University of Southern Queensland

Faculty of Sciences
Centre for Rural and Remote Area Health

Spirituality in men with advanced prostate cancer

"It's a holistic thing … it's a package"

A dissertation submitted by:

Laurence Lepherd
BA, MEd (Hons)

For the award of
Doctor of Philosophy

2012

Abstract

The aim of this doctoral research was to explore the nature of spirituality in men with advanced prostate cancer, and to discover the role that spirituality might have in these men as they face the challenges associated with living with their disease. The concept of spirituality is widely discussed in literature but definitions of it can be confusing. The term is often used synonymously with religion but such juxtaposition can be misleading. This research sought to describe the concept of spirituality through an analysis of literature and through an understanding of what spirituality meant to men in specific circumstances. A qualitative approach using a methodology that incorporated hermeneutic and dialectic principles, case study and narrative method was used to explore the spirituality of nine men with advanced prostate cancer who volunteered to participate and to tell the story of their cancer journey with particular focus on their spirituality. In this study, advanced prostate cancer referred to the condition existing when the cancer had become non-localised by spreading beyond the prostate gland to other parts of the pelvic area, or had metastasised to other parts of the body. The study found that spirituality for these men was a "holistic thing" that involved physical, psychosocial and spiritual matters that enabled them to transcend the everyday difficulties of their journey and obtain greater comfort and peace of mind during what was for many of them a traumatic time. The central theme in the men's stories was that of Connectedness – to themselves, to their partners, sometimes to a higher being and also to other people such as their family and friends. It was also observed that their physical and spiritual journeys progressed in parallel. The findings of this research will have considerable benefit to healthcare practitioners who are frequently involved in caring for men in this condition who have a need to discuss their spirituality as their life's journey ebbs and flows.

Certification of dissertation

I certify that the ideas, work, results, analyses, interpretations and conclusions reported in this dissertation are entirely my own work, except where otherwise acknowledged. I also certify that the work is original and has not been previously submitted for any other award.

_____ _____

Signature of Candidate Date

Endorsement

_____ _____

Signature of Supervisor/s Date

_____ _____

Acknowledgements

This research could not have taken place without the generous involvement of nine special men. They were all enthusiastic about telling their stories in the hope that others would gain benefit. Unfortunately, two of the participants did not live to see the finished project. I sincerely trust that the conclusions reached in this research will achieve what they and the other men anticipated.

I have special gratitude for my supervisor, Professor Cath Rogers-Clark who has been a source of infinite wisdom, patience and encouragement. Her experience and expertise have been a source of inspiration for me. My long-time friend and colleague Dr Des Coates was always perceptive and incisive in his observations as an Associate Supervisor. His insight and encouragement are also appreciated.

During the course of my research I have had the pleasure of having frequent discussions with, and the support of, a number of colleagues. I especially thank Dr Susanne Pearce for her challenging and good humoured discussions, and Dr Jenny Moffatt for providing perspectives that I have found informative. I have appreciated the support of my colleagues in the Department of Nursing and Midwifery at USQ, especially those also undertaking the PhD journey. I thank colleagues in the Centre for Rural and Remote Area Health who have shown considerable interest in my work and always offered encouragement.

I gratefully acknowledge the help of my colleagues at Cancer Council Queensland – Megan, Sylvia, Brigid and Alex, the Prostate Cancer Foundation of Australia, particularly David and Daryl, the Toowoomba Prostate Cancer Support Group, and Pastoral Carers at the Toowoomba Hospital, especially Lyn, for their diverse assistance, interest and encouragement. I have also received support from many other friends and colleagues and I am very grateful for this.

I owe a debt of gratitude to Dr Denise Miner-Williams, whose work, acknowledged during this dissertation, was a catalyst for some of my thinking on spirituality. I also acknowledge with thanks the proofreading carried out by Ms Judy Brewer.

My family is always a source of love and support and I especially thank my daughter, Louise, and my son Philip. My wife Marie Anne has my deepest thanks and love for her constant support and devotion during my PhD journey and over a much, much longer married life.

The poem on the following page is quoted from *Tao Te Ching,* translated by Stephen Mitchell (1988).

We join spokes together in a wheel,

but it is the centre hole

that makes the wagon move.

We shape clay into a pot,

but it is the emptiness inside

that holds whatever we want.

We hammer wood for a house,

but it is the inner space

that makes it liveable.

We work with being,

but non-being is what we use.

Tao Te Ching

Table of Contents

List of Conceptual Maps

List of Figures

List of Tables

Chapter 1 – INTRODUCTION

This study explores the nature of spirituality in men with advanced prostate cancer by considering the challenges and suffering that men face during their journey, what spirituality is for them, if it assists or hinders them during their journey, and how it is manifested.

It was the eminent psychiatrist Viktor Frankl (1997) who suggested that spirituality is often part of our unconscious being. Many people do not consciously consider it and, often, people do not distinguish between spirituality and religion (Tanyi, 2002) and this can lead to confusion. Sometimes an even casual mention of the word "spirituality" will bring a hasty "I am not religious" reaction. Frequently, neither spirituality nor religion figures in people's consciousness until there is a major event in their life that causes them to reflect. Such an event can greatly affect their spirituality (Murray, Mitchell, Meredith, Wilson, & Hutch, 2007). Illness generally is a time for such reflection, when lives are turned upside down by a significant challenge.

Prostate cancer, a challenge for men who are diagnosed with it, and for those who love them, is becoming more prevalent in Australian society as the age of the male population increases (Australian Institute of Health and Welfare, 2007). As well as being "cancer", per se, with its often perceived connotations of tragedy, prostate cancer can have added psychological and emotional difficulties. For example, for many men it is not just an illness; it is an assault on their manliness because both the illness and some of its treatments can affect their ability to engage in normal sexual activity. Consequently it becomes more difficult for them to cope with the illness and to try to overcome it (Hagen, Grant-Kalischuk, & Sanders, 2007).

As a cancer survivor, I have confronted the challenge of being diagnosed with a cancer, and dealing with the uncertainty this creates. In a broader context in my role as a pastoral carer supporting people in many of life's circumstances, I have often experienced the situation where a sudden event has resulted in individuals reflecting carefully on their existence, which includes their personal future and that of their

families. It was witnessing the confusion of thinking about the nature of spirituality, and the recognition of the prevalence of prostate cancer in our society, that motivated me to undertake research to discover what relationship there might be between the two, and to see the extent to which a positive relationship might lead to an improvement in the way in which men cope with their illness, or, regrettably, where spirituality might have a negative effect.

I had no illusions when I first started the study that I would be involved in constant deep, meaningful discourse on spirituality. I assumed that spirituality would be expressed and discussed in a variety of ways. However, I was somewhat surprised that, when I first introduced my research to a group of men (and their partners) who had prostate cancer, most of the more "serious" discussion on spirituality was provided by the partners. The men were largely silent on the matter. I was even further surprised when the final statement of the discussion came from a man who jokingly blurted out that his spirituality involved being on the golf course each Saturday afternoon. This prepared me for some of the findings of this study where it became increasingly evident that for some men, such pastimes were viewed as components of their spirituality. It became evident that, for many men, spirituality has a range of dimensions and expressions and does not always consist of something that is deeply experienced or thought of conceptually.

Armed with this salutary and fundamental introduction to my research, I embarked on a journey for myself, assisted most notably on the way by the nine men who were prepared to talk in detail about their prostate cancer journey and their spirituality. In this dissertation, these men are the centre of my research because they provide the substance – they had prostate cancer, and they expressed a spirituality that was often an integral part of their personal journeys.

This dissertation begins with this chapter **(Chapter 1)** providing a statement about the background of prostate cancer in our society and a brief account of the possible scope of spirituality. I present the aims of the study and the research questions, and this is followed by an expanded statement of the reasons for my personal involvement in the research. This reflection is important because it helps to define my personal locus in the research process and informs the reasons for the decisions I

make during the course of the study. It is also consistent with the research paradigm and process I discuss later in the dissertation. The chapter concludes with an overview of the study sections.

Background

Prostate cancer is the most common cancer diagnosed in Australia (Prostate Cancer Foundation of Australia, 2008). It is estimated that in Queensland, and in Australia as a whole, 1 in 5 men will be diagnosed with prostate cancer before the age of 85. In Queensland, the life-time risk of a man dying from prostate cancer is 1 in 22. Prostate cancer is the second most common cause of death through cancer of men in Queensland. It makes up 13% of all male cancer deaths. The average length of survival after men have been diagnosed with prostate cancer is 10 years (Australian Institute of Health and Welfare & Australasian Association of Cancer Registries, 2008; Queensland Cancer Registry, 2009).

With this illness so prevalent in our society, it is important to be aware of the need for men to receive support during the stressful times of their illness. This support can be provided through various interventions, one of which can be through spirituality. It is recognised that the spirituality of patients having a variety of illnesses can have a positive influence on their well-being (Büssing, Ostermann, & Matthiessen, 2007).

For this study, advanced prostate cancer refers to the condition existing when the cancer has become non-localised by spreading beyond the prostate gland to other parts of the pelvic area, or has metastasised to other parts of the body. This statement is consistent with the definitions of the National Cancer Institute (2010) and The Australian Cancer Network Management of Metastatic Prostate Cancer Working Party (2010).

Increasing recognition is being given to holistic healthcare. For some, this is broadly described as body–mind–spirit (Burkhardt & Nagai-Jacobson, 2005; Heelas, 2006; Stern & James, 2006). Others see mind as incorporating psychosocial concepts or further break this concept into psychological and social constructs (Bloom, Petersen, & Kang, 2007; Walton & Sullivan, 2004). Acceptance of these two positions leads to

a recognition that holistic healthcare consists of four domains: physical, social, psychological, and spiritual. These domains cannot be regarded as being discrete; there is overlap between them (Bloom, et al., 2007; Walton & Sullivan, 2004). Spirituality is an important part of the care of an ill person's well-being as it concerns the integrity or the wholeness of a person (Winslow & Wehtje-Winslow, 2007).

Many terms are used in describing spirituality. These include religiosity (extrinsic and intrinsic), faith, purpose and meaning, existential, the Ultimate, higher power, and transcendence. Hodge (2001), for example, suggests it is "whatever is held to be the Ultimate that fosters a sense of meaning, purpose and mission in life". (p. 204)

Spirituality, however it is defined, is generally experienced and expressed individually. Many people have some kind, and some level of depth or intensity, of spirituality, and this differs from person to person. It can differ according to a person's ethnic origin, or culture, and environment, and can be different within the same broad culture. The spirituality of a Christian, for example, might be different from that of an Australian Aboriginal person, or a Buddhist, or an atheist. These matters are discussed more fully in the literature review.

By studying men with advanced prostate cancer and recording their spiritually related experiences during their journey, and then analysing their stories, it is anticipated that a deeper understanding of these phenomena will be reached. This information might be used by any men with advanced prostate cancer and healthcare practitioners in a variety of disciplines. This will build their capacity to provide even greater support to the men in their care. D'Sousa (2007) provides a perspective by stating that people almost always appreciate a doctor's sensitivity to the beliefs of religious and spiritual patients. Fairly obviously, the same sensitivity in nurses and other healthcare practitioners could be valued by patients.

Aim of the study

It is the aim of this study to explore the nature of spirituality in men with advanced prostate cancer, and to discover the role that spirituality might have in these men as they face the challenges associated with living with their disease.

Research questions

Four important questions are identified in relation to spirituality in men with advanced prostate cancer.

1. *Perception.* How do men with advanced prostate cancer perceive their personal spirituality?
   General perceptions of spirituality will be discussed in the literature review but, under the premise that spirituality is a very individual matter, the nature of spirituality for men with this illness is of considerable interest.

2. *Experience*. What are the challenges and suffering experienced by men with advanced prostate cancer during their journey?
   Men can experience suffering in physical, psychological and emotional ways when challenged by a significant illness. It will be useful to identify these ways specifically in men with advanced prostate cancer as the foundation for examining the role spirituality may have in helping men during their illness.

3. *Effect.* If a man's spirituality assists his well-being as he faces the challenges and suffering during his journey, how is this achieved?
   While recognising that all men have spirituality, and exploring what this is for each man, it can also be useful to determine if his spirituality assists him, or if it hinders his ability to cope. Either way, the means by which his spirituality is demonstrated may provide a frame of reference for others, including healthcare practitioners, as they engage in caring activities.

4. *Analysis.* Are there common aspects of spirituality in men with advanced prostate cancer, even though they may have different life experiences?
   The identification of common elements of the spirituality of men with this condition may inform other men with a similar condition of possible ways to cope with their illness.

The researcher

Researchers become committed to a particular topic for a variety of reasons, often related to their life's vocation and experiences. In my case, my vocation was totally unrelated to health issues. I was a practising musician and music educator, having

had a career starting as a general primary school teacher in a rural one-teacher school, changing to a staffed primary school, thence to secondary school music teaching, and later in higher education in both teacher education with music specialisation and the training of professional musicians.

The onset of partial deafness brought on my early retirement. While I was able to participate in conversations, involvement in the training of professional musicians was no longer something I found ethically defensible. I had always had a commitment to a spiritual life as a practising Christian. The enforced change of personal direction arising out of my hearing loss facilitated my change to undertake training in the field of pastoral care and I was subsequently appointed as a voluntary pastoral carer at the Toowoomba Hospital.

Two years after working in this position I was diagnosed with bladder cancer. This was discovered "accidentally" during routine laser treatment for benign prostate enlargement. After quite traumatic treatment and subsequent recovery, I undertook training with Cancer Council Queensland as a volunteer in the Cancer Connect and Community Education programs. I also started to spend more time in the pastoral care of patients with cancer at the Toowoomba Hospital and spent four years working in the Day Oncology Unit and also in wards with longer-term cancer patients.

The consequence of these experiences at both personal and community levels has been that I have become aware of many issues relating to how people, and men in particular, react to the cancer experience. I have personally experienced the fluctuating emotions of having cancer, from the first confirmation diagnosis (in my case given as a probability within 10 minutes of becoming conscious after surgery), through the difficulties of treatment and the anxiety before and relief after regular check-cystoscopies. I have also experienced the varied reactions of my wife, my family and friends to my illness and treatment. During community education presentations on prostate cancer, I have witnessed the range of emotions, reactions and fears exhibited by men – from those who are intensely interested because they, or a near relative or a friend, have it, to those who seem to deny that it exists and who do not wish to talk about it.

My experience of using my own spirituality to cope with the physical and emotional stresses associated with this illness, and my reflection on the way men reacted to the existence or possibility of prostate cancer in them, led me to commit myself to exploring the ways in which men with this condition use, or do not use, their own spirituality to cope with their illness. Colleagues at Cancer Council Queensland drew my attention to the lack of research they perceived in the specific issue of advanced prostate cancer, a perception I confirmed when carrying out the literature review.

Part of my training in pastoral care, and with the Cancer Council, involved my recognising the importance of person-on-person care. I decided on a qualitative approach to the research as this is particularly suited to the exploration of individuality, the essence of spirituality. This paradigm has presented some real challenges for me, in that my previous research background used two methodologies, one of which was quantitative and the other comparative. (My comparative studies in international music education systems were based on what Hsieh and Shannon term "summative content analysis" (2005, p. 1277).) Despite the difficulties, my commitment to helping men with a demonstrated problem with recognising and using their spirituality in their coping with prostate cancer, has been the driving force for my completion of this dissertation. This, together with the enthusiastic support of the men directly involved in the research, and a commitment to honouring my family, friends and colleagues who have shown interest and encouragement in a new "career path" for a septuagenarian, has resulted in my completion of this journey. In this sense, I have embarked on a journey that, to some extent, mirrors the journey of the men who participated in the study.

Research outline

This dissertation commences in this chapter, **Chapter 1,** with an Introduction to the main issue of spirituality and advanced prostate cancer and the possible relationship between the two. Spirituality is placed in a context of holistic healthcare. The research questions have been stated above.

Chapter 2 is a literature review. The **first part** considers spirituality. Many attempts have been made to define spirituality. In this inquiry the words "describe" or

"description" have been used rather than the word "define". Such an intangible concept possibly defies definition except in the broadest terms because it is so personal, individual and varied. It is appropriate to describe some of its inclusive dimensions rather than attempt to define it precisely. During the course of this chapter issues such as religion and religiosity, and a sense of the sacred are discussed briefly, and there is a focus on what the literature regards as an important aspect of spirituality – transcendence. Much of the literature indicates that it is transcendence that distinguishes spirituality from other psychosocial constructs. The outcomes of spirituality are also discussed.

The **second part** of **Chapter 2** reviews the literature relating to prostate cancer. The prostate gland, and the stress associated with various phases of a man's journey such as diagnosis and treatments, and psychosocial effects, are considered briefly to provide an important context for the study as the participants frequently refer to these matters in the stories they tell.

Also discussed is spirituality in relation to people with cancer, and then to men with prostate and advanced prostate cancer. This chapter lays foundations for the main thrust of the research: spirituality and advanced prostate cancer. In the process, the concepts of spirituality and well-being, psychosocial constructs, holistic health, and spiritual needs and distress are also discussed briefly.

The literature review provides a synthesis of literature. It is my synthesis, particularly in the form of a conceptual map (Conceptual Map 2.1), that offers a perspective from which spirituality can be viewed.

Arising from the consideration of spirituality and prostate cancer, **Chapter 3** considers the paradigm and process used in this research. This study is centred on humans as individuals so a qualitative, constructivist framework using a methodology that incorporates hermeneutic and dialectic principles, case study and narrative method was selected. Such an approach enables individuals to tell their experiences in their own words rather than provide answers to preconceived questions in the form of a questionnaire. It is the inherent nature and individual spirituality of men with prostate cancer that is being researched in this project. The

use of narrative provides a greater opportunity for a man to present his inner, personal feelings and to construct his journey.

The foundations for the research paradigm and process used having been considered, **Chapter 4** discusses the project design and method. This includes detailed information about the selection of the nine participants, the specific use of narrative method and the issues of narrative and thematic analysis.

An important consideration in Chapter 4 is the principle of ethical research with formal ethics approval from a human research ethics committee (HREC) an essential pre-condition. This was necessary because the project involved highly sensitive and personal issues with human participants who were confronting a life-threatening illness. Given the personal nature of the study, the importance of confidentiality was also fully recognised.

Also included is a statement on the way rigour and quality have been addressed during the research as a whole. The issues of the qualitative equivalent of reliability and validity are considered.

Chapter 5 provides the narratives of each of the men interviewed. Narrative analysis is used to construct each man's story and to provide a free-flowing account of their respective journeys. **Chapter 6** proceeds with a thematic analysis of the information provided in the narratives of the men's experiences. It considers the medical, physical, psychological, emotional and spiritual aspects of their journeys.

Chapter 7 discusses the information gathered from the participants and draws together both the common and disparate elements of the men's spirituality. **Chapter 8** seeks to answer the research questions, indicate some of the inquiry's limitations and draws conclusions from the study providing questions for future research that have arisen from it.

Note on use of the first person

Spirituality is a personal issue. While there may be aspects common to most people, its existence in a person is dependent on the individual. For this reason, I frequently

depart from normal academic convention and use the first person in the text. More details are provided in Chapter 3.

Terms

The general term *healthcare practitioner* is used frequently through this inquiry. This refers to doctors, nurses, psychologists, pastoral carers, naturopaths – anyone who is involved in the healthcare of men with prostate cancer or any other people with illness. The all-inclusive term is used to avoid itemising each different practitioner whenever implications of the findings are mentioned.

I have also used the term *Conceptual Map* instead of *Figure* or *Diagram* in this dissertation because this term reflects more appropriately the conceptual nature of integration of the elements that are the substance of each illustration.

I now proceed with the literature review.

Chapter 2 – LITERATURE REVIEW

> A spiritual journey and associated experiences tend to be intimate, private, and are frequently hard to capture in words. (Wink & Dillon, 2002, p. 90)

This chapter reviews the literature associated with key concepts in this inquiry – spirituality, and its presence in men with advanced prostate cancer. Relevant literature from the fields of healthcare and nursing, as well as psycho-oncology and prostate cancer is reviewed, together with a number of publications written by cancer organisations for the public in general. The latter were used with caution and only when the relevant statements had a recognised scholarly base. Considerable use was made of databases and search mechanisms to seek out relevant literature. These included CINAHL (Ebsco), MEDLINE and PubMed, Sage Humanities and Social Science, Wiley Online Library (and other publisher collections and databases), PsycInfo (American Psychological Association), Web of Knowledge, Health, and Health and Wellness Resource Centre, as well as digital theses available through TROVE and Proquest Dissertations and Theses, and Google Advanced Scholar,

The review adopts a framework identified by Cronin, Ryan, and Coughlan (2008) who describe a traditional or narrative literature review as summarising a body of literature and synthesizing it, drawing conclusions about the topic that is the object of scrutiny. They indicate that such a review may assist in refining and focussing the broad research question, and they allude to the review's helpfulness in developing a conceptual framework with the potential for discovering gaps in current research. Adoption of this approach in this research has enabled a methodical review of the relevant literature and has highlighted the research gap, particularly more recent, relating to spirituality in men with advanced prostate cancer.

Four research questions have been identified:

1. How do men with advanced prostate cancer describe their personal spirituality?
2. What are the challenges and suffering experienced by men with advanced prostate cancer during their journey?

3. Does a man's call on his spirituality assist his well-being as he faces the challenges and suffering during his journey and, if so, how?
4. Are there common aspects of spirituality in men with advanced prostate cancer, even though they may have different life experiences?

Ultimately the aim of this research is to illuminate the spiritual journey of men with advanced prostate cancer, which will provide insight and guidance to the men themselves, their loved ones and their carers. This should also produce insights in helping other men make use of their own spirituality. It is important to understand the essence of spirituality in each man's life and see how this can affect the way he copes with advanced prostate cancer, especially considering that the condition might eventually lead to his death.

A major event in a man's life can be the symptoms that will lead to possible prostate cancer testing and diagnosis. Once cancer has been diagnosed and the stages and grades of the cancer determined, he has to consider the possible treatments. This is complicated and can impinge on the psychosocial and spiritual aspects of his life. The advent of prostate cancer can have a great effect not only on a man's own life but on the life of his partner, if he has one, or his family and other friends. Some of these psychosocial aspects are discussed.

From this review was extrapolated a framework in the form of a Conceptual Map (Conceptual Map 2.1) that synthesises the essential aspects of what authors have suggested is the nature of spirituality. The literature review continues by considering briefly literature on prostate cancer, focussing particularly on the challenges men face. It concludes by considering the relationships between spirituality and cancer, and spirituality and prostate cancer. Attention is finally drawn to the gap in understanding the nature of spirituality in men with advanced prostate cancer.

About spirituality

> Spirit is the life principle – the soul, will, and thought. The vital life force in humans, spirit is the pervading animating principle or characteristic. (Villagomeza, 2005, p. 286)

In this section, aspects of spirituality are identified as they arise from the literature, with the framework and subheadings (Table 2.1) being categorisations of these aspects. These sections and their relationships are synthesised in the Conceptual Map 2.1. After the Conceptual Map is presented, the remaining part of this section examines some additional and closely related elements.

Much literature alludes to the highly individual nature of spirituality and contends that it differs from person to person and from culture to culture. It can also differ according to an individual's circumstances (Aldridge, 2005; Dyson, Cobb, & Forman, 1997; Murray, et al., 2007).

Some issues are prominent in the literature with a key concept being that spirituality comprises dimensions and that these are internalised before they become manifest externally. The dimensions can overlap and be present in an individual concurrently to a greater or lesser degree, while the various outcomes of manifest spirituality can also be demonstrated concurrently and to a greater or lesser degree of intensity.

Table 2.1 – Overview of five sections in the literature review of spirituality

Spirit and spirituality

The English word "spirit" was derived from the Latin word "spiritus", meaning "soul, courage, vigor and breath" (Barnhart, 1988, p. 1047). This word was used in the Latin Vulgate translation of the Bible where the original Hebrew and Greek words were "ruach" and "pneuma" respectively. Harper (2001) contends that the word spirit generally alludes to a person's soul. The Concise Oxford Dictionary defines the word as "animating or vital principle of person or animal; intelligent or immaterial part of person, soul" (Sykes, 1982).

There seem to be almost as many definitions of spirituality as there are writers on the subject with authors referring to the diversity of understanding the concept in such terms as "puzzle" (Miner-Williams, 2006), "nebulous" (Daaleman & Frey, 2004, p. 502; Holland, et al., 1998, p. 461; Kaut, 2002, p. 221) and "fuzzy" (Zinnbauer, et al.,

1997, p. 549). In the following, the word "description" is used rather than definition when referring to aspects of spirit and spirituality.

The works of many authors demonstrate their different understandings of spirit, and the following references come from both secular and religious sources. Miner-Williams (2007, p. 1218) and Schultz (2005, p. 161) state that it is the "core of a person's being". The Apostle Paul describes the Greek word "pneuma" as being a person's "inner being" (The Bible, Ephesians 3:16 New International Version). Watson (1989) relates spirituality to the soul by suggesting that it is the "essence of the person" which has a sense of self-awareness and inner strength, and the power to allow a person to transcend their normal self (p. 224). These observations are consistent with that of Villagomeza cited above where he refers to spirit being a pervading life-force and human characteristic.

If the human spirit refers to mind, soul or inner being, then spirituality can refer to the state or condition of the human mind (Kluger, 2004). Spirituality is also regarded as a universal human phenomenon, present in everyone whether religious, humanist, hedonist or atheist (Goddard, 1995, pp. 808, 809). This is an important factor in answering those who believe that they are not spiritual because they are not religious. The significance for this inquiry is that if the assumption is accepted, every man with advanced prostate cancer has a spirit and it becomes a matter of trying to understand the inclusions in that spirit. The significance of all these statements is that no single faith or religious tradition can claim that its understanding of spirit is unique to a specific way of thinking but rather is a characteristic of humanity.

Citations above indicate the belief that a person's spirit is his or her inner being. It is theoretically possible for a human being to maintain his or her spirit in an entirely internal location. However, for many men and women their spirituality is both internal and external (Cotton, Levine, Fitzpatrick, Dold, & Targ, 1999; Heelas & Woodhead, 2005; Mytko & Knight, 1999; Plante & Sherman, 2001).

A term that is sometimes used interchangeably with spirituality is "sacred". Some regard spirituality as being at the heart of religion that is at the centre of how people integrate the sacred into their identities and lives (Pargament, 1999). In outlining the

views of a number of writers, Plante and Sherman suggest that spirituality is seen as the major function of religion and involves the search for the sacred (2001). Further perspectives are provided through the suggestion that an existential search by an individual for ultimate meaning is related to an understanding of the sacred (Wink & Dillon, 2002) and that there is an important relationship between spirituality and the sacred or transcendent (Sinnott, 2001).

An important aspect of sacred is that it can be considered as providing a greater power to a concept of spirituality.

> Invoking the label "spiritual" adds luster and legitimacy to any number of values and practices, but the label may ultimately lose meaning and power when it is separated from its sacred core. (Pargament, 1997, p. 465)

Pargament contends that spiritual and sacred are not synonymous terms but that sacred implies a deeper facet of spirituality. He also believes that "divine" is an important concept in considering religion and spirituality and speaks of "notions of a force that created and maintains the universe, a power transcending natural forces, or a personal Being intimately involved in the world" (1997, p. 30). In discussing these terms Pargament seems to emphasise the complex nature of the concept of spirituality where this and the term divine, together with sacred and transcend, add different facets to the concept.

A sense of the sacred is also related to the psychology of religion and it is sometimes evident that a sense of sacred as a separate entity is essentially a Western predilection because this culture separates sacred and secular whereas other cultures see the two concepts as integral (Fontana, 2003). Sorajjakool shares this perspective, seeing spirituality as a "symbol of the sacred" (2006, p. 19), and draws attention to the varied understandings of what sacred means across cultures and formal religions. Another explanation is that sacredness is part of a classical understanding of religion (Tirri, 2006). It can be regarded as the common denominator of spirituality and religion (Hill & Pargament, 2008).

These disparate perspectives allude to a wider controversy about how spirituality and sacred exist in relation to one another. Is spirituality a component of sacred, or is sacred a part of spirituality? Use of the term sacred can be almost as confusing as the word spirituality itself. In referring to the work of others, Wink and Dillon (2002) allude to an understanding of the existential aspect of spirituality by using the word sacred but do they not proffer meaning for the term. A more meaningful understanding of the role of sacred can be found in Sinnott's reference to transcendence (2001) where she suggests that spirituality is one's personal relation to the sacred or transcendent which then "informs other relationships and the meaning of one's own life" (p. 199). If this juxtaposition is accepted, it can place spirituality, sacred and transcendence in a closer and more readily understood association.

The above discussion highlights the importance of authors being clear about what they mean when using these terms in their own writings. The terms spiritual, sacred, divine and religion need to be clearly described, together with the perceptions of their nuances, for research to be more significant.

Spirituality and religion

This section discusses in more detail the difference between two commonly used terms identified above – religion and spirituality, because, as noted above, they are often used interchangeably. It is contended that indiscriminate use of the terms can lead to confusion (Tanyi, 2002). While some authors regard spirituality and religion as being complementary, not identical, concepts (Highfield, 2000), others indicate that some studies have foundered because researchers have not been clear about their definitions of the terms (King, Speck, & Thomas, 1994).

A distinction is sometimes made between the terms whereby religion can be regarded as a formal and organised part of a person's inner being whereas spirituality relates to a broader state of mind that might not necessarily involve expression through formal organisation. A number of authors attest to the organisational implications of religion as distinct from the personal nature of spirituality. Plante and Sherman (2001) suggest that the distinction is sometimes a quagmire but they see a necessity for health workers to have some definitional concept. They distinguish between

religiosity and spirituality by referring to religion having theological beliefs and practices with commitments and congregational activities, whereas spirituality has greater reference to the individual and might not have association with an organised institution. This view is supported by Burkhardt (1989) who believes that religion is a component of spirituality where collective spiritual beliefs of people are organised into a system.

Historically, a distinction between spirituality and religion has not always been evident. William James (1982) regarded religion as the "feelings, acts and experiences of individual men in their solitude" and the way they understand themselves in whatever they regard as the divine (p. 21). This suggests that religion has not always been associated with organised spirituality, but the history of the Christian church, at least in the societies where it has been prominent, has not always regarded the individual in a self-focussed sense.

An organised concept of religion is now seen to be giving way to a more broadly based spirituality (Heelas & Woodhead, 2005). These authors contend that religion is related to a person's association with traditional aspects of life that involve being more conformed to a traditional notion of the way their life should be led rather than a more individual freedom of life. The "life-as" concept is seen as moving away from "'objective' roles, duties and obligations" determined by the religious organisation to a life lived in reference to an individual's inner experiences (p. 3). Individualism is seen as having the courage to answer only to one's own authority, not following a traditional path but focussing on "self" and observing Shakespeare's pronouncement "To thine own self be true". This might be regarded as a post-modern approach to spirituality where an absolute of religion gives way to the relational and broader concept of spirituality.

Spirituality can also be regarded as "a feeling or a state of mind" and religion as the way that that state becomes classified into law (Kluger, 2004). This statement is overly simplistic. Not all people who are religious and spiritual would believe that their religion is equated to law. The spirituality might be organised but it might not be legally binding as the word law implies.

The broader differences between spirituality and religion are appropriately summarised by Thoresen and Harris (2002) who suggest that a frequently held view is that religion is a social phenomenon involving social institutions which adhere to certain rituals and practices, whilst spirituality is a more personal experience that can be associated with religion but which is becoming increasingly viewed as being more independent.

Another term that is used occasionally is "religious spirituality". Swinton (2006) uses this to distinguish between religious and non-religious spirituality. The term could also be applied to circumstances in which a person's spirituality is closely linked but not necessarily limited to his religion. Spirituality may refer to a person's inner being; religion could imply an organised basis for a person's inner direction; and religious spirituality may refer to a person's inner being in relation to an organisation. However, the introduction of this third term can imply that it is possible for a person to be religious without being spiritual. The person who observes mechanically all the external requirements of a religion, but without a corresponding internal experience or commitment, would fall into this third category. This is a situation where introducing more terms might serve only to deepen the quagmire associated with trying to understand spirituality.

It is not always appropriate to make assumptions about a positive value of spirituality. Koenig (2009) does not believe that spirituality is necessarily consistent with good mental health. So that he can maintain "the purity and distinctiveness of the construct" he proposes that "spirituality be defined in terms of religion, where religion is a multidimensional construct not limited to institutional forms of religion". He then prefers to use the terms religion and spirituality synonymously. While Koenig's warning about assumptions may be valid, his definition is at odds with many other authors and does not reflect the now widely recognised distinction that religion has a proportion of organisation or system associated with its concept, whereas spirituality is less formal and more individually focussed. At the same time, it is not axiomatic that the two concepts need be polarised. There seem to be weighty arguments for recognition of the two words as having their own integrity but also some overlap in their conceptualisation.

So far, reference has been made to literature relating to spirituality, religion, a sense of the sacred and transcendence. A more detailed discussion on transcendence is provided below but, for the purposes of this research, a simple description of spirituality is that it relates to a person's inner being and that everyone has it. What distinguishes spirituality from psychosocial constructs is the concept of transcendence. Religion is understood as being a spirituality that is shown through an organised group of people having a similar spirituality. A sense of the sacred can apply to a person's perception of their spirit that can exist in the inner being as well as in a more formal religion. Transcendence permeates the spirit, religion and the sacred.

Multidimensional nature of spirituality

If the above paragraph places four terms in a broad perspective, the next step is to review literature that seeks to explain the term spirituality in more detail and practical living terms. Concepts of spirituality can be diverse (Canda & Furman, 2010) and the multidimensional nature of spirituality is acknowledged by many authors (Brelsford, Marinelli, Ciarrochi, & Dy-Liacco, 2009; Büssing, et al., 2007; McSherry, 2000; Plante & Sherman, 2001; Yanez, et al., 2009). The review that follows makes use of a variety of terms found in the literature. There are many dimensions that amplify the concept of spirituality and these frequently overlap and, in practical life, interact. To separate concepts into discrete compartments can lead to an artificial reductionism that does not occur in real life. In the framework that follows all components can be seen as inclusive and interrelated. It is the internalisation then outward manifestation of spirituality that adds to the way it might be understood more fully.

If spirituality is a "state of mind", there must be aspects or facets that exist in that state. Emphasis here is on *a* state of mind, not *the* state of mind. State of mind is a term often associated with other concepts such as an "agitated state of mind" or an "optimistic state of mind". Being in a spiritual state of mind implies incorporating a number of dimensions. Following are dimensions evident in the literature.

Integrative energy (force and power)

Integrative energy (force and power) can be seen in spirituality at three levels. Firstly, it can be observed at an individual level where it can lead to intrapersonal harmony in the domains of body, mind and spirit (Goddard, 1995). Other writers have also referred to power, energy and/or life force as dimensions of spirituality (McSherry, 2000; Miner-Williams, 2006; Plante & Sherman, 2001; Villagomeza, 2005). It can also include a dimension of faith in a traditional religious sense and can relate to transcendence (Fowler, 1980).

While still applying to an individual, at a second level, power (or force), referred to by Murray et al. (2007) in their definition of spirituality, has a wider meaning. To them, spirituality "often propels a person to seek relationship with others, the environment, or that force beyond" (p. 16).

At a third level, power in relation to spirituality is seen in a wider sense by Martin Luther King when he refers to spiritual power (1977) and applies his Christian-based perspective to the wider implications of the problems in a society that embraces scientific power over spiritual power. He alludes to the centricity of the power of spirituality by observing that society has minimised the internals of our lives and maximised the externals. King refers to spirituality in its broadest sense – to distinguish generally between *the* spiritual and *the* material, although he relates this to an assessment of society at large rather than to individual spirituality.

The three levels mentioned above are not necessarily progressive – level one is basic, level two is more focussed and level three is broader, but they do have some inherent association. Power and integrative force can assist in fostering spirituality and this can be increased not only through a connectedness with a higher power but through a recognition of power in the cosmos as distinct from a reliance on the material, something King sees as the antithesis of the spiritual.

Values and beliefs in spirituality

There are various models for what is embodied in spirituality and they all generally include values and beliefs that can lead to a greater meaning in a person's life (Plante & Sherman, 2001; Tanyi, 2002).

Values have many aspects and can include love, hope, trust and wisdom (Hart & Waddell, 2003), as well as honesty and imagination (Dossey & Guzzetta, 2005). Sherman and Simonton (2001) refer to a number of studies that support the view that among older patients (and to middle-aged patients to a lesser extent) with internalised values that guide their life, there were lower levels of depression and emotional distress when there were higher levels of intrinsic religiousness. Lin and Bauer-Wu (2003), in conducting an extensive review of research associated with psycho-spiritual well-being in terminally ill people, and specifically those with advanced cancer, observed that many participants found considerable strength in the beliefs and comfort in their faith. They concluded that more research needs to be carried out using examples from diverse cultures to determine what may be effective interventions that will contribute to the psycho-spiritual well-being for people towards the end of their life. This is a significant conclusion, especially if greater emphasis is given to recognising the richness of the diversity of spirituality of people in different cultures and of ethnic origins.

There is increasing recognition of the therapeutic worth of the spiritual values and beliefs of clients or patients by healthcare practitioners. Hodge (2006) refers to studies demonstrating that many people want their values and beliefs to be part of a therapeutic dialogue and that they wish for their values to be respected. Hodge has a Christian background but is a strong advocate of a broad construct of spirituality. He has worked with people of different cultures and has been a prolific writer on matters relating to spirituality. He has researched and written extensively on spiritual assessment and developed a model assessment instrument, qualitatively based, that explores the spirituality of people in a variety of circumstances associated with healthcare. This instrument conforms to the American Joint Commission on Accreditation of Healthcare Organizations Spiritual Assessment Recommendations (2005). His respected input lends credence to the wider acceptance of the possible breadth of the concept of spirituality and also the presence of the dimensions of values and beliefs. Winslow and Wehtje-Winslow (2007) provide similar perspectives on the importance of these dimensions.

Still within the sphere of the importance of values in a person's well-being, respect by health practitioners for a client's values can assist in breaking down barriers of

race, ethnicity and culture (Moadel, et al., 1999), while the value of understanding a client's psychological goals within a broad context of their values, faith and commitments can also help in therapeutic work (Chirban, 2001).

Some healthcare practitioners have a dilemma about the relationship between their own values and beliefs and those of the patients with whom they work. Burkhardt and Nagai-Jacobson (2005) believe that nurses who work with clients must recognise that their own values and beliefs should not be imposed on their patients. The General Medical Council (United Kingdom) (2012) has guidelines which emphasise the need for doctors to recognise and respect the values of patients. In a similar vein, Epstein and Street (2011) draw attention to the increasing recognition of the partnership between patients and medical practitioners that is predicated on mutual respect of values. Healthcare practitioners can often find that the understanding of their own values can assist them in understanding the different values of others. This theme is taken up in Chapters 3 and 4 of this dissertation when researcher values in interviewing participants in this study are discussed.

Love: a common, special value

One of the common value dimensions of spirituality is regarded as love, defined in the Concise Oxford Dictionary as "warm affection … affectionate devotion" (Sykes, 1982). In a United Kingdom study based on responses from 57 religious professionals (77% men, 23% women; 47% Christian; representing seven different religious affiliations), more than four-fifths regarded love as always being present in religion and spirituality (Rose, 2001). The results of this study, however, need to be viewed with caution. The participants were "priests, rabbis, monks, temple presidents, etc" (p. 193) and it might be expected that such religious specialists would regard love as being an important value. Other authors who attest to the importance of love in spirituality are Hassed (2000) and Karren, Hafen, Smith and Frandsen (2002).

Love is not always seen in isolation but is sometimes coupled with other values such as restitution, faith, hope, guilt and forgiveness. These concepts, together with suffering, hope, forgiveness, grace, peace and peace-making, contribute towards the

broad dimension of what embodies love (Burkhardt & Nagai-Jacobson, 2005; Moritz, Kelly, et al. 2007).

That love is a consequence of spirituality is a position taken by Tanyi (2002). This presents an interesting perspective and raises some questions. Love may be a common and desirable value in spirituality but is it necessarily a consequence? Does love develop because of spirituality or does spirituality develop because of love?

One further value is that of hope and this can take many forms. In a general sense patients can have hope for a cure of their disease or hope in an after-life. More specific hope, especially when the reality of a cure is not possible, can assume immediacy: can I see my family tomorrow?; can I have a drink this afternoon?; can my pain be lessened by lunchtime? (Brutz, 2011; Edey & Jevne, 2003; Johnson, 2007; Murray, et al., 2007).

Process and journey

One dimension of spirituality to which mention is often made is that it is a life-long, developmental process (Arles, 2004; Halstead & Hull, 2001; Murray, et al., 2007; Narayanasamy, 2004; Sorajjakool, 2006). This dimension can be taken a further step by recognising it as a journey of the spirit that is related to a decision of a person to respond to the discovery of purpose and meaning in life (Lapierre, 1994).

Another perspective is that spirituality shapes a person's life-journey and, in fact, is shaped by our life's journey (Burkhardt & Nagai-Jacobson, 2005). This implies that spirituality and life interact with each other, especially in relation to purpose and meaning. It also implies that spirituality is an integral part of daily life with life's forces assisting in the development of the inner being and, in turn, the reshaped inner being reflects on the way people continue to live their life.

If it is accepted that spirituality is an individual state of mind, it can also be asserted that a spiritual journey is distinctly personal. Wink and Dillon (2002) suggest that it is "intimate, private and … frequently hard to capture in words" (p. 90) while Murray et al. (2007), agreeing with the principle, also suggest that no other person, even someone very close to an ill person, could assume that they understand the

depth of the ill person's spirituality. This has implications for healthcare practitioners who may seek to explore an ill person's spirituality to assist the patient, but it cannot be assumed that the depths of the patient's spirituality can be reached.

Connectedness: self; others; higher being; other; place

Connectedness in general

Spirituality embodies a universal human capacity to transcend self and connect with people, surroundings, nature, and powers outside of self including a supreme being, and is present regardless of whether or not people participate in an organised religion (Highfield & Cason, 1983; McEwen, 2005; Meraviglia, 1999; Moadel, et al., 1999; Murray, et al., 2007).

An overarching concept of connectedness was advocated by Hassed in a radio interview with Rachel Kohn (Hassed, 2000). Hassed has had significant experience in working with cancer patients as a therapist using meditation. He referred to a number of aspects of connectedness and spirituality.

> Spirituality in the literature often is referring to the difficulty to measure things, like a sense of connectedness, a sense of inner peace, a sense of love, and of course the sense of belief in something larger than yourself, as a law and intelligence throughout nature of which you're a part, like a great web of life, of which you're a part. (p. 10)

It is recognised that this statement is not intended to be a tightly conceived description of spirituality. However, while it includes a number of elements, it can lead to confusion because the elements are put together in a somewhat random fashion. It is not always helpful to simply articulate a number of inclusions without trying to see some more meaningful structure, especially in relation to unwell people. The essential point in this citation is the importance the interviewee placed on connectedness.

Connectedness with self

This is the most important aspect of connectedness because spirituality is the core of a person's inner being. If a person does not understand or connect with him or

herself, how can it be possible to have a meaningful connectedness with others? Connectedness with oneself can involve feeling an interconnectedness with others in part of personal growth (Mackenzie, Carlson, Munoz, & Speca, 2007) and it can have a role in "self-becoming" (Burkhardt & Nagai-Jacobson, 2005, p. 143).

The concept of self-connectedness is contiguous with concepts of self-awareness, self-understanding, self-control, self-actualisation and self-reverence. Watson (1989) has linked some of these concepts to spirituality when suggesting that poets, sages and philosophers have proposed that these come "through attention to the inner, spiritual life" (p. 224). She also suggests that self-understanding may be a critical aspect in self-healing.

The link between self-understanding and a person's inner being is central to the concept of spirituality. The term "intrapersonal" is sometimes used in relation to spirituality where the concept is that spirituality is at least in one sense a self-issue, being connected to oneself, as well as being connected to others (Reed, 1992).

Connectedness to others

The value of connecting with other people who endeavour to share a man's journey is directly stated by authors such as Roach (2005) who indicates that such support by understanding people enables a man with prostate cancer to express himself without fear of being judged or rejected. "Others" can be family (including a partner), friends or other people (Hassed, 2000; Hodge, 2005a; Kuczewski, 2007; Walton & Sullivan, 2004). The value of other people journeying with men with cancer is implied through the activities of prostate cancer support groups that are established in many countries.

Connectedness with a higher being

Within a broad understanding of spirituality there are many people who accept that a higher being can be an important element in their spirituality, although this connection is not always prevalent. In a study involving 13 self-referred participants suffering from emotional distress, Moritz et al. (2007) found that "the cultivation of a sense of connectedness with other beings, nature, the universe or a higher power was a key perception that interviewees described" (p. 197). Similar views of connectedness to a higher power or being are advocated by Reed (1992), Miner-

Williams (2006) and Doka and Morgan (1993). It might be noted here that a higher being or power does not necessarily mean a god. It can be described as a spiritual or life force (Gall, 2004; Hart & Waddell, 2003; Sheldon, 1992), or something greater than self (Kaut, 2002).

Other connectedness

Spirituality can be developed through connectedness with a variety of other entities that are not necessarily related to physical human beings. One such entity is the arts with a number of authors attesting to the value and place of the arts in relation to spirituality (Kandinsky, 1977; Wuthnow, 2001). The eminent sitarist Ravi Shankar suggests that the highest form in music is spirituality (Bhattacharya, n.d.). This view is also supported by Averill (1998) who contends that spiritual experiences are characterized by a sense of vitality, connectedness, and meaning. He believes there is an element of sacredness about spirituality and includes wonder (awe) and aesthetics, especially music.

Connectedness with animals can also be a major influence in a person's personal spirituality (Bekoff, 2001) and in their healing process (Halm, 2008). Connectedness may also occur with a place or places – a particular natural location, for example, may be significant in recognising or encouraging spiritual experience (Lapierre, 1994). The American poet, philosopher and transcendentalist Henry Thoreau lived for two years in Walden Pond where he engaged in introspection on his life (Pennell, 2006) and this placename has subsequently become a euphemism for place and nature in the pursuit of meditation and reflection.

Indigenous cultures frequently embrace a spirituality that is totally integrated to land (Anonymous, n.d.; Harrison & McConchie, 2009). One Aborigine, Mudrooroo, (Anonymous, n.d.) has said

> "it's like picking up a piece of dirt and saying this is where I started and this is where I'll go. The land is our food, our culture, our spirit and identity." "Spirituality is expressed by ceremony, rituals or paintings. It can change and has absorbed elements of other beliefs." "Our spirituality is a oneness and an

> interconnectedness with all that lives and breathes, even with all that does not live or breathe".

Canadian First Nations cultures take a similar view – the land does not just represent a physical space but, rather, represents the interconnected physical, symbolic, spiritual and social aspects of these people (Wilson, 2003).

It is also possible for non-indigenous people to have a connectedness with the land (Pearce, 2010; Pickering, 2002). In her study, Pearce discovered the importance of place in 17 men and women who had various forms of cancer and who lived in rural areas and found that they had a special bond to the land that manifested itself spiritually, emotionally and physically.

Heelas and Woodhead (2005) refer to "holistic milieu" in relation to the heart of New Age spirituality as distinct from more conventional religion, and attest to the value of connectedness in this concept. "On entering the milieu, one is immediately struck by the pervasive use of 'holistic' language: 'harmony', 'balance', 'flow', 'integration', 'interaction', 'being at one', and 'being centred'. The great refrain, we might say, is 'only connect'" (p. 26). Connectedness can be an integral part of and beneficial in spiritual development.

Existential – purpose and meaning in life

A frequently expressed dimension of spirituality relates to the "existential" – the nature of existence – and, in particular, a person's meaning and purpose in life (Chirban, 2001; Cole & Pargament, 1999; Hodge, 2005b; Karren, et al., 2002; Shapiro, et al., 2001).

One of the great proponents of the value of meaning in life was Victor Frankl. Frankl (1985) regards man's search for meaning as a primary motivation in his life. His experiences in a concentration camp during World War II provided a test for his emerging philosophy that what man needs in his life is a sense of meaning and purpose. He developed a theory of *logotherapy* which he described as assisting "a patient to find a meaning in life" (p. 125). A value of existentialism for Frankl was in its relationship to the religion of an individual but that religion must be born of free

choice. Frankl (1997) also saw transcendence as an important aspect in the religion-spiritual-existentialist nexus.

While the terms spirituality and existentialism can be seen as interchangeable (Kearney, 2000; Mytko & Knight, 1999; Plante & Sherman, 2001; Vivat, 2008), existentialism is an integral part of spirituality and, as can be observed in the above citations, has additional dimensions. These include the belief that spirituality is not just concerned with theology and matters relating to existentialism but equally concerned with ordinary, everyday matters (McSherry, 2000).

Some authors suggest that there are a number of aspects of existential concerns relating directly to spirituality. These include:

> loss of personal meaning through suffering and loss; peace and harmony; hope (Henoch & Danielson, 2009, p. 226).

> sense of control; dignity; life satisfaction; hope/hopelessness; meaning; autonomy; self-esteem; being positive; loving others; relating to God; need for information; being with family (Henoch & Danielson, 2009, p. 229).

Quality of life is another aspect associated with existentialism (Bassett, et al., 2005; Center for Spiritual Development, n.d.; Vivat, 2008). It should be noted, however, that not all writers accept the position that existential issues are part of spirituality, or that there is a need for a spirituality concept. Salandar (2006) asks if it is really meaningful (p. 647). There is further discussion on this in Chapter 7.

Manifestation of spirituality through behaviour

It is proposed in this part of the synthesis of the literature that, on the basis that a person's spirit is in-dwelling, or, as has been said, the core of a person's being, it can be manifest through behaviour. This is a position taken by Miner-Williams (2007). Manifestation might be referred to as operationalising, although Plante and Sherman believe that operationalising of some of the manifestations of spirituality can be elusive (2001).

That spirituality can result in behaviour is also asserted by Kiesling, Sorrell, Montgomery, and Colwell (2008). They define spiritual identity as "persistent sense of self that addresses ultimate questions about the nature, purpose, and meaning of life, resulting in behaviors that are consonant with the individual's core values" (p. 51).[1] They came to this conclusion after studying 28 "devout" men and women aged between 25 and 72.

Spirituality does not have to be manifest externally. An example of existence without external manifestation is the connectedness that a person might continue to feel to a parent who has died many years previously. It becomes manifest intrinsically if the person thinks about, or reflects on, the memory of that parent. It becomes manifest extrinsically if the person takes a bunch of flowers to the parent's graveside, or, in fact, "talks" to the parent at the graveside or talks about the parent to others.

Another example of where the external manifestation of the dimensions of spirituality can be readily seen is in such activities as attending religious services. But the same spirituality, wherein a person feels close to a higher being, need not be "seen" by another person, despite being strong in the person (Thoresen, Harris, & Oman, 2001). Outer spirituality can still reflect a person's interaction with the transcendental. A person who is observed attending and participating in a religious ritual can still be totally involved in the transcendental. Furthermore, outer behaviour can influence and change inner spirituality. This can be seen in mindfulness-based stress reduction activities (Baer, 2003) (discussed in more detail below), and also in many musical activities such as hymn singing and performance of "Whirling Dervishes" (Friend, 2001). Involvement in these activities can reflect an inner expression of spirituality but also be the catalyst for the development of spirituality. In these cases the spirituality may be both inner and outer. An understanding that spirituality can be internally or externally manifest in a person's life underpins the following discussion.

[1] In the context of this quotation, the authors regard the terms "spiritual identity" and "spirituality" as synonymous.

Meditation: reflection and contemplation; prayer; mindfulness

Meditation – reflection and contemplation, prayer and mindfulness can be significant practical components of a person's spirituality (Carr & Haldane, 2003; Fowler, 1980; Haldane, 2003; Highfield, 2000; Ho & Ho, 2007). They can be evident internally or externally where, for example, inner or external connectedness with a higher being, a god or God, can include personal meditation outside of a religious ritual, or it can be as a participant in a religious ritual, or both. A person might sit in a particular way, close their eyes and appear to others to be meditating. Whether, in fact, any meditation is taking place only the individual can verify.

Meditation can have a clearly defined technique and be an experience of thoughtful awareness that can be reduced to awareness of just one stimulus for a specific period. It facilitates focus on a specific object that can assist in the development of spiritual insight and can assist in bringing mental processes under control (Bond, et al., 2009). That meditation and reflection are important to people facing death has been alluded to by Walton and Sullivan (2004) and the Australian Government's Department of Veteran Affairs (2008). They are important elements in the wholeness of life in a variety of cultures, including, for example, the followers of Tibetan Buddhism (Sorajjakool, 2006).

Prayer is both a form of communication – connectedness – and can include reflection and meditation (Jantos & Kiat, 2007). It is included in this section as well as later in the religion manifestation section because it is used as a means of personal, internal communication with a higher being as well as a more formal, organisational prayer in a community (Kotila, 2006).

Mindfulness: sensations, perceptions

The concept of mindfulness is given separate mention here because it involves more than just meditation and reflection. While it includes these practices, it is more a deliberate kind of intervention in the development of spirituality.

Mindfulness has its origins in Buddhism and is closely associated with spiritual development (Carmody, Reed, Kristeller, & Merriam, 2008). It has been regarded as bringing awareness to current experience and becoming aware of changes in

thoughts, feelings and emotions from moment to moment (Bishop, et al., 2004). This leads to greater self-connectedness in that other thoughts are excluded by self-focus on matters that are internal and external to the individual at the time (Baer, 2003).
One specific activity based on mindfulness is the Mindfulness-Based Stress Reduction program (MBSR). This is a structured group program that uses mindfulness meditation to foster a person's sense of well-being (Grossman, 2008). Its effectiveness has yet to be widely determined through rigorous research, although there is anecdotal confirmation from individuals who have been involved in a mindfulness-based program of its usefulness in reducing stress (S. Burns, personal communication, September 7, 2011). It is a complex concept, and thus measures of it are difficult to construct (Carmody, et al., 2008; Langer & Moldoveanu, 2000). Reference is made to another study (Carlson, Speca, Patel, & Goodey, 2004) later in this chapter.

A related program, Mindfulness-Based Cognitive Therapy (MBCT), while designed to reduce the risk of relapse of depression (Mason & Hargreaves, 2001), is being applied to assist men with prostate cancer (S. Burns, personal communication, September 7, 2011). One study concluded that a MBCT program is potentially effective when associated with men with advanced prostate cancer (Chambers, Foley, Galt, Ferguson, & Clutton, 2011). The authors recognised the limitation of the study in that it applied only to a small number of participants – 19 men commenced the program and 15 completed it – and that there was no control group included in the design. Much of the analysis was statistically based although there was some in-depth telephone interviewing at the conclusion of the program. With the predominantly quantitative methodology applied to such a small group, the authors' reservations about their findings are well-founded. The value of such a program would benefit from more comprehensive research involving a larger number of men.

Concept and practice of values: forgiveness, hope …

Spirituality may involve the manifestation of the many values referred to above. A summary of references that mention links the authors see between values and spirituality is provided below (Table 2.2). All of these can not only exist as internal values but be practised in a person's life.

Table 2.2 – Concept and practice of values: summary of references

Values	References
Anger	(O'Connell & Skevington, 2005, p. 387)
Empathy	(Davis, et al., 2009, p. 250)
Faith	(Kaplan, Munroe-Blum, & Blazer, 1994)
Forgiveness	(Murray, et al., 2007, p. 45; Davis, et al., 2009, p. 250; O'Connell & Skevington, 2005, p. 387; Highfield, 2000, p. 115; Aldridge, 2005, p. 72; Cotton, et al., 1999; Ho & Ho, 2007, p. 69)
Grace	(Burkhardt & Nagai-Jacobson, 2005, p. 137; Aldridge, 2005, p. 72)
Guilt	(Kaplan, Munroe-Blum, & Blazer, 1994; O'Connell & Skevington, 2005, p. 387)
Hope	(Murray, et al., 2007, p. 45; Kaplan, Munroe-Blum, & Blazer, 1994; Burkhardt & Nagai-Jacobson, 2005, p. 137; Highfield, 2000, p. 115; Aldridge, 2005, p. 72)
Hurt	(O'Connell & Skevington, 2005, p. 387)
Legacy	(Murray, et al., 2007, p. 45)
Loneliness	(Murray, et al., 2007, p. 45)
Love	(Murray, et al., 2007, p. 45; Davis, et al., 2009, p. 250; Kaplan, Munroe-Blum, & Blazer, 1994; Burkhardt & Nagai-Jacobson, 2005, p. 137; Highfield, 2000, p. 115)
Meditation	(Aldridge, 2005, p. 72)
Patience	(Aldridge, 2005, p. 72)
Peacemaking	(Burkhardt & Nagai-Jacobson, 2005, p. 137)
Prayer	(Burkhardt & Nagai-Jacobson, 2005, p. 137; Aldridge, 2005, p. 72)
Reconciliation	(Kaplan, Munroe-Blum, & Blazer, 1994)
Regret	(O'Connell & Skevington, 2005, p. 387)
Relief	(O'Connell & Skevington, 2005, p. 387)
Restitution	(Kaplan, Munroe-Blum, & Blazer, 1994)
Security	(Murray, et al., 2007, p. 45)
Shame	(O'Connell & Skevington, 2005, p. 387)

Religion; ritual; prayer; community; pilgrimage

Earlier, the perspectives were discussed of a number of authors on the difference between spirituality and religion. In this small section the focus is on religion – understood in this research, after consideration of the literature reviewed earlier in this chapter, as the formal organisation of spirituality. A person's religion can be both internal and external with one of its key aspects being prayer. Many religions

engage in rituals – practices or services that become an integral part of a person's spirituality. Prayer can be regarded as a means of communication with a higher being (Johnston Taylor, Hopkins Outlaw, Bernardo, & Roy, 1999), and used particularly in expressing gratitude (Lambert, Fincham, Braithwaite, Graham, & Beach, 2009).

Prayer is an important means of communication for people of many different theistic beliefs (Jantos & Kiat, 2007) and, as mentioned above, it can be either internal or external. It has a role in demonstrating spiritual awareness (Karren, et al., 2002; Reed, 1987) and also in altering consciousness and leading to greater spiritual health (Fontana, 2003; Shaw, et al., 2007). Pilgrimage is an aspect of the external behaviour of spirituality because the process and achievement of reaching a destination is sacred within the pilgrim's individual belief system (Digance, 2003).

Outcomes of spirituality

So far in this review the multidimensional nature of spirituality and its inward and outward manifestation have been discussed. A logical progression is to consider the outcomes of spirituality – what is the result of its presence and manifestation and its being an integral part of each person? The literature refers to at least two general forms of outcomes – peace of mind and self-fulfilment, and their associated concepts.

Peace of mind: harmony, comfort, alleviation of suffering

One recognised outcome of spirituality is peace of mind and the associated concepts of harmony, comfort and the alleviation of suffering, suffering that can be both physical and psychological (Baldacchino, 2006; Culliford, 2002; Miner-Williams, 2006). One of the world's eminent spiritual leaders, the Dalai Lama, believes that joy, peace, and serenity are basic spiritual qualities that are vital in a person's life (Dalai Lama, 1999).

An often used quantitative measuring instrument of spirituality, the Functional Assessment of Chronic Illness Therapy Spiritual Well-being measurement instrument (FACIT-Sp-Ex, n.d.), a 23-item scale designed to measure spiritual well-being, includes questions that are peace-of-mind related, a point noted by Carmody

et al. (2008) and Mytko and Knight (1999).[2] It is also recognised that peace of mind is relevant in a consideration of death (Kaut, 2002; National Cancer Institute, n.d.-b).

Spirituality can lead to positive thinking and internal harmony that can enhance well-being (Goddard, 1995), while, conversely, spiritual distress can lead to disharmony and a disruption to hopes, values and beliefs, and a person's purpose in life (Villagomeza, 2005). This concept can be more generalised through reference to "universal harmony" (Catanzaro & McMullen, 2001, p. 222) although such a generalisation is less meaningful because it does not identify what might be the components of positive harmony.

The alleviation of suffering may also be an outcome of spirituality. In one study of 39 women with breast cancer (Gall & Cornblat, 2002), it was found that 31of the participants found solace during their illness through their relationship with God. However, Koenig (2009), in a review of studies examining the relationship between religion and mental health, found that sometimes religious beliefs can have a detrimental effect on a person – through neuroses, hysteria and psychotic delusions – rather than alleviate their suffering.

Self-fulfilment: being, knowing and doing

As the concept of spirituality relates to a person's inner being, or the core of their being, an outcome of that spirituality is a demonstration of the person's ability to fulfil that being and this requires the person to "be", to know her/himself, and "to do"; a concomitant term is self-actualisation (Dossey & Guzzetta, 2005; McSherry, 2000; Williams, 2006). Fulfilment is one of the many metaphors used to express the concept of spirituality (Halstead, 2003).

Expressions complementing those above are also used when referring to outcomes. Burkhardt and Nagai-Jacobson (2005) believe that spirituality "infuses our unfolding awareness of who and what we are" (p. 137) and they also suggest that being and knowing lead to doing, which they regard as the more visible aspect of spirituality. A

[2] The latter reference is to the earlier 12-question version of FACIT-Sp but applies equally in the later version that includes 23 questions.

health professional participant in a study referred to by Heelas and Woodhead (2005) suggested that what matters is "helping people to connect with who they are and the potential of who they are" (p. 27). In addition to this is the contention that spirituality leads to a greater awareness of life and a focussing on direction, purpose and achievement (Wright, 2008).

A different perception of fulfilment in spirituality was found in a major English study. As the result of their study of people in 25 congregations in Kendal (England) rooted in the Christian tradition, Heelas and Woodhead (2005) found that 83.5% of respondents regarded the statement in the study questionnaire "the important thing is to do your duty" was closer to their belief than the statement "the important thing is to fulfil yourself" (15%). The researchers attributed this finding to the emphasis in congregational worship placed on self-sacrifice and to "the saturation" of the liturgy with the language of obedience, self-giving and surrender (p. 14). It would be interesting to see what the results of a survey of a broader cross-section of a more secular community would be. Another perspective might be that confusion may arise when participants consider the questions because they are closely related. "Doing one's duty" may well be part of self-fulfilment so the answers should not necessarily be seen in an either/or context.

The above observations point to the notion that it is important to be wary of seeing too much compartmentalisation of spirituality. It is noted that, in the literature reviewed in this dissertation, outcomes are more specifically related to an inward result of spirituality as distinct from an outwardly observed manifestation of spirituality. It is, for example, possible to witness a person's manifestation of love by the way another person is treated but it is less possible to observe the peace of mind that is an outcome of the manifestation.

Transcendence – fundamental to spirituality

The frequent mention of the concept of transcendence in spirituality literature points to its perceived importance. Tanyi (2002) came to her own proposed definition as the result of carrying out a major review of literature on the subject. Her review included dictionary definitions and some 76 articles and 19 books that included definitions

and research studies that investigated the meaning of spirituality to an individual's health. She concluded that the results of a strong spirituality included "the ability to transcend beyond the infirmities of existence" (p. 506). In this paper Tanyi cited six nurse authors who referred to the concept of transcendence as being important in relation to spirituality. The theme of transcendence is also prevalent in the writings of Eckersley (2007), Ka'opua, Gotay, and Boehm (2007), Aldrich (1993) and Albaugh (2003).

Even taking just one reference to transcendence "the ability to extend the self beyond the immediate context to achieve new perspectives" (Aldridge, 1993, p. 5), it can be seen that transcendence is core to spirituality. This facet sets spirituality apart from other psychosocial constructs.

Transcendence is often mentioned in contrast to the mundane whereby people try to rise above the anxiety and oft-time trauma of their illness (Fowler, 1980; Gridley, 2009), although it is possible that people can see spirituality in the mundane (Burkhardt & Nagai-Jacobson, 2005).

Commitment to values that transcend the mundane is recognised as important in older people (Ka'opua, et al., 2007). The reasons suggested for this include the possibility that it is developmentally oriented and related to the higher likelihood of illness associated with older age. It is noted, however, that the authors do not provide examples of the way in which commitment is expressed. A slightly different perspective is presented by Coward (1996) who describes self-transcendence as reaching beyond personal boundaries and attaining a wider perspective, which facilitates finding meaning in life's experience.

Amenta (1986) summarises many elements of transcendence in the following way:

> The spiritual is the self, or I, the essence of personhood, the God within, that part which communes with the transcendent. It is that part of each individual which longs for ultimate awareness, meaning, value, purpose, beauty, dignity, relatedness, and integrity. (p. 117)

Koenig (2007) believes in the need to be careful when defining spirituality too broadly, and in terms of "positive psychological characteristics", because it can lead to confusion in understanding relationships between spirituality and other mental health constructs. Koenig argues that in order to study scientifically the relationships between religion, spirituality and health, there is a need to ensure there is no overlap between understandings of these concepts. This position is hard to sustain because it has been shown in other literature and studies that achieving a separation of religion and spirituality can be, in life, artificial and not realistic.

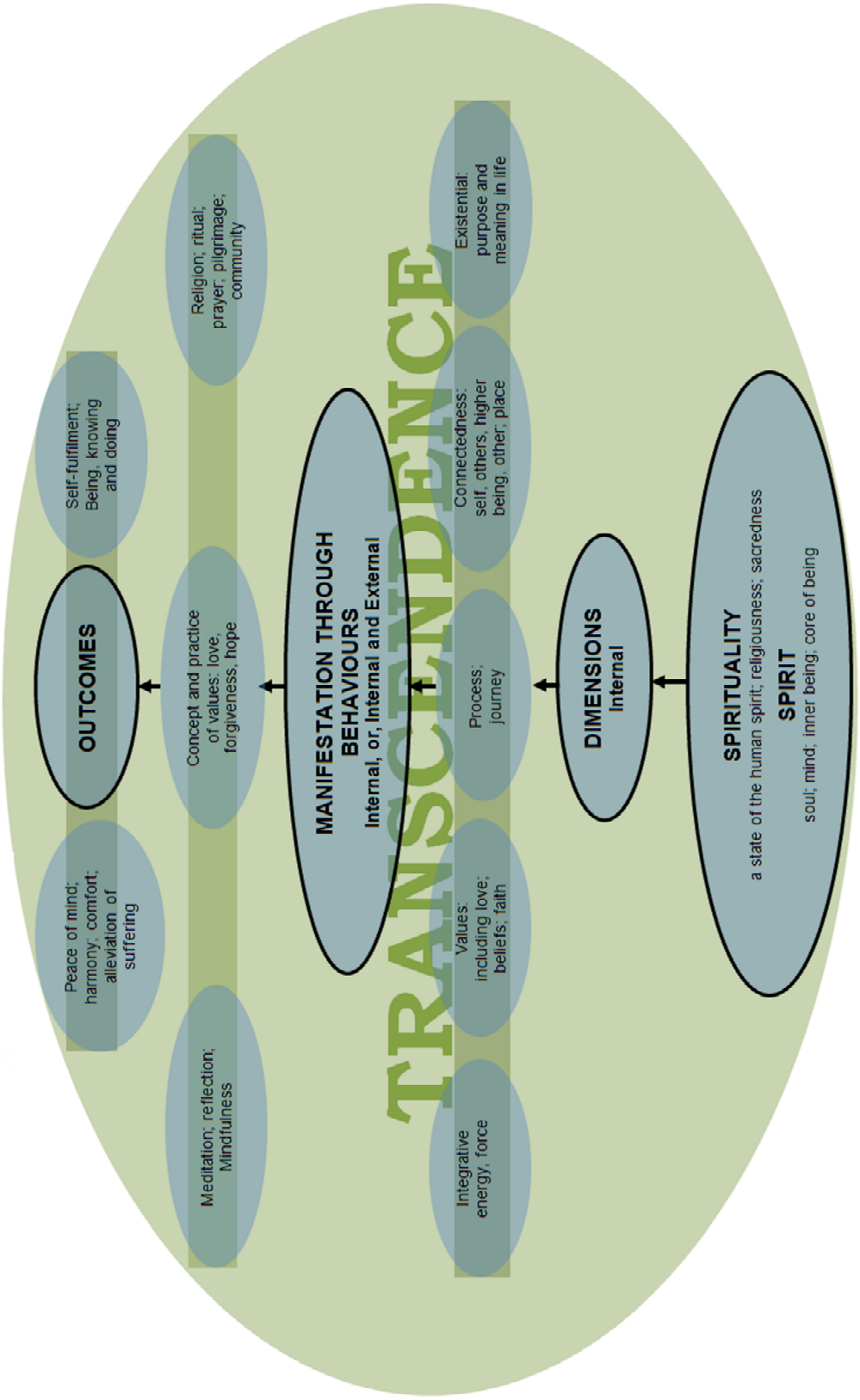
It is, then, not an easy task to define spirituality broadly enough to encompass the multiplicity of expressions of this construct, yet focussed enough to avoid it being another "umbrella", non-specific term within the psychosocial domain. I contend that it is the permeating presence of transcendence that goes beyond psychosocial concepts and provides a distinction from them. It is this concept of transcendence that can be seen to be the centre of spirituality.

With such disparate observations on the concept of spirituality that have been discussed in the foregoing, it is possible to see why there is so much confusion. This study seeks to identify what a particular group of men understand it to be for themselves. Ultimately, the understanding of an individual is of prime importance because the concept itself is so individual.

Conceptual Map 2.1 below places the above aspects and dimensions of spirituality in a diagrammatic form. Key elements of spirituality are indicated by bands that illustrate the integration and overlapping nature of the elements listed. Reading from the bottom upwards, the lowest component places the Spirit and then Spirituality as the foundation of being human. This leads (arrow) to Dimensions of spirituality with a band illustrating these and their interrelatedness. The next ellipse (arrow) suggests that dimensions exist internally but normally become manifested externally through observable behaviour, as discussed in the foregoing review. The next band (indicated by an arrow) shows these behaviours. It is the Manifestation that can lead to the Outcomes of peace, alleviation of suffering and self-fulfilment (the top band with progression indicated by an arrow). However, it should be noted that spirituality need not always be manifest externally in order for outcomes to be experienced. This is

reflected in the map and annotated as External, or, Internal and External in the Manifestation ellipse. This means, for example, that it is possible for a person to meditate internally without ever showing it externally. As noted above, Transcendence – lifting above the mundane – permeates the complete model. This distinguishes the concept of spirituality from other psychosocial constructs.

Conceptual Map 2.1 – Spirituality: synthesis of the literature



Other considerations

While the first concept to explore in this inquiry relates to spirituality in general, before searching for what spirituality is to men with advanced prostate cancer, reference needs to be made to a number of associated spiritual matters.

Spiritual depth or intensity

If the definitions of spirituality in the literature are confusing, expressions of an understanding of depth or intensity of spirituality are even more elusive. There are numerous references in the literature to depth or intensity of spirituality or religiousness during a person's illness, but how this affects an outcome is rarely discussed. Examples of these references without explanation can be seen in such statements as businessmen who have "deeply held values" and who "deeply integrate their spirituality and their work" (Fry, 2003, p. 713) and "deepening one's spiritual life" (Dunne, 2003, p. 97).

Dy-Liacco, Piedmont, Murray-Swank, Rodgerson, and Sherman (2009) refer to a 4-item Religiosity Index that claims to document the intensity of religious behaviour that they list as "praying, reading primary and secondary religious or spiritual literature, and attending services" (p. 36). A problem with this is that such measuring instruments can rely on outward observances of religiosity rather than inner reflection. Is, for example, a person who is seen to kneel and pray four times a day, six days each week, more deeply spiritual than someone who prays privately once in a day, unobserved, for one hour?

Another example of the problem of a measurement of depth of religiosity can be seen in a study by Xavier, Ferraz, Marc, Escosteguy, and Moriguchi (2003). These authors used an index that asked participants such questions as "Are you intensely religious?" or "religious?" or "hardly religious?". Other questions were "Do you watch religious broadcasts?" and "Do you attend religious celebrations daily weekly or monthly?". Responses can not necessarily determine the intensity or depth of the person's religiosity, or, in the broad sense, spirituality. The person might go to a religious celebration because they are expected to, or to meet friends. A person might

watch a religious telecast to observe the style or charisma of the presentation. The initial questions about whether the person regarded him/herself as "intensely" or "hardly" religious contained no criteria on which the person might adjudge the intensity of his/her religiosity. Other authors also refer to depth or strength of spirituality or associated concepts – religiousness and faith, but do not go further in suggesting how this depth is manifest (Hodge, n.d.; Lukoff, n.d.; Plante & Sherman, 2001; Thoresen, et al., 2001).

Some have made an attempt to describe spiritual experiences in superlative language such as "'ineffable,' 'a vastness transcending the self,' 'my lifeblood, deep, mysterious, intuitive … learning … what [God] sounds like, what he tastes like,' 'all-encompassing,' and 'Koranic consciousness.'" (Kiesling, et al., 2008, p. 58). Authors such as Burkhardt and Nagai-Jacobson (2005) have reported the words of others in describing their affinity with nature as providing "deeply spiritual experiences" (p. 141). Other terms used are "greater spiritual well-being" (a different construct to simply "spirituality") (Sherman & Simonton, 2001, p. 180), "deep spiritual assurances" (Carr & Haldane, 2003, p. 4), "deep inner structures of meaning, value and purpose that form the infrastructure to all human experience" (Culliford, 2002, p. 251). Burton and Watson (1988) state that intense feelings related to spirituality emerge as death approaches, while Karren, et al. (2002) refer on five occasions in the *Healing Power of Spirituality* to "a deep sense of" spiritual strength or spirituality (pp. 443-445). But, again, there is no reference to the way intensity is manifest.

A problem with the use of these terms is that, while reference is made to them, what constitutes depth or intensity of spirituality is not often described. Is it, for example, a person's strength of the feeling (emotion) of connectedness with people, higher being, the land, or animals? Is it a feeling of more energy or inner power? Is it an increased focus on the person's purpose in life? Much of the fuzziness associated with intensity of spirituality relates to an incomplete understanding of the meaning of spirituality and is consequently harder to measure.

Measurement of spirituality

There is a large body of literature devoted to the quantitative measurement of spirituality and religiosity. In many quantitative instruments the questions asked either in surveys or personal interviews (as, for example, in admission to aged care facilities) are based on the survey developers' perception of the meaning of spirituality. As this varies considerably, it is hard to use results of such research to generalise to individuals.

Quantitative research based on questionnaires can have a valid and complementary role in research into spirituality. It is difficult to make more specifically useful observations about spirituality unless carrying out hundreds of qualitatively based, individual interviews, but this would not be viable logistically. It is more appropriate and viable to gain a greater understanding of spirituality in a specific and limited population base, such as the participants in the current study – men with advanced prostate cancer.

Notwithstanding reservations about the use of quantitative measures, the commonly used 23-question FACIT-Sp-Ex (n.d.) does give some idea of spirituality. As there are some omissions in the broad context of the questions, however, use of such a survey to measure spirituality in individual people could overlook some dimensions that are particularly relevant to the individual. Two dimensions evident in the literature but not covered in FACIT-Sp are Integrative force and energy, and Process. However, this, and other questionnaires, can provide some insight into what some authors and some participants regard as important in measuring spirituality.

One of the difficulties of spiritual assessment using quantitative measures is that the tests do not necessarily articulate the bases for the formulation of the questions. The development of such measuring instruments needs to be clearly conceptualised and practically germane (Rumbold, 2007).

Spiritual needs and distress

As well as having spirituality, people often have spiritual needs to enable their spirituality to develop and assist them in their life (Narayanasamy, 1991; van

Leeuwen, Tiesinga, Jochemasen, & Post, 2007). Often the spiritual needs of a person may not be met. For example, forgiveness can be a value *dimension* of spirituality and the *need* is for a person to forgive (to enhance a relationship with someone who has been wronged), or be forgiven (for a wrong they have committed). In such a context McEwen (2005) suggests that spiritual needs must be satisfied for a person to attain and maintain health, although she does not provide evidence for such an assertion.

Spiritual needs can include meaning and purpose in life, love and harmonious relationships, need for forgiveness, the need for a source of hope and strength, creativity, trust, the need to maintain spiritual practices, the need to express one's own belief in God or deity, the ability to express one's own personal beliefs and values (McSherry, 2000). McSherry accepts the value of recognising that spiritual needs can be as varied as each individual, especially with regard to belief in a deity because he suggests that God or deity is defined by an individual.

Spiritual distress can be the negative connotation of spirituality and may be the outcome of spiritual needs not being met. A person may have some spirituality in terms of the dimensions indicated in the literature but the outcomes of the spirituality might have deficiencies, might not lead to peace of mind and might foster anxiety (Villagomeza, 2005). The relationship of distress to needs is that if there are impairments to the realisation of a person's spirituality, there may be the need to reduce these to create the environment for a more effective use of spirituality in promoting improvement in mental health.

That spirituality can assist people in reducing stress was confirmed in a study that sought to understand the value of a home-based spirituality program. The study involved a non-blinded, randomised, wait list-controlled trial of 165 individuals with mood disturbance recruited from primary care clinics in a Canadian city between August 2000 and March 2001. The study used three groups of participants: a spirituality group (an 8-week audiotaped spirituality home-study program), a mindfulness meditation-based stress reduction group (attendance at facilitated classes for 8 weeks), and a wait-list control group (no intervention for 12 weeks). It was found that the level of distress decreased and overall quality of life of the participants

in the spirituality group was significantly enhanced when compared to the other groups (Moritz, Quan, et al., 2006).

It is not intended to address this important issue of spiritual need or spiritual distress in detail in this dissertation. The intention is to recognise only that these conditions may exist and should be recognised, and, where possible, addressed by healthcare practitioners.

Such a broad concept of the inclusions in a description of spirituality means that healthcare practitioners, with appropriate training, may be able to identify a patient's spirituality and the possible dimensions. It is not the role of healthcare practitioners to be "all things to all people". However, being able to identify spiritual issues as they arise, and using their training in communication to listen effectively to what a patient is saying, may assist them to help the patient explore their issues. Through such articulation, the patient may move part of the way to receiving greater peace of mind as they journey through their illness.

While some of the literature on spirituality refers to the pieces of a puzzle, a significant amount of it is rooted in three phenomena: the concept of spirituality being a state of mind, how that state might be manifest and what the outcomes of spirituality may be.

> Spirituality is a part of the whole human persona. It is a sensitive and powerful phenomenon that is individually defined.
>
> (Halstead & Hull, 2001, p. 1541)

About prostate cancer

This part of the literature review discusses briefly prostate cancer and its prevalence in our society. Some medical information is provided because the interviewees frequently make reference to specific conditions and it is important to place their references in the appropriate medical context. The review then addresses the issue of stress associated with the disease and draws attention to the literature that recognises the times in a man's cancer journey where stress occurs. This stress may lead to the man's recourse to spirituality to assist in his coping. The review then considers advanced prostate cancer and identifies its complexities such as treatment options, side-effects of various treatments and some psychosocial effects.

The disease and its prevalence

Dealing with prostate cancer as a disease is complex because a man needs to make a decision about testing for its presence, discuss possible treatments, and then determine the most effective treatments for him.

Prostate cancer occurs through the uncontrolled growth of abnormal cells. These cells can commence growth in the gland and spread within it (localised), or on the outside of it (extracapsular), and to the surrounding tissues and organs in the pelvic area. Eventually they can spread to other parts of the body (metastasise) by travelling through the bloodstream (Prostate Cancer Research Institute, n.d.).

The most significant "driver" of prostate cancer is increasing age (Australian Institute of Health and Welfare, 2007). While prostate cancer is often flippantly referred to as an "old man's disease", the figures in Table 2.3 below indicate that the disease can be found in younger men.

The prostate cancer survival rate is among the highest of all cancer survival rates (Baade, Steginga, & Aitken, 2005b) and this has implications for people caring for men with prostate cancer. It means that, while the rate of incidence of prostate cancer in the population is increasing, and the mortality rate is decreasing, men will live longer and may need greater access to the development and use of their spirituality

and other coping strategies during this longer period. This, together with an increase in the medium term of the number of older men in Australia (Australian Institute of Health and Welfare, 2007), suggests that there is going to be a greater need for more services that assist in the caring of men with this illness, services that may include an increased understanding of spirituality.

Table 2.3 – The chance of occurrence of prostate cancer

(Cancer Council Queensland, 2007)

For a man aged 40	1 in 1,000
For a man aged 50	14 in 1,000
For a man aged 60	49 in 1,000
For a man aged 70	80 in 1,000
For a man aged 80	102 in 1,000

Medical issues

Presence of symptoms

The presence of the disease usually manifests itself in one or more ways which may include the need to urinate frequently, possibly urgently, especially at night, trouble urinating, blood in the urine or semen and a pain in the back, hips, or pelvis that does not go away (National Seniors Foundation, 2006; Wyatt, Friedman, Given, Given, & Beckrow, 1999).

To screen or not to screen?

A man may have symptoms and then contemplate screening or testing to determine the possible presence of prostate cancer. There is continued debate in Australia about the value of early screening for prostate cancer (Steginga, Pinnock, Jackson, & Gianduzzo, 2005c). There is no conclusive evidence in Australia that screening will lead to an extension of life as the result of the identification of prostate cancer. It may lead to early identification but this does not necessarily lead to greater life expectancy. Similar observations were reported in a British journal (Grubb, et al., 2008). However, in a study commenced in the 1990s and involving more than 162,000 men in Europe, it was found that PSA (prostate specific antigens) testing led to a 21% reduction in death from prostate cancer (Prostate Cancer Foundation of

Australia, 2012). It is unclear from this press release whether the reduction in death was due to the testing itself or to the action taken from the results of the PSA outcomes. The Prostate Cancer Foundation recommends that further research is needed on establishing evidence-based guidelines that will enable best practice.

Digital rectal examination and prostate specific antigen

Prostate cancer is diagnosed through a number of tests. Two of these are normally carried out by a general practitioner. The digital rectal examination (DRE) enables the general practitioner to determine whether the prostate gland has become enlarged, or whether it has any bumps or lumps.

A second test involves the taking of a blood sample and measuring the occurrence of PSA. This consists of proteins produced by cells of the prostate gland and released into the bloodstream. An increased PSA score can indicate an abnormality in the gland (Cancer Council Queensland, 2008). A particularly high score can suggest the increased presence of prostate cancer, as can the rate of increase of the PSA level.

Transrectal ultrasound

A combination of an enlarged or abnormal prostate gland determined through a DRE and an increased or high PSA score will usually lead a general practitioner to recommend a third test, a Transrectal Ultrasound (TRUS). Ultrasounds help in diagnosing, determining the staging, and enabling a more informed understanding of treatment possibilities if cancer is diagnosed. The TRUS gauges prostate gland volume, recognises variance in patterns (nature of cells) of cancer, and identifies the most appropriate sites for biopsy (Us TOO International Prostate Cancer Education & Support Network, n.d.). A biopsy is the only really definitive way of determining the presence of cancer (Cancer Council Queensland, n.d.) but sometimes even this procedure can miss finding a growth.

If as the result of screening the disease is diagnosed, the next issue is to determine the most effective treatment for the man given his own particular circumstances. Stress can occur through men's lack of knowledge about the disease and often by a general practitioner's lack of confidence in discussing the values of testing (Steginga, et al., 2005a).

Men are encouraged to take a major role in making their own decisions about their treatment once the disease has been diagnosed, after receiving help in arriving at their decision from their urologist and other healthcare practitioners. In one study, for example, it was concluded that 68% of men (n=111) preferred that the decision-making be shared equally between them and their doctor (Steginga & Occhipinti, 2004). Men can have a very stressful time at all points of decision-making during the progression from testing to treatment, particularly those who are newly diagnosed (Steginga, et al., 2008).

If prostate cancer is diagnosed as the result of the screening processes, a man is usually designated with a Gleason score, and a Stage and Grade. A Gleason score is determined by the extent to which the cancerous growths are found in the prostate. The Gleason score is determined in association with stages and grades. While the Gleason score suggests the nature of a growth's aggressiveness, the stages and grades indicate the extent of the cancer.

Advanced prostate cancer and treatments

The following review of basic elements of advanced prostate cancer and its treatments is included because it provides a framework within which the stories of the participants may be viewed in Chapter 5. Many of the participants refer to these treatments.

Advanced prostate cancer can be divided into two categories. The first is localised advanced cancer where the cancer has spread outside the gland itself but stays within the region. The second is when the cancer spreads to other parts of the body or metastasises (Prostate Cancer Foundation of Australia, n.d.). It is generally at an advanced stage that there is little hope of recovery but treatments can prolong life (National Cancer Institute, 2010).

Decisions on the most appropriate treatments usually relate to the Gleason score, the stage and grade of the cancer, and a man's preference for how he wishes to cope with the presence of the cancer – in particular, the quality of life that will ensue from treatment. Following is a brief description of some of the more common types of

treatment for prostate cancer. Some of the side-effects associated with each treatment that can cause stress are also indicated.

Radiotherapy – extrinsic and intrinsic. *External radiotherapy* can be used in men with advanced prostate cancer to try to reduce the growth in the gland itself and control some of the pain. However, it can have side-effects that include irritation of nearby tissues and, depending on the location of the growths, can affect the bladder and other surrounding areas. *Intrinsic radiotherapy*, or Low Dose Rate Brachytherapy, is used mainly for localised prostate cancer and is less relevant to men with advanced prostate cancer.

Surgery – radical prostatectomy. This is not common in advanced prostate cancer; it is normally only carried out on men who have cancer in its early stages (National Cancer Institute, 2010). It is usually used to reduce symptoms arising from the cancer rather than to try to cure it (Cancer Council Australia, 2009).

Another form of surgery is orchiectomy or orchidectomy. As the testes are responsible for the manufacture of testosterone, and testosterone is a major factor in the progression of prostate cancer, the surgical removal of the testes resulting in the cessation of the manufacture of testosterone is often considered (Cancer Council Australia, 2009; Kunkel, Bakker, Myers, Oyesanmi, & Gomella, 2000).

Side effects of a radical prostatectomy can include impotence and incontinence. An orchiectomy can result in lack of sexual desire due to the absence of testosterone.

Hormone therapy. This is a common treatment for men with advanced prostate cancer**.** Hormones are produced by glands and are distributed by the blood throughout the body. As cancer cells need the hormone testosterone to grow, hormone therapy can inhibit the production of testosterone (Prostate Cancer Foundation of Australia, n.d.).

A number of drugs can be used to remove or block the action of these hormones in the prostate gland. As testosterone is one of the androgen group of hormones and is produced in the testes, drugs used in hormone treatment are anti-androgens. This is

also called Androgen Deprivation Therapy (National Seniors Foundation, 2006). Androgens (such as testosterone) are responsible for male characteristics. The blocking of these can retard the growth of cancer cells in the prostate. Common side-effects of hormone treatment are hot flushes, reduced sexual function and libido and weakened bones (National Cancer Institute, n.d.-a).

Chemotherapy. A number of drugs, including hormone therapy and chemotherapy, may be used to reduce the further spread of the cancerous cells (National Cancer Institute, 2010). Chemotherapy is usually employed in a situation where it is difficult to control the cancer by other means and it can prolong life. The use of chemotherapy associated with advanced prostate cancer can be a time when a man's spirituality becomes more important in the life that remains.

As issues, and stress, relating to prostate cancer diagnosis and treatment are complex, men are being encouraged to become more informed about how they perceive their disease so that they can make the most appropriate decision for their well-being and future.

Stress

A number of authors allude to the presence of stress associated with the cancer journey (Carlson, Speca, Faris, & Patel, 2007; Coker, Sanderson, Ellison, & Fadden, 2006; Steginga & Occhipinti, 2006). There are at least seven times during a man's journey with prostate cancer where stress can be evident: early symptoms, diagnosis, treatment, cessation of treatment, survival, recurrence and towards the end of life (Sargeant, 2006).

Men often have to make decisions at a time when they are under the stress which can be associated with the initial diagnosis, or even before if there is a decision to be made about whether testing should take place at all. In one study of 111 men with localised prostate cancer, it was found that their disposition to optimism led to less stress in decision-making (Steginga & Occhipinti, 2006).

In a different report based on the same study (Steginga, Occhipinti, Gardiner, Yaxley, & Heathcote, 2003), the authors confirmed that the greatest stress men had was at the time of diagnosis. Psychological distress decreased 12 months after treatment (irrespective of the form of treatment) and, for many, the ensuing quality of life was not different from another group of men without cancer. The authors drew attention to a limitation of this study in that the sample was of a group of men in a city environment. They questioned whether the situation might be different for men without the same level of services in a more remote environment. At the same time, they reported that a sub-group of men remained highly stressed. This could indicate that there is a need to assess the coping ability of men and determine ways in which those who are stressed are provided with the support they need, support that might include helping them to nurture their spirituality.

Stress can sometimes be associated with lack of information provided to people with cancer (Adler & Page, 2008; Oxlad, Wade, Hallsworth, & Koczwara, 2008). This observation was made specifically about men with prostate cancer in a Canadian study (Santos Zanchetta, Cognet, Xenocostas, Aoki, & Talbot, 2007).

Another potential stressor is a man's realisation of his risk of death associated with the disease: a man of 50 diagnosed with prostate cancer has a greater risk (60%) of dying prematurely (before 80 years) of the disease than a man diagnosed at the age of 70 (38%) (Baade, Steginga, Pinnock, & Aitken, 2005a). Associated with stress is resilience and spirituality can assist in encouraging resilience in the face of many of life's challenges (Hassed, 2005; Moritz, et al., 2007).

Coping with stress

There is a considerable amount of literature available which is designed to assist men in coping with their stress. For example, the Queensland Cancer Fund (n.d.) suggests a number of practical ways in which men can help themselves to cope.

> Don't try to block out or fight unpleasant thoughts or feelings. Talking about the problem with friends, your wife or partner can help reduce feelings of tension. (p. 14)

In addition, literature suggests that having a positive attitude is important in coping during a cancer journey (Büssing, et al., 2007; Henoch & Danielson, 2009; Rogers-Clark, 2002) and can contribute to quality of life (Visser, Garssen, & Vingerhoets, 2010). There is a lack of evidence, however, that a positive attitude can prolong survival (Boyes, 2009).

If the above examples are individually psychological, there are social aspects associated with the concept of support groups. In the prostate cancer context, support groups can involve a number of men with the same disease meeting to mutually support one another through sharing experiences (Burt, Caelli, Moore, & Anderson, 2005; Mackenzie, et al., 2007). They might share their experiences of symptoms that are common, and they might also share their experiences of coping. The psychological element of psychosocial may be evident if the men discuss their experiences with a counsellor who may be able to assist them cope with any psychological issues they may have. Support groups often include men's wives and partners as they are also affected by the man's illness (Chambers, et al., 2008).

A Prostate Cancer Peer Support Inventory was developed, and, together with other measuring instruments, was used to ascertain the usefulness of peer support groups (Steginga, Pinnock, Gardner, Gardiner, & Dunn, 2005b). It was established that most of the 1,224 men who responded to a survey found peer support as a positive experience. This experience was related to men of a younger age, who perceived a better quality of life, who had good clinician support and who had little pain. At the same time, some men were less satisfied with peer support if they had lower quality of life and higher psychological stress. One noteworthy aspect of this study was the conclusion that the differences in the survey responses were not influenced by the men's association with a support group but were determined by their individual situations.

Despite the level of stress associated with prostate cancer diagnosis, many men have positive experiences as the result of their diagnosis. These include a reconnection with those they love which can lead to reasons to create meaning in their lives (Davis, 2002), as well as enhanced appreciation of the value of their life (Hagen, et al., 2007), improved relationships with others, and positive changes in self-concept

(Thornton & Perez, 2006). One limitation of the studies associated with the last two works cited was that they applied only to Caucasian men. To what extent the same conclusions could be reached with more widely based ethnic and cultural cohorts would need to be the subject of further studies.

In this part of the literature review a description of prostate cancer has been provided covering issues relating to testing, diagnosis and treatment options. This is designed to place consideration of spirituality in men with advanced prostate cancer in the physical context.

When it can be seen that stress can be prevalent throughout the journey, it is important that attention is given to encouraging a man to cope so that his quality of life can be at least comfortable. There are many ways of coping with stress and one of these may be to receive strength through spirituality.

In the next part of this chapter, I review the literature associated with spirituality and cancer generally, then specifically with advanced prostate cancer.

Spirituality, well-being, cancer and prostate cancer

Spirituality and well-being

That there are many dimensions in the concept of spirituality and that there is some spirituality, however expressed, in every human being, has been acknowledged earlier in this review. This is an important recognition when working with men with advanced prostate cancer. Healthcare practitioners may be more effective in their support of these patients when they recognise the importance of a man's spirituality and the way it may assist his well-being.

Spirituality is recognised as important as part of a coping process during a person's illness. One phenomenological study explored the spirituality of seven men and women who were experiencing a life-threatening disease. One of the three key points in the findings of this study was that spirituality is integral in dealing with life-threatening illness. It was concluded that "spirituality greatly affected patients' journeys through a life-threatening illness and provided a sense of meaning despite the illness" (Albaugh, 2003, p. 593).

This conclusion is echoed in other studies wherein spirituality is regarded as an important part of wellness and the healing process, and is indispensable in holistic care (Adegbola, 2006; Aldridge, 2005; Hill & Pargament, 2003; O'Connell & Skevington, 2005).

In a discussion on the relationship between spirituality and mental health, Culliford observed that human beliefs are beyond scientific measurement and because of this the effects of the beliefs are unpredictable (2002). However, he strongly advocated the need – for psychiatrists in particular – to be clearer about what constitutes mental health and consequently develop a non-denominational language of spirituality because the evidence shows spirituality can assist in developing positive health outcomes, a position also taken by Swinton (2001). In commenting on Culliford's writing, Brazier (2002) expands the concept of the breadth of spirituality by

advocating that Buddhism, a spirituality that enables people to develop the wisdom that helps them cope with the vicissitudes of life, should also be recognised as having potential value in the healing process.

Holistic care

Holistic care is now accepted as being an appropriate approach to healthcare (Burkhardt & Nagai-Jacobson, 2005; Miner-Williams, 2006; Taylor, 2005). More emphasis is being placed on recognising that unwell people can have a greater degree of comfort during their illness if their treatment addresses their psychological, social and spiritual as well as their physical needs, and that these needs can be catered for by healthcare workers from a range of disciplines in a team approach (Puchalski, 2002). That spiritual care is specifically an important aspect in holistic care is argued by a number of authors (Baldacchino, 2008; Gray, 2006; Miner-Williams, 2006; Murray, et al., 2007; Taylor, 2005; Walton & Sullivan, 2004).

While a team approach to healthcare is now accepted, there is also increasing recognition of healthcare practitioners coming from a range of disciplines – including medical practitioners, nurses, physiotherapists, for example – who might be able to assist in the aspect of spiritual care (Baldacchino, 2008; Doka & Morgan, 1993; Highfield, 2000; Kuczewski, 2007; National Breast Cancer Centre and the National Cancer Control Initiative, 2003). One argument is that these healthcarers might be in a position to respond immediately to spiritual issues if and when they arise during a consultation (Baldacchino, 2008). In some circumstances clinicians may be required to "become more involved, personally engaging in discussion and disclosure of religious and spiritual worldviews" (Kuczewski, 2007, p. 4). One difficulty of this is that such carers might not have the confidence to cope with the spirituality in patients (Kristeller, Sheedy Zumbrun, & Schilling, 1999).

Chaplains or clergy have in the past provided spiritual assistance for patients (Doka & Morgan, 1993; Kristeller, et al., 1999). However, whereas traditionally spirituality has been virtually synonymous with religion and inferentially associated with pastors and the clergy, as had been pointed out earlier in this review, it is now more broadly understood to be applicable in a wider sense of life and part of people who might not necessarily be part of organised religion (Heelas & Woodhead, 2005). Healthcare

practitioners with suitable training in a broader understanding of spirituality can play an important role in assisting in the well-being of patients. It has been noted in one study, for example, that, in the UK, nurses are now more likely to be involved in spiritual care in holistic nursing because of the patient-centred thrust of the National Health Service. This involves listening carefully to the patient and determining the most appropriate treatment (Heelas, 2006).

There can be a positive relationship between spirituality and health in patients with general illnesses as well as with cancer, including, in some cases, prostate cancer. For example, one study in Germany of some 7,000 men and women (mean age 63.9 years; 34% female, 66% male) confirmed the possibility of some form of spirituality being helpful during illness. It was found in the same study that women with breast cancer specifically engaged in spiritual and existential practices to cope better with their illness (Büssing, et al., 2007). The authors concluded that spirituality "may help one to adapt by finding meaning, hope, and coherence in illness, albeit it is still controversial whether SpR (*spirituality*) causes health or is an effect of well-being" (p. 201).

Mytko and Knight (1999) reviewed a number of studies that found positive relationships between spirituality and well-being in people with illness. In another study, Laubmeier, Zakowski, and Bair (2004) found that spirituality, in particular an existential component, was associated with reduced symptoms of stress in cancer patients. Their definition of spirituality was based on an amalgam of RWB (religious well-being – achieving harmony with God) and EWB (existential well-being – finding meaning and purpose in life). A difficulty with this definition is that it implies that religious well-being may not include an element of purpose and meaning in life. Many religious people do have an existential element in their life that is God-related. The results of the study need to be regarded with caution because of this confusing definition on which the research was predicated. The authors noted one limitation to this study in that the participants were mostly white, middle to upper class women.

While evidence shows that a relationship between religiosity and health can be beneficial, the relationship between spirituality and health is not as well studied

(Carmody, et al., 2008). This can be attributed to confusion in understanding the meanings of religiosity and spirituality. While the study of Carmody et al. was about the efficacy of a Mindfulness-Based Stress Reduction program, the authors' observations about confusion are nonetheless relevant.

Spirituality and cancer

Attention has been drawn to a number of authors who have asserted that there is a link – usually positive – between spirituality and well-being during illness. There are also research findings that attest to such a link between spirituality and people who have cancer (Daugherty, et al., 2005; Foley, et al., 2006; Gall & Cornblat, 2002; Micke, Büntzel, Mücke, & Glatzel, 2008; Rogers-Clark, 2002; Skalla & McCoy, 2006).

Bloom, Petersen, and Kang (2007) carried out a review of multidimensional quality of life studies on the long-term survivorship of people who had had cancer, including prostate cancer. The review encompassed four domains: physical, psychological, social and spiritual well-being. They concluded that, of these, spiritual domain outcomes were reported the least often. While no reason for this was proposed, their conclusion could reflect my observations that the understanding of spirituality is confused.

Some insight on spiritual issues with people who have cancer is provided by the Australian National Breast Cancer Centre and the National Cancer Control Initiative (2003). The Centre refers to existential and spiritual issues in a breast cancer patient's life towards the end of their life, suggesting that existential concerns may become more important to people with advanced cancer.

A study by Westman, Bergenmar, & Andersson (2006) examined the existential reflections of 10 men and women who had breast cancer and prostate cancer (five of each). The results showed that all patients believed they needed existential support but indicated that there were often obstacles to realising that support which included a lack of time, continuity and knowledge, resulting in a lack of understanding of existential issues.

A qualitative study of 10 Caucasian women by Halstead and Hull (2001) concluded that spirituality was important in the lives of the participants, and that the spiritual experience was individual and developmental for them. This study was based on grounded theory within a symbolic interactionism frame of reference. This methodology implies that the researchers developed theory as their study progressed and that the analysis was based on the symbols detected in their interactive discussions with participants (Blumer, 1969). The 10 women who participated (eight of whom had breast cancer) were involved in two semi-structured interviews. Data were analysed using the constant comparison technique of grounded theory. The importance of this study was the conclusion that the women were able to provide in considerable detail their spiritual experiences, making the data collected personal and individual. The method enabled a structured searching of spirituality in the women. Among the findings were two important issues: that spiritual development is not necessarily age-related and that spiritual concerns vary across a life-span and at different times during a cancer journey. Part of the findings are consistent with the view of Burton and Watson that spirituality can increase as death approaches (1988).

Many authors suggest that spirituality can be of assistance to people who have, or have had, cancer in coping with their illness. This assistance can include patients being realistic but hopeful (Daugherty, et al., 2005), having faith and trust in the goodness and general purpose in life (Gall & Cornblat, 2002), participating in organised religion (Rogers-Clark, 2002) and connecting with self, others, God and nature (Halstead & Hull, 2001).

Studies discussed below have shown that some cancer patients regard spirituality as a Complementary and Alternative Medicine (CAM) that can be used with more conventional medicines. One New Zealand inquiry (Chrystal, Allan, Forgeson, & Isaacs, 2003) found that CAMs recognised by the 200 respondents (cancer patients) to a survey included vitamins, anti-oxidants, herbal remedies, naturopathy, relaxation, hypnosis and spirituality among the 18 items listed. It was unclear from the study who determined what the CAMs were as the questionnaire used in the research was not included in the report. A consequence of this omission was that recognition of spirituality as a CAM gave no indication of what the patients understood by spirituality.

In another study involving 215 Australian and 159 Finnish women with breast cancer, it was found that spiritual and church healing was listed by 12% of the Australian respondents as being part of their complementary and alternative medicine approaches to their cancer care (Salminen, Bishop, Poussa, Drummond, & Salminen, 2004). These researchers also used a questionnaire that they indicate was validated in a previous study but the report of this study did not include the questionnaire nor did it indicate how the validation was carried out (Salminen, Lagström, Heikkilä, & Salminen, 2000). What was meant by spiritual and church healing was not discussed, neither was the basis for the terms being included in the results explained by the researchers or by the participants. These two examples highlight the difficulties faced by researchers when dealing with spirituality – that is, identifying what it means to them and to participants.

In addition to the factors already mentioned, some other elements are relevant. There is a nexus between spirituality and cancer treatment in people from different cultural backgrounds. This was observed in a study of African American women with breast cancer (Gibson & Smith Hendricks, 2006). It is also possible for adolescents to receive benefit through their spirituality (Hendricks-Ferguson, 2008), and spiritual assistance can be relevant to people of different faith tradition background – for example, Greek Orthodox (Assimakopoulos, et al., 2009) and Christian (Rippentrop, Altmaier, Chen, Found, & Keffala, 2005; Yanez, et al., 2009).

Spiritual problems

Not always is spirituality seen as a panacea for improved quality of life or peace of mind. Some researchers have found that it can be stressful and create disequilibrium in a patient's life (Ando, Morita, Okamoto, & Ninosaka, 2008; Villagomeza, 2005). White (2004) stated that "cancer challenges people's views of the world as meaningful, purposeful and coherent" (p. 470), and that these challenges can lead to an unsettled time in their illness. While recognising that spirituality can assist in a person's well-being it is also seen that there can be negative religious aspects (Koenig, 2009; National Cancer Institute, n.d.-b; Pargament, Koenig, Tarakeshwar, & Hahn, 2004). These can include perceptions of God punishing an individual through their illness, reappraisal of the role God has in a person's life and a possible

loss of faith, discontent in a religious congregation and trying to determine religious boundaries.

There are straightforward ways of finding out the status of a person's spirituality. Steinhauser et al. (2006) found that, by asking patients if they are at peace, physicians can have a brief gateway to determining if a patient has spiritual concerns. Literature referred to earlier (Baldacchino, 2006; Culliford, 2002; Miner-Williams, 2006) suggests that peace is an outcome of spirituality. Use of a peace question avoids asking patients about their spirituality especially if they equate spirituality with religion. The question focusses practically on their immediate well-being. In their summary of the Steinhauser et al. (2006) article cited above, Fromme, Hughes, Brokaw, Rosenfeld, and Arnold (2008) suggest that, before asking the question, doctors would need to be trained in how to respond to a patient's answer.

Spirituality and prostate cancer, and advanced prostate cancer

Prostate cancer

There are many issues relating to prostate cancer and how men cope. The following review of the literature draws attention to a number of these through referring to some specific studies. In general, the literature recognises the importance of spirituality in coping and provides some insights that help inform my study.

Some aspects of advanced prostate cancer are unique to this illness. Significant side-effects of treatment can create real challenges for men with the disease, as well as their loved ones. There can be major treatment side-effects, such as urinary incontinence, sexual impotence and ongoing pain. These physical problems may then lead to psychological issues, such as embarrassment, emotional volatility and subsequent effects on social relationships, especially with the man's partner, if he has one (Hagen, et al., 2007; Kunkel, et al., 2000). These issues in advanced prostate cancer (as well as other cancers) can adversely affect the man's self-esteem (Mottet, Prayer-Galetti, Hammerer, Kattan, & Tunn, 2006).

White and Verhoef (2006) explored the role of spirituality in cancer management in men with prostate cancer who had declined conventional treatment and were using complementary and alternative medicine (CAM). Whilst they drew a conclusion that spiritual beliefs and practices do have an important role in determining the treatment choices for some men, their findings were based on a small – and decreasing – sample of interviewees. The authors initially started with 29 men and, of these, 11 men identified spiritual practices as a type of CAM in the questionnaire given to all 29 participants. Spirituality emerged as a theme in interviews for 10 of these 11 men. While their conclusions may have been valid for the 10 men in the sub-set, the question might be asked as to whether or not the other 19 men had any place for the role of spirituality in their decision-making. This result could indicate that, for a number of men who choose CAM, spirituality is not important, which could have implications for healthcare practitioners working with such men.

In addition to the Westman et al. (2006) study mentioned previously, other research examines broad aspects of a relationship between spirituality and prostate cancer. Bowie, Sydnor, Granot, and Pargament (2004) found that for 38 men with prostate cancer, religion and spirituality had a positive influence on their ability to cope. Interestingly, the men seemed to make a distinction between formal religion and a belief in God or a higher power "with the former not being necessary for the latter" (p. 41). Nelson (2002) found that, in his mixed-method study of 124 men with "late stage" prostate cancer, men who were intrinsically religious or spiritual had a lower progression of their PSA levels, although an anxiety known as General Prostate Cancer Anxiety present in the men also led to a lower progression of PSA.

Reference was made earlier to the Mindfulness-Based Stress Reduction (MBSR) program. Carlson et al. (2004) drew attention to the value of this program in relation to prostate cancer. They found medically that there was an improvement in self-reported stress symptoms. This is an important study because the medical improvement was measured; the results can complement studies that provide the perspective of patients.

Yoshimoto et al. (2006) carried out a study in which they explored the religious coping practices adopted by 101 men and their wives in problem-solving while the

men had prostate cancer. (They had been diagnosed within the previous 15 months.) The authors referred to a list of religious coping mechanisms that men and women generally might use and these included prayer (private, or at a place of worship), meditation, watching or listening to radio and TV programs, reading religious literature, and religious counselling. They concluded that when couples share when turning to religion as a means of coping with the man's illness, they can have improved problem-solving. Sole religious coping by the wife may lead to inferior problem-solving. It would seem that in this study the authors are not necessarily referring to inner spiritual transcendence in the couples, as the substance of the spirituality discussed by the couples was not reported in the published article.

The means of connecting with one's spirituality is not necessarily always through an internalised motivation. Lukoff (n.d.) found an instance of a man with prostate cancer who was able to reconnect with his own spirituality through association with his religious community. Lukoff found that healthcare workers do not need to be religious to help people during a spiritual crisis and he expressed the view that compassion, and recognising the value of being there for the patient, were important components of the workers' approach. A sensitive approach by the practitioner may be of great value and all that is necessary to stimulate an awakening of spirituality in a patient that may lead to greater peace of mind and quality of life.

Two other studies of men with prostate cancer should be mentioned. Gall (2004) concluded from her research into men's relationship with God that such a relationship was complex and could include positive and negative aspects. Thornton and Perez (2006) pronounced the findings of their research as commensurate with other literature indicating that men with prostate cancer could find positive consequences to some stressful experiences, including prostate cancer. Their study was specifically oriented to Posttraumatic Growth (PTG) with "modest" positive experiences occurring one year after a radical prostatectomy. The positive consequences included an element of spirituality but this was the least positive of the five areas of PTG that were identified, the others being (in order of importance) relating to others, new possibilities, personal strength and appreciation of life.

The Thornton and Perez study had some limitations because the Posttraumatic Growth Inventory (PTGI) on which it was based had a less than clear statement of the understanding of spirituality. The PTGI was developed by Tedeschi and Calhoun (1996) and their foundation for discussing spiritual issues was more related to religiosity than to a broader concept of spirituality. The construction of PTGI was initially based on the responses made by groups of undergraduate psychology students to 34 items. Component analysis on the items developed six factors, one of which was labelled Spiritual Change. The two statements that comprised the Spiritual Change Factor were that the respondent had "a better understanding of spiritual matters" and "a stronger religious faith". There was no indication in the article of the demographic spread of the undergraduates involved in the development of the test except that 409 participants were women and 199 men. The authors stated that the age of participants ranged from 17 to 25 years, indicating a narrow age spread of a population and possible distortion of results if the inventory were to be applied in a study of people in a broader age range. In addition, there was no indication of ethnic or cultural issues in the article. As considerable literature mentioned earlier in this review mentions the disparate nature of religion and spirituality in different cultural and ethnic circumstances, the notion of spirituality as perceived by the respondents could be widely varied, and there is no knowing what their perception of spirituality was. The authors seemed to use the term interchangeably with religion.

With a questionable basis for asking participants in any survey to respond to the statement "I have a better understanding of spiritual matters" or "I have a stronger religious faith", as currently used in the PTGI online personal questionnaire (American Psychological Association, 2011), it is hard to determine what the participants would use as the basis for their better understanding. This becomes critical in the Thornton and Perez (2006) findings where Spiritual Change was last of the five factors identified in PostTraumatic Growth when they used the PTGI as the basis for their research. What did the participants imagine spirituality was? If they had no understanding of what was meant by the researchers, how could they respond if they equated spirituality with religion and they were not religious? This study is another example of the need to ensure that questions are based on clearly described fundamentals of what might constitute religion and spirituality. The significant

correlation between the religious participation aspect and the Spiritual Change factor in the earlier validity testing of PTGI (Tedeschi & Calhoun, 1996) give further support to the notion that spirituality and religiosity were regarded as similar by participants. The question must be asked again: if some participants did not regard themselves as religious, how did they respond to relevant statement? Perhaps if there was a clearer statement of what components spirituality may include the responses to the survey might have been different.

A study by Walton and Sullivan (2004), which could be regarded as a prequel to my research, explored what spirituality meant to 11 men with prostate cancer and how it influenced their treatment within a few days following a radical prostatectomy. The authors found that hospitalised patients regarded spirituality as one of the major priorities in their care. They concluded that:

> Spirituality was not a separate or isolated component in the lives of participants. Spirituality permeated all aspects of the cancer experience. Spirituality was evident throughout all aspects of their lives and transcended the physical, psychological, and social domains. (p. 137)

While the cohort of the study was small, the findings do indicate the importance some men see in spirituality. It should be recognised, however, that most participants regarded themselves as Christian and this could explain why they saw prayer as being an important part of spirituality.

The issue of faith and religion is important to men of different ethnic backgrounds. Seventeen African-Caribbean men in the United Kingdom with prostate cancer were found to have strong faith that was rooted in their upbringing. This helped them to have strength during their cancer journey (Nanton & Dale, 2011). In other studies it was found that spirituality and religiousness were significant positive factors in the prostate screening activity of African American men (Case, 2006), and that in men of a similar ethnic background who had prostate cancer, spiritual needs were important to their health (Jones, 2005). While it is recognised that there is no single intervention that enables the total treatment of prostate cancer (Chambers, Baade, &

Pinnock, 2010), the value of spirituality in contributing to a patient's well-being should not be underestimated.

Advanced prostate cancer

Whereas in prostate cancer before an advanced stage attempts are made to cure the disease and assist in improving quality of life, even though some side-effects make this difficult, in advanced prostate cancer emphasis is on disease control rather than cure (Kunkel, et al., 2000). Spirituality may play a part in this specific prostate cancer issue.

In the United States Zavala, Maliski, Kwan, Arlene Fink, and Litwin (2009) carried out a study involving 86 uninsured men of diverse ethnic origins and low income who had advanced (metastatic) prostate cancer. Their aim was to explore how spirituality affected their quality of life during their coping with the disease. They concluded that "greater spirituality was associated with better health-related quality of life (HRQOL) and psychosocial function, and that meaning/peace is closely associated with HRQOL" (p. 753).

While Jonsson, Aus, and Berterö's study (2009) was not designed to specifically gain a greater understanding of spirituality in men with advanced prostate cancer, it did uncover some issues that were spiritually related. The authors found, for example, that the men gained a new perspective on life after diagnosis. They became more aware of their mortality and this caused some of them to reflect more on spirituality. In some, spiritual doubts arose, causing them to "reconsider their ideas about existence, a necessity to reflect on life's goals, existential purpose and roles and friendships in the future" (p. 272).

Many therapies can be used to assist men with prostate cancer; these can also be applied to men with advanced prostate cancer. One such therapy consists of spiritual practices and these help to "reduce stress, instil peace and improve one's ability to manage challenges" (Cancer Council Australia, 2009, p. 73). The Council suggests further that "religious faith or a sense of spirituality can also be a source of strength and comfort" (p. 148).

Conclusion

A review of the literature exploring connections between spirituality and prostate cancer shows that use of spirituality may help men with prostate cancer to cope, particularly if the spirituality is seen as permeating all aspects of a man's life.

There is little literature relating to research in spirituality and advanced prostate cancer, hence this inquiry. However, that which is available points to a positive effect that spirituality may have in men with this condition.

The complete literature review associated with this inquiry has highlighted two particular issues. The first is that there is a confused understanding of what constitutes spirituality. However, a synthesis of views expressed in the literature as seen in the conceptual map (Conceptual Map 2.1) has shown that there are dimensions that can give greater insight on what spirituality may include, how it may affect a person during illness, and how it may be helpful to them.

Secondly, the studies that seek to illustrate the role spirituality may play in healthcare generally, and for men with prostate cancer in particular, are frequently based on a narrow or undefined understanding of spirituality. It is difficult to help men realise a role spirituality may have in their search for better health if the foundation for research does not have a well-understood basis, and that the men themselves are unclear about what spirituality may mean to them.

My research seeks to address these issues by providing more information about spirituality generally, and what it is for men with advanced prostate cancer, so that its possible positive benefits might be more widely understood and be of greater value to men with this disease. The methodology used in this inquiry to gain a greater understanding of this intervention is now described in detail in the following chapters.

Chapter 3 – RESEARCH METHODOLOGY

> Spirituality is, at its core, intensely personal and experiential, and cannot be distilled in a test tube or captured on a questionnaire. (Plante & Sherman, 2001, p. 3)

Paradigm and methodology

In the previous chapters, I identified the question I wanted to answer – what is the nature of spirituality in men with advanced prostate cancer? – and reviewed the literature discussing the many and varied facets of spirituality and prostate cancer. The next step was to determine the most appropriate methodology for exploring the possible answers to the question. This involved choosing an appropriate paradigm and methodology.

In this project, I used a qualitative research paradigm and a constructivist position with a methodology that has a hermeneutic and dialectic perspective, and using narrative method for the collection and analysis of data. Nine men with advanced prostate cancer were interviewed. The transcripts of the interviews were explored using narrative and thematic analysis with conclusions being induced from the information collected. This section discusses the project in more detail, based on the approaches of Denzin and Lincoln (2005) and Lincoln, Lynham, and Guba (2011).

Quantitative, qualitative or mixed methodologies?

Many research studies relating to spirituality have been carried out involving quantitative research. This has one major advantage in that it can solicit meaning on a topic from a large number of people with a consequence of gaining a broad cross-section of what people understand by such a term as spirituality. It has been shown in the previous chapters, however, that the questions on which large cohort surveys are based can be too broad, resulting in many people saying that they are (or are not) spiritual but providing no insight into what this actually means for them. A question that asks respondents to rate on a scale of 1 to 5 the state of their peace of mind

might indicate that they are at peace (or not at peace) without revealing the how and why of their response. The quotation at the beginning of this chapter suggests that it is difficult to explore spirituality using test tubes or questionnaires, a reference to scientific experiment and statistical results.

While it can be over-simplistic to describe briefly the differences between quantitative and qualitative research, it is useful to indicate that quantitative research can be described as regarding knowledge as being absolute, research questions hypothesised, methods concerned with objectivity and findings quantified in numbers, whereas in qualitative research knowledge is regarded as relative, questions are open and tentative, approaches are concerned with subjectivity and findings are qualified in words (Roberts & Taylor, 2002).

At the heart of this inquiry is the issue of spirituality which, as has been emphasised, is highly individual and therefore it would be difficult to determine an absolute understanding of its meaning. Each individual person is different and this renders spirituality as relative. The question is best asked in an open-ended way – what is it for each individual, rather than hypothesise and then test the hypothesis to determine if it is something absolute. It is extremely difficult to measure what it is objectively if spirituality is different for each person, and even more difficult to quantify the results of such an inquiry. The best result that might be obtained from quantitative inquiry may be that, say, 500 people regard purpose in life as being more or less important on, say, a 1-5 scale, but this does not indicate what such a purpose might be. A qualitative study may provide a deeper understanding of what such a purpose could be; it would almost certainly be different for each person.

I chose a qualitative approach to this inquiry because it enabled me to examine the relative nature of spirituality for each individual, to ask an open question without pre-empting an answer, to explore subjectively and in some detail the personal nature of spirituality and to report findings in text based on the words provided by the participants in the inquiry, not in text based on statistical data.

There may be a place for a mixed-method approach to such an inquiry where a large number of participants might be involved in in-depth interviews from which

dimensions of spirituality may be constructed and then formed into a questionnaire that could be used with an even larger number of participants. The rationale for this would be that what some people regard as spirituality might be determined first and then explored in a wider community. Mixed-method was used in one study where a list of questions on the way people coped with their cancer using qualitative methods (47 participants) was developed into a questionnaire to cover a larger group of people (359 responded with useable data) (Zebrack, Ganz, Bernaards, Petersen, & Abraham, 2006). While this study did not specifically include spirituality, nor was it restricted to prostate cancer, it shows a possible use of mixed-method research. From my perspective in my current project, such a use of mixed methodology was not logistically feasible but may have potential for future research.

Qualitative paradigm – constructivist position

Taylor, Kermode, and Roberts (2006) describe qualitative research as an endeavour to "interpret meaning by exploring, explaining and describing things of interest in order to make sense out of them" (p. 583).

Insofar as my research attempts to explore, explain and describe the spirituality of men who have advanced prostate cancer, and tries to gain an understanding of this phenomenon, it falls comfortably within a qualitative paradigm. Qualitative research "is interested in questions about human consciousness and subjectivity" (Taylor, et al., 2006, p. 7). Murray et al. (2007) suggest that spirituality is about human consciousness. My study is consistent with both of these views. Qualitative research is also founded on relative, not absolute, issues (Guba & Lincoln, 2005), and is interpretive in that it seeks to explain and describe (Taylor, et al., 2006). My study adopts these concepts.

There is a paradigm development observable in research associated with the relationship between science and healthcare. Culliford (2002) asserts that we are "moving beyond positivism, which limits knowledge to observable facts … to a participant-observer … whereby observation is assumed to be value-laden, thus an interpretative process" (p. 283). My research is consistent with this position.

Lincoln, Lynham, and Guba (2011) refer to basic beliefs (metaphysics) associated with what they term "alternative inquiry paradigms" (p. 98). They believe that there are three bases for inquiry paradigms – *ontology*, *epistemology* and *methodology*. Ontology is the study of the nature of being, epistemology relates to the nature and scope of knowledge, and methodology refers to the most appropriate framework developed to undertake a study. They refer to five types of inquiry in their summary of possible paradigms, and what they comprise: positivism, postpositivism, critical theory, constructivism and participatory (Table 3.1 below).

Table 3.1 – Basic beliefs of alternative inquiry paradigms – updated

(Lincoln, et al., 2011, p. 100)

Issue	Positivism	Postpositivism	Critical Theory et al	Constructivism	Participatory
Ontology	Naive realism – "real" reality but apprehendible	Critical realism – "real" reality but only imperfectly and probabilistically apprehendible	Historical realism virtual reality shaped by social, political, cultural, economic, ethnic, and gender values; crystallized over time	Relativism – local and specific co-constructed realities	Participative reality subjective-objective reality, co-created by mind and given cosmos
Epistemology	Dualist/ objectivist; findings true	Modified dualist/ objectivist; critical tradition/community; findings probably true	Transactional/ subjectivist; value-mediated findings	Transactional/ subjectivist; co-created findings	Critical subjectivity in participatory transaction with cosmos; extended epistemology of experiential, propositional, and practical knowing; co-created findings
Methodology	Experimental/ manipulative; verification of hypotheses; chiefly quantitative methods	Modified experimental/ manipulative; critical multiplism; falsification of hypotheses; may include qualitative methods	Dialogic/dialectical	Hermeneutical/ dialectical	Political participation in collaborative action inquiry; primacy of the practical; use of language grounded in shared experiential context

Creswell (1998) adds two more elements to the Lincoln, Lynham, and Guba (2011) paradigm through what he calls five philosophical assumptions relating to qualitative research. These additional elements are *Axiological* and *Rhetorical.* All five assumptions are listed in Table 3.2 below, together with the way they will be applied in my research.

Table 3.2 – Five philosophical assumptions about a constructivist paradigm

After Creswell (1998)

Assumption	Description	Applicability
Ontological	What is the nature of reality?	I am examining the "reality" of spirituality in a man with a particular "condition".
Epistemological	What is the nature and scope of knowledge?	I am exploring the knowledge associated with spirituality and collaborating with individuals to ascertain this "knowledge".
Axiological	Relating to value or quality.	I am recognising that spirituality is value-laden and embraces ethics and aesthetics.
Rhetorical	Style of language used by the researcher.	I will be using the 1st person because spirituality is highly personal.
Methodological	The process of the research, involving inductive logic and studying within its context.	I will be interviewing participants in their own surroundings and be using inductive logic to identify experiences that will lead to information about a man's spirituality.

Lincoln, Lynham, and Guba (2011) see constructivism as one position within an inquiry paradigm. They see the ontological elements as being related to "local and specific co-constructed realities" (p. 98). Epistemological elements are subjectivist with co-created findings while methodological elements are hermeneutic and dialectical – knowledge comes through interpretation, and the dialogue between participants in the research and the researcher.

Schwandt (1994) suggests that a constructivist approach to research is based on the notion that we do not just find or discover information, we construct it. Having constructed it, we modify it in the light of experience. Hence the parallel nature of a paradigm that is both qualitative and constructivist is appropriate for a study that tries to make sense of, and helps construct, men's spirituality at a time when they have advanced prostate cancer.

I positioned my study in the constructivist paradigm. Ontologically, I tried to understand the nature of spirituality in men with advanced prostate cancer. Epistemologically, I studied the nature and scope of the knowledge associated with this topic, and I used a methodology based on hermeneutics and dialectic. I employed narrative method to collect information because this facilitated the expression of individual reality and enabled the dialogue. Men with advanced prostate cancer have a specific reality, their beliefs and experiences are subjectivist. The method I used fostered knowledge through the interpretation of their stories.

I have refrained from ascribing a label to the specific methodology in this research because labels can mean different things to different people. I have preferred to adopt the Denzin and Lincoln description of a paradigm that does not specifically use the term methodology as a phase, but illustrates the possible inclusions of hermeneutics and dialectics in a qualitative methodology.

Research process

There is one simple structure that can form the foundation of the research process. Denzin and Lincoln express this process in terms of five phases (2011, p. 12).

Phase 1	The researcher
Phase 2	Interpretive paradigms
Phase 3	Design and strategies of inquiry
Phase 4	Methods of collection and analysis
Phase 5	The Art, practice and politics of interpretation and evaluation

In this process the researcher is considered first because he or she is located in a particular historical moment and is responsible for guiding and determining the limits of the inquiry. The next task is to develop an interpretive paradigm which embodies questions of ontology, epistemology and methodology. Once a decision of the paradigm is made, the issue of how the inquiry is planned is considered. The aim of this is to find the most appropriate strategy that will enable focus on the research question and provide a framework for a decision on the most appropriate way of collecting information. In qualitative inquiry information has to be interpreted, not just reported, and this usually involves selecting appropriate methods for interpretation which include analysis. This can then result in the report becoming political inasmuch as findings can influence social policy development.

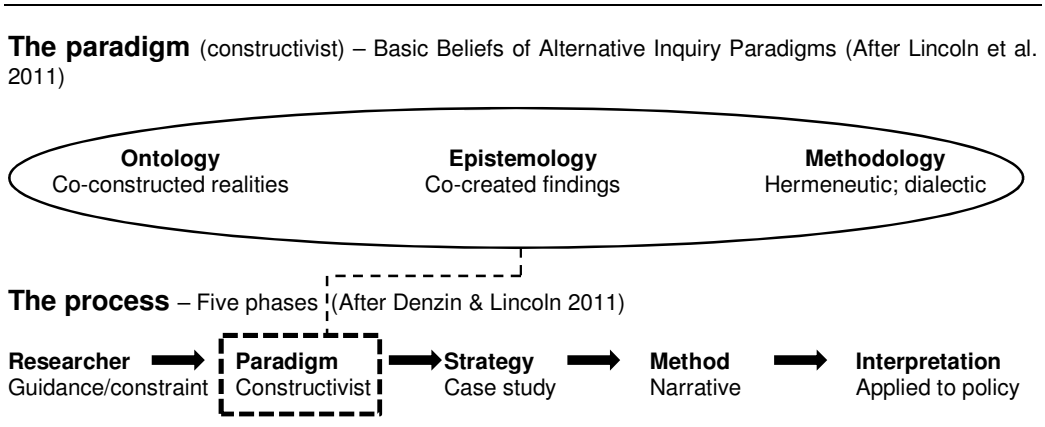
A fundamental component of the qualitative approach is that it is relative and this implies that there is no interpretive truth associated with the findings. In fact, Bold (2012) claims that there is no certainty in narrative research because it is possible for people, including the researcher, to interpret the same information differently. These matters are a core of my inquiry because spirituality is not absolute and a paradigm

that enables inquiry into something so individual has to be used and appropriate design, method, analysis and reporting developed. The process is discussed in more detail below.

The Denzin and Lincoln (2011) suggestion of five phases of research is a useful framework within which to view the process of my research. The above discussion has drawn attention to a qualitative research paradigm, the "world view" in which this particular project is located. I now view this project from a process perspective – that is, how I as the researcher see the way in which the project evolves. My inquiry is qualitative, constructivist research carried out in a hermeneutic, dialectic framework using narrative methods.

The following Figure (3.1) is a diagrammatic overview of the paradigm and process for this inquiry. The paradigm is indicated in the ellipse and amplifies the constructivist, paradigm phase of the process continuum.

Figure 3.1 – Paradigm and process for this inquiry



The following explanations are based on the Denzin and Lincoln suggestions for components of the phases and extend the observations made earlier in this chapter.

Phase 1 – The researcher

The inclusion by Denzin and Lincoln of the first step in the process of a focus on the researcher is an important element of the process, and a starting point in my research

especially when the paradigm is qualitative and constructivist and seeks to understand such an individual and personal matter as spirituality. The qualities, expertise and context of the researcher will help to determine the kind of research that will be carried out. It is for this reason I have explained my own background and reason for my interest in this research in Chapter 1.

Within the framework suggested by Denzin and Lincoln and supported by Grbich (2007) I recognise that I, the researcher, am an integral part of the research and my research is located in a particular time in the history of the man with advanced prostate cancer whose spirituality I am exploring. The moments in this man's life at which he is diagnosed and subsequently treated are unique to him and this time location has to be respected. His life before his diagnosis places him in a chronological context that is considerably changed once the diagnosis and subsequent events unfold.

I have endeavoured to guide the research in an ethically sound way and to recognise the constraints in my research that relate to a sensitive and personal aspect of the man's life. My personal ethics are an important part of my involvement in an inquiry. This is not so much a requirement to abide by an institution's ethics policy as a personal commitment to appropriate ethics when working with humans in a qualitative process. In this project, I have worked with men who are narrating their innermost being and this requires my sensitivity to their story and attention to the confidentiality they expect. While in this inquiry the men participating are the focus, the researcher has a key role and responsibility.

Phase 2 – Interpretive paradigms

Having recognised my role as the guider of the research, I decided to adopt a qualitative, constructivist paradigm. This encompasses a basic set of beliefs that guide my action in the formation of the inquiry. These beliefs mean, as indicated in Table 3.2, that I explored the reality of a man's spirituality (ontology), I explored the knowledge associated with this spirituality through interviewing them and then constructed their story and its meaning in collaboration with them through questions, their explanations and our combined endeavours to achieve the most accurate

statement about their spirituality as we could. This approach is often termed "naturalistic" in that it does not require a specific intervention on the part of the researcher (Morse, 1994) and because it takes place in a not-contrived, naturalistic setting (Schneider, Elliott, Beanland, LoBiondo-Wood, & Haber, 2003).

Part of a paradigm according to Lincoln et al. (2011) is the research methodology to be adopted. In the qualitative, constructivist paradigm, these authors suggest that a most appropriate methodology includes hermeneutics and dialectics. There is a variety of explanations of the concept of hermeneutics – for example, it is regarded as "an approach to the analysis of texts that stresses how prior understandings and prejudices shape the interpretive process" (Denzin & Lincoln, 2011, p. 16). In this reference the emphasis is on textual analysis, but for others a hermeneutical approach involves a shared understanding that occurs through dialogue between people (Gilbert, 2006). This approach also involves the researcher in deducing the "hidden assumptions" of the research participants (Gerrish, McManus, & Ashworth, 2003, p. 106) and does not seek causal explanation (Schwandt, 1994). It also allows a sharing of meanings between people and this has practical value (Crotty, 1998). Pre-understanding of an issue is also important for both so that there can be more meaningful interaction with the participant, hence my description of physical and psychological matters relating to prostate cancer in the literature review.

The dialectic element of a research approach suggests that there are at least two people involved in the pursuit of understanding the matter being discussed. It is a situation where people try to construct and reconstruct meaning (Abma, Nierse, & Widdershoven, 2009) through their interaction with one another and, in this sense, it is not a matter of the participant telling a story but the participant and the researcher working together to interpret what has happened, and is happening. The result is entirely consistent with the concept of the constructivist research paradigm in which the researcher and participants build a story together through interpretation and interactive dialogue – hermeneutics and dialectics.

This leads to a case study strategy and narrative data collection outlined in the next phases of the process.

Phase 3 – Strategies of inquiry

Having recognised the researcher's role and determined the most suitable framework in which the research can be carried out, this phase considers the strategies to be used in the collection of information. There needs to be a clear focus on the research question so that the most appropriate strategy can be devised.

In this inquiry, having decided that the approach would be qualitative, constructivist in concept employing hermeneutic and dialectic principles, it was appropriate to decide on a case study approach that would enable the hermeneutic interaction between me as the researcher and the participants. Case study is defined as "a strategy of inquiry in which the researcher explores in depth a program, event, activity process, or one or more individuals" (Creswell, 2009, p. 13). It is also described as "the intensive study of a single case where the purpose of that study is – at least in part – to shed light on a larger class of cases (population)" (Gerring, 2007, p. 20). Such study may incorporate multiple case studies although he observes that the more single cases there are, the more likely the research is labelled as a cross-case study where the larger number of cases may be seen as a sampling of a population. The approach is also referred to as a collective case study (Stake, 2005). In the current project, I study a small number of individual cases in depth that may help to shed light on a larger number of men – that is, I study the cases of nine men with a view to shedding light on what other men in the same health circumstances might experience with regard to their spirituality. The nature of the case study is suitable for my use as an in-depth and intense study of a small number of men in specific circumstances, a position taken by Flyvbjerg (2006).

A case study is both the process of learning about the case and the product of our learning (Stake, 2005). Stake also makes the observation that a case study is not just a choice of methodology, but a choice of the object of study. He emphasises that a key question is what can be learned (epistemology) from a single case.

In summary, the value of a case study is to learn as much as is possible about a specific issue over a period of time so that there is an intensive analysis of all the factors relevant to that issue (Roberts & Taylor, 2002). These authors also observe

that there is no specifically designated way of carrying out a case study but that the researcher must be systematic in the way information is collected.

My use of a case study approach in this inquiry is consistent with the paradigm that involves using hermeneutic and dialectic principles in that I am eliciting from individual cases in an in-depth manner information about their spirituality as it exists over a period of their life and especially at the time of their narrative, and interpreting this to shed insight on the issue that may be of value to others in a similar health situation.

Phase 4 – Methods of collection and analysis

For this inquiry, the most appropriate method for collecting information was through the use of narrative. In its simplest form, narrative involves the telling of a story. Narrative method uses telling a story to try to understand, or give meaning to, some elements of a person's life experiences.

> Narrative meaning functions to give form to the understanding of a purpose to life and to join everyday actions and events into episodic units. It provides a framework for understanding the past events of one's life and for planning future actions. It is the primary scheme by means of which human existence is rendered meaningful. (Polkinghorne, 1988, p. 11)

In a similar vein, the commonality of narrative seen by many researchers is that all humans are storytellers because stories give meaning and structure to our lives (Lannamann & McNamee, 2011).

Squire, Andrews, and Tamboukou (2008) attest to the popularity of narrative research and comment that sometimes it seems that this is being carried out by all social researchers. At the same time, they observe that it is a difficult and much discussed concept and even a definition is a matter of some dispute. One of the issues observed is the controversy over whether stories represent the internal state of an individual or a set of external social circumstances. This concern is not shared by

Webster and Mertova (2010) who believe that narrative method has the ability to focus on critical life events and concurrently explore holistic views.

The appropriateness of this method in my inquiry can be seen in that the individual stories are told by nine men who can see the episodes in their own lives as individuals but the method also has the potential for enabling them to see themselves and their prostate cancer experience in a more holistic perspective.

Associated with the use of narrative method in collecting information are the elements of narrative and thematic analysis. Denzin and Lincoln see analysis as being an important element in the method phase of an inquiry. Collecting information through narrative and associated interview is only one part of the method. Information has to be analysed and, in terms of the constructivist paradigm, interpreted.

Narrative and thematic analysis

There are two layers of analysis – narrative and thematic. Narrative analysis is the process of constructing a meaningful story from interview transcripts (Chase & Lincoln, 2005; Niessen, Abma, Widdershoven, Van Der Vleuten, & Akkerman, 2008; Polkinghorne, 1988). This involves refining the script of an interview recorded as part of the narrative process by deleting unwanted words, phrases, corrections and interviewer questions during the course of interview so that the narrative flows with greater ease. This analysis is carried out at the time of the interview and immediately after, and before thematic analysis is carried out.

Thematic analysis is defined as "a method for identifying, analysing and reporting patterns (themes) within data" (Braun & Clarke, 2006, p. 79). It involves structuring themes in stories that are commensurate with the prominence of events and constructing an interpretation of the lived experience of each participant in a study (Swinton, Bain, Ingram, & Heys, 2011).

A more detailed description of these analytic methods and their relevance to the current inquiry is given in Chapter 4. It is sufficient at this stage to describe what they are in terms of Denzin and Lincoln's phases of research.

Phase 5 – Interpretation and evaluation

Denzin and Lincoln make a number of points about this phase in the research process: they indicate that it can be of an applied nature; and they allude to the artistic nature of the qualitative process in that it is creative and interpretive. It is interpretive because it represents the researcher's attempts to make sense of the information he has gathered. This becomes the public text that eventuates in the form of reports, manuscripts and other media that are available to the public. They also refer to a political aspect of the process in that there may be changes of policy as a result of the research findings. They also draw attention to evaluation that is associated with qualitative research with an emphasis on the "situated, relational, and textual structures" (p.15).

This part of the research process is also relevant to my inquiry wherein I am conducting applied research which involves creative interpretation. It is anticipated that this will eventuate in public text that will assist healthcare practitioners and, perhaps, support organisations and governments, in the development of policies that will assist men in a similar condition.

Conclusion

In this Chapter I have outlined the framework for my research that is based on a qualitative, constructivist paradigm using a methodology based on hermeneutic and dialectic principles and a narrative method. I have determined that this approach is appropriate to the task of discovering the personal nature of spirituality in men with advanced prostate cancer and the way in which it is integral to their lives. In Chapter 4 I continue with Phase 3 of the research process outlined in Chapter 3 and describe the design and methods of this inquiry in more detail in preparation for the collection and analysis of data in Chapters 5 and 6.

Chapter 4 – DESIGN AND METHOD

The broad nature of a qualitative, constructivist paradigm and narrative method that enables an in-depth, personal exploration of the spirituality of men with advanced prostate cancer was discussed in Chapter 3. In Chapter 4, details are provided of the design and narrative method used for this specific project. This includes discussion of the basis for selecting the men for the study, determining the interviewing process, acknowledging some potential difficulties including specific issues in interviewing men, and recognising ethical matters. Following this is a discussion of the way narrative and thematic analyses were carried out and a statement on the way research rigour was applied in a qualitative study and an account of my personal involvement as a researcher in this inquiry.

Participants

Selection

A limited number of participants was sought for this research because I was exploring their spirituality in a detailed and personal way. The narrative method is intense and exceptionally time-consuming, but it is an appropriate and worthwhile choice as individual stories are constructed by each participant in conjunction with the researcher.

The selection process was purposive. Flannelly, Ellison, and Stroc (2004) describe purposive sampling as "choosing participants for a study because they have certain specific characteristics" (p. 1236). Taylor et al. (2006) describe it as "particular people fulfilling certain criteria, such as gender, age, professional experience, or experience of the phenomenon to be studied … recruited intentionally to the research" (p. 332).

In this study the criteria used for purposive sampling of participants were:

- Male;
- Living with advanced prostate cancer;
- Able and prepared to give informed consent to participate in this study;
- From, as far as possible,
  - different cultures and spiritual bases;
  - rural, regional or urban locations; and
  - a variety of socio-economic backgrounds.

The aim of this sampling was to seek men from a variety of backgrounds and with a diversity of experiences that are likely to influence their journey with prostate cancer.

This sampling was almost entirely achieved in this project, although it eventuated more out of the way men volunteered rather than specific selection.[3]

Recruitment assistance

I have been working as a volunteer with Cancer Council Queensland since 2006 and have built up a network of contacts that I was able to explore further during the recruitment process. This network included liaison with, and "honorary" membership of, the Toowoomba Prostate Cancer Support Group.

In addition, I contacted the Queensland Chapter of the Prostate Cancer Foundation of Australia which provided assistance through advertising in the *Prostate Cancer News*, the Chapter magazine. This had a distribution of more than 3000 copies. At the suggestion of the Prostate Cancer Foundation (Queensland), I contacted the co-ordinators of the prostate cancer support groups in Queensland, focussing on southern Queensland, with a request for them to draw attention to the promotional material seeking participants. I also arranged for media releases in newspapers in southern Queensland and carried out Australian Broadcasting Corporation regional radio interviews.

[3] No men who volunteered to be interviewed came from different cultural or ethnic backgrounds although I made a considerable effort to encourage volunteers through liaising with key community groups.

When the men contacted me by email, postmail or telephone, they were sent an Information Sheet and Consent Form that explained the study, the terms of their involvement and safeguards to protect their privacy and monitor their immediate well-being. (Appendix A).

Interviews

Narrative method is described as the relating of a "sequence of events and the (claimed) causal connections between them" (Paley & Eva, 2005, p. 83). The use of narrative in research enables the researcher to encourage participants to tell their story and organize their information into a pattern that helps explain their experience (Cortazzi, 1993). In addition, Roberts and Taylor (2002) suggest that narratives involve participants in interpreting their self-understandings.

In my research, participants were encouraged to tell their individual stories so that they could gain more self-understanding about their spirituality and see its relativity to their own circumstances rather than establish an absolute, universal truth about it.

Interviews are a prime part of qualitative data collection (Atkinson & Delamont, 2005; Cortazzi, 1993; Hove & Anda, 2005). Oliffe and Mroz (2005) regard them as one of the most powerful of qualitative research data collection methods, while Fontana and Frey (2005) suggest that interviewing is one of the most powerful ways in which we try to understand our fellow humans (p. 698).

Di Cicco-Bloom and Crabtree (2006) succinctly state the aim of carrying out interviews.

> The purpose of the qualitative research interview is to contribute to a body of knowledge that is conceptual and theoretical and is based on the meanings that life experiences hold for the interviewees. (p. 314)

In relation to spirituality, Burton (2003) stated that assessment of spiritual pain depends "as much upon the spirituality of the caregiver, and upon their capacity for contemplation, for close listening to narrative, for intuition, and for discernment, as it

will upon the results of any neatly developed questionnaire" (p. 442). The value of qualitative narrative interview in these circumstances is important, not only to the researcher but to the participants, a point made by East, Jackson, O'Brien, and Peters (2010).

I embraced this form of information collection, sometimes called "interpretive narrative method" (McQueen & Zimmerman, 2006, p. 475), because it was consistent with my aim to allow men to express themselves in their own terms within a focussed framework.

Unstructured, semi-structured or structured interviews?

There is considerable discussion on the value and purpose of each of these forms of interview. Swanson (1986) explains that "an unstructured interview is considered the most fitting means to elicit the personal viewpoint of the participants, to preserve the flexibility required to follow themes and clear up inconsistencies arising from the data" (p. 314). Unstructured interviewing also assists in understanding complex behaviour without using pre-established categories for an interview, or having a predetermined direction (Fontana & Frey, 2005; Nicoll & Beyea, 1997).

An unstructured interview, in a narrow sense, might be seen as being more consistent with narrative method insofar as a man's story is best left for him to relate in his own words and his own sequence of events. Nicoll and Beyea further indicate that such an interview may commence with a simple question: "Please tell me more about your experience …" (p. 927).

The structured interview is the converse of an unstructured position where, instead of using the open questions of the unstructured interview, interviewers used a prepared list of closed questions, the aim being to try to gain consistency of data collected across a number of interviewees (Whiting, 2008).

The semi-structured interview is, logically, at some point on the continuum between the other two. The purpose is to allow interviewees to tell their story in their own words, yet, at the same time, enable some direction in the interview by asking some

open questions in the area being researched. This is the most widely used form of interview in qualitative analysis and usually has a number of components that include that they are usually scheduled in advance and organised around a series of open questions. At some stage during the interview, some more questions may evolve (Di Cicco-Bloom & Crabtree, 2006).

I used a semi-structured interview approach within the above framework. In documentation provided to each participant two or three weeks before the interview, and immediately prior to it, a brief mention was made about spirituality in terms of it being something that lifts up a person above the ordinary or mundane. (See Appendices A, B, C and D.) This description was consistent with the emphasis on transcendence emerging from my literature review. Subsequent questions depended on the way they answered this focus question but were designed to assist the participants in describing the connections between the events they narrated. The purpose of the prepared questions was to ensure that I enabled the interviewees to focus at some stage on the reason for their involvement in the research. They volunteered to participate on the basis that they would be able to contribute something about their spiritualty. At the same time, the broad approach to questioning enabled them to place their spirituality in their own personal context.

The following questions gave purpose to the interview. The questions were constructed through general reference to relevant literature and to research studies associated with the nature of spirituality.

Each participant was asked these questions – not necessarily formally, or in this order.

1. How old are you?
2. How would you describe your general cultural and spiritual background?
3. When were you diagnosed as having advanced prostate cancer?
4. What treatment are you having?
5. How long have you been having this treatment?
6. Can you tell me what lifts you above the illness you are experiencing?
7. How would you describe your spirituality, if spirituality means being close with something “higher” than your everyday life?

8. How does your spirituality show itself in you?

If, in the course of the interview, some issues were not covered in each man's narrative, they were addressed through the following questions.

9. From where do you get strength to cope with your cancer, especially when you feel stressed?
10. Has your spirituality remained the same, increased or decreased overall during your illness?
11. Were there special points during your journey that your spirituality increased, or decreased?
12. Has the intensity of your spirituality increased or decreased at any time during your illness?
13. If your spirituality has increased during this stage of your journey, how has this increase been shown?
14. Have you received spiritual support during this part of your cancer journey? If you have, how was that provided?
15. Would you like spiritual support now? If so, in what way?
16. Do you believe that you receive spiritual strength from more than one source? If so, how does this happen?
17. Has your spirituality helped you in coping with your illness?

In practice, I asked each participant no more than two or three of these because the others were already covered during their narrative.

Interviewing process

Considerable attention was given in my research to the way in which an interview was conducted. Endeavouring to tease out a man's spirituality, and the related inner-being concepts of emotions, when men are not always forthcoming in these areas, required considerable thought and planning.

There are key elements of an interview designed to facilitate the narrative process – for example, there needs to be a relaxed environment conducive to informal discussion (Morse, 1994; Taylor, et al., 2006; Yong, 2001). This may mean use of

the interviewee's home where the person is familiar with his surroundings and does not feel threatened. At the same time, care has to be taken to reduce distraction normally associated with the home environment, such as telephone interruptions, other family members and pets. Balanced with this is the possibility that such interruptions lead to the greater feeling of homeliness and the participant's security.

There is also a need for the interviewer to establish a rapport with the participant so that there is an ease of relationship that will encourage him to be more forthcoming on matters that are more intimate (Di Cicco-Bloom & Crabtree, 2006). This may mean that the interview commences with normal, everyday discussion about the participant's colourful garden, large library and other items that might be observed.

A fundamental aspect of the interview that commences before the topic in hand is specifically introduced is the need for active, compassionate or empathetic listening (Lang, Floyd, & Beine, 2000; Nugent & Halvorson, 1995; Robertson, 2005; Wasner, Longaker, Fegg, & Borasio, 2005; Woll, Hinshaw, & Pawlik, 2008). This involves the researcher in indicating from the outset that he is there to listen to the participant's story.

The most common term is *active listening* and this involves verbal and non-verbal communication including vocal tone and inflections, posture, facial expressions and gestures (Robertson, 2005). Robertson also indicates that subsequent skills that allow the participant to relate his story involve such elements as a few encouraging interventions (nodding of head, non-committal "uh-huh"), and attentive silences, as well as timely and considered questions. A final element she suggests is that of reflection – the interviewer acknowledging the interviewee's story through occasional paraphrase and summarising major issues. As a practising pastoral carer I used these skills during the interviews.

Thought was also given to the medium used for recording the conversation. This should be unobtrusive and non-distractive. I used a netbook computer placed on a table with a built-in microphone that enabled direct recording of the conversation. I placed the screen saver on to a two-minute "blank-out" to avoid the distraction of the voice visual pattern being visible to the interviewee. I also used a mobile phone (with

an enlarged recording capacity) as a back-up device. Both of these were approved in each case by the participant.

One principle that is important in the interview process is that the interviewer is an integral part of the interview and, as such, is a human who has his/her own contexts. The modern interview is one where the interviewer seeks "to advocate social policies and ameliorate the conditions of the interviewee" and, because an interview involves a partnership, neutrality is not possible and is, in fact, undesirable (Fontana & Frey, 2005, p. 696). I was aware of these issues when I interviewed the participants in my research, and endeavoured to limit my own pre-developed understanding of some issues while using my background to help the men build their own stories.

Interviewing men

Interviewing men can present some difficulties of a gender-specific nature, and there can also be cultural, religious and socio-economic factors that can impinge on the interview process. In addition, commonly used interview formats do not take into consideration attitudinal differences between the sexes (Bonhomme, 2005). Schwalbe and Wolkomir (2002) suggest that men are "internally diverse" (p. 206), meaning that men who might be regarded as, for example, of the same class, or ethnicity, will not have the same internal characteristics. They counsel interviewers to rely on the interview itself to reveal the individual. This position is commensurate with my study because I sought to understand a highly individual aspect of a man's inner being. It cannot be assumed that men with advanced prostate cancer are a "category" (Schwalbe and Wolkomir's term) that will result in all men in this condition being alike.

Sometimes an issue with interviewees is that they will try to control an interview rather than succumb to control exerted by the interviewer (Schwalbe & Wolkomir, 2002; Yong, 2001). My approach to this was to manage the interview through appropriate questions to enable the focus of the research to be maintained.

Schwalbe and Wolkomir also address the strategies that might be used when interviewing men who are reluctant to discuss their emotions. These include avoiding

immediate questioning on emotional issues, making use of past tense rather than seek a feeling that is current, referring to feelings expressed by other men, as also suggested by S. Burns, M. Ferguson, and B. Hanley (Personal communication November 19, 2010), and asking about thoughts rather than feelings, then working back to feelings. As my research focusses on what, for many people, can be deep-seated spirituality and its emotional connotations, it was important for me to try to understand the extent to, and means by, which I could encourage men to narrate their deep-seated feelings.

Men are often reluctant to discuss their inner emotions, especially with someone with whom they have only a temporary acquaintance, such as me as a researcher. My task was to gain their confidence quickly so that they felt comfortable with discussing such highly personal issues (Arendell, 1997). One approach that has been successful on occasions is to suggest to a man being interviewed that men in similar circumstances have sometimes stated that they had particular kinds of feelings (S. Burns, M. Ferguson, and B. Hanley, Personal communication November 19, 2010). The aim here would be to provide a stimulus that might provoke a trigger for the interviewed man to describe his own emotions. Another purpose here is to provide "permission" for the interviewed man to express his own feelings because others have done it before him. That emotional distress occurs during the various stages of the cancer journey is accepted (Cancer Council Australia, 2009; Hagen, et al., 2007; van Servellen, Sarna, Padilla, & Brecht, 1996). The difficulty is to encourage men to talk about it and their spirituality that may assist them in coping with the stress.

One element of interviewing men with prostate cancer is often unstated. One of the common side-effects of prostate cancer is that of sexual (erectile) dysfunction. It is hard to estimate whether or not the reluctance of men to volunteer was associated with concern that such an issue would be raised in an interview.

One other challenge I had to face was that men are less likely to seek healthcare than women, and are reluctant to involve themselves in introspection and often disassociate themselves from emotions (Bonhomme, 2005). I used the framework and components mentioned in the foregoing to address this issue.

Working with participants

Each man who participated voluntarily in this study met with me on one occasion for about one hour to talk about his cancer journey. The meetings were scheduled at a time and place (mostly in their home) suitable to the participant, and I took some notes as well as recorded (audio) the interview.

I managed the interviews by visiting individually no more than two men in any one day. This ensured that I could interview the participants, transcribe the audio recording into written form, edit this to form the core story (Emden, 1998), then return it to the participants for member checking as quickly as possible. In each case, the transcript was returned for checking within a week. I telephoned two men once each to check on an aspect of their story. I carried out the transcription process myself and found this very useful in becoming more acquainted with each man's story.

Difficulties

Personal experience, supported by the experience of colleagues, suggested that men do not often volunteer to talk about such a personal illness, or such a personal aspect of their inner being as spirituality. Considerable attention was given to alleviate concerns during recruitment and through sensitive communication with them when arranging interviews.

Obtaining participants in the research proved to be a great challenge. Yong, in her study (2001), observed that men with prostate cancer were reluctant to volunteer to talk about their illness. One of ten difficulties addressed by Oliffe and Mroz (2005) in planning and executing interviews with men indicated that men do not respond to recruitment through general advertising or through email soliciting. Commensurate with this is my observation as a pastoral care worker that men do not necessarily want to volunteer to discuss their spirituality, often because they do not have a broad understanding of what it is. They can regard it as something to do with God, church or religion, all of which may be irrelevant to them. They may fear that their personal, innermost feelings might be subject to scrutiny or judgement by the researcher.

Recruitment, therefore, involved couching promotional, recruitment material in terms that described the scope of the research in broad, yet clear, terms, and reassuring them of the respect that would be held for their personal integrity. The material also suggested benefits that might accrue to them and others through their involvement. (See Appendices.)

After this initial promotion, I engaged in more personal contact with men who had prostate cancer with the aim of using them to make information about the research known to their associates to indicate the help that they could offer through participation. This personal contact, word-of-mouth recruiting was the aspect of recruitment Oliffe and Mroz (2005) found most effective.

Ultimately, of the nine men I interviewed, four responded to the articles in *Prostate Cancer News* and the other five volunteered after contact with support group co-ordinators. Two men responded to newspaper and radio promotion but these were ineligible because they did not have advanced prostate cancer. One other man agreed to participate through the encouragement of one of his friends but withdrew just before the scheduled interview because he had received some negative news from his medical practitioner about his condition and preferred not to have any discussions.

Ethical considerations

There were a number of ethical issues associated with this project. Any health problem is entirely a personal matter requiring respect of a person's privacy. Confidentiality was an important concern in this project. Each man who agreed to participate was given a pseudonym, even though one participant did not mind his real name being used on the grounds that he wanted to be identified with advocacy of prostate cancer awareness. Immediately the men consented to participate, their names were changed. Real identities were kept on paper and locked in a filing cabinet at the University of Southern Queensland (USQ) as was all permission information. Original audio files arising from the interview were copied to a USB stick and also locked in the filing cabinet. The audio files were also stored on a password protected computer to ensure adequate backup of essential data. In this dissertation, only pseudonyms are used and all other identifying information has

been changed – the names of other people mentioned by the men (including their wives and partners), and treatment and residential locations.

Men invited to participate were assured that their involvement was entirely voluntary and that there would be no pressure on them to commence, continue or finish if they chose not to. They were also informed at the time of recruitment that there would be no adverse effect if they chose to discontinue involvement. Rather than this being a problem, the men continued contact well after the interviews were completed although the death of two of them precluded contact with them after a few months. No reimbursements, payments or incentives (apart from altruistic incentive of participation) were offered to any participant. Participation was entirely voluntary. All men agreed to the publication of findings arising from the research with the provision that their own confidentiality would be maintained.

It was recognised from the outset that some men could find talking about such a personal element of their life confronting, especially as their cancer became increasingly more advanced. I was prepared for the possibility of a difficulty arising during the interview. As a trained pastoral carer, I have had considerable experience in listening to people tell stories associated with their serious illnesses and I have also undertaken grief counselling workshops. I also conduct funeral services where I work with families and their friends who are experiencing grief. In many cases I spend considerable time with the dying person just prior to death. While being compassionate and moved by a man who suffers distress talking about his experiences, I am able to recognise the suffering of each person with whom I am talking and to stay in control to help them. If the man is distressed to the extent that I, as a pastoral carer (not a counsellor), am unable to assist, I encourage the participant to contact the Cancer Council Queensland Helpline where free counselling is available from 8am-6pm each weekday. A summary of this service is provided in Appendix E.

Ethics approval was granted by the University of Southern Queensland Human Research Ethics Committee. Prior to approval, the Committee requested that details be provided of the support participants could receive if they experienced difficulties

during the interview process (Appendix E). In practice, no difficulties were experienced by the men who were interviewed.

Analysis

Narrative analysis

A brief statement was made about narrative analysis in Chapter 3. Emden (1998, p. 35) expands on the basic concept by suggesting that it involves preparing a "core story". She describes core story creation as a process that "aids the analysis process". The result of this creation and narrative editing is then returned to the participant for member checking. Angen (2000) describes this as "the process of returning analyses to informants for the confirmation of accuracy" (p. 383). Taylor et al. (2006) discuss some of the elements of member checking and its potential value of validating data collected. This may include the researcher seeking clarification of aspects of the participant's narrative (including theirs and the researcher's interpretation) and the participant adding, removing or changing data on subsequent reflection.

In practice, in my narrative analysis carried out with the transcripts presented in Chapter 5, little editing was needed to construct the core story. The men were enthusiastic about telling their story and were generally focussed on "cutting to the chase" from the beginning. The individual interviews, based on the questions noted earlier in this Chapter, were reviewed by the researcher within one week of the interview, and soon after checked for accuracy by each participant. Each participant reviewed the edited transcript and made corrections, additions or deletions as they saw appropriate. They then returned the revised transcript to me. Ultimately, the result was their endorsed story.

To ensure that as much as possible of each participant's character was retained in the transcripts, I carried out very little editing of stylistic, grammatical or idiomatic features. The retention of such features as colourful language, pauses in speech and non sequiturs is important in reflecting the individual character of participants, a key element of what I have argued as important in the concept of spirituality. In one case (noted in the transcript introduction), I left the narrative unaltered when the language

indicated that the participant was labouring to tell his story while he was affected by medication. During this process, I recognised that each individual's story should be accepted as "worthy of study" in its own right (Sandelowski, 1996, pp. 526, 527) before analysing across the group of individuals.

One principle adopted in this process was that no attempt was made to reconstruct the narrative in the form of introduction, plot and conclusion as is sometimes found in narrative analysis (Grbich, 2007). In some instances greater meaning was evident when participants kept coming back to the same issue. The occasional return of a particular theme during the course of an interview can reflect more significantly the man's concern about that issue. In addition, the integration of some elements in less sequential circumstances in many of the narratives reflected the natural juxtaposition of the physical, psychosocial and spiritual domains during a man's life.

The narrative analysis used in this project was more consistent with what Grbich (2007) regards as a psychocultural approach where "… personal narratives tend to be fairly concise and relate to specific incidents which have been observed or experienced" (p. 130). While she applies this more to a subsequent (thematic) analysis rather than narrative analysis as advocated by Emden (1998), it is also appropriate to the construction of the initial story. In the case of the participants in this research, they did tell about specific incidents that they experienced and they tried to make sense of these in the context of their lives. As the researcher, I helped them construct the meaningfulness of this during the interview and subsequent refinement of the core story.

While Bold (2012) writes from an educational perspective, her observations on aspects of narrative method are also pertinent in this health context. I adapt her statement by interpolating this project's relevance in italics.

> Understanding how individuals are affected by different contextual influences, through a narrative approach, is more likely to help teachers *(healthcare practitioners)* provide the most appropriate support for the child's learning *(patient's support)*. (p. 21)

The events and experiences in the participant's life should be recorded as they see them as this can provide a greater insight into the context and meaningfulness of their experience and allow it to be understood more fully.

Thematic analysis

Once the core story was finalised by me and the participant, the scripts were analysed thematically. In addition to the observations made in Chapter 3, Madill and Gough (2008) describe this as "producing clusters of text with similar meaning, often searching for concepts appearing to capture the essence of the phenomenon under investigation" (p. 258). Keywords and concepts were identified and organised to form a meaningful construct of the narratives. An inductive process was used to enable the individual realities of the men's experiences to be reviewed and eventually understood collectively in a broader thematic context.

Having heard and recorded the interviews conducted with participants and carried out the narrative analysis, I commenced the thematic analysis. The initial question of "Would you like to tell me about your cancer journey?" placed in the context of the promotional material to which they responded, the initial documentation forwarded to each responder and the consent form, together with general discussion while I was setting up the recording equipment, meant the participants were aware that my purpose in visiting them was to hear their cancer story with a particular focus on their spirituality. I reiterate that the only description of spirituality I gave to each man was broadly related to transcendence. I was also conscious that even using this word might prove to be "academic" so I placed it in the context of being lifted up above the ordinary or everyday. To elaborate any further would have inappropriately tried to answer the question I was asking.

I bore in mind at all times the questions I was seeking to answer:

1. How do men with advanced prostate cancer describe their personal spirituality?
2. What are the challenges and suffering experienced by men with advanced prostate cancer during their journey?

3. Does a man's call on his spirituality assist his well-being as he faces the challenges and suffering during his journey and, if so, how?
4. Are there common aspects of spirituality in men with advanced prostate cancer, even though they may have different life experiences?

A number of procedures for analysis have been described in literature. These include annotating keywords and phrases in identifiable different colours, and using suitable qualitative data analysis software that might be helpful (Richards & Richards, 1994; Taylor, et al., 2006). Codes are an important concept in qualitative analysis and are used to discover and organise key elements in a story. They can be keywords, phrases, sentences and, in some cases, paragraphs (Miles & Huberman, 1994). In a comprehensive manual for coding, Saldaña (2009) proposes an approach that considers the function of codes and a list of coding methods. He describes codes as a word or phrase that "symbolically assigns a summative, salient, essence capturing, and/or evocative attribute for a portion of language based or visual data" (p. 3).

I developed a process for preliminary analysis using a web design basis and Microsoft Word as the software. Any software that has hyperlink facility could be used. The names of participants and a link to their transcript were placed at the top of the key or index page. Each transcript was read independently, noting possible themes. As each transcript was read, key words, phrases and themes were added to the analysis. A greater understanding of key issues associated with, firstly, each participant, and, subsequently, all participants, was developed in this way. This process was carried out four times to check that no themes had been missed in earlier analyses. Themes were reviewed to determine any overlap between those identified. Refinement involved assimilating some elements of each story into slightly wider themes. This refined list was assembled on the key page and hypertext-linked to other pages that referred to topics inserted in the key page. Key sentences from each of the men's stories relating to a theme were then electronically pasted on the relevant linked page.

After this, I developed a matrix to check the extent to which each theme was mentioned by each participant. The single 'x' in the Matrix indicates the mentioning of the theme and makes no attempt to portray the degree of its importance to the

participant. This is discussed in more detail with some participants in the detailed thematic analysis of the narratives in Chapter 7. Diagrams exemplifying these processes are included in Appendix F. The processes were helpful in providing a framework for the preliminary management of the data that then facilitated a detailed textual and thematic analysis of the men's stories.

Research rigour and quality

There is often discussion about the differences between quantitative and qualitative research rigour. Quantitative research rigour is usually associated with scientific inquiry and its associated concepts of validity and reliability. Golafshni (2003) suggests that in qualitative research credibility, transferability and trustworthiness encompass these concepts.

Sandelowski (1986) refers to the truth value and applicability of qualitative research that will assist in pursuing rigour. She proposes that a study should be auditable – the researcher should have a clear, logical trail of decision-making from the study's beginning to its end. One key element of this is the process of member checking when collecting and processing the data. Another is ensuring that descriptions, explanations and theories about the data contain all relevant elements. Tuckett (2005) also refers to the value of member checking and the use of audio recording. He advocates these elements of attaining rigour in qualitative research as a verification of the position of trustworthiness proposed by Guba and Lincoln (2005).

One issue that needs to be considered is that of possible researcher bias (Appleton & King, 1997; Suri & Clarke, 2009). There is considerable debate about how this might be handled – some believe it should be acknowledged and limited (Whiting, 2008), while others suggest that it is important for the researcher to become involved in the research process and to focus less on objectivity. Porter (1993), for example, states that "the interpretations, values and interests of the researcher are central to the research process" (p. 137), while both he and Hand (2003) believe in the value of reflexivity in the research process. This is described as "an awareness of the researcher's contribution to the construction of meanings throughout the research

process, and an acknowledgment of the impossibility of remaining 'outside of' one's subject matter while conducting research" (Community Eye Health Journal, 2007).

It is possible that researchers can experience difficulty in trying to manage their subjectivity (Heshusius, 1994). Heshusius asks, for example, do researchers try to recognise the parts of themselves that are subjective?; and are the parts of themselves that are not subjective therefore objective? He proposes a "participatory mode of consciousness" that necessitates us to let go the focus on our self during our research. This, in turn, recognises the "deeper kinship between ourselves and other" (p. 17). Heshusius' arguments present the principle that the researcher participates in the interview and does not try to manage his own subjectivity because the distinction between subjectivity and objectivity can be blurred.

Keeping in mind Heshusius' position, I recognised the need to limit my own spirituality during each interview, while allowing the interviewee to express his spirituality in his own terms. As well as minimising researcher bias, I recognise the importance of rigour and quality in my research through observing the concepts of credibility, transferability, trustworthiness and auditability as advocated by Golafshni (2003).

Credibility refers to the integrity of the data collected during an inquiry and the most important procedure for determining this in a narrative inquiry is member checking (Moen, 2006). In this study member checking was carried out thoroughly so that each participant was satisfied that, on reading the transcript, his story reflected the accuracy of his feelings and circumstances.

Transferability alludes to the situation wherein the results of one study may be similar to the results that could be found in a similar study in a different situation (Jonsson, 2009). While in my study the cohort was small, the men were sufficiently diverse in their backgrounds and circumstances to assert that transferability would be generally consistent in a similar study with a different cohort. The importance of purposive sampling in facilitating transferability is attested to by Tuckett (2005).

Hsieh and Shannon (2005) allude to the value of a good coding scheme used in the analysis of data to promote trustworthiness. My systematic analysis using the observable processes outlined contribute significantly to this value in my inquiry. Having a clearly expressed research process at all stages of an inquiry is also seen as a necessity to foster trustworthiness (Blignault & Ritchie, 2009). My research achieves this.

Auditability is the creation of a research path that enables the scrutiny of research by others to determine the consistency of the research approach used and where another researcher using a similar approach would arrive at similar conclusions (Taylor, et al., 2006). I have endeavoured to achieve auditability by clearly indicating my approach at all stages and am confident that someone following the same processes could arrive at similar conclusions. Another factor in this striving for auditability is that my research structure and processes have been used frequently in this kind of inquiry. A rigorous approach focussing on quality has been vigorously pursued in this inquiry.

Personal statement

I am motivated by the following statement to make a personal statement about my own perceived role in this research:

> The complexity of human experience and our shared humanity must figure in our questions, our investigative processes, and, ultimately, our answers. Our own location must be carefully considered and clearly explained. (Angen, 2000, p. 392)

My pastoral care training and experience have equipped me to use my own spirituality as a frame of reference, but to endeavour to limit prejudice in my discussions on spirituality with others. My personal spirituality is Christian-based so I am aware of issues as indicated in the dimensions, manifestations, outcomes and spiritual intensity discussed above. I have experienced cancer and am aware of some of the stress and emotional issues associated with the illness.

One of the most important parts of my training as a pastoral carer was the constant reference to the phrase "Infinite respect". It was expected (and readily accepted) that pastoral carers respect the individuals with whom they work, and especially their personal spirituality. In caring for those who are ill it is always recognised that it is the patient who is the focus of attention, not the carer.

My practical experience has enabled me to have discussions with many people who have varied spiritual bases. I have spoken with a man dying from cancer whose spirituality (something that lifted him above his everyday illness) was associated with the inspiration he received from the cyclist Lance Armstrong. The man himself was a cyclist. I have spoken with a woman who was lifted up by the courage of her two sons who were dying of a rare illness. I have spoken with people who are atheists who have varying kinds of spirituality. In many cases, the people have been transcended by their connection with other people, place, and with a higher being, as distinct from Higher Being.

Using my own spirituality, and endeavouring to limit bias, enables me to work with people more effectively. This is more beneficial than trying to promote an artificial distance or objectivity that can dehumanise interpersonal interaction.

Conclusion

The aim of this study was to try to understand more about what is the nature of spirituality in men with advanced prostate cancer. Important issues arising from the literature review are that spirituality is personal and that advanced prostate cancer, while it has some aspects common to other cancers, also has some elements that are unique. Having reviewed paradigms and methodologies that have been used in a wide variety of research studies, I decided that the most appropriate for this study was qualitative in concept, used a constructivist position, employed a methodology that embodied hermeneutic and dialectic principles and a strategy based on case study and narrative method. This allowed men to tell the story of their highly individual spirituality and to construct meaning for themselves as they traversed their journey. The design and method centred on individual case study, and narrative

provided the framework for the collection and processing of the information received from the participants.

In Chapter 5 the stories as they were told by the participants are presented, having been subject to narrative analysis as described earlier in this chapter. Chapter 6 then proceeds directly to thematic analysis. These two chapters constitute Phase 4 of the research process outlined in Chapter 3.

Chapter 5 – MEN'S STORIES

In the stories that follow the names of all people and places are fictitious, except for eminent, international figures.

Michael

Michael was most interested in being interviewed. He was already an advocate for the advancement of the understanding of prostate cancer and was doing all he could to educate others about its vagaries. The interview was carried out in Michael's home in quite relaxed circumstances. He appeared a little anxious initially but we spent a few minutes talking about a variety of matters to facilitate an easing in to the conversation.

Beginnings

Well I guess the best place to start is at the beginning and it goes back to the first indication that something was wrong was on Easter Monday '08 when I had severe pain across my lower back, buttock region and in my right side at 2 or 3 in the morning. It eventually eased off and I went to see the on-call doctor at my local medical practice in Cairns and, after about a half-an-hour examination he diagnosed it as acute sciatica. I went to see my own GP and he confirmed the diagnosis after another thorough examination.

Unfortunately, after 2 to 3 months there was no real improvement in the pain. My GP got on to a visiting neurosurgeon and referred me to him. The neurosurgeon was pretty candid about it and said "I don't like the sound of this at all. If I have to operate on your spine there's only a 50-50 chance of success" and he said, "If it goes pear-shaped, you can end up in a wheelchair". I said "Oh, great!" But he said, "However, let's get a bone scan, MRIs and CT scans". All of that was arranged. We saw him again on the 7th of July and he said, "I'm afraid I have good news and bad news. The good news is we know what's causing the sciatic pain. Unfortunately, it's

these shadows at the base of your spine". And, Margaret, my wife, who was with me, said "You mean these are secondaries, don't you". He said, "I'm afraid so. We need to find the primary". He said, "I suspect it's prostate cancer but that's not my field. I'll refer you to a urologist in the hospital." We saw him a few days later and he did a digital rectal examination and a PSA and I went back later for a biopsy. My PSA was 126. A week later when I had the biopsy it was 138. The biopsy confirmed that I had prostate cancer Stage IV T3 M1+ with a Gleason score of 8.

Shock of diagnosis

The urologist was very candid about it and said, when we asked him about it, I had a life expectancy of three to four years; maybe a bit less, maybe a bit more. He said, "We will have a cure for it one day, but you're not going to live to see it and you've got to look at it as bringing forward your retirement age by 20 years". I was given two choices of treatment: 1) surgical castration or hormone therapy treatment. Other treatments were not suitable as the cancer was not clearly defined and had left the prostate and surrounding areas and had travelled to my skeleton. The first medication was a tablet called Cosudex, to bring the PSA under some sort of control, and then a slow-release implant injection, Zoladex, which lasts three months, and my PSA came down. The hormone therapy aims to reduce the testosterone because the testosterone feeds the cancer and it's important to control it.

Seeking a normal life

I carried on working. My background is in the mining industry, specifically explosives, drilling and blasting. I work for myself as an explosives security and safety consultant. We were living a very active life at the time and I had no side-effects. And that's the problem with prostate cancer. There are no uniform real indicators. Everybody responds differently and the symptoms are different for everybody. Some have them; some don't. I didn't have any. And, again, similarly with treatment. Everyone responds differently to the treatment. I have hot flushes and also cold flushes, which I think were worse than the hot flushes. You just can't get warm sitting in front of the fire. You try a cup of tea or coffee in the middle of the night. You're frozen. You're not shivering; you are just cold – very cold.

In early March '09 I went for radiotherapy, solely for pain management. My pelvis was riddled with it (the cancer) and it was very uncomfortable to sit on a seat. The secondaries actually were at the base of the spine, thoracic spine, ribs and my right shoulder. However, there may have been other secondaries there but they did not show up in the scans. I think they've got to be bigger than 3 mm to show up. The radiotherapy was for a month and they did, I guess, two thirds of my pelvis and my right shoulder.

Then in September '09 we decided to come back to the Gold Coast for our support network, not for access to better medical treatment but the support network and easier access for my sons. I think it will be better for them as we have no family here in Australia apart from the two boys, one in Brisbane and one in Sydney.

Treatment and side-effect trauma

So, at present, the drugs are still working. My PSA is 0.13. How long that will last is anyone's guess. The side-effects are, I guess, worse than the treatment because I have psoriatic arthritis that makes it very difficult to write. Also, I have osteoporosis so there is medication for both. There's the hormone therapy but one of the common side-effects that hasn't affected me but I'm having treatment for it as the predominantly long bones become very brittle because of the treatment so I have a monthly infusion of Zometa (that places) a scaffolding type structure over the bones to help strengthen them. And that's it.

The treatment I am on is solely for the control of my testosterone because the testosterone feeds the cancer. In time, the tumours will build up a resistance to the drugs and, when that happens, that's it. I have the option of chemotherapy but I haven't quite decided whether I will take that because the side-effects are rubbish!, and the last three months I've been pretty down because of the side-effects from the cancer treatment and from the other drugs – complete loss of energy, very lethargic and not interested in things. I've actually come off one of the drugs – Cosudex, still on the Zoladex, and, whether it's psychosomatic or not, I think I'm marginally better but I'll know next week whether that has made a difference to controlling the cancer. I'm due for a PSA on Monday and will find out if it's risen.

Coping with stress

We've had our ups and downs. I think we've handled it very well. I mean, one of the first things we did when I was first diagnosed was to send over 100 emails out to family, friends, work colleagues and people I've met and told them what had happened to me and quite a few wrote back and said, "Thanks very much for the reminder – we are off to see the doctor for a check-up". A few followed it up and said, "Thanks for saving my life" because they were in fact diagnosed with cancer; they were in the early stage and were successfully treated.

I should also say that Dad had it but didn't die from it; my older brother has prostate cancer and has been successfully treated with radiotherapy. I was having checks done on an annual basis and nothing was picked up. The urologist said to me, "Look, don't beat your head around. That's it. You have a very aggressive cancer". The only absolute definitive test for prostate cancer is a biopsy. Even then, if you don't cover the whole prostatic capsule, you could miss out some areas. And he said, "You could have come in here and I could have done a biopsy and in another six weeks you could have come back here and you would have got it because that's the nature of the cancer you've got". It's very aggressive.

Communicating with others

The life expectancy I was given was three to four years. I was not in a position to stop work. It's not in my make-up to just pull down the blinds and lock the door and wait for the rainy day. As I say, I communicated with other people … to help. That's how I've handled it. I've carried on working to the best of my ability. I no longer do site work so my income has been slashed. Fortunately, we have income protection, otherwise we'd be in Queer Street. I've always given something back to the community. I've been in Rotary off and on since the '70s in Singleton in the Hunter Valley, and I've been in Lions as well. In January 2010 I became a Prostate Cancer Foundation of Australia (PCFA) Ambassador and that helped me cope with it. I go around to industry groups, service clubs talking about prostate cancer to raise the awareness of prostate cancer among Australians. I always say, especially in industry groups, that female employees should come along as well so they can pass the information along to their husbands, partners, brothers, fathers, uncles etc … So that's how I cope. I'm not a religious person.

It doesn't fully go away. It's there all the time. I get on with my work. I do a little bit of administrative work for a client in Tasmania when I feel like it. I'd be lucky recently if I did one or two hours a week.

Life experience – a traveller

If you asked me what sort of person I am, I would say I am a travelling man. By that I mean that in my working career in contract blasting, explosive manufacturing etc I've travelled around the world – Africa, Middle East, Asia, Australia, Europe – I have seen abject poverty and people struggling to make a crust and yet they give hundreds of dollars to the church but they don't still get anything back in return. Yes, they can give help to some people but overall, for the world-wide community, I don't think they do a great deal. I've had a great life. I've always given something back to the community. That's why I'm an ambassador. People say, "why do you talk about it?" If I talk to a hundred people and save one life, it's worth it.

Climbing a mountain, and a positive attitude

Cancer changes you; I don't know whether it (my spirituality) does or not. It may have fluctuated a little bit, I suppose, in that I suffered from depression – and there have been days that I have, without question. Yes, it's a bugger, but I'm not going to let it get me down. I'm going to climb above it.

Getting on to being an ambassador – people say, "why do you do it?" Well, I'm giving something back to the community. I'm helping people that are perhaps less fortunate than me. And people will listen to somebody who has travelled the journey and they'll get something out of it, even if it's the wives nagging "well, go and see the doctor". I mean, the key message really, particularly for men, is that they should listen to their body. If they have a pain in their body, it doesn't matter where it is, they should go and see a doctor. It means there is something wrong with them. I try to relate that to them owning an expensive car, boat, piece of plant or equipment. They value it and look after it. A lot of men in today's western society don't look after themselves. I think that's the key message. We've got to try to change that attitude. We've got to try and help ourselves by looking after ourselves.

Support of friends

I don't think I need more spiritual support personally. I mean, we have a good bunch of friends around. If I'm asked how I feel, I normally get into trouble from Margaret when I say "I'm fine", and she says, "You're not fine", and of course it's only Margaret that sees the ups and downs and there are some days I'll be physically down; I'll be ashen. And that can last for a few hours; it can last all day.

When someone has a terminal illness, they expect you to be losing weight, being withdrawn and so on and so forth. I've put on a little bit of weight, but that's the drugs, and normally my colour's pretty good.

Breakdown in the medical support system

I mean, talking about support, this is where the whole system (and this is not so much spiritual support but medical-type support), for people diagnosed with advanced prostate cancer, you've got to go out and find it all yourself, and that's no disrespect to the medical specialists and the GP. They have to be educated themselves. And this is where the PCFA agents have got to do a lot more in putting together booklets for specialists and GPs and giving the GPs more information about prostate cancer support groups. It's that type of thing that I want to raise with the PCFA – I mean, they are aware of that and they are starting to do it. They've got a teleconference this Thursday and I've already put a lot of these issues on the agenda. The biggest gap is that there is no case manager for somebody diagnosed with a terminal illness. I mean, I have other illnesses as well which I'll talk about to highlight what pings us off. I've got Essential Tremor, Coxsackie B4, I've got ulcerated colitis, I've got psoriasis, psoriatic arthritis and osteoporosis. Do the doctors communicate with each other about these things? No. You've got to tell them to send the results of the various tests to each other. I think it's crazy. You're the one that's sick but you're reminding the doctors to do what I think is part of their responsibility, because, if somebody is diagnosed for one of my conditions, you don't know what the impact is on another one – maybe yes, maybe no.

In industry, if there is a major workplace accident, someone is appointed to facilitate an investigation. It's a case. I believe that the absence of such a provision for medical issues is a big, big gap that makes it much harder for people with a terminal illness.

My working career has been associated with contract blasting and explosive manufacturing. In twenty years now I've been in occupational health and safety in the explosive mining industry. Now, I firmly believe that everybody has a right to come home from work in the way they went to work. To be a Loss Control Practitioner, you've got to have a hard head, and you've got to be prepared to beat it against a brick wall, until the management of a company change their way of doing things. We're talking about the lack of indirect medical support; it's not there. So if I can help in change, then it's been worthwhile.

Leaving a mark

Women talk about their health issues. Men don't. The example I use is breast cancer. There is only one national group for prostate cancer. There are 33 groups – which is crazy as far as I'm concerned – for breast cancer. In the end, there's a lot of money being wasted on administrative duties whereas, if there were one or two for breast cancer, perhaps they would be much further ahead. If I can encourage men to go to the doctor, look after themselves on a regular basis, then it has not been in vain in getting prostate cancer. Sure, it's still going to be hard on the family and everything else, but perhaps I'll have left a mark somewhere.

I'd like to raise the awareness of men and their partners. They have to ask questions and, if they don't get satisfactory answers, they've got to get them somewhere else. GPs and urologists and, to a lesser extent, pathologists have to be far more candid and frank with their patients. Quite a few people were not given correct information about their treatments and side-effects and this has resulted in the breakdown of the marriage. They weren't told that their loss of libido was going to happen. Suddenly they find out the hard way. And that really pings me off. I won't say they are not doing their job but the PCFA has to get some guidelines out to the specialists and doctors. My wife, Margaret, has been with me all the way and her career as a nurse and nurse educator has been extremely beneficial when talking to the medicos, and asking questions in a different way. This helps us better understand the answer.

Craig

I arrived at Craig's home after about three hours of travel and was warmly welcomed by both Craig and his wife, Dianne. Craig was unsettled during the interview because of the medication he was taking and some parts of the narrative show this.

Dianne was not present for the interview but it was evident that Craig relied on her a great deal for verification of some matters. If Dianne was in the near vicinity as she went about her housework, Craig would occasionally ask her to confirm some matter of date or place.

Spirituality – early days

I was brought up Church of England. I started writing a story of my life and got up to quite a few hundred pages. A few years ago I stopped doing it. For some reason I could not start again. I could type 30 words a minute but now I can't type one word a minute.

I was a choir boy; I went to High Church of England and my mother said, for school, Sunday school and church, "You can do anything you like, you two boys; you can lie on the ground, kick, say you're sick, but you'll go to school every day and you'll go to church on Sunday." Although, when I was aged 14, I was given a choice.

I actually found a good Sunday School at Waterford. My dad bought a nice home there, and I went there because I respected Mr Molton who was the lay preacher. We went there a while ago and we found a little plaque at the front saying that the foundations were laid in his memory. We painted the roof of the church and we did it because we all liked him. Then, I went my own way, was married and had a couple of children.

The start of prostate cancer – "the worst …"

I was finding it very difficult to void in 1993. I had actually bought a milk run. I was living in Cairns, flew down, saw the broker and saw the books, although you can't really tell from the books. I could have bought a home in Brisbane and a taxi for the

price I paid for the milk run, but my wife and I rented a house and did the milk run. After a short time deregulation came in. There was a lot of heart-ache for milk vendors. Before I did that I went to see a doctor and he gave me a clean bill of health. I said that I was going to be working 12 hours a day, seven days a week, and I've got to do that for four solid years. He gave me a full set of tests, sent me to the urologist who did tests; he passed me. Then after a few years I started to void continually. I kept putting off … I went to see a urologist who in those times was the number one person and he said, "This is the worst … ah … the worst … urethra I've ever had dealings with". I said, "What happens?", and he said "I've got to clean it, repair it". I said, "When?" and he said "NOW, TODAY, YOU'VE GOT TO GO TO HOSPITAL NOW!" I told him what I was doing and he said, "You're going to be stretchered out of here any second". He did the operation.

"Devastated"

I was devastated! Devastated, yeah, devastated, because it's, um … an attack on your manhood! I was silly enough to be thinking along those lines, and a lot of men do think along those lines, don't they, do you agree?

Yeah, yeah … so when he did the operation, I was badly burned by the laser so the next day … talk about agony … it's a step above agony. I couldn't get out of bed. The sisters and doctors came up and I'd have to show them and my scrotum was about huge and the doctor came and said, "I'm sorry, old chappie, I had to make a decision". He said, "I should have stopped but it wasn't finished, so I had to take a chance and complete it". He said, "I took my last decision, and … it's mucked up". He gave me a certificate saying I couldn't work for six months, and after a few months I went back to him and he did another operation – a TURP. He cleared it through the prostate into the bladder so then I was able to return to work. Going through the prostate they take samples and it didn't show cancer.

Rising … and falling PSA

A few years later my GP ordered a blood test including a PSA which showed 27 and I said, "What does that mean?" and he said, "Well, it means that your antibodies are fighting something – it could be cancer, it could be something else". He said, "If you get … a, um … if your bladder gets infected, it could make the PSA rise". He said

there are many, many reasons but the thing we worry about is cancer and so I went back to the urologist who did a biopsy – without anaesthetic, without anything … quite painful … but he said, "Hang on there, old chappie, I'm just going to go through and grab a piece". "Bang … snap …", they knock you out now. So the eight samples showed no cancer, and then the PSA dropped. Because I was not so well informed about everything as now, I waited 18 months, it was out of my hands, and, I'm not ashamed to say that, because of the biopsy, and the pain, I thought, well, I want to avoid that. I was not told it was important to get more PSA tests or biopsies.

So then it rose to 38 and I had another biopsy which showed cancer and the Gleason reading – we thought he said seven, but later learned it was six. Our GP got a letter from the specialist saying, "Craig is not a candidate for the radiation, so I'm putting him on hormone treatment and I will inject him every six months and I'll get you to inject him the other three-month intervals between". So I did that for four years and I had awful side-effects with … and, um … well, I love working around the house and I could get bags of concrete – cement, and I couldn't get them out of the car; I had no strength.

"You've got 12 months to live!"

And, um … so how did I get off the hormones? … the PSA started to rise again, after my heart surgery so, OK, when you're in that treatment, you read 0.7, 0.9, and I attended a support group on the Sunshine Coast, until one was started at home. When the PSA started rising again, I saw a new urologist – oh, that's right, my specialist retired so I went to another leading urologist.

This urologist did not examine me or do any tests but declared I had had it and he said, "You've got 12 months to live!". We were not satisfied with his verdict so we saw another urologist who was in the hospital in Brisbane. About the same time a man working for the radiation from the Brisbane Hospital came to the Sunshine Coast and gave a talk at the Support Meeting. "Any questions?" Well, I didn't have any questions then but when he finished I gave him my background and he said, "Well you're a candidate for radiation". But I said, "I've got a letter at home …" but he said, "Well, it's changed so much now that the new doctors coming through have an entirely different mindset to the old doctors". … The Brisbane urologist said he

couldn't see how the Sunshine Coast urologist came to the decision without any tests and he would restage me. He got in touch with the radiologist and recommended radiation for me. That was five years after I was first diagnosed and it's been five years since then.

Decision-making stress

I was diagnosed only by him looking at me. And I said, "How long have I got to live?" and he said, "You've only got 12 months". And I said, "What happens?" and he said, "Ring me and I'll give you narcotics to ease the pain." So he obviously wanted us to go because he had a full room, and then, I was delivering books next day to the various nursing homes around here, and I sat down, and – I'm in shock – said to the guy delivering the books with me, "You go ahead, Major, I'm resting here" and I sat down and thought, I'll ring a Brisbane urologist Dr MacDonald up because I saw him treating and speaking so kindly to the man in the bed next to me, I remembered that. When I came home Dianne, my wife, said … (I came home positive that I was going to get a second opinion) … so Dianne said, "I have been talking with a support group I read about in the paper and they said we should see someone else, so I phoned for an appointment with that nice urologist in Brisbane". And I said I was going to come home and say to ring! So we saw Dr MacDonald. In the meantime we went to the support group and you had to stand and give your story and I told them mine. Dr X's name came up and they booed, hissed and booed, and had all these stories of him, including the man who is living at the end of my street here. When he saw him, he told him he was going to die and he said, "How long have I got?", and he said, "Well, you're 79 – how long do you expect to live?" It was unbelievable. So I knew then I was sent to the wrong person. So I saw Dr MacDonald and he said, "I don't see how he can make a diagnosis on that scant evidence", so I told him about this radiologist speaking at our meeting. He gave him a ring so he said, um, "Yes, I'm referring him to you for radiation". So, and in the meantime … radiation had been pretty horrendous in the past; everyone had these stories of being totally beggared after radiation – massive burns – but now it has improved so much we feel that, by delaying the radiation for the few years, I got through reasonably unscathed even though I had bad side-effects for quite a few years. The PSA had dropped quite considerably before the radiation but we decided to go ahead with it anyway and it dropped further after it.

"I'm in the last lap"

Sometimes the pain is so much that I scream and cry and wish I'd die. I'll be lucky to be here in a few months' time. I'm starting this treatment Tuesday. Ah … well, I'm in dire straits. I'm in the last lap. I've had other operations to clear the urethra. The last time in 2007 Dr MacDonald did it, and, to help me, he said he would give me a dilator which was 15 inches long, so two sisters came along and put me under a shower (very embarrassing – I shouldn't have been because this is just normal) showed me how to feed it through, leave it there, then remove it. I did that daily for, maybe, two years.

My growing spirituality

Dianne has always been a practising Christian, always going to church, went to church on her own, without her husband. She decided with me that she wasn't going to church without me. So I got the Bible out. It was very easy to find in the Bible something to laugh at, criticise, like Abraham and Sarah, like, hundreds of examples you can poke fun at … I'm probably not as bad as I'm making out, but I did say that the Bible, you couldn't live like that because, um, the angry God, and then we, ah … I could see how much she missed the church so we started going to church and then, um, I probably, um, I probably turned around about 10 years ago.

I was looking at the Bible – reading it, generally without a thought to criticise but to find some truth. Everyone our age knows of Helen Keller. We heard a sermon and Helen Keller was mentioned, and so we got the book we knew she had written about her religion called now *A light to my darkness* but was originally *My Religion*. Anyway, we read the book and could see something special there. I loved it and read it and re-read it so my wife bought me a copy. Her first marriage was in what they call the New Church. This was formed by a society of people who read Emanuel Swedenborg's writings. He actually wrote 32 books – about a thousand-odd pages in each book – mostly on the Old Testament. So, I worked it out as 30 words for every word in the Old Testament. He really has explained how to understand the Old Testament and the Gospels and Revelation. He never tried to preach or start anything. He just wrote for people to read or not read.

You just couldn't help but get involved with Helen Keller. About this time I had discovered that my ancestor, James McKnight, was a great theologian and had done a new translation of all the Epistles. These rare books in a set of six volumes were available through the internet and they also had his biography in the first volume. We purchased these and I was inspired by reading his commentaries knowing that he was a direct great-great-great-grandfather so I felt a connection. So it was Divine Providence that my family history came to light about the same time I was searching. I'm thinking that a miracle's happened, and I think it's a miracle from heaven, from above. Previously I had not even heard of him. My spirituality commenced slowly but for Dianne it was reignited.

I'm just thinking that this had been pre-arranged that Helen Keller would be introduced to the writings of Emmanuel Swedenborg when a dear friend translated them into Braille for her. So I thought this man's special. So we were able to get many, many books – more modern translations of Swedenborg as he wrote 200 years ago and in Latin. The more I read, the more it appeared that, that … I haven't embraced the New Church, I've met many people from the New Church and I find them all to be inspirational type of people.

I wanted to find out more but I found it very difficult to find out more because I was 75 at the time, roughly, and my brain's not as nearly good as it was – my brain's probably never any good – and Emanuel Swedenborg is not easy to read, so I found it very difficult to pick up one of his books and to read it and immediately get inspired, because he is a fact man; now that's probably putting it wrongly … in essence, the main thing was that it took away my fear of death. He wrote a book – *Heaven and Hell* – about him visiting heaven. I must say I haven't read the whole lot, I've read bits and pieces; Dianne's probably read it two or three times. I've got to be honest, I'm not really sure he did visit heaven but certain he had some sort of experience or vision.

Spirituality in practice

I think I am a reasonably pleasant person to live with. I still become unpleasant at odd times … but this has helped me have a greater communion with God. Before, I never had a clue about God; I never had a clue about Jesus …

I think church itself is … you know, you get some wonderful sermons, you get other sermons; sometimes it's a pain in the neck to get ready to go. There's the social side of church, there's the wonderful people you meet in church, but generally … generally the sermons really don't lift me up, no.

What does lift me up is being able to talk things over with Dianne; she's very matter-of-fact, and can get me back on the right leg, the right road, by a few simple words. And also today I had 51 minutes of talking with the Support Group Convenor. He's the Reverend John Tills. He's a prostate sufferer. He is one of the most down-to-earth Christians Dianne and I have ever met. He's to the point. He makes being a Christian so simple. He says, "Love the Lord and love your neighbour". He says, "What's hard about that?" And he's helped some homosexuals who were moving house and he does a weekly service, but some people criticised him for helping them, and he said, "I'm here to help people"; he said, "Someone else judges them".

"Things like that lift you up"

My spiritualty has never decreased. I wish it would increase. I think that, unless I can reignite it, I think at the minute I'm stagnant. I struggle intellectually. I'm not capable of getting up high. I wish I could. There are dozens and dozens of really great books I wish I could just pick them up and spend four hours reading them but I can't. I find that after 15 minutes my mind wavers and I read things in there that really inspire me. I feel disappointed about this. I really think I should have started years before when I was in the wilderness. Yeah, disappointed.

I wish my spirituality would become more intense. I know I keep bringing up my partner, my wife, all the time. She's very, very spiritual compared with me. Very spiritual. I'd love to lift myself closer to her. OK. I got lifted up yesterday by the dentist, the x-ray people, the lady who took us into the place where I'm having this treatment next Tuesday. I got lifted up by Reverend Tills yesterday when I mentioned spirituality. We had a lady come in next door and she sat there and you could see kindness all round her. Things like that lift you up.

The only greater support I would like comes from my soul. With better knowledge. I think it is up to me to lift, not other people. But Dianne is my crutch.

When the chips were down

There were times when the chips were down and the back was against the wall; you really wanted to get the books out and read and get help, but I notice in the last four or five months I'm not doing it like I used to. I notice that my memory is really getting, ah … I also like watching and listening to (religious) CDs, DVDs and sermons. I have a lot of wonderful friends who call in often. I love the company and chatting about things and reminiscing about the boxing in Australia and past champions. Ex-boxers are a fine group of people. I follow the racing on Saturdays and my interest in horses goes back to my school days. Happy memories of caravan trips with my wife are important as we made the last trip late 2009 and we knew it would be our last and have recently sold our van.

I had some contact with Craig and Dianne after the interview to maintain some caring elements with them, especially as Craig's condition was deteriorating. Unfortunately, he passed away three months after the interview.

Wayne

Wayne lived by himself in a retirement village. For a man of 85, he was exceptionally active in the village and in his church. He was articulate and focussed. Towards the end of the interview he received a telephone call and we interrupted the interview. He was a little distracted after this but retained sufficient focus to contribute more to his story. After the interview had been completed he told me that the phone call was from the doctor giving him some unpleasant news concerning his future treatment. He coped with this well, as he had seemed to be coping with many things during his life. I spoke of the context of spirituality prior to asking him to talk about his prostate cancer journey.

First signs

I, for some years, had a problem with an unexplained pain on the left side of my penis, and I was fortunate that on one occasion when I went to see my GP, in whom I had a great deal of faith, that he wasn't available and I saw one of the doctors that was standing in for him. He said straight away that at your age, which would have been somewhere in the mid-50s at the time, he said that I should have a PSA around 5, and, of course, it happened to be somewhere near 8, 9. It was elevated. So he said, "Well, we won't worry about it at this stage but we'll keep an eye on it" and it continued to rise. When it got up to 14, I was sent for a biopsy of the prostate, and, I'll say with hindsight, unfortunately for me, that in those days they carried out a four-needle biopsy which only covered 80% of the gland and my first biopsy was clear. It was found necessary to have a second biopsy done in six months. The second biopsy showed that the prostate cancer was certainly there, and not only was it there but it was already outside of the gland. I was unfortunate that I couldn't have the gland removed and be cured. I was put on a course of the drug Androcur to see how the cancer would respond to that. After six weeks it was found that the PSA had dropped to 1.2. Oh, and I thought that was a magic figure and I thought this was something I was going to be on for the rest of my life until the urologist hit me straight between the eyes. He said, "Now that we've proved that, we've got to remove the source of the hormones – the source of the hormones being your

testicles". And I said, "Well, what if I don't have the operation?" "Well", he said, "it's the rest of your life we're talking about."

"The whole ground was taken away"

Well, the whole ground was taken away out from under my feet. But, at the same time, I couldn't do anything else but stare the reality of it in the face if I was going to live for any reasonable length of time from that point on. I had to have the operation. So I just said, "When do we have the operation?" By this time, I might add, my wife had developed Alzheimer's disease and she wasn't available to discuss anything with me and, unfortunately, I had to make all these decisions on my own and this made things much more difficult as far as I was concerned because a problem shared is a problem at least halved, isn't it? Anyway I went ahead and had the operation in a reasonably short time. I would have been about 70 at the time, I suppose. I went through everything they tell you that you go through – hot flushes (the Americans call them "flashes"). They are not very pleasant, but …

Comfort of the church

I had come back to my church some time prior to this and I was very, very grateful that I had because it was the source of not simply comfort, but enormous support because a) I had a priest to talk to, and b) the Lord was there to help – every moment of every day and I found I could get over all these problems given they were as difficult as they were, especially the hot flushes. They can happen at any time. They just weren't pleasant.

By talking to the priest at least I was sharing my problems with someone, and then by praying you get the comfort. The Lord's hand is comfort. It is available to you at all times to give comfort. It is real. It is not pie in the sky. It is real and you take the comfort from your prayers. You can lift your head up and say, right, the Lord's with me. I'm going to cope with this with His help. I was able to cope.

"I was no longer any use to them whatsoever!"

When I look back over the whole time, nothing was done as far as treatment was concerned. I wasn't offered any treatment; they simply said that we go ahead and see what develops and nothing developed virtually over the whole time. I might say that

the PSA, after the removal of the testicles, went down to 0.1 and remained at 0.1 over a period of some years – quite some years. But at the back of my mind I always knew that the day was going to come that this was going to lift off the bottom, that I had not had a cure; it was just on hold. I had a PSA every six months and finally it went to 0.2, 0.5, then 1.0 and slowly progressed upwards from there.

It came to the point where the urologist was on a panel of doctors who were looking for men with a rising PSA and they wanted to test a new drug called Denosumab to prevent the spread of the cancer to the bones. They asked me if I would go on to that and I said, "Certainly I will". I went on to that program, visiting a Russian lady doctor at the hospital every month for nearly three years. Everything seemed to go along very well. I had bone scans, MRIs and this was a very good thing as far as I was concerned because they had a close look at my progress which I wouldn't have got if I had not been on the program. But the day came when one of the bone scans indicated that I had a secondary in one of my pelvic bones. I was no longer any use to them whatsoever for their program.

More disappointment

I was thoroughly disappointed. I had developed a very nice relationship with this lady doctor. She was comforting – someone to go to every month to have someone to talk to. I knew that that had come to an end. So it was most unfortunate as far as I was concerned.

However, I was still going to the doctor who was overseeing my whole program; he was still my urologist. I was still going to see him every six months anyway. I think it took probably over 12 months and he said to me that there was a panel of doctors – of which he was one – from different disciplines that were looking at what he called difficult cases. He said he would like to refer my file to that panel to see what came up in discussions from different points of view. Then as recently as September last year (2010) I had a letter from that panel saying that there was a novel treatment being looked at by a group of doctors in California based on your own immune system and they intended to develop a vaccine and that they would probably offer me this novel treatment. Well, that was the last I heard of that until recently when I

asked about it and they said that, as with some new things, funding dries up and that seems to be what has happened.

I had a back pain – this is quite recent, going back only three or four weeks ago – and I intended to see my physio who had treated the same area of my back three or four months back successfully. My GP said, "No, I want a bone scan done before you do that". (I hadn't had a bone scan done for about two years.) They found many more secondaries, in my ribs this time and virtually the whole length of my spine. He said no more physio; bones could be broken. That's the point that I'm virtually at now.

Treatments – "We'll see what happens"

I have seen my urologist again and he has given me a new drug which is to help, in his own words, in knocking down the secondaries and bringing the PSA down. I'm sorry, there was a point in July of last year where they had suggested that 10 days of radiation might be useful; and it was. My PSA dropped from 52 down to 14 by the radiation. But one month later it was up to 16, another month it was up to 25. I asked my GP to lay it on the line – what's the score from here on? "Well", he said, "PSA is the story. If the PSA continues to go up at the same rate, you might have another 12 months to live, but if it levels out you might have another five years." When I told my urologist about that, he said, "Well, it's a brave doctor who will start talking about exact times". He said, "You might say six months but your patient's bouncing around still in two years' time." He said, "Sure, your PSA's increasing which is not a good thing" (this was about the time of the new drug) "so we'll see what happens with that".

Spiritual activity and slow physical decline

Getting back to spirituality … I was very blessed in that, quite close to the time when I was first diagnosed, I lived here at a retirement village and we had a church service once a week in the middle of the week. They needed an assistant, and in Anglican terms they wanted a liturgical assistant (LA), to assist at the altar. I was asked, even though I was 70 years of age, would I take on that role. Well, I thought, I'd never done this before in my life but it was something certainly I would very much like to do, and I did. The Lord has blessed me greatly because every week I'm involved in a minimum of two services here and at St Alban's on Thursdays and then I take my

turn in our own church which is at least once a month. Sometimes I sit in for other people when they are not able to be there, so I'm able to be part of the sanctuary party for the service, which is a lot better than simply sitting in the pew.

I think, myself, that I've been slowly declining as far as my physical strength is concerned – my legs and my back – and had I not been participating as an LA, I think I would have just given up maybe two years ago, but I've got the strength through my faith and from the Lord; He can hold you up.

I did my LA work here today at the retirement village and, even though I'm knocked out because I have to do a patrol around the wings for people who are bed-bound, and that's physically exhausting, but I'm still able to do it. I have to rest most Wednesday and Thursday afternoons, but nevertheless I'm still able to do it and, with the Lord's help, I'll continue to do it for at least some little time to come.

Spiritual strength

I think my religious activities only strengthen me. Just as an example, I belong to a group of people who meet on a Monday night fortnightly for prayer and praise. For a time, the host and hostess of that group had health problems and I just said, "Well, my little unit doesn't hold very many people but you're welcome to come to my place if you want to". There were only three of us here on Monday night this week, but each one gets something out of coming. I certainly do. I would not like to see the early demise of that group.

My spirituality has been increasing and the closer I get to the point where I know my lifespan is getting shorter and shorter … oh, I'm welcoming that fact because of what I have taken from my Christianity. I welcome the time when I can meet my Lord.

Wayne's worship

I've got formal worship in church each Sunday and I've got formal worship here every Wednesday morning, and Thursday mornings over at St Alban's. Apart from that, there are times throughout each day when you see something. You'll be outside and you might see a bird fly over, or you might see a particular formation of clouds. It just strikes you that you thank the Lord for the beauty He has created. Those things

come to mind. Then, apart from that, I have a time each night before I go to sleep; I've got three different daily devotionals – although I don't use them all each night. There's a Scripture reading and then a discussion on that Scripture reading by the author. One of them is Martin Luther. I enjoy his point of view coming down through the centuries. And then there are always Bible readings. We have a church lectionary and I always do the daily readings. There's a Psalm for the day before I go to sleep each night. There was a time when I tried to do a morning prayer before breakfast but I just found that the world sort of rushes in every morning when you wake up – there are so many things to do and I wasn't able to keep that up. I've never got into meditation; it's something that would be worthwhile to do.

Spiritual beginnings

I'll go right back to my childhood for a start. My parents were not church-goers. But my mother saw to it, not so much for my two older brothers but for my sister who is three years older than me (and I am the youngest) but my sister and I, wherever we lived – and we had moved three or four times – my mother saw to it that my sister and I went to the nearest Sunday School and it didn't matter what denomination it was. When, later in my life, when I had time to sort these things out for myself, I was so thankful that I had that Sunday School background. Even when I was in the army I always looked for church parade. I even got myself into trouble one time when I insisted on going to church parade. The thread was always there because of that early training in Sunday School even though I drifted away from the church partly because my wife developed agoraphobia early in our marriage. Actually, she was a church-goer when I met her and I started going to the Anglican Church because she was Anglican. I had not been going to an Anglican Church at that time, and I was so thankful because I love the Anglican ritual and I love the structure of the Anglican service.

Coping with the stress of prostate cancer

My faith – it's always there. It's not something I think about. I think it's there in the background all the time and when there are these stress points and, certainly, I'll put it this way: it's happened three or four times now and in one of them I had a complete blockage and I had to have an emergency operation, and what you go through prior to this emergency operation I was praying. That's helped me many

times when I've been waiting for things such as operations (and I've been through a number of them over the years): prayer prior to an operation has been a priority as far as I am concerned.

Some activities – lifting the spirit, or just hobbies?

I wonder if you would call some activities spiritualities or whether you would tend to call them interests. I've had an interest as an amateur astronomer and I've had an interest as an amateur wireless operator. Those two things can absorb you completely and you can switch off from the world.

They used to lift me. Not so much being a ham, partly because of the sunspot situation. Old spotty face up there hasn't got a spotty face at the present time. Our radio waves go straight through; they don't come back. As far as astronomy is concerned, it does because it's the most absorbing thing outside anything else I've ever done. It lifts you up and takes you away from any problem you might have.

Continued spiritual support

I've been very fortunate that the priest of our parish who asked me to become a liturgical assistant, I had quite a close relationship with him but I've had an even closer relationship with the two priests that have followed him in the parish and especially the one we've got at the present time. I've got all the spiritual support that I could possibly hope for from our current priest. He's a wonderful fella.

All in all, I feel quite blessed in that my illness has curtailed what might otherwise have been a more active self-seeking life. The necessity of being at the nursing home daily during my wife's long illness gave me the opportunity to develop my own long association as a volunteer with the occupational therapy staff and dealing with other people's problems diverts you from your own.

Colin

Colin was very welcoming. He was excited to tell his story because he believed he had something to contribute. He lived with his wife and two small, sometimes noisy dogs in a very comfortable home. He was a well-organised person and this showed in the way his story was constructed.

The beginning of the journey

I had very little spirituality. I left school and then I had 40 years of nothing. And then I developed spirituality from then on so it was a big gap. I had no background of Christ or the Bible or anything, really. When I left school it was put out of my mind so I had that long gap. So when I come into it now it's all new.

Probably about six years ago the doctor did a complete blood test and the PSA showed up there. So that was the start of it; so then he got me into a urologist and he had a look at it and did all the tests on me. The Gleason score was seven and the PSA was 39 which they said was pretty high. So we did some more tests where they found that the cancer had metastated to the bone. So I've got a spot on the sacroiliac joint which is where it is now and it hasn't changed.

Going back to the urologist, he gave me a book to read on all the different treatments for prostate cancer, and the alternatives. I read through it pretty carefully. I like to know what they are going to do to me. There was one there that looked fairly good to me; it wasn't invasive. It meant getting an injection every three months. It was the hormone therapy treatment. So I went through the book and marked it all out and highlighted this particular one. When I went back to him, he looked at me and said, "Well, we've got a few options. In your case it has escaped the capsule from the prostrate and it's into the bone. We can do chemotherapy or radiation". I looked at him and he said, "Hmm. There's one other one and that's hormone therapy treatment". And I said, "What chances have I got with it?" and he said, "Very good". So I opened the book and showed it to him – this was the one I had already highlighted. So I said, "We'll go for that". So we started on the injections and every three months I go around to get one. The PSA has dropped back to 0.2 and for the last six years it's been pretty close to 0.4 or 0.5. So it's running at that and, while it's

maintained at that, we'll stick with it. I've had about 25 injections – which is six years. He's quite rapt in it. He said I must be one of the lucky ones. I said, "Well, I have a lot of help". That's where I am now and that's where it all came about.

Force in spirituality

I wasn't a Christian at that time; I was a hypnotist practising in sports. I used to work on sportspeople and that type of thing and there was one guy I used to watch on TV. His name was Benny Hinn. He was an American evangelist. I used to call Pamela, my wife, out and say, "Have a look at this; he's unbelievable at what he does". I used to watch him because I wanted to learn how he did it. I thought he was the best hypnotist I'd ever seen. This went on for a while and, in that time Pamela became a Christian, got baptised and did all the things. I wasn't quite ready for it at that stage. My uncle was living in Sydney and he was getting a bit old so I thought I'll go down and see him. At the same time Benny Hinn was having a crusade in Sydney and that was 2006. I booked in and went down and went to the crusade. I got in there and there must have been 1,000 people there. I got a seat that was looking right over the stage and the music came on and everybody started to sing and dance and wave their arms and carry on and I thought, what am I doin' here? It was quite amazing and Benny Hinn walked out on the stage and I look around and think, hey, I'm doin' the same thing. They'd got me. There was a lot of power there and a lot of force. I know that was the first time I felt the Holy Spirit. So that's where the spirituality started. When I came back from there I was convinced that, OK Benny, you must be getting a lot of help from above, from the Lord, and I thought, wow, this is pretty amazing stuff. The people Pamela was doing the Bible study with, they talked to me about joining and I said, no, I'm not quite ready; I need to do a couple of things.

I didn't tell Pamela. I had to read the Bible and I had to get baptised, then I'd do the rest of it. So that's my journey in that area. We found a church. Pamela did the churches. She went to about four churches. She didn't like them all that much so she decided to go to one out at Jindalee. When she got out there she came home, she said, "Wow, that's really good; it's just like being at home". So we went out there and joined in with everything. We went to Bible study at Church and in home groups and it was really good. And then I discovered that, OK, something happened when I

was in Sydney – whatever it was, whether it was a very good doctor or I was getting a lot of help – and my PSA hasn't changed in four years.

No prostate symptoms

I have no trouble with the waterworks – it's all working fine and I've got no symptoms. I had to go and ask the doctor how I should feel. I feel very good. I've lost a fair bit of weight but looking at the hormone therapy treatment and what it does to you, you lose your muscle mass and bone mass as the side-effects and I kept talking to him about that and asking what's the treatment. Finally he put me on to Actonel which is Calcium and Vitamin B combined tablets, so I keep those up. I didn't like losing weight. I lost about 10 kilos. But I still do the gardens and lawns; I still do weights four days a week and this seems to keep me fairly active. At the moment, all of the treatment is through hormone therapy.

A positive approach

Well, I have it cancer and the first thing I thought of was how can I beat it? I'm pretty positive with what I do and I said, well, what's the options?, let's look at them and see where we can go and what we can do. So I looked at everything that was available to me and that's how I decided I would treat it. I wasn't a Christian at that stage.

I had a bone density x-ray. That's just a while ago. I wasn't impressed with that either. They did the left side and I have the problem on the right side. They said everything is all right. They were quite happy with what they were doing. I might not be happy but I think they should know what they're doing.

Prostate cancer and my spirituality

There is probably a direct relationship between my cancer and spirituality. I pray for a miracle and a healing, and I know that my inner self is a lot stronger. I have no fears or doubts. I'm here now and everything's been done that I could possibly do and I'm in the Lord's hands. I'm quite confident in what's happened.

The Bible is the greatest source of my spirituality. Most of the passages in the Bible are related to "ask and ye shall receive"; "the Lord gives"; "the Lord is a healing God". He is very caring so I know I'm in good hands.

Benny Hinn is someone who gives me a tremendous amount of encouragement. I like his teachings, I like his manner and I know he does a lot of good. He's one of the top evangelists in America. He does crusades throughout the world every month. He doesn't say, "You've got to do this or you've got to do that". He's got a good manner about him. If they start to tell me what I've got to do, or don't do, I kind of back off. He gives me what I need – put it that way.

We go to church on Sundays. It's a very good service. We've got a very good preacher. He's a teacher and a preacher. The people there are very good people. We're very comfortable there. It's like being at a family reunion.

Spiritual growth

My spirituality has increased because I had nothing until I started four years ago. We did look at a couple of things when we came up here from Melbourne. We settled into the house and everything and we got involved in sports and all that type of stuff and as I got a bit older the sports faded out a bit. We both knew there was something better. We were looking for something; we didn't know what it was. We looked at Buddhist and Tai Chi and a couple of other ones, you know, but nothing was there that we needed or wanted. Then we met a lady who used to walk past here every morning. We had a blow-out with a water pipe and she knocked on the door and told us we had water everywhere. Then we got talking. She was a Christian and Pamela got involved with her and they went to home Bible study which was very good and I got the backwash of this all the time which was pretty good, and it developed from there. That's how Pamela got baptised and became a Christian. Then when I got baptised and became a Christian and Pamela found the church she liked, I said, "That's good enough for me".

The cancer has been on hold for six years. My spirituality has helped me a lot because it has given me a good mindset. I've got no doubts. I've done everything in my power, and the Lord's help, to keep it there, to lie dormant. I expect it to go

away. I asked the doctor after getting the PSA report and he reads it and says, "That's good", and I said, "Well I expected it to go away, to be zero". He looked at me as if I'm a bit strange. I honestly expect it to be zero one day.

I've never really felt down during the time of my cancer. I would say I get a little doubtful when I go for the blood tests. It's there at the end of the three-month period and I feel, ah … let it be nothing. I don't do anything special before my tests. I know I'm going, what is going to happen and I'll get the report off the doctor. I expect him to tell me that it's gone down. I have a good mindset with it before my tests. I know where I'm goin' and I know what I'm doin'. I know it's there; it hasn't gone away. But it's not going to get me!

Practising spirituality

I tell you what, it's, … I'm in a sports club. I compete every weekend – Saturday – with a group of guys there. Their manner and attitude has changed around me. They used to come out with all the dirty, filthy jokes, and now they don't tell them. I'm quite amazed at that really, because one of the guys has a joke every week, every day, you know, and he said to me last Saturday, "Oh, Colin, I've got a good joke for you – it's all right, it's a Christian joke". The people around me have changed. It's quite amusing really. I think this change in others has happened because of the change within me, the change within my manner, aura, whatever you like to call it. I can't think of the word. Something has changed around me because my whole life has changed. For about 40 years I worked in pubs; my life was in pubs so you know what I dealt with. I dealt with different things then so my life has really changed and the people around me have changed. It's a good feeling.

Physical and spiritual support

I went to the prostrate cancer meeting every month and they have some good lectures there and some good people and people give testimonials about what they are doing but there wasn't enough input. Everyone wanted to talk about their own problems, not solving the problems and moving forward into another area where they'd come up with treatments or herbs or new work, or something like that. I felt they just weren't going in the direction I wanted to go. But I listened and learnt everything I could but I just dropped out of it. But I still get the cancer magazine which is very

good. If you read it there's so much information in it. It's way above me in technical terms but I can read what progress they're making, what new things are coming out, where they're going – but it's all key news of the future. I still like to read it. I enjoy reading about the stuff they're doing now – the vaccine they've perfected and are still testing. OK, the thing works, it's wonderful, it's wow, wow, wow, but 10 years down the track we might get it.

Spirituality during stress

Probably the stress points have been every three months when I get the needle. I know I'm going to get that, but I can switch off it, I can cut it out. I use my hypnosis. I know I'm going to get it. I can deaden the side. I don't feel it. I go and get it and I'm out in 10 minutes. Sometimes he talks, sometimes he doesn't.

My hypnosis began with sport – I was involved in sports for 50 years. Concentration and focussing are two of the main things. We used to get psychologists coming in to give us a lecture on something. They were never related to what we were doing. Then, when I gave up work, I got involved as a coach – level 3. I ran into a guy who was involved with hypnosis and I said, "Do you think I can do it?" and he said, "Yes, you would have no trouble doing it". I think there was about 300 hours of practical, hands-on hypnosis. I learnt a lot from it and then developed my own techniques and methods which I started to pursue and I've used it right through. It gave me a lot of insight into people and a lot of control over my own body – switching off, pain, deadening areas, all that type of stuff. Pretty open really. It's a wonderful media to use in a lot of places.

Hypnosis is probably part of my spirituality, because it is a relationship between you and a person. They've got to have faith in you before you can do it. They give themselves to you; they put themselves in your hands. And I have done a little bit of healing. The hypnosis and the healing come in together, and spirituality. If you say it's in God's name you're healed, or, if the healing process is in your mind, it is accelerated. You can feel the power – the mind taking over ruling the body. Probably where I am, I've got to be a little bit careful in what I do. I'm not stepping forward and doing it; I'm there. I can do things with people that are very good but I'm not going to get up on the stage and do it. There's a lady praying over a girl. I was there

in the group and they said to do something so I put both hands on her knee and I said, "Feel the power of healing". When she was finished she was outside rubbing her leg and I said, "How are you going?" and she said, "Oh, really good. The leg's still hot". So something worked. She said that it feels good; it was very hot.

My spiritual source

I only have one source of spirituality. I think there is only one God – three people. We have the Father, the Son and the Holy Spirit. The main source is the Holy Spirit and He's the one that guides you and helps you. I'm only new at this but I listen to Benny Hinn. He was on this morning. He was talking about the spirit and soul. There's the Holy Spirit, my spirit, my soul and my body. It's quite interesting really how he broke it up, how one intercedes with the other.

I think my spirituality is a gift. It is a gift. My hypnosis, healing and spirituality are all part of the one.

Colin was excited when he phoned about three weeks after the interview to say that he had a very positive result from his most recent bone scan. Quoted below is part of the doctor's report:

> *"Comparison with the previous study performed on 12/01/05 shows that the intense increased tracer activity previously seen in the right hemi sacrum entailing to the midline is no longer visualised. … Previously noted abnormal tracer activity within the right hemi sacrum has resolved. There is no new skeletal metastasis."*

Colin said that he thanked the Lord for this wonderful news. He was on a high when he walked out the door and said that he told the doctor "I had help". He believed that the good results were directly attributable to his spirituality.

Ben

Ben lived by himself in an apartment near the coast. He was anxious to tell his story because so much of his life, especially around his prostate cancer journey, was disturbing for him. Once the interview had concluded I suggested he might make contact with the local advanced prostate cancer support group as he seemed to be desperate for some interactive human support. I have had a number of communications with him since the interview and he has told me that he has joined the support group.

No symptoms

I didn't have any symptoms at all. There had been bits in the news about prostate cancer and I'd never been tested and someone told me I should go along to my doctor, my GP, and ask him to be tested so I did that. He'd never suggested prior to that that I have a test. Twelve months prior to this I was feeling really tired at work and went to my GP and told him that. He put me on a course of vitamin tablets. I was also a bit low on iron so I took some iron tablets for a while. Initially it helped me and I got over that tiredness but twelve months later someone told me I should go and have the tests so I had a test for bowel cancer and a few other tests but I never had the prostate cancer test so I went along and said to him, "Can I have this test?" So he did the digital examination first, then I had the blood test, then it came back and I had a PSA of 26 which he said was pretty high because the average is about 2 or 3, I think. I was astounded, and then I had an scan and it confirmed that I was just full of cancer.

It was in August 2009 when I went to my GP and he said I needed to see a specialist straight away and it was the next day. Normally it takes three months to get in to a specialist but, because it was so bad, they took me the following day. I had more scans and the results came back and confirmed that the cancer was really bad.

"Just blurt it out!"

They took samples and they discovered I had the aggressive cancer and they were able to confirm that the cancer had already spread to the vas deferens and the lymph

nodes. When my specialist saw the x-rays, he turned to me – well, he wasn't saying anything and I said to him, "You're not saying anything" and I said, "What's wrong?", and he said, "I don't know how to tell you" and I said, "Well, just blurt it out!" and he said, "Well, I don't think you can be cured". And, of course, that came as a hell of a shock to me from having no symptoms to all of a sudden having a death sentence. And then he said, "We're going to have to remove the prostate. It's going to be a huge operation. You need to get yourself as fit as you possibly can". But I was already fit because I was working at the time and doing a lot of walking during the day and was really fit anyway.

I was just due to have holidays and I asked if I had to be operated on now and should I wait and they said, "No, go and have your holiday and when you come back we'll have the operation".

A state of shock

So I was in a state of shock. So I rang my son. I had a son living in Bendigo, Victoria, and I thought, how am I going to get through this?; how am I going to get through this operation? So, I went on sick leave from work straight away because I had to have this operation and I needed a recovery time afterwards. About 10 days before I had the operation I decided to go and see my mother in New Zealand for four days. Then I went to visit my son and that gave me the strength to help me get through the operation because it was going to be a huge operation and I just had to find the strength to be able to get through and that enabled me to have the strength to survive the operation. So I had my holiday and came back and had the operation. I had the prostate removed.

I was in private health, in the Mercy Private Hospital. I was there for four nights, then allowed to go home. I had a catheter for two weeks. I had to stay with an elderly male friend that I knew who was good enough to let me stay at his place for a couple of weeks after the operation. I was able to survive the operation – wearing a catheter I didn't like; it was horrible, actually – I was so pleased to get rid of that. After that I remained on sick leave because it takes months to get over an operation like that. You have difficulties with walking to begin with. There was also incontinence that went on for about three months – that's not very pleasant. You have to do exercises

to try to help strengthen the pelvic floor. Eventually, over time, I regained my strength.

Treatments and tests

I also decided to go to a Chinese herbalist. For six weeks I had a course of Chinese herbs which I used to boil up every day and drink the mixture. That really gave me a boost. The herbalist also gave me some Ginseng. I boiled water and put the dried Ginseng into a mug and drank that. That really lifted my spirit and it was of real benefit to me. I got all my energy back and I started to feel good. This was for six months after the operation.

After the operation I was having blood tests to see what level the PSA was. About six weeks after the operation the level had gone down to almost zero. Every six weeks I had more blood tests.

At the end of April it showed that the cancer was spreading at an alarming rate; that it was actually doubling every six weeks. So the day I got these results, he said, "I'll start you on hormone injections straight away". I had to take hormone tablets for a few weeks and then I had to have an injection every three months. To begin with it kept the level right down – almost undetectable. I had a blood test on Monday of last week and I got the results back yesterday. I am now back to square one. I'm at the same level today as I was almost 10 months ago. The hormone treatment has started to become ineffective in the sense that the cancer is starting to take over again. It's now 0.19. The previous reading was 0.05 so it's doubled and almost doubled again.

So I had an injection yesterday. The specialist said, "You'll possibly have one more injection", then said, "I'd like you to think about having some chemo". I said I wasn't very interested in that. Prior to having hormone treatment they suggested I have radiotherapy. They said there was only a 5% chance that this would cure me and that there was a 20% risk that it would damage some other organs. I was not prepared to take that risk. I wouldn't feel comfortable if I damaged my bowel and if had to have a colostomy bag. I talked it over with my son and he said, "Don't put yourself through that". So that's when I decided to go for the hormone treatment. But now the specialist is talking about the chemo and I'm reluctant to do that because I

was diagnosed with terminal right from the start and there was little chance of me being cured.

A tough journey

I was in the situation where I live by myself; I had my son and I had close friends but I found it very difficult, so I actually turned to God – I'm not a religious person – but I turned to God to give me strength. I prayed every night and every morning in the hope that I could be cured. For a long time I'd be feeling really well but over the last month I have not been feeling all that well. I wake up during the night and I feel ill, sick in the stomach. Some mornings I feel light-headed and I can't walk in a straight line. To be honest with you, I've actually stopped praying now. I can't explain why because it was just something that … like I said, I wasn't a religious person but I turned to that in the hope that, yes, you haven't got much when you're diagnosed with a terminal illness. It hits you like a rock; there's not much to grasp hold of, really. So that's why I started praying.

And another way I was able to cope with it was to tell as many people as I knew or even some people I didn't know all that well that I had this cancer, as I found it was too big a burden for me to carry and that lightened the load. Well, in a funny sort of way I wanted to spread it around, although I didn't want to spread the illness, but I wanted to spread the story, I suppose, just to take the weight off my shoulders because when you are diagnosed with a terminal illness it's just a huge burden and, yes, it's really hard to cope with. We all cope with it differently. Yes, that was my way of coping with it, yes … it's, ah …it's shattering, especially at my age.

"It's hard to accept"

I feel that my GP really let me down. He was a professional and he should have known. There's a lot of people do know, but there's a lot of people don't know, like myself, that there's a lot of people saying that even at 40 men should be tested every 12 months, and, yes, I felt very let down by the doctor because he never ever said. But then I went up and saw another specialist in Brisbane and I mentioned that to him and he said, no, there's heaps of doctors who, if they saw a 56-year-old man walking in looking fit, they wouldn't even mention it. This is why I want to tell my story and maybe I can help someone else, because it's … just so … tragic. Like, my

father lived to be 86, and, like, I'm thinking that maybe I'll reach that age, or maybe 90 and I've got another 30 years ahead of me; then, all of a sudden, I find that I'll be lucky to reach my 60th now. I feel robbed, really. But I never really got angry about it; there's no point in doing that; you can carry on as much as you like but I just, I just had to come to terms with it. It's hard to accept but, you know, but that's the way it is and I've just got to cope with it as best I can.

I have had the support of a few close friends – a half a dozen or so. I also decided that when I was diagnosed with it I no longer worked so I've officially retired now. That's my decision – I just thought, you know, if I haven't got all that long to live, well, I'll just enjoy what little time I have left and make the most of it. I know of another case – he hasn't got prostate, he's got bowel cancer. He had an operation and is still choosing to work. That's his choice. I had an open prostatectomy. It was a about a 7-inch cut.

The lifts

I did have a lady friend who was very supportive. I was in a relationship with her prior to this. She helped me a lot. Every time I saw her it gave me strength. And then, of course, from one or two other friends, the guy that I met through my work as a delivery driver, he was very supportive. And my son. Not so much now but from the time I was diagnosed he was ringing every two or three days to see how I was. That gave me tremendous strength to cope with it.

Now it's not easy. There are times when I … I've been on antidepressants ever since I've been diagnosed with it and I'm still on antidepressants. And since I've been on hormones I've been on blood pressure pills – my blood pressure went right up. I guess I'll be on them for the rest of my life. I'll continue on the antidepressants because I wouldn't be able to cope at all otherwise. They have really been beneficial.

Support and counselling

I had one session with a support counsellor. I was offered six sessions actually. The counsellor was actually a woman. We talked for about 50 minutes. I just came away really angry. I think that, at the time, it was just focussing on my illness for that length of time. I didn't have any more after that. Recently I've had more stress

because my mother is in a rest home in New Zealand. She has dementia and is not going to live much longer and over the last month I've been pretty stressed out about that. The new GP that I have suggested that I have some general counselling with another organisation and I've found that very beneficial; it's really helped me. I did ring a prostate cancer support group when I was diagnosed and spoke to a gentleman there but I haven't gone down that path. I suppose if I had a partner I might have gone along and it might have been beneficial for my partner but sometimes I just like to keep to myself and maybe that's not the best way to go.

Painful side-effects

I've had a bit of sweating. Only today actually I'm all flushed in the face which I haven't had before, and also I can hardly walk today. I have aching legs and I've never had that before. When I first started I was sick in the stomach. I was really sick for three or four weeks. I took pain-killers to help me with this.

A need for strength

Often I really think about it and wonder how I'm going to gain the strength to get through this. Sometimes it might get all too much and then I might see friends and sometimes I might talk to them about it and they don't mind. A problem shared is a problem halved. It just works that way. When I was first diagnosed and told people, a number of people said to me, "I don't know what to say". And I said to them, "You don't have to say anything; I just have to get it off my chest". Some people were embarrassed, obviously. I said, "Don't worry about it". I just have to say it. It's helping me by saying it.

I bought a bike a month after the operation and now I try to ride my bike every day for exercise. I try to catch up with my friends and have a coffee; sometimes go out to breakfast – every Sunday actually with a group of about six of us.

A lot of times I keep to myself. Sometimes I have to push myself to get out. I don't know whether it's because of my star signs – I'm a Cancerian, I was born in June. Yes, I like to be by myself sometimes. Sometimes I'm just happy in my own environment; that's my way of coping with it. Sometimes I don't want to talk about it; other times I do tell people about it but I don't really want to burden other people

with it. I can go to a counsellor and just blurt out whatever I like; it can bring tears to your eye but it doesn't really matter. Next day I've woken up feeling much better after getting that off my chest. It's not something I can burden my friends with but I can burden a counsellor with it. It's been very helpful, that. My GP says that I have so much on my plate with my mother, my cancer and that, I need to see a counsellor from time to time.

My mother and my son both gave me great inspiration. It's very difficult with my mother because when I told her I was sick she couldn't comprehend because she has dementia. She didn't know how bad it was for me. Now she doesn't really know how tragic it is. Even so, she gave me inspiration. She turned 90 in November 2010 and when I went over there we actually went out to lunch with our cousins. She was reasonably good but since then she has deteriorated a lot.

"I got the short straw!"

I just can't believe what's happening to her and to myself … In some cases some people on hormone go for 10 years and still going. Studies have shown that 99% of men under the age of 60 diagnosed with prostate cancer have the less aggressive type; the remaining 1% have the aggressive type of which I have. It is assumed that, once detected, you don't worry too much because chances are you will have the slower-moving type. But what about the other 1%? It seems that it is just plain bad luck. I think I got the short straw!

Jason

Jason lived with his son and his son's family near the coast. He was so enthusiastic about telling his story that he wanted to start the moment I arrived. I overcame this by telling a little about my research while I was setting up the recording equipment and trying to establish a rapport.

Spiritual and religious basics

I am in my high 60s and I've done everything right throughout my life. I'm a Catholic. I go to Church at Christmas and Easter but that's about it. All my family have grown up in the Catholic faith. They have gone to Catholic schools and so have my grandchildren. I'm religious and believe in spirituality.

Frustrations

But, with my story, I'm very annoyed about the whole process. I guess misinformation could be a word. Probably for the last 10 years I've been aware of the word "cancer". I've been doing the PSA. I've been doing the cholesterol and I've been doing the digital, and all that. It's all been fine, 1.9 on the scale of things, all been fine, OK. About nine months ago I thought I'd better do a bowel check as suggested by the TV ads. So I went to the chemist and paid the $15, got the bowel screen check, did the stool sample, sent it away, and it came back OK. I thought, well, that's good. Now for some reason I went to another one a few months later. In the meanwhile I had blood in the bed, blood in the bed. Yes, my second stool sample came back OK. In the meantime I went to a doctor for the blood in the bed. Not my family doctor because I had changed addresses. So I went through the process of having a bowel test so I had a referral to a private hospital for a colonoscopy with Dr Fry. The doctor said, "Well, you're OK in that department but what you need is a prostate check, now!" With that I went to a public doctor – I'm only a pensioner; I'm not on private healthcare cover. I got a referral to a urologist, Dr Edmed. After doing the digital examination he immediately said, "Yes, you are positive". So I was listed in the hospital scheme of things and I waited and waited to get an appointment. I was trying to get an appointment and, in desperation, after 4 to 6 weeks I became very aggressive about it. So I wrote a long letter to the Health Minister. I said, "This is not

good enough" and other things; "I just want an appointment. Prostate does kill. I just want a time. I don't care if it's six months but just give me an appointment, not a maybe some time". His secretary replied next day and I got an official letter three days later saying that things are happening but are a bit slow in the hospital system.

"What?"

I was sent to a private hospital to accelerate the process – excellent doctors and nurses – where they took a biopsy. Seven of the eight nodules were contaminated. What? I was then referred back to the hospital scheme of things, and they said, "OK, this is what you do". Being a public hospital patient, you are still under the guidance of a urologist, whatever. I got a CT scan and it did show up positive. The cancer had progressed into my bones and upwards. Then I had to wait another couple of weeks for another CT scan, a bit higher this time, and it did show scatterings in the lung. Wow, that's a knock in the face! So, armed with all this evidence, I went back to the hospital again on appointments. It wasn't too bad considering, once it started, it really did flow. It just took a long time to get started. That was my single biggest problem. So when it got started, there was a guy there, very good. I'd seen a few doctors over the times. They were only juniors but very versed in knowledge with the back-up of the local urologist. Well, this Dr Williams said, "We can't give you radiation because it's progressed. We can't give you chemo either because it's progressed too far; an operation is out of the question. You'll still have some sexual functions, maybe". An important part of my life is sexual function, really.

What are the options?

Anyway, what happened was that I was one of the unlucky ones with high testosterone. It had slipped through the radar. It didn't show up on all the PSA ratings like 2, 5, 8, 12, 15 or higher, it just didn't show up; it was just normal, normal, normal, normal. So I had no warning. So they said, "Well, it's progressed too far", and I said, "What options have I got?", and they said, "The only option you've got is hormone treatment". So I said, "What does this involve – how often, every month, two months …?" and he said, "Every three months. I'll give you a script, you take it to your chemist, then take it to your local GP and he'll give you an injection in the butt". And I said, "Is that it?" and he said, "Well, that's it!" I said, "Well, can't I do anything else?" and he said, "No. No. See you in three months. It was confirmed

with the urologist". "Are you sure that's it?" "Yes, sure, that's it." So, I'll be disillusioned if that's it! My three months is coming up in three or four weeks. I've got to get a PSA to go along with that. Whether it shows anything or not, who knows! I don't know. They'll make a decision on all that. I do feel OK in my body but my mind is a bit screwed up.

Simple "signs"

But a couple of points come to mind. For years I've had an itchy sensation down below. Some people call them crabs or something else but I don't even know that word. Sometimes you scrub yourself in the shower and it's still there. It's an internal sort of thing and you always find that they happen in different places – down below, front and rear. And for years, three or four years I've been asking the local doctor "What's this? Can I get some creams or this or that?" "No, you've got nothing there." One doctor said, "If you think there's something, get some sticky tape on it and we'll examine it". But that wouldn't do any good because it's internal.

But my partner then, well, she had cancer the same year. She had breast cancer. She said, "On reflection now, I've had an itchy nose for the last couple of years. Internal. You can't scratch it." Maybe that's some little sign. If someone had said to me, some smart doctor, or someone, like I'm saying to you now, hey, you don't know, just a wild shot here but how about having a scan done, or something else. This may be a prelim. to something.

So I'm glad you are here to document this because, maybe other people … I spoke to some of the cancer support people and said, "Hey, guys, have any of you had a sensation down there or around, do you …?" "As a matter of fact, we have." No, no doctor told me this.

"Mandatory tests"

On reflection, a couple of years ago maybe, I would have had a scan or biopsy or whatever. Now, my son is faced with the same scenario. He's 40-and-a-bit. It's inherent. My mum died of a cancerous thing as well – in the stomach. So he's in line to progress on from me. I said, "It's mandatory, mate, that you get these biopsies done, and colonoscopies". One guy at a workshop a few weeks ago, he stood up and

he said, "Is there any man here who hasn't had a colonoscopy in the last year?" Anyway, a few put their hand up and he said, "The rest of you are bloody crazy. Every man our age has got to have a colonoscopy, or a biopsy, and/or other tests." The PSA and the digital is the only one they've got and it's not good enough. There's the progressive side of it.

An emotional road

After being at support groups it was recommended that I see a nurse at another private hospital. Very, very good; highly recommended. She deals in basically erectile dysfunction. All these new words I'm learning – pelvic exercises, outercourse, and others – no doctors told me these words. I've got a lot of information in books. Some I've pushed aside, others are quite relevant. I even pushed some on to my son last night. I haven't had sex really since I've started hormone treatment and that bothers me a lot. I have no urge and definitely no length; it's ÷ 2.

My partner I had before has left me. She had cancer. I tried to follow her through hers but she said I was never her "light", so anyway. She said, "What comes around goes around". Oh, thanks a lot. So I am so fortunate with another lady now who is really, really on side with me. She knows what's happening exactly, precisely. She's offered to come with me next time at a counselling session. I suggested it but she said, "I was going to ask you the same thing". So we have the same thoughts. There were eight or nine couples there at the last prostate support meeting. It was so good to see.

I get quite teary now. I can watch a movie I've watched before with no effect, but now, something happens – the female hormones must kick in, I don't know. All of a sudden the tears are streaming out of my eyes. I don't know what this is. Hot flushes – I haven't had a lot but I have experienced them.

Alternative medicine

I'm on alternative medicine – pawpaw or papaya leaves. I've been reading up about this. I've got on to the internet and I belong to a men's group called "Men's Shed". There's about a hundred people who are fairly active in it and we get to talk. This is

fantastic because guys can talk to guys. There are two there coming out of prostate cancer. Men our age can just get together and talk to each other and, if they want to, they can build something. They mightn't have a garage at home – they might be in a high-rise. It's very important for men to get together and chat and you just get to build things. All the tools are there and if you build something it costs $2 for that day for private projects. They build all sorts of things – wooden ducks, horses and toys for the community or charity, so we're actively trying to help these men with something to do. And you get to talk.

I put a sign up saying that I wanted some pawpaw leaves. I've read up about this and I said, "That's for me". So I talk to people and they say, "Yes, I've got some pawpaw leaves, I'll bring some round" or "Come round and we'll get them" and all this. So, I'm into pawpaw leaves. I cut them up. I squash them up. The first lot there were a couple of spiders in there but that's OK – a bit of fresh meat doesn't matter; it's all good! So I cook these things up for two hours, strain it off and get the juice. I'm drinking about 500 or 600 mls per day. I make a couple of 2-litre bottles. This gives me something to do; it gives me a purpose. I feel I'm actively doing something over and above, and instead of, "Well, come back and see me in three months", I'm doing something there. It's good for my mind and it's good for my body. Well, I'm not sure about my body, but I believe it's going to help me. I really believe this. I believe it so strongly, spiritually and otherwise; this is my little grasp on things. I don't pray a lot but I try and meditate. On these pawpaw leaves – I believe it will cure me. I've got people looking for me. They drive along the street and say, "There's some pawpaw leaves over there. I'll take the number down". I'll call them later and have a look. A couple of times I've asked guys and they've said, "Why, are you doing a cook-up, are you?" But I'm certainly aware that it may have some benefits.

Family-based spirituality

I've always been a 100-mile-an-hour guy. I'm a go, go, go guy. I'm an engineer by trade. I've travelled the world a fair bit; I've seen a lot. I've seen half of my own country. I thought work was more important than family. But it's not. In fact, it's very second rate to family. I'm now staying with my son here. He said, "Dad, come and stay with us while we sort this out". So I'm doing that. I believe in God. I believe in spirituality. My family and grandkids are my spirituality.

Personal spirituality

I believe it's a thought. It's a future for me. I can pray for myself. I don't get down and kneel but I certainly believe in the Lord. I know this helps me. I don't think, why is it me? Why me? I don't think that. It's happened and it's happened. I will get on with my cure.

I just think that out there there's some other being. There's a lot of things out there and spirituality is one of those things. I've been reading about well-being and relaxation and I can't quite relax properly. I'm still geared up. But, in my own mind, if I go hard and fast … the problem won't go away but I won't think about it too much. I'm on a regime now with a medical lady at a fitness centre. I go this afternoon to do the first exercises and weights. I would like God to help me. I know God can't heal everybody but I can put myself out there for Him to look down upon me and give me some reason to live. I've been healthy all my life. It's just this last "little speed bump" in my life. I'm not a sick person. I'm reasonably healthy and reasonably fit. So as far as a lot of intensive spirituality – I'm not. I'm not. I've got thoughts that the pawpaw leaves will guide me and God will guide me. I don't pray at night much. I watch a good Catholic movie sometimes. I would like to go to church more often but I don't. I feel life hasn't passed me by. I've had a good life. I've had a good life more than most, actually. I've seen a lot of the world. I've been to India; I've been to the Shah's palace in Iran. I've been to a lot of places. I've been an engineer. It's so great that Australia is Australia. It's just nice to get back to Australia. When you look at what's been happening overseas. Recently a company has gone broke. They employed over 10,000 people; they paid 10 bucks a day and then they skipped off with all their passports. I mean … that's pretty rough; we are still lucky in Oz. And, I've been given a figure … my Gleason score is 9, which is right up there.

I've turned to a computer to occupy myself and I'm into playing around with these dating sites. People come up; I have a little chat. So I feel there is something else. This will take me through, and other things. Now I'm with a special lady at the moment and she says, "No more coffees". She is right. We give ourselves a very good chance of being happy together. Seriously. She's still working for a couple of years. She's a kindergarten teacher and we go away together. In fact we're going

away this weekend. She understands erectile dysfunction but we will work through this. A man loses a lot, particularly in the mind, when this occurs.

More lifts

Well, I like boating. Boating is a big part of my life. I say I have a boating attack. If I can't use my boat at least once in a month, I get depressed. I walk to the beach or go and see some boats. That lifts my spirit. It makes me feel good.

I'm still a believer. I believe in God and say my prayers. In fact, my family and I discussed it last week when we saw "disciple birds" around at a dam while we were fishing. There are always 12 or 13 of them. There are a number of things that lift me. I see the pawpaw leaves as a tool and I believe that, with J.C., and my family, they will guide me through this. The pawpaw is pretty horrible stuff – a bit like Kava. Some people say Aloe vera juice is good. I've given it to a few of my mates and they say, "No! No!" … But I just drink it. It'll get me through this. I don't really feel that if I went to church it would cure me, but I am an optimist – it can only help. I still believe in God.

Also my family lifts me greatly. I live for my family. They don't quite know that. They've always said, "Dad, you must come around more". So that is my spirituality as a rule. I had a partner for seven or eight years on and off, and we had a bit going. That's all gone now, which is a shame because maybe we could have made it. It was just the little things, not the big things that cause the problems. This will never happen again. One must love and be loved back equally.

It was seven months ago that I was directly diagnosed as having advanced prostate cancer – straight off. Boom! And that was because I pushed the issue. No one suggested there were high PSA readings or digital, saying, "Hey, let's check!" And I just thought, well, some blood in the bed, that sort of kicked things off, then the bowel scan. I didn't know anything about the prostate. Everything seemed OK.

Annoyances

I've been annoyed with a few things in my life. My dad died of war wounds. I thought things would have been much better. He was a normal bloke – drank and

smoked. He went to the war and come back as a Baptist and gave to the Church 25% of his salary. I followed in his footsteps as being religious, even though I was a Catholic. I thought that things may have been different in life if he'd been around. I'm here for my son now. He has a small business and his wife has her small business. Together they try to make it all happen. It will happen.

Showing spirituality

Well, I don't go to church very much. I haven't been for quite a while. I still respect J.C. I still believe that there is a high power out there. There has to be. We were created for a reason. I've always wanted to do something, to change the world. And I have. I put together my own company. I travelled the world. I invented a product that was quite unique and it's still being used now. I stepped away from it 13 years later. So, in fact, I have done something to change the world in my own little style. I'm still after the magic widget – an inventor with no money to promote.

Over the last few months my spirituality has definitely increased. Through God, doctors, hospitals and injections, family and pawpaw leaves, I believe this will happen. I know people who are relying on other medications, $400 a week or something. I can't afford that. I chose God and the pawpaw leaves to lead me through.

Different avenues for support

I didn't need any support initially. I've received support from a couple of groups of men who have advanced prostate cancer. Some of these groups are up to 100 people. I've come away feeling, "Wow, I'm not alone in this journey". I didn't need any support initially but I'm now very, very grateful for what's there. I now need all the help I can get. Sex has been a big part of my life, but reading books and hearing discussions in the men's group when men talk about sex, they say they are closer now to their partners, even though they do not have a sexual function or can't do it properly. They are closer spiritually and in mind and comfort to each other. A few men in the men's group have a problem and it's also in the books and magazines I'm reading. There are a few good ones around that I'm reading – *Coping With Cancer*, *Localised Prostate Cancer* … They're excellent. They say the same thing. I'm trying to deal with this because I feel I'm no longer a man. I just can't get it up. They call it

"erectile dysfunction"; they have a name for everything. I have now realised that life has more relevance.

My spirituality has a role in helping me cope with my illness because it's been the whole package that has come together. I believe this. Talking with people … there are other aids to being close, there's tablets, there's Viagra, injections. For a man, you lose your manhood. You lose your esteem. I'm in tears talking about it. There's all these books I can get. Some are relevant, some are not.

"Added value"

One of the main things I wanted to add was that I want to document about this itching and irritating. No one had ever said anything about this to me before. If we can document it and a few doctors know about it, maybe someone will say, "Well, maybe it is a precursor to something". And I just want you to document the pawpaw tree leaves. I know that U.S. and British medical companies cannot isolate or patent its benefits properly. How they can help, tie it in with J.C. and spirituality. There have been instances where it has cured people but it hasn't been documented properly. I mentioned this to my local GP. He's broad-minded enough to see that it may help, or at least for my mind. If I can help, and people can relate to something I've said, and they get cured, well, the world's set on fire; cancer might just be a word.

Stephen

Stephen lived in a resort complex near the ocean. He was keen to explain the reason that he had volunteered to be a participant in the study because he believed he had benefited considerably from his personal experiences in spiritual development. He had tried many ways to approach his illness and eventually found the approach that was suiting him.

The beginning of the physical journey …

It started six years ago. I had a busy legal practice in Brisbane and what was happening was that I had tried to ease off a bit and we bought this house and worked in Brisbane for four days and came down here for Friday, Saturday and Sunday and I played golf. I was really putting six days' work into four. Prior to that I was really working six and seven days a week. I was really working hard and my wife was working in the business as well. But that was OK. I had high blood pressure and high cholesterol but I'd been on medication for that for 30 years. I thought I had a heart attack a few years ago but it wasn't; it was just that my blood pressure was high. But really, my other health was OK. One thing that was happening was that my sexual activity was declining but when you go to the doctor he just says, oh, I'll just give you some Viagra or something; you know they never really … you know … So this was happening but no one was really … you know, the prostate thing never came up. No one ever suggested that there might have been a prostate problem or doing anything about it. I was having a PSA test in with my cholesterol but everyone was watching my cholesterol more than the PSA. I wasn't even conscious of what a PSA was. I mean, that was the most shocking thing, it wasn't on the radar. No one ever mentioned to me that you are going to get prostate cancer.

So, I was coming down and playing golf and all of a sudden I started to get some bone pain in my legs. So I went to the physiotherapist – blah, blah, blah – I'd go away. I stopped playing golf and then it came back again so I went back to the physio. So this went on and off, then, all of a sudden, one day it didn't go away.

… and the spiritual journey

Talking about spirituality, I went to a funeral of one of my clients, and, at the funeral, my legs started to become really sore. We went to the wake and then it seemed someone was telling me that something was wrong with me. I think it was funny that it started at a funeral and this time it didn't go away. It became very bad on the weekend; I might have taken some Panadol or something. It got worse so I went back to my doctor and he said straight away, "You'd better go and see a bone specialist". I had an appointment in the next few days and I told the guy my symptoms. He tried to move my legs around and he said, "Gee, you might need a hip replacement" and I said "That's pretty scary". Anyway, he said, "Go and get an x-ray straight away" so I did an x-ray and I came back to him and he said, "No, it's not that, it's something else". And he was thinking, and he said, "You'd better go and get an MRI". So he arranged for this and referred me to a bone guy. All this was just happening. One good thing – I was privately insured and I wasn't jerked around by the medical profession. A lot of people take six months to get diagnosed. Within a week I had all the tests and they found that I had an enlarged prostate. They saw that I hadn't had a PSA test for a while. The last one I'd had it was 3 and then within two years it was 24. I'd missed the test I was supposed to have. I'd just forgot about having it. Before that the guy had rung me up when he'd got the MRI results and said, "You've got something on your bone". He called me in and he said, "Look, I'll give you a scan. You might be lucky, you might just have prostate cancer – a secondary". He referred me to a prostate cancer guy. In the meantime they did a biopsy and found that it wasn't bone cancer, it was prostate cancer in the bone, a secondary which is bad enough. Then I got shovelled from one guy to another and the last guy I saw was a urologist and, like the oncologist, he said it was incurable – blah, blah, blah – so within the space of a week …

Feeling like …

I felt like shit! I mean, I'm thinking, I'm going to die. I mean, they said they could treat it but not cure it and everyone is sticking their finger up my bum, and you know … And I thought, this is ridiculous, how can it be happening? I've got cancer; I'm supposed to die of a heart attack. By this time they're talking about something I've never known about, know nothing about … By the time you get to see the urologist – he's the last guy – they've already worked out what it was and he said, "Well, you've

done a biopsy and it's confirmed; the Gleason score is a 4 plus 4, which is not the worst but is not good, together with a PSA of 24 – it's in the bone already". I must admit that the bone pain had gone up so I took some Voltarin so that did help. It wasn't that big – they'd picked it up early. So I said, "What are my options?" and he said, "Well, you've got no options – you can have a hormone injection or nothing". That was it. So, what do you do? Just have a hormone injection – bang.

So the hormone injection dropped it down from 24 to 1.7, then it went to 1.0, and it didn't go much lower than that. So that sort of worked.

All the side-effects – "that stuff"

So I had all the side-effects – the hot flushes, the memory thing, the depression – all that stuff was going on and I had a busy practice. I've got people ringing me up for advice about all sorts of things every day and I've got two offices and I think I can't … you know … I can't do this. Eventually, it kills you. The doctor says you don't know how long it's going to last. The hormones only last for so long. It slows the cancer growth but after that it will start growing again. After that, there's not much at that stage you can do. You can have some chemotherapy that can have a small benefit. You get bone pain, and you take pain-killers … It's not much of a prognosis, so I'm thinking, I don't see much point in working any more, so, I'm thinking (I didn't even consult my wife), I said, "I'll put the practice on the market". So we sold one fairly easily – the best part. The other one I kept for six months and just kept on running that. Then I had a disability policy that would pay until I was 65 and I was 62. It paid $4,000 a month. So we had enough money. We were reasonably comfortable. We were self-funded retirees so we didn't have any pension. So I sold both practices for a reasonable price. So that was good. If I had to work I could have but I thought, if I've only got a few years to go, I may as well enjoy it, so what the heck! I'm 67 now and this started in 2005 so it's been six years. I was thinking about retirement but I was just a workaholic and we were making good money. So that all happened, and we decided to sell everything up. Bingo!

Spiritual development

What happened in the meantime, the Thailand thing came up and I'll just explain what happened there. We worked in Thailand back in the 70s. We lived there in

Bangkok for two years. I worked with a big company there and it nearly killed me, but I was young and silly. We left there and didn't go back for 25 years. Anyway, before I was diagnosed, we had collected enough frequent flyer points to travel Business Class somewhere. So, we'd been working our guts out and decided to close the office for two weeks. So we decided to go to Chiang Mai (North Thailand) – we hadn't been there for a long time. So we booked the tickets. Then, six months later, before I was diagnosed, we were at a party and we were talking to someone who had been to some resort in Chiang Mai – some health resort – and he said we should go there. That sounded interesting so I talked to my wife – she's into health stuff; I'm not into anything natural – I'm straight down the line. So we decided to Google it and found out the things they did – it was a Tao centre and they taught Tai Chi, Qi Gong and all that stuff. I booked in for a few days and thought we might then go somewhere else. So, I get diagnosed in August and we're going there in December.

So I'm thinking I might need this for myself now so we might spend the whole time there. So we sold one part of the business and we get there and stay there and we start doing all this stuff – meditation, massages, Qi gong and others; so we started doing all this stuff and you get up in the morning and start doing these exercises and breathing and – blah, blah, blah – you know, a lot of stuff, and they say if you do this every day you can live to be a hundred. And then they start saying you can start strengthening the lungs by internal means – not, like, running around the block – and also the liver, your bones, and I'm thinking, this cancer is going to get into all these places, maybe … maybe I can do something about it. It started me thinking – the doctors are not going to cure me; they've given me a bit of time – all they've done is bought me some time – so I've got to work out what am I going to do with the time I've got. I could just sit around and have some red wine every night, do nothing and get fat, but I might as well do something about it. The stuff I was doing at the resort all started to make sense; this was the first time I had a bit of hope. I didn't quite know how I was going to do it. It wasn't a cure hope; it wasn't going to be hard work, that I had to "do this" , do it every day – blah, blah, blah – it's not praying to a god or anything, it's really bringing energy from the universe into your body and all this stuff.

The beginnings of change

At this time I'm still pretty depressed. The side-effects of the drugs – I couldn't think; you go from having a normal testosterone down to nothing – you know, you're feeling like shit. But I started to change. We were staying in a town house for two weeks and then we found out that all the places there we could buy. They were all owned by people and then they rent them out. Then we found out the guy who owned the house we were in wanted to sell – US$130,000. So I'm thinking, if I need to do this practice I've got to come over here a lot. So we thought – we had the money anyway – so we could buy the house and rent it out. It wasn't a particularly good investment except it would be for my health. Maybe it would help me live a bit longer. So we came home, thought about it, went back again and did the deal – we bought the place and we've had nearly 20 visits. We've been to other places – Europe and so on – but that's all we do now. We go two or three times a year to Thailand. The reason we do it is that there is a guru there. He runs a training place. The training lasts five weeks, twice a year, so we always go – there's one in July/August and one in January/February. Sometimes we do the course and sometimes we just spin off the courses. You pay some extra money and go there in the morning and do some meditation and there's extra stuff that's on that you can do. So that's what we started to do and that's all it really was, but it really was something that I decided to do, to make the effort to make myself fit and healthy. That was the best advice my urologist said. I said, "What can I do to live longer?" and he said, "Well, all I can say is that there is a lot of other stuff that people go on with and talk about – food, vitamins, magic cures, but if you keep yourself fit and healthy you've got more chance". I think I know now what being fit and healthy means. It's not that easy when the drugs are working against you but I thought I'd go to Thailand and try to turn my head around. So that was the first turning of my head. That gave me a bit of optimism. So, of the six years, that was probably what I call stage one of my life. It was going to Thailand and doing stuff there.

Treatments – more "stuff"

As I came into stage two, my PSA had dropped from 24 and settled down around the 1 mark; it went down and came up a bit occasionally. Some guys try to get it right down. They make a big thing of getting it down to zero but I read all the stuff about having more drugs. I was having monotherapy – one injection; other people have

many things – triple androgen. I have it every six months. I have a drug called Eligard – one of the newer ones, and maybe I was lucky about that. So I have it every six months – used to have it every three but it doesn't really matter whether it is six or seven months. It's not going to make any difference. So that's kept my PSA down around the 1 mark. Sometimes it goes up and down a little bit but I seem to be able to turn it down. I go back to Thailand and do a lot of stuff. I had acupuncture. I wasn't doing much meditation at this stage but I seemed to be able to turn it down when I had to turn it down. What you've got to avoid is this PSA thing. It can get out of hand, then it's really hard to knock this back. You can't ever let it go. So I reckon, from all I've read, I just have to keep my PSA under control.

More frequent meditation

So the next stage I really got into meditation. I did a little bit up in Thailand but I eventually got to a camp (back in Australia) that was mainly for women with breast cancer. So I went there but thought it wouldn't be much because it was really for women. (I went to a support group once for men – supporting each other. I gave my story and I was feeling pretty good but then all the other men started moaning and groaning. They were talking about their chemotherapy and all that stuff. All they wanted to do was tell their story; they weren't interested in my story. They sucked all the energy out of me and I didn't have enough to share so I didn't go back. I'm OK in myself but I can't support anyone else; I just haven't got enough strength.)

So I'd been to the camp once and I decided to go back there again to do some meditation. So I started doing some of this and I found it very hard. And then they said that they were having a retreat and that they'd like me to come – they needed some men. So after some umm-ing and ah-ing I decided to go. There were three guys there and, to me, I was really the only normal man there. Anyway, there were nine women there telling their stories and I'm there telling my story. After hearing theirs, I thought, I'm lucky. They're all females and they had their problems – their husbands had left them or their kids hated them, they're struggling with their chemo, they've got all these treatments, they're taking this and that, they've got no money; and I'm thinking, I'm not complaining. I reckon my cancer had a worse prognosis than all of theirs but I'm doing better. So that was a real turning point, realising that

I'm doing better than I should be for whatever reason, so I started to do a lot more meditation.

I made some good friends out of that. We talk about connection. I made a good connection with a woman there. She was crook at the time but she's OK now. But all this meant that I felt I want to help these people. I felt I had something to give.

I got more into meditation. About this time my PSA jumped from about 1.1 to 1.8. That was a big shock. I don't know what happened. I thought, maybe there's some reason … This changed me a bit, like emotionally. A few things happened which affected me. I don't know why it happened but it did. I was able to get it back again. It has jumped again. I did a test the other day. It's 2.4 now. I was a bit unwell; I had a virus and my brother was sick so I think that affected me. My doctor's not worried about it. It does jump a bit but in my mind I can turn it around again.

With all of this you can do things with your mind. From that time of meeting new people and talking with them, I started to get insights into people's mind. Like, all of a sudden, people started talking to me. All sorts of people would talk to me about all their problems. People would spill their hearts to me and tell me everything. All of a sudden I could understand relationships for the first time in my life – love and friendships all that kind of stuff.

"Feeling" experiences

The other thing was that I did have a treatment with a shaman. Back in Thailand. This guy did some exorcism on me. It did have an impact on me because what he kept saying to me was, "What do you feel, what do you feel?" From that time, I did feel things. I feel a lot more than I ever did. I think differently about relationships and am more conscious of this. Maybe it's because of the low testosterone I have that makes me think more like a female maybe, or something like that.

My attachment to a female friend was part of it. That was a bit unexpected so that might have had something to do with it. But the meditation seemed to help; it seemed to be part of it but maybe this was a way of dealing with it. The shaman, meditation and the attachment all helped a bit.

Substance of meditation

I do three lots of meditation really. I do meditation in camp which is more mindfulness, which is really, you know, guided meditation, breathing or counting or something like that, or sometimes going down and sitting in a cave. Basically, sometimes it's guided – you must be going down a hill, sitting in a cave or sitting on a beach or something like that. That's interesting but I don't do it that much. Maybe it can work. It's mainly just calming your mind and trying to keep yourself quiet; just not thinking about anything. It's really like a half-sleep; I did some yesterday.

Then there's Zen meditation – totally silent – where you sit and do nothing; try not to think at all. There are different techniques. They say don't think, don't do anything; you've just got to sit there for 20 minutes. You don't say anything. What are you going to do? You can count; you can breathe. There are different forms of meditation. I just think that the basic thing is that it calms you down and it has a good effect on you. It actually improved my golf game – which is quite amazing. It made me play better golf even though I'm not a great golfer. I seem to be able to do it when I want to. I'm not a great meditator but it's giving more calmness. I don't do much at home but I do it twice a week at another place; I mean, you're supposed to do it every day. I do listen to meditative music at night and in the morning.

Mindfulness is a general meditation with some guidance. The man we go to does some of this but he is more into Zen which is total silence and breathing. I don't relate to that so much.

My spiritual background

Just looking at the religious side (I know that's not the whole thing), I was raised an Anglican and went to Sunday School until I was an older boy and all that stuff. Now I'm not a disbeliever, I'm probably a believer but I don't go to church or anything like that. Thailand is Buddhist. It's a nice religion and we've been to a lot of Buddhist stuff but I don't see myself as a Buddhist, although I've taken on board some Buddhism. I feel comfortable in that sort of environment but I've never bothered to practise it too much. Buddhism is a nice thing to have in Thailand because when you go to a Buddhist thing it's very peaceful and things like that. The Dao stuff is Chinese-based, of course, and, while they do have symbols and all that,

it's really not a "god" thing. You're halfway to god but you don't pray for him to help. If you want to be cured, you've got to do it yourself and look after your own body. If you want to be cured and have a long life, it's hard work and a healthy life and you can do all these practices. This is the thing that has resonated with me. I guess the Dao practice is a form of religion. The other thing is helping people. I do find myself helping cancer patients although sometimes it has a negative effect on me. Somehow I've developed some spirituality, whatever that is …

Getting a lift – "I can do it"

If I want to, I can lift myself above but I've got to want to do it. If I want to manipulate my PSA, I can do it. If you want to lift yourself up to shoulder height, you can. The hardest thing is staying there. I think that's why some religious gurus get up there and stay there. Before, I didn't know there was an "up there" sort of thing. The hardest thing is finding the focus to let you do it. And, I want to get there and stay there.

It's easy to get knocked off the perch. I'll give you an example. The last time I went to Thailand we went over there for two months and we invited some friends, or a guy who had prostate cancer and his wife that I met at a camp. She had breast cancer and the guy's PSA had shot up. And I said, "Come over to Thailand and see us". It was just a throwaway thing. The next thing they'd booked a plane and came for two-and-a-half weeks which I didn't really intend them to. So that had a negative effect on me – like, the type of people they were. He was a cheapskate and he just wanted a cheap holiday; they took advantage of my hospitality. That upset me and I got sick; I got a virus. That visit rattled me; I knew them reasonably well but it just threw me. That was the worst thing, but then I came back to see my brother and he was dying and then I had a blood test and my PSA goes up.

Using my spirituality

Well, it comes down to where you are with your life. We all have certain routines but I want to spend time with people who care. I'm choosy about how I spend my time; that's the important thing. Sometimes I play golf with a guy who is also unwell but he's OK, he's not a drainer. I try to avoid the sorts of people who drain your energy and have a negative effect on you. You have to keep away from those sorts of

people. It can knock you around too much otherwise. It knocked me around and I thought I was stronger than that.

I think it's a matter of focussing. I use my PSA as a guide because that's the only thing I've got. I've just got to keep that under control and when it goes up a bit I don't necessarily do more things but I focus more on what I'm doing. It's really getting my head around it. I think the secret is it's your head. If my head's right, I'm OK, but people sometimes disrupt it or upset you. The other thing is that because of the drug I'm on – I mean, I have no testosterone – the side-effects of what I'm doing – it's been a long time – six years – you get depression, you get emotional. I mean, this emotional thing can be caused by the drug – and there's memory loss, depression; a lot of what I am doing is counteracting the effects of the drug. That brings you back to normal, so you can live a normal life. But what I'm doing focusses your mind – it's a bit like when I saw my brother and I thought, "I'm not going to finish up like that". I thought, "That could be me in five years' time". I'm not going to sit around waiting to die. I've got to find another way around it. Sometimes you do feel you can't do something – well, what's the point of this?; it would be easier not to be here. No one really cares, or … but they really do care, but … you know what I mean. I guess you are more sensitive …

Sometimes I wonder if I should have given up work or not. I couldn't have done it in the first couple of years but lately I've wondered. It's not that I miss the work but I miss the contact with people; but in my case, I had to do what I had to do.

Special points along the journey

Recognising the Tao system of spirituality was the first point on my journey. The second was with the camp retreat where we had the discussions with other cancer patients. That triggered other things and enhanced my spirituality. That changed me as well. I've had little changes up and down since then. Those two were the most significant. The recent Thailand experience with the "friends" was also significant. It made me wary of what I do. Sometimes you think you are stronger than you are. It was really a wake-up call to say that you've just got to protect yourself when you're doing things. I got knocked off my perch and I came home sick. That was the first

time I really came back from Thailand not well. It was hard to accept that when I go there to be well. You do have down times. People will bring you down.

Additional activities contributing to spirituality

A couple of things. Golf is important to me. When I was first diagnosed, I just couldn't concentrate. The secret of golf is concentrating and focussing and I couldn't. I was up and down. One of the things that has come out of my calmness is some extraordinary moments on the golf course where I've done some great things. I don't know why or how; they've just happened, especially when I've come back from Thailand and that's more of a focussing. It's a calmness and focussing on the course. If I can go around the course calm, I know I'm in good shape. Now I know that if I can play good golf, I know my health's good.

The other thing I've gone back to is music. My mum was a good musician. She was a classical pianist. I had a few lessons but she taught me how to play rock'n'roll chords and things like that. I did play in a band when I was at university. That was something I always enjoyed. I drifted away from that and now I've just gone back to it. I bought a keyboard and I'm learning again, so that's something that's important. That's something I'm obviously going to keep pursuing and developing.

I think that playing golf in a nice, calm way – to me it's not so much that I'm playing a good game but it's that I'm at peace with myself and I keep thinking that if I can do that I'm physically OK. I can walk around the golf course and come back very tired, as I was yesterday after 18 holes. At one time I didn't have the energy to walk around the course. But now, it's not just the enjoyment, but it's my mental state. It's more than just playing golf. I know that if I can do that I'm OK.

"Keep your head around it all"

The only other thing I want to add is that I went to a doctor and discussed healthy living with him. That's the thing that you get off the track with. I really need to do some focussing on what I'm eating. That's all you can do except keep your head around it all.

Alan

Alan had a long cancer journey. Some of the circumstances in the weeks prior to the interview were also traumatic for him in that his immediate family had been affected by the Queensland floods. He demonstrated his ability to adapt to the circumstances. We met in a guesthouse common living room as he was having treatments and living away from home. His usual home was in a country town some 350 kilometres from Brisbane.

Boundaries for spirituality

The only thing with this spirituality – as long as it's not used to trivialise people's religions. I've been a scout leader in Queensland. Originally, that was started off by Lord Baden Powell. His focus was not on individual achievement but what a team could achieve. He just modelled it on military lines. He had a pledge that they used to have to take that they would honour the Queen, do their duty to God, help other people and live by Scout law; and that's what he meant. As it became international – it's the biggest youth organisation in the world now; the world jamboree is one of the biggest functions in the world – they had to work out how they were going to incorporate other religions. So in different countries the wording got changed to do their duty to their god. What he (Baden Powell) meant was the Christian God, then it got changed to "their god" and it kept on being modified. Then it virtually meant that you could worship that stool over there, and that could become your god, just about. It devalued it. There were people who wanted to become leaders and have their children join and get accreditation as Queen's Scouts and such like because they could see the advantages but they didn't want to take the pledge because they didn't believe in a god. So it got watered down and watered down. It reminds you about this thing, about spirituality. It doesn't have to be a religion, it can be anything that uplifts somebody. It devalues people who have serious religion – their efforts in religion. It makes it palatable to atheists but it devalues it in the lives of any kind of Christian believer. It devalues it for anyone who does have a real vision of a God. I thought I would give you that preamble to let you know where my thoughts were on that aspect.

The start of prostate cancer

Well, I'm 63 and I had an abnormal reading way, way back. I was officially diagnosed over seven years ago. First of all I had a scare – I had a thyroid growth; they couldn't find out whether it was benign or whether it wasn't. They took the growth and some of my thyroid out and decided it was benign. So after that the doctor said, "I'd better do a test to see if you are coping with half a thyroid. I'll give you a PSA test too". When he did that, it came up as 13 or something. I had the test several years before but the doctor said, "It's a little bit above average. We'll have to keep an eye on it". In that intervening time I'd gone through a marriage break-up, divorce and that sort of thing, and the last thing you are doing is going to the doctor for a PSA test. There are that many other things going on. It just got away from me, I guess. By the time I was diagnosed it was up around 17.2. The urologist said there was about a 35% chance that if we do take the prostate out we will get a cure. So I thought, 35% is better than nothing so I'll go with that. So they did, and, with much persistence, I actually spoke with the person who reported on the outcome of the surgery. He said that the cancer was within 0.4 of a millimetre of the outer casing of the gland. So it was still within and they considered it still local.

Communication difficulties

That was quite an episode in itself because I rang up and asked to speak to the doctor who wrote the report. The receptionist said, "No, no, I can't give you that information – confidentiality …" and all this sort of stuff. "If you want to know anything about that, you'll have to ask your GP and he'll have to talk to the reporting doctor to find out what the answer is." I said, "No, it's my report, I'm entitled to know what the report is". I kept ringing up until I got a different receptionist and she put me through to the doctor that signed the report. He came on the phone. He was very good; he talked about everything I wanted to know. He kept saying, "Is there anything else that you want to know before I hang up?" He answered everything I wanted. That's how persistent you've got to be to get the information you want. They pull this "privacy" on you because in many cases they are just too lazy to have to do anything.

Biopsy trauma – "I tell you what …"

When I did the needle biopsy before the prostatectomy, they told me you had no feeling in the prostate and that anaesthetics wouldn't do any good, but, I tell you what, one of the biggest lies that can be told is that you have no feeling in the prostate. Other fellas have said that they had an anaesthetic when they had theirs done. It shouldn't be done without anaesthetic. But after the third needle you are that bruised you don't feel that much.

Consequences of surgery

After I had the prostatectomy, I had a lot of trouble with incontinence for about eight months. I got on to a doctor who was a physiotherapist and who had similar problems. He got on to a heavy exercise program and eventually cured himself so he published this. I spoke to him on the phone several times; I've only met him once. After eight months I got on top of it. I went back to work then and eventually the readings started to rise again. I had bone scans but they couldn't tell me where the cancer was. I went back in three months and had another bone scan and the cancer showed up in four places. Obviously there wasn't enough to show up earlier. The cancer was in the rib, the sternum, shoulder blade and … probably the other shoulder … They wanted to put me on Androcur or one of those anti-androgen drugs that suppress the testosterone. I had been on a course of Androcur prior to the surgery because the doctor said it would help control it and shrink the prostate a certain amount and this would make it easier to remove. About four weeks prior to the surgery the PSA dropped down from 17.2 down to 0.3 or something. So that probably helped me quite a bit, but after the surgery it rose again and, as I said, I got cancer in the bones then.

They wanted to put me back on something like Androcur but I had some of the worst headaches I'd had in my life when I was on Androcur. I had pains in me head – it wasn't like a normal headache where you'd have pain in one part of your head. This one was like having a marble rolling around inside your head where it would move from one part of the head to another, and these were the worst headaches I'd ever had in my life and I wasn't going back there again. So I elected the older type of treatment – a bilateral orchiectomy. That dropped my PSA down for quite a long time but, after 12 months or so, that failed. I then went on to chemotherapy – six

months of that – and got quite good results. This then failed and I had to go off that. Meanwhile, I was on steroids while I was on that. I had to have medication while I was taking that because I was having reflux problems – I'd eat something and it would come straight back up.

Trauma of treatment

I wasn't very sick when I was on that chemo. When that finished I went on to something else and that made me sick so I came off that then and I really went downhill. The PSA just kept rising – as far as 6,380 – and I was down to the stage where I would crawl out of bed at 4 o'clock in the afternoon, have a shower, have a bit of tea and go back to bed. That was the limit.

Then I got on to a trial that was run at the Wesley Hospital – MDV 3100 – I had to take four capsules every day. They weren't destructive of the healthy cells but they affected the cancer cells. It was an androgen antagonist that stopped the body producing hormones that the cancer could feed on. I did very well on that and moved away from being virtually bedridden. I got back on my feet and got to the stage where I could get out of bed, get out to service the motor vehicle; I went back to old-time dancing – enough to go dancing 'til midnight of a Saturday night – this sort of thing. This made a marvellous difference. In six months it took my PSA from 6,380 to 640 – a tenth in six months. After that the readings started to rise about 700 a month average. After another three months they took the supply tablets from me because they weren't working. It's climbing again now uncontrollably. I'm looking now at going on to another trial drug that was very similar to the first chemo I went on, maybe in a month's time. At this stage, I probably will refuse it because I will have to go on to a steroid that I was on for 16½ months. This gave me a cushion on the soles of my feet – when you walk you feel as though you're walking on a cushion, which wasn't good for my dancing. It affected my eyes to the extent that I gave up reading; I had trouble reading street signs. I complained about this to the eye specialist and he said, "Oh, it would be the chemo that was doing it". I complained to my oncologist and he said, "No, it would be the steroids that would be doing it. It changes the sodium level in the eyes. It's then not possible to focus sharply". Meanwhile, the cancer's spreading. It's in all my ribs, pelvis and spine, and

shoulders. It's now obviously spreading into the femurs because they're aching. And I've had to go on to pain medication to tolerate it.

I had to have a blood transfusion yesterday because my creatine readings were too high and I couldn't have Zometa. I've been having this every month ever since I started on chemo to stop the migration of calcium from going from the bones into my bloodstream and clogging up my kidneys and liver. So now it's a case of juggling the pain medication. These things affect your bowels and you finish up with constipation; then you have to take stuff for constipation and you get nauseous and you have to take stuff for that. Every drug causes another complication. There's nothing treating the cancer of the bone. It's all pain management. The PSA readings are now up to 4,930 again, where they were 6,380 last time.

Feelings and emotions

I've isolated myself pretty well. In the last 10 years when my marriage broke up I've lived by myself ever since, pretty well. I've virtually no support from my family. I get a little bit of support from my daughter. She's officially my carer but she's limited to what she can do at the moment because she was affected by the floods in January; she hasn't got a house to live in so I can't stay with her, even though I'm sick – that's why I'm staying in an accommodation lodge while I'm having treatment. She's living in a caravan. The only thing in her house is a toilet and a washing machine. The rest of it is gutted. So she's not in a position to help me.

Spiritual basis

Well, I've always been brought up in a Christian religion. I grew up a Methodist. I voted for the formation of the Uniting Church, which I thought just made sense because there are so many parallel religions. There was really no reason for them to be separate. In some places it has worked; in others it has created four religions instead of three. I'll attend any church that's convenient to me at the time. When I'm visiting one member of my family I'll attend the Church of Christ because it's the only church there. When I'm in another centre, I'll go up the road to the Uniting Church. When I'm at home I go to the Presbyterian Church where other members of my family go. These days I feel that a lot of those churches are very generic. A lot of them do not have full-time ministers that can give you the spiritual support that they

used to years ago. At one time you used to have a minister in your town for your religion that you could go to for counselling if you wanted to. These days they're supposed to cover two or three towns so they are never there when you want them. A lot of it is done by lay preachers these days and they just have a series of church services laid out for the year or they go on to the internet and download church services from the internet and you can virtually go to half a dozen different churches. All the services are, as I say, generic. I've got no problem with that, I suppose, but they might celebrate the communion slightly differently. They might have different thoughts on what age a child might be baptised, but you can live with that as long as they follow God the Creator … I was brought up basically on the Apostles' Creed. "I believe in God the Father, maker of heaven and earth, Jesus Christ His only Son and our Lord, conceived of the Holy Spirit, born of the virgin Mary, suffered under Pontius Pilate, was crucified, dead and buried …" you've got this summary of the Christian religion. A lot of these religions, you can go along and say, "Yep, I can agree with all that, but we're Presbyterians, we're Church of Christ, Wesleyans or something – but they all agree with that basic creed".

Religious support – "I'd like to sit down and talk …"

To assist my spirituality I'd like to sit down and talk about where I am at and pray about my future, you know. You either do it yourself or the person you pray with has to be sincere – they're not just a wage-earner; it's not just their job; they've got to be sincere.

I don't find myself involved in a lot of personal spirituality. I do like to go and worship with people. I like to sing, pray, have communion … fellowship. You've got friends who will sit down and talk with you. This is where this spiritualty as a broad, floating, umbrella sort of thing – I don't really agree with that sort of thing. You get a congregation and within that congregation you do have a real spirituality. You just can't have a floating sort of thing where everyone can have their own spirituality. It's got to have a base on something.

I can sit down with people of many religions and enjoy discussing religious matters. They can be Mormons, they can be … as long as there is common ground. But I

can't sit down with an atheist and have a discussion about spirituality because they don't want to know and they don't understand. They haven't had the education.

Over the period of my cancer journey my spirituality has stayed much the same. Oh, it may have increased a little. The thing is, some people will ask, "How do you cope with it?" and I say, "You get used to it". I mean, I've been living with it that long … I've counselled a lot of people who have been diagnosed with it or have had members of their families who have been diagnosed. They're just knocked out by the diagnosis and all the treatment they're going to go through. And I say to them, "Look, you do become used to it. You just become used to it after a while. I mean, it's like going to the dentist – you mightn't like going to the dentist, you know you've got to go, and you know it's for your own good that you go so you do it. It's the same thing; you just keep lining up for treatment".

I first started with a support group and they were a great help to me when I was first diagnosed because, when the doctor first tells you it is a cancer, the rest of the conversation is a blur. You don't remember it. I just tell them that that's normal.

The lifts – "you smile all the time"

I used to be in photography a lot but I've lost interest in that. My main interest is old-time dancing. I've always done it; I do a lot of new ones down here. I've been going to dancing down here whenever I come down. I know enough people now that, if I don't know a dance, the ladies are happy to help me learn the dance. It lifts me because of the music. You've got to dance with the music; you've got company and contact. You forget about all your problems; you just concentrate on enjoying the dance. You have a laugh and a joke. One of the ladies said, "You smile all the time", and I said, "When I get it right, I smile; when I get it wrong, I laugh"; so I'm always happy; it doesn't matter.

Spirituality helps – "I'm not scared of dying"

My spirituality helps me a lot. I'm not scared of dying; it's the pain and suffering that worries me. I'm ready to die and any time; that doesn't worry me. I could go to bed tonight and die in my sleep and that would not worry me at all.

I'd like more spiritual support from people close to me, especially in my home town. Nobody wants to get too close to somebody who is going to die, unless they are very rare people. I've got good friends. I've got one in particular at the moment and she said, "It's a pity you're so sick", and I said, "If I wasn't so sick I wouldn't be here, I'd be back at home working." She couldn't accept that. She's a little bit older than me and she's still working; she does nursing, on call. I said, "That's what we do – as long as we're well enough, we work. If we're not well enough, we stop work. If we are too sick to work and too sick to enjoy life, that's the way of our lives; it's silly, but that's what we do".

There was another lady – we're still good friends; she's been a great help to me religion-wise – and everything was fine until it was described to her one day that prostate cancer was acute until the stage where it escapes from the prostate and metastasises to elsewhere in the body when it becomes chronic. That hit her like a ton of bricks and after that she decided she didn't want to be a serious friend any more. She couldn't cope with it. That is the case when you reach this stage – you can't expect anybody to be too close because they know they are going to get hurt.

Ken

Ken lived in a comfortable home near the coast. The interview was carried out in a relaxing environment, in the outdoors, next to his swimming pool. Ken's wife would have been willing to participate but I suggested that, in this instance, it would be better to have just Ken's story. Her offer did raise the issue of a partner's involvement in the story, particularly because, as will be evident in Ken's interview, he worked with and relied on his partnership with his wife to help him develop his spirituality and to cope with his illness.

The beginning of the cancer journey

The early part of the journey started when I had high PSA levels. I was fit and healthy and the GP agreed that I was one of the last people he would expect to see with a problem. After a couple of more PSA and other normal checks and biopsies, it turned out that it was an aggressive cancer and had to be attended to and removed as soon as possible. So the prostate was removed and it was found that the cancer was outside the gland and the post-surgery PSA results weren't good so subsequent radiation pulled things down to a reasonable number for about three months but then it started to sky-rocket again. It was the doubling rate that caused the doctors concern about what to do next. So I then went on to hormone treatment for about two years. That held it at bay for a while. I tried a number of others things: Chinese herbal medicine; and I went on to a trial program with a professor up in Queensland – a melaleuca-based trial. The end result was that after two years the PSA level was rising.

At that stage the doctors were predicting a shorter life-span after I went to an oncologist over 12 months ago, and I was told that it had spread to the bones and there wasn't much they could do for me. They told me to go away and enjoy myself and get my affairs in order and probably by about the middle of 2009 things should go pretty badly by that stage. They didn't say I was going to die by then but they didn't have much hope of me getting beyond that.

The beginning of the spiritual journey

In the meantime, Peter, a friend of my middle son whom I'd met from time to time at various family functions – Christmas and birthdays and things – was a Christian guy. I had as a young fellow been involved in a church but I had an experience with a minister at the time who I thought was a bit of a Smart Alec. I steered away from that as the result of the couple of experiences and basically left the church alone as a result of it. But when this friend of my son's (Peter) spoke to me one day and said that his father-in-law had contracted prostate cancer – and this fellow asked if I would like to spend a little bit of time with his father-in-law to give me a bit of help and guidance. I did that and then Peter rang up and said, "God has spoken to me and basically He suggested that I talk to you and maybe you might like to come along to our church". It was a really emotional phone call. I'm one who is reasonably strong-willed and strong-minded but I can get emotional like anybody; … that struck a chord with me and I went along to the church. My wife, Sue, was brought up as a Catholic and had traditional upbringings of a Catholic which is something a lot of people aren't comfortable with because it's a bit of fire and brimstone and "repent your sins" type of approach, whereas this church we went along to, which was a non-denominational church – Reach Out for Christ – the guy who was the pastor there had a totally different outlook on preaching the Bible. It was basically built around "Jesus loves you no matter what and he died on the cross for our sins and we can be born again free of sin" and he basically did that for the betterment of our life. I clicked on to this and so did Sue. As an offshoot of this particular church there was another Reach Out for Christ church a few kilometres away. Dr David Mitchell was the preacher there and we went up to what he called his healing Wednesday sessions and that really struck a chord.

This went on for a few weeks and spread into a few months. In the meantime, I had reached the stage where the oncologist said, "Well look, it's in your bones now and you might make it to Christmas 2009; Christmas 2010 I don't like your chances". But I was still feeling OK and still believed I could beat it but what I found was that, as I started to get more and more involved in the church and go back and read the Bible and learn what its teachings and preachings were on a Sunday, Sue and I realised that there were a number of things that happened from the time we made a

decision to move from Sydney to come here. These things could not have been just coincidence; they were deemed to happen from a higher order.

Naturopathy

As a result of the things that happened on the way, we came in touch with a naturopath who was from the Seventh Day Adventist group and part of the Christian Naturopathic Association. He came to talk to the group and I liked what he had to say so we went and saw him. His approach to help people with serious health issues (and not so serious health issues for that matter – people might just have digestive problems and things like that) … his basic teaching was that we came from the dust and basically we should be living a lifestyle where our food source comes from the land. Sue and I always ate fairly well, we thought, but when we got involved with this naturopath, he started to talk about things that coincided with what we were reading as I was making my way through the Old Testament, and I thought, "This is clicking; this is making sense".

The oncologist said at that stage, "You've got what we call headlights – spots in your bones from where the cancer has gotten to – and all we can do is keep zapping these"; and I found out that what they were doing was not curing the cancer but trying to bring the pain level down – but I didn't have any pain.

Coming together

So I put all together what I had learnt from the naturopath, and the reading of my Bible, and what had happened with a number of events that had happened one after the other that caused us to relocate to where we are living now. Had we not come here I would never have come across the church or I would never have come across Peter, the guy who rang me up and said that God had spoken to him. I would never have come across the naturopath.

The naturopath was basically saying that our belief is above all reproach and our lifestyle was needed to be followed in a particularly healthy way with the Bible in the background giving us direction. He made the comment that most people who came to him had difficulty in following the tight regime on lifestyle that he would suggest to us. I know I am strong-willed and I'm not one who follows the general public. I'm a

leader, not a follower. You give me a brick wall – I'll knock it down. He said to me, "You are going to have to take this slowly because people often can't handle the regime". I said that I had a lot going for me. I've got God on my side and my wife who really is attuned because of her training in health and she is a great support and what I was getting out of the church was a great support so I said, "Bring it on!"

Anyway, I'd been going to church for about six months, and, after these healing sessions with Dr David Mitchell (each Wednesday he would have healing sessions there for those who had health issues), I'd thought very seriously about becoming a born-again Christian and I went out one day to have hands-on healing from him. And, it's pretty emotional for me right now to think about that day because I felt this warm glow come through my body like I'd never felt before; I knew something had happened and it was really something I had never experienced before. It was very emotional.

Severing ties with the doctor

So I kept going there. I went back to the Wednesday sessions a couple of times. I didn't always go out to the front for the healing. A couple of times I did and each time I could feel this warm glow coming over my body which I could never explain. Anyway, the bottom line was that the doctors said they could do nothing but slow the cancer down but I said, "I'm not about that; I want to cure it". I believe that what I was doing with the naturopath and my approach to believing in God that He would speak to me and keep directing me – Sue and I sat down one day and we said, "We're not going back to the doctors because they said, 'Go away and enjoy yourself; there's nothing we can do for you. We'll just put you on hormone treatment' – that's not going to cure anything; that's just going to slow it down". So I said, "Why go back to get these PSA numbers because they are no absolute guarantee that you've got cancer; all it's going to do is add anxiety". So we made a conscious decision not to go back to the doctor. This was about six months ago.

I've got to the stage where I go to the naturopath and he does live blood cell tests. I first went to him about 18 months ago when we were in the crucial stage where the doctors were saying that there was not much they could do for me. Christmas 2009 was approaching and we said that these blood tests – which were basically different

to those of a pathologist – these were live blood cell tests where they look at the cellular make-up of the blood. They were in a mess, according to the naturopath, and I embarked on the approach he recommended and I could see improvement to the point now where yesterday I went to him for the first time for about four months and he said I was going really well. I've become his star pupil, because not too many people can handle the regime. Sue and I have, and I feel in excellent shape and I don't think I've got cancer any more.

The total package

The church has been a huge inspiration to have this direction in the back of my mind all the time. I think about a lot of things and I research and analyse a lot of things and I'm getting a lot of direction from the church and my involvement with God. I exercise a lot and I ride my bike to the support group to the point where quite a number of guys ask me what I'm doing. I've got a total of about 14 people talking to me from time to time getting input on what I'm doing. Only one of them so far has responded to the benefits of a spiritual approach. The rest are certainly switched on to looking at the naturopathic approach; some are even looking at meditation and relaxation – not many of them. I keep saying to them that it's the holistic approach that is everything: it's diet; it's exercise; it's belief; it's meditation; it's relaxation. All those things for me are important, and when people ask me what single thing can they do to improve their situation I say I don't know of any single thing. I think all these things are vital.

So, I've now beaten the Christmas 2010, the third prediction; the naturopath said yesterday that he was very happy with the way things were looking, and I'm feeling in great shape so I believe it's been a total journey.

Turning life around

I read a book when I first found out about the diagnosis where a lady said she was glad she got breast cancer because it was a journey that allowed her to turn her life around. When I read this, I thought, "Oh, this is garbage; who needs this sort of a journey". Four-and-a-half years down the track I now understand where she was coming from, and it is a journey and for those who want to take notice of what is presented to you in that journey I believe you can beat the problems. But it does take

a very strong-minded person who had a belief and who believes in what they are doing.

I don't know of anybody in the support group who hangs in there and is dedicated to a diet regime. People do bits and pieces but not the lot; this is a bit too hard for most people. So, at the end of four-and-a-half years the blood tests are looking great; I'm feeling good; I have no pain; and the oncologist? He can get his business elsewhere as far as I'm concerned; I'm not going to the doctor's.

Thinking things through

Given that I've been a born-again Christian for about 14 months or so, I've had no serious downturn, but there have been a couple of times where I've been in a situation where I was thinking, "What do I do next?" So I won't say I get disappointed or lose faith, but it causes me to think long and hard about generally the situation I am in. But, because I am an analytical person, it's more of a thinking things through that causes me to write the pros and cons down about the particular thing I've been thinking about, so it causes me to think a little deeper but I can't say I've had any doubts most of the time during this. I can never say it's been a waste of time doing this.

Emotional involvement

I've been very emotional on each of the three times I have seen this Dr Mitchell – he's an evangelistic type of minister; he's been overseas a lot – to Pakistan and Czechoslovakia and other countries – and he's been gifted through God with the power of healing people. There have been some films on what he has done where people have had some serious health issue – people can't walk, are blind, things like this – and I'd say those times when I've been forward in the healing sessions and have had him "laying on of hands" for healing – when that's happened, that's when I've felt a heightened awareness, really, to the point where a couple of times I was a blubbering mess afterwards because the emotion was just so intense. Even now when I talk to people about it – I'm getting better at it – but when I first started explaining to people about it, I really had trouble trying to control my emotions when telling them. Yeah, it's really heightened at that time.

Everyday spirituality

I used to be a fairly hard-nosed person; at work I had a fairly responsible job and I used to say to people, "I don't get stressed, I give it". I had a lot of people working for me and a lot of union matters to attend to; I was in middle management. So I was in a mentally tough life. But I'd say that what's happened in the last 18 months is that I'm now much more forgiving about those things and I don't get involved in that sort of stuff anymore. So I'm calmer in myself; more placid. If someone wants to have an in-depth discussion that I don't agree with, I probably handle it more tactfully than I used to – it was "a spade was a spade and, if you want an argument, step right up". So I've certainly changed in that respect. Sue's noticed it and a few other people have noticed it, and I've had a couple of people say to me – knowing me from a long while ago – they couldn't believe that I'd changed to the point where I became a Christian; they never thought I would do that. I've become more relaxed in myself.

Focus in life – "to live as long as I can"

My purpose in life is now to live as long as I can, as healthy as I can, with a high quality of life. Sue and I have a great life together and I want to maximise that. I just don't want to be here for the years, I want to be in good health rather than be here and just breathing – there's no point in that, hence the intensity of exercising, relaxation, meditation, good diet, a belief in what I am doing, being a born-again Christian – all of that is just part of achieving the objective.

Personal spiritual support

There is spiritual support if I want it. On Wednesday nights we go to home group and there's usually about anything from 10 to 15 people there. It gets fairly personal from the point of view of being one on one. People talk about where they're coming from. I have had a couple of discussions individually with both pastors. It's here if I want it but in recent times I haven't felt any need for it; no problems at all. The guy who runs the first church we went to came from a very interesting background himself. He was involved in drugs and alcohol and had a tough earlier part of his life. He saw the light. He's a down-to-earth character who is totally different to a formal ministry, but his teachings from the Bible are given in a practical, down-to-earth, easy-to-understand way. So if I ever want to talk to him, there's no problem.

Meditating

Basically, I could never relax to the point where I could switch off entirely mentally. I don't need a lot of sleep, and Sue did yoga which, in the early stages, is meditation. I needed to get my mind in a more relaxed state. So I went along for a few weeks to meditation classes and came home and said to Sue, "I'm never going to get the hang of this". I was lying on my back there and I just couldn't get into it, couldn't switch off. Sue said, "Just hang in there, hang in there". After about a month, it started to click. Because I'm a goal- and objectives-setter and things like that, even though I'm not working, I still do that even though it's in a much smaller way than when I was working. So if I went to bed at night and I wasn't tired and my brain was still going, I've now developed a technique where I get out of bed and lie in a darkened room and I'll stretch and do relaxation and I do some meditation for probably about half or three-quarters of an hour. Usually I can go back to bed and go to sleep without too much trouble having done that.

I have a couple of forms of meditation. One is a routine where you breathe using a specific technique, and the other one is where you get your mind to concentrate, starting with your big toe, and go through your body parts and you try and communicate with your body parts – your toes, your ankles, leg, knees, hips right up to your head. I suppose some people say that's like counting sheep, but it does put your mind and body into a state where you are not thinking about what's going on from day to day.

Strong spiritual support

I've got plenty there – between the two churches and the two ministers. I have to say, too, that we've found some very nice people in the church we go to on Sundays. The church we go to on Wednesdays for healing is a much bigger church. A few people go to both churches so we've got contact with a few people more regularly, and there's much more of a family environment there but, no, I don't see any need to get any extra input or involvement.

Closer to people

I've found that I have become closer to people through greater friendliness. Two of the guys down there have issues. One bloke was separated later in life. Another guy

has a few problems with pain and he is wanting to improve his quality of life from a health point of view, so there's a bit of dialogue going on there – back and forth, but me helping him really. They're interested in what Sue and I are doing and stuff like that. It's friendliness. What it's done for me is that I was very disappointed, and am still very disappointed, with the way the human race was going generally. When I see all the things people are doing through lack of direction and showing a lot of pent-up hate and things like that, I found it very hard to come across people that I felt were quality human beings and it was good to come across a bunch of people in these two locations where there is some hope, there is some good people who have a good outlook on life. Unfortunately, they're in the very small minority, not the majority. It's disappointing to see that. Many people, like myself, were rushing past this sort of life and it's not 'til a wake-up call occurs that people stop like I did and take a look at what's going on around them. And all this rushing around and work and squeezing everything I can in at the weekend and so on is fine, but there are some other things in life as well. So, is that age? Is it because I've had a wake-up call? I think it's probably both.

I've worked on a couple of the tables for the prostate cancer support group where they talk with people at seniors' meetings and marine shows and things like that, and what I've found is that a lot of those who have been identified with a prostate cancer problem put their whole existence in the hands of the doctors and they're looking for that magical outcome based on what the doctors are going to give them or suggest what they should do. I think they're falling well short of what the potential is for them to do. I think if they're relying on the doctors, they don't have much hope. The doctors have their place but it's just a small cog in the whole exercise.

A regime – exercise and diet

I exercise regularly. I ride a bike anything from 1¾ hours to 2¼ hours every second or third day. I do weights; when it's raining I have a static bike inside that I ride. Push-ups, sit-ups and crunches – that sort of thing. I found particularly that, as I learnt from a book I read from a guy who runs another support group, I found a technique that gave a better outcome for incontinence problems. (I'm not incontinent after four years.) So I have a very active, healthy exercise regime.

From a diet point of view, Sue and I are vegetarians bordering on vegan and this came about because of my exposure to the naturopath. While we ate well, we didn't eat much meat; very seldom ate fried food, didn't go to Maccas and that sort of thing, but we learnt that there was another step forward. So we basically have no sugar, dairy, meat, yeast, alcohol – and never did smoke – and we eat fresh food. If it comes out of the ground, we eat it. We are very much built around a vegetarian diet.

Spirituality for me …

It is a package. Sue and I had a set of circumstances that occurred after I was diagnosed – we had a boat in Sydney and we used to spend our weekdays on the boat and, whenever I went down on the weekends, we'd go home. I'd been retired a few years by then; I retired at 60. The boat was costly and the maintenance would have been very costly except I did all the maintenance myself. When the doctors had completed the operation and the radiation – that's when they said there's not much they could do for me – we started preparing for me not being around much longer. We thought that the last thing we wanted to do was sell the boat, but we decided that if I wasn't around there'd be no point in having it; it would be a huge burden and weight for Sue, so we sold it. There were a number of things that happened when we decided to change our direction. When we decided to sell the boat and house, it happened very quickly.

It wasn't until we were up here for quite a while, and family was up here as well, we started to go to the church; we sat down one night and thought that all the things that had happened might have been a coincidence – but they weren't. There were too many coincidences that had occurred in a short space of time for them to be coincidence. We were directed; but we didn't know it at the time. So that's why I say it's a holistic thing because we probably had about five or six things that occurred in a short space of time that got us to this point of the church and Christianity and getting to the naturopath. If we hadn't made that first move in Sydney, none of that would have happened. We were directed, but we didn't realise it.

Coping with stress

It was a journey unfolding. I didn't want to accept that. When I was first diagnosed, it was a huge crush for Sue and I, sitting in the doctor's office, to hear him say, "I'm

sorry, you have cancer". You could have knocked me down with a feather. I felt, give me a brick wall – I want to bust it down – because this shouldn't have happened to me: I've led a good lifestyle; I've always been active and exercised; I've had a very positive mind. This cancer happens to other people, not me. Sue and I had only been married for about six months at that point, so that was a huge hit. But then, pretty quickly, I thought, hang on, I'm hearing this doctor and we've got to find out everything we can right now because this bloke's appointment time is not going to last long. So we started looking for what was the next step. So that was a pretty heavy time.

Then when the operation was done, they used the scatter gun around the prostate and pelvic area in the hope of killing any other cancer cells. So after this surgery and treatment – the second point in my journey where I was crushed – I thought, I'm strong-minded, I'll get over this real quick! The percentage of survival was low. When I was told that the operation didn't deliver the success they had hoped for, that was another big down-turn, big blow, but it made me even more determined that I was going to beat it. Then at the end of the radiation when the PSA dropped, I thought, "Beauty!" But then after treatment and the trial program my PSA started to double every 1.3 months, I thought, this is not looking good; I'd better get on to the hormone treatment. That was another big setback but I kept saying, "There's got to be a way, there's got to be a way!".

Suddenly, I finally came to terms with the real issue. I said to the doctors, "What do I have to do to fix the problem? I don't want to have to react to the problem after the event". Nobody in the medical profession could deliver that. So I thought that there had to be an answer somewhere else. So then the rest of the journey started to evolve. When I started to go to the naturopath and about that time started to go to the church, that's when I knew that I was going to win this; I'm going to beat it. I keep saying to Sue, "I know that when you are diagnosed with prostate cancer there are no symptoms, so what's to say there is no problem right now? I have no symptoms". When I recall the blood cell tests about 18 months ago that showed a pretty poor quality of my blood, and I look at it now and my general well-being I'm really "up there!", and I've got all those things that are left to do in my life.

Incredible partner support

I have to say that if I hadn't had Sue in my life I would never have beaten it because it's taken a huge effort on her part to throw it. She lived in Korea for a few years and she had a pretty good outlook on quality cooking and Asian cooking and things like that – she did a lot of good cooking, and, basically, she put it and all the condiments to one side and had to start from scratch. She did a huge amount of research and I wouldn't have gotten by without her. She's had a huge impact on me having a good result.

I now just intend to keep on with the way I am going. We were talking one day about wanting to spread the word and minister other people. I didn't really think about it until one of the guys said, "You're actually doing that through those who are ringing you up and wanting you to talk about what you are doing". I hadn't really thought about it that way. I was sitting one day having a haircut and the lady … and we had a chat and she started to embark on a more healthy lifestyle as a result of that chat. She said to me one day, "I have a friend of mine who has some serious health problems and she's wanting to look at a natural approach. Do you mind if I give her your number so she can give you a call?" I said, "No". Anyway, this lady rang me on two occasions and we chatted about quality of life and a healthy life. She didn't have a religious background at all. What I didn't realise around that time was that I was ministering to those who see what's happening in their lives and want to learn a bit more.

Conclusion

Each of these stories is unique; they reflect the individuality of the participants. They not only show how challenging life is to men who have advanced prostate cancer, but they show how each man was frequently creative in the way he tried to cope so that his life continued to have value. The thematic analysis of the data is presented in the next chapter.

Chapter 6 – THE JOURNEY

Two perspectives

It became clear while carrying out the narrative analysis that each participant had embarked on a journey that had two prominent perspectives – the medical, physical, psychological and social perspective; and the spiritual. While reference has been made earlier to the use of the term *code* to identify clusters of ideas that are deduced from the information, I prefer to use *theme* as this is more relevant to thematic analysis.

The conceptual maps included in this chapter illustrate two perspectives of the thematic analysis. Conceptual Map 6.1 (p. 182) illustrates the medical, physical, psychological and social journey, and Conceptual Map 6.2 (p. 200) illustrates the spiritual journey. In Chapter 7, Conceptual Map 7.1 (p. 231) combines Conceptual Maps 6.1 and 6.2 to show the "Holistic Package" that is evident from the complete analysis, or the combined elements of the medical, physical, physical, psychological and social and the spiritual journeys they experienced. The constant reference to spirituality involving transcendence, or lifting up, and holism, underpins the whole of the analysis and is shown in Conceptual Map 7.1.

Themes emerging from the analysis of the medical, physical, psychological and social journey (Conceptual Map 6.1) are reported because it became evident that they impinge ultimately on the spirituality of each man. These are: medical – beginning of the prostate cancer journey, diagnosis and treatments; physical elements – activity, age, food, sex; psychological aspects – emotions, attitude, stress and suffering; social matters – support and dissatisfaction. These are discussed briefly but this brevity belies their importance; they were important to the men because significant reference was made to them.

A central theme of the spiritual journey was connectedness, with the dimensions of self, partners, others and higher being mentioned. Other themes emerging that are

integrated with connectedness are values, purpose and meaning, peace and fulfilment, and process and journey.

As is usually the case with qualitative research, it is recognised that the small number of participants does not necessarily imply that all of the themes identified are going to be replicated with the same degree of emphasis in a different group of men with the same condition. The following is an analysis of themes that are induced from this specific sample of men. The themes indicate that, if they emerge from this sample, they might also be seen in other men with a similar condition. There is overlap among all of the aspects mentioned above. On some occasions it is necessary to mention some themes in two different contexts. The reason for this will be observable in the following text.

I have employed "thick descriptions" in the following analysis as these assist in placing individual narratives in the perspective of context (Geertz, 1973; Moen, 2006) and are rich in portraying in considerable detail the constructed story of participants. Such description enables a deeper understanding of their spiritual personas where the voices of the participants are heard directly rather than an interpretation only of the researcher. In order to give a maximum voice to the participants through thick description, I have repeated some parts of the participants' conversations to highlight the themes extrapolated from the narratives. (In keeping with conventional reports associated with narrative method, excerpts are indicated in the thematic analysis through the use of *italics*.)

The participants all volunteered to talk about their prostate cancer journey and their spirituality and they all demonstrated different life experiences. The age of the men at the time of interview, and the length of time each man had been experiencing advanced prostate cancer, is given in Table 6.1 and provided as background information. All of the participants lived in urban environments – either regional or metropolitan cities – except for one who lived in a country town.

Table 6.1 – Age-related matters

Age of each participant at time of interview and length of cancer journey since diagnosis at the time of interview (years).

Participant	Age	Journey length
Michael	64	3
Craig	79	5
Wayne	85	15
Colin	79	6
Ben	56	3
Jason	69	1
Stephen	67	6
Alan	63	7
Ken	69	2

This chapter continues with a thematic analysis of the medical, physical, psychological and social, and, lastly, the spiritual aspects of the cancer journey for the participants. It is divided into three parts: the medical, physical, social and psychological journey; and then the spiritual journey, as this division emerged as being fundamental to the men's experiences. The third part combines the first two parts together as a summary while the holistic theme arising from the analysis is discussed more fully in Chapter 7. The headings are summarised in Table 6.2.

Table 6.2 – Overview of subheadings used in the thematic analysis

- **The journey – medical, physical, psychological and social**
  - Medical matters
    - Beginnings
    - Diagnosis
    - Treatments
  - Physical matters
    - Age
    - Sex
    - Keeping active
    - Food
  - Psychological matters
    - Attitude
    - Stress
    - Emotional volatility
    - Suffering
  - Social matters
    - Support
    - Dissatisfaction
- **The journey – spiritual**
  - Connectedness
    - Connectedness with self
    - Connectedness with a partner
    - Connectedness with a higher being
    - Connectedness with other(s)
  - Process and journey
  - Values
  - Purpose and meaning
  - Religion
  - Peace of mind, fulfilment and alleviation of suffering
- **"It's a holistic thing … it's a package"**

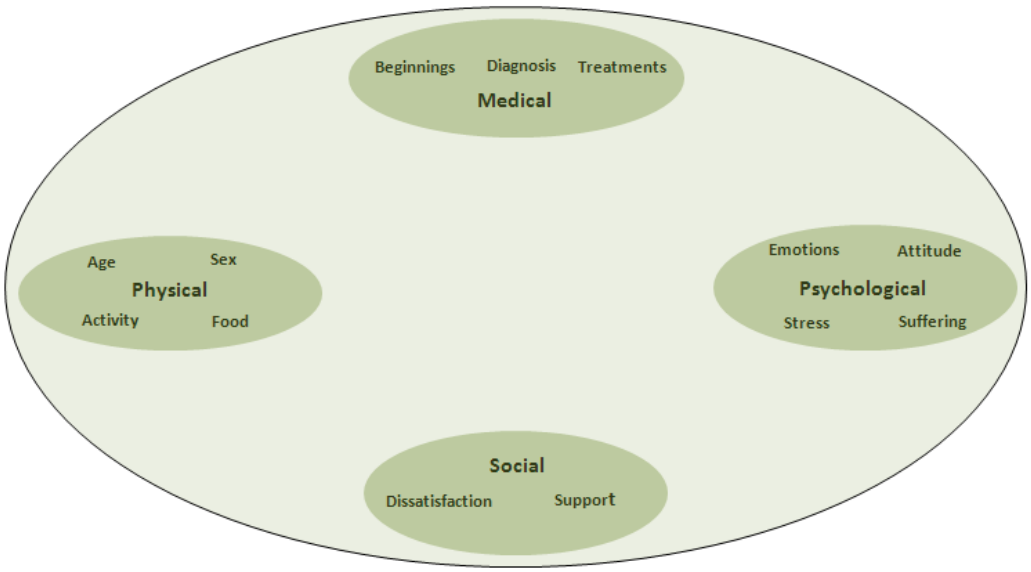
The journey – medical, physical, psychological and social

How can I beat it? I'm pretty positive with what I do. Colin

The participants in this inquiry had common general experiences with respect to some medical, physical, psychological and social issues. The cancer did not have the same effect on all of them as sometimes their circumstances were dissimilar. It is evident that, when the participants experienced a similar problem, they often coped with it differently according to their circumstances and their spirituality, and also their attitude and coping skills.

In Conceptual Map 6.1 (below) small font is used to imply the less central themes evident in the stories compared with the more major issues discussed in the spiritual journey. This will aid the reading of the Map 7.1 which combines Maps 6.1 and 6.2. (It will be observed in Map 7.1 that Map 6.2 sits in the blank centre space of Map 6.1.) (The four ellipses within Map 6.1 indicate the presence of the medical, psychological, physical and social elements without implying any form of hierarchy.)

Conceptual Map 6.1 – Thematic analysis: the medical, physical, social and psychological journey



Medical matters – climbing a mountain

Beginnings – "a hell of a shock"

The nine men in this study found out about their prostate cancer almost incidentally. Michael had a pain in his lower back and was initially diagnosed as having acute sciatica. Craig had trouble urinating. Wayne had a pain in the side of his penis. Colin had a complete PSA test although he did not indicate whether this was routine or whether it was the result of any symptoms. Ben did not have any symptoms but was advised by a friend to have a PSA blood test. He was shaken to find that he had cancer. He said, *And, of course, that came as a hell of a shock to me from having no symptoms to all of a sudden having a death sentence.*

Jason had been having regular PSA tests that showed no specific prostate problem, but was alerted to a possible problem through the appearance of blood in his bed. Stephen noticed a possible problem through a decline in his sexual interest. Alan visited the doctor for a possible thyroid problem and the doctor decided to do a PSA blood test. Ken had a regular blood test and was found to have a high PSA reading.

Ken did not have any symptoms but summed it up when he said, *I was fit and healthy and the GP agreed that I was one of the last people he would expect to see with a problem*.

The beginnings of the cancer for these men were diverse. In only two cases was the cancer diagnosed through regular screening. In other cases, it is notable that, while the ultimate problem was diagnosed as prostate cancer, some medical practitioners did not look at this in their initial consultations. The symptoms, when there were any, were disparate. The absence of symptoms, or pain seemingly unrelated to the prostate, clearly did not mean the absence of prostate cancer.

Diagnosis – "a knock in the face"

When finally diagnosed, most of the men had advanced prostate cancer. In most cases the cancer had metastasised to the bone, and, for Jason, it showed up in the

lung. They all had high PSA scores and Gleason scores and all but Ben stated that they had had a TRUS (Trans Rectal Ultra Sound). This was a blow for each of them. Jason described it as *Wow, that's a knock in the face!*

The diagnosis was often traumatic for them, especially the TRUS and biopsy. Alan had his biopsy without an anaesthetic. He said, *One of the biggest lies that can be told is that you have no feeling in the prostate*. It was a very painful experience for him. Craig had a similar experience. The biopsy was so painful he was *not ashamed* to admit to being hesitant about having another one. He was not told that, when the results of the first were negative, having another biopsy was important at some stage in the future.

Stephen was colourful in his description and there was no doubt that the diagnosis was a traumatic experience for him, especially as he had been treated for high cholesterol and potential heart problems. On being told he had cancer he said,

> *I felt like shit! I mean, I'm thinking, I'm going to die. I mean, they said they could treat it but not cure it and everyone is sticking their finger up my bum, and you know … And I thought, this is ridiculous, how can it be happening? I've got cancer; I'm supposed to die of a heart attack.*

While Ben's and Ken's descriptions were not so colourful, their reaction was similar. Alan spoke of conversations that he had with many men who had been diagnosed with prostate cancer. His observation was that *They're just knocked out by the diagnosis and all the treatment they're going to go through*. These men illustrate that stress at the time of diagnosis can be profound.

Treatments – "that's it?"

Whilst the diagnosis process was traumatic, the decision on treatment was also stressful. In most cases, as the cancer had spread beyond the prostate, there was no real alternative but to undergo hormone therapy. Wayne was told that one means of reducing the hormones was to have an orchiectomy. His reaction reflected his anxiety: *Well, the whole ground was taken away out from under my feet.*

Michael did not say very much about his treatment. He was given the choice of an orchiectomy or hormone therapy and he chose the latter. He was fully aware that, when the tumours became resistant to the drugs, then, he believed, *That's it!* The pause after he said this could reflect his not wanting to say any more about something that was traumatic for him. His choice of words, brevity and pause conveyed his reaction clearly.

Stephen and Colin were brief in their reference to the only option available to them: hormone treatment. It was hard to determine if this implied sadness at less intensive and infrequent treatment, or that they had simply accepted the decision. Jason's view was similar in that he would have preferred to have had more substantial treatment. He wanted to be more proactive. The urologist gave him a prescription for an injection with the direction to buy it at the pharmacist and take it to his GP where *he'll give you an injection in the butt*.

> *And I said, "Is that it?" and he said, "Well, that's it!" I said, "Well, can't I do anything else?" and he said, "No. No. See you in three months. It was confirmed with the urologist". "Are you sure that's it?" "Yes, sure, that's it." So, I'll be disillusioned if that's it!*

Ben and Ken both had prostatectomies. Ben's anticipation of this surgery was traumatic.

> *So I was in a state of shock. So I rang my son. I had a son living in Bendigo, Victoria, and I thought, how am I going to get through this?; how am I going to get through this operation?*

Radiation was used as an adjunct to the treatment of Ken, Ben, Wayne and Craig. The participants gained the impression that the treatment was aimed not at destroying the tumour and curing the illness but rather at reducing the size of the cancers. Little personal observation was made by the medical practitioners of the effect radiation had on each of the men.

Side-effects of the illness and treatment – "rubbish!"

Most men had many of the side-effects mentioned in Chapter 2. These included pain, hot flushes, reduced sexual function and libido, and weakened bones. Michael first indicated that he had no side-effects but he later said that he experienced hot and cold flushes. He said, *the side-effects are, I guess, worse than the treatment* and *the side-effects are rubbish!* These effects were also experienced by Wayne, Ben, Jason and Stephen. Stephen commented, *the side-effects of the drugs – I couldn't think; you go from having a normal testosterone down to nothing – you know, you're feeling like shit.*

It could be postulated that the others on hormone treatment experienced such effects as well. For Craig and Alan, the side-effect of pain might have overshadowed the flushes. Colin experienced bone and muscle mass loss.

Side-effects for Craig and Alan were intense and involved considerable pain. Jason had significant emotional fluctuations as did Ben. Michael had proactive treatment to avoid a side-effect of hormone treatment – bone density loss. Additional effects for Ben involved muscle pain. Changes in sexual desire and performance and loss of libido were also side-effects and, because of their importance to some of the participants, are discussed in more detail below. Altogether, side-effects were a problem for most men and involved them in trying to cope with the physical and psychological stress that engulfed them.

"PSA is the story"

In terms of physical aspects of each man's journey, PSA levels and an associated Gleason score were prime concerns for the participants. In all cases, the men mentioned their PSA level as being their main concern both at the time of diagnosis and as far into the journey as the day they were interviewed. While this was an important factor at the time of diagnosis, it appeared to increase in importance as the journey progressed. Most of the men were focussed on reducing their PSA level. Stephen summed up the general feeling:

> *What you've got to avoid is this PSA thing. It can get out of hand, then it's really hard to knock this back. You can't ever let it go. So, I reckon, from all I've read, I just have to keep my PSA under control.*

This was confirmed by Wayne's doctor: *Well … PSA is the story*. Colin's PSA had not changed in four years. He stated that he *expected it to go away, to be zero.*

PSA was to each man in the cohort the single most physical aspect of their journey that was of common concern. This meant that it did cause them some stress, and they exerted considerable effort to have it lowered. They seemed to believe that their PSA level was the main barometer in measuring the results of their efforts to minimise their cancer. This could be a misperception they developed themselves or inferred from their doctors. However, while PSA level is important, there is no medical evidence to suggest that it is the only indicator of the degree of a man's prostate cancer. It is possible that the men were unduly concerned about the importance of PSA during their journey.

Physical matters – "look after your own body"

Age – "I feel robbed"

The participants' age and length of time they experienced prostate cancer seemed to be a factor in their attitude to their illness. While attitude will be treated separately below, some statements from the men do enlighten their perception of the effect age had on them.

Michael, Craig, Wayne and Colin had journeys of varying lengths and, in each case, they had their *ups and downs*, but each was satisfied with his life. This was expressed by Craig as *happy memories*.

Ben's reaction was quite different. He was 56 when he was diagnosed and he was devastated that, at his age, he had prostate cancer. *I feel robbed … it's shattering, especially at my age.* Ben thought he would have a further 20 or 30 years of life. His

father had lived until he was 86 and Ben thought that maybe he himself could live until he was 90.

Age did not appear to be a major concern for the other four men: Jason – 69, Stephen – 67, Alan – 63 and Ken – 69. They did not mention age as a factor in their discussions.

It is difficult to draw certain conclusions from such a small sample but it does seem that the age of the participant can affect their perception of their illness. Ben, the youngest of the participants, was expecting a long life whereas Wayne, the oldest, was at peace with himself in that he had lived a full and productive life. He had lived for 15 years post diagnosis. Others (Michael, Colin, Jason and Stephen) were less concerned with their age and more concerned about the length of time they had to live and how they would spend that time. This cohort of participants seems to suggest that three elements relating to age – actual age, length of their life since diagnosis and length of time remaining in their life – can be of importance in the way men approach their illness.

Sex – "I'm no longer a man!"

The effect of prostate cancer and its ramifications can include impact on a man's sexuality and his perception of what it means to be a man sexually. The inability to be involved in sexual activity was a major concern for some of the men. One of the consequences of a radical prostatectomy or androgen deprivation therapy can be erectile dysfunction.

Craig was asked how he felt after he was told of the need for surgery on his urethra.

> *I was devastated! Devastated, yeah, devastated, because it's, um … an attack on your manhood! I was silly enough to be thinking along those lines, and a lot of men do think along those lines, don't they, do you agree?*

He was shocked at the immediate effect on his sexuality such surgery would have. He did not indicate whether the surgery itself was an attack on one symbol of his

manhood – his genitals – or whether there could be a longer-term effect on his sexuality. Notwithstanding the possible reasons for his feeling, the concept of such surgery was significant for him.

Jason was also shattered that his lack of some sexual function was going to be a problem. His reaction to the doctor's statement that he could "maybe" still have some sexual function was to state that *An important part of my life is sexual function, really*. Later in the interview he said, *I haven't had sex really since I've started hormone treatment and that bothers me a lot. I have no urge and definitely no length; it's ÷ 2.* This last comment was added in writing by Jason at the member checking stage. It has been cited exactly as he wrote it as the simple statement of his inability to have a normal erection highlights the pathos of his predicament.

He went on to say:

> *I'm trying to deal with this because I feel I'm no longer a man. I just can't get it up. They call it "erectile dysfunction"; they have a name for everything. I have now realised that life has more relevance.*

And later again:

> *Sex has been a big part of my life, but reading books and hearing discussions in the men's group when men talk about sex, they say they are closer now to their partners, even though they do not have a sexual function or can't do it properly.*

He iterated the effect on him personally. *A man loses a lot, particularly in the mind, when this occurs*. Jason could see that it was a problem not only for him but for others. For him, it was a major stress point.

Stephen saw the issue early on in his journey. In fact, one of the earliest signs that he believed was part of the emerging prostate problem was that he had declining sexual interest. While Michael did not express a personal problem with sexuality, he did

draw attention to a major issue and that is that men are not often informed of their potential loss of libido because of prostate cancer.

However, there can be some benefits from facing the difficulty. Jason had a significant comment about this. He was talking of a group of men working together who talked about their sexual difficulties and their relationship to their partners. He commented, *they are closer spiritually and in mind and comfort to each other*. This was a positive outcome from an otherwise stressful problem.

The issue of sex and sexuality was, for some of the men, one of the most significant issues in their coping with their illness. It struck at their perception of themselves as men and it affected their life in both positive and negative ways.

Keeping active – "dancing lifts me"

Most of the men engaged in a physical activity of some kind as a means of achieving some quality of life, maintaining their health and dealing with the stress. Michael's was not of a structured nature but he moved about a great deal in his role as Prostate Cancer Foundation Ambassador. He relied heavily on being able to be active. He also continued to work as much as he could but his energy levels made this difficult sometimes. He commented, *It's not in my make-up to just pull down the blinds and lock the door and wait for the rainy day.*

Wayne's physical activity involved visiting residents in his village when assisting in church services. He admitted that at the age of 85 this physical activity was exhausting. Jason noted that he enjoyed boating, Ben liked bicycle riding; Colin was a member of a sports club and competed every weekend. He did weight training four days a week. Stephen played golf. Alan enjoyed dancing; it lifted him *because of the music*. Ken did weight training, other gym exercises and bicycle riding: He said, *I still do weights four days a week and this seems to keep me fairly active*.

They have all showed that, for them, being active is important during the journey. Some were more structured in their approach to regular exercise than others. One important aspect of this activity relates to energy levels. It has already been noted

that Wayne found continued physical activity difficult. Craig did not mention it at all but his status as being in *dire straits* precluded him from being very active.

Food – "If it comes out of the ground, we eat it"

Food was seen as important for a number of men but not all of them stated their belief in the need to maintain a careful diet during their journey. The strongest advocate of the importance of food was Ken. He enthusiastically embraced a very strict food regime which, he admitted, required considerable discipline. He was encouraged in this by his naturopath and supported by his wife. He was so convinced that his diet and activity was vital in the maintenance of his health that he established a vegetable garden. He was a strong advocate of non-processed food, saying: *If it comes out of the ground, we eat it*.

Ben turned to Chinese herbs and Ginseng and was pleased to say, *I got all my energy back*. Stephen saw value in maintaining good eating habits but not necessarily a strict diet. Jason became very enthusiastic about pawpaw leaves. He believed that his adherence to a daily intake of juiced pawpaw leaves was helping him in his journey:

> *I feel I'm actively doing something over and above, and instead of, "Well, come back and see me in three months", I'm doing something there. It's good for my mind and it's good for my body.*

And,

> *Well, I'm not sure about my body, but I believe it's going to help me. I really believe this. I believe it so strongly, spiritually and otherwise; this is my little grasp on things.*

Jason did have a little doubt about the pawpaw leaves but the essential thing for him was that he was actively trying to pursue some benefit for himself. This was a significant issue for most of the men. On the whole, they recognised the value of eating appropriately but differed in the extent of the discipline with which they approached their diet.

Psychological matters – "I have a good mindset"

Four themes were particularly evident that relate to psychological matters – attitude, emotional volatility, suffering and stress – and there is overlap between some of these themes. They have been separated in this inquiry because some of the men's statements are more specifically relevant to the general connotation of each theme.

Attitude – "it's not going to get me!"

Most of the men were positive in their attitude to the way they managed their illness. Ben had the greatest struggle with coping. Attention has already been drawn to his negative emotional state at various stages of his journey. It is significant that he stated, *I just had to come to terms with it. It's hard to accept, but, you know, but that's the way it is and I've just got to cope with it as best I can.*

Stephen commented: *If you want to be cured, you've got to do it yourself and look after your own body.* Colin stated, in response to a question about the time before a test, *I have a good mindset with it. I know where I'm goin' and I know what I'm doin'. I know it's there; it hasn't gone away. But it's not going to get me!*

The positive attitude of Wayne and Michael was evident through their desire to help others. Wayne commented that *dealing with other people's problems diverts you from your own*; while Michael spent considerable time actively trying to promote a better environment in which men could traverse their cancer journey.

Stress – sometimes "the chips were down"

The participants in this inquiry acknowledged stress in a number of different circumstances and this sometimes led to the emotional volatility addressed in a subsequent theme.

Michael had stress associated with his loss of work; his income was *slashed.* A possible clue about Michael's more directly cancer-related stress lies in the doctor's observation: *Look, don't beat your head around. That's it. You have a very*

aggressive cancer. Michael also had multiple illnesses. Stress associated with these is implied in his statements associated with his wish for greater support.

Craig had immense stress when he was first diagnosed, especially as the surgery that was needed urgently coincided with the establishment of his new business; and he had similar stress over his continuing problems. One example of stress was associated with the conflicting views he received from a variety of doctors and specialists. Another stressor related to his need for two registered nurses to show him how to use a dilator in the shower to facilitate his passing urine. This stress continued when he had to use the dilator on many occasions. He also had stress when he had to consult a doctor whom he did not know.

Wayne was stressed at losing his contact with his *lady doctor*. Colin had some stress associated with what he thought was incorrect testing: *I wasn't impressed with that.* He also admitted to stress points every three months when given his injections. Ben had a combination of stresses – his illness, the illness of his mother, his partner breakdown, his surgery and his side-effects (incontinence). He was also disappointed in his doctor for not having diagnosed the problem earlier. He also had elevated blood pressure and was taking antidepressants. Fluctuations of PSA seemed to cause stress for all men (except Ken), especially as they were so intent on keeping the PSA levels down.

There were many varied stresses mentioned as arising from the participants' life journey associated with their cancer. Much of the stress seemed to have been alleviated the further along the journey the men went. It could be that the men became more used to their condition or associated treatments, a point noted by Alan: *You just become used to it after a while.*

Emotional volatility – from "Beauty!" to "blubbering mess"

Emotions – whether positive or negative – figure prominently in each man's journey. A positive emotion such as happiness reflected the satisfaction that some men had at various stages of their journey and was usually associated with encouraging results of their medical tests. The negative emotions were often related to diagnosis,

treatment, frustrations from medical or organisational matters and also negative results of tests.

Jason had some negative emotions about his treatment. He described his diagnosis as being a *knock in the face* to him. He also confessed to becoming quite teary watching some television shows. He stated that he gets teary talking about his cancer. (Tears welled-up during his interview.) When asked what his feelings were at the time of his extreme physical suffering, Alan responded with further observations about his sickness. Emotional distress was very much implied in his response.

Ken had mixed emotions and some of this volatility may have been related to his prostate cancer but also to his conversion to Christianity, the latter possibly due to his realisation of hope in his life, and a relief from his initial shock of diagnosis. *I've felt a heightened awareness, really, to the point where a couple of times I was a blubbering mess afterwards because the emotion was just so intense.* Ken also felt an emotional high when, at one stage, his PSA went down. *Beauty!* was his reaction. Further on in the journey, Ken indicated that he was much calmer.

In two cases there were emotional benefits as well as losses. Jason, for example, was excited when he realised he was not alone in his journey; while Stephen was excited that he was able to sell his work practice – *Bingo!* – a direct consequence of his cancer.

Ben had some negative responses to some aspects of his journey – his story contains such words and phrases as *astounded*, *hell of a shock* (twice), *I feel robbed*, *all of a sudden* (following his realisation that he might not reach the age of 60), *angry*, *bad luck*, *shattering* and *tragic*. It should also be noted that he was treated for significant depression. Wayne's words were graphic: *the whole ground was taken away from under my feet*; he was *thoroughly disappointed*. His observation that a trial program was discontinued resulted in a sadly intonated comment that he was *no longer any use to them* – that is, to the medical professionals.

Craig experienced devastation and disappointment. Michael was less demonstrative emotionally – his most expressive emotion was his response to a neurosurgeon who

told him that if he operated Michael could well end up in a wheelchair. *Oh, great!* was Michael's understated response that was vocally intoned with gentle sarcasm. He became more emotional in his description of the lack of co-ordination in the management of men with multiple illnesses.

An emotion sometimes implied in a transcript was that of loneliness. Wayne, Ben and Alan seemed to experience loneliness in one way or another. Wayne, for example, even in the "busyness" of daily life in the church seemed to be lonely in relation to the absence of his wife. Ben's loneliness also seemed to be more marked after his breakdown with his partner. He also stated that his way of coping was to spend time by himself sometimes. Alan's loneliness was also related to his divorce from his wife, and he seemed saddened by (but perhaps resigned to) the decision of a good friend not to develop the friendship further because of what Alan regarded as her desire not to be hurt when Alan could no longer be with her.

Suffering – "the pain … worries me"

The phrase in the above sub-heading expresses the physical and psychological nature of suffering found in the participants. It was Alan who commented: *It's the pain and suffering that worries me. I'm ready to die and any time; that doesn't worry me*. The pain was physical but the worry about it was psychological. Suffering has been included in this section of the analysis rather than the physical section because emotional and psychological suffering is more relevant to coping through spirituality.

The physical pain was often excruciating. For Craig the pain was so much that he would scream and cry and wish that he would die, the latter comment a psychological response to a physical difficulty. Ben was distressed about the catheter that he *didn't like*, while Stephen and Michael found their pain physically and psychologically stressful.

All of these psychological matters were important in the lives of the participants. They had to learn to cope psychologically with both the physical and psychological matters related to their journey.

Social matters – "they were a great help to me"

Many social matters impinged on the men's journey and the following highlight two that appeared important to them – support and dissatisfaction.

Support – "Wow, I'm not alone in this journey!"

Support was mentioned in the men's stories in a variety of ways. Sometimes they were critical of the lack, or inadequacy, of systemic support; but they were also appreciative of good peer support. In general, the support from their families was strong. Where it was relevant, some acknowledged the spiritual support they received.

Medical support

Many of the men experienced considerable difficulty on some occasions in communicating with medical professionals and organisations. Michael drew attention to the lack of a co-ordinating body to monitor multiple illnesses where these existed, and also expressed concern about the lack of proactive medical support.

> *I mean, talking about support, this is where the whole system (and this is not so much spiritual support but medical-type support), for people diagnosed with advanced prostate cancer, you've got to go out and find it all yourself.*

Wayne mentioned that there was confusion over medical trial information while Jason was angry over the delay he experienced in even getting an appointment in the State system to obtain a clearer diagnosis of his problem. Craig found it difficult to find satisfactory and non-conflicting statements about his condition. He was certainly disappointed with the attitude of at least one medical practitioner. Alan was disappointed with the "run-around" he received from a receptionist. Ben and Jason were disturbed that they were not diagnosed early enough by the practitioner.

While some difficulties were experienced, the men who were initially dissatisfied eventually found someone who was able to provide the service they wanted. Craig,

Wayne, Jason and Alan all became satisfied with their support, especially from individuals within a system.

It seems that, while in the long-term matters were resolved, many of the men had to go through considerable stress to reach satisfaction. Stress, again, can lead to a less conducive environment for relief of the symptoms and realities of the cancer journey.

Support groups

All of the men had varying degrees of satisfaction with specific prostate cancer support groups. In general, they were appreciative of the services offered but with occasional reservations. While Michael was critical of both government and peer support in one area, he was also very enthusiastic about the value of peer support to the extent that he made a major contribution to support groups, even though he was, at times, physically exhausted as the result. Craig, Jason, Stephen, Alan and Ken found occasional valuable information and peer support from various support groups. Alan commented that, especially at the beginning of his journey, *they were a great help to me*. They had occasional reservations about individuals within the groups who wanted to use the facility for their *moaning and groaning* (Stephen), or when the group became too bogged down in clinical matters but, on the whole, they found them to be helpful, especially in that men were able to talk about their issues in a relaxed environment (Jason).

Spiritual support

Spiritual support was appreciated by those who had church-related affiliations. Craig received support through the medium of spiritual telecasts and DVDs. Wayne was especially supported by his direct involvement in his church's services. Stephen found support in the religious organisational activities of some establishments in Thailand. Alan, Ken and Colin received their support through their church but, in each case, in a different manner.

Because the spirituality of Michael, Ben and Jason was a little different, and was less related to religion and more to connectedness, their particular cases will be addressed in the following chapter. Support for these men was an important issue and it related generally to their particular kind of spirituality.

Dissatisfaction – "my GP really let me down"

There was quite an amount of dissatisfaction among the men who participated in the research. This was mostly associated with diagnosis, the care and treatment received, but also included dissatisfaction with some medical support services.

Jason was dissatisfied because he was not encouraged to take a screening test. He eventually had tests because he *pushed* the issue. He also indicated that misinformation was a problem for him. He went through a convoluted process of checks. He did have PSA tests, and DREs, bowel screening and cholesterol checks but it was only when he found blood in his bed that he went further for checks that revealed a prostate problem. As he was a pensioner and not a member of a private health scheme, he had to wait for an extended time for an appointment to have a biopsy to confirm his prostate disease. He was so dissatisfied that he eventually wrote to the Minister for Health to try to expedite the process. Arrangements were eventually made but not before he experienced considerable stress. Understandably, he was dissatisfied. He was *very annoyed about the whole process*.

As mentioned earlier, Colin was dissatisfied that he was not receiving what he thought was appropriate testing. Even if the testing was appropriate, he believed that if details of his testing had been conveyed to him, some of his suffering might have been alleviated and his resultant dissatisfaction reduced. Ben expressed his dissatisfaction with the lack of testing this way: *I feel that my GP really let me down. He was a professional and he should have known.* Craig had an extremely disconcerting experience that led to his dissatisfaction. During one instance of surgery, according to him, his surgeon made an error. Craig was given much confusing information, some of which he perceived as inaccurate. His recounting of the lack of esteem with which one specialist was held by other patients appears to be a serious matter.

Alan had a dissatisfying experience when he was trying to find out information to which he was entitled. *They pull this "privacy" on you because in many cases they are just too lazy to have to do anything.* As he says in his story, he believed that he had been given the run-around by a receptionist. Alan's experience demonstrates that

there can be difficulties at all levels of a cancer journey. These experiences led to dissatisfaction that, in turn, leads to stress and a non-helpful environment.

A significant expression of dissatisfaction was made by Michael. His observations were in relation to himself and then transferred to more systemic failures. At the personal level, Michael had a number of illnesses. His dissatisfaction was with the system that did not allow for a monitoring of him as a person with multiple illnesses. Each illness was significant in its own right and was being treated by a different specialist. There was no co-ordinating doctor or team to monitor Michael's progress as a whole. Michael saw the need for the system to have a monitoring structure in place.

Dissatisfaction with what the participants perceived to be basic provisions for them to cope more effectively with their journey was prominent in their stories. Their source of dissatisfaction seemed to be primarily social in that it involved personnel who, to the participants, did not appear to be fulfilling the duties expected of them. At a time where there is considerable stress in the men's lives, by implication they believed it important that their treatment by some people should have been more understanding.

The medical, physical, psychological and social issues arising from the men's stories were important to each of the participants. They were an integral part of their journey and demonstrated the positive and negative aspects of the ways they tried to cope. While at first glance it might not seem that the issues impinge on the men's spirituality, it will be suggested later in this chapter and in Chapter 7 that there is an important relationship between these aspects of the men's journey and their spirituality.

The journey – spiritual

My spirituality has helped me a lot because it has given me a good mindset. Colin

It has become apparent through analysis that there are many dimensions that, either directly stated or implied, the men regarded as comprising their spirituality. Their

respective stories were couched in a spiritual framework. It was clear to them at the time of their acceptance of participation in the research, and immediately before the recording of their story, that the research focussed on their spirituality in relation to their prostate cancer. While it cannot be assumed that everything they said was an integral part of the spirituality, it is evident that many aspects of the men's lives contributed to it.

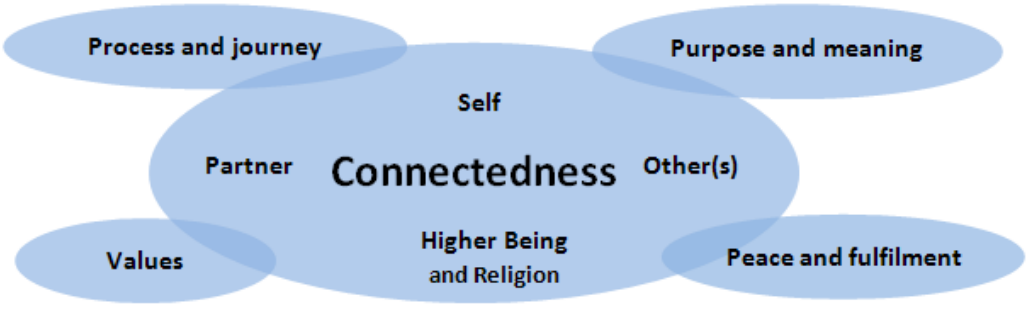
Having looked at medical, physical, psychological and emotional themes in the first part of this chapter, the following discusses Connectedness in what I see as a central theme in the men's stories. There were other important themes in the narratives that are related to the centrality of Connectedness and these are mentioned below. The related themes are mentioned in less detail because they were not as prominent in the narratives, yet they were nonetheless important to the men, as seen through their frequent significant comments.

Connectedness – "a problem shared"

A problem shared is a problem at least halved, isn't it? Wayne

The central theme in the stories of the nine men who participated in this inquiry was Connectedness. This is illustrated in Conceptual Map 6.2 with Connectedness being at the centre of the men's spirituality and comprising close connections with Self, Partner, Higher Being (and Religion) and Others. Also associated and integrated with the centrality of Connectedness were the dimensions of Process and journey, Purpose and meaning, Values, Peace and fulfilment.

Conceptual Map 6.2 – Thematic analysis: the spiritual journey



Spirituality was not a matter of the men being connected with only one or two of the dimensions indicated. It was evident that each man had more than one form of connectedness. For example, some men demonstrated a closer affinity to a higher being than others, and, at the same time had differing degrees of connectedness with a partner or with family. Purpose and meaning in life was in some men more pronounced than in others, while they all had different emphases in their values. This illustrates that spirituality is highly individual in each person so it is appropriate that this is respected when illustrating the theme in each of the men.

Connectedness with self

Underpinning all the stories was the notion that spirituality starts in the individual and connectedness with self involves a man reflecting on and knowing himself. For this reason the issue of connectedness with self is addressed first.

Wayne carried out a lot of personal reflection. He said, for example, that he looked back over 15 years. This reflection revisited the amount of time he had spent in understanding his illness, and, at one stage, he mentioned that his *hindsight* (reflection) enabled him to see that it was unfortunate for him that he had had early biopsies that were not as comprehensive as later biopsies. It also involved musing on the decline in his physical strength. It can be interpreted that Wayne's connection with others sometimes distracted him from reflecting on his own difficulties. His personal prayers involved some reflection and communication with himself because, in order to pray for assistance, it was necessary for him to reflect on his own need first. He reflected that

> *The Lord's hand is comfort … It is real and you take the comfort from your prayers. You can lift your head up and say, right, the Lord's with me. I'm going to cope with this with His help.*

Wayne's story shows that his thinking and reflection was important in his connecting with himself and centring his spirituality.

Ken's reflection involved him and his wife trying to make sense out of their lives, especially in relation to his illness; he stated that they *realised* that some aspects of their lives had a purpose. Ken also recognised that, on reflection, some of the things stated by a naturopath made sense to him. In other words, he thought about what had been said and placed it in his own, personal context. His reflection also involved his question, *What do I do next?*, making a decision for his own progress based on his own self-concept. Ken's assessment of his change in the time he had prostate cancer involved a reflection on this change and a greater knowledge of himself: *I'm calmer in myself.* He was also enthusiastic about meditation. His meditation mostly took place at night and involved him *switching off* to everything. Ken described one method of his self-connection as concentrating on his body parts. The value of this, he said, was in taking his mind off the things of that day which were occupying his mind and not enabling him to sleep. Ken's key reflection was when he realised that he, himself, had to do something about the problem.

> *Suddenly, I finally came to terms with the real issue. I said to the doctors, "What do I have to do to fix the problem? I don't want to have to react to the problem after the event." Nobody in the medical profession could deliver that. So I thought that there had to be an answer somewhere else. So then the rest of the journey started to evolve.*

For Ken, the crux came when he connected with himself. When he did that, the rest of the connections became clearer to him.

Stephen's self-connection also came during his journey when he realised the need, on reflection, to do something within himself.

> *It started me thinking – the doctors are not going to cure me, they've given me a bit of time – all they've done is bought me some time – so I've got to work out what am I going to do with the time I've got.*

In this process, he recognised his need to bring *energy from the universe* into his body: *I decided … to make the effort to make myself fit and healthy.* Ken attributed

much of his self-connectedness to the meditation in which he became involved. His summary was that *it calms you down and it has a good effect on you*.

Stephen was delighted that one of the side-effects of his coping approach was that his golf game improved. His meditation was sometimes guided, sometimes in the Zen Buddhist mode of thinking of nothing, although he did not enjoy this very much, and sometimes was done to music. He was also adamant that *getting my head around it* was important for him. This can be understood as self-connection – he wanted to ensure that what he was doing was right for him.

Alan's self-connectedness seemed to come at a later stage in his journey. In talking about spiritual support he expressed the desire to talk to others about *where you are at*. He wanted to be connected with himself but wished to have spiritual support to do this. *I don't find myself involved in a lot of personal spirituality. I do like to go and worship with people. I like to sing, pray, have communion … fellowship.* His final statement indicated his self-connection in that he was at peace with himself and where he was going. He was self-assured in his future and this implied that he knew his inner self. *I could go to bed tonight and die in my sleep and that would not worry me at all.*

Although Michael was less revealing about his connectedness with himself, it was undoubtedly present. He stated that it was not in his *make-up to just pull down the blinds and lock the door and wait for the rainy day.* He knew himself and decided on a course of action. His comment, *We've got to try and help ourselves by looking after ourselves*, is telling. To help ourselves we need to know ourselves, to be reflective and self-connected.

Jason struggled initially in self-connectedness and coping with the treatment of his illness. *I do feel OK in my body but my mind is a bit screwed up.* Ironically, recognising his own confusion is an example of self-connection. But, as his journey progressed, he became more self-connected through his enthusiastic belief in the value of pawpaw leaves and meditation. He said, *I believe it so strongly, spiritually and otherwise; this is my little grasp on things. I don't pray a lot but I try and*

meditate. Jason was convinced in himself, on reflection, that the pawpaw leaves were going to help. He was not convinced by someone else of their potential value.

A telling statement on Colin's self-connection was: *My spirituality has helped me a lot because it has given me a good mindset*, and, *I know where I'm goin' and I know what I'm doin'*. He recognised his control over his mind.

Craig went through a journey towards self-connectedness. He took the first steps initially to be company for his wife at church. He then started to read the Bible and other writings and became more personally convinced of the direction he wanted to take. The great outcome for Craig of his *peace with himself* was that *in essence the main thing was that it took away my fear of death*. It is also interesting that Craig's connectedness was not to a church, per se. He seems to have addressed a connectedness that was personally based, yet with some connectedness to his wife, God and other people. He realised the importance of self-knowledge when he said, *No, the only support I would like comes from my soul; with better knowledge. I think it is up to me to lift, not other people.*

Ben really struggled with himself; he tried to gain support through God but this was an external connection. He was not even sure in himself if he believed in God. While he stated that he was happy in his own environment, he did not seem to show self-knowledge.

The above examples, given in some detail, show how different each man's connectedness with himself was. It is hard to see commonalities in the way they viewed themselves. Even amongst the Christian men where some kind of commonality might be expected, the way they connected was different, moving from the highly personalised self-focussed connectedness of Craig, enhanced by his affinity with various kinds of exposure to Swedenborg and Keller, to the need for Alan to experience his self-connectedness through his religious association with people in a congregation. Each was challenged by the context in which he was facing his illness and each had to reflect on his own personal circumstances to understand himself and develop the way he would cope.

Connectedness with a partner

Another important aspect of the participants' spirituality was their connectedness with a partner. Within the context that the interview focussed on their spirituality, it is significant that all participants indicated at some stage that their connectedness with the partner had an important influence in their spiritual life. It was clear that they relied on their partner, even if this was sometimes in an unusual way.
Michael appreciated his wife's ability to understand the medical issues:

> *My wife, Margaret, has been with me all the way and her career as a nurse and nurse educator has been extremely beneficial when talking to the medicos, and asking questions in a different way.*

Craig (as was evident during the interview) was so much in *dire straits* that he was dependent on his wife for almost everything. He commented:

> *I know I keep bringing up my partner, my wife, all the time. She's very, very spiritual compared with me. Very spiritual. I'd love to lift myself closer to her … Dianne is my crutch.*

The "absence" of his wife because of her Alzheimer's disease and subsequent death was an indication of Wayne's longing for her company to help him through the various stages of his journey. *I had to make all these decisions on my own and this made things much more difficult as far as I was concerned.*

Colin accepted his wife's judgement on the selection of a church to attend: *Pamela found the church she liked. I said, "That's good enough for me".* Ben had a relationship with a woman who helped him: *She helped me a lot. Every time I saw her it gave me strength.* While that relationship did not continue, I spoke with him after later treatment and found that his former partner had come back to stay in the house with him to support him during his treatment. He appreciated this.

Sometimes a partner's relationship can have unusual circumstances. Jason's first relationship ended in disappointment for him but he was delighted in the connection

he had with his current friend who was very supportive during his cancer journey. *I am so fortunate with another lady now who is really, really on side with me.* Stephen formed a supportive relationship with a woman who was not his wife but with whom he had formed an attachment as the result of a shared group cancer support experience.

Alan highlighted a major problem for him. He had been divorced and had been living by himself for some time but had become friendly with another person. She was unable to sustain the relationship because of Alan's uncertain future.

> *… she decided she didn't want to be a serious friend any more. She couldn't cope with it. That is the case when you reach this stage – you can't expect anybody to be too close because they know they are going to get hurt.*

This was a sad situation for Alan and seemed to affect him considerably. The loss of someone who had become a close friend was experienced as suffering and made a difficult situation worse.

Ken summed up his situation by saying that he could not have progressed as well as he had without his wife. *I have to say that if I hadn't had Sue in my life I would never have beaten it because it's taken a huge effort on her part to throw it.* Ken recognised the significant support he received from his wife.

This connectedness with a partner, in both positive and negative senses, at some stage of the cancer journey permeated all interviews. It was important in both its presence and its absence, the former leading to a stronger degree of coping and the latter leading to either stress or sadness. It was implied in the interviews that in most instances the presence of a partner gave the men a lift and helped them transcend the difficulties of their illness.

Connectedness with a higher being

Not all participants connected with a higher being. Most of the men, without prompting before or within the interview, recognised a distinction between religion and spirituality.

For Craig, Wayne, Colin, Alan and Ken, their spirituality was closely related to their religion. Jason and Ben acknowledged a higher being and their religion except that they were not as committed to a full participation in it. Michael stated that he was not religious. Stephen did not acknowledge a higher being and recognised religions such as Buddhism, even though he did not embrace them.

Wayne, Alan, Colin and Ken were regular attenders at church services. Craig was less regular but nonetheless committed. Craig's difficulty at the time of his interview was associated with the problem of being physically able to attend. He stated that *sometimes it's a pain in the neck to get ready to go*, and, besides this, he indicated that *generally the sermons really don't lift me up, no.* Craig received most of his spiritual sustenance through books and DVDs (and his wife).

Wayne, even at the age of 85, was totally committed to his religious involvement in the church and to his quiet, personal reflective connection with God. He was very active in his retirement village as a liturgical assistant. As well as this, he participated in small-group theologically based activities and reflected on his worship of God privately. He had a range of activities that fostered his spiritual connectedness to a higher being. *I think my religious activities only strengthen me.*

Colin's relationship with a higher being came through his conversion to Christianity. This eventuated through his connection with a TV evangelist. Colin was impressed with the evangelist's achievements in healing. Colin had an affinity with this because of his own strong interest in practising hypnosis. His connection with a higher being involved attendance at church services and especially through his conviction that his spirituality and his own developed hypnotic abilities were God-given: *I think it's a gift. It is a gift. My hypnosis, healing and spirituality are all part of the one*. He also expressed his spirituality in these terms:

> *The hypnosis and the healing come in together, and spirituality. If you say it's in God's name you're healed, or, if the healing process is in your mind, it is accelerated.*

For Colin, insofar as he revealed it in his story, his spirituality was practically oriented.

Alan acknowledged a higher being in a religious sense as his connectedness was through his church. His denominational orientation was what might be described as liberal in that he was less associated with one religion: *I'll attend any church that's convenient to me at the time*. For Alan, prime spirituality and connectedness had to be with a higher being, God. His connectedness came through his attendance at church services rather than through private, personal reflection. He said, *I don't find myself involved in a lot of personal spirituality. I do like to go and worship with people. I like to sing, pray, have communion … fellowship.* Later he said, *You get a congregation and within that congregation you do have a real spirituality.*

Ken's connectedness to a higher being came initially through his contact in a church. He maintained his association of this connectedness through constant church attendance and his conviction that his renovated lifestyle was able to give him confidence in his future. In a similar way to Colin, Ken found that his connection with God came through the practical healing he witnessed at various church services. He commented:

> *The church has been a huge inspiration to have this direction in the back of my mind all the time. I think about a lot of things and I research and analyse a lot of things and I'm getting a lot of direction from the church and my involvement with God.*

Jason's spirituality was more generally associated with his individual persona than to religion. He acknowledged his association with the Catholic Church but stated that he did not go to church very often. He said, *I'm religious and believe in spirituality*, and *I certainly believe in the Lord*. He also stated, *I believe in God and say my*

prayers, indicating his personal connectedness with a higher being but not necessarily through religion, per se.

Ben had a passing connectedness with a higher being. He was not religious in the formal sense of the word but turned to God at one stage during his journey. *I wasn't a religious person but I turned to that in the hope that ….* He stated later that he had stopped praying; he did not understand the reason except that he was not *a religious person.*

Religion

Religion, in the sense of formal spiritual organisation, featured prominently in the spirituality of most of the men and is related to the men's connectedness to a higher being. The essential feature of the Christian spirituality of six of the men was that, while Christianity may have a common basis, it was manifest differently for each individual.

Church connection was important for Craig, Wayne, Colin, Alan and Ken. Jason was more loosely connected to church but still maintained his faith as an individual. Craig and Wayne were experiencing greater difficulty during their cancer journey and were declining in their physical ability; in Craig's case, his mental willingness to continue participation in formal church activities was also declining. Craig was much less mobile and Wayne was becoming that way. He found it increasingly exhausting to participate in the church rounds of his retirement village. Alan's involvement in church activities depended on where he was. He seemed to go to church only when he was in his home town. Nevertheless, he was adamant that his spirituality was based on his fellowship with similarly minded Christians. Colin and Ken were vigorously involved in their church in both worship and practical activity with other church members – Colin through his use of hypnosis in helping others, and Ken in his enthusiasm to tell others about his lifestyle which he believed was helping him immensely. The non-religious spirituality of Michael, Ben and Stephen did not detract from the value that their personal spirituality was to their coping during their cancer journey.

Connectedness to a higher being was an important part of most of the men's spirituality and was translated into religious activity for some of them. It assisted them through their belief in the direct benefits that it gave them through God's intervention (Colin, Craig, Alan and Ken) and in their acceptance of the comfort associated with that connectedness (Jason and Wayne).

Connectedness with other(s)

The use of the term "other(s)" reflects the disparate nature of the way in which the nine participants in this study expressed connectedness outside of the self, partner and high being. The grouping of the following is a reflection only of the emphasis given to the respective components by the men in this study. It might not reflect the importance of other human or non-human connectedness in other studies. The human aspect of other connectedness in these men was seen through their relationship with their families and with other people. The non-human aspects reflected their connectedness with their activities that lifted them above the ordinary.

Human other

The human other seen in the men's stories embraced their immediate families including parents and children, their friends in church, sporting clubs and support groups, medical professionals and acquaintances with whom they connected as the result of their illness. This connectedness also lifted the men above their everyday attempts at coping with their illness.

Michael indicated that after his diagnosis he moved to a different location to be closer to his sons. Craig mentioned his parents incidentally at the beginning of his story on spirituality. His mother insisted that he and his brother go to Sunday school.

> *"You can do anything you like, you two boys; you can lie on the ground, kick, say you're sick, but you'll go to school every day and you'll go to church on Sunday."*

I detected great pride in Craig's reference to his mother. He seemed pleased that she took this stand, even though he did not follow it up at the time. He also seemed to

develop connectedness with his remote grandfather. He was pleased to have discovered his theological writings and this was certainly tinged with family pride. It seemed that Craig's connectedness to his family was directly related to his family's spirituality.

Wayne, Colin, Stephen and Ken did not mention family, apart from their wives. Alan's connectedness with his family was not strong. However, both Jason and Ben had a close family connectedness. Ben was very close to his son and, in the absence of a partner, he relied on his son to talk over issues with him. Ben was also close to his mother, even though she was elderly. It was his mother's illness and her distance from him (New Zealand) that added to the stress of his prostate journey.

Jason was even more forthright in his recognition of the connectedness he had with his father and sons. He acknowledged that his own life might have been different had his father *been around*. Jason acknowledged his connectedness with family in these terms: … *my family lifts me greatly. I live for my family … My family and grand-kids are my spirituality.* It was obvious that Jason's family lifted him above the ordinary. They were special for him.

Michael has a strong connectedness with other people. He had devoted the past few years of his life to working with men who have prostate cancer. In his role as a Prostate Cancer Foundation Ambassador he had made a significant number of presentations to community and industry groups in which he drew attention to many of the issues associated with prostate cancer. He had a great deal of empathy with men; as well as their partners. He was adamant that partners should be involved in discussions as well as the man with the cancer.

> *I always say, especially in industry groups, that female employees should come along as well so they can pass the information along to their husbands, partners, brothers, fathers, uncles etc …*

In his connectedness and empathy with men, he indicated his desire to promote to other people their betterment in relation to prostate cancer.

> *If I can encourage men to go to the doctor, look after themselves on a regular basis, then it has not been in vain in my getting prostate cancer. … I'd like to raise the awareness of men and their partners.*

Craig also had a strong connectedness with others. In his case, the strongest connection was with Helen Keller and Emmanuel Swedenborg. Of interest here is that the connection came through his reading, and that the connection was to people who, while physically dead, were "alive" through their writings. There were other religious people in his life as well. But it was not only religious people he valued; he found good in many people.

> *I got lifted up yesterday by the dentist, the x-ray people, the lady who took us into the place where I'm having this treatment next Tuesday. I got lifted up by Reverend Tills yesterday when I mentioned spirituality. We had a lady come in next door and she sat there and you could see kindness all round her. Things like that lift you up.*

Spiritual leaders were important for many of the men. Wayne identified closely with his priests. At the same time, his relentless service to the people in his retirement village indirectly showed his determination to be connected with others. Colin was connected to the evangelist Benny Hinn and later to pastors in his church. This was also the case with Stephen, who became emotionally involved with the healing activities of his pastors. Alan would have liked to have been more connected to pastors to gain added spiritual support but placed the qualifier on this:

> *… the person you pray with has to be sincere, they're not just a wage-earner; it's not just their job.*

Two of the men became connected to the medical practitioners who cared for them. Wayne was closely connected to his Russian doctor, while Ken became reliant on his naturopath.

Connection with others also included people with whom the men associated. Michael, Craig, Jason, Stephen, Alan and Ken all had varying amounts of contact

with men in support groups. Colin was less connected and there were occasions where others were negatively connected. Stephen, for example, did not like the *moaning and groaning*, as he described it, that went on at some support group meetings. He commented that the people *sucked all the energy out of me and I didn't have enough to share so I didn't go back.* Stephen also found that other negative connections, like his experience with "friends" in Thailand, created more tension and that did not help him. He also made a connection with a woman in a broadly based support group. He found this helpful at the time.

Ben found connection with people he knew through his writing to them to tell them about his illness at the time of its diagnosis. He said:

> *I wanted to spread the story, I suppose, just to take the weight off my shoulders because when you are diagnosed with a terminal illness it's just a huge burden and, yes, it's really hard to cope with. … It's helping me by saying it.*

Alan connected with women at old-time dance sessions, although he also mentioned that the dancing lifted him because of the music. Ken connected with men at his church.

Non-human other – spirituality through doing

It was evident in the men's stories that connectedness to other could be spiritual; it could lift a person beyond the everyday, or ordinary. Mention was made earlier of Alan who found that dancing and music lifted him up. Music was also an element in Stephen's story of the things he did to cope.

Craig was certainly lifted by the books he read, especially those relating to Helen Keller. He also found connection with horse-racing and boxing.

Jason found boats and boating helpful for his spirit. *I walk to the beach or go and see some boats. That lifts my spirit. It makes me feel good.* Colin was a sports hypnotist and found a close connection between his hypnosis activities and his spirituality.

Wayne probably put "other" in perspective when he said of his affinity with astronomy and amateur radio operation:

> *I wonder if you would call … them spiritualities or whether you would tend to call them interests. … Those two things can absorb you completely and you can switch off from the world.*

The men generally recognised that there were many other things in their lives that lifted them above the ordinary and were special to them. The extent to which these issues were sacred – another aspect of spirituality – will be discussed later in this dissertation. It was evident in this inquiry, however, that men with advanced prostate cancer regard human and non-human connectedness generally as something within their spiritual realm.

Connectedness – being lifted

An issue with connectedness is whether it is just a psychosocial construct, or whether it is part of the man's spirituality. Some of it appears to be psychosocial. Other parts can be recognised as being an integral part of the man's spirituality in that he stated that he was lifted up by his connections. In the stories told by the men in this research, there are many examples of the way in which men are connected with someone or something in a connectedness that is beyond the psychosocial and well into the realm of spiritual connectedness through its transcendence and sense of the sacred. The broader issue is discussed more fully in Chapter 7.

I now proceed to discuss themes emerging from the narratives that are closely related to connectedness, as indicated in Conceptual Map 6.2 – Process and journey, Purpose and meaning, Values, Peace and fulfilment.

Process and journey

Another theme evident in the men's stories is that each had a spiritual journey that was almost parallel to his physical journey. Each man spoke of his cancer very early and each then started to relate his spirituality alongside his physical condition. Each

part of this journey involved connectedness with one of the four aspects identified above.

Very early in their journey Michael and Ben commenced their connectedness with other people, part of their spirituality. Michael sent out more than 100 emails to family and friends as soon as he was diagnosed so he could encourage men to be screened and avoid what he was going through. His satisfaction was that some responded that they had been diagnosed with prostate cancer saying to him: *Thanks for saving my life.*

Ben's immediate response was to connect via phone to his son. He also went to see his mother, who, while not in a mental state to understand Ben's situation very well, was nonetheless one of the two people with whom Ben particularly connected during the early part of his spiritual journey. While Ben was undergoing treatment and recovery he also tried another form of holistic care – herbal medicine. Another part of his spiritual journey was his attempt to connect to God but, because this seemed to be not working for him, he discontinued this connection.

> *To be honest with you, I've actually stopped praying now. I can't explain why because it was just something that … like I said, I wasn't a religious person but I turned to that in the hope that, yes, you haven't got much when you're diagnosed with a terminal illness.*

This illustrates the point that not always will connectedness be positive, nor will spirituality be cumulative.

Another development in Ben's journey was his connectedness with other people when he wrote to many he knew well and to some he did not know so well so he could share his burden with them. Ben also regarded his spiritual journey as being a little volatile. He said of his relations with other people that sometimes it might *get all too much.* At other times he might talk successfully with them. *It just works that way,* he said.

Some of the men started their spiritual journey in direct response to their diagnosis. Ken was prompted by a friend of his son to take greater interest in connecting to a higher being. His interest in religious spirituality developed alongside his physical progression to the stage where it might almost be said that his spiritual journey had subsumed his physical. He believed his holistically spiritual life-regime had been so successful he had no further need of doctors. He said:

> *I believe that what I was doing with the naturopath and my approach to believing in God that He would speak to me and keep directing me – Sue and I sat down one day and we said, "We're not going back to the doctors …"*

Craig's religious spirituality commenced about the same time or just a little after his cancer diagnosis. He started going to church with his wife. He was influenced by Helen Keller and Emmanuel Swedenborg and, spiritually, he regarded his conversion and, ergo, his spiritual journey, as a miracle. His spirituality developed alongside his cancer journey to the extent that his spirituality *took away my fear of death*.

Colin had no defined spirituality before his diagnosis. Soon after this he became connected to an evangelist and saw the relationship between his developing Christianity and his illness. He stated categorically that his spirituality *increased because I had nothing until I started four years ago*. His life became committed to spirituality and has continued to develop.

Wayne had the experience of starting a spiritual journey earlier in his life and then letting it lie stagnant until before his cancer diagnosis. He had come back to the church and found that it was a *source of not simply comfort, but enormous support* to him at the time. As his cancer progressed, so did his spirituality; he said his church activities *only strengthen me*. The implication was that his spirituality was continuing to develop.

As Alan's cancer developed he faced enormous difficulties but his spirituality remained the same. He was brought up a Christian and had always attended church. He was still attending church which was the source of his spirituality. He stated that during his cancer journey his spirituality stayed the same, except *Oh, it may have*

increased a little. This is an example of the way a man who has developed religious spirituality during his life taps in to that when he needs to at the time of stress.

Jason had always been a Christian and, although he attended church only twice a year, he believed emphatically in God and Jesus Christ. Even though he had that basis, it is evident that his spirituality continued to develop, not in religion so much as with other dimensions of spirituality. His introduction to, and current reliance on, the value of pawpaw leaves – which he regarded as part of his coping developed along his journey.

> *It's good for my mind and it's good for my body. Well, I'm not sure about my body, but I believe it's going to help me. I really believe this. I believe it so strongly, spiritually and otherwise; this is my little grasp on things.*

Jason's optimism that his action was going to help him illustrates the part pawpaw leaves would have in his journey. At the same time, his family became more meaningful to him as well, as did his connectedness with other people. His comment, *My family and grandkids are my spirituality*, was made as a result of his recognition that he was going to stay with his family while the problem was resolved. Implied here is a recognition that this spiritual connectedness was growing with his physical journey.

Stephen's spiritual growth adds a new aspect. This did not occur until he was into his cancer journey. It occurred almost by accident as the result of a planned holiday to Thailand. He had heard about a health resort and had planned – before he was diagnosed – to visit there with his wife. He became interested in healthy food, meditation and associated activities. It was this inclusive activity, particularly meditation, that he regarded as his spirituality. His spirituality developed to help him cope, not only with this cancer but with his life as a whole. He directly relates his spirituality to improvements in his PSA.

In eight of the nine men, it can be observed that their spiritual development took place alongside their cancer journey. The catalyst for the awakening of, or significant

increase in, each man's spirituality differed according to his circumstances, and the development also was linked to the fluctuation in the cancer growth itself.

Values

The men's stories either implied or directly stated the presence of, for example, love, faith, trust and hope, and that these were integrated with connectedness. These comprise some of the values seen in the literature review of Chapter 2[4]. As well as these values being evident in some of the men interviewed, instances were recounted wherein some values were not evident in the lives of some people around them. It can be seen here that the absence of some values in others had a negative impact on the participants. It is instructive to note the relationship between values and connectedness – the men in the study had internal values and manifested these practically through their lives in their connectedness with others.

The most evident value was that of love; love of their partners was observable in Craig: *Dianne is my crutch*. Colin was complimentary about the role his wife played in his conversion to Christianity. Jason had a partner of whom he spoke very highly in her support of him as his cancer journey was progressing; while, of his wife, Ken said, *She's had a huge impact on me having a good result*. This was spoken in a very loving way. Michael appreciated the presence of his wife at discussions with medical practitioners and in other support.

While Ben experienced a breakdown in his connectedness with a partner initially, he mentioned sometime after the interview that she had returned to his house to help him through a six-week period of radiation therapy; he spoke with love for her at this gesture. This may be a case of someone loving another person but the couple being unable to live together for any length of time. The love and care might still exist and still be useful during a prostate cancer journey.

[4] Burkhardt and Nagai-Jacobson (2005); Hart and Waddell (2005); Lin and Bauer-Wu (2003); Morritz et al. (2007).

Alan and Jason had negative experiences with their partners. Alan attributed the process of his divorce to a lapse in organising PSA tests that might have picked up his cancer earlier: *It just got away from me, I guess.* Jason was dismissive of his partner had who said at the time of her departure, *What comes around goes around. Oh, thanks a lot*, said Jason. He followed this statement with a tribute to his current partner because she was *really, really on side with me* during his illness. The juxtaposition of the two statements might suggest the lift Jason was experiencing with his current partner as distinct from the previous partner whom he had supported during her cancer journey.

Following the connectedness theme and its relationship to love, it can also be observed that love – "affectionate devotion" – permeated the connectedness participants had with their families – Ben with his son and mother, Jason with son and grandchildren. Love also permeated the connectedness men had with others. Michael, for example, loved his fellow men enough to enthusiastically advocate men's issues in the community to try to help them avoid going through what he had been through. For Michael, if he could *encourage men to … look after themselves on a regular basis*, his getting prostate cancer would not have been in vain. Ken had a similar love. He wanted men to *learn a bit more* about the way they could cope with their illness, hence his interest in ministering to those who had prostate cancer.

An important aspect of love for many of the men was for a higher being. Craig, Wayne, Colin, Alan and Ken each had developed a very strong connectedness with God that was based on an understanding of what they believed God had done for them through the sacrifice of His Son, and through the living of Christian principles. This was manifest for them mostly through their church or religious commitments. Jason's love was also evident but he had greater commitment to individual expression of his love for God rather than through religious association.

In what way is connectedness to self exemplified in love? In the participants it can be observed through their respect (love) for themselves in trying to handle the physical aspects of their existence. They had a love of life in that they tried to do whatever they could to prolong it. This was difficult at times for Ben (depression), and Craig and Alan (extreme pain), but they continued to try. All the participants showed love

and respect for themselves through their dealings with other people. They were comfortable in their personal existence. Their love went further than just connectedness; "affectionate devotion" was evident in all the men at some stage in their connectedness with others.

Faith and trust are similarly oriented values and these were revealed in the men's stories in instances of showing trust in the people who were helping them. They each believed that those caring for them would help them through and these people included doctors, nurses, therapists, support groups and almost everyone who cared for them.

Sometimes their trust was shaken through the activities, or reported activities, of some of the people they would normally trust. Craig's trust was brought into question when a surgeon made an error during an operation on his urethra. Craig also reported that men at a support group *booed, hissed and booed* when a particular surgeon's name was mentioned. Stephen's trust in a couple to do the right thing by him when he invited them to Thailand was shattered when they overstayed their welcome and Stephen's health suffered as a result.

Jason trusted in the government health system to help him in the initial stages of diagnosis. He was let down because he trusted in the delivery of services that were not provided when they were expected. Michael was similarly disillusioned with systemic provision of some services he trusted should be provided and consequently spent much time trying to advocate the establishment of these services. His view was that it was a matter of trust that those responsible for ensuring services should provide them. *We're talking about the lack of indirect medical support; it's not there.* He was similarly critical of the implied trust that men have in their medical practitioners to provide the information (such as loss of libido as the result of some treatments) to which men should be entitled.

Other values can be observed in varying degrees in the narratives. Hope is often regarded as a value but it is not intended to discuss this here as, in the context of the narratives, it is more appropriately discussed in the next section on purpose and meaning in life.

There is considerable overlap in values and other dimensions – which is humanly understandable. I have tried to avoid questioning the integrity of some definitions by, in some cases, attributing some statements in the narratives to a number of different spiritual dimensions. Values are demonstrably part of a person's spirituality, the aspects of a person's life that can lift them during their illness. It was occasionally observable in the narratives that negative values can have an adverse impact on a person's spirituality and health.

Purpose and meaning

The dimension of purpose and meaning in spirituality is readily observable in the men's stories. It was unclear to all the men how much longer they had to live. While this observation might be made of any person, for men with advanced prostate cancer there is certainly a cloud over their longevity. The cloud helped each man give greater focus to his aim and purpose in life.

Michael was adamant that his purpose was to improve the future for men who had advanced prostate cancer and also, and even more especially, those men who had multiple illnesses. Michael believed that men had to be given better information and more focussed medical support. They had to be encouraged to talk more readily about their illness and to take more care of themselves. His purpose was clear.

> *If I can encourage men to go to the doctor, look after themselves on a regular basis, then it has not been in vain in getting prostate cancer. Sure, it's still going to be hard on the family and everything else, but perhaps I'll have left a mark somewhere.*

Jason's similar purpose throughout much of his life was stated in these terms: *I've always wanted to do something, to change the world. And I have*. After some years of prostate cancer he still had a purpose to assist: *If I can help, and people can relate to something I've said, and they get cured, well, the world's set on fire; cancer might just be a word.* He wanted to be able contribute to the welfare of others.

Meaning in Craig's life related to his service to God. He wanted to continue doing this and continue to support his wife. Meaningfulness for Craig involved enjoying a wonderful relationship with his friends. He wanted to have better knowledge relating to his spiritual life but was becoming frustrated that he was not able to concentrate and continue to be productive in his pursuit of greater spirituality. He said, … *the only support I would like comes from my soul; with better knowledge*.

Wayne's continual service to God through his church demonstrated that meaning in life for him was to serve God through serving others. He had been doing this for many years. The basis for his purpose was, as he put it: *My faith – it's always there*.

Craig believed he had something to offer through his Christian faith and his hypnosis ability. He was cautious about how much he used this ability but he was still willing to demonstrate his purpose of helping others and serving God. Of his hypnosis he said, *It's a wonderful media to use in a lot of places*. His purpose was to use this *gift* to help others where he could.

While these aspirations were far-reaching, Ben's purpose was more modest. As he was going through periods of depression, he was more focussed on trying to help himself through his illness. He stated his purpose as *I try to ride my bike every day for exercise. I try to catch up with my friends and have a coffee; sometimes go out to breakfast – every Sunday actually with a group of about six of us*. At the same time, he was happy with his own company. The subtle mix of exercise, company and quiet personal time for himself showed his aspirations.

Stephen had great resilience and determination (purpose) not to let his illness defeat him. *I'm not going to sit around waiting to die,* he said. *I've got to find another way around it. I think that's how you redouble your efforts.* Later he spoke of wanting to keep his head *around it all*.

Alan's purpose was more implied than stated directly. He was a Christian and his purpose was to worship God. His journey had been so traumatic that often his purpose was to exist with basic comfort. His purpose in treatment was pain management.

Ken defined his purpose when he was not satisfied with the way treatment was going. His purpose was to find an answer. *There's got to be a way!* he exclaimed. When he found a way, he said, *I now just intend to keep on with the way I am going.* He had defined his purpose as having a broad spectrum of activities that related to his health. He and his wife eventually wanted to help others but friends reminded him that in discussing his illness and its treatment he was already helping others.

As mentioned above, hope is discussed in this section because it is closely related to purpose and meaning. For example, Michael's purpose was to try to change the way the co-ordination of men's multiple illnesses could be handled. It was also his hope that this would take place. In all the men's narratives, their purpose in life, and life's meaning related to their hope.

Craig's purpose was to continue to support his wife and his hope was that this could be achieved. Each man's purpose articulated above can be seen as a hope that might be fulfilled. Ben's hope was particular – he lived from day to day hoping he could ride his bicycle, have coffee with friends.

The issue is probably summarised best in Ken's statement where his purpose and hope overlapped. He wanted *to live as long as I can, as healthy as I can, with a high quality of life. Sue and I have a great life together and I want to maximise that.*

A question here is the degree to which the purpose, meaning and hope are related. The men's stories show that they are closely related. Implied hope was the expectation or the desire that each man's purpose, illustrated in the previous section, might be fulfilled. Hope also existed at a more immediate level. For example, it was Alan's purpose to reduce his level of pain and it was his hope (expectation) that his medication would achieve this. In each case, the purpose and hope were elements of connectedness – to, for example – self (Alan's reduction of pain; Ben's daily life) self and wife (Ken and Sue; Craig), other men (Michael) and service of God and other people (Wayne).

In summary, the purpose and meaning in life, as part of their spiritualty, was different for each of these men. There were those who saw themselves in the cosmos

as having a broad aim to help others. Others were more focussed on day-to-day living. It can be noted that the more pain and trauma there was, the more short-term and focussed was the man's purpose in life. This is particularly evident in Craig and Alan, the two men whose health had deteriorated more than the others.

Peace of mind, fulfilment and alleviation of suffering

Each of the men in this study exhibited to some extent outcomes of peace of mind, fulfilment and alleviation of suffering as the result of their connectedness with one or more of the four dimensions indicated in the Connectedness general theme. These outcomes are consistent with the literature reviewed in Chapter 2. It was also evident that each man's spirituality helped him realise these outcomes in different ways.

Colin, Jason and Ken used their spirituality to have a positive look at the future. Each had peace of mind because they were confident that their spirituality was helping them to cope, and they were adamant they were going to overcome their illness. Their action, including prominence of their spirituality, meant that they were not suffering. Colin used his hypnosis powers, part of his spirituality, to alleviate his suffering, particularly when he was having an injection. Ken said, *I'm calmer in myself; more placid* and *I now just intend to keep on with the way I am going*.

Craig, Wayne and Alan were more settled about their future as they could see the end of their life approaching. Craig expressed his peace of mind by indicating that his spirituality took away his *fear of death*. Wayne stated: *I know my lifespan is getting shorter and shorter … oh, I'm welcoming that fact because of what I have taken from my Christianity. I welcome the time when I can meet my Lord.*

Alan's peace of mind was expressed in this way:

> *I'm not scared of dying … I'm ready to die and any time; that doesn't worry me. I could go to bed tonight and die in my sleep and that would not worry me at all.*

Stephen suggested that his spirituality was able to help him with a peace of mind, especially when playing golf. He also made an insightful comment: *It's not just the enjoyment of playing, but it's my mental state.* There was little doubt for Stephen that he saw his spirituality as helping in his peace of mind.

Ben may represent an example of spirituality – in his case, connectedness with others – not providing a great deal of peace of mind or fulfilment. There was no evidence in his initial story that spirituality helped alleviate his suffering, although his connectedness with his former partner when she returned to assist him indicated that he had developed a greater peace of mind through her support. At the stage of his journey when he was interviewed, he had become depressed. There was no statement in his story of any sense of self-achievement. Rather, he felt *robbed* that his life was being shortened and he was disturbed about this.

Examples of self-fulfilment are evident in the stories. While Michael's mission was to assist men in the future, he was also satisfied with his own achievements during his life. One such achievement was associated with his cancer journey. He expressed his achievement in these words: *Well, I'm giving something back to the community. I'm helping people that are perhaps less fortunate than me*. This was from a man who had significant health problems in addition to his prostate cancer. Jason had a similar sense of fulfilment. *I've had a good life. I've had a good life more than most, actually.*

Outcomes of the realisation of a man's spirituality can be an important aspect of his cancer journey. Peace of mind and self-fulfilment were significantly evident in the participants' stories, while alleviation of suffering was more implied than overt in that peace of mind could normally result in alleviation of psychological suffering. The next part of this chapter draws attention to one broad concept evident in the participants' stories – holism, and what this comprised for them.

"It's the holistic approach … it's the whole package"

> *I chose God and the pawpaw leaves to lead me through.* Jason

It was Ken who made the "holistic" observation during the course of his story. When I asked him "… is (there) one single kind of spirituality that you have …?", he answered:

> *It's the holistic approach that is everything; it's diet; it's exercise; it's belief; it's meditation; it's relaxation. All those things for me are important, and when people ask me what single thing can they do to improve their situation I say I don't know of any single thing. I think all these things are vital.*

Jason gave a similar response. When I asked him "Do you find your spirituality has a role in coping with this particular problem?", Jason responded: *Yes, because it's been the whole package that has come together.*

While the terms holistic and package were used by only two of the men in the study, analysis of the information provided in the stories of all the men shows that their spirituality was holistic and influenced their lives accordingly. Ken, for example, placed great emphasis on lifestyle in that he exercised and followed a very strict diet. He connected with many people, particularly his partner, and his connectedness to a higher being was also important.

Jason indicated that his spirituality would increase *Through God, doctors, hospitals and injections, family and pawpaw leaves, I believe this will happen* and *I chose God and the pawpaw leaves to lead me through.* Jason was not being flippant when referring to the pawpaw leaves. He believed that he had to do something – to be proactive – rather than sit around just having an injection every three months. In addition to these things, he had his interest in boats that he found uplifting. He was particularly lifted by his family: *My family and grandkids are my spirituality*.

It was outlined above that Michael connected with himself, his partner, family and especially others. While he made no mention of any particular diet, he was active in his moving around to visit people in his ambassador duties, even though such activity did not constitute an exercise regime. Stephen was very holistic. He watched what he ate but the spiritual dimensions were very evident. He was physically active, involved himself in music, played golf and meditated often.

Wayne demonstrated holism in that he connected with so many people and God. His age (85) meant that he could not be as active in physical exercise as he wanted. But he was still managing to have an active lifestyle. Colin still involved himself in sport as well as his connectedness with other people and especially to God; while Craig was well-connected, especially to his partner, God and other people. While he could not be active, he maintained interest in some sports.

Ben was connected to his son (and his mother before she died), and engaged in a great deal of bike riding to ensure his physical activity. Alan had his connectedness with God and other people, the latter especially through dancing, which for him was an important physical as well as social activity.

In summary, Ken, Stephen and Jason articulated the holistic nature of their spirituality while the other men implied it through their description of their journeys.

Conclusion

In Chapter 6 I have analysed the themes discernible in the men's stories. Many of the dimensions that authors have ascribed to spirituality were evident in the stories though some were not. There was overlap among some dimensions and their prevalence varied considerably from man to man. In Chapter 7, these facets of the research are drawn together to understand more clearly what comprises spirituality for these men.

It's been a total journey. Ken

Chapter 7 – "THE WHOLE PACKAGE THAT HAS COME TOGETHER"

My spirituality has a role in helping me cope with my illness because it's been the whole package that has come together. Jason

Introduction

In the previous chapter I analysed the men's stories for themes. I concluded that, as the result of identifying what the men saw as the elements of their journey, the overriding concept was that of spirituality as being holistic, and thus manifested in many aspects of the participant's lives. This was made up of the themes and dimensions related to their medical, physical, psychological, social as well as spiritual aspects of their journey.

They all had physical experiences that resulted in suffering and some of these experiences were unique to prostate cancer. They all experienced psychological suffering at some stage of their journey and much of this was due to the nature of the illness and also closely related to their treatments. They all wanted to tell their stories because they wanted to be helpful to other people; they each had a different story to tell.

They each exhibited many of the dimensions of spirituality that were found in the literature review for this inquiry, none exhibited all dimensions. Many of the manifestations of the dimensions were quite disparate; however, there was no indication in the reviewed literature that spiritual dimensions are similar for all people. To the contrary, there was considerable indication that the dimensions, while having a broad categorisation, are varied for each person.

There was wide variance in the way the men coped through their spirituality. This confirms my generally broad assertion earlier in this inquiry that spirituality is an individual matter. However, what has emerged in this research is that the men regard

spirituality as a *holistic thing*, something consisting of many dimensions that, combined, can better assist them in coping with their illness. Their individuality demonstrated that what constituted holism was different for each one of them.

In the following, I address some dimensions and then the way in which spirituality and holism provided a frame of reference for the participants' coping. Not every episode in their journey can be equated to a specific instance of spirituality; it was a long process for them rather than many individual spiritual episodes, although there were identifying episodes at various stages of their journey. These episodes are part of a life journey overall; part of a spiritual journey which helped the men cope.

I then look at some broader issues that arise from a consideration of this holism and its application to men as they cope with their illness. These include the relationship between spiritual and psychosocial matters, the issue of what is meant by depth of spirituality and the relation this has to a sense of the sacred, and whether or not the men's spirituality did assist in alleviating their suffering.

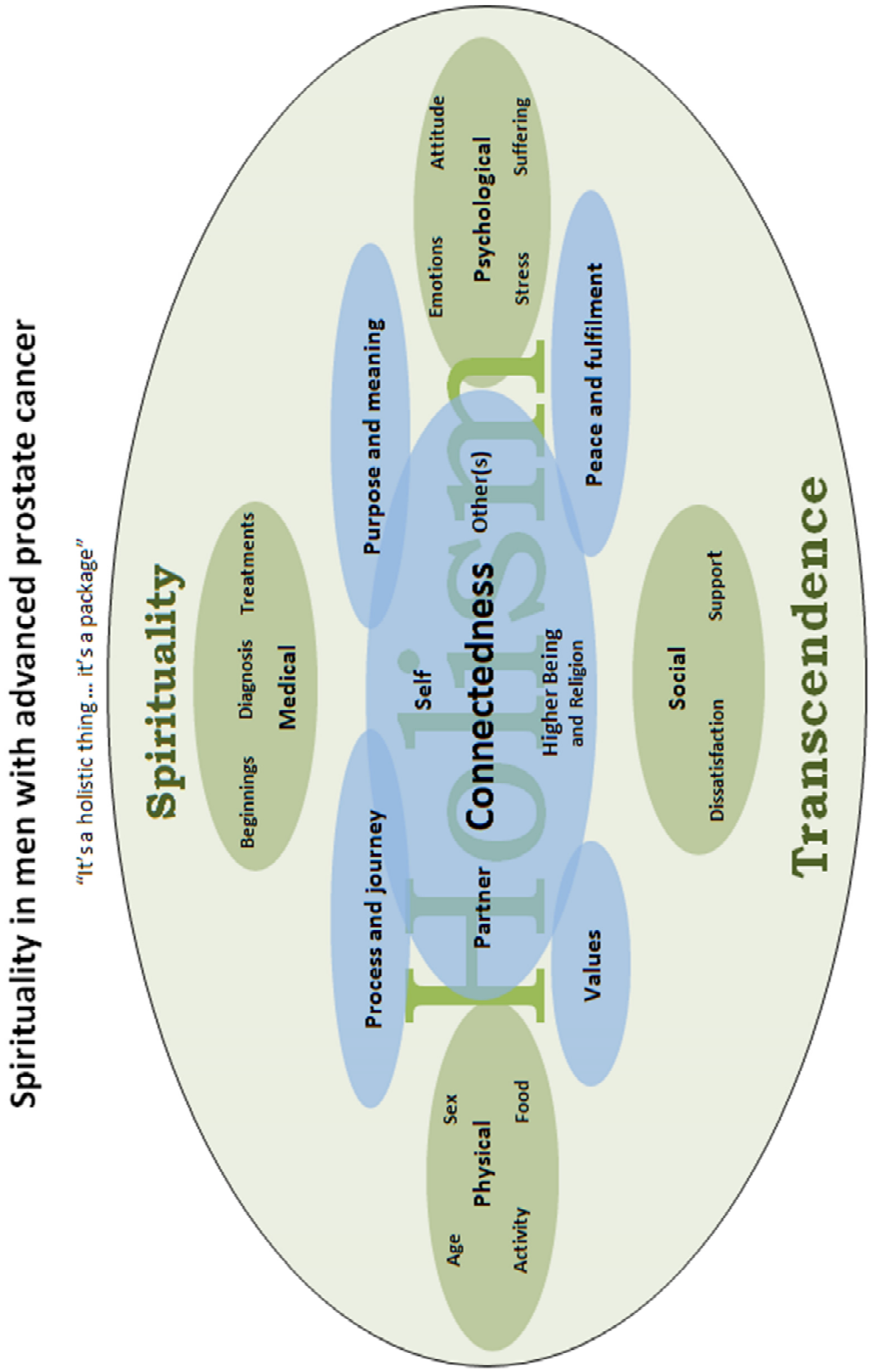
What follows draws together the many aspects of spirituality in men with this condition and seeks to understand what spirituality is for them and what role it plays in their prostate cancer journey. I seek to relate the information gathered to what was found in the literature review with the aim of placing their journey in a perspective that will help to inform others and to provide the support in this domain that will enrich the lives of men living with prostate cancer, especially those with advanced disease.

The dimensions of spirituality illustrated in the men's stories can be observed in the literature reviewed in Chapter 2 and synthesised in Conceptual Map 2.1. This map illustrated that spirituality was at the core of an individual and that its dimensions included integrative force and energy, values, process and journey, connectedness and purpose and meaning. The map also showed that these were often manifest through behaviour and that the outcomes of the presence of the dimensions included peace of mind, alleviation of suffering, and self-fulfilment. The two conceptual maps constructed in Chapter 6 as the result of the analysis of the participants' stories showed aspects of the men's journeys and their relationship to spirituality. The first

showed the less central themes of their Medical, Physical, Psychological and Social Journey (Conceptual Map 6.1) while the second showed the central theme of the Spiritual Journey and its integrated elements (Conceptual Map 6.2). The Conceptual Map that follows (7.1) brings together the holistic spiritual package in the participants as evident through the thematic analysis. The Map consists of the central theme of Connectedness, its four integrated elements of connectedness to self, partner, higher being (and religion) and other(s) and the associated dimensions of process and journey, purpose and meaning, values, and peace and fulfilment that were evident is the men as a whole. This central theme is surrounded by the four less central themes discussed in Chapter 6. Permeating the package is the concept of transcendence – the lifting up of the men through their experiences.

Conceptual Map 7.1 is consistent with description of spirituality developed from the literature review and synthesised in Conceptual Map 2.1. That spirituality is the centre of a person's being, consists of various dimensions that can be manifest both internally and externally, and that can eventually lead to an outcome of peace of mind, was evident in the literature review and in the analysis of the stories of the nine men. The difference between the maps is that 2.1 provides a view of a concept of spirituality in a global sense, while 7.1 focuses on what spirituality was for a group of individuals. The spirituality of the individuals was holistic; for both the global description and the spirituality of the men, a key element was transcendence.

Conceptual Map 7.1 – Thematic analysis: the "Holistic Package"



Spiritual dimensions and outcomes – were they evident?

Many dimensions of spirituality were evident during the journeys of the nine participants in this inquiry and it can be demonstrated that these dimensions were consistent with those evident in the Literature Review of Chapter 2 (Conceptual Map 2.1).

Spirituality was the core of the being of these men and reflected the assertions of such authors as Miner-Williams (2007), Schultz (2005) and Watson (1989). For these participants the core had dimensions that were all-embracing and became holistic for them. Central to their spirituality was their connectedness to self, partners, higher being (in most of the men) and other(s) and these dimensions were also alluded to by Highfield and Cason (1983), McEwen (2005) and Murray et al. (2007). What was seen in their stories was that the way they connected was through the dimension of values. Their values included love, hope, trust and wisdom – referred to by Hart and Waddell (2003) – as well as honesty and imagination as seen by Dossey et al., (2005). Faith was also evident in the men and this dimension is alluded to by Kaplan et al. (1994). The list is not exhaustive.

Other dimensions of the men's spirituality included their sense of purpose and direction. They had meaning and purpose in life, to varying degrees and in a variety of circumstances. In most instances it was a purpose involving connectedness with self and others, an illustration of the overlapping of many dimensions.

It was evident that the participants' spirituality also had integrative energy, a dimension that other authors have seen as part of a person's being (McSherry, 2000; Miner-Williams, 2006; Villagomeza, 2005). Spirituality, especially connectedness, seemed to be the core of each man's existence and it gave rise to energy that directed them in their life. This direction encompassed such aspects as their ability to connect with others, their pursuit of treatments that would enable them to transcend the difficulties of their daily living, and their activities that led them to a more positive approach to their illness. At the same time, it can be observed that, while the participants mostly had quite demonstrative drive, this often depended on their

physical energy levels which were related to either their age or to the point of their cancer's progression.

It was also evident that their spirituality involved a journey that was closely related to their physical journey. Burkhardt and Nagai-Jacobson (2005) suggest that a spiritual journey can be closely related to life's circumstances and this was seen in this inquiry with this particular group of men. Certainly, their life changed with the ebb and flow of their spiritual and physical circumstances. In addition, many of the men found that their life changed significantly as the result of their cancer journey and this change was directly related to their spirituality in that their search for meaning and purpose, the strengthening of their individually specific connections and the physical and psychological elements of their journey were closely integrated. A change in one aspect often resulted in change in others. Their encounter with many obstacles in the elements of their cancer journey made them more aware of their spiritual journey and the way in which their spirituality gave more meaning to the unfolding of their life journey as a whole, a contention also made by Burkhardt and Nagai-Jacobson (2005).

That spirituality can be both internal and external is evident in the participants' stories and is consistent with the views of Heelas and Woodhead (2005) and Plante and Sherman (2001). There were times when the men described their spirituality as being simply within themselves. But the concept was, naturally, more evident in their descriptions of external manifestation – the ways they showed and practised their spirituality. This could be seen in the practising of their values of love exhibited vividly in the way they connected with other people in general and a higher being in particular.

It was evident in the men's narratives that most saw religion as part of their spirituality as they engaged in communal as well as private worship and prayer. Spirituality and religion are terms that are frequently used in juxtaposition (Highfield, 2000) but not necessarily synonymous (Burkhardt, 1989). It was clear that some of the participants who acknowledged religion in their lives regarded it as an adjunct to the development of their inner being but that it was not interchangeable

with it. In some men it was quite evident that, if they did acknowledge its existence in them, their religion was a minor part of their holistic concept of spirituality.

The men in this inquiry manifested their spirituality externally through their involvement in many activities that included personal connectedness with the community with whom they identified. This included support groups, friends and church-goers as well as their partners and family and health practitioners. This internal and external manifestation was consistent with the contentions of Miner-Williams (2006).

The spirituality was also manifest through their use of meditation, a recognised dimension of spirituality (Carr & Haldane, 2003; Ho & Ho, 2007). Not all participants meditated or engaged in mindfulness in the formal sense of the words but they all reflected on their life (self-connectedness), and on their connectedness with others.

Outcomes of holistic spirituality were demonstrated by the participants through the presence of its dimensions, and the manifestations of these internally or externally. The outcomes of peace of mind, harmony, comfort and alleviation of suffering were all evident in these men, as was their self-fulfilment and achievement and a greater knowing of themselves. This finding is consistent with the contention of many authors who believe that, ultimately, spirituality leads to outcomes (Baldacchino, 2006; Miner-Williams, 2006). It was also evident that these outcomes were more prominent in some than in others. This is in keeping with the notion of the individuality of spirituality.

One final aspect of the men's journeys was that, while they exhibited general dimensions of spirituality that have been observed in other studies, there were aspects of some dimensions that were unique to prostate cancer in the way they used their spirituality to cope with their illness. Some of these unique aspects have been referred to in the thematic analysis. Overall, they relate to treatments (especially hormone therapy) and side-effects (especially erectile dysfunction). The men coped spiritually in a holistic way – that is, they saw the solution to coping in a combination of thoughts and actions that helped them transcend their illness; they did not rely on a

micro spiritual response, such as engaging in prayer or meditation for the solution to a particular problem. Heelas and Woodhead (2005) see a mind-body relationship as comprising holistic spirituality and believe it is important in maximising better health outcomes, a position support in this current study.

The holistic nature of the men's coping through their spirituality demonstrated in their stories comprises many dimensions. The absence of some dimensions in the men's narratives does not imply that they were not present in the men's lives. They might have been so focussed that they did not mention a particular dimension. From my perspective, even though my method used semi-structured interviews, I did not feel the need to ask about a holistic spirituality because this was something that only became evident during the analysis of the interviews. I used a communications technique in which I followed up key words and phrases used by the men with more searching questions. Patterson (1998) makes the valid point that holistic healthcare can only be understood in relation to an individual's perception of what constitutes holism. She also asserts that holism is individualistic and that therapies and interventions will be understood differently by different people. In the case of these men, they have stated or implied their perception of spiritual holism. It is different for each of them even though some exhibit general similarities. This is consistent with views in the relevant literature (Aldridge, 2005; Dyson, et al., 1997; Murray, et al., 2007).

The holistic demonstration of the men's coping included, for some, controlled eating, regular exercise and substantial connectedness and other dimensions. While all of these were not evident in all men in this inquiry, there was sufficient evidence to suggest that, where it existed, it did help in their ability to cope.

The next question raised is: if I contend that spirituality was holistic for these men, does this mean that controlled eating and regular exercise transcend the everyday or mundane? In an almost banal way, can the drinking of pawpaw leaf juice, part of Jason's holistic spirituality, be regarded as transcending the everyday? There are two parts to the answer of this question. Firstly, Jason was convinced through his reading that pawpaw leaf juice was helpful in the physical coping of his journey. He believed it had medicinal properties that helped reduce the physical condition of his illness.

The second part is that he believed that taking the juice involved him in doing something positive that lifted him up above, say, having a drink of water. This, together with the other aspects of his journey, contributed towards his holistic approach that helped him transcend.

This view was quite different from that expressed by Alan, who was askance at the dilution of Christian terminology to the point where an item of furniture (a stool) might be considered spiritual. But this divergence of perception about what constitutes spirituality only strengthens my view that the concept of spirituality, what helps a person to transcend the everyday to help them cope with life's vicissitudes, is divergent. Ultimately, it is difficult to argue with a person who states that a certain aspect, or aspects, in his life lift him to a higher level. If that is what he claims is his spirituality and it helps, it is important, from healthcare practitioners' perspectives, to tap into this person's perception and help him strengthen it to enable him to cope more effectively.

A final element evident in the analysis of the men's stories that confirms some of the assertions seen in the literature review was the role of transcendence in the men's spirituality. Insofar that transcendence denotes a lift above the mundane, and that the men were asked what lifted them during their journey, the notion of transcendence was very evident in this inquiry because all of them at some stage indicated what lifted them above the mundane. It was different for each man but it was evident in each. This confirms contentions in the literature review that transcendence is an overarching component of spirituality (Albaugh, 2003; Sinnott, 2001; Tanyi, 2002) and that it is associated with lifting above the mundane (Fowler, 1980; Gridley, 2009).

Spiritual – or psychosocial?

Reference has been made to the centrality of connectedness in the men's stories with specific instances of connectedness with people. Connectedness can be regarded as a psychosocial construct. For example, if one person is connected to another person on a straightforward, everyday basis the connectedness might be regarded as being psychosocial. However, the connectedness can become spiritual if the relationship

lifts the one person above the everyday to the extent that they are inspired by the other person. Another way of putting it is to suggest that the connectedness is one of a number of elements that enables transcendence in an ill person, an observation made by most of the participants in this inquiry and consistent with the views of a number of authors (Highfield, 2000; Rumbold, 2007; Watson, 1989). A similar situation can apply to connectedness with "other". A person might listen to a piece of music which is "present" but means or does nothing for the person. An example of this is the "on-hold" music played while a caller waits for a person to respond to a telephone call. If, however, a piece of music inspires the person, lifts them up away from the everyday, that music can be spiritual for that person. Lack of connectedness, however, can lead to loneliness and stress. This was evident in the stories of four of the men.

There has been debate in literature on the nature of spirituality, and, indeed, whether it exists or whether we need it. Salandar (2006) draws attention to what he perceives as a lack of a theoretical basis for spirituality. He comments that there is so much diversity of views as to what it constitutes, it might be appropriate to abandon the concept altogether. He specifically questions whether existentialism is part of spirituality or just another psychosocial construct. He also questions whether the general applicability of a fuzzily defined and conceptualised spirituality can be applied equally to religious middle-class Americans as to French middle-class people. Salandar suggests it would be more appropriate to use the terms religious and existential as two distinct entities rather than use a poorly defined concept of spirituality. Breitbart (2007), in response, acknowledges the importance of existential issues in that they deal with examination of our existence. He asserts:

> Acknowledging that we are grounded in the human condition and yearn to seek what lies beyond our imitations is where the existential and the spiritual perhaps meet. (p. 106)

The problem with Salander's view is that he seems to be criticising a narrow, Christian concept of spirituality even though referring to a view that is broad and fuzzy.

Sagan (2006) makes the observation that spirituality is the "search each human being undertakes to find a sense of peace in one's relationship to the universe" (p. 150). This is a profound observation. It could be true in the loftier situation in each of the men interviewed in this research. In my inquiry, each of the men was trying to find a sense of peace in his universe, so, in a broad sense, the statement is sustainable. However, such exalted sentiments need to be brought down to earth with more fundamental considerations. It is hard for men facing death, sooner or later, and in considerable pain, to think so broadly. The narratives showed that men frequently struggled with their day-to-day experiences, although many of them were able to transcend through their various kinds of connectedness. While their spirituality often came at a quite fundamental level, it can be observed that it is some of life's normally mundane activities that can help men arise above the mundane and seek their peace during their illness journey. It was Burkhardt et al. (2005) who propounded that it is possible to experience spirituality in the mundane as well as the profound. Almost all of the men in this study found peace in their universe through a number of different activities. Food, for example, by itself might not lead to transcendence but, combined with other aspects of a man's life, it may contribute to a holistic spirituality. This was the direct belief of at least two participants. They directly stated that a combination of activities, thoughts and processes helped them transcend their illness.

The participants demonstrate that not all dimensions of spirituality as found in the literature are present in everyone, nor have all of the aspects of their lives that inspire and lift them been necessarily stated in their narratives. In relating these stories the men, through having some time to think about their story before the interview took place, spoke of the things that were most important to them.

Another issue in these stories was that, in addition to the observation of the relationship between the process of their physical and spiritual journeys, the men's spirituality fluctuated from time to time during their cancer journey. These times were generally associated with fluctuations in their treatment and their degree of suffering.

The men were mixed in their reactions to whether their spirituality increased or decreased overall. Some wanted their spirituality to increase. Most stated that it had increased over time and one thought that his spirituality generally had stayed much the same. This raises the question: what is meant by an increase of spirituality? What does it constitute? How is it manifest? What is the difference, if any, between depth and intensity? How did men see their spiritual depth or intensity?

What is spiritual depth?

None of the men's stories provided any real insight into what is meant by spiritual depth, and this reflects my findings in the literature review. How can depth or intensity of spirituality be assessed to determine how the level of a man's spirituality might help him cope? While the descriptive nature of language used, frequency of mentioning some concepts, tone of voice and visual expression can play an important part in recognising the signals, it is important to determine that the concept of spirituality is well described first. Care must also be taken to ensure there is no confusion in meanings between religiosity and spirituality. It would not necessarily convey any understanding of a person's spiritual depth to ask them how often they go to church and then to assume that they have greater depth if they go to church five times a week instead of only once a week.

It is clear that the men in this study saw their spirituality as comprising many dimensions. Given that much of the literature speaks of many dimensions in a wide variety of contexts, what makes this spirituality so special for men with advanced prostate cancer? Is it different to the spirituality of a woman with breast cancer? There must be an assumption that every person's cancer journey (and illness) and every person's spiritual journey is different because it is contended that spirituality is different for everyone. Advanced prostate cancer has a different set of medical aspects than prostate cancer in earlier stages. The treatments are often different, as are side-effects for individuals. The participants had different coping mechanisms and approaches to their holistic spirituality. The stories relating to their stresses and spirituality demonstrate the intersection between the uniqueness of the individual and some of the common consequences of having advanced prostate cancer.

Transcendence – a "lift"

The relationship between spirituality and transcendence is an important issue. While it is acknowledged in the literature that transcendence is at the core of spirituality, the question must be asked how high does a lift need to be to raise it above a psychosocial construct? In speaking of Indian spirituality, Wig (1999) states:

> The central theme in spiritual approach to life is that there is an essential mystery at the heart of all things. This mystery cannot be understood but has to be experienced. From the experience of this mystery we get this urge for 'transcendence', which is the essential feature of all spiritual approaches. (p. 96)

Wig's contention is that there is a danger in assuming ethno-centricity in our attempts to understand spirituality in patients. I would go further and suggest that there is a danger in making any assumption about any person's spirituality. It is vital that healthcare practitioners seek out a person's spirituality through encouraging the person to talk about their life. It is probable that the person will respond to a question about what lifts them, takes them to a higher plane, during their illness.

However, Wig raises an important issue. When he talks about mystery, how comprehensible is this to an everyday person? In terms of this research, what is the mystery at the heart of the spirituality of men in this study? The men experience life, but is it a mystery which they are seeking to explain? It would be possible to postulate about the mystery in the men in this research, but, essentially, their transcendence is more pragmatic. Two or three of the men were searching for (and had found) something more substantial or mysterious in their life but, at the same time, they, as well as the others, were trying to exist in the best way they could in a very practical, day-to-day sense. Spirituality for them was not so much a mystery as something that lifted them above the ordinary; something that was sacred for them. Through their stories it might be inferred that this lift may have been higher in some than others, but it was still rooted in the reality and, as Burkhardt et al. put it, the sometimes mundane aspects of their lives (2005). This pragmatic element of spirituality also needs to be recognised in the work of healthcare practitioners.

Another question to emerge in this study is about the relationship between the terms spiritual, divine, transcendence and sacred. Are they interchangeable terms or do the last three terms just add to the meaning of spiritual? This issue bears further consideration.

Does holistic spirituality help in coping with stress?

It has been observed that the men in this inquiry experienced stress and many fluctuations in emotions and this is in keeping with findings in the literature review that there are many stress points in a man's prostate cancer journey (Sargeant, 2006) and that many men return to a more normal state (National Seniors Foundation, 2006). Emotions were usually associated with high and low points of the men's physical journey. One man, for example, had an emotional high when his PSA level became low. Another man experienced an emotional low as the result of one specific incident, and he believed this affected his physical health through a higher PSA level. Another factor in this consideration is the length of time men can have prostate cancer and, especially, the age at which he is diagnosed (Baade, et al., 2005a). In this study, dealing only with advanced prostate cancer, it was evident that a long time-frame for its development can give men opportunity for a greater call on their spirituality.

A question arises then as to how, if at all, does holistic spirituality help men in coping with this stress, and over a journey of some years, and where there might not be any imminent threat of death? Does holistic spirituality assist in their resilience?

The men in this study demonstrated that they used a holistic approach to their lives to cope. This seemed to be on two levels. The first was using their spirituality to cope in immediate situations, and the second was that they used their spirituality to cope with stress over a long period.

Immediate situations

Four of the men, for example, had specific, immediate stressful issues with which to cope. Wayne reflected that at the times he had hot flushes, he recognised that *the*

Lord was there to help – every moment of every day. Colin indicated that his hypnosis ability, part of his spirituality, was useful each time he went to have his three-monthly injection. He could *deaden* his *side* through his hypnosis. Ben and Michael both had an immediate connectedness to their friends when they were first diagnosed. Both were astonished by their diagnosis and immediately sought to connect with their friends. This was more than just a psychosocial connection because it lifted them up to try to transcend their everyday world which had been shattered.

While it is not possible to generalise on all issues from the stories of this small sample of men, the experiences of some of them highlight a potential problem for others. Healthcare practitioners need to be aware, for example, that sexuality can be a problem of considerable immediacy for men with this illness. Erectile dysfunction is recognised as a physical problem but commensurate with this is a psychological problem where the difficulty can impinge on a man's self-esteem and also on an intimate relationship with a partner. This, in turn, can lead to a breakdown in relationships and cause a secondary stress, well beyond the inability to function sexually. These findings reaffirm statements made in a number of relevant publications (Australian Cancer Network Management of Metastatic Prostate Cancer Working Party, 2010; Chambers, et al., 2008; National Breast Cancer Centre and the National Cancer Control Initiative, 2003).

Another immediate issue is dissatisfaction. There are many reasons that men can have stress due to dissatisfaction and the participants in this inquiry expressed some, such as dissatisfaction with the level of information they received. This was reflected in a more general cancer context in some of the literature (National Breast Cancer Centre and the National Cancer Control Initiative, 2003; Oxlad, et al., 2008). Suffering and dissatisfaction leads to stress that can result in a negative healing environment. Even if some of the narratives contained inaccurate perceptions of the way events were handled by people around them, it was those perceptions that led to the patients' stress. In some instances, the dissatisfaction was immediate. Perhaps more can be done for more accurate and helpful information to be provided to patients by healthcare practitioners and administrators to alleviate the difficulties experienced both for immediate and longer-term situations.

Longer-term

For the men in this study, the use of their spirituality in stress reduction was greater in a holistic sense in longer-term coping than was the case with immediate difficulties. This observation is consistent with the views seen in literature (Moritz, et al., 2007; van Leeuwen, et al., 2007) Some saw controlled or specialised food and diet as important aspects of their journey over time. Some saw regular exercise and activity as important. Some were inspired by religious experiences and some engaged in regular meditation, reflection and prayer. All connected regularly with someone or something. This was not only a psychosocial connection; it was spiritual because it lifted them above the stress of their everyday life in which prostate cancer was present. Even though, in many cases, their stress was reduced at various times during their journey, they still practised the dimensions of their spirituality to provide continual self-help.

Diversity

Another observation of the holistic nature of spirituality that helped the men cope with their stress is that the spirituality is diverse, a position taken by Canda and Furman (2010) with respect to a wider community and also alluded to by Rumbold (2004). In the current study, each person's background was different. Each man brought different aspects of the dimensions regarded as being part of spirituality. Six of the men had a Christian orientation in varying degrees of faith and commitment, yet their spirituality was different. The whole concept of diversity has important implications for healthcare practitioners. At most, it can be said that people with a Christian basis for their spirituality *might* have some broad elements in common. Christian spirituality can be as different as the individuals who practise Christianity. This premise, together with the recognition that many people in society are not Christian, suggests it is vital that practitioners involved with men in this condition make no assumptions about a man's spiritualty. Practitioners have a responsibility to encourage men to express their spirituality for themselves.

Resilience

The men in this inquiry showed considerable resilience in the way they coped with their stress and much of this was related to their spirituality. Attention was drawn in the literature review to the role that spirituality might have in the fostering of

resilience in the face of stress (Hassed, 2005; Moritz, et al., 2007). The participants were involved in physical activities either through exercise or other practical ways. Above all, they were active in their connectedness in its broad understanding. They were lifted especially by their partner, their families, their friends and their god. They proactively sought solutions to their difficulties. None of the men was prepared to sit by and await more difficult times. Over the period of their journey they demonstrated their resilience by moving up after their down. "Up" in this instance was the lifting enabled by their spirituality.

Holism and inductive reasoning

It was stated in Chapter 3 that I would use a qualitative research paradigm and an inductive process to enable the individual realities of the men's experiences to be reviewed and eventually understood collectively in a broader context. The men's life experiences were real. I have been able to use inductive reasoning to extrapolate from their stories their concept of holism in the use of their spirituality to lift them during their journey. Their individual spiritualities were diverse but this diversity enables their spirituality to be seen in a holistic way and in the broad context of their universe.

Conclusion

In Chapter 7 I have drawn together the essential elements of the analysis of Chapter 6 with focus on the holistic nature of the men's spirituality and with reference to the literature reviewed in Chapter 2. The men saw their spirituality as a complete entity that embraced medical, physical, psychological and social aspects of their life journey, and that integrated frequently with their transcended inner being to lift them above their everyday difficulties and help them cope with their life's circumstances.

In Chapter 8, Phase 5 of the research process, I answer the questions asked at the beginning of this inquiry, make recommendations, with implied policy suggestions, that it is anticipated will enable healthcare practitioners and carers help men in this situation, and draw attention to some possible future research.

Chapter 8 – CONCLUSIONS AND RECOMMENDATIONS

Outcomes of this research

It was stated at the beginning of this study that its aim was to explore the spirituality of men with advanced prostate cancer, and to discover the role spirituality might have in these men as they face the challenges associated with living with their disease. It is not possible to generalise on the nature of spirituality from analysing the narratives of just nine men who have advanced prostate cancer. However, the differences in their personal spirituality can be seen as a portent of the personal differences that might exist in a wider sample of men, even if they have a similar spiritual basis such as Christianity.

In relation to the research question about how men with advanced prostate cancer describe their personal spirituality, it was seen that the men studied described their personal spirituality either directly or indirectly as holistic and this consisted of many dimensions. The most dominant of these was connectedness. Ultimately, for the most part, their spirituality lifted them away from the difficulties of their illness; it helped them transcend; it helped them to find what to them was sacred.

The second question sought to understand the challenges and suffering experienced by men with advanced prostate cancer during their journey and it was evident that the men faced many challenges. Physically, they were challenged by the sometimes extreme nature of the diagnosis, symptoms, treatments and side-effects of advanced prostate cancer. The physical challenges sometimes led to such psychological challenges as suffering, emotional fluctuations, achieving a positive attitude and increasing self-esteem. This, in turn, sometimes led to spiritual challenges relating to the development of their inner being and transcendence to rise above their illness.

Another question this inquiry sought to answer was whether or not a man's call on his spirituality assists his well-being as he faces the challenges and suffering during his journey. It can be asserted as the result of their stories that, in their own perception, the men were helped by their spirituality. To what extent this perception was real in medical terms was not researched but might be useful to research in the future.

The last question sought to determine if there were common aspects of spirituality in men with advanced prostate cancer, even though they might have different life experiences. There were many common aspects in the spirituality of the men studied. These were outlined in the analysis chapters with the most significant of these being connectedness. However, even though connectedness and dimensions were broadly common, each man showed that there were still significant differences between them in relation to these two elements of their spirituality.

In addition to the answers to the research questions provided above, one important finding of this inquiry has been that there is a distinct relationship between the cancer journey and the spiritual journey. With knowledge of this relationship in the nine men studied, it should be useful for healthcare practitioners to be aware of the value in helping men to alleviate their suffering, and lead them towards a peace of mind through strengthening the spiritual dimensions that may be evident in their lives. It is hoped that the quality of the information that has been discovered will provide insight into the understanding of how a man's personal spirituality might act in his life in a particular set of circumstances.

Limitations of this research

It is emphasised that the description of men's spirituality in this research has not necessarily provided generalised insight into all men who experience advanced prostate cancer. Some limitations applying to this research have been mentioned earlier and have centred on the nature of the cohort of participants.

The men interviewed all volunteered to talk about their experience. This might imply that the men acknowledged they had spirituality. There is no way of telling why some men did not volunteer. Was it because they did not think they had spirituality?

Was it because, notwithstanding explanations of the broad nature of spirituality in promotional material, they confused spirituality with religion and simply did not regard themselves as religious? Was it because they did not want to talk about something so personal as spirituality, or the illness of prostate cancer? Alternatively, did the participants volunteer because they had found some help through their own spirituality?

There were other limitations. Despite my efforts, which included specifically targeted promotion and community liaison, no eligible men in rural or remote areas volunteered to participate in the research. No man volunteered who was of non-Caucasian ethnic origin, and the participants were either non-religious or had a Christian-based spirituality. There were no participants who had fundamentally different religious or spiritual orientations, for example, indigenous Australians, Buddhists, Hindus, Taoists or Muslims. Exploring the spirituality of men with quite different origins, cultural and religious backgrounds, and geographical circumstances, might provide greater insight into the breadth of spirituality that is evident in men with advanced prostate cancer. As it is, my research provides a broad framework that will allow the men themselves, and their health practitioners, to become more aware of some different aspects of spirituality.

Significance, future research and recommendations

This inquiry has drawn attention to some important issues in the way men with advanced prostate cancer cope during their journey. It has some important outcomes, and has inevitably raised some questions for future research. The most important outcomes were expressed above in the answers to the questions this study addressed. There were other outcomes and these are discussed in the following section, together with some recommendations for consideration.

Benefits to the participants

An inquiry such as this is primarily designed to contribute to an understanding of the way men may benefit from their own spirituality. One co-benefit of the study was the way in which the participants benefited immediately from their involvement. While

this study did not use formal narrative therapy (Botella & Herrero, 2000; Shapiro & Ross, 2002), literature does suggest that the telling of a story can provide a person with some insights into their own life and have some therapeutic value (Pennebaker & Seagal, 1999). Insofar that I, as the researcher, helped to provide an opportunity to the participant to relate his story and reflect on his life, there was some benefit to the participant through the interview and review process. An informal questioning of seven of the participants at the end of my research (some five months after the interviews) found that each of the men believed they had benefitted from the telling of their story. (Unfortunately, one had passed away, and another was unavailable.) They used descriptions such as, "It was helpful to talk to someone who understands"; "It helped to bring it out in the open. I had never talked to anyone about it before"; "I was able to clarify things for myself"; and, simply, "I felt a lot better". This is an important outcome because it strengthens the view of qualitative researchers using narrative method that it is not just the benefit that accrues to the wider community as the result of an interview and subsequent analysis and reporting, but that the participant also receives immediate benefit.

At the same time, in order for men to talk about their spirituality, there is a need for practitioners who are skilled in eliciting their story from men in this condition, both for their immediate benefit through telling the story and for longer-term benefit through identifying issues that need to be addressed. ***I recommend that training programs be established that a) help men with (advanced) prostate cancer realise more fully the value of their own spirituality which can assist them during their cancer journey; and b) that such training programs be conducted by men with (advanced) prostate cancer who themselves are trained to offer such peer support.*** Peer support has been recognised as important to the men in this study and I could anticipate even greater significance of spirituality in a man's life if its value were more focussed.

Benefits to healthcare practitioners

The availability of information arising from this research could provide healthcare practitioners with a greater insight into the role spirituality might have in men with this advanced illness. It could also provide the basis for an education and training program that will help them develop the skills to use these insights. D'Souza (2007)

advocates that healthcare practitioners should be required to learn how spirituality and culture can help influence a patient's needs and recovery. It is unclear whether D'Souza is referring only to ethnic culture or to even more broadly based social culture. While this study did not encompass ethnic culture, there was a small yet significant diversity of social cultures amongst the participants. D'Souza's recommendation still applies and should be recognised if a training program were to be developed.

How can spirituality be fostered in a medical setting? This was a question arising out of my research but was also originally raised by the National Cancer Institute (n.d.-b). None of the men in this inquiry indicated that healthcare practitioners made any allusion to spirituality in their regular consultations. However, could their journey have been less stressful if there were some consideration of spirituality in any of the medical settings in which they found themselves? While the Institute's question was originally designed for cancer research generally, the results of my inquiry suggest that they are applicable to advanced prostate cancer.

From a healthcare perspective, practitioners might consider what the "holistic package" is for the person under their care and work towards reinforcing this rather than use some predetermined concept. This inquiry provides a broad map of spiritual holism that might be used as a frame of reference in working with men in this condition. It could provide a starting point for care. ***I recommend that a broad concept of spirituality be included in training programs for all healthcare practitioners (where they are currently not included), so they may be able to respond immediately to men (and women) who raise spiritually related matters during the course of their consultations and discussions.*** Such education should take place during initial training programs and also be available as continuing development programs. It would not be designed to be comprehensive but should be sufficient to enable practitioners to respond in an informed way as a precursor to follow-up with more specialised practitioners such as social workers, counsellors and pastoral carers.

Another issue that arises from this research is that men with the potential for this condition might need to be more conscious of discussing the possibilities of prostate

cancer with their healthcare practitioner when they reach the age where this illness is more prevalent. Practitioners need to be aware of the reluctance of some men to talk about the issue and the need for all men to receive comprehensive information about the condition and their specific circumstances.

The combination of researching an area not already researched, together with the publication of findings in refereed journals and other manuscripts, and the possible development of training materials based on this research, should enable a range of benefits to accrue to various sectors of the community. In addition to these possibilities, ***I recommend that such organisations as the Prostate Cancer Foundation of Australia and the State and federal Cancer Councils publish a brochure or leaflet that outlines the benefit of holistic-based spirituality with a focus on the importance of Connectedness to men in these circumstances.***

What is spirituality in the partner of men with advanced prostate cancer?

One important finding has been the significance of the connectedness men have with their partners. Partners were of immense strength to the men during their journey. Because they were so important, ***I recommend that research be carried out into the way in which spirituality in partners can be used or developed to strengthen further their men partners who have cancer, and receive help for themselves under very stressful circumstances.*** Such a study might help the partners to understand the potential hurt that may come through the death of their partner with prostate cancer.

What is spirituality in men of different cultures?

The extent to which spirituality is different in men with prostate cancer who have different ethnic cultural backgrounds cannot be assumed as the result of this study. It is emphasised that this study involved men who were Anglo-Saxon and lived in urban environments. ***I recommend that research be undertaken that focusses on the value of spirituality during the journey of men from different cultural and geographical backgrounds.*** A challenge to carry out this research would be to encourage such men to volunteer to participate.

How does spirituality develop over time in men with advanced prostate cancer?

I researched men who were at a particular point in their cancer journey. In their interviews the men reflected on their past. It was not possible to predict whether and how a man's spirituality might change as he went further into his journey. It would be useful to monitor a man's spirituality at various points along his journey. ***I recommend that longitudinal case study research is carried out that could provide greater insight into the way spirituality develops over the continuum of the journey, especially towards its end.***

Spiritual depth and intensity. What is it?

Attention has been drawn to the lack of clarity in understanding what is meant by spiritual depth. There is a need for further research on depth of spirituality and to develop criteria for estimating depth. While the men in this study generally progressed in that spirituality became more helpful to them, their manifestation of spirituality fluctuated from time to time. One essential question is what understanding of spirituality could be used to measure its progress. The diverse nature of the results of this study draws attention to its breadth of inclusions. How can it be possible to equate connectedness with a higher being, important in one person, with connectedness to a partner, important to another person? Perhaps there is substance in the contention that a theoretical basis needs to be developed for the concept of spirituality (Salandar, 2006).

Notwithstanding the difficulties in understanding spirituality, it could be beneficial to explore whether greater development of spirituality in some people might be more helpful to men themselves and to healthcare practitioners if deeper spirituality could be seen to have a positive effect on the way men cope at various times in their illness. Could depth of spirituality be explored more meaningfully for greater benefit to other men with advanced prostate cancer and to those who care for them? ***I recommend that a theoretical basis for spirituality be developed that includes reference to what might be understood by spiritual depth and intensity.***

Conclusion

This research has explored the nature of spirituality in men with advanced prostate cancer. It has provided insight into the way a group of nine men coped using this aspect of their life during their illness. The findings have implications for partners, family members and healthcare practitioners. There is little doubt that spirituality does play an important role in these men. It might also play a similar role in other men with the same illness. This concluding chapter has identified a number of implications arising from the study, raised questions for future research and made recommendations for further consideration. The men in the study were committed to helping others in a similar situation to theirs. It is anticipated that the recounting of their experiences will contribute to a greater success in the coping of other men with this illness.

The stories told by the participants in this inquiry demonstrate that they were on a journey that commenced before diagnosis and continued throughout the rest of their life. The suffering began with the suspicion of something being wrong with their health and was confirmed at diagnosis; it then ebbed and flowed in rhythm with the man's illness, his treatment, his response to treatment, his disease progression, as well as his own capacity to manage using his spirituality which was normally strong but sometimes faltered. The spiritual strength seemed to build through a combination of personal effort (in the face of adversity) and support from those close to him (especially his female partner, if he had one). The presence, or absence, of a supportive partner seems very important in this journey. The spiritual journey is individual, often shaky, and evades easy characterisation. It is a holistic thing and encompasses both suffering and survival. It is at times focussed on self-preservation but, for some, can become an outward journey, where the inner self is nurtured by an attempt to help others. The men's experiences draw attention to the need for holistic considerations for greater holistic human well-being.

REFERENCES

Abma, T. A., Nierse, C. J., & Widdershoven, G. A. M. (2009). Patients as partners in responsive research: Methodological notions for collaborations in mixed research teams. *Qualitative Health Research, 19*(3), 401-415.

Adegbola, M. (2006). Spirituality and quality of life in chronic illness. *Journal of Theory Construction & Testing, 10*(2), 42-46.

Adler, N. E., & Page, A. E. K. (2008). Cancer care for the whole patient. Washington D.C.: National Academies Press.

Albaugh, J. A. (2003). Spirituality and life-threatening illness: A phenomenologic study. *Oncology Nursing Forum, 30*(4), 593-598.

Aldridge, D. (1993). Is there evidence for spiritual healing? *Advances, 9*(4), 4-21.

Aldridge, D. (2005). Spirituality and medicine: Complementary perspectives. *Spirituality and Health International, 6*(2), 71-80.

Amenta, M. (1986). Spiritual concerns. In M. Amenta & N. L. Bohnet (Eds.), *Nursing care of the terminally ill* (pp. 115-155). Boston: Little, Brown and Company.

American Psychological Association. (2011). Post Traumatic Growth Inventory Retrieved January 6, 2011, from http://cust-cf.apa.org/ptgi/

Ando, M., Morita, T., Okamoto, T., & Ninosaka, Y. (2008). One-week short-term life review interview can improve spiritual well-being of terminally ill cancer patients. *Psycho-Oncology, 17*(9), 885-890.

Angen, M. J. (2000). Evaluating interpretive inquiry: Reviewing the validity debate and opening the dialogue. *Qualitative Health Research, 10*(3), 378-395.

Anonymous. (n.d.). *Aboriginal Indigenous spirituality and beliefs* Retrieved August 25, 2009, from http://www.creativespirits.info/aboriginalculture/spirituality/

Appleton, J. V., & King, L. (1997). Constructivism: A naturalistic methodology for nursing inquiry. *Advanced Nursing Science, 20*(2), 13-22.

Arendell, T. (1997). Reflections on the researcher-researched relationship: A woman interviewing men. *Qualitative Sociology, 20*(3), 341-368.

Arles, N. (2004). Spirituality and culture in the practice of pastoral care and counselling. In J. Foskett & E. Lartey (Eds.), *Spirituality and culture in pastoral care and counselling* (pp. 77-90). Cardiff: Cardiff Academic Press.

Assimakopoulos, K., Karaivazoglou, K., Ifanti, A. A., Gerolymos, M. K., Kalofonos, H. P., & Iconomou, G. (2009). Religiosity and its relation to quality of life in Christian Orthodox cancer patients undergoing chemotherapy. *Psycho-Oncology, 18*(3), 284-289.

Atkinson, P., & Delamont, S. (2005). Analytic perspectives. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (3rd ed., pp. 821-840). California: SAGE Publications, Inc.

Australian Cancer Network Management of Metastatic Prostate Cancer Working Party. (2010). *Clinical practice guidelines for the management of locally advanced and metastatic prostate cancer.* Sydney: Cancer Council Australia and Australian Cancer Network.

Australian Institute of Health and Welfare. (2007). *Cancer in Australia: An overview, 2006*. Canberra: Australian Institute of Health and Welfare (AIHW).

Australian Institute of Health and Welfare & Australasian Association of Cancer Registries. (2008). *Cancer in Australia: an overview 2008*. Canberra: Australian Institute of Health and Welfare.

Averill, J. R. (1998). Spirituality: from the mundane to the meaningful – and back. *Journal of Theoretical and Philosophical Psychology, 18*(2), 101-126.

Baade, P. D., Steginga, S. K., & Aitken, J. F. (2005b). *Current status of prostate cancer in Queensland: 1982 to 2002.* Brisbane: Viertel Centre for Research in Cancer Control, Queensland Cancer Fund.

Baade, P. D., Steginga, S. K., Pinnock, C. B., & Aitken, J. F. (2005a). Communicating prostate cancer risk: What should we be telling our patients? *The Medical Journal of Australia, 182*(9), 472-475.

Baer, R. A. (2003). Mindfulness training as a clinical intervention: A conceptual and empirical review. *Clinical Psychology: Science and Practice, 10*(2), 125-143.

Baldacchino, D. R. (2006). Nursing competencies for spiritual care. *Journal of Clinical Nursing, 15*(7), 885-896.

Baldacchino, D. R. (2008). Spiritual care: Is it the nurse's role? *Spirituality and Health International, 9*, 270-284.

Barnhart, R. K. (1988). *Barnhart Dictionary of Etymology*. [Bronx, N.Y]: H.W. Wilson Company.

Bassett, R. L., Thrower, J., Barclay, J., Powers, C., Smith, A., Tindall, M., et al. (2005). One effort to measure implicit attitudes toward spirituality and religion. *Journal of Psychology and Christianity, 24*(3), 210-218.

Bekoff, M. (2001). The evolution of animal play, emotions, and social morality: On science, theology, spirituality, personhood, and love. *Zygon, 36*(4), 615-655.

Bhattacharya, S. (n.d.). An interview with sitar maestro Pandit Ravi Shankar Retrieved January 10, 2009, from http://www.lifepositive.com/Mind/arts/music/ravishankar.asp

Bishop, S. R., Lau, M., Shapiro, S., Carlson, L., Anderson, N. D., Carmody, J., et al. (2004). Mindfulness: A proposed operational definition. *Clinical Psychology: Science and Practice, 11*(3), 230-241.

Blignault, I., & Ritchie, J. (2009). Revealing the wood *and* the trees: reporting qualitative research. *Health Promotion Journal of Australia, 20*(2), 140-145.

Bloom, J. R., Petersen, D. M., & Kang, S. H. (2007). Multi-dimensional quality of life among long-term (5+ years) adult cancer survivors. *Psycho-Oncology, 16*(8), 691-706.

Blumer, H. (1969). *Symbolic interactionism: Purpose and method*. Englewood Cliffs, NJ.: Prentice-Hall, Inc.

Bold, C. (2012). *Using narrative research*. Thousand Oaks: Sage.

Bond, K., Ospina, M. B., Hooton, N., Bialy, L., Dryden, D. M., Shannahoff-Khalsa, D., et al. (2009). Defining a complex intervention: The development of demarcation criteria for "meditation". *Psychology of Religion and Spirituality, 1*(2), 129-137.

Bonhomme, J. J. E. (2005). Editorial comment: Men interviewing men about illness and health. *The Journal of Men's Health & Gender, 2*(2), 261-262.

Botella, L., & Herrero, O. (2000). A relational constructivist approach to narrative therapy. *European Journal of Psychotherapy & Counselling, 3*(3), 407-418.

Bowie, J. V., Sydnor, D., Granot, M., & Pargament, K. I. (2004). Spirituality and coping among survivors of prostate cancer. *Journal of Psychosocial Oncology, 22*(2), 41-56.

Boyes, A. (2009). Issues for cancer surviors in Australia. *Cancer Forum, 33*(3).

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Psychology, 3*, 77-101.

Brazier, D. (2002). Commentary on Spiritual care and psychiatric treatment: an introduction (Culliford). *Advances in Psychiatric Treatment, 8*, 249-261.

Breitbart, W. (2007). Who needs the concept of spirituality? Human beings seem to! *Palliative & Supportive Care, 5*(2), 105-106.

Brelsford, G. M., Marinelli, S., Ciarrochi, J. W., & Dy-Liacco, G. S. (2009). Generativity and spiritual disclosure in close relationships. *Psychology of Religion and Spirituality, 1*(3), 150-161.

Brutz, J. (2011). Redefining hope in terminal illness. Retrieved July 27, 2011, from http://ezinearticles.com/?Redefining-Hope-in-Terminal-Illness&id=4777697

Burkhardt, M. A. (1989). Spirituality: An analysis of the concept. *Holistic Nursing Practice, 3*(3), 69-77.

Burkhardt, M. A., & Nagai-Jacobson, M. G. (2005). Spirituality and health. In B. M. Dossey, L. Keegan & C. E. Guzzetta (Eds.), *Holistic nursing: A handbook for practice* (4th ed.). Sudbury, Mass.: Jones & Bartlett Publishers, Inc.

Burt, J., Caelli, K., Moore, K., & Anderson, M. (2005). Radical prostatectomy: Men's experiences and postoperative needs. *Journal of Clinical Nursing, 14*, 883-890.

Burton, M., & Watson, M. (1988). *Counselling people with cancer*. England: John Wiley & Sons Ltd.

Burton, R. (2003). Spiritual pain: A brief overview and an initial response within the Christian tradition. *Journal of Pastoral Care and Counseling, 57*, 437-446.

Büssing, A., Ostermann, T., & Matthiessen, P. F. (2007). Adaptive coping and spirituality as a resource in cancer patients. *Breast Care, 2*, 195-202.

Cancer Council Australia. (2009). *Advanced prostate cancer: A guide for men and their families*. Sydney: Australia Cancer Network and Australian Prostate Cancer Collaboration.

Cancer Council Queensland. (2007). The early detection of prostate cancer in general practice: supporting patient choice. Retrieved November 10, 2009, from www.prostate.org.au

Cancer Council Queensland. (2008). Finding prostate cancer early; Community Speakers Program. Brisbane: Cancer Council Queensland.

Cancer Council Queensland. (n.d.). Fact sheet: prostate cancer Retrieved October 27, 2009, from http://www.cancerqld.org.au.titan.imagin8.com/icms_docs/54030_Prostate_cancer.pdf

Canda, E. R., & Furman, L. D. (2010). *Spiritual diversity in social work practice: The heart of helping.* New York: Oxford University Press.

Carlson, L. E., Speca, M., Faris, P., & Patel, K. D. (2007). One year pre-post intervention follow-up of psychological, immune, endocrine and blood pressure outcomes of mindfulness-based stress reduction (MBSR) in breast and prostate cancer outpatients. *Brain, Behavior, and Immunity, 21*, 1038-1049.

Carlson, L. E., Speca, M., Patel, K. D., & Goodey, E. (2004). Mindfulness-based stress reduction in relation to quality of life, mood, symptoms of stress and levels of cortisol, dehydroepiandrosterone sulfate (DHEAS) and melatonin in breast and prostate cancer outpatients. *Psychoneuroendocrinology, 29*, 448-474.

Carmody, J., Reed, G., Kristeller, J., & Merriam, P. (2008). Mindfulness, spirituality, and health-related symptoms. *Journal of Psychosomatic Research, 64*, 393-403.

Carr, D., & Haldane, J. (2003). Introduction. In D. Carr & J. Haldane (Eds.), *Spirituality, philosophy and education* (pp. 1-7). New York: RoutledgeFalmer.

Case, A. S. (2006). *Knowledge and prostate cancer screening in African American men: The effects of a religiocultural intervention.* Doctor of Psychology Dissertation, Fuller Theological Seminary. (UMI: 3223092)

Catanzaro, A. H., & McMullen, K. A. (2001). Increasing nursing students' spiritual sensitivity. *Nurse Educator, 26*(5), 221-226.

Center for Spiritual Development. (n.d.). Spirituality measures. Retrieved September 5, 2009, from http://www.spiritualdevelopmentcenter.org

Chambers, S., Baade, P., & Pinnock, C. (2010). Supportive care intervention in prostate cancer: Recent advances and future challenges. *Cancer Forum, 34*(1).

Chambers, S., Foley, E., Galt, E., Ferguson, M., & Clutton, S. (2011). Mindfulness groups for men with advanced prostate cancer: A pilot study to assess feasibility and effectiveness and the role of peer support. *Support Care in Cancer, 20*(6), 1183-1192.

Chambers, S., Schover, L., Halford, K., Clutton, S., Ferguson, M., Gordon, L., et al. (2008). ProsCan for couples: Randomised controlled trial of a couples-based sexuality intervention for men with localised prostate cancer who receive radical prostatectomy. Retrieved May 31, 2012, from http://www.biomedcentral.com/1471-2407/8/226

Chase, S. E., & Lincoln, Y. S. (2005). Narrative inquiry: multiple lenses, approaches, voices. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (3rd ed., pp. 651-679). California: SAGE Publications, Inc.

Chirban, J. T. (2001). Assessing religious and spiritual concerns in psychotherapy. In T. G. Plante & A. C. Sherman (Eds.), *Faith and health* (pp. 265-290). N.Y.: The Guilford Press.

Chrystal, K., Allan, S., Forgeson, G., & Isaacs, R. (2003). The use of complementary/alternative medicine by cancer patients in a New Zealand regional cancer treatment centre. *The New Zealand Medical Journal, 116*(1168), 296 ff.

Coker, A. L., Sanderson, M., Ellison, G. L., & Fadden, M. K. (2006). Stress, coping and social support, and prostate cancer risk among older African American and Causcasian men. *Ethnicity and Disease, 16*, 978-987.

Cole, B., & Pargament, K. (1999). Re-creating your life: a spiritual/ psychotherapeutic intervention for people diagnosed with cancer. *Psycho-Oncology, 8*(5), 395-407.

Community Eye Health Journal. (2007). Glossary. *Community Eye Health Journal, 20*(61), 17.

Cortazzi, M. (1993). *Narrative analysis*. London: The Falmer Press.

Cotton, S. P., Levine, E. G., Fitzpatrick, C. M., Dold, K. H., & Targ, E. (1999). Exploring the relationships among spiritual well-being, quality of life and psychological adjustment in women with breast cancer. *Psycho-Oncology, 8*(5), 429-438.

Coward, D. D. (1996). Self-transcendence and correlates in a healthy population. *Nursing Research, 45*(2), 116-121.

Creswell, J. W. (1998). *Qualitative inquiry and research design: Choosing among five traditions*. Thousand Oaks, CA: SAGE Publications, Inc.

Creswell, J. W. (2009). *Research design. Qualitative, and mixed method approaches* (3rd ed.). Thousand Oaks: SAGE Publications Inc.

Cronin, P., Ryan, F., & Coughlan, M. (2008). Undertaking a literature review: A step-by-step approach. *British Journal of Nursing, 17*(1), 38-43.

Crotty, M. (1998). *Foundations of social research*. St Leonards, Sydney: Allen & Unwin Pty Ltd.

Culliford, L. (2002). Spiritual care and psychiatric treatment: An introduction. *Advances in Psychiatric Treatment, 8*, 249-261.

D'Souza, R. (2007). The importance of spirituality in medicine and its application to clinical practice. *MJA, 186*, S57-S59.

Daaleman, T. P., & Frey, B. B. (2004). The spirituality index of well-being: A new instrument for health-related quality-of-life research. *Annals of Family Medicine, 2*(5), 499-503.

Dalai Lama. (1999). *Ethics for the New Millenium*. New York: Riverhead Books.

Daugherty, C. K., Fitchett, G., Murphy, P. E., Peterman, A. H., Banik, D. M., Hlubocky, F., et al. (2005). Trusting God and medicine: spirituality in advanced cancer patients volunteering for clinical trials of experimental agents. *Psycho-Oncology, 14*(2), 135-146.

Davis, D. E., Worthington Jr., E. L., Hook, J. N., Van Tongeren, D. R., Green, J. D., & Jennings II, D. J. (2009). Relational spirituality and the development of the Similarity of the Offender's Spirituality Scale. *Psychology of Religion and Spirituality, 1*(4), 249-262.

Davis, J. D. (2002). *Coping with prostate cancer: The lived experience.* Doctor of Philosophy Dissertation, Texas A&M University, College Station. (UMI: 3058157)

Denzin, N. K., & Lincoln, Y. S. (2005). Introduction: the discipline and practice of qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (3rd ed., pp. 1-32). California: SAGE Publications, Inc.

Denzin, N. K., & Lincoln, Y. S. (2011). Introduction: The discipline and practice of qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (4th ed., pp. 1-19). California: SAGE Publications, Inc.

Department of Veterans Affairs. (2008). Spiritual and pastoral care procedures. *VHA Handbook 1111.02.* Retrieved August 5, 2009, from http://www1.va.gov/vhapublications/ViewPublication.asp?pub_ID=1720

Di Cicco-Bloom, B., & Crabtree, B. F. (2006). The qualitative research interview. *Medical Education, 40*, 314-321.

Digance, J. (2003). Pilgrimage at contested sites. *Annals of tourism research, 30*(1), 143-159.

Doka, K. J., & Morgan, J. D. (1993). Introduction. In K. J. Doka & J. D. Morgan (Eds.), *Death and spirituality* (pp. 1-2). Amityville, New York: Baywood Publishing Company, Ltd.

Dossey, B. M., & Guzzetta, C. E. (2005). Holistic nursing practice. In B. M. Dossey, L. Keegan & C. E. Guzzetta (Eds.), *Holistic nursing: A handbook for practice* (4th ed., pp. 5-39). Sudbury, MA: Jones and Bartlett Publishers.

Dunne, J. (2003). After philosophy and religion: Spirituality and its counterfeits. In D. Carr & J. Haldane (Eds.), *Spirituality, philosophy and education* (pp. 97-111). New York: RoutledgeFalmer.

Dy-Liacco, G. S., Piedmont, R. L., Murray-Swank, N. A., Rodgerson, T. E., & Sherman, M. F. (2009). Spirituality and religiosity as cross-cultural aspects of human experience. *Psychology of Religion and Spirituality, 1*(1), 35-52.

Dyson, J., Cobb, M., & Forman, D. (1997). The meaning of spirituality: A literature review. *Journal of Advanced Nursing, 26*, 1183-1188.

East, L., Jackson, D., O'Brien, L., & Peters, K. (2010). Storytelling: an approach that can help to develop resilience. *Nurse Researcher, 17*(3), 17-25.

Eckersley, R. M. (2007). Culture, spirituality, religion and health: Looking at the big picture. *MJA, 186*, S54-S56.

Edey, W., & Jevne, R. F. (2003). Hope, illness, and counselling practice: Making hope visible. *Canadian Journal of Counselling, 37*(1), 44-51.

Emden, C. (1998). Conducting a narrative analysis. *Collegian: Journal of the Royal College of Nursing Australia, 5*(3), 34-39.

Epstein, R.M. & Street, R.L. Jr. (2011). The values and value of patient-centered care. *Annals of Family Medicine*, *9*(2), 100-103.

FACIT-Sp-Ex. (n.d.). FACIT-Sp-Ex test sample. Retrieved September 19, 2009, from www.facit.org

Flannelly, K. J., Ellison, C. G., & Strock, A. L. (2004). Methodologic issues in research on religion and health. *Southern Medical Journal, 97*(12), 1231-1241.

Flyvbjerg, B. (2006). Five misunderstandings about case-study research. *Qualitative Inquiry, 12*(2), 219-245.

Foley, K. L., Farmer, D. F., Petronis, V. M., Smith, R. G., McGraw, S., Smith, K., et al. (2006). A qualitative exploration of the cancer experience among long-term survivors: comparisons by cancer type, ethnicity, gender, and age. *Psycho-Oncology, 15*(3), 248-258.

Fontana, A., & Frey, J. H. (2005). The interview: From neutral stance to political involvement. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (3rd ed., pp. 695-727). California: SAGE Publications, Inc.

Fontana, D. (2003). *Psychology, religion, and spirituality*. Oxford, U.K.: BPS Blackwell.

Fowler, J. W. (1980). *Stages of faith*. San Francisco: Harper.

Frankl, V. E. (1985). *Man's search for meaning*. New York: Washington Square Press.

Frankl, V. E. (1997). *Man's search for ultimate meaning*. New York: Insight Books Plenum Press.

Friend, R. C. (2001). Spirituality in Iranian music and dance: Conversations with Morteza Varzi. *Habibi, 18*(2).

Fromme, E. K., Hughes, M. T., Brokaw, F. C., Rosenfeld, K. E., & Arnold, R. M. (2008). Update in palliative medicine 2008. *Journal of Palliative Medicine, 11*(5), 769-775.

Fry, L. W. (2003). Toward a theory of spiritual leadership. *The Leadership Quarterly, 14*, 693-727.

Gall, T. L. (2004). Relationship with God and the quality of life of prostate cancer survivors. *Quality of Life Research, 13*, 1357-1368.

Gall, T. L., & Cornblat, M. W. (2002). Breast cancer survivors give voice: A qualitative analysis of spiritual factors in long-term adjustment. *Psycho-Oncology, 11*(6), 524-535.

Geertz, C. (1973). *The interpretation of cultures*. New York: Basic Books.

General Medical Council (UK). (2012). Good medical practice: Duties of a doctor. Retrieved November 13, 2012, from http://www.gmc-uk.org/guidance/good_medical_practice/duties_of_a_doctor.asp

Gerring, J. (2007). *Case study research: principles and practice.* Cambridge: Cambridge University Press.

Gerrish, K., McManus, M., & Ashworth, P. (2003). Creating what sort of professional? Master's level nurse education as a professionalising strategy. *Nursing Inquiry, 10*(2), 103-112.

Gibson, L. M., & Smith Hendricks, C. (2006). Integrative review of spirituality in African American breast cancer survivors. *Association of Black Nursing Faculty Journal, 17*(2), 67-72.

Gilbert, J. (2006). Reflecting on intercultural dialogue in nursing. *Texto Contexto Enferm, 15*(1), 131-136.

Goddard, N. (1995). "Spirituality as integrative energy": A philosophical analysis as requisite precursor to holistic nursing practice. *Journal of Advanced Nursing, 22*(4), 805-815.

Golafshani, N. (2003). Understanding reliability and validity in qualitative research. *The Qualitative Report, 8*(4), 597-607.

Gray, J. (2006). Measuring spirituality: Conceptual and methodological considerations. *The Journal of Theory Construction & Testing, 10*(2), 58-64.

Grbich, C. (2007). *Qualitative data analysis: An introduction*. London: Sage.

Gridley, H. (2009). Psychology, spirituality, religion and culture – harvesting the gifts of all our ancestors. *In-Psych Bulletin.* Retrieved November, 2, 2009, from http://www.psychology.org.au/inpsych/spirituality/

Grossman, P. (2008). On measuring mindfulness in psychosomatic and psychological research. *Journal of Psychosomatic Research, 64*, 405-408.

Grubb, R. L., Pinsky, P. F., Greenlee, R. T., Izmirlian, G., Miller, A. B., Hickey, T. P., et al. (2008). Prostate cancer screening in the Prostate, Lung, Colorectal and Ovarian cancer screening trial: Update on findings from the initial four rounds of screening in a randomized trial. *British Journal of Urology International, 102*(11), 1524-1530.

Guba, E. G., & Lincoln, Y. S. (2005). Paradigmatic controversies, contradictions, and emerging confluences. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (3rd ed., pp. 191-215). California: SAGE Publications, Inc.

Hagen, B., Grant-Kalischuk, R., & Sanders, J. (2007). Disappearing floors and second chances: Men's journeys of prostate cancer. *International Journal of Men's Health, 6*(3), 201-223.

Haldane, J. (2003). On the very idea of spiritual values. In D. Carr & J. Haldane (Eds.), *Spirituality, philosophy and education* (pp. 11-25). New York: RoutledgeFalmer.

Halm, M. A. (2008). The healing power of the human-animal connection. *American Journal of Critical Care, 17*(4), 373-376.

Halstead, J. M. (2003). Metaphor, cognition and spiritual reality. In D. Carr & J. Haldane (Eds.), *Spirituality, philosophy and education* (pp. 83-96). New York: RoutledgeFalmer.

Halstead, M. T., & Hull, M. (2001). Struggling with paradoxes: The process of spiritual development in women with cancer. *ONF, 28*(10), 1534-1544.

Hand, H. (2003). The mentor's tale: A reflexive account of semi-structured interviews. *Nurse Researcher, 10*(3), 15-27.

Harper, D. (2001). Etymology of 'spirit' Retrieved January 23, 2010, from http://www.etymonline.com/index.php?term=spirit

Harrison, M. D., & McConchie, P. (2009). *My people's dreaming*. Sydney: Finch Publishing.

Hart, T., & Waddell, A. (2003). *Spiritual issues in counseling and psychotherapy: toward assessment and treatment.* Retrieved May 20, 2009, from http://66.160.135.235/acrobat/hart_and_waddell.pdf

Hassed, C. (2000). Prescribing spirituality in *The Spirit of Things*. *Discussion on ABC (Australia) Radio 15/10/00*.

Hassed, C. (2005). The essence of health care. *Australian Family Physician, 34*(11), 957-960.

Heelas, P. (2006). Nursing spirituality. *Spirituality and Health International, 7*, 8-23.

Heelas, P., & Woodhead, L. (2005). *The spiritual revolution*. Malden, MA: Blackwell Publishing.

Hendricks-Ferguson, V. (2008). Hope and spiritual well-being in adolescents with cancer. *Western Journal of Nursing Research, 30*(3), 385-401.

Henoch, I., & Danielson, E. (2009). Existential concerns among patients with cancer and interventions to meet them: An integrative literature review. *Psycho-Oncology, 18*(3), 225-236.

Heshusius, L. (1994). Freeing ourselves from objectivity: Managing subjectivity or turning toward a participatory mode of consciousness. *Educational Researcher, 23*(3), 15-22.

Highfield, M. E. (2000). Providing spiritual care to patients with cancer. *Clinical Journal of Oncology Nursing, 4*(3), 115-120.

Highfield, M. F., & Cason, C. (1983). Spiritual needs of patients: Are they recognised? *Cancer Nursing, 6*, 187-192.

Hill, P. C., & Pargament, K. I. (2003). Advances in the conceptualization and measurement of religion and spirituality: Implications for physical and mental health research. *American Psychologist, 58*(1), 64-74.

Hill, P. C., & Pargament, K. I. (2008). Advances in the conceptualization and measurement of religion and spirituality: Implications for physical and mental health research. *Psychology of Religion and Spirituality, S*(1), 3-17.

Ho, D. Y. F., & Ho, R. T. H. (2007). Measuring spirituality and spiritual emptiness: Toward ecumenicity and transcultural applicability. *Review of General Psychology, 11*(1), 62-74.

Hodge, D. R. (2001). Spiritual assessment: A review of major qualitative methods and a new framework for assessing spirituality. *Social Work, 46*(3), 203-214.

Hodge, D. R. (2005a). *Developing a spiritual assessment toolbox: A discussion of the strengths and limitations of five different assessment methods.* Retrieved May 20, 2009, from http://www.accessmylibrary.com/coms2/summary_0286-11964112_ITM

Hodge, D. R. (2005b). Spiritual lifemaps: a client-centered pictorial instrument for spiritual assessment, planning, and intervention. *Social Work, 50*(1), 77-87.

Hodge, D. R. (2006). A template for spiritual assessment: a review of the JCAHO requirements and guidelines for implementation**.** *Social Work, 51*(4), 317-326.

Hodge, D. R. (n.d.). *Conducting spiritual assessments: An overview of a complementary family of assessment instruments* Retrieved May 20, 2009, from http://w3.stu.ca/stu/sites/spirituality/HodgespiritualassessmentV18-9-06.pdf

Holland, J. C., Kash, K. M., Passik, S., Gronert, M. K., Sison, A., Lederberg, M., et al. (1998). A brief spiritual beliefs inventory for use in quality of life research in life-threatening illness. *Psycho-Oncology, 7*(6), 460-469.

Hove, S. E., & Anda, B. (2005). *Experiences from conducting semi-structured interviews in empirical software engineering research.* Paper presented at the METRICS, 11th IEEE International Software Metrics Symposium.

Hsieh, H.-F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research, 15*(9), 1277-1288.

James, W. (1982). *The varieties of religious experience: A Study in human nature*. Harmondsworth, Middlesex, England: Penguin Books.

Jantos, M., & Kiat, H. (2007). Prayer as medicine: How much have we learned? *MJA, 186*, S51-S53.

Johnson, S. (2007). Hope in terminal illness: an evolutionary concept analysis. *International Journal of Palliative Nursing, 13*(9), 451-459.

Johnston Taylor, E., Hopkins Outlaw, F., Bernardo, T. R., & Roy, A. (1999). Spiritual conflicts associated with praying about cancer. *Psycho-Oncology, 8*(5), 386-394.

Joint Commission on Accreditation of Healthcare Organizations. (2005). Evaluating your spiritual assessment process. *Joint Commission: The Source, 3*(2), 6-7.

Jones, R. A. (2005). *Use of complementary and alternative practices and products among African American postate cancer survivors.* PhD Thesis, University of Virginia, Charlottesville. (UMI: 3169691)

Jonsson, A. (2009). *Prostate cancer and its influence on men's daily lives.* Gothenburg: Göteborgs Universitet.

Jonsson, A., Aus, G., & Berterö, C. (2009). Men's experience of their life situation when diagnosed with advanced prostate cancer. *European Journal of Oncology Nursing, 13*, 268-273.

Ka'opua, L. S. I., Gotay, C. C., & Boehm, P. S. (2007). Spiritually based resources in adaptation to long-term prostate cancer survival: Perspectives of elderly wives. *Health & Social Work 32*(1), 30-39.

Kandinsky, W. (1977). *Concerning the spiritual in art*. New York: Dover.

Kaplan, B. H., Munroe-Blum, H., & Blazer, D. G. (1994). Religion, health and forgiveness: Traditions and challenges. In D. L. Levin (Ed.), *Religion in Aging and Health* (pp. 52-77). Thousand Oaks, CA: SAGE Publications, Inc.

Karren, K. J., Hafen, B. O., Smith, N. L., & Frandsen, K. J. (2002). *Mind/body health*. San Francisco: Benjamin Cummings.

Kaut, K. P. (2002). Religion, spirituality, and existentialism near the end of life: Implications for assessment and application. *American Behavioral Scientist, 46*(2), 220-234.

Kearney, M. (2000). *A place of healing: Working with suffering in living and dying.* Oxford: Oxford University Press.

Kiesling, C., Sorell, G. T., Montgomery, M. J., & Colwell, R. K. (2008). Identity and spirituality: A psychosocial exploration of the sense of spiritual self. *Psychology of Religion and Spirituality, S*(1), 50-62.

King, M., Speck, P., & Thomas, A. (1994). Spiritual and religious beliefs in acute illness: Is this a feasible area for study? *Social Science and Medicine, 38*(4), 631-636.

King, M. L. (1977). *Strength to Love*. Glasgow: Collins.

Kluger, J. (2004, October 25). Is God in our genes?, *Time*.

Koenig, H. G. (2007). Religion, spirituality and medicine in Australia: Research and clinical practice. *MJA, 186*(10), S45-S46.

Koenig, H. G. (2009). Research on religion, spirituality, and mental health: A review. *Canadian Journal of Psychiatry, 54*(5), 283-291.

Kotila, H. (2006). Contemporary worship as an expression of post-modern spirituality. In K. Tirri (Ed.), *Religion, Spirituality and Identity* (pp. 65-83). Bern: Peter Long.

Kristeller, J. L., Sheedy Zumbrun, C., & Schilling, R. F. (1999). 'I would if I could': How oncologists and oncology nurses address spiritual distress in cancer patients. *Psycho-Oncology, 8*(5), 451-458.

Kuczewski, M. G. (2007). Talking about spirituality in the clinical setting: Can being professional require being personal? *The American Journal of Bioethics, 7*(7), 4-11.

Kunkel, E. J. S., Bakker, J. R., Myers, R. E., Oyesanmi, O., & Gomella, L. G. (2000). Biopsychosocial aspects of prostate cancer. *Psychosomatics, 41*(2), 85-94.

Lambert, N. M., Fincham, F. D., Braithwaite, S. R., Graham, S. M., & Beach, S. R. H. (2009). Can prayer increase gratitude? *Psychology of Religion and Spirituality, 1*(3), 139-149.

Lang, F., Floyd, M. R., & Beine, K. L. (2000). Clues to patients' explanations and concerns about their illness: A call for active listening. *Archives of Family Medicine, 9*, 222-227.

Langer, E. J., & Moldoveanu, M. (2000). The construct of mindfulness. *Journal of Social Issues, 56*(1), 1-9.

Lannamann, J. W., & McNamee, S. (2011). Narratives of the interactive moment. *Narrative Inquiry, 21*(2), 382-390.

Lapierre, L. L. (1994). A model for describing spirituality. *Journal of Religion and Health, 33*(2), 153-161.

Laubmeier, K. K., Zakowski, S. G., & Bair, J. P. (2004). The role of spirituality in the psychological adjustment to cancer: A test of the transactional model of stress and coping. *International Journal of Behavioral Medicine, 11*(1), 48-55.

Lin, H.-R., & Bauer-Wu, S. M. (2003). Psycho-spiritual well-being in patients with advanced cancer: An integrative review of the literature. *Journal of Advanced Nursing, 44*(1), 69-80.

Lincoln, Y. S., Lynham, S. A., & Guba, E. G. (2011). Paradigmatic controversies, contradictions and emerging confluences revisited. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (4th ed., pp. 98-128). California: SAGE Publications, Inc.

Lukoff, D. (n.d.). *DSM-IV* religious & spiritual problems Retrieved September 4, 2009, from http://www.spiritualcompetency.com/dsm4/dsmrsproblem.pdf

Mackenzie, M. J., Carlson, L. E., Munoz, M., & Speca, M. (2007). A qualitative study of self-perceived effects of mindfulness-based stress reduction (MBSR) in a psychosocial oncology setting. *Stress and Health, 23*(1), 59-69.

Madill, A., & Gough, B. (2008). Qualitative research and its place in psychological science. *Psychological Methods, 13*(3), 254-271.

Mason, O., & Hargreaves, I. (2001). A qualitative study of mindfulness-based cognitive therapy for depression. *British Journal of Medical Psychology, 74*, 197-212.

McEwen, M. (2005). Spiritual nursing care: State of the art. *Holistic Nursing Practice, 19*(4), 161-168.

McQueen, L., & Zimmerman, L. (2006). Using the interpretive narrative research method in interdisciplinary research projects. *Journal of Nursing Education, 45*(11), 475-478.

McSherry, W. (2000). *Making sense of spirituality in nursing practice*. Edinburgh: Churchill Livingstone.

Meraviglia, M. G. (1999). Critical analysis of spirituality and its empirical indicators. *Journal of Holistic Nursing, 17*(1), 18-33.

Micke, O., Büntzel, J., Mücke, R., & Glatzel, M. (2008). Spirituality in radiation oncology - from belief to bedside: A new focus for research? *European Journal of Integrative Medicine, 1 - Supplement*, 12.

Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis*. Thousand Oaks: Sage.

Miner-Williams, D. (2006). Putting a puzzle together: Making spirituality meaningful for nursing using an evolving theoretical framework. *Journal of Clinical Nursing, 15*, 811-821.

Miner-Williams, D. (2007). Connectedness in the nurse-patient relationship: A grounded theory study. *Issues in Mental Health Nursing, 28*, 1215-1234.

Mitchell, S. (1988). *Tao Te Ching: A new English version*. New York: Harper and Row Publishers.

Moadel, A., Morgan, C., Fatone, A., Grennan, J., Carter, J., Laruffa, G., et al. (1999). Seeking meaning and hope: Self-reported spiritual and existential needs among an ethnically-diverse cancer patient population. *Psycho-Oncology, 8*(5), 378-385.

Moen, T. (2006). Reflections on the narrative research approach. *International Journal of Qualitative Methods, 5*(4), 56-69.

Moritz, S., Kelly, M., Angen, M., Quan, H., Toews, J., & Rickhi, B. (2007). The impact of a home-based spirituality teaching programme: Qualitative exploration of participants' experiences. *Spirituality and Health International, 8*(4), 192-205.

Moritz, S., Quan, H., Rickhi, B., Liu, M., Angen, M., Vintila, R., et al. (2006). A home study-based spirituality education program decreases emotional distress and increases quality of life - a randomized, controlled trial. *Alternative Therapies in Health and Medicine, 12*(6), 26-35.

Morse, J. M. (1994). Designing funded qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 220-235). California: SAGE Publications, Inc.

Mottet, N., Prayer-Galetti, T., Hammerer, P., Kattan, M. W., & Tunn, U. (2006). Optimizing outcomes and quality of life in the hormonal treatment of prostate cancer. *BJU International, 98*(1), 20-27.

Murray, J., Mitchell, G., Meredith, P., Wilson, P., & Hutch, R. (2007). *Spiritual care in palliative care. Self-directed learning package*. Brisbane: The University of Queensland.

Mytko, J. J., & Knight, S. J. (1999). Body, mind and spirit: Towards the integration of religiosity and spirituality in cancer quality of life research. *Psycho-Oncology, 8*(5), 439-450.

Nanton, V., & Dale, J. (2011). 'It don't make sense to worry too much': The experience of prostate cancer in African-Caribbean men in the UK. *European Journal of Cancer Care 20*, 62-71.

Narayanasamy, A. (1991). *Spiritual care - A resource guide*. Lancaster and Nottingham: Quay Publishing Ltd & BKT Information Services.

Narayanasamy, A. (2004). The puzzle of spirituality for nursing: A guide to practical assessment. *British Journal of Nursing, 13*(19), 1140-1144.

National Breast Cancer Centre and the National Cancer Control Initiative. (2003). *Clinical practice guidelines for the psychosocial care of adults with cancer*. Camperdown: National Health and Medical Research Council.

National Cancer Institute. (2010). Prostate cancer treatment (PDQ®) health professional version. Retrieved July 5, 2010, from http://www.cancer.gov/cancertopics/pdq/treatment/prostate/HealthProfessional

National Cancer Institute. (n.d.-a). Prostate cancer treatment (PDQ®) Retrieved September 28, 2009, from http://www.meb.uni-bonn.de/cancer.gov/CDR0000062965.html

National Cancer Institute. (n.d.-b). Spirituality in cancer care (PDQ®) Retrieved September 25, 2009, from http://www.cancer.gov/cancertopics/pdq/supportivecare/spirituality/HealthProfessional/allpages

National Seniors Foundation. (2006). *Localised prostate cancer - a guide for men and their families.* Spring Hill, Brisbane: Australian Prostate Cancer Collaboration Inc.

Nelson, C. J. (2002). *The impact of religiosity and spirituality on PSA levels on men with prostate cancer.* PhD Thesis, College of Long Island University. (UMI: 3086805)

Nicoll, L. H., & Beyea, S. C. (1997). Selecting research instruments to measure the reliability and validity of nursing research studies. *Association of periOperative Registered Nurses Journal, 66*(5), 927-928.

Niessen, T., Abma, T., Widdershoven, G., Van Der Vleuten, C., & Akkerman, S. (2008). Contemporary epistemological research in education: Reconciliation and reconceptualization of the field. *Theory and Psychology, 18*(1), 27-45.

Nugent, W. R., & Halvorson, H. (1995). Testing the effects of active listening. *Research on Social Practice, 5*(2), 152-175.

O'Connell, K. A., & Skevington, S. M. (2005). The relevance of spirituality, religion and personal beliefs to health-related quality of life: Themes from focus groups in Britain. *British Journal of Health Psychology 10*, 379-398.

Oliffe, J., & Mroz, L. (2005). Men interviewing men about health and illness: Ten lessons learned. *The Journal of Men's Health and Gender, 2*(2), 257-260.

Oxlad, M., Wade, T. D., Hallsworth, L., & Koczwara, B. (2008). 'I'm living with a chronic illess, not ... dying with cancer': A qualitative study of Australian women's self-identified concerns and needs following primary treatment for breast cancer. *European Journal of Cancer Care, 17*(2), 157-166.

Paley, J., & Eva, G. (2005). Narrative vigilance: The analysis of stories in health care. *Nursing Philosophy, 6*(2), 83-97.

Pargament, K. I. (1997). *The psychology of religion and coping*. New York: The Guilford Press.

Pargament, K. I. (1999). The psychology of religion *and* spirituality? Yes and no. *The International Journal for the Psychology of Religion, 9*(1), 3-16.

Pargament, K. I., Koenig, H. G., Tarakeshwar, N., & Hahn, J. (2004). Religious coping methods as predictors of psychological, physical and spiritual outcomes among medically ill elderly patients: A two-year longitudinal study. *Journal of Health Psychology, 9*(6), 713-730.

Patterson, E. F. (1998). The philosophy and physics of holistic health care: Spiritual healing as a workable interpretation. *Journal of Advanced Nursing, 27*(2), 287-293.

Pearce, S. (2010). *Healing properties: Connection to land and cancer survivorship.* PhD Dissertation, University of Southern Queensland, Toowoomba.

Pennebaker, J. W., & Seagal, J. D. (1999). Forming a story: The health benefits of narrative. *Journal of Clinical Psychology, 55*(10), 1243-1254.

Pennell, M. M. (2006). *Masterpieces of American Literature*. Westport: Greenwood Press.

Pickering, M. (2002). Looking through the fawn-skin window. *Australian Historical Studies, 118*, 223-238.

Plante, T. G., & Sherman, A. C. (2001). Research in faith and health. In T. G. Plante & A. C. Sherman (Eds.), *Faith and Health* (pp. 1-12). N.Y.: The Guilford Press.

Polkinghorne, D. (1988). *Narrative knowing and the human sciences*. Albany: State University of New York.

Porter, S. (1993). Nursing research conventions: Objectivity or obfuscation? *Journal of Advanced Nursing, 18*, 137-143.

Prostate Cancer Foundation of Australia. (2008). *08/09 Collaborative research update.* Lane Cove: Prostate Cancer Foundation of Australia.

Prostate Cancer Foundation of Australia. (2012). Prostate Cancer Foundation reinforces position on benefits of Prostate Specific Antigen (PSA) tests: Can cut deaths by 21%. *Media release, 22 May, 2012.*

Prostate Cancer Foundation of Australia. (n.d.). Advanced prostate cancer Retrieved November 9, 2009, from www.prostate.org.au

Prostate Cancer Research Institute. (n.d.). Glossary of prostate cancer related terms. Retrieved November 4, 2009, from http://www.prostate-cancer.org/resource/gloss_s.html

Puchalski, C. R. (2002). Spirituality and end-of-life care: A time for listening and caring. *Journal of Palliative Medicine, 5*(2), 289-294.

Queensland Cancer Fund. (n.d.). *Coping with a diagnosis of prostate cancer.* Brisbane: Queensland Cancer Fund.

Queensland Cancer Registry. (2009). *Cancer in Queensland: Incidence and mortality 1982 to 2006. Statistical Tables.* Spring Hill: Queensland Cancer Registry and Cancer Council Queensland.

Reed, P. G. (1987). Spirituality and well-being in terminally ill hospitalized adults. *Research in Nursing and Health, 10*, 335-344.

Reed, P. G. (1992). An emerging paradigm for the investigation of spirituality in nursing. *Research in Nursing & Health, 15*(3), 349-357.

Richards, T. J., & Richards, L. (1994). Using computers in qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 445-462). California: SAGE Publications, Inc.

Rippentrop, A. E., Altmaier, E. M., Chen, J. J., Found, E. M., & Keffala, V. J. (2005). The relationship between religion/spirituality and physical health, mental health, and pain in a chronic pain population. *Pain, 116*, 311-321.

Roach, D. (2005). *Finding hope in a world of pain.* Paper presented at the Multi-Faith Ceremony, World Cancer Day, Adelaide.

Roberts, K., & Taylor, B. (2002). *Nursing research processes: An Australian perspective* (2nd ed.). Southbank, Victoria, Australia: Thomson.

Robertson, K. (2005). Active listening: More than just paying attention. *Australian Family Physician, 34*(12), 1053-1055.

Rogers-Clark, C. (2002). *Resilient survivors: Rural women who have lived through breast cancer.* PhD Dissertation, University of Southern Queensland, Toowoomba.

Rose, S. (2001). Is the term 'spirituality' a word that everyone uses, but nobody knows what anyone means by it? *Journal of Contemporary Religion, 16*(2), 193-207.

Rumbold, B. D. (2007). A review of spiritual assessment in health care practice. *MJA, 186*, S60-S62.

Sagan, C. (2006). The God hypothesis. In A. Druyan (Ed.), *The varieties of scientific experience: A personal view of the search for God* (pp. 147-168). New York: Penguin Books.

Salandar, P. (2006). Who needs the concept of spirituality? *Psycho-Oncology, 15*(7), 647-649.

Saldana, J. (2009). *The coding manual for qualitative researchers.* London: Sage.

Salminen, E., Bishop, M., Poussa, T., Drummond, R., & Salminen, S. (2004). Dietary attitudes and changes as well as use of supplements and complementary therapies by Australian and Finnish women following the diagnosis of breast cancer. *European Journal of Clinical Nutrition 58*, 137-144.

Salminen, E. K., Lagström, H. K., Heikkilä, S. P., & Salminen, S. J. (2000). Does breast cancer change patients' dietary habits? *European Journal of Clinical Nutrition, 54*, 844-848.

Sandelowski, M. (1986). The problem of rigor in qualitative research. *Advances in Nursing Science, 8*(3), 27-37.

Sandelowski, M. (1996). One is the liveliest number: The case orientation of qualitative research. *Research in Nursing and Health, 19*(6), 525-529.

Santos Zanchetta, M., Cognet, M., Xenocostas, S., Aoki, D., & Talbot, Y. (2007). Prostate cancer among Canadian men: A transcultural representation. *International Journal of Men's Health, 6*(3), 224-258.

Sargeant, H. (2006). Psychosocial aspects of the cancer journey. Brisbane: In-service workshop, The Queensland Cancer Fund.

Schneider, Z., Elliott, D., Beanland, C., LoBiondo-Wood, G., & Haber, J. (2003). *Nursing Research: Methods, critical appraisal and utlilisation.* (2nd ed.). Marrickville, NSW: Elsevier (Australia) Pty Limited.

Schultz, N. (2005). The spiritual dimension in nursing care. In C. Rogers-Clark, A. McCarthy & K. Martin-McDonald (Eds.), *Living with illness* (pp. 160-170). Marrickville: Elsevier.

Schwalbe, M. L., & Wolkomir, M. (2002). Interviewing men. In J. F. Gubrium & J. A. Holstein (Eds.), *Handbook of interview research: Context and method* (pp. 203-219).

Schwandt, T. A. (1994). Constructivist, interpretivist approaches to human inquiry. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 118-137). California: SAGE Publications, Inc.

Shapiro, J., & Ross, V. (2002). Applications of narrative theory and therapy to the practice of family medicine. *Family Medicine, 34*(2), 96-100.

Shapiro, S. L., Lopez, A. M., Schwartz, G. E., Bootzin, R., Figueredo, A. J., Braden, C. J., et al. (2001). Quality of life and breast cancer: Relationship to psychosocial variables. *Journal of Clinical Psychology, 57*(4), 501-519.

Shaw, B., Han, J. Y., Kim, E., Gustafson, D., Hawkins, R., Cleary, J., et al. (2007). Effects of prayer and religious expression within computer support groups on women with breast cancer. *Psycho-Oncology, 16*(7), 676-687.

Sheldon, M. G. (1992). Spirituality, healing and medicine [Letter to the editor]. *British Journal of General Practice, 42*(354), 38.

Sherman, A. C., & Simonton, S. (2001). Religious involvement among cancer patients. In T. G. Plante & A. C. Sherman (Eds.), *Faith and health.* (pp. 167-194). N.Y.: The Guilford Press.

Sinnott, J. D. (2001). Introduction: Special issue on spirituality and adult development, Part I. *Journal of Adult Development, 8*(4), 199-200.

Skalla, K. A., & McCoy, J. P. (2006). Spiritual assessment of patients with cancer: The moral authority, vocational, aesthetic, social, transcendent model. *Oncology Nursing Forum, 33*(4), 745-751.

Sorajjakool, S. (2006). *When sickness heals: The place of religious belief in healthcare*. West Conshohocken, PA: Templeton Foundation Press.

Squire, C., Andrews, M., & Tamboukou, M. (2008). What is narrative research? In M. Andrews, C. Squire & M. Tamboukou (Eds.), *Doing Narrative Research* (pp. 1-21). London: Sage.

Stake, R. E. (2005). Case studies. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (3rd ed., pp. 236-247). California: SAGE Publications, Inc.

Steginga, S. K., Ferguson, M., Gardiner, R. A., Nicol, D., Gordon, L., Occhipinti, S., et al. (2008). ProsCan for men: Randomised controlled trial of a decision support intervention for men with localised prostate cancer Retrieved November 18, 2009, from http://hdl.handle.net/10072/22896

Steginga, S. K., & Occhipinti, S. (2004). The application of the heuristic-systematic processing model to treatment decision making about prostate cancer. *Medical Decision Making, 24*(6), 573-583.

Steginga, S. K., & Occhipinti, S. (2006). Dispositional optimism as a predictor of men's decision-related distress after localized prostate cancer. *Health Psychology, 25*(2), 135-143.

Steginga, S. K., Occhipinti, S., Gardiner, R. A., Yaxley, J., & Heathcote, P. (2003). Prospective study of men's psychological and decision-related adjustment after treatment for localized prostate cancer. *Urology, 63*(4), 751-756.

Steginga, S. K., Pinnock, C., Baade, P. D., Jackson, C., Green, A., Preston, J., et al. (2005a). An educational workshop on the early detection of prostate cancer. *Australian Family Physician, 34*(10), 889-891.

Steginga, S. K., Pinnock, C., Gardner, M., Gardiner, R. A. F., & Dunn, J. (2005b). Evaluating peer support for prostate cancer: The Prostate Cancer Peer Support Inventory. *British Journal of Urology International, 95*, 46-50.

Steginga, S. K., Pinnock, C., Jackson, C., & Gianduzzo, T. (2005c). Shared decision-making and informed choice for the early detection of prostate cancer in primary care. *British Journal of Urology International, 96*, 1209-1218.

Steinhauser, K. E., Voils, C. I., Clipp, E. C., Bosworth, H. B., Christakis, N. A., & Tulsky, J. A. (2006). "Are you at Peace?". *Archives of International Medicine, 166*, 101-105.

Stern, J., & James, S. (2006). Every person matters: enabling spirituality education for nurses. *Journal of Clinical Nursing, 15*(7), 897-904.

Suri, H., & Clarke, D. (2009). Advancements in research synthesis methods: From a methodologically inclusive perspective. *Review of Educational Research., 79*(1), 395-430.

Swanson, J. M. (1986). The formal qualitative interview for grounded theory. In W. C. Chenitz & J. M. Swanson (Eds.), *From practice to grounded theory*. Menlo Park, California: Addison Wesley.

Swinton, J. (2001). *Spirituality and mental health care: Rediscovering a forgotten dimension*. London: Jessica Kingsley.

Swinton, J. (2006). Identity and resistance: why spiritual care needs 'enemies'. *Journal of Clinical Nursing, 15*(7), 918-928.

Swinton, J., Bain, V., Ingram, S., & Heys, S. D. (2011). Moving inwards, moving outwards, moving upwards: The role of spirituality during the early stages of breast cancer. *European Journal of Cancer Care, 20*, 640-652.

Sykes, J. B. (Ed.) (1982) *The Concise Oxford Dictionery* (7th ed.). Oxford: Oxford University Press.

Tanyi, R. A. (2002). Towards clarification of the meaning of spirituality. *Journal of Advanced Nursing 39*(5), 500-509.

Taylor, B. (2005). Health, wellness, illness, healing and holism, and nursing. In C. Rogers-Clark, A. McCarthy & K. Martin-McDonald (Eds.), *Living with illness* (pp. 8-25). Marrickville: Elsevier.

Taylor, B., Kermode, S., & Roberts, K. (2006). *Research in nursing and health care: Evidence for practice.* South Melbourne: Thomson.

Tedeschi, R. G., & Calhoun, L. G. (1996). The posttraumatic growth inventory: Measuring the positive legacy of trauma. *Journal of Traumatic Stress, 9*(3), 455-471.

Thoresen, C. E., & Harris, A. H. S. (2002). Spirituality and health: What's the evidence and what's needed? *Annals of Behavioral Medicine, 24*(1), 3-13.

Thoresen, C. E., Harris, A. H. S., & Oman, D. (2001). Spirituality, religion and health: Evidence, issues, and concerns. In T. G. Plante & A. C. Sherman (Eds.), *Faith and health.* (pp. 15-52). N.Y.: The Guilford Press.

Thornton, A. A., & Perez, M. A. (2006). Posttraumatic growth in prostate cancer survivors and their partners. *Psycho-Oncology, 15*, 285-296.

Tirri, K. (2006). Introduction. In K. Tirri (Ed.), *Religion, spirituality and identity*. Bern: Peter Lang AG, International Academic Publishers.

Tuckett, A. G. (2005). Part II. Rigour in qualitative research: Complexities and solutions. *Nurse Researcher, 13*(1), 29-42.

Us TOO International Prostate Cancer Education & Support Network. (n.d.). Prostate cancer - newly diagnosed Retrieved November 4, 2009, from http://www.ustoo.org/Newly_Diagnosed.asp

van Leeuwen, R., Tiesinga, L. J., Jochemasen, H., & Post, D. (2007). Aspects of spirituality concerning illness. *Scandinavian Journal of Caring Science, 21*(4), 482-489.

van Servellen, G., Sarna, L., Padilla, G., & Brecht, M.-L. (1996). Emotional distress in men with lifethreatening illness. *International Journal of Nursing Studies, 33*(5), 551-565.

Villagomeza, L. R. (2005). Spiritual distress in adult cancer patients: Toward conceptual clarity. *Holistic Nursing Practice, 18*(6), 285-294.

Visser, A., Garssen, B., & Vingerhoets, A. (2010). Spirituality and well-being in cancer patients: A review. *Psycho-Oncology, 19*(6), 565-572.

Vivat, B. (2008). Measures of spiritual issues for palliative care patients: A literature review. *Palliative Medicine, 22*, 859-868.

Walton, J., & Sullivan, N. (2004). Men of prayer: Spirituality of men with prostate cancer: a grounded theory study. *Journal of Holistic Nursing, 22*(2), 133-151.

Wasner, M., Longaker, C., Fegg, M. J., & Borasio, G. D. (2005). Effects of spiritual care training for palliative care professionals. *Palliative Medicine, 19*(2), 99-104.

Watson, J. (1989). Watson's philosophy and theory of human caring in nursing. In J. P. Riehl-Sisca (Ed.), *Conceptual Models for Nursing Practice* (3rd ed., pp. 219-236). Norwalk, Connecticut: Appleton & Lange.

Webster, L., & Mertova, P. (2010). *Using narrative inquiry as a research method.* Abingdon Oxon: Routledge.

Westman, B., Bergenmar, M., & Andersson, L. (2006). Life, illness and death: Existential reflections of a Swedish sample of patients who have undergone curative treatment for breast or prostatic cancer. *European Journal of Oncology Nursing, 10*, 169-176.

White, C. A. (2004). Meaning and its measurement in psychosocial oncology. *Psycho-Oncology, 13*(7), 468-481.

White, M., & Verhoef, M. (2006). Cancer as part of the journey: The role of spirituality in the decision to decline conventional prostate cancer treatment and to use complementary and alternative medicine. *Integrative Cancer Therapies, 5*(2), 117-122.

Whiting, L. S. (2008). Semi-structured interviews: Guidance for novice researchers. *Nursing Standard, 22*(23), 35-40.

Wig, N. N. (1999). Mental health and spiritual values. A view from the East. *International Review of Psychiatry, 11*, 92-96.

Williams, A.-L. (2006). Perspectives on spirituality at the end of life: A meta-summary. *Palliative and Supportive Care, 4*, 407-417.

Wilson, K. (2003). Therapeutic landscapes and First Nations peoples: An exploration of culture, health and place. *Health & Place, 9*, 83-93.

Wink, P., & Dillon, M. (2002). Spiritual development across the adult life course: Findings from a longitudinal study. *Journal of Adult Development, 9*(1), 79-94.

Winslow, G. R., & Wehtje-Winslow, B. J. (2007). Ethical boundaries of spiritual care. *MJA, 186*, S63-S66.

Woll, M. L., Hinshaw, D. B., & Pawlik, T. M. (2008). Spirituality and religion in the care of surgical oncology patients with life threatening or advanced illnesses. *Annals of Surgical Oncology, 15*(11), 3048-3057.

Wright, M. (2008). Good for the soul?: The spiritual dimension of hospice and palliative care. In S. Payne, J. Seymour & C. Ingleton (Eds.), *Palliative care nursing: principles and evidence for practice*. Maidenhead: Open University Press, U.K.

Wuthnow, R. (2001). *Creative spirituality: the way of the artist*. Berkeley and Los Angeles: University of California Press.

Wyatt, G. K., Friedman, L. L., Given, C. W., Given, B. A., & Beckrow, C. K. (1999). Complementary therapy use among older cancer patients. *Cancer Practice, 7*(3), 136-144.

Xavier, F. M. F., Ferraz, M. P. T., Marc, N., Escosteguy, N. U., & Moriguchi, E. H. (2003). Elderly people's definition of quality of life. *Revista Brasileira de Psiquiatria, 25*(1).

Yanez, B., Edmondson, D., Stanton, A. L., Park, C. L., Kwan, L., & Ganz, P. A. (2009). Facets of spirituality as predictors of adjustment to cancer: Relative contributions of having faith and finding meaning. *Journal of Consulting and Clinical Psychology, 77*(4), 730-741.

Yong, V. T. F. (2001). Interviewing men on sensitive issues. *Contemporary Nurse, 11*, 18-27.

Yoshimoto, S. M., Ghorbani, S., Bauer, J. M., Cheng, K. W., Banthia, R., Malcarne, V. L., et al. (2006). Religious coping and problem-solving by couples faced with prostate cancer. *European Journal of Cancer Care, 15*, 481-488.

Zavala, M. W., Maliski, S. L., Kwan, L., Arlene Fink, A., & Litwin, M. S. (2009). Spirituality and quality of life in low-income men with metastatic prostate cancer. *Psycho-Oncology, 18*(7), 753-761.

Zebrack, B. J., Ganz, P. A., Bernaards, C. A., Petersen, L., & Abraham, L. (2006). Assessing the impact of cancer: Development of a new instrument for long-term survivors. *Psycho-Oncology, 15*(5), 407-421.

Zinnbauer, B. J., Pargament, K. I., Cole, B., Rye, M. S., Butter, E. M., Belavich, T. J., et al. (1997). Religion and spirituality: Unfuzzying the fuzzy. *Journal for the Scientific Study of Religion, 36*(4), 549-564.

APPENDICES

A Consent Form

USQ UNIVERSITY OF SOUTHERN QUEENSLAND

TOOWOOMBA QLD 4350

SPIRITUALITY IN MEN WITH ADVANCED PROSTATE CANCER

CRRAH

INFORMATION SHEET/CONSENT FORM

9 NOVEMBER, 2010

My name is Laurence Lepherd (Laurie) and I am currently enrolled in a PhD (Doctor of Philosophy) program at the University of Southern Queensland (USQ). In my doctoral research, I have decided to study what 'spirituality' is in men who have advanced prostate cancer. This is cancer that has spread beyond the prostate gland into the pelvic area, or has metastasised to other parts of the body. Spirituality can be regarded as the centre of a person's 'inner being' that lifts them above everyday life. It is commonly recognised that 'spirituality' exists in everyone, whether or not they have a religious or cultural association.

Through hearing men's stories about their experience, specifically in relation to their spirituality, I hope to learn what is important for them during this aspect of their cancer journey, and how their spirituality may help them cope with their illness. It is anticipated that through the publication of the results of my research, carers and health professionals will be better informed on how to understand men who are in their care.

If you currently have advanced prostate cancer (described above) I invite you to participate in this study. You may find it beneficial to tell your story and to reflect on what this experience has meant for you, particularly in regard to your spirituality. I am very interested in your experiences, so my role would be to sit and listen and try to understand.

Participating voluntarily in this study will involve you meeting with me on one or more occasions, to talk about how you are surviving your illness. These meetings would take somewhere between one and two hours, and I would like to take some notes as well as record (audio) your interview. The meetings would be scheduled at a time and place suitable to you. After the first interview, I would summarise and interpret your story. I would then send you both the summary of your interview and my interpretations for you to look at. Shortly after, I would like to talk with you again, to check that I've accurately recorded and interpreted your experiences, and that you are satisfied with the outcome.

While in most cases I know that if you agree to participate in the study you will not find talking about your spirituality too stressful, you may feel like stopping your story if the memory of an experience is difficult for you. Please be assured that you can stop at any time. Should you become distressed, I can arrange for you to receive help through telephoning the Cancer Council Queensland Helpline for assistance. This is a very professional service that assists hundreds of people with cancer every year.

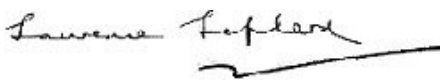
If you agree to participate, I can assure you that your privacy will be maintained. Anything you tell me will be kept strictly confidential. I will ask you to choose a fictitious name, or 'pseudonym', to identify your story, so that when it is published your actual identity will be hidden. We may change other details of your story, such as the town in which you live, to be absolutely certain that no-one could identify you. I will lock all printed information that I collect in a filing cabinet at USQ, to which only I have access. Recordings of interviews and e-document files will be stored on a password protected computer.

There might be other concerns that you would like to have addressed, before agreeing to enter the study. I would be pleased to talk with you about any such issues. We can add specific conditions to the consent form, if you wish. It is entirely your choice whether you participate in this study or not. If you do decide to

participate, you are free to withdraw at any time, and I will entirely respect your decision. During interviews, you can choose not to answer some or all of the questions I ask.

If you want further information about this study, please feel free to contact me. I welcome your questions and comments. My USQ phone number is (07) 46315459, and my mobile number is 0418 192 517. My email address is lepherd@usq.edu.au. Thank you for taking the time to read this sheet and considering my request.

Should you have any concern about the conduct of this research project, please contact the USQ Ethics Officer, Office of Research & Higher Degrees, University of Southern Queensland, West Street, Toowoomba QLD 4350, Telephone +61 7 4631 2690, email ethics@usq.edu.au



Laurence Lepherd
Centre for Rural and Remote Area Health (CRRAH)
University of Southern Queensland

CONSENT

I, _____ agree to participate in this research project, being conducted by Laurence Lepherd (Laurie) from the University of Southern Queensland.

I am aware of the aim of the study, and agree to be interviewed by Laurie one or more times (at my convenience) to explore my experiences of living with advanced prostate cancer. I have read the information above, and have asked Laurie to explain any details of the study and my participation that I was unsure about.

I agree to participate on the basis that strict confidentiality is maintained in respect to the information that I give Laurie. I am aware that all or parts of my story may be published in a research thesis and in journals, or other publications, but that my name and any other identifying characteristics will be changed to protect my privacy.

By signing this consent form, I indicate my willingness to participate in this study, but reserve the right to withdraw from the study at any stage, without any adverse consequences.

Signed _____ Date _____

Researcher _____

Please post this signed form to: Laurie Lepherd
Centre for Rural and Remote Area Health
University of Southern Queensland 4350

Questions? Please contact Laurie through: email: lepherd@usq.edu.au ; phone: 07 4631 5459 (Business hours); mobile: 0418 192 517 (Any time)

B News release to *Prostate Cancer News*

How are you coping?

Men have found many ways to cope with the stress they experience during the many phases of prostate cancer. Some have found that their spirituality helps.

What is spirituality? Is it a belief in and reliance on God? This is probably true for many people. But, for others, it may be closeness to the land, or a deep sense of purpose and meaning in life, or personal fulfilment.

Often spirituality is culturally related. Australian Aboriginal and Torres Strait Islander people have a spirituality closely connected with the land and with their cultural traditions.

It can be also religiously related. One aspect of Christian spirituality is focussed on the value of love, as shown by God and His Son. The concept of love, however, is not just for people who belong to a particular religion.

Buddhist spirituality is related to mindfulness, an important element in the path to 'knowing' about life and one's self.

Sometimes a person's spirituality may be through the arts – poetry, music, theatre, and the visual arts. Others find that their connection to other people or families can be very spiritual.

One common aspect for many men is that spirituality is something which 'transcends' every day life, something that lifts their spirit to something greater than the ordinary.

A person's spirit is often described as the centre or core of a person, or their inner being.

Spirituality has a number of ways in which it can be shown. One way is for it to be kept in the mind – a source for personal and private meditation or contemplation.

It might also be shown practically through religious ritual – church attendance and prayer.

For those who connect with a place very comforting, they might go there and find their peace of mind.

Another aspect of spirituality is that people can experience it in different amounts of intensity. At a time of crisis they might increase the time they spend in 'being' in the natural world that surrounds them. They might pray more regularly to a 'higher being', or spend time on anything that takes their mind away from the stress of their illness.

Above all, spirituality is very personal and individual. It differs from person to person. It is used in different ways by many people to cope. Writers are generally agreed that everyone has it!

I am currently carrying out research into the spirituality of men with advanced prostate cancer. What is it is for them? How it may help? How does it show itself in them?

Through this research, I aim to assist men in understanding their spirituality in the hope that their experiences (shared and reported confidentially) might help others receive greater comfort during their cancer journey.

More details will be provided in the next issue of the *News* but, in the meantime, if you are interested in the topic, and have something to share on your spirituality, particularly if you have advanced prostate cancer, could you let me know your thoughts by sending me an email - lepherd@usq.edu.au ? Alternatively, you can phone me on 07 4631 5459 (office hours) or 0418 192 517 (any time). I'd love to hear from you.

Laurence Lepherd
Centre for Rural and Remote Area Health
University of Southern Queensland

C Second news release to

Prostate Cancer News

How are you coping?

I am currently studying what spirituality is in men who have advanced prostate cancer. Spirituality can be regarded as the centre of a person's mind or 'inner being' that lifts them above everyday life. It is commonly recognised that spirituality exists in everyone, whether or not they have a special religious or cultural association. Advanced prostate cancer is described as cancer that has spread beyond the prostate gland into the pelvic area, or has metastasised to other parts of the body.

What lifts you above your illness? Is it a religious belief? Is it a 'connection' you have with other people, or a higher being, or with the land? Is it a sense of purpose? Is it … ? Through hearing about your personal spirituality, I hope to learn more about how spirituality may be used in helping men to cope with the advanced part of their cancer journey.

If you currently have advanced prostate cancer, I invite you to participate in this study. You may find it beneficial to yourself to tell your story (confidentially) of surviving advanced prostate cancer, and to reflect on what this experience has meant for you. I am very interested in your experience. Talking to me would involve about an hour of your time in a place suitable to you. I hope that when the research is completed, and the (anonymous) results made available through publications, carers and health professionals, and other people, will have a greater understanding of the way men can be given even more support during their illness.

About the researcher
I retired from full-time work at the University of Southern Queensland in 2000 and soon after contracted bladder cancer, prostate cancer's neighbour! (I have been subsequently 'cleared' of my cancer.) I have been involved for some five years as a volunteer in Cancer Council Queensland's Cancer Connect and Community Education programs, and as a pastoral carer in Toowoomba Hospital. During these activities I have noted the prevalence of prostate cancer in our community. I would like to help men to be more comfortable within themselves during their illness. This study will lead to a PhD degree and has received approval of the USQ Human Ethics Committee.
If you would like more information, or would like to participate in the research, I would be grateful if you would contact me in any of the ways listed below. Participation will involve you talking with me about your 'spirituality' and your cancer for about an hour or so at a time and place convenient to you. Your privacy will always be respected.

Email: lepherd@usq.edu.au Phone: 07 4631 5459 (Business hours) Mobile: 0418 192 517 (Any time)
With best wishes
Laurence Lepherd

D Letter to individuals

Would you like to help others?

Many men going through a prostate cancer journey like to help others in a similar situation. If you would like to share your experiences so that you can help others to cope with their illness, here is another opportunity for you!

Men have found many ways to cope with the stress they experience during the many phases of prostate cancer. Many have found that their spirituality helps.

What is spirituality? Is it a belief in and reliance on God? This is probably true for many people. But, for others, it may be closeness to the land, or a deep sense of purpose and meaning in life, or personal fulfilment. Often spirituality is culturally related. Australian Aboriginal and Torres Strait Islander people have a spirituality closely connected with the land and with their cultural traditions.

Some people gain benefit through their religiously related beliefs – Christian, Buddhist, Islamic and others. Sometimes a person's spirituality may be through the arts – poetry, music, theatre, and the visual arts. Others find that their connection to other people or families can be very spiritual.

One common aspect for many men is that spirituality is something which 'transcends' every day life, something that lifts their spirit to something greater than the ordinary.

Above all, spirituality is very personal and individual. It differs from person to person. It is used in different ways by many people to cope. Writers are generally agreed that everyone has it!

How can I help? Share your experience!

If you have advanced prostate cancer – that is, your cancer has become non-localised and/or has metastasised to other parts of your body, you have probably been calling on your spirituality to help you cope. Would you like to share with others the way you cope using your personal spirituality? This sharing will most likely be a great help to others.

I am currently carrying out research into the spirituality of men with advanced prostate cancer. What is it for them? How may it help? How does it show itself in them? Through this research, I aim, through various publications, to assist men in understanding their spirituality in the hope that their experiences (shared and reported confidentially) might help others receive greater comfort during their cancer journey. **Please help by sharing your experiences with me, and later, with others.**

Please send me an email to lepherd@usq.edu.au , or, alternatively, you can phone me on 07 4631 5459 (office hours) or 0418 192 517 (any time). If you phone, please leave a message and I will return your call. I'd love to hear from you.

Laurence Lepherd
Centre for Rural and Remote Area Health
University of Southern Queensland

E Cancer Council Queensland Helpline

The following information relates to the Cancer Council Helpline.

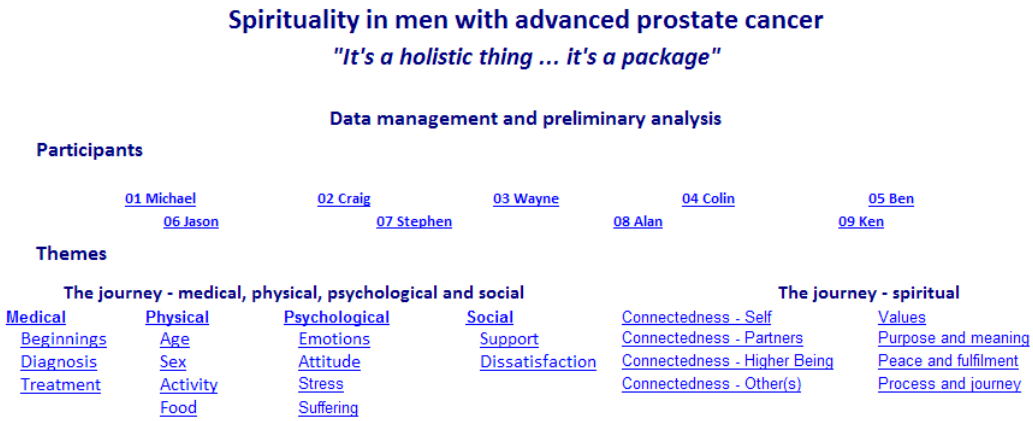
1. I phoned the Helpline and was able to speak directly to a Helpline staff member within 2.5 minutes.
2. The Helpline is open from Monday to Friday 8am to 6pm.
3. Areas of help include:
   - Information about cancer and cancer treatments;
   - Support in coping with cancer;
   - Referrals to cancer care and support services within Cancer Council Queensland; and,
   - Links to other sources of cancer information.
4. Initial contact through the Helpline is made with staff who are either nurses or social workers. Either way, they have degrees and have specific training in an initial assessment of a caller's 'problem' and telephone assistance techniques. They have specific knowledge of, and experience and training in, cancer-related issues.
5. While the Helpline staff member is capable of offering preliminary emotional support, if he/she assesses that the caller needs advanced emotional support, the staff member instigates a procedure whereby the caller is able to receive counselling by a fully qualified (APA accredited) counsellor.
6. Contact between the caller and the counsellor is normally made within a week.
7. In some circumstances, if the situation is assessed as an emergency by CCQ Helpline staff, arrangements can be made for immediate assistance, dependent on where the caller lives. This emergency help may involve contact by a doctor or, in some cases, a visit by the ambulance service for possible transfer to hospital. These arrangements are made by CCQ staff.
8. Counsellor contact may be face-to-face but 80% of communication is by telephone, whether or not the caller lives in an urban or rural area. Face-to-face contact is available in three regions in Queensland.
9. The cost of initial contact is that of a local phone call, no matter in what part of the state the caller lives.
10. Subsequent counselling is at no cost to the caller.

Laurie Lepherd
11 August, 2010

F Analysis processes

Please note that hypertext links on this page are not active.

Preliminary analysis key page



Hypertext link from preliminary analysis key page

Home Treatment

01 Michael
I was given two choices of treatment: surgical castration (removal of the testes), or hormone therapy treatment. …

02 Craig
Our GP got a letter from the specialist saying Craig is not a candidate for the radiation, so I'm putting him on hormone treatment and I will inject him every six months and I will get you to inject him the other three-month intervals in between. …

03 Wayne
I was put on a course of the drug Androcur to see how the cancer would respond to that. …

04 Colin
No, all of the treatment is the hormone therapy. …

05 Ben
So I had my holiday and came back and had the operation. I had the prostate removed. …

06 Jason
So they said, "well, it's progressed too far", and I said, "what options have I got?", and they said, "the only option you've got is hormone treatment". …

07 Stephen
So I said, "what are my options?", and he said, "well, you've got no options; you can have a hormone injection or nothing". That was it. …

08 Alan
The urologist said there was about a 35% chance that if we do take the prostate out we would get a cure. So I thought 35% is better than nothing so I'll go with that. So they did. …

09 Ken
So the prostate was removed and they found that the cancer was outside the gland. …

Themes evident in narratives

	Michael	Craig	Wayne	Colin	Ben	Jason	Stephen	Alan	Ken
General									
Food					x	x	x	x	x
Activity	x		x	x	x	x	x	x	x
Age	x	x	x		x				
Sex	x	x			x	x	x	x	x
Suffering	x	x	x	x	x	x	x	x	
Emotions	x	x	x		x	x	x	x	x
Attitude	x	x	x	x	x	x	x	x	x
Support	x	x	x	x	x	x	x	x	x
Dissatisfaction	x	x	x						
Stress	x	x	x		x	x	x	x	x
Connectedness									
Self	x	x	x	x	x	x	x	x	x
Partner	x	x	x	x	x	x	x	x	x
Higher Being	x	x	x	x	x	x	x	x	x
Others	x	x	x	x	x	x	x	x	x
Holism									
Connectedness	x	x	x	x	x	x	x	x	x
Purpose & meaning	x	x	x	x		x	x	x	x
Process & journey	x	x	x	x	x	x	x	x	x
Peace & fulfilment	x	x	x	x	x	x	x	x	x
Values	x	x	x	x	x	x	x	x	x