a feeling that we are connected any way, wherever you are."

The spirit and the Afterlife

Belief in the afterlife was not restricted to religious participants: Jo, Gemma and Estelle also believed in the existence of an afterlife. However, it seemed that they did not have such specific understandings of what the afterlife involved as the religious participants, who had a formal religious framework that provided them with information about the afterlife. Jo and Gemma expressed an uncertainty and shifting ideas of what the afterlife may involve. For example, Jo remembered dying patients having death-bed visions (Rose's descriptions of death-bed visions were discussed previously in this section). These death-bed visions were thought-provoking experiences for Jo and she often pondered on where the spirits of the dead go. She recounted a specific event where a dying lady saw the spirit of her deceased brother, John. Jo said:

So I mean this John was able to be there for his sister, so where does the energy of a dying person go to? Does it go to a parallel universe? Or does it go to heaven? I have been thinking about that. But, if John is living somewhere, where will John be living? He doesn't live behind Mars. Or, does he perhaps exist at a different vibration?

Gemma thought that complete clarity about what the afterlife entailed was not possible or even necessary. She explained her afterlife thoughts: "Do I believe in the afterlife? Absolutely, but it could be like an alternative universe. I have no

idea.” Later during the interview she reflected on another possibility that the afterlife might involve; a specific time and place where deceased loved ones would meet with a dying person: “I think it is a brief time that we have, just as we are dying, that those that dearly love us can come forward.” She emphasised that the content of the belief is not as important as the belief itself. To her it is the belief that strengthened her life: “And whether that is a shadow of my imagination, I don’t know. I don’t really care because it strengthens me.” Gemma seems to be making a very powerful insight in to human nature; that there is a power of hope in quite uncertain beliefs. It seemed that the afterlife to Jo and Jane was more about potential and possibilities than about specific understanding and convictions.

A major difference between spirituality inside and outside of religious borders seemed to be that the of the body-spirit connection. Within Christian religious understandings there existed a duality of body and spirit. The body and spirit were seen as separate entities. However, for these ‘spiritual but not religious’ participants there did not seem to be such a divide. For example, Jo said the Universal or God energy was within people, therefore spirituality related to a mind-body connection which was reflected in activities participants reported to be involved in, such as yoga, Pilates, mindfulness and meditation which gave them a sense of connection to who they really were or their inner selves.

In agreement with the present study, Gall, Kristjansson, Charbonneau, and Florack (2009) reported that their participants drew on more general terms to describe spirituality, such as “something between heaven and earth” or a “higher being”. In addition, some of their participants kept their definitions limited to

aspects of the human mind, and connectedness with one's inner self and philosophy.

Māori Spirituality

Although this study did not have any Māori participants, many participants spoke about Māori spirituality. For example, Gemma explained that conversations with palliative care patients changed during their illness; there was a deeper level to their conversations as their illness progressed. To her these were “real conversations.” She thought that Māori customarily had conversations at a deep, soul to soul level, not only when they were dying. She explained:

And maybe that is why I enjoy Māori so much, you know, Māori culture because they have the tendency to work in that field, to work in that space and therefore to have conversations with someone who is Māori, who is strongly Māori, is really great because it's so. They can operate at that level and that is great.

Rose explained that Māori were very accepting of deathbed visions and often heard the dying person call out someone's name, or knew that they were calling on ancestors or their ancestors were calling them, which prepared family members for the patient's death. Estelle confirmed this point. She remembered the experience of a particular client clearly:

I have had a Māori lady say to me that it was the old people who had come for her. Now the old people are people who have gone before them. And she saw clearly this person had come for her. And she felt very comforted that just seeing that person and in recognising that person she felt very comforted.

Participants also spoke of the value of Māori funeral rituals as well as the treasured wisdom they gained from attending these rituals. For example, Rose's father died when she was a young girl, and at that time children were excluded

from anything associated with death or dying. When she married a Māori man and attended her first tangi (traditional Māori funeral) she said “the whole death and dying thing was very open” and it opened up many unresolved feelings about her father’s death. She felt as if his death was a “non-event” in her life and explained that during her the first tangi “was like my dad’s death had been fast forwarded, like with a remote control.” Afterwards she felt she had gained power and control over this experience and could “fine-tune” her feelings by revisiting her father’s death and making peace with it. These experiences taught her “when I am looking after patients who are dying, we could do things better you know, take time to involve the family.”

Judy, Jeannette, Hilda and Mattie reported the importance of knowing about the past. Mattie and Hilda explained that within their church they actively work on genealogy because:

We are very aware of ancestors, that is why we are doing the genealogy. They are as important to us as our future generation what do you call them ... anyway; the past is as important to us as our future. Now that for Māori and Polynesian people that also is very strong, their past ancestors are as important to them as their future. So we all fit in together.

This description also points to the importance of whanaungatanga (kinship ties and relationships) which help to support whanau through difficult times. These findings suggest that a Māori understanding of spirituality is an essential element to life, and may shape thoughts on spirituality in New Zealand regardless of ethnicity. These results are echoed by Stirling, Furman, Benson, Canda and Grimwood (2010) who compared the spirituality of New Zealand social workers to that of UK social workers. Despite the mutual heritage of secularism, NZ social workers were generally more appreciative of spirituality and were more likely to

include spirituality in practice when compared to social workers in the UK. They concluded that the influence of traditional Māori spirituality is helping to shape NZ social work into a more spiritually responsive mode when compared to UK social workers.

Importance of religion and spirituality

This study revealed that when patients and their family members were informed of life-threatening illness, they experienced a whole range of feelings, from denial to intense anxiety, anger, sadness, distress, and fear. Participants were anxious, in differing degrees, about their diagnosis, treatment, side effects of the treatment, pain, social and personal consequences of illness and the treatment, and were also anxious about death. Lazarus & Folkman (1984) proposed that any given threat may cause anxiety in terms of how it is appraised. Firstly, a patient may evaluate their illness to determine its severity. Secondly, the resources available to deal with the threat would be appraised.

Medical treatments of cancer (chemotherapy, surgery, and radiation) all have negative side effects which add to the stress and impact emotionally on the lives of patients and caregivers. Anne, Lydia and Gemma anticipated chemotherapy with fear and anxiety, and were often anxious about hair loss. These expectations of the side effects and their beliefs about the nature of the treatment may contribute to distress and cause increased stressful reactions (Thuné-Boyle, Myers, & Newman, 2006). Severe side effects of chemotherapy and radiotherapy include loss of concentration, depression, weight changes, vomiting, nausea, loss of hair and fatigue. These side effects often occurred and the patient's fears were

realised. However, fears and anxieties may amplify the gravity of these side effects (Thuné-Boyle, Myers, & Newman, 2006).

Spirituality and religion supported participants in coping with the challenges mentioned above, because it provided them with a belief system and offered specific approaches that were available to reduce suffering. Coping gave participants a sense of comfort, strength and encouragement during life-threatening illness.

Summary

This chapter explored how spirituality is understood and how spirituality changes while living with dying. Voices represented in this section are not only from health care professionals, but also from patients' and family viewpoints. The relationship of spirituality and religion was highlighted as most participants started conversations about spirituality by talking about religion. In relation to religion, spirituality could be understood as synonymous with religion, complementary to religion or not the same as religion. The key difference articulated between spirituality and religion was that spirituality provided a connection to God or a higher being while religion was seen as an ongoing relationship with God. Many participants found that connection through religious avenues, while others found it through personal routes. Most participants believed in a God or a higher being, the afterlife and the mysterious unseen worlds between heaven and earth. Stories of seemingly paranormal events were understood as spiritual in nature. Health care professionals recognised these events as a common occurrence in the context of death and dying.

Many participants held religious and/or spiritual beliefs prior to their illness experiences. These beliefs formed a foundation for the appraisal of coping resources and assessment of the meaning and purpose of an illness for many participants. Participants applied and explored their spiritual and religious beliefs and resources during times of illness. The findings of this study suggest that spiritual changes often occur while living with dying, especially during the palliative stage. However, not all participants reported spiritual changes during the course of their illness. Some people used religious and/or spiritual beliefs to cope while living with dying. Other participants, who were neither spiritual nor religious, found meaning in significant relationships and activities. Moreover, many participants looked for spiritual meaning in a Māori spiritual context.

Chapter 5: Conclusion

In this final chapter I first discuss some implications of this research. Following that I discuss the limitations of this study and suggest avenues of future research in relation to the current research findings. The implications presented here are tentative in nature and are suggested as guidelines based on the findings of this study.

General implications

Participants used religion as a baseline to describe their understandings of spirituality. Some participants, religious and non-religious, equated the terms religion and spirituality. Some religious participants understood spirituality to be a broader concept than religion: a connection to God. ‘Spiritual but not religious’ participants distinguished the two terms. These findings suggest that for most participants neither religion nor spirituality was understood in exactly the same way. Similarly, Swinton et al., (2011) concluded that one cannot assume a global understanding of religion or spirituality.

A general implication from the present study arises from the finding that a number of participants indicated that they use the terms ‘spirituality’ and ‘religion’ synonymously. This could be of crucial clinical importance, especially with respect to spiritual care services. For example, a non-religious person, like Jeanette or Lydia, who viewed the terms spirituality and religion as synonymous, may be uncertain about an offer of spiritual care because of the assumption that spiritual care is aimed at religion. If health care providers are mindful of this, it may help them understand the person’s ambivalence. Therefore health care

professionals should explore the individual's understanding of, and attitude toward, spirituality as it may be erroneous for the health care provider to assume that the term spirituality is universally understood.

Different participants used quite different ways to define spirituality. These included a belief in God or a higher being, the continuation of the human spirit or soul into the afterlife, and the understanding that mysterious and paranormal events are spiritual in nature. It may be important for health care professionals to recognise that the use of these definitions may stem from different spiritual perspectives and this need to be taken into account when spiritual care is offered. A 'spiritual but not religious' individual's concept of God may be completely different to that of a religious person who makes no distinction between religion and spirituality ('religious/spiritual'). For example, Gemma, from a 'spiritual but not religious' perspective understood the concept of god as "something within each person" while Mattie, from a 'religious/spiritual' perspective, understood God in a Christian context.

This study described some afterlife beliefs and suggests that discussions about afterlife, by healthcare professionals as a part of spiritual care, may be helpful for many people. An important finding of this study was that caregivers may have different spiritual needs than patients do. People with life-limiting illnesses tended to talk about spirituality and how spirituality helped them cope with their illness. In contrast, caregivers (like Jeanette and Grace) emphasised the afterlife: they seemed to have a need to talk about the afterlife, a need not always shared by their dying loved ones. Health care professionals may in future be mindful of this difference. Further research is needed to gain more insight into the needs of caregivers.

Some participants interpreted unexplained and paranormal experiences such as angels (Laura), visiting mediums (Judy), death-bed visions (Rose) or clairvoyance (Jo) as spiritual in nature. Individuals who have experienced an unexplained or paranormal event may need the opportunity to explore the meaning their experience, within the context of a trusting relationship. However, their experience may not necessarily fit into their existing religious and/or spiritual schema and the person may be fearful that their attempts to make meaning of their experience may be invalidated by religious figures or family members (as explained by Laura). As mentioned by health care professionals in this study (Estelle, Jo and Rose) paranormal or unexplained events in the context of death and dying are not uncommon. A further suggestion is the development of pamphlets that provide patients and family members with information about possible unexplained and paranormal events that may occur in the context of death and dying and give information on where to find support and direction if it is needed. However, further research is needed to explore unexplained and paranormal events in this context.

Contemporary definitions of spirituality include meaning and purpose as descriptors (Egan 2009). However, in the present study, only Estelle, a counsellor, used the language of meaning and purpose. For the participants in this study, meaning and purpose seemed to be the outcome of, “rather than the essence of spirituality” (Koenig, 2013, p. 2624). In other words, spirituality provided many participants with meaning and purpose. For example, Anne wanted to make sense of her illness and she used religion (for Anne spirituality and religion were synonymous terms) to find meaning and purpose. Her illness was part of God’s plan for her life to make her a better person. Spirituality and religion seem to

operate as a system of coping and meaning-making on an individual level and are fundamental for many people living with dying.

The present study and findings from previous research indicate that finding personal meaning in the experience of living with dying is an essential part of coping with a life-limiting illness. Clinical services should therefore ensure that patients and family members who are affected by life-limiting illnesses have an opportunity to explore this with an appropriate spiritual care provider who may help patients and family members develop helpful ways of understanding their experience. Given the diversity of ways of understanding spirituality, health care providers may need a framework which allows them to consider and recognise the diversity of understandings. Applying the Diversity of Spirituality Model (refer to Figure 6), may help health care professionals to identify patient and caregivers' spiritual beliefs and perspectives. A tentative suggestion as a possible way to support health care providers to identify patients' spiritual perspectives may be to use the characteristics of each spiritual perspective identified in this study to base their judgements on. The main characteristics have been set out in Table 1. Please note that Table 1 below is based on the findings of the present study only. This study consisted of a small participant group and findings cannot be generalised. This table is in no way a complete description of spiritual understandings in a multi-cultural country like New Zealand.

Once spiritual preferences have been recognised, patients and/or family members may be placed with an appropriate spiritual care provider. For example, religious/spiritual participants may want to talk to a member of the clergy. Spiritual but not religious people may want to talk to a spiritual care counsellor. However, the exploration of the specific spiritual needs people may experience

goes beyond the scope of this study and future studies are needed to understand how spiritual needs may differ between people with different spiritual perspectives. The findings of this study also indicate that spiritual perspectives may change while living with dying.

	Religious/Spiritual (Religious person who makes no distinction between their religion and spirituality)	Spiritual and Religious (Religious person who makes a distinction between their religion and spirituality)	Spiritual but not Religious	Not spiritual or Religious
Concept of God	Christian concept of God as benevolent (Mattie) and active in the lives of humans (Anne, Sophia)	Christian concept of God. God is everywhere (Grace) God is Love (Judy)	Higher being (Jo) Something within all people (Gemma)	No specific belief in any God or higher being (Jeanette and Lydia)
Interaction with God	Ongoing relationship with God (Hilda, Mattie, Sophia, Rose and Maria)	Moments of connection with God (Grace, Judy and Laura)	Connection with inner self through spiritual activities such as mediation (Gemma and Jo)	N/A
Afterlife beliefs	Heaven (Hilda, Mattie, Sophia and Maria)	Heaven (Grace, Judy and Laura) Other people may have a different version of the afterlife depending on beliefs (Grace)	Parallel universes (Jo) Reincarnation (Jo, Gemma) Moment before death when family members meet dying person (Gemma)	Essence of deceased person lives on in the memories of loved ones still alive (Jeannette) No belief, but it may be a possibility (Lydia)
Unexplained and paranormal events	Constructed by God (Anne)	No explanation	No explanation	No explanation

Table 1: Characteristics of different spiritual perspectives as identified in the current study.

Spiritual changes

Spirituality can be fluctuating, and can change in unpredictable ways. The importance of and need for spiritual assessment in the palliative care and hospice context in New Zealand was highlighted by Egan (2009). Assessments can give health care providers a general background of the patient. However, as the findings of this study suggest, spiritual changes often occur, especially during the palliative stage. Some people may become more mindful of and involved in spiritual matters, some for the first time in a long while. For some people, the meaning of the term 'spirituality' may change. Therefore, spiritual assessment should be ongoing. Health care professionals ought to attend carefully to the differences between and among patients (Walter 2002) in order to provide comprehensive holistic care (Seibaek et al., 2013).

Educational implications

On a broader level, there are also implications from the present study that may relate to the education of health care professionals. Recommendations regarding proper educational preparation for health care professionals, doctors and nurses, cleaning staff, and hospice volunteers have been proposed extensively in academic journals, government policies, (MoH, 2003; 2008) and by Hospice New Zealand (2012). Currently a lack of adequate training to achieve these requirements has been identified. McSherry, Cash, & Ross (2004) suggested that spirituality in the health care sector may be taught in a very simplistic and generalised way.

The different individual perspectives identified in this study and others (eg., Ammerman, 2013 and Zinnbauer et al., 1999) may be used as part of spiritual

education programmes, research and assessments. The present study suggests the use of the Diversity of Spirituality Model (refer to Figure 6) to develop vignettes, based on the four main spiritual perspectives and Māori spirituality identified in this study, as a resource for health care professionals working in the area of death and dying. In health care education or continuing education workshops, vignettes may be incorporated to demonstrate the complexity of spirituality by illustrating the range of understandings people may have of the term. Vignettes have been shown to have educational value and have been successfully utilised as a curriculum resource in the training of nurses and doctors. For example, Emanuel & Cross (2012) found vignette-based educational sessions to be valuable in enhancing nursing students' understandings about stroke and its management. They recommend vignettes, based on real clinical situations, for future nursing training as they enable educators to bring life to theory in an effective way in the classroom. Their study also suggested that the majority of students appreciated this style of learning, and were motivated to actively engage in group discussions. In addition, their students supported the use of vignette-based education sessions for future use in education. Wallord & Singh (2006) used clinical vignettes in education for doctors and similarly found them to be of high educational value. Van Leeuwen, Tiesinga, Middel, Post, and Jochemsen (2008) identified the use of vignettes as useful in the evaluation of spiritual education programmes for nurses. In addition, researchers found vignettes to be a stimulating alternative to asking questions, and an effective way to build rapport and encourage conversations, especially when exploring topics that may be sensitive for participants (Hughes and Huby, 2002; Kagan & Tippins, 1991; Barter & Renold, 1999).

Another suggestion from this study comes from one of the participants, Jeannette, who suggested the commencement of education programmes at a community level to provide ordinary people with education, information and advice about how to talk to and care for friends and family members with a life-threatening illness. Murray (2000) similarly recommended community education to provide care. Hopton (1995) recommended that community support programmes be developed in consultation with those who are living with a life-limiting illness. Having their voices heard and valued may empower those with life-threatening illnesses. Furthermore the collaboration between health care workers and the public, or to use Jeannette's words the 'ordinary people,' may shed light on differences between these two groups. It may be a process of reciprocal learning which may evolve into an action research project.

Research Limitations

This study addressed a major gap in the current literature surrounding spirituality by exploring potential spiritual changes. There are a number of limitations to this study. Firstly, participants were recruited using a convenience sampling approach. A convenience sampling method does not produce representative findings (Robson, 2002). Even though the data was rich and appropriate to the experiences of the participants, non-random sampling techniques used in this study produced a relatively homogeneous sample: all my participants were female, white and middle class. Additional studies are necessary to research the experiences of men. The participant sample was also self-selected and thus could be biased toward individuals who were interested in spirituality and religion. As a consequence, the results cannot be generalised into the wider population. Religions and spiritual

societies have different traditions, customs, and teachings. Therefore, it is realistic to consider that differences may occur in the experience of spirituality and the corresponding changes at the end of life. More research is needed to address this limitation. Future studies exploring spirituality and spiritual changes could recruit research participants through a more random sampling method.

Further, conversations with health care providers only delivered a snapshot view of the various patients they talked about and it is impossible to know the patients' background and whether gender, culture and severity of illness influenced their experience of spirituality. Furthermore, all accounts were retrospective. Future longitudinal studies into the spiritual changes people experience while living with dying is recommended.

In the New Zealand context, Māori spirituality appeared to help shape spirituality for these participants. Māori spirituality is in the backdrop of the changing religious and spiritual milieu in New Zealand and is a stable source of knowledge to draw from for many New Zealanders. Although this study was open to all, unfortunately no Māori participants were recruited. Undoubtedly, the Māori voice would have supplemented this study with rich and valuable insights into spirituality at the end of life from an indigenous perspective.

Future research

The spiritual perspectives and corresponding themes mentioned in this study cannot be generalised and further research may be warranted to investigate their generalisability and to identify additional perspectives and themes that may not have been identified in this study. For example, the 'spiritual and religious' theme appeared to be very complex and may consist of more subthemes.

Further research is encouraged to understand what spirituality entails for a wider selection of New Zealanders. Currently, study participants have been restricted to mainly older adults within cancer care (Egan, 2009; Knitter, 2011). Research on spirituality within palliative care needs to be expanded to a) a younger demographic, b) a wider range of life-limiting illnesses and c) wider cultural backgrounds and different world views.

An interesting finding in this study was that not all people wanted to talk about spiritual issues; however that often changed when a person perceived their illness was getting more severe. How do people judge their when their illness is getting more severe? Is it only related to physical symptoms or are there other factors that cause these perceptions? Further research is needed to identify what influences people's spiritual perceptions.

Research into individual understandings of spirituality consistently shows that people have various and multi-dimensional ways of understanding spirituality (Asgeirsdottir, et al., 2013; Egan, 2009; McSherry, Cash, & Ross, 2004). This study was no exception; spirituality was understood as different things by different people and is a complex, vague and subjective concept. Each participant's personal spiritual perspective was important and relevant in their lives. Spirituality and religion were important coping resources for those living with dying. This finding confirms the importance of spirituality for people living with dying or at the end of life. Spirituality is a multidimensional concept and we may relate 'spirituality' to the words of Rob Bell when he talks about God. "The moment God is figured out with nice neat lines and definitions, we are no longer dealing with God."

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Appendix A

Letters of Invitation

Letters of invitation differed slightly between groups (i.e. health care professionals, caregivers and participants with life-threatening illnesses). A copy of the Letter of invitation for health care professionals is included below.

Letter of Invitation – Health Care Professionals

My Name is Deidre du Toit and I am a Masters student in Psychology at the University of Waikato. As part of this degree I am undertaking a research study leading to a thesis. The study I am undertaking involves exploring spirituality and the potential spiritual changes people with a serious health condition might experience. I am writing to invite you to participate in this study conducted by Dr Tess Moeke- Maxwell, Dr Neville Robertson and myself.

The aims of this study are to:

- investigate spirituality and the spiritual changes people living with dying might experience and what these changes mean to them
- identify if there are any common themes of spiritual change among the participants
- better understand the characteristics of the changes/transformation: what type of changes occur; how frequently do changes occur; is there anything particular that causes the changes; what are the consequences of the changes?

- identify if there are spiritual changes that occur at particular times of an illness more than other times

We hope to include a diverse group of people who have had different life experiences in this study, therefore data will be collected from two groups. Group 1 consists of health care professionals; nurses, counsellors, doctors, psychologists and volunteer workers working in palliative care or hospice. The second group is people who have experienced or are experiencing a life-threatening disease.

You are invited to contribute to this study as part of group 1, where we want to talk to health care professionals about the spiritual changes they observe in individuals who have or had a serious health condition. We are also interested in the evolving spiritual journeys you notice in the family members of your patients.

We want to meet with people who are open and willing to talk about their experiences working with patients and families who are or have been living with a serious health condition. During the interview you will be asked to reflect on events and consider how patients and their families understand and make meaning of living with dying and how the meaning-making system evolves.

We are also interested in how you, as a health care professional, take care of yourself spiritually. Your experience will give us insight into health care professional's response to patient experiences which provides an opportunity to gain vital information on the skills gained by health care professionals working in this field. These skills can be used in the future as guidance to other clinicians confronted in similar situations.

The interviews will be transcribed and a copy will be sent to you to read through and make any changes you feel are necessary. When all the interviews are

completed the thesis will be written up and all participants will be offered a summary of the findings or alternatively a copy of the thesis can be sent to you.

The study has been approved by the School of Psychology Research and Ethics Committee, University of Waikato. If you have any questions about any ethical issues related to this research please contact Dr Nicola Starkey, 07 838 4466 ext. 6472 or email nstarkey@aikato.ac.nz.

If you are interested in being interviewed for this study, please email me dd61@students.waikato.ac.nz, give me a call on 07 849 0239 or you can leave me a text message on 0120450848. If I do not hear from you soon I will give you a call to see if you are interested in being involved. You may find more information on this study by reading the Information Sheet attached to this letter. We have also provided a consent form. I look forward to contacting you shortly by telephone to confirm your interest in participating in the study.

Kind Regards

Deidre

Appendix B

Information Sheets

Information sheets differed slightly between groups (i.e. health care professionals, caregivers and participants with life-threatening illnesses). A copy of the Information Sheet for Health Care Professionals is included below.

Information Sheet – Health Care Professional

My name is Deidre du Toit and I am working on an MA in Psychology under the supervision of Dr Tess Moeke-Maxwell and Dr Neville Robertson at the University of Waikato. My thesis centres on spirituality and the spiritual changes people living with dying might experience. You are invited to take part in this research study and will have a two-week period to decide whether you want to participate or not. Please read the information sheet carefully before you agree to take part in this study. You do not have to participate if you do not want to and we thank you for considering our invitation.

WHAT IS THE AIM OF THE RESEARCH?

The aims of this study are to:

- investigate spirituality and the spiritual changes people living with dying might experience and what these changes might mean to them
- identify if there are any common themes of spiritual change among the participants

- better understand the characteristics of the changes/transformation: what type of changes occur; how frequently do changes occur; is there anything particular that causes the changes; what are the consequences of the changes?
- identify if there are spiritual changes that occur at particular times of an illness more than other times.

WHAT WOULD PARTICIPATION IN AN INTERVIEW INVOLVE?

Your involvement requires you to participate in a face to face interview. You will not be identified in any publications or presentations resulting from this study.

HOW MUCH OF YOUR TIME WILL PARTICIPATION TAKE UP?

The interview may take up to one hour, depending on how much you want to say.

HOW WILL I KNOW WHAT TO DO?

If you decide to participate in the study please contact Deidre. She will arrange details of your interview which can be held at a time and place of your convenience. Before the interview you can ask her any questions you have. The interview will be recorded with your permission. You do not have to answer questions you do not want to and the interview can be stopped at any time without having to explain why.

WILL I BE IDENTIFIED IN RESEARCH PUBLICATIONS AND WILL ANYONE KNOW THAT I HAVE PARTICIPATED?

No. You will not be identified in any way. Only Deidre will know you participated in the study. She is not allowed to talk to anyone else about your

participation in the study. No material that could personally identify you will be used in any publication or presentation.

WHAT IF I DECIDE I DO NOT WANT TO BE PART OF THIS STUDY?

Taking part in this study is voluntary and your involvement is entirely up to you. You can withdraw at any time before the research is written up. If you decide to withdraw from this study you can just let Deidre know without having to explain why.

WHAT WILL HAPPEN AFTER THE INTERVIEW?

Your interview will be typed up and you will receive a copy of the transcription. You are welcome to make changes to your transcript before it is used in the study. Deidre will contact you two weeks after the transcript has been sent to you to effect any changes you wish.

WHAT WILL HAPPEN TO MY INFORMATION?

Your recordings and interview transcripts are stored in a secured file on Deidre's computer, hard copies of the interviews will be locked in a file cabinet in her home office. All identifiable information will be removed before storage. It will be held for a period of 4 years and then it will be destroyed.

HOW WILL I FIND OUT ABOUT THE RESULT OF THE STUDY?

All participants will receive summary of the results of this study. On the day of the interview Deidre will ask you if you want a copy of the thesis after it has been written up: this will be noted in your consent form and a copy will be sent to you if requested.

ETHICAL APPROVAL

The study has been approved by the School of Psychology Research and Ethics Committee, University of Waikato. If you have any questions about any ethical issues related to this research please contact Dr Nicola Starkey, 07 838 4466 ext. 6472 or email nstarkey@waikato.ac.nz.

WHO SHOULD I CONTACT IF I HAVE ANY FURTHER QUESTIONS?

If you have any further questions you can email or phone Deidre du Toit or Dr Tess Moeke-Maxwell.

CONTACT DETAILS

Deidre Du Toit

dd61@waikato.ac.nz

07 849 0239 or 021 045 0848

Tess Moeke-Maxwell

tessmm@waikato.ac.nz

07 8485033 or 021 240 4666

Appendix C

Consent Forms

Consent forms differed slightly between groups (i.e. health care professionals, caregivers and participants who have experienced life-threatening illnesses). A copy of the Consent Form for health care professionals is included below.

Consent Form - Health Care Professionals

Title of Study: Investigating spirituality and the potential spiritual changes in people living with dying.

Researchers: Deidre du Toit and Dr Tess Moeke-Maxwell.

Participant's name

.....

Please circle **YES** or **NO** to the following statements:

1. I have read the information sheet dated I understand this study has been designed to learn more about spirituality and the spiritual changes that may occur for people who live with a serious or life limiting illness.

YES/NO

2. I am being invited to participate in a face to face interview. I have had the opportunity to discuss this study with Deidre and I am satisfied with the answers she had given me.

YES/NO

3. I understand that taking part in this study is voluntary and I may withdraw at any time if I wish.

YES/NO

4. I have had time to consider whether to take part.

YES/NO

5. I understand that participation in this study is confidential. No material that could identify me will be used in any publications of this study.

YES/NO

6. I know who I can contact if I have any questions after the interview or if anything happens which I think is a reason to withdraw from this study.

YES/NO

7. The study has been given ethical approval by the School of Psychology Research and Ethics Committee, University of Waikato and I know that the researchers must follow appropriate ethical procedures.

YES/NO

8. I understand that the interview will be recorded and transcribed.

YES/NO

9. I understand that the interview will be stopped if it appears harmful to me.

YES/NO

10. I wish to receive a copy of the final results of this study

YES/NO

If YES, please write a postal or email address below:

.....

.....

.....

.....

I (Full name) hereby agree to take part in this study.

Signed:

Date.....

(Participant)

Signed:

Date.....

(Researcher)

Appendix D

Loss and grief support telephone numbers

Loss and grief support telephone numbers to call if you want to talk to someone immediately.

Lifeline: 0800 543 354

Lifeline's 24/7 telephone counselling is there to support you, 24 hours a day, 365 days a year. The service is free and confidential and staffed by trained counselling volunteers.

Cancer Society Helpline: Helpline 0800 CANCER (226 237)

The Cancer Society Helpline provides a telephone support service staffed by nurses.

For loss and grief support you can contact Hospice directly. Keep in mind that you might not be able to see or talk to someone immediately, but will need to make an appointment.

Hospice Waikato: (07) 859 1260

Appendix E

Proposed Themes for Face to Face Interviews

Proposed themes for face to face interviews with health care professionals.

1. Background information.

Can you tell me a little about yourself and how you came into this work?

Can you tell me what the term spirituality means to you?

2. Observations of spirituality in patients and family.

What have you observed about spirituality within families that you support? For example can you describe particular values, beliefs or customs associated with different families?

3. Observations of spiritual changes.

Have you noticed any spiritual changes that occurred in patients?

Can you give me examples?

Are there any times the patient relies more (or less) on spirituality? What about the families?

4. How do you look after yourself, spiritually, to do this work?

Proposed themes for face to face interviews with participants who have, or are experiencing a serious health conditions.

1. Life before the illness.

Can you tell me a little about who you are?

Can you tell me what the term spirituality means to you?

Can you explain or describe your spiritual life to me, your beliefs and values, before you became unwell? What gave meaning to your life?

2. Discovery of the illness.

Can you tell me about your health problem and how it came about?

Prompts: What was it like for you? What can you remember thinking about a lot during that time? Did you notice any changes in your spiritual beliefs and values during that time? What about the way you saw the world? Did you question your beliefs at all?

3. Life now.

I can imagine that there have been lots of changes in your life since your diagnosis: have there been any changes in your beliefs and values since your diagnosis? Can you explain?

Prompts: Do you find yourself reflecting more on the meaning of life? Do you seek more spiritual support? From whom? When? Do you look at yourself differently, as a partner/parent/friend?

Can you give me examples of things that happened to you when you were likely to lean more (less) towards spiritual beliefs?

Did you notice any changes in spirituality in your family? Can you give me a few examples?

4. Is there anything about spirituality that you would like to talk about?

