Faculty of Education and Social Work

Spirituality of Young People with Cancer
An exploratory study

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Submitted in partial fulfilment of the requirements
for the degree of Doctor of Social Work

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Author’s Declaration

This is to certify that:

I. This thesis comprises only my original work towards the Doctor of Social Work Degree.

II. Due acknowledgement has been made in the text to all other material used.

III. The thesis does not exceed the word length for this degree.

IV. No part of this work has been used for the award of another degree.

V. This thesis meets *The University of Sydney’s Human Research Ethics Committee (HREC) requirements for the conduct of research.*

Signature .................................................................

Name: Jennifer Ann Broadbent

Date:
Abstract

This study focuses on how young people with cancer understand, describe and experience spirituality. The motivation for the study was twofold. Firstly, there were gaps in the initial literature review, which revealed the data were drawn mostly from adults, reflecting on their own adolescence or as parents or healthcare professionals speaking for young people. This meant there was a distinct lack of empirical data from young people about their spirituality in a context of cancer. The second motivation was that in my two professional domains, social work and palliative care, while both espoused a holistic approach, I have found that the spiritual dimension has often been overlooked.

While the literature revealed spirituality is often seen as an alternative to religion and secularism, in this study, it included traditional religion and is described as the personal search for meaning and purpose in life, connection to self, others, places, or a Higher Being and transcendence beyond people’s daily lives and physical bodies.

This qualitative study used a phenomenological approach to explore and give voice to the meaning of spirituality for young people (12 to 24 years of age) in a context of cancer. I interviewed eleven participants who were recruited from CanTeen, the Australian organisation for young people living with cancer. Most participants opted for the ‘prompt’ questions in preference to the ‘free narrative’ interview style. The data analysis revealed that while many participants believed in a Higher Being or ‘something there’, others rejected belief in a Deity. Most participants’ experience of cancer had affected their spirituality temporarily or permanently, and this was consistent with previous studies. Both traditional spiritual practices (such as prayer and church attendance) and less traditional spiritual practices (such as voluntary
work and connecting with nature) were discussed. Participants reported talking to others about their beliefs and many were actively exploring other spiritualities through books, films, internet, and experimentation. Five significant themes emerged from the data: spirituality as a self-defined concept, spirituality as an evolving process, believing and exploring but not belonging, optimism and individualism. While some of these themes have been discussed elsewhere, this research adds new dimensions. The thesis closes with documentation of participants’ recommendations and discussion about inclusion of spirituality in social work practice.
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In my social work practice I have often emphasised to clients the importance of having a ‘support’ team who believe in them, support them through the challenges and celebrate their achievements. Undertaking qualitative research with consumers and writing a thesis also required a support team! I would like to thank the many wonderful people who generously gave their time, resources and expertise.

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Dedication

This thesis is dedicated to my dear friend, Lyn Voss (1960-2001), who provided the impetus for my interest and journey in the area of spirituality and my subsequent work and study in the areas of cancer, life-threatening illnesses, palliative care, and death and dying. Her love, energy and spirit continue with us in every beautiful rainbow.
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CHAPTER ONE

Introduction

Relevance of the research study

This study focuses on how young people — who currently have or have had cancer — understand, describe and experience spirituality. In this context, spirituality encompasses religion and is described as the personal search for meaning and purpose in life, connection to self, others, places, things or a Higher Being and transcendence beyond our daily lives. The study uses a phenomenological approach to provide an opportunity for young people with cancer to speak for themselves about their lived experience of spirituality.

The rates of diagnosis and death from life-threatening illnesses for young people are low, and there is a growing population of long term survivors of childhood cancer (Parry, 2002). For those young people who are diagnosed and live with a life-threatening illness such as cancer, and for those who may subsequently die from cancer, the effects of their illness or untimely death have an enormous impact on their life, their family and the wider community. As young people are entering adulthood, they are often well connected to their community through school, work, sport, family and community participation. Hynson, Gillis, Collins, Irving and Trethewie (2003) noted that “when a child dies, the community feels an immense sense of loss” (p521) because it is out of the ‘natural order’ for a child to die before the adults and elders of the community (Jones and Weisenfluh, 2003).

Often a diagnosis of a life-threatening illness will raise questions and concerns about the meaning and purpose of life, about mortality and about whether a
greater power exists (McClain, Rosenfeld and Brie Bart, 2003; Stuber and Houskamp, 2004). Healthcare professionals, such as social workers and oncology and palliative care clinicians, may become involved with young people and their families to provide support and guidance at this sensitive and vulnerable time. Healy (2005) has noted that people using social work services (‘clients’) may specifically turn to social workers to explore their religious or spiritual issues as they may view the social work profession as not directly aligned to any one religious or spiritual base.

The data from this research study will enable health and community professionals, supporting young people living with a life-threatening illness, to better understand and support young people’s spiritual needs and care. Since both social work and palliative care espouse a holistic approach and both work with young people who have or have had a life-threatening illness such as cancer, this research focuses on these two professional contexts. However, both social work and palliative care often marginalise or inconsistently include the spiritual dimension in their approach (Cox, 1985; Dane, 2004; Davies, Brenner, Orloff, Sumner and Worden, 2002; DeVeber, 1995).

I now briefly examine the relationship between social work and spirituality, and between palliative care and spirituality. This is discussed in greater detail in Chapter Two.

Social work perspectives

Over the last century, the degree of attention given to clients’ spirituality by social workers in Australia has been influenced by the impact of an increasingly secularised society and social work’s enthusiasm for acceptance within the scientific community (Lindsay, 2002; Rice, 2002). The profession has also been eager to distance itself from its religious origins, when assistance was based on moral judgments (Rice, 2002). Furthermore, social workers have often been reluctant to raise the issue of spirituality for fear of
being seen as imposing their own beliefs (Lyon, Townsend-Akpan and Thompson, 2001). However, over the last twenty years, social work has shown a growing interest in spiritual and religious influences (Pellebon and Anderson, 1999) and in the relevance of spiritual issues in social work practice. Proponents from both North America and Australia have argued that social workers who neglect the spiritual or religious beliefs of clients may be insensitive (Behrman, 2002; Jones and Weisenfluh, 2003; Lindsay, 2002; Pellebon and Anderson, 1999). Edwards (2002) and Kissman and Maurer (2002) (cited in Healy, 2005) have noted that clients’ spiritual and religious needs are inseparable from their other needs and are a key dimension of holistic care. Rice (2002) has also noted that restoring the spiritual dimension to social work practice just keeps pace with clients’ needs.

*The palliative care perspective*

Any description or definition of palliative care, whether in connection with a hospice or as a social movement or as a philosophy or model of care, is synonymous with and incorporates the notion of holistic and multidisciplinary care. This involves attention to the physical, social, emotional, psychological and spiritual domains (Davies et al, 2002; Noppe and Noppe, 1999). Rumbold (2002) noted that contemporary spiritual care, which encompasses religious beliefs, incorporates what was previously the domain of religion prior to the 1970s. He also considered that it provides an appropriate framework in a secular society such as Australia, to deal with a person’s existential or meaning-of-life issues. However, the practice in reality is that spiritual needs and care often receive the least attention, both in research and clinical practice (Davies et al, 2002).

In essence, this research topic, *The Study of Spirituality of Young People with Cancer*, relates to the social work profession’s growing recognition of re-connecting the spiritual dimension in a client’s experience to the bio-psycho-social-cultural factors (Rice, 2002). This thesis also relates to palliative care’s
attempts to include the spiritual dimension in its holistic and multidisciplinary care. The changes in social work and palliative care also coincide with a more general growing interest in spiritual matters (Taylor, 1994).

Origins of the research

In a professional sense, the importance of this topic has now been defined, so where did this topic begin and how did it develop for me, as the researcher? Many factors influenced the formation of this topic and I examine the intersection of the personal, the professional and the socio-political contexts. I describe the events and influences in my personal life; those in the professional realm cover my observations in my own social work practice and in the practices of other social workers and in the cancer and palliative care clinical areas. Finally, in the socio-political domain I look at the social, economic and political influences in the lives of young people in the twenty-first century. This is followed by a brief overview of the research study, definitions or descriptions of the key concepts, and an outline of the thesis.

The personal domain

Until the mid 1990s my personal life had been a rich mix of a supportive family, good health, satisfying employment, tertiary study as a mature aged student, extensive travel overseas and in Australia, fulfilling interests and activities, lifelong relationships and friendships, and my own home with a garden in Sydney. I had been blessed with no experience of serious illness or death in my childhood and I had enjoyed all four grandparents until I was 21 years of age. However, my personal world of relative innocence and indulgence was turned upside down when my best friend, Lyn, was diagnosed with breast cancer in 1996, whilst four months pregnant with her second child. It was a serious cancer and she immediately embarked on a life-changing journey and as her friend, I walked beside her, on a practical,
emotional and spiritual level. Although I had grown up as a Christian and through my travels had briefly explored other religions (Buddhism, Hinduism and Judaism), it was through the experience and exploration of deep emotions (following Lyn’s diagnosis) that my own spiritual journey was re-ignited and developed. Together, my friend and I discovered and experienced that ‘underneath’ our deepest and most challenging emotions of grief, loss, sadness, fear, anger, frustration, worry and so on, what supported us and provided a level of resilience, was a belief in and feeling of a connection to and closeness with people in our lives. This connection and intimacy extended to something greater than ourselves (which oscillated between ‘the universe’ and God or ‘Higher Being’). We considered that these profound and deep feelings were at the core of our being or spirit or soul, and in turn, our core was connected to or part of the universe or Greater Being, which resulted in feeling supported or nurtured. Sadly my beloved friend died in 2001. However, my interest in matters of spirituality continued as did my interest in life-threatening illnesses and death and dying.

The professional domain

Around the same time as my interest in spirituality was renewed, I began to notice its absence in social work. I observed that spirituality was generally not included in a regular social work assessment, alongside questions about biological, social, emotional and psychological aspects. Interestingly, when I changed clinical areas from child and adolescent mental health and child protection, to cancer and palliative care, I had expected greater acknowledgement of the spiritual dimension, however, it was still omitted. I remember one social worker in palliative care informing me ‘that spirituality/religion was not really relevant in a secular society’. Yet both social work and palliative care espouse holistic practice. I had two concerns with this. Firstly, I was concerned that we were not being truly faithful to social work values and ethics or palliative care policy and protocols. Secondly, I was
concerned that we might be doing clients a disservice by omitting a vital part of their life and a significant resource to call upon.

The socio-political context

At the same time, I was aware that many Australians, and particularly young people, were less interested or not participating in traditional religion. I was also aware that young people’s experiences of adolescence reflected something more than a transition from childhood through to adulthood: they were living during a unique period of time. While developmental psychology implies that the transition is context-free, social workers operate from a perspective that there is always a context, it always ‘depends on the circumstances’. Some of these changes include that young people are studying and living at home longer (McCrindle, 2006; Smoking Gun Productions (SGP), 2008), that they have high levels of debt and low levels of home ownership, that technology in all its forms is ‘part and parcel’ of daily life (SGP, 2008), that individualism and consumerism are their mantras, that the environment is under duress, and that significant national and world events have taken place in recent years (for example, September 11, the Bali bombings in 2001 and 2002, the subsequent wars in Afghanistan and Iraq and the Global Financial Crisis of 2008).

Notwithstanding Australians’ declining interest in traditional religion since the 1970s, there has been increased interest in non-traditional, evangelical religions (such as the Pentecostal Church) and alternative spiritualities, as an alternative to religion and secularism (Kohn, 2003). Signs of spirituality are evident in a range of diverse ways and they reflect a focus on individualism. Mainstream bookshops devote sections to New Age spirituality. Self help groups such as Alcoholics Anonymous and cancer support groups promote a belief in a higher power (Taylor, 1994). Spirituality is also prominent in music (for example, chanting), art, dance, exercise (for example, yoga, tai chi, martial arts) and nature (for example, activists and indigenous people’s
connection to the land, forests, oceans, mountains) (Taylor, 1994). It also has a role in food (for example, vegetarianism, organics, macrobiotics), in healing agents (for example, crystals/stones, affirmation/prayer cards) and psychiatry has included ‘spiritual emergencies’ in its Diagnostic and Statistical Manual (Taylor, 1994).

The research study

When I commenced this research study in 2006, there was a distinct lack of recent empirical data from young people themselves about life-threatening illnesses and about their spirituality. Most of the literature was drawn from an adult perspective, as adults reflecting back to when they were young, and as parents and healthcare professionals speaking on behalf of children and young people (Hutchison, King and Hain, 2003; Hynson et al, 2003; Judd, 2001; McSherry, Kehoe, Carroll, Kang, and Rourke, 2007). For this reason, I adopted a phenomenological approach to facilitate giving ‘voice’ and validity to the lived experiences of the young people themselves. There were broad areas I was interested in exploring with the participants: whether questions of meaning and purpose interested young people, whether there was a relationship between spirituality and the cancer experience, whether young people had a similar or different spirituality to their families, whether social demographics such as gender and class influenced young people’s interest in spirituality and the nature of young people’s spirituality.

Eleven participants, who were aged between 12 and 24 years, and who were at least three months after their cancer diagnosis, were engaged in the research study. They were recruited from CanTeen (the Australian organisation for young people living with cancer). I used traditional qualitative methods, such as face to face interviewing, and I also employed technological methods that were age appropriate to young people, for example, a website blog. The interviews were conducted at CanTeen offices, local libraries and at their homes. Almost all participants were interviewed...
once only with the duration of interviews ranging from 85 to 155 minutes. The transcribed interviews were coded into Nvivo 8, a computer supported qualitative data analysis program, and categories and themes were developed from the research questions and from the data itself.

**Key concepts**

*The participants*

While a number of different terms are used in the relevant literature (‘child’, ‘children’, ‘teenager’, ‘adolescent’, ‘youth’, ‘young people’, ‘young person’, ‘Generation Y’ and ‘Gen Y’) to describe the research cohort of interest in this study, I use the term ‘young people’ to describe those aged 12 to 24 years of age. However, as some of the literature does not distinguish between children (generally up to 12 years of age) and young people or adolescents (usually from 12 years of age), or refers to all dependent young people as ‘children’ or ‘young people’, or where the data referring to younger children is relevant for this research study, this literature is also included. The language used therein (‘children’, ‘adolescent’, ‘young person’, ‘youth’ and so on) is also repeated when reference to that literature is made in this thesis.

Since the participants are aged 12 to 24 years and all have experienced a life-threatening illness necessitating prolonged treatment, it is quite likely that their families will be relevant and involved in their lives at least to some degree. For instance, while 12 to 18-year-olds are generally dependent and reliant on adult carers (socially, financially and/or emotionally) there are many young people aged 18 to 24 years currently living at home, often due to housing and higher education costs. In these circumstances, they are often living with their family in a family context with varying degrees of independence. Consequently, this research cohort is also viewed in the
context of their family system, and hence ‘family’ or ‘families’ in this research will refer to the parents, siblings, carers or extended family of the young person.

*Cancer, life-threatening illnesses, palliative care*

This study focuses on the potentially life-threatening illness of cancer. The Australian Institute of Health and Welfare (AIHW) (2007) described cancer as representing a range of diseases in which cells become abnormal, grow in an uncontrolled way and form a mass called a neoplasm or a tumour, which can be benign or malignant. While benign tumours do not spread to other parts of the body, malignant tumours can spread to other parts of the body (metastasis) and can develop from most cell types in the body (AIHW, 2007). While cancer is the focus of this study, I have reviewed and included the literature on serious illnesses where it relates to young people. This may be termed ‘critical illness’, ‘chronic illness’, ‘life-limiting illness’, ‘life-challenging illness’, ‘life-threatening illness’ or ‘terminal illness’. What separates these illnesses from other regular illnesses is that while these illnesses may be curative through medical intervention, there is also a chance of mortality (Collins, 2002).

Again, notwithstanding that the focus of this study is cancer, the literature on cancer often discusses dying and death as a possible consequence of cancer or as part of the illness trajectory, and hence I have included these data so far as they relate to young people. I also anticipated there was a possibility that in the interviews, the participants might discuss or mention dying and death, even though there were no specific questions about dying and death. Hence words and expressions such as ‘dying’, ‘palliative care’, ‘palliative approach’, ‘end-of-life care’ and ‘terminal care’ are used to describe the time and/or care preceding death when there is no further active or curative treatment available. Nonetheless, the term ‘palliative care’ and the like can mean different things in different contexts and this is discussed in more detail in
the literature review (Chapter Two). For the purposes of this study, Schrijvers and Meijnders (2007) provided a useful definition of palliative care: “... as supportive care to optimize comfort, function and social support of the patient and the family when the illness is not curable anymore” (p616). They also made an important point that palliative care in “adolescents has an extra dimension since it should take into account the normal physical and psychological changes associated with adolescence, including attainment of independence, social skills, peer acceptance and self-image building” (p616).

**Spirituality, religion and faith**

In the literature, the terms ‘religion’, ‘spirituality’ and ‘faith’ are sometimes used interchangeably as each shares a belief in the unconscious and/or external sources of spiritual knowledge or insight (Pellebon and Anderson, 1999). However, there are subtle differences. ‘Religion’ tends to be a formalised and structured practice in a group setting “with an integrated belief system about behaviours, the meaning of existence and death and reverence for supernatural being or beings” (Pellebon and Anderson, 1999). While the concept of ‘faith’ is often connected to organised religion, Fowler (1981) defined faith as a person’s or group’s way of “… finding coherence in and giving meaning to the multiple forces and relations that make up our lives” and as “a person’s way of seeing him- or herself in relation to others against a background of shared meaning and purpose” (p4). Boeving (2003), drawing upon Fowler (1991), noted that “each person has a need to have faith in something, and that something is variable -- a god figure, a concept of the universal whole, even oneself” (p8).

In contrast to religion, ‘spirituality’ has been found to be a more individual experience (with or without a structured belief system) which has three dimensions: meaning, connection and transcendence. Specifically, spirituality “is the general human experience of developing meaning, purpose and morality” (Canda, 1989 cited in Pellebon and Anderson, 1999). It also
involves connectedness with places and things, with oneself, with significant others, with groups and communities (Rumbold, 2003) and a relationship with God, with a Higher Being, with a creative force or the universe (Kane, Barner, John, Tichenor and Camp, 2000), or “a transcendent dimension of existence” (Peterman, Fitchett, Brady, Hernandez and Cella, 2002) beyond the human experience.

There are a few qualifying comments about spirituality. Firstly, Rumbold (2002) and Walter (2002) argued that spirituality is closely aligned with and difficult to separate from emotional needs and issues. Spiritual and emotional concerns are blended together in comments such as the notation of Sommer (1989) that in facing death “… we are … destined to know the agony of self-doubt and confusion, destined to feel the pain of sadness, fear, guilt and loneliness” (p229). As well as the spiritual dimension, the intensity of feelings is significant and it is sometimes through deep expressions of emotion that spiritual awareness develops.

Secondly, differentiating religion and spirituality, Walter (2002) reflected on feminist spirituality in Britain and North America and considered that if religion had to do with the institutional, and therefore patriarchal church, then it was spirituality that women sought. He also noted that spirituality was largely a female discourse, such as a discourse of healing and caring (p136).

Thirdly, in the study by Mason, Singleton and Webber (2007), who looked at the spirituality of young people in Australia, the researchers described ‘spirituality’ as “a conscious way of life based on a transcendent referent” (‘a conscious way of life’ pre-supposing some element of reflectiveness and ‘transcendent referent’ meaning a reality that is beyond the individual, either something that is supernatural or religious or otherworldly (Singleton, Mason and Webber, 2007, p250). Their early pilot study revealed that many of the younger adolescents found the language of ‘spirituality’ difficult to
understand, and this alerted me to the premise that the language of ‘spirituality’ may not be accessible to some of the research cohort.

Fourthly, from my social and professional observations, ‘religion’ and ‘spirituality’ are often seen as separate entities, and people who follow a traditional religion often identify as ‘spiritual’: sometimes exclusively, sometimes in conjunction with their ‘religion’ identity, and sometimes as a way of avoiding negative connotations associated with traditional religion. However, people who identify as ‘spiritual’ generally do not see themselves as connected to an organised traditional religion and are often explicit that they are ‘spiritual but not religious’. Nonetheless, spirituality in this study is viewed as the overarching concept, which will include ‘religion’ and ‘faith’ as a part of spirituality. The terms ‘religion’ and ‘faith’ have been purposely included in the research documents provided to the participants as this language may assist some participants to express themselves or to access their own opinions and ideas. Even so, in the interviews with the participants, I provided the following description of spirituality as a guide:

“Spirituality can mean different things to different people. In this research, it includes traditional religion and is described as the personal search for meaning and purpose in life, connection to oneself, others, places/things, groups or communities, or a Higher Being, and transcendence beyond our daily lives and our physical bodies.”

Outline of thesis

In this chapter I have explored the importance of the topic: that there has been a dearth of research to inform us about young people’s spirituality in a context of a life-threatening illness. In addition, the spiritual dimension in the holistic approach of social work and palliative care has often been marginalised. I have also looked at the origins of the research study from a personal, professional and broader socio-political perspective and I have
provided definitions or descriptions of the key concepts in the research: the participants, the nature of cancer in relation to young people, and spirituality, religion and faith.

Chapter Two comprises the literature review in four sections. Firstly, I look at the group or generation of young people (often known as ‘Generation Y’) who are the subject of this research from a demographic and sociological perspective in Australia. Secondly, I examine the epidemiological data about young people and cancer in Australia, and the experiences of young people and their families with regard to cancer. In the third section, I look at spirituality in contemporary Australian society, spirituality from a human development perspective, and spirituality, young people and the health and illness trajectory. In the last section, I discuss two professional contexts relevant to the research topic: social work and palliative care.

In Chapter Three, I examine my methodological approach to the research study. This includes my epistemological approach and theoretical perspective, ethical considerations and the methods employed for data collection and data analysis from a phenomenological approach.

Chapter Four comprises the findings of the study and begins with a demographic and descriptive profile of the participants. This is followed by a comprehensive account of the participants’ experience of cancer at three points, during diagnosis, during treatment and the post-cancer phase. Prognosis, concerns and positives from the cancer experience are also discussed. I then explore the phenomenon, the focus of the study: spirituality. This is discussed in terms of beliefs, practices, influences, relationships, worries and concerns and relevance.

In Chapter Five I discuss the key concepts or themes emerging from the research data: spirituality as a self-defined concept, spirituality as an evolving process, believing and exploring but not belonging, optimism and
individualism. I also provide a narrative in relation to the spirituality of young people with cancer, and a grand-narrative in relation to the lives of young people with cancer. Furthermore, I look at the research experience, both the participants’ involvement and my own reflections and observations. This chapter concludes with an outline of the strengths and limitations of the research study.

In the final Chapter Six, I discuss the participants’ recommendations for health and community professionals and implications for my social work practice, along with some concluding comments.
CHAPTER TWO

Literature Review

In the previous chapter, I established that the motive for this research study was conceived from there being insubstantial recent empirical data in the related areas of young people and cancer, and young people and spirituality. I also drew attention to the fact that spirituality (particularly its meaning-making component) was a relevant and important factor in people’s lives that was often omitted from the professional domains of social work and palliative care practice, both of which emphasise holistic assessment and care as a pivotal element of their practice.

In this chapter, I now examine in detail the relevant literature and past research studies in four key areas: young people in the twenty-first century, young people and cancer and life-threatening illnesses, young people and spirituality, and spirituality in social work and palliative care contexts. At the beginning of each of the four sections, I outline the topics to be described and discussed.
SECTION ONE

Young people in the twenty-first century

INTRODUCTION

In this section, I provide a generic profile of young people in the age range of the research cohort in this study. I commence with a definition of the generation of young people and this is followed with relevant demographic data and the circumstances of young people’s lives in the current social, economic and cultural context in Australia. I make brief comparisons and references to previous generations and to young people in one other country and I conclude with outlining some of the health, economic and cultural challenges and issues that young people currently face. This chapter provides a sociological perspective, and bio-developmental and psychosocial developmental processes are examined in the context of spiritual development, discussed later in this chapter.

Generation Y

In this thesis, I draw on the literature relating to Generation Y as it provides useful socio-cultural data and it neatly corresponds with the research cohort, young people 12 to 24 years of age, at the time of interview (from 2007 to 2010). While this term is used to describe a whole population of young people, I am aware that this is a generalised term and like all generalisations, it is likely to exclude some young people.

According to Australian social researcher, McCrindle (2006), young people are often described by the widely-used term ‘Generation Y’ (hereafter, in the
text, referred to as ‘Gen Y’) and less commonly as ‘Millenials’ and the ‘Dot.Com generation’. Australian sociologists and youth researchers, Wyn and Woodman (2006) argued that Gen Y is a preferable term to ‘youth’ and ‘adolescent’ because the latter denotes a transitional stage or phase of life (for example, school to work) and generally ignores the current societal context. In brief, generations usually span 15 to 20 years and according to Owen (2006) they “are typified and defined by sets of attitudes formed under the influence of family and other societal experiences” (p37). Wyn and Woodman (2006) broadened the description of ‘generation’, adopting a structural functionalist sociological perspective, as “people who belong to a common period of history, or whose lives are forged through the same conditions” and have “a ‘generational consciousness’” (p496) and that “each generation is located within its social, political and economic milieu” (p497).

There is some debate about the exact year boundaries of Gen Y. Mason et al (2007) reported that some authors used 1976 to 1990, while others used 1981 to 1995, as defined by the Australian Bureau of Statistics (ABS). Like Mason et al (2007), who adopted the age boundaries of the ABS, I have also used the latter definition and consequently references to previous generations refer to Generation X as representing people born between 1966 and 1980 and Baby Boomers as born between 1946 and 1965.

Demographic characteristics of young people in Australia

Statistical data relevant to this research study (for example, numbers of young people, their residential distribution, country of origin, family structure and household composition) have been drawn from the AIHW (2007). In June 2006, there were approximately 3.7 million young people in Australia, representing 18% of the total population, with indigenous young people making up only 3.4% of all young people in Australia (AIHW, 2007). In 2005,
68% of young people lived in major cities, 20% in inner regional areas and 9% in outer regional areas. In 2006, young people aged 15 to 24 years of age born overseas represented 16% of young Australians (AIHW, 2007). While the nature of family households varied, in 2003 the majority of young people still lived in couple families (80%) as compared to lone parent families (20%) (AIHW, 2007). From these statistics, a number of factors arise as relevant for this research study. Firstly, the most striking point is that young people live in diverse families and households and this characterises the young people in this study. Secondly, young people represent approximately one-fifth of the Australian population and as such, they are a substantial group, which rather than being viewed as at a transitory point from childhood to adulthood, should be considered a separate entity in terms of services, programs and policies. Thirdly, as most young people live with their families, this supports the inclusion of relevant literature and research data on young people’s families.

Social, economic and cultural context

McCrindle (2006) noted that Gen Ys are “… derided as fickle, self-focused, and transient” but he aptly recognised that “they just reflect their times” (p12). He argued that Gen Ys have lived through significant national events, such as the Thredbo landslide (1997) and the Bali Bombings (2002 and 2005), as well as international events such as the New Millennium, the age of the internet, cable television, September 11, globalisation and environmentalism. It may be that McCrindle has over-reached with some of his examples, but his point is that there have been significant events in the lives of Gen Y. Of course, since McCrindle’s report, there has also been the global financial crisis in late 2008. As there have been significant shifts in the Australian landscape since the 1970s (which cover both Generation X and Y), some of these changes are detailed under the following sub-headings: education,
employment, health, relationships, families and households, communication and information technology, and values, beliefs, and characteristics.

**Education**

Since the 1970s, the number of people in their twenties with a tertiary education qualification has increased from 38% to 45% for men and from 24% to 45% for women. Post-compulsory education (education beyond the school leaving age) is now a normative experience for Australian young people according to Wyn and Woodman (2006). Driven by the needs of the economy, more vocationally oriented education provided the particular skills the economy needed (Wyn and Woodman, 2006). The Australian Government promoted post-compulsory education in the 1980s by implementing policies for income support being paid only to young people over the age of 18 or those engaged in education or training or employment (Wyn and Woodman, 2006).

**Employment**

Since the 1970s, the level of participation of men in their twenties in the labour market has decreased slightly from 92% to 87%, while women’s employment has increased from 57% to 75%, suggesting that work for women was more than an interim arrangement until marriage (Wyn and Woodman, 2006). On the downside, though, there has been a substantial increase in non-standard work hours as well as short term, part time and contractual work. This age group also experienced high rates of unemployment, and while many combined work and study (Wyn and Woodman, 2006), others had difficulty gaining places in tertiary education (Eckersley, Wierenja and Wyn, 2005).

Furthermore, young people in their twenties were three times more likely to change jobs in a year than those aged in their forties and fifties. Young
people also looked for opportunities to retrain for another career or work overseas, and sought post-compulsory education options (McCrindle, 2006). McCrindle noted that changing jobs had become the ‘norm’ and led to Gen Ys often being criticised for their lack of loyalty or poor work ethic. However, he considered it was more the result of a new work environment where there was little job security and a competitive environment was commonplace. He also noted that Gen Ys looked for a work environment that not only provided opportunity and challenge, but also a place where they could interact socially and work collaboratively.

In brief, we can see that the education and employment landscape has changed enormously since the 1970s. While job security and loyalty were once valued, flexibility and different options are now a standard work practice and expected by employee and employer alike. Later on we will see that each of the participants in this study was engaged in their own individual vocational pathway, combining education (secondary and tertiary) and work (full time, part time, casual and voluntary).

Health

Life expectancy at birth has improved over the last 20 years, as have death rates among young people 12 to 24 years of age. They halved between 1980 and 2004, largely due to decreases in deaths owing to injury (for example, transport accidents, suicide and drug dependence disorder) (AHIW, 2007).

Not surprisingly, then, young people rate their health very positively. Over the last 20 years, the number of young people with a severe disability represented only 2% of young people, asthma prevalence declined from 16% to 13%, melanoma incidence decreased by 23% for males and 14% for females, the incidence of most vaccine-preventable communicable diseases was low and increasing proportions of young people were free from clinical tooth
decay (AIHW, 2007). Areas of concern relating to health are discussed later in this section.

Relationships, families and households

Since the 1970s, both men and women have been marrying and having children later and living in a range of different households and traditional and alternative relationships. These include group households with predominantly people of the same age, multi-generational households with parents and siblings, de facto relationships and on their own (Wyn and Woodman, 2006). Again, we will see that the participants in this study reflect this. While more people in their twenties in 2001 were living in group households than previous generations (Wyn and Woodman, 2006), by 2008 50% of Gen Ys lived at home with their parents (SGP, 2008). This was partly due to housing affordability. At the time (and no doubt still current), Gen Ys were paying six to ten times the average wage for an average house compared to Baby Boomers who only paid two to three times the average wage (SGP, 2008). More young people studying into their twenties (McCrindle, 2006) and the cost of tertiary education were also factors. Nonetheless McCrindle (2006) noted that Gen Ys have a strong relationship ethic and living at home allowed them to nurture their relationship with their parents and family (Wyn and Woodman, 2006).

This description, though, is not the case for all young people. Eckersley et al (2005) reported that for some young people, family life was one of conflict, abuse and neglect, and/or poverty, disadvantage, inequality and parental unemployment. Reporting on an American study (Luthan, 2003), Eckersley et al (2005) noted that young people in affluent families “may in fact be more likely that other children to suffer substance use problems, anxiety and depression … as a result of excessive pressure to achieve and isolation from parents” (p16). It is reasonable to expect that this is also the case in Australia.
Communication and information technology

As noted, Gen Ys were born during the boom of the internet and its technological incumbents and many have grown up enjoying instant satisfaction and “everything at their fingertips” (SGP, 2008). The internet and other forms of technology have been considered an essential part of young people’s life as they use email, online games, online journals, facebook, myspace and messaging as their preferred mode of communication (SGP, 2008). Many young people have also created an online representation of themselves and spend large amounts of time, or have become addicted to their virtual life on the internet (SGP, 2008). Mackay (cited by Wolters, 2010), a consistent and enthusiastic proponent of Gen Y, emphasised that young people were not only unfazed by modern technology, they actually thrived on it.

Values, beliefs and characteristics

Like other generations, there are a number of values, beliefs and characteristics that influence Gen Y. I confine the discussion to the following: individualism, materialism/consumerism, egalitarianism, political interest, religiosity, optimism, and resilience. Foremost, Mason et al (2007) considered that Gen Ys have an over-riding and sacrosanct attachment to individualism. This is evidenced by young people’s belief that truths are based on personal experience or science, that individual rights, in a context of human rights and social justice, are preferred to laws, and that morals are relative to the person or situation, rather than there being definite rights or wrongs (Mason et al, 2007). The latter point was illustrated by a candid comment made by one young person in a Sydney newspaper article, “we learn our morals from other people’s experiences” (Jopson and Murray, 2009). Furthermore, self-sufficiency and self-responsibility are key elements of individualism. To this end, by becoming educated and looking after their physical and mental health with diet and exercise, young people in Australia and also the United Kingdom
and Scandinavia (Wyn and Woodman, 2006), are more likely to accept responsibility for creating their future life. They also strived for balance in their lives, ensuring they had the resources to engage in ‘present-centred experiences’ (Wyn and Woodman, 2006; Eckersley et al, 2005).

The other significant value for young people is materialism and its associated practice of consumerism. Gen Ys’ focus on materialism: the pursuit of money and the acquisition of possessions by shopping for the latest technological equipment and devices, amongst other things, has meant that in Australia 40% of 18 to 24-year-olds have personal debts (SGP, 2008). Watson (2009) noted that while young people have enjoyed easy credit, they have also been “aggressively targeted by banks and financial organisation with pre-approved credit cards” (p1).

Moreover, Mason et al (2007) noted that while Gen Ys subscribed to egalitarianism, in practice they had a low level of social concern for others. Similarly, Huntley (in SGP, 2008) noted that only a small minority were heavily involved in politics, with the majority of Gen Y being disinterested, apathetic or cynical about politics at any level (SGP, 2008). Likewise, Eckersley et al (2005) noted that Gen Ys were abandoning traditional religions — with beliefs in a Higher Being — and were developing their own meaning-making and embrace “eclectic, hybrid, deeply personal expressions of spirituality” (p39). Mason et al (2007) also noted that Gen Ys were tolerant of people who followed traditional religion but they would challenge those who forced their beliefs on them. Spirituality is explored in greater detail in the third section of this chapter.

Lastly, Gen Ys have a propensity for resilience and optimism. They have been found to have an ability to cope and adapt to a changing environment. In fact, they thrive on change, which makes them more resilient to potentially negative conditions and circumstances. This also gives them capacity to be positive about their possibilities and they can afford to ‘keep their options
open’, as Mackay coined it (cited in Wolters, 2010). Moreover, they can also be optimistic about the future because as Mackay noted, “they have learned how to adapt, learned how to be flexible, how to incorporate uncertainty and unpredictability in their approach to life” (cited in Wolters, 2010). We will see that resilience and optimism, as well as individualism, resonate in the participants’ accounts of their experience.

**Generation Y: comparative findings**

*Generation Y, Generation X and Baby Boomers*

In brief, Gen Ys live in an international society that is the subject of rapid change and technological enhancements (Owen, 2005). They also work in a globalised labour market and economic deregulation has contributed to insecure work (Eckersley et al, 2005). Gen Ys are studying longer and living at home longer, they value relationships with their family and friends, they accept their responsibilities, and they present confidently and are optimistic about the future. In contrast, when Gen Ys’ Baby Boomer parents were teenagers it was the ‘swinging sixties’, when work was very easy to find. Work, even now, is an extremely important part of their identity (Consumer Trends Discussion 2002 (CTD) cited in Owen, 2005). Baby Boomers were politically active (Savage, Collins-Mayo, Mayo, Cray, 2006) and one of their main characteristics was to challenge. They wanted “to be an individual, to confront, doubt, ask questions and change” and to “fight for their rights” (CTD cited in Owen, 2005, p37). Quite differently, the teen years of Generation X (the generation between Gen Y and Baby Boomers) were in the boom years of the 1970s and early 1980s. As they entered the workforce, however, the recession began and “there were large scale redundancies and down-sizing” (CTD cited in Owen, 2005, p37) that led them to develop a sense of cynicism. Owen was of the view, though, that this generation was non-confrontational about their views and tolerant of others’ different views.
They were also less influenced by money and possessions and strived to balance “life, friends and family, work and play” (CTD cited in Owen, 2005, p38).

**Generation Y in Australia and the United Kingdom**

Remarkable similarities between young people in Australia and the United Kingdom (UK) are noted in the large empirical research study of Savage et al (2006). The experiences of young people in the UK are discussed in three areas: information technology, religion, and education and the labour market. Firstly, and not surprisingly, young people in the UK were highly engaged with information technology. Computers, emailing, text messaging and the internet were a standard in their lives (Savage et al, 2006). Secondly, with the bulk of manual and unskilled jobs in the UK being outsourced overseas, young people were being strongly encouraged to continue their education so they could provide a skilled and flexible labour force for the economy. Nonetheless, young people accepted the uncertainties of employment and were self-reliant and looked to their families for support and help (Savage et al 2006). Thirdly, the study found church attendance to be generally low for young people, although many were happy to attend for special occasions such as weddings and christenings. The study also found that some churches were faring better — particularly those that employed professional youth workers or who were charismatic churches. Young people saw God as a benevolent, personable figure and they supported the notion that beliefs and practices should be selected and interpreted according to the individual’s need. Overall, young people were described as having a ‘happy midi-narrative’ where they were essentially concerned for their immediate circle: self, their friends and their family.

To this point, the data on Gen Y have reviewed the social, economic and cultural context of young people’s lives. To some extent it is an optimistic picture. More young people now have a tertiary education qualification than
previous generations, they have adapted to their insecure work environment, 
they enjoy good health, they are living at home longer, they are 
technologically astute, they have abandoned traditional religion and 
developed their own meaning-making, and they value material possessions 
and the rights of the individual. While Gen Y Australians are different to 
previous generations, they are remarkably similar to their UK counterparts. I 
now present another angle to the lives of Gen Y — the challenges they 
experience.

Contemporary challenges and issues faced by Generation Y

Health issues

Today most young people are resilient and adapt to changing social conditions 
well. Their health, measured in terms of life expectancy and mortality, 
continues to improve. However, Eckersley et al (2005) reported that many 
young people are not faring well and some of their main health concerns are 
as follows. Foremost, injury, including poisoning, continues to be the leading 
cause of death for young people. Of the deaths as a result of injury, transport 
accidents accounted for 45% and intentional self-harm accounted for 27% 
(AIHW, 2007). Secondly, mental disorders (from psychoactive substance use, 
schizophrenia and depression) accounted for almost 50% of the total disease 
burden among young people in 2003 (AIHW, 2007). Thirdly, hospitalisations 
for diseases such as Crohn’s disease and diabetes have increased over the last 
15 years and notification rates for transmittable disease such as whooping 
cough and chlamydia have also increased (AIHW, 2007). Fourthly, in 2004-
2005, one-quarter of young people were overweight, obese or inactive. This 
puts them at risk of diabetes, heart disease and some cancers (AIHW, 2007; 
Eckersley et al, 2005). Fifthly, suicide and drug related deaths have 
decreased as a result of help-seeking behaviour rather than the problem 
diminishing (Eckersley et al, 2005). Sixthly, melanoma remains the type of
cancer with the highest incidence rate among young people. Lastly, almost 31% of young people drank alcohol in amounts that put them at risk or high risk of alcohol-related harm in the short term and 11% at risk of long term harm. Around 17% of young people were current smokers in 2004 and young women were more likely to smoke during pregnancy than mothers in other age groups (AHIW). Population groups where higher rates of death, injury, chronic diseases and hospital admissions were found concern: young indigenous people, young people in regional and remote areas and young people suffering sociol-economic disadvantage (AIHW, 2007). In sum, cancer (in particular, melanoma) is amongst the significant health issues faced by young people today and some risk-taking behaviours young people are engaged in are also linked to cancer.

**Economic challenges**

Gen Ys’ insecure income due to the casualisation of the labour market has resulted in many young people being left without superannuation, sick pay, and long service leave (Eckersley et al, 2005). This, of course, means that many young people will never own their own home, will carry debts from their education, and raising a family will require two incomes. Eckersley et al (2005) noted that Gen Ys were aware of Australia’s ageing population and the likelihood that they will need to support older generations of Baby Boomers in their ageing years. Furthermore, while some dimensions of gender inequality have improved (for example, in education), there continues to be unequal outcomes in terms of pay, which means educational success does not necessarily lead to occupational success (Eckersley et al, 2005).

**Cultural challenges**

As well as the more visible pressures facing young people today in western society such as an uncertain transition to work, the rising cost of higher education, family breakdown and isolation from parents, there are cultural
concerns. Namely, the pervasiveness of two values that young people are attached to: materialism and individualism (Hodder, 2007). Materialism and individualism, both integral parts of the modern capitalist economy in western society, present dilemmas. Materialism may bring satisfaction in the form of material objects — albeit perhaps momentary satisfaction — however there is dissatisfaction when material goods are not enough to sustain happiness because isolation and anxiety remain (Eckersley et al, 2005). Materialism can also lead to the commodification of things like spiritual beliefs and practices. Similarly, Hodder (2007) identified that individualism often brings a dilemma. It can facilitate self-fulfilment but the development of the autonomous individual can also draw people away from the community (Hodder, 2007; Eckersley et al, 2005). In contrast, Mackay (cited in Wolters, 2010) reported that young people were committed to and feel connected to their family and friends. A further cultural challenge is the influence of the media, which provides thin, superficial narratives. Eckersley (cited in Eckersley et al, 2005) called these a ‘cultural fraud’ because they promoted images and ideals that serve the economy but do not meet psychological needs or reflect social realities.

CONCLUSION

In sum, it has been suggested that Gen Ys have significant challenges in their lives in the form of insecure and uncertain employment, housing affordability, personal debt, high rates of mental health problems, the tyranny of choice, and the driving forces of the media to name a few. At the same time, though, they are experiencing higher levels of tertiary education and improved health outcomes, they embrace and adapt to changing conditions with relative ease, and they are confident and optimistic about technology, the global market and society. In later chapters, we will see how the participants, the subject of this study, compare with the generic profile of young people in Australia. In the next section of this literature review, I
examine the relevant context of the lives of the participants in this study: the experience of cancer.
SECTION TWO

Young people with cancer

INTRODUCTION

In the previous section, I examined the socio-cultural context of the lives of young people in contemporary Australian society, corresponding with the age range of the participants in this study. This section now looks at young people’s experience of cancer, which represents the context of the lives of the participants in this study. Firstly, I consider the epidemiological data in relation to young people’s experience of cancer and cancer-related deaths in Australia. This is followed by an examination of young people’s experiences of living with cancer and their understanding of death and dying. The section concludes with an exploration of the experience of families of young people living with cancer.

While the focus of this study is young people, as noted earlier, information relating to children is included where it is relevant or where there is no clear distinction made between children and young people in the literature. Moreover, while the focus of this study is young people’s spirituality in a context of cancer, the literature on cancer often discusses dying and death as a possible consequence of cancer or as a part of the illness trajectory and hence this literature has been included so far as it relates to young people.
Epidemiological profile of cancer for young people in Australia

The incidence of cancer in young people

The 2007 data from AIHW indicated that young people experienced different cancers to adults. As at 2007, the leading cancer diagnoses for adults were colorectal, breast and prostate cancers whereas for young people it was melanoma (30%), Hodgkin’s disease (11%), testis (9%), leukaemia (9%), followed by thyroid, non-Hodgkin’s lymphoma, bone, brain, connective and soft tissue, colorectal and other cancers (AIHW, 2007). There were also gender differences in the types of cancers experienced by young people. Melanoma, Hodgkin’s disease and cancer of the thyroid were more common among females, whereas more males were diagnosed with non-Hodgkin’s lymphoma and leukaemia (AIHW, 2007). Interestingly, while incidence rates of melanoma, testicular cancer and Hodgkin’s disease increased with age for young people, rates for leukaemia decreased (AIHW, 2007). These statistics are revisited in the Findings chapter alongside the data of the participants in this study.

Even though the incidence of cancer among young people in Australia is relatively uncommon compared to the general population, it is the sixth leading cause of disease among 15 to 24-year-olds and it “accounted for an estimated 9% of years of life lost due to premature mortality, and less than 1% of years of ‘healthy’ life lost due to poor health or disability” (AIHW, 2007, p42). Specifically, in 2002, there were 943 new cancers diagnosed in young people and in 2004-5, there were 4,995 hospital admissions for 12 to 24-year-olds with a main diagnosis of cancer. This represented less than 1% of the total number of hospital admissions for young people and did not include admissions for radiotherapy and chemotherapy. Furthermore, survival rates for all cancers in young people aged 10 to 24 years increased between 1982 to 1986 and 1992 to 1997 from 72% to 81% for males and from 82% to 85% for females (AIHW, 2007).
Further relevant data from AIHW (2007) about the incidence of cancer in young people follow. Firstly, the incidence of cancer increased with age. That is, in 2002, most new cancers (52%) were diagnosed among the older age group of 20 to 24 years of age (AIHW, 2007). Interestingly, most of the participants in this study were diagnosed with cancer in their late adolescence. Secondly, while between 1993 and 2002 melanoma decreased by 23% for males and by 14% for females aged 12 to 24 years, it remained the cancer with the highest incidence rate (AIHW, 2007). Melanoma, however, was not evident for the participants in this study. Thirdly, between 1993 and 2002, the annual cancer incidence rate in young people increased by 10%, with the rates slightly higher for males than for females (AIHW, 2007).

Deaths from cancer in young people

The 2007 AIHW data indicated that the death rates among young people aged 12 to 24 years halved between 1980 and 2004 and the leading causes of death in young people continued to be land transport accidents and intentional self-harm. This contrasted with the general population who die from ischaemic heart disease and cerebrovascular disease. After land transport accidents (30.1%), intentional self-harm (18.5%), accidental poisoning (5%), and ill-defined conditions (3.8%), cancers featured as a leading cause of death for young Australians, with malignant neoplasms of lymphoid, haematopoietic and related tissue representing 2.7% and malignant neoplasms of the brain representing 1.9% of all deaths of young people (AIHW, 2007). Between 1995 and 2004, there was a decrease of 1.6% in death rates due to cancer in Australia. However, Thomas et al (2006, cited in AIHW, 2007) noted that Australia lagged behind other countries in terms of improvements in cancer outcomes for young people compared with advances achieved for children and older adults.

Children and young people die in a range of places. In a 1991 study in South Australia, it was found that most children (82%) died in hospital (in intensive
care units, in emergency departments and a small number in the oncology ward) with the remaining children (18%) dying at home at the end of their illness (Collins, 2000). Notwithstanding that most child deaths occurred in hospitals, children who have a terminal illness more frequently died at home, and children who attend specialist children’s hospices (for example, Very Special Kids in Melbourne and Bear Cottage in Sydney), do so mostly for respite (Hynson et al, 2003). This was also the case in the United Kingdom (Hutchinson et al, 2003).

Young people’s experience of living with cancer

Psychosocial issues during the illness trajectory

While the literature on psychosocial issues that young people face with a diagnosis and subsequent treatment of cancer is extensive, I confine my discussion to the following topics: disruption to normal adolescent development, the hospital environment and treatment, consent and decision-making, body image issues, support needs, relapse and end-of-life care, and after-cancer life.

In terms of adolescent development, in their Belgium study in 2007, Schrijvers and Meijnders made the point that the impact of living with a terminal illness varied according to the different stages of adolescence. In early adolescence, physical appearance and mobility were significant, whereas autonomy and peer and relationship issues were paramount in middle adolescence. Concerns about vocational and relationship issues dominated late adolescence.

Moreover, normal adolescent development, which is characterised by emerging independence, puberty and sexuality, together with a sense of immortality, may be interrupted by a diagnosis and treatment of cancer.
Equally devastating, the prospect of dying at a time when one is living life fully may be utterly incongruent (Judd, 2001; Thomas, 2007). Indeed, the disruption or incongruence may even result in non-compliance with treatment (Faulkner, 2001; Su-Ming Yeo and Sawyer, 2009), which was significantly higher in adolescents than children and adults (Abrams, Hazen and Penson, 2007). Previously it was assumed that young people with cancer did not participate in health-risk behaviours (for example, smoking, alcohol and other drug use), however, conflicting data have now emerged. Some studies show that young people experimented at the same rate as the general population, while other studies indicated they had reduced involvement in health-risk behaviours (Su-Ming Yeo and Sawyer, 2009).

Secondly, even though cognitively young people have an increased capacity for abstract thought, logical reasoning and flexibility in problem solving, this varied from person to person and situation to situation and differences arose. Thomas (2007) made the point that young people are not homogeneous and they may vary from an immature 15-year-old to a 25-year-old with two children, from a 16-year-old living away from home to a 25-year-old living at home. Moreover, some young people can become socially isolated from their peers as a result of treatment or overprotective parents, while others can regress to dependence on their parents in order to cope and obtain their medical treatment (Abrams et al, 2007; Judd, 2001). They may also want their parents to stay with them during hospital admissions, yet adult hospitals cannot accommodate parents staying with their adolescent child. In any event, Thomas (2007) noted that there was also a tendency for adolescents and young adults to be treated like ‘big children’, which resulted in doctors often directing their questions and explanations to a parent rather than the young person. Interestingly, as noted in the Findings chapter one of the participants found it difficult when she turned 17 years of age and she had to make the decisions about her health rather than her parents. Issues of informed consent and assent may also arise for young people diagnosed with cancer (Abrams et al, 2007). In Australia, while the age of consent is legally
18 years of age (when young people can vote), there are state-by-state variations depending on the issue at hand. For example, in New South Wales young people aged 16 years can make some decisions regarding their health.

Thirdly, during cancer treatment, body image issues may also arise for young people. Abrams et al (2007) noted that “hair loss, presence of a central venous catheter and weight changes as well as scars from surgery are the most disturbing physical changes and can be devastating to an adolescent’s self-image” (p626). The effects of cancer treatment can also interrupt the development of a positive sexual identity and chemotherapy, in particular, can affect young people’s fertility. Fertility preservation is emerging as a topical issue in recent Australian and American oncology literature (Hanson, Hunt and Merz, 2009; Parry, 2003; Vadaparampil, Quinn, King, Wilson and Nieder, 2008) and the participants herein raised this as a concern.

Fourthly, young people’s support needs vary from that of adults. Abrams et al (2007) noted that while adults preferred an empathic response during diagnosis and treatment, young people needed a more specific response that helped them to access established coping strategies — relying on their social supports, believing in recovery and getting back to normal life as soon as possible. Returning to school, university or work might be a smooth and positive transition back to normality, but some young people may need assistance with reintegration in light of neuro-cognitive deficits and learning difficulties from the cancer itself or its treatment (Su-Ming Yeo and Sawyer, 2009). Others, still, might need to review their career options (Hanson et al, 2009). Returning to school, starting university and establishing new career prospects were issues for the participants in this study. Abrams et al (2007) also noted that young people gained different types of support from their families, peers, and treatment team and in some instances spiritual or pastoral leaders. This was also mentioned by the participants in this study. However, Abrams et al (2007) noted that a significant minority (17-30%) of young people experienced symptoms of depression and anxiety, while Rourke,
Hobbie, Schwartz and Kazak (2007) found that a subset of young adult survivors of childhood cancer suffered post traumatic stress disorder. This was usually related to a particular type of belief about the cancer experience (for example, that it was still threatening their life) rather than demographic or disease and treatment factors.

Fifthly, the issue of relapse can be a major concern for young people as they settle into normal life after their cancer treatment. De Graves and Aranda (2008) noted that relapse can be more distressing than the original diagnosis due to the increased awareness of the threat of death and greater uncertainty surrounding survival. Not that ignorance is ever bliss. Uncertainty had its own problems because it brought the dual realities of hope (for survival/cure) and fear (preparing for the reality of death or loss). Nonetheless, when the cancer was no longer curable, palliative care clinicians assisted with the young person’s symptoms. Most notably, they helped with fatigue, reduced mobility, pain (physical, psychosocial and spiritual), poor appetite and dyspnoea (Schrijvers and Meijnders, 2007) and when they did so, it was with an awareness that normal physical changes with puberty may be stopped or reversed due to previous treatment.

Lastly, and in contrast to relapse and end-of-life care, is ‘after-cancer’ life. While quality of life in long term survivors of childhood cancer has been researched (Parry, 2003; Parry and Chesler, 2005), near to early cancer survivorship is a relative new area of research. In their small empirical study in the United States, Cantrell and Conte (2009) used a web-based intervention program to engage young women who had experienced childhood cancer. Like the findings of De Graves and Aranda (2008) about relapse, Cantrell and Conte found that their participants lived dual realities. In light of a forced dependency on adults (during treatment) and losses of everyday things, they had to negotiate a new reality, coupled with an accelerated maturity and wisdom. They also had to reinvent an identity that could incorporate the loss and effects of treatment as well as the gains from the experience.
Additionally, they had to deal with others’ unrealistic expectations that they should always be positive and grateful, despite the frustrations and irritations they experienced. In truth, they simply wanted to be treated normally but also wanted acknowledgement of their experience of cancer. Furthermore, they felt both uncertain and hopeful about the future and they experienced guilt that they had survived whereas others had not.

**Young people and adult differences**

In examining the differences between children and young people as one group and adults as another group, I examine three areas: the hospital system, disease and treatment, and palliative care. In the first instance, the location of treatment for young people in Australia is somewhat age-dependent. That is, young people under 16 years of age are treated in children’s hospitals, which are not set up to have acutely ill children alongside children with a life-threatening illness. Young people, 16 years of age and over, are generally treated alongside adult cancer patients commonly in the 60 to 70-year-old age range (Phillips, 2009) in adult hospitals which are not set up to accommodate parents staying at the hospital. Additionally, young people with a ‘childhood’ cancer may continue to be treated in a children’s hospital after reaching adulthood; this was the case for one of the participants in this study. There is a current movement, both in Australia and internationally, to develop units specifically for young people with cancer (Phillips, 2009; Thomas, 2007) that can accommodate late wakening, open visiting hours and recreational space (Abrams et al, 2007). This is something close to the hearts of some of the participants in this study.

Secondly, while the majority of adults with a life-threatening illness have malignant disease, children and young people with life-threatening illnesses are a diverse population. Less than half, for instance, have a malignancy while the remainder have a range of rare conditions (Hynson et al, 2003). Bleyer (2009) noted that “whereas the diagnosis of cancer in adolescents and
young adults (AYAs) used to have … a better prognosis than children with malignant disease” (p5), the survival trends are now worse than in younger patients and may be worse than in older patients. Furthermore, Bleyer noted that there is growing evidence of a distinct biology of cancer in AYAs, resulting in AYAs having different outcomes with the same therapy used in younger and older patients. Hanson et al (2009) noted that young people’s access to clinical trials for cancer was also poor. Abrams et al (2007) commented that “the toxicities of cancer treatment are more severe and difficult to cope with during adolescence and that QOL [quality of life] during treatment is poor” (p624). Moreover, Hynson et al (2007) noted that children generally suffer the side effects of certain medications more so than adults, and that pain management in some children can also be complex, requiring sophisticated technology and the use of medications that have not been adequately researched. It was noted by one of the participants in this study that the child’s dosage of chemotherapy had affected him severely.

Thirdly, palliative care for adults and children has always been different. While the actual number of children needing palliative care is quite small compared to adults, Hynson et al (2003) noted that at any one time there were approximately 5,300 Australian children (aged 0 to 19 years) who have a life-threatening condition and about half may need ‘active’ palliative care. This also included children who previously would have died early in life but now survived for longer periods and required palliative care for lengthy periods before the actual terminal phase (Faulkner, 2001; Hynson et al, 2003). The net effect of this is that it is likely to place an increased demand on paediatric palliative care services. The Belgium paper of Schrijvers and Meijnders (2007) estimated that “between 10% and 40% of adolescents will ultimately develop incurable disease after primary treatment and they will need palliative care” (p616). However, because palliative care in Australia began with a focus on caring for adults dying of cancer, the concept of palliative care for children can be abhorrent to many people and it can result in children who are imminently dying being treated aggressively, rather than
receiving pain and symptom management (Noone, 1998). From my clinical experience, this has also been the case for adults.

Children and young people’s understanding of death and dying

Children’s understanding of death has been well researched with healthy children and young people (Kenyon, 2001) and to a lesser extent with children and young people with a life-threatening illness. In this segment, I examine children and young people’s understanding of death and dying. The data are gleaned from empirical research of children and young people with and without a life-threatening illness — albeit much of it dated — and from the experience of healthcare professionals and researchers working in the field.

A leading pioneer in the 1960s in the study of dying and death was Swiss-born Elisabeth Kübler-Ross. Although she relied heavily on her clinical experience rather than empirical research with adults and children, she remains highly influential for her ground-breaking work with adults who were terminally ill. In On Death and Dying (1969) and On Children and Death (1983), she assisted people to cope with loss, grief and dying. She is renowned for her formulation of a stage theory of loss and grief, and dying, and her characterisation of dying for children. Briefly, the latter involves viewing the physical body as a cocoon, which on death, opens up and releases the child’s butterfly and the cocoon (not the butterfly) is buried (Kübler-Ross, 1991). The evidence was that both children and adults responded favourably and accepted this explanation and it became the basis for many people’s understanding of death and dying, not just children. In effect, it brought dying out of the silence of earlier years.

Moreover, the study of Vernick and Karon (1965) concerned 51 children and young adults aged nine to twenty years of age who were hospitalised with
leukaemia in the United States in the early 1960s. The study revealed that despite medical staff and carers working hard to conceal a death on the ward, children were aware of the event through their interpretation of their non-verbal environment. The authors also found that when children were told of the diagnosis of their illness, they “accepted these explanations without untoward reaction and many with obvious relief” (p395) because they were more worried about the secrecy. In a similar vein, during the next decade, was the nine month study of anthropologist, Bluebond-Langer (1978). She used observation, conversation and informal interviews with 40 dying children aged from 18 months to 14 years who were in hospital in the United States for leukaemia. She found that all the children had an awareness of their impending death long before they were told formally and, along with their significant others, they concealed their awareness in ‘mutual pretense’.

While these studies are American and European-based and somewhat dated, their findings continue to be influential and still relevant. In essence, despite a child’s impending death being kept a secret, what we take from the studies is that children who are terminally ill may be aware of their dying before their death is imminent and any admissions of awareness at that time are generally in vague terms only (Bluebond-Langer, 1978). It also means that children practise ‘mutual pretense’ as a way of preserving the social order (that children outlive their parents), because it allows both children and adults to fulfil the roles and responsibilities in society (Bluebond-Langer, 1978). In practice, it means that both the patient and the patient’s family, carers and medical team all know that the patient is dying but act otherwise. One alternative to mutual pretense is ‘open awareness’, which allows greater honesty, openness, intimacy and closeness, but it does not necessarily free up people from conflicts and dilemmas (Bluebond-Langer, 1978). Again, from my clinical experience, mutual pretense is widely practised today with adults in oncology and palliative care settings.
Studies with healthy children revealed that many factors influence their understanding of death — for example, religious/cultural beliefs and practices (Faulkner, 2001) and socio-economic status and ethnicity (Morin and Welsh, 1996). However, it was generally considered that by 10 years of age most children have mastered the four key components of death in terms of its irreversibility, its universality, its non-functionality (of the body) and its causality (identification of the reason for the death) (Kenyon, 2001). By 12 years of age, children are in Piaget’s formal operations phase of cognitive development and their thinking is generally logical and consistent with reality. They can speculate on the implications and ramifications of death, but they generally conceive their own deaths in the future rather than a present possibility (Faulkner, 2001).

Furthermore, the American study of Noppe and Noppe (1997) with 95 students aged between 13 and 20 years of age examined the nature of a mature understanding of death that extended beyond the four standard death components (noted above) to reflect beliefs such as reincarnation and the after-life, referred to as ‘non-corporeal continuation’. They found that young people’s understanding of death differed over early, middle and later adolescence. In early adolescence, issues of separation and loss were evident. In middle adolescence, their own mortality, dying without a legacy, leaving others and wondering about life after death, were apparent. By later adolescence, though, legacy issues superseded personal mortality. McSherry et al (2007) considered that adolescents tend to have a more adult-like understanding of death and may feel more overtly sad at anticipated losses. At the same time, however, a young person with a life-threatening illness may still distance themselves from the reality. We will see in the Findings chapter that the participants discuss dying and after-life, predominantly in the abstract. They also acknowledge dying had been a real possibility during their treatment and they consider it a possibility if they relapse.
Familial context of young people living with cancer

Children are inherently dependent and reliant on their adult carers. To a lesser extent, this is also the case for young people as they are often emotionally, socially and/or financially dependent on their parents/families. For this reason, many family members experience a similar suffering to their child-patient. Many feel, for instance, pain, fear, failure, despair, powerlessness, hopelessness and vulnerability (Kane et al, 2000). Kane et al (2000) identified that parents are often torn between responding to many stressors and demands and their own emotional reactions, limitations and vulnerabilities, responsibilities for other family members (siblings and grandparents) and practical matters such as work, financial stresses and lifestyle changes. Moreover, Cincotta (2004), considered that parents of children imminently dying also had to contend with the following: overcoming and dealing with shock and disbelief, remaining connected to their child’s needs (providing joy and pleasure and creating memories), maintaining the family’s integrity (with family routines and rituals), continuing to make sound choices and decisions, living with hope (for survival, for a good death) and living with anticipatory grief (separation anxiety, existential aloneness).

Furthermore, the close child-parent relationship often means that what is happening for the young person affects and is affected by their family. Overwhelmingly, the literature in Australia, the United Kingdom and North America highlighted a preference for a family-centred model of care for children and young people living with a life-threatening illness (Gilmer, 2002; Hart and Schneider, 1997; Hutchison et al, 2003; Jones, 2005; Jones and Weisenfluh, 2003; Kang, Hoehn, Licht, Mayer, Santucci, Carroll et al, 2005; Noone, 1998; Stuber and Houskamp, 2004). This approach also underpins paediatric hospice and palliative care (Davies et al, 2002). Widger and Wilkins (2004) also noted that the family-centred model of care, where parents were part of the child’s palliative care treatment plan (for example,
as a decision-maker and providing insight into their child’s views and experiences), had been adapted to include families for adults in palliative care.

Notwithstanding the close connection between the child and parent, and the merits of the family-centred approach, Hynson et al (2003) and Pellebon and Anderson (1999) cautioned that there were times when children, and in particular adolescents, had different views and needs to their families and needed separate time and space. Hynson et al (2003) noted that adolescents may want to deal privately with an altered body image or a change in their independence and Jones and Weisenfluh (2003) cited the example of the atheist parent refusing their child’s wish for a priest to be present at their death.

CONCLUSION

This section of the literature review examined the contextual circumstances of the participants’ spirituality. That is, being diagnosed with, and living with, cancer. I have explored the epidemiological data of young people with cancer and cancer-related deaths, young people’s experience of cancer, young people’s understanding of death and dying and the familial context of young people’s experience of cancer. The aim of this was to draw out the main issues in relation to young people’s experience of cancer. It also aimed to examine the significance of family involvement, institutional issues, adult and adolescent differences, treatment effects, psychosocial issues, and the development of understanding about death. Thus far in the literature review, I have looked at the lives of young people, the participants’ peers, and the participants’ particular circumstances — cancer. In the next section, I explore the phenomenon being studied: spirituality.
SECTION THREE

Spirituality and young people

INTRODUCTION

In the previous sections of this literature review, I discussed the research cohort (young people) in their broader socio-cultural context, and their particular circumstances: cancer and the illness trajectory. I now turn to the phenomenon being studied: spirituality. Spirituality can mean different things to different people. It is often described as the personal search for meaning and purpose in life, connection to oneself, others, places, things, groups or communities, or a Higher Being, and transcendence beyond our daily lives and our physical bodies. Spirituality is often used interchangeably with religion, but in this thesis, it is used as an ‘umbrella’ term, which overarches and includes traditional religion. At times, spirituality appears ubiquitous in contemporary society, as evidenced by a spiritual dimension expressed in self-help and social justice groups, music, exercise and food, to name a few (Taylor, 1994).

Spirituality can be approached from a number of angles. I start this section by examining spirituality in contemporary Australian society through a sociological lens, looking at the general population and highlighting specific references to young people’s spirituality. Secondly, I explore spirituality from a psychological perspective, looking at spiritual and faith development in adolescence and young adulthood, the two developmental stages relevant to the research cohort. I discuss Fowler’s stages of faith development, alongside other developmental processes, because Fowler adapted his stages on the foundations of Piaget’s cognitive development, Erickson’s psychosocial development and Kohlberg’s moral development. A brief critique of
development and stage theories is followed by an exploration of feminist spirituality, which offers an alternative to the traditional developmental theories. The third part of this section shifts to a contemporaneous exploration of spirituality for young people in Australia, the relationship between spirituality and the health and illness trajectory, and finally, the relationship between spirituality and children/young people and life-threatening illnesses.

**Spirituality in contemporary Australian society**

*‘spiritual but not religious’* *(Rumbold, 2003)*

In the first section of this literature review, I produced evidence that many young people were increasingly moving away from organised religious institutions and practices (such as prayer and church attendance), and they were developing their own meaning-making and personal expressions of spirituality *(Eckersley et al, 2005).* The question arises as to how young people compare with the general population of Australia. I start with a brief historical overview because our history influences where we are today. Bouma *(2006)*, sociologist and commentator on religious life in Australia from a personal, sociological and theological perspective, has contextualised and emphasised the uniqueness of Australia’s history and contemporary society: our Aboriginal origins, British settlement, European migration, our alliance with United States in foreign policy and our proximity to Asia. Lindsay *(2002)*, Australian social work educator *(and Bouma, 2006)* has highlighted the significant influence of migration in terms of religious identification in Australia. Lindsay *(2002)* noted that increased migration from the Philippines, Vietnam and Italy between 1947 and 1971 and decreased migration from the United Kingdom between 1933 and 1996 resulted in Catholicism overtaking Anglicanism as the largest religious group in Australia between 1981 and 1991. Nonetheless, Lindsay noted that since the first national census in 1911, there has been a steady decline in traditional Christianity as the dominant religion
of Australia, while the fastest growing groups in the 1980s were Buddhism, Pentecostal and Islam (although starting at a low base). She also noted that growth in Baptist, Lutheran and Pentecostal religions was more influenced by transfers from other religious groups than from migration and births.

Furthermore, the 2001 Census indicated that only a small number of indigenous Australians held traditional Aboriginal beliefs, with most indigenous Australians identifying with Christian religions (Bouma, 2006). Nonetheless Lindsay (2002) noted that Aboriginal spirituality continues to permeate Aboriginal life and culture. Aboriginal spirituality is popularly known for its deep connection with the land. From the land comes Dreamtime, from which Aboriginal people developed the rules and structures of life (Bouma, 2006). Armstrong (2002) noted that Aboriginal spirituality also had a strong sense of belonging to family and community, it was characterised by its value and respect for its elders as a source of knowledge and skill, and it used storytelling and rituals to embed the spirit and search for transcendence.

In contrast to Aboriginal spirituality, non-indigenous spiritualities in Australia have often been characterised by a relationship with a Deity or Higher Being (that may or may not be personified). Nonetheless Tacey (2003), spiritual educator of young people in Australia, noted that there was some movement towards a connection with the natural world (animals, trees, water, rocks, the stars), which may have been appropriated from Aboriginal spirituality. Tacey argued that European Australians’ spirituality is outwardly expressed (through chanting, communal worship) or it is inwardly reflected and explored (through meditation, private prayer) and it often emerges at crisis times. This arises for the participants in the study and is noted in the Findings and Discussion chapters. Tacey also redefined spiritual experience as “a deeper and more profound apprehension of our ordinary lives” and he suggested we should look through “the mundane encasement of our lives to the mystery beneath, within and around us” (p78). He emphasised that spiritual
experiences can often be something small and humble and are not necessarily something grand and “… doctrinally correct or theologically sound …” nor “… otherworldly …” (p78). Tacey’s point resonates with the participants’ description of their spiritual experiences.

Tacey (2003) also identified that Australians have particular expectations and approaches to religion and spirituality. These include: a tendency to be laid back and quiet, to attend church infrequently, to have a non-exuberant expression, to have a low level of consistency between belief and practice, to expect religious groups to be on the margin, and for the transcendent to be distant, localised and diffuse yet accessed directly or through professionals (p35). Furthermore, Liddy (2002), added that Australians do not confine themselves to a single tradition but often subscribe to traditional religion as well as New Age expressions of spirituality at the same time.

In brief, Bouma, Lindsay and Tacey have all argued that spiritual life in Australia continues to evolve. They made two arguments. The first is that while mainstream religion is in decline, religious and spiritual life is thriving with greater diversity: more Christian denominations and more ‘other religious’ groups (Bouma, 2006). The other argument is that spiritual life in Australia presents differently: it is quieter, less public and explicit compared to evangelical America and yet is more animated than Europe (Bouma, 2006). However, it will be interesting to observe how the more vocal and physically energetic tendency of the emergent Pentecostal and charismatic groups (Lindsay, 2002) interact with the more reserved, shy persona of traditional European Australians.

So where does youth spirituality fit in with mainstream Australian spirituality? Can one extrapolate that young people’s spirituality has some resemblance or connection to that of the general population? Tacey (2003) wrote specifically about youth spirituality. He argued that people become interested in religion from a conventional extrinsic place (through the church and traditional
religion) or from an inward spiritual awakening (that is deeper, based on personal experience, and tolerant towards difference). He saw youth spirituality gravitating to inward spirituality. He identified a new model of youth spirituality that is holistic, informal and individual and “the sacred is intimate and close, a felt resonance within the self, and a deep and radiant presence in the natural world” (p70) (for example ecology, nature, physical world, or stars, planets and stellar cosmology) (p80). Notwithstanding that the ‘self’ is often devalued and seen as narcissistic and indulgent by traditional religion, Tacey asserted that one has to go deep inside oneself to get to the true self and in the true self, God is to be discovered. This is consistent with Eastern religions such as Buddhism, which espouse internal reflection. However, Tacey did qualify that he accepted accessing God through the self as a legitimate doorway to the sacred, as long as it went beyond the subjective self to inward objectivity. In other words, this frees-up young people to establish a personal relationship with the sacred outside the church and without its guidance and support. Tacey’s argument about accessing the sacred through internal reflection is revisited in one of the themes identified in the Discussion chapter.

In contrast to the perspectives of Bouma, Lindsay and Tacey on the position of religion and spirituality in Australian society, Possamai (2005) focused specifically on New Age spirituality in Australia. He argued that the term ‘New Age’ had been used in the literature and everyday language as an overall description for an array of discernible religious phenomena, which were grouped together as a ‘family’. ‘New Age’ itself was considered a member of this ‘family’. Possamai’s research, conducted in Melbourne in 1996 and 1997, involved anthropological immersion and lengthy semi-structured interviews with 35 adults, aged in their late 20s to 70s, from a snowball sample. He discovered that those who formerly referred to themselves as New Age no longer identified as such. He also found that the original shared consensus on a substantive core of what constituted New Age spirituality had been replaced by heterogeneity and diversity in contemporary
New Age practices, that he termed postmodern spirituality. Possamai found that while his participants were involved in many religious practices, each tended to specialise in one specific type of activity. They used the authority of the inner self as the arbiter of the spiritual quest. He concluded that there was a new type of postmodern spirituality, presentist perennism, which focused on the present and the individual. These ideas have some relevance for the experience of the participants in my study (see the Discussion chapter) notwithstanding the age difference between Possamai’s participants and the participants in my study.

**Spirituality from a human development perspective**

Having looked at spirituality in Australia through a sociological lens, I now shift to a psychological focus. Developmental psychologist, James Fowler, documented his theory of faith development in his book *Stages of Faith: the Psychology of Human Development and the Quest for Meaning* (1981). His theory was based on interviews with 359 children and adults from the United States and Canada from 1972 to 1981 about their attitudes and values in life. His respondents were “overwhelmingly white, largely Christian, evenly divided by sex and distributed throughout the age categories” (p317). His data led him to propose six stages of faith development. I examine stage three adolescence and stage four young adulthood, as the relevant stages for this study, and have omitted the first two stages, early and middle childhood and the final stages (that generally applies to people who can encompass the whole of human kind and act in a detached and selfless way, for example Ghandi and Mother Theresa).

Because Fowler built on the foundations of Piaget, Erickson and Kohlberg, I discuss his stages alongside the theories of Piaget’s cognitive development, Erickson’s psychosocial development and Kohlberg’s moral development. While I have discussed the different developmental/stage theories side by side...
side, there are two main categories. Erickson’s psychosocial developmental theory is held in a sequential, invariant and universal manner and the “eight stages of psychosocial development correlate closely with biological maturation and chronological age” (Fowler, 1981, p50). Like Erickson, Fowler considered that a person had to resolve the tasks at each stage before moving to the next stage (Nierenberg and Sheklon, 2001). However, structural developmental theorists, such as Piaget and Kohlberg, do not tie strictly to maturation and time, and movement from one stage to another is not automatic or inevitable (Fowler, 1981). In the following discussion, unless otherwise stated, the interpretation to follow is that of Fowler.

Stage three: Adolescence (13 to 21 years of age)

From Erickson’s perspective, during adolescence, young people are establishing their identity by integrating their own images, views and feelings of themselves with those of their significant others. According to Piaget, full cognitive development is achieved at adolescence, where a capacity to think about thinking, to think hypothetically and deductively and to reflect on life from outside themselves, is typically imbued. Morally, young people construct right behaviour as that which conforms to the expectations of their significant others (for example, peers, family, sport coaches) (Kohlberg, 1976).

Fowler argued that by adolescence, young people have reached his third stage, in what he called Synthetic-Conventional Faith (‘conventional’ as it is seen as everybody’s faith and ‘synthetic’ as it is untested analytically). The adolescent’s experience of the world goes beyond the faith of their family to include school and work, their peers, public life, media and perhaps religion. Their faith needs to synthesise the values and information from these diverse areas as well as assist with their identity and outlook (Lindsay, 2002). During this stage, the ultimate environment is structured in interpersonal terms with the young person very aware of the expectations and judgments of their
significant others (‘the tyranny of they’ as is described by Parks, cited in Fowler, 1981). The adolescent’s beliefs and values are deeply felt, but they are tacitly held and have not been examined explicitly or objectively.

*Stage four: Young adulthood (21 years onwards)*

Piaget’s stages of cognitive development are completed by adulthood. However, Erickson’s psychosocial developmental stage predicts that during the young adulthood stage, young people are developing the capacity to commit to concrete affiliations and partnerships. At this time, moral development is centred on conforming to personal expectations and doing one’s duty as defined by law or rules governing roles. Fowler argued that by young adulthood, young people had reached his fourth stage, in what he called Individuative-Reflective Faith. As the name suggests, it is a time when the ‘self’ or individual emerges and the person differentiates themselves and their views from the views of others. It is also a time of objective and critical reflection and for the person to choose their own beliefs, values and commitments to form their own worldview (Lindsay 2002).

Looking at developmental and stage theory perspectives, we will see evidence in the data in the Findings chapter of the participants establishing positive identities and valuing interpersonal relationships with family and friends. It may also be that prior to the research interviews, the participants’ views with regard to their spirituality had not been critically examined and this may explain their changing views during the interview.

*Challenges and issues with developmental/stage theories*

Having briefly summarised the developmental and stage theories of Piaget, Erickson and Kohlberg so far as they relate to the foundation of Fowler’s theory of faith development, I now examine some of the challenges and issues that arise with universal theorising with human beings. I briefly look at the
theories of Piaget, Erickson and Kohlberg but concentrate on Fowler’s faith development theory. Firstly, Piaget’s cognitive development is criticised for confusing performance (ability) and competence (prior knowledge), which skewed the cognitive competence of young children and the testing material did not take into account that many young people’s cognitive ability depended on the way the problem was presented (White, Hayes and Livesey, 2005). Similarly, Erikson’s psychosocial development theory is criticised as descriptive in nature rather than explanatory, because there is no account for “the motivational aspects of personality or what drives individuals from one stage to the next” (White et al, 2005, p229). The model also does little to acknowledge the influence of world events, like wars (White et al, 2005), and significant life events, such as cancer, on a young person’s independence and familial relationships (Robbins, Chatterjee and Canda, 1998). Thirdly, Kohlberg’s model is criticised as having a cultural-bias to western capitalist countries (White et al, 2005), and Bandurra (1991, cited in White et al, 2005) argued “that moral development does not simply accumulate with age; rather, new moral standards are adopted” (p346). Gilligan (1993) argued that Kohlberg’s theory fails to account for gender differences in moral development, and feminist spirituality is discussed below.

Lastly, faith development does not appear to have been critiqued in the same way the other models have been evaluated. In the first instance, Fowler himself acknowledges that his sample was not randomly selected. The main criticism is that normative structures like Fowler’s faith stages do not address the non-linear fluctuations and the true complexities of the lives of young people and their families. Examples of this are different cultural practices and religious/spiritual views between family members (Jones and Weisenfluh, 2003). They also do not accommodate a child who is intellectually gifted and has knowledge of spiritual concepts beyond their age (Lovecky, 1998). Nor does Fowler’s faith stages take into account the impact of negative life events, such as bereavement, violence, poverty, and the challenges of a life-threatening illness such as cancer (Abrams et al, 2007). Taylor (cited in
Lovecky, 1998) argued that spirituality was “a process in which depth of understanding might change over the course of several moments” (p4) and this variability is discussed in the Findings and Discussion chapters. A final point by Robbins et al (1998), that developmental and stage theories take a reductionistic view of people “that portrays all behavior as genetically determined and all mind processes as essentially biochemical [leaving] little room for human agency, free will and the interpretive process” (p255) seems to sum it up.

In contrast to this linear perspective on development formulated by adults, where adults were constructed as ‘beings’ and children as ‘becomings’ (Fattore and Mason with Sidoti, 2005), a sociology of childhood developed in the 1980s which focused centrally on children and on children’s own voice. This approach was supported by the United Nations Convention on the Rights of the Child (1989) which expressed “a broader human-rights approach to participation of children as legal persons” (Fattore and Mason with Sidoti, 2005, p18). The Convention provided for children to be accepted as participants in their own right and for their participation to be taken seriously. For these reasons, I preferred the more empowering and accommodating nature of the sociological point of view. Such an approach is also consistent with the phenomenological approach adopted in this study. Hence the human development perspective is only minimally referred to in the Findings and Discussion chapters.

**Alternative spirituality: feminist spirituality**

Gilligan (1993) brought a feminist analysis to stage theories and her work has been influential in distinguishing and reclaiming women’s moral and spiritual development from that of men. She argued that women’s moral orientation is founded in relationships and responsibilities and is more care-oriented whereas men are concerned with rules and abstract justice-oriented principles (Robbins et al, 1998; White et al, 2005). Feminist spirituality is
grounded in women’s experience of disempowerment, and it emphasises the importance of giving women voice about their experiences. It also has a profound concern about the environment and social justice (Lindsay, 2002). While Gilligan did propose a three stage developmental process, she did not attach ages to her categories. The stages centre on care: care for self, care for others, and care for both self and others. The final stage, ‘interdependence of self and others’, recognises that the needs of self and the needs of others are interconnected and interdependent, which is seen as a strength (Robbins et al, 1998). In the participants’ data, relationships and caring arise as important factors.

**Spirituality and children/young people**

In this segment, my emphasis is on reviewing the work of Mason et al (2007) whose large-scale national study examining the spirituality of Gen Y; it was published during the course of this study. However, I start with two research studies relating to younger children’s spirituality because their findings are influential and also relate to this study.

*Spirituality of younger children*

Child psychiatrist, Robert Coles (1991) drew on interviews with individual children and groups of children during the 1970s to 1980s looking at their religious and spiritual life. He interviewed approximately 500 eight to twelve-year-old children over one to two years. He interviewed Protestant and Catholic children from North and South America and Europe, Jewish children from North America, Europe and the Middle East, and Islamic children from Europe, Africa and the Middle East. Coles, influenced by his psychoanalytic and clinical background, adopted a phenomenological and narrative approach. His key finding was that, irrespective of their religious background, children asked spiritual questions outside the tenets of religion. Davies et al (2002)
noted that Coles’ study made only one brief reference to a dying child. Coles’ findings concurred with Mountain’s Australian study (2005). Mountain, a chaplain and former teacher, conducted individual semi-structured interviews with 60 children, about 10 years of age in six schooling systems in Melbourne (Catholic, Independent/Christian, Christian, Orthodox Jewish, Islamic and Government) regarding the use of prayer by children. She found that all children reported using prayer, even though “one-third of the participant group came from families where religion was not reported to be a family activity and the formal school religious education was minimal” (p302). Similarly, participants’ use of prayer is discussed in the Findings chapter.

Hay and Nye (2006) conducted research with 38 children, who were randomly sampled from lower middle class state primary schools in large industrial cities in the United Kingdom. Using grounded theory, they developed a ‘relational consciousness’ model of children’s spirituality, which defined ‘consciousness’ as something more than mentally attentive and ‘relational’; this meant that every remark was qualified by a reference to a specific relationship. For example, children related to things, other people, themselves, God, the natural world.

**Spirituality of young people**

In 2007, Mason et al reported the first Australian study on contemporary forms of spirituality in young people through a representative national sample. They relied on personal narratives rather than directly asking about ‘spirituality’. The researchers, whose backgrounds included religion/spirituality, sociology, gender, research, and youth and family studies, were funded by the Australian Catholic University, Monash University, the Australian Catholic Bishops Conference Pastoral Research Council and the Christian Research Association to carry out the study over the years 2003 to 2006.
The study had three stages. In stage one, 91 qualitative interviews were conducted with young people from a diverse range of backgrounds. The results were used to design the national telephone survey. In stage two, 1619 telephone surveys were conducted nationally with approximately 400 of each of four life stages: i) 13 to 15 years of age (primary school to secondary school), ii) 16 to 18 years of age (early to late secondary school), iii) 19 to 24 years of age (leaving school, entering tertiary study/job, early adulthood), and iv) 25 to 59 years of age (representing Generation X and Baby Boomers) as control groups. Again, there was both good representation and a good participation rate. A broad range of topics were covered: demographics, media use, self-development activities, activities related to seeking peace and happiness, the meaning of life, values, social concern, altruistic behaviour, volunteer activities, decision-making, religious and alternative spiritualities beliefs, practices, exploration and so on. In stage three, 26 personal interviews were conducted and specific types of spirituality and significant life changes were targeted. These interviews covered the following topics: school, university or work, friends, activities, life defining experiences, what they valued and how they wanted to be remembered when they died, and religious and spiritual beliefs and practices.

Overall, the researchers' analysis revealed that the major types of spirituality for young people were: traditional (Christian) representing 46%, New Age (non-traditional religious or spiritual paths) amounting to 17%, secular (neither traditional religious nor New Age spirituality and based on human experience and human reason) calculated at 28% and a further group of other world religions (Buddhism, Islam, Hinduism and Judaism) at 6% and Theists at 3%. It was noted that the level of engagement was low in the traditional Christian and New Age spiritualities whereas it was significantly higher in the other two categories. I now discuss the salient findings from the three categories, paying particular attention to data that are relevant to the participants in this study.
TRADITIONAL (CHRISTIAN)
Firstly, looking at religious denomination, the survey results indicated that the number of young people raised as Anglicans and Catholics was decreasing; they were shifting to the New Age and secular categories. The shift was connected with ‘issues’ with the church, religions generally and God.

Secondly, looking at young people’s beliefs, it was found that, similar to their Baby Boomer parents, about half the young people believed in God and most of “those who did not believe in God or were uncertain … affirmed belief in some alternative kind of higher being” (p87). This Higher Being had personal characteristics and a caring role for people, rather than a higher power that started the universe. Characteristic of Gen Y, most young people agreed that the individual should have the right to ‘pick and choose’ their religious beliefs and that morals were relative (there were no definite rights and wrongs). Other significant beliefs included: only one quarter of the young people considered religious faith important in their life, most young people strongly believed in ‘life after death’ but mostly ‘Other Christians’ (Uniting Church, Pentecostal, Orthodox and Baptist) strongly believed in miracles.

Thirdly, religion was often expressed (and measured) in terms of church attendance. The survey results indicated that, in general, there was a low level of attendance for all ages, with Anglicans and Catholics usually attending church less than once a month and Other Christians usually attending once a month or more. Many young people did not attend church because they had other priorities (for example, sport), they had had a negative experience of a church or church leader or they were dissatisfied with the moral teachings of the church.

Fourthly, personal prayer was also a common religious practice. Again a high proportion (49%) of Other Christians (particularly, Pentecostals) prayed once or more than once a week, while fewer Catholics (21%) and Anglicans (23%) prayed daily. Of all the young people surveyed, though, only 35% prayed
regularly (daily to monthly). Regular scripture reading sessions were dominated by the Other Christian group at 41%, in contrast to Anglicans (14%) and Catholics (11%). The Other Christians also prayed with others, listened to religious/Gospel music and attended religious groups. On the other hand, Catholics and other religions (Buddhist, Muslim, Hindu, Jewish) tended to wear religious jewellery or clothing.

NEW AGE SPIRITUALITIES
New Age spiritualities are often seen as an alternative to organised religion and secularism (Kohn, 2003) and the range of choice is often known as ‘the spiritual marketplace’ (Mason et al, 2007). Complete packages, for example Wicca and Paganism, are offered but other practices can be used as separate components. Examples of this are numerology and crystals. Mason et al (2007) noted that young people of all backgrounds explored other religions/spiritualities by seeking and gathering information (81%) and a small number (19%) go further by taking part in a ritual. Half of the young people, though, did not hold any New Age beliefs. A central theme to New Age spiritualities is the paranormal. In popularity, reincarnation came out just ahead of astrology, the possibility of communicating with the dead, and the power of psychics. In terms of New Age spiritual practices, the most common were yoga, meditation, tai-chi and tarot reading. However there was generally low uptake by Gen Y, possibly due to the cost involved.

SECULAR
The third category, secular, has three elements: the non-religious (10%), those who never believed in God and are more scientifically-oriented, the ex-religious (4%), those who once believed in God and were raised in a religious tradition, and the undecided (14%) — those who are uncertain but may believe there is ‘something there’. Former believers explained their disinterest in terms of their study of science, that they did not accept a God with the suffering in the world, that there was no convincing evidence of God, and they were disillusioned with the church or religious organisations. This is not
too dissimilar to those explanations raised by young people in the traditional (Christian) category.

In brief, the results of the national study indicated that young people are moving away from traditional religion and religious expressions such as prayer and church attendance, although there is growth in evangelical, Pentecostal and religions other than Christianity. Belief in God has not changed in the last 20 years but today’s young people strongly believed in the individual’s right to pick and choose their beliefs. Furthermore, young people are interested in alternative spiritualities and readily adopt beliefs such as reincarnation but do not engage in any practices. The researchers considered that the decline in the salience of religion is characterised by notions such as individualism, science, and rationality increasingly dominating society. They were also concerned that young people’s self-constructed spirituality and eclecticism left them without a solid ideological or philosophical foundation. This latter point is revisited in the Discussion chapter.

**Spirituality and the health and illness trajectory**

I now shift the focus to the role of spirituality in the health and illness trajectory. Human beings are made up of many different facets: biological/physical, emotional, social, cultural and spiritual, and all aspects are inter-related and relevant in healthcare. Even though the spiritual dimension is often ignored or dismissed in healthcare, Abrams et al (2007) noted that the spiritual dimension can play a significant role in people’s lives, especially when people are dealing with a serious illness or crisis. In this segment, I explore spirituality in adolescent health, the role spirituality plays in the illness trajectory, and the nature of spiritual concerns that often arise in the course of a serious illness. Conversely, there appears to be little data about the impact of health and illness on religion and spirituality.
Spirituality and adolescent health

Numerous studies document the benefits of spirituality in adults’ health (Koenig, 2000). Plante and Thoresen (2007) identified that adolescent research has focused on religion/spirituality in relation to risky health behaviours, with less research on relationships with mental health (trauma), physical health (chronic illness such as asthma), or health-promoting behaviours (exercise or healthy diet). Nonetheless, the empirical study of Davis, Kerr and Robinson Kurpius, (2003) found that higher spiritual wellbeing predicted lower trait anxiety among at-risk adolescents in the United States. Barnes, Plotnikoff, Fox and Pendleton (2000) and Cotton, Zebracki, Rosenthal, Tsevat and Drotar (2006) also noted that religion and spirituality can be a protective factor against negative health outcomes.

Spirituality and the illness trajectory

Spiritual issues can arise at any point along the illness continuum: at the acute symptomatic or diagnostic point, during treatment for the illness, throughout living with a chronic or life-threatening illness or during end-of-life. Spirituality can contribute to positive coping and assist with living with the uncertainty and changes of a chronic condition (Fulton and Moore, 1995) and guard against depressive symptoms and end-of-life despair (McClain et al, 2003). Astrow, Wexler, Texeira, Kai He and Sulmasy (2007) noted that patients with cancer appear to have a greater interest in the spiritual dimension than other patients.

D’Souza (2003), writing about Australia and Astrow et al (2007) writing about the United States, noted that people want their healthcare professionals to consider their spiritual needs in their care plan. However, Astrow et al made the distinction that people who describe themselves as ‘spiritual but not religious’ would not welcome inquiry about their religiosity. They would think it more appropriate to be asked about their spiritual needs. This supports the
point made at the beginning of the section that inquiries about spiritual/religious needs would best be couched under the umbrella term of ‘spirituality’ before considering a specific inquiry about religion.

**Spiritual concerns**

For most people, serious or prolonged illness interferes with a person’s entire being and can prompt a person to search for answers and explanations (Fulton and Moore, 1995) that often have a spiritual or existential dimension. These regularly concern worldly matters such as the meaning and purpose of life, death and suffering, whether a greater power and an after-life exist (McClain et al, 2003; Rousseau, 2000) as well as personal matters like the causal nature of the illness, whether they contributed to it or whether they were being punished by ‘God’ (Lyon et al, 2001).

Paediatric palliative care social workers and chaplains identified what they considered universal spiritual concerns that children and young people with life-threatening illnesses experience. These centred on the following: life and existence, separation from loved ones, unconditional love, forgiveness (for the illness), hope (and validation of achievable goals), safety and security (about after-death), legacy (being remembered), and loneliness (Sommer, 1989; Thayer, 2001, Jones and Weisenfluh, 2003). Davies et al (2002), noted that spiritual concerns can be expressed in different ways, for example, play, art, poetry or story-writing, music and bibliotherapy.

**Spirituality, young people and illness**

While there are very few specific studies that cover the three elements of the research topic: young people, cancer and spirituality, there are two recent American studies. The first study sheds light on the fluidity or variability in the nature of young people’s engagement in spiritual matters. The second
study determined that living with cancer can have some positive outcomes in terms of one’s psycho-spiritual growth. Specifically, Hendricks-Ferguson’s 2006 study with adolescents diagnosed with cancer, used measurement scales to assess hope and spiritual wellbeing at different intervals along the illness trajectory. There were limitations to the study. It used a convenience sample drawn from a Roman Catholic paediatric hospital and private paediatric oncologist and 95% of respondents were Caucasian. Two interesting findings are nevertheless worth noting. Firstly, while ‘hope’ remained consistent throughout treatment, ‘spiritual wellbeing’ was mostly high during the first two years during diagnosis and treatment, after which adolescents tended to decrease their reliance on spiritual support as they came to terms with their illness and shifted back to peer support (Hendricks-Ferguson, 2008). The clinical paper for nurses by Hart and Schneider (1997) also noted that adolescents with cancer tended to use prayer as a resource to cope with the stressors associated with cancer treatment. We will see that Hendricks-Ferguson’s study concurs with the participants in this study. Her study also found that the developmental phase and/or gender can influence adolescents’ level of hope and spiritual wellbeing as they cope during the cancer experience. In particular, adolescent girls expressed more hope than adolescent boys, and there was stronger religious wellbeing during middle adolescence than during late adolescence.

The other recent empirical study contrasts the many studies of young people with cancer that identify the negative psychosocial outcomes. Parry (2003) and Parry and Chesler (2005) on the other hand, examined quality of life in long-term survivors of childhood cancer and identified a number of positive aspects to the cancer experience. Parry used a multi-method, multi-stage study between 1996 and 2000 with young people aged 17 to 29 years, using the records from a children’s cancer treatment centre in Midwest, USA, who were at least three years post-treatment. She adopted a grounded theory approach. The questionnaire and interview findings revealed that while living and coping with the uncertainties of cancer (the tenuousness of remission, the
possibility of relapse and the side effects of treatment) could be distressing, when balanced with certainties (one’s strength and resilience), it could be a transformative experience: “a catalyst for growth, a deepened appreciation for life, greater awareness of life purpose, development of confidence and resilience, and optimism” (Parry, 2003, p233). Parry proposed that examining the certainties against the uncertainties can lead survivors to explore deeper issues, such as a belief in a higher power, the meaning and purpose of life.

Parry and Chesler (2005) also argued that some survivors of cancer experienced positive effects or psychosocial thriving, a term she used to describe changes such as increased psychological maturity, greater compassion and empathy, new values and priorities, new strengths and increased recognition of vulnerability and struggle. She considered that psychosocial thriving involved some level of personal agency and empowerment, and a process of exploring deeper issues (for example, the meaning and purpose of life, belief in a higher power and reaching some resolution about the meaning of the cancer), which can lead to psychospiritual growth.


CONCLUSION

In this section of the literature review, spirituality has been approached from a range of angles. Firstly, I examined spirituality in an Australian context and this highlighted the uniqueness of Australian spirituality and youth spirituality. This was contrasted with a developmental perspective, which looked at spiritual and faith development alongside cognitive, psychosocial and moral developmental theories. I then looked at research studies regarding spirituality and children and young people, spirituality and health and illness,
and finally, spirituality, young people and cancer. In the following section, I look at spirituality in two professional contexts, relevant to young people with cancer and that espouse spiritual needs and care as part of their holistic approach, that of social work and palliative care.
SECTION FOUR

Professional contexts:
Social Work, Palliative Care and Spirituality

INTRODUCTION

Thus far the literature review has looked at young people in Australia in the twenty-first century using social markers such as health, education, employment, family and household, and beliefs and values, to name a few. It also examined young people and cancer from an epidemiological perspective and also young people’s actual experience of cancer. The phenomenon being studied, spirituality was discussed from both a sociological and psychological perspective as well as its connection to health and illness.

I now turn to the professional context for this study, that of social work and palliative care and I look at the relationship of spirituality within the professional practice of social work and clinical practice of palliative care. While the clinical practices of oncology and paediatric oncology could also be relevant, attention to the spiritual dimension is still in development in oncology (personal communication). Patients’ spiritual needs and spiritual support are acknowledged in the Cancer Action Plan of the Victorian Government Department of Human Services, 2008-2011 (www.health.vic.gov.au/cancer) but how they are to be operationalised is yet to be articulated. In palliative care, there is explicit acknowledgement of and reference to the spiritual dimension. Moreover, a health-promoting palliative care approach, which supports people ‘living with dying’ and focuses service provision from the time of diagnosis rather than at ‘end-stage’ cancer care (Kellehear, 1999) is a very appropriate perspective to hold in this study, particularly with those who have had multiple cancer diagnoses.
Health-promoting palliative care aims to support people with a life-threatening illness to adjust to changes in their life and encompasses raising awareness about “health, dying and death” and goes beyond direct practice to “… research, community development and policy criticism and development with … everyone in the community” (Kellehear, 1999, p77-8). This approach is also consistent with the philosophy of CanTeen, and as I discovered, the participants’ outlook on life.

I begin this section by examining social work’s values and commitment to holistic practice, and Australian social work’s historical origins and connection to religion. I then explore the challenges and resistances to inclusion of the spiritual dimension in social work practice, as well as the renewed interest and argument for inclusion of the spiritual dimension. This is followed by an exploration of palliative care in Australia. I document the different meanings of ‘palliative care’ and again look at its historical roots as well as the current issues relating to spirituality in palliative care practice.

**Spirituality and social work**

Social work has always accepted a broad mandate of holistic care (Edwards, 2002). Holistic care includes all aspects of human needs: the physical, the emotional, the social and the spiritual. Social work’s commitment to holistic care also protects its professional values. The Australian Association of Social Workers (AASW) describes social work values as respect for human dignity and worth, social justice, service to humanity, integrity and competence (AASW, 1999 and 2003). The International Federation of Social Workers (IFSW) synthesises social work values into three areas: human rights and human dignity, social justice, and professional conduct (IFSW, 2010). Social work theory, which imbues social work values, also emphasises the importance of working with clients in a holistic or systemic way (Canda and Furman, 1999, cited in Rice, 2002). Notwithstanding the connection between social work...
and its professional values and holistic care, the social work literature since the 1960s has recognised that the spiritual dimension of holistic care has been absent or neglected (Cox, 1985).

The social work profession in Australia has a long history with religion. Australia’s colonial history meant that social work in Australia was influenced by social work in Britain. While early British social workers, many of whom were religious, lived out their convictions by providing ‘indiscriminate almsgiving’ to the disadvantaged (Lindsay, 2002), there were powerful challenges to this model of working. Firstly, the charitable organisations, which preceded social work, emphasised value in positivist ideologies (as well as spirituality). The proponents considered that a push for ‘newer knowledge’ and ‘well trained workers’ would bring approval from the scientific community, which would in turn improve service delivery and the profession’s credibility (Lindsay, 2002). Secondly, during the 1920s and 1930s, psychoanalytic theory became the dominant theory of social casework and while Freud conceded religious belief could lessen anxiety, essentially he regarded it as an unnecessary crutch (Lindsay, 2002). Similarly, Marx emphasised detached objectivity and devalued “subjective constructs such as morality, spirituality, and cultural or personal belief systems” and is well known for his critical comment that religion was “the opiate of the people” (Lindsay, 2002, p17-18).

Furthermore, Lindsay (2002) noted that over the last century, attention to clients’ spirituality by social workers has been influenced by the increasingly secularisation of Australia. There were also professional factors facing social workers. As noted above, some helping professions criticised religious orientation as ‘irrational’ or a ‘crutch’ (Davis et al, 2003). Social work was also eager to be accepted in the scientific community (Edwards, 2002; Lindsay, 2002) and it was concerned about assistance being given on the basis of moral judgments about the deserving and undeserving (Rice (2002). These factors resulted in the profession distancing itself from its religious origins.
In a contemporary sense, social workers often report that they feel inadequately trained to deal with spiritual matters (Dane and Moore, 2005; Feudtner, Haney and Dimmers, 2003; Fulton and Moore, 1995; Sheridan, 2009). Social workers have also reported that they are reluctant to raise the issue of spirituality for fear of being seen as forcing their own beliefs (Edwards, 2002; Lyon et al, 2001). In addition, many social workers cannot reconcile spiritual issues with various aspects of social work theory (for example, Marxism and Feminism) that criticise spiritual matters (Edwards, 2002). Lastly, in the Australian hospital setting, where the different facets of people’s lives are compartmentalised, social workers often defer spiritual issues to the province of chaplaincy or pastoral care.

Notwithstanding the influence of positivism and other resistances, Lindsay (2002) argued that Australian social work had held onto its spiritual origins and she drew attention to the humanistic nature of its professional values in its code of ethics (noted above). She also considered that there was increasing recognition of other sources of knowledge, truth and validity, and interest in clients’ construction of meaning, and that phenomenological theories were receiving greater validity. The growing interest in spiritual and religious influences over the last twenty years (Canda, 2008) has led a number of American spiritual and religious commentators to argue that social workers may be insensitive if they neglect spiritual or religious beliefs of clients (Behrman 2002; Hodge 2004; Jones and Weisenfluh, 2003; Pellebon and Anderson, 1999). Australian social workers interviewed for Edwards’ 2002 paper argued that clients’ spiritual and religious needs were inseparable from their other needs and a key dimension of holistic care — neglect of which may “risk alienating clients or invalidating their inner experience” (p82) (also noted by Matthews, 2009).

Moreover, Callahan (2009), argued that social workers may need to provide spiritual support to “… patients and others who may not identify with an organized religion …” (p181). Similarly, Healy (2005) suggested that clients
may specifically turn to social workers to work on their religious or spiritual issues as they may view the social work profession as not directly aligned to any one religious or spiritual base. For example, in the case of a client with a cancer diagnosis, a hospital social worker often develops rapport and trust during their work around the adjustment to illness and the addressing of practical issues. This often provides a safe forum for a client to raise existential or spiritual issues, questions about meaning and purpose of life, mortality (McClain et al, 2003). Cox (1985) made a pertinent point that, while social workers may not necessarily be better placed than any other professional group to answer issues of meaning and wholeness, “they have more opportunities than most to support individuals’ search for the spiritual dimension, to perhaps alert to the possibility of its existence ...” (p11). At the same time, Rice (2002) argued that inclusion of the spiritual dimension in social work practice amounted to just keeping pace with the client needs. For example, social workers often encourage clients to use meditation and affirmation, albeit not necessarily viewed as spiritual interventions.

Social workers may therefore be cautious about including a spiritual dimension in their practice. They may well feel ill-equipped or may not see it as their domain. Nonetheless, I would argue the spiritual dimension remains part of the human condition.

**Spirituality and palliative care**

‘Palliative care’ has different meanings or understandings in different contexts and this was briefly referred to in the first chapter. Palliative care originated from the ‘hospice movement’ in the 1970s in the United Kingdom (Rumbold, 2003). In a contemporary Australian context, what were formerly called ‘hospices’ are now often called ‘palliative care [units]’ and refer to a facility where people can receive palliative care and end-of-life or terminal care. ‘Palliative care’ often refers to the active and specialist healthcare
when a person’s illness or disease is non-curative and there are no further curative interventions available (Palliative Care Australia (PCA), 2000). Then, the focus of treatment or care is management of pain and distressing symptoms and comfort and care measures to optimise the best quality of life (PCA, 2000). Palliative care units also provide pain and symptom management and respite (when death is not immediately imminent). Furthermore, palliative care services can be provided in the home, in community-based settings such as nursing homes, and in hospitals (PCA, 2000). A ‘palliative approach’ is a philosophy of care that is synonymous with a commitment to holistic and multidisciplinary care. This means addressing the physical, psychological, social and spiritual care needs of patients and their families and caregivers (Department of Health and Ageing (DoHA), 2000; Davies et al, 2002; Noppe and Noppe, 1999; PCA, 2000).

Prior to hospitals becoming the dominant place of death, people knew of and experienced dying at close hand (DeSpelder and Strickland, 2005; DoHA, 2000). However, the medicalisation of dying and death meant that people became removed from end-of-life care (Kellehear, 2007) and modern palliative care evolved to provide a multi-faceted approach to dying and death. Traditionally, questions about life and death and meaning-making were the domain of religion. However, the founder of the modern hospice movement, Cecily Saunders, was committed to developing a broader perspective of spiritual care: “openness, mind together with heart, and a deep concern for the freedom of each individual to make his or her own journey towards their ultimate goals” (Saunders, 1996, p319). She was keen to validate that each person (rather than religion) needed to define and pursue their own journey and find their own answers. Furthermore, Rumbold (2002) noted that “spirituality is seen as dealing with the same existential issues and fulfilling many of the same social functions that religion has done in past eras” (px). His premise was that all human beings, irrespective of their religious or atheistic beliefs, have spiritual or existential questions and concerns to resolve. Moreover, he had a vision that the inclusion of spiritual
care in palliative care might have the effect of influencing contemporary society with regard to spiritual care as an appropriate framework to deal with ethical issues that arise in a secular health system.

There are a number of issues that dominate the literature on palliative care and spirituality. Firstly, there is significant debate that focuses on which profession/s should provide or are best equipped to deal with palliative care clients’ spiritual needs (Kellehear, 2000; Rumbold, 2002; Walter, 2002). On the one hand, Rumbold (2003) and Kellehear (2000) considered that all palliative care workers have responsibility for acknowledging and working with the spiritual needs of palliative care clients. Indeed, Rumbold took it further and suggested that social workers, psychologists and pastoral care workers may be the most appropriate because they have “expertise in processes of self-understanding, changing perceptions, and spiritual development” (p513). However, Walter (2002) questioned the premise that spiritual care can and ought to be able to be provided by palliative care workers regardless of their faith and professional training. He looked at this pragmatically: a palliative care client’s belief and experience in the after-life could be difficult for a Christian chaplain or a psychiatrist to provide a response. This could then present as an argument for social workers doing spiritual care as they are not professionally aligned with any religious or spiritual group, but of course, they may be personally aligned.

Gordon (2004) took it a step further and advocated for a competence-based model of care where different workers had different responsibilities with regard to spiritual need and care. He argued that at the one end of the continuum, workers needed to understand that people have spiritual needs, whereas at the middle points, workers needed to identify and respond, and assess and develop a care plan, and at the other end, workers needed to manage and facilitate complex spiritual and religious needs. While this is a very inclusive model, it has its problems. If religious and spiritual care becomes the responsibility of all palliative care workers, there is a risk it will
be overlooked as the various disciplines (medical, nursing, allied health and so on) prioritise their core business, and religious and spiritual care is put to the side for when there is time.

Secondly, there is discussion about operationalising all aspects of a person’s spiritual needs in a palliative care setting. Saunders and her colleagues observed that people became aware of spiritual need “through their changed physical, emotional or social environment; through seeking to redefine their personal identity in changing circumstances; or as a result of their religious beliefs and practices” (Rumbold, 2003, p512). Kellehear (2000) named this as situational, moral/biographical and religious needs and incorporated them in a multidimensional model.

Thirdly and closely related to the previous point, there is discussion about differentiating spiritual care from psychological-emotional care and differentiating spirituality from religion. There is also a need for establishing a comprehensive definition of spirituality (Kellehear, 2000).

Lastly, and similar to social work practice, spiritual needs within palliative care (particularly paediatric palliative care) have often received the least attention, both in research and clinical practice (Davies et al, 2002; Jones and Weisenfluh, 2003).

CONCLUSION

In summary, it is clear that spiritual care has always been espoused as a fundamental part of palliative care, and palliative care has been pre-occupied with operationalising spiritual care within palliative care. For social work, the situation is different. The inclusion of spirituality is implied in social work as part of its holistic approach. Even though social work has its origins in religion and its current code of ethics reflects a spiritual base, the influence
of positivist thinking and secularisation have dominated social work practice. Moreover growing recognition of the value of the spirituality is undermined by the fact that many social workers have ideological and practical issues with the spiritual dimension of holistic care. Nevertheless, in both professional contexts, spiritual need, as part of holistic care, receives somewhat marginal attention.

The exploration of the two professional contexts (of social work and palliative care) that are relevant to this research study brings the literature review to a close. In the next chapter, I explore the methodology for this research study. This includes an outline of my epistemological and theoretical perspectives, the ethical issues addressed in this study, and my research methods for data collection and data analysis.
CHAPTER THREE

Methodology

INTRODUCTION

In the previous chapter, the Literature Review, I discussed the small number of significant studies (Hendricks-Ferguson, 2006, 2008; Mason et al, 2007; Parry, 2003; Parry and Chesler, 2005) that have focused on either young people and spirituality or young people with cancer and spirituality. However, earlier literature reviews revealed there were very little data on this topic that were recent, or Australian, or from the viewpoint of young people. The available literature provided adult perspectives of young people’s spirituality: either as adults reflecting back to when they were children or young people, or parents and healthcare professionals speaking on behalf of young people (Hutchison et al, 2003; Hynson et al, 2003; Judd, 2001). The dearth of empirical literature also led Sydney-based paediatric palliative care consultant, Collins (2000) to suggest that research initiatives into the spiritual domain of care of dying children were needed.

For these reasons, I concluded that an exploratory study was a suitable approach to initiate research in this area. Furthermore, as the views and opinions of children and young people are often marginalised in society, I was keen to provide young people with an opportunity to speak for themselves. This was also consistent with the United Nations Convention on the Rights of the Child (1989) which provided for children to participate in their own right and that their participation was to be taken seriously (Fattore and Mason with Sidoti, 2005) (discussed in Chapter Two). It was also in accordance with the NSW Commission for Children and Young People, which advocates for the
“right of children and young people to play an active role in the decisions and actions that shape their lives” (http://kids.nsw.gov.au). Moreover, it was a good fit with the research site, CanTeen’s philosophy of ‘member empowerment’.

With these aims and objectives in mind, I selected research methods and a methodological approach that would facilitate obtaining the desired research data. At the same time, the data collection process would also be conducted in a manner that would proffer empowerment and validation of the experiences of the young people recruited. In the first part of this chapter, I discuss my selected epistemological and theoretical perspectives. This is followed by a discussion of the ethical considerations relevant to this topic and this population and a description of the ethics approval process for this study. In the second part of the chapter, I discuss my methodological approach to the research. This includes a comprehensive description of the research: the nature of the research inquiry, the research design, the participants, the research site, and the recruitment process. Before describing the data collection and data analysis processes, I provide an account of my personal and professional assumptions, expectations, biases and reflections about the research.

Epistemological and theoretical perspectives

Epistemological perspective

In terms of epistemologies, essentially the researcher has one of three options with regard to theories of knowledge (D’Cruz and Jones, 2004). In the first instance, I rejected operationalising objectivism as an epistemology, as this would have meant searching for an absolute or objective truth, with an understanding or belief that reality is external of the social actor. Given the
subject matter/phenomenon of spirituality, (which was described in Chapter One as variable and debatable), I considered this was unfeasible. Nonetheless objectivism could be viewed as relevant in relation to one aspect under the broader description of spirituality: religion. Viewed as an organised system of beliefs in a structured and institutionalised group practice (Pellebon and Anderson, 1999), religion could be seen as an entity separate to the social actor.

Again, given the subject matter/phenomenon of spirituality and the participants being young people, straddling adolescence and young adulthood, during the changes and challenges of modern life, as well as enduring a life-threatening illness, I anticipated difference and diversity. The aim of the research was to capture the different perspectives and different meanings and interpretations of spirituality, at possibly different times in the participants’ lives and during the illness trajectory as well as to see how their spiritual views, beliefs, experiences were developed, processed and expressed. As such, the most appropriate epistemology for this research study was constructivism, which recognises that meanings are socially constructed rather than discovered, that is, that “meanings are constructed by human beings as they engage with the world they are interpreting” (Crotty, 1998, p43).

The third alternative epistemology, subjectivism takes a more radical approach on the epistemological continuum and suggests that “meaning does not come out of an interplay between subject and object but is imposed on the object by the subject” (Crotty, 1998, p9). In this research topic, that would suggest that the participant (the subject) derived its meaning exclusively out of the phenomenon in question: spirituality (the object). In other words, this happens without any other influences, for example, other people’s ideas, past experiences and so on. This would have suggested spirituality was a more simplistic and linear concept than it is and hence subjectivism was not a workable proposition.
Theoretical perspective

Again, the researcher has a number of options in terms of theoretical perspectives. However, there are two opposing points of view. Without doubt, interpretivism, which emphasises the importance of (empathic) understanding of the research data, is more suitable for the social sciences, and for a study that sought to draw upon the direct experiences and subjective viewpoints of the participants and their sense of meaning and interpretation. This contrasts positivism, which seeks to find explanations for phenomena, and which is generally applied to the natural sciences. Furthermore, within interpretivism, I adopted a phenomenological approach to the research. I now briefly discuss the historical roots and varying types of phenomenological theory, by way of explaining my chosen strand of phenomenology: hermeneutic phenomenology. I also describe the process for data collection and analysis, as well as the strengths and limitations of phenomenology. There is some generalised commentary about phenomenology however the main focus will be the application of phenomenology to this research study.

The main thrust of phenomenology is its emphasis on the meanings that human beings derive from their lived experiences of a particular social phenomenon. Herein, I aimed to look at the actual experiences of young people, who have or have had cancer, in relation to spirituality, as the social phenomenon. This was based on a premise that human beings act on meanings they draw from their behaviour and the behaviour of others (Bryman, 2001). Many definitions of phenomenology highlight meaning through description, which implies some level of interpretation by the social actor, while other definitions actually acknowledge an interpretative element. For example, Pollio, Henley and Thompson (1997) defined phenomenology as “a determinate method of inquiry directed toward attaining a rigorous and significant description of the world of everyday human experience as it is lived and described by specific individuals in
specific circumstances” (p28). DePoy and Gitlin (1998) defined it as “one form of naturalistic inquiry, the purpose of which is to uncover the meaning of how humans experience phenomena through the description of those experiences as they are lived by individuals” (p310). However, Welch (2001) noted that “a person’s reality is formed through the meanings they attribute to personal experience; how people describe their experience is how life is for them; it is through interpretation of the lived world that a person gives meaning to their lives” (p61, my italics).

Within the broad theory of phenomenology, there are two main traditions with differing histories that explain the varying definitions or different emphases. In the first instance, there is hermeneutic phenomenology, which emphasises that it is not only a description but also an interpretive process in which the researcher makes an interpretation of the meaning of the lived experiences (Creswell, 2007). Secondly, empirical, transcendental or psychological phenomenology is less focused on the interpretations of the researcher and more on the description of the experiences of the participants (Creswell, 2007). The historical roots of each tradition explain the different emphasis. Phenomenology was founded in Germany by Husserl in the 1960’s to investigate the essence of human experience. Schutz (a follower of Husserl) fled Nazi Germany and moved to New York in 1939 and he developed a North American version or new phenomenology, which was less concerned with revealing the essence of experience and more concerned with describing the ways in which humans give meaning to their experiences or the ways people interpret social phenomena (Denscombe, 2003). Whilst it can be difficult to separate the two traditions as aspects were imported back and forth, this does not detract from hermeneutic phenomenology, with its interpretive element, being an appropriate theoretical perspective to adopt for this research study. A point of interest is that at the outset of this study, I was intent on the more descriptive North American model, which would have primarily focused on the participants’ interpretations of their social reality or behaviour. However, with the benefit of the research data, I identified that
there were rich research data that I could mediate across. I also considered I
could not only describe the participants’ interpretations of their data but also
provide my own interpretations of their interpretations of their data.

I now turn to the data collection and data analysis techniques of
phenomenology and its strengths and limitations. The principal method of
data collection in phenomenology is through in-depth interview (with a small
number of participants, that is, five to 25) (Creswell, 2007). Other methods
such as observation, journal, art, poetry and music (Creswell, 2007) can also
be used. Primarily, the participant sets the course of the interview and the
aim of the dialogue is to obtain a first-hand account of the particular human
experience (Barnacle, 2001). The role of the researcher is to immerse
themself into the stories of the participants and any questioning is recursive
in nature to evoke description and clarification of the participants’ lived
experience (Barnacle, 2001).

The first step, and a fundamental element of phenomenology, is for the
researcher to set aside their own experiences and assumptions of the
phenomenon, in this case spirituality, referred to as ‘epoche’ or bracketing.
The purpose of this is so that the researcher enters the data collection with
an open mind and does not cloud the research data and does not impose an a
priori hypothesis on the experience (Creswell, 2007). Next, the researcher
lists all significant statements from the interviews and gives them equal
value, referred to as ‘horizontalisation’. The researcher then clusters
statements into themes or meaning units, removing overlapping and repetitive
statements but also seeking divergent perspectives. From the themes the
researcher establishes how the phenomenon was experienced by the
participants (a structural description) and what was actually experienced by
the participants (a textural description) before concluding with an essential,
Invariant structure or essence, which reduces the structural and textural
descriptions into a brief description that typifies the experiences of all
participants (Creswell, 2007).
A phenomenological approach has a number of strong points. It provides a structured model for small research projects where the researcher wishes to obtain an in-depth account of the phenomenon and all its complexities from a small number of participants. Furthermore, phenomenology’s focus on the lived experiences and interpretations of the participants demonstrates an inherent value and respect to participants and their experiences (Denscombe, 2003). However, like many qualitative traditions, phenomenology’s focus on subjectivity, description and interpretation, is often criticised as lacking scientific rigour and generalisability. Moreover, bracketing of the researcher’s experiences of the phenomenon encourages openness in data collection (Hayes, 1997) and hence subsequent conclusions are a result of the immediate experience of the person rather than the prior assumptions of the researcher (Spinelli, 1989). However, there are difficulties with the concept of bracketing. I question how realistic it is to totally bracket off one’s assumptions and experiences of spirituality, although I appreciate Spinelli’s point that bracketing at least highlights the need for awareness of biases. Social workers, as a profession, are well placed to do this, as we are trained to be aware of our biases and judgements and to not act on them. My last point concerns whether phenomenology’s indirect and open approach to data collection means that it may be more suited to articulate persons and may not accommodate some population groups. To demonstrate this point I draw on the two questions Creswell (2007) suggests in terms of data collection: ‘what have you experienced in terms of spirituality [the phenomenon]’ and ‘what contexts or situations have typically influenced or affected your experiences of spirituality [the phenomenon]?’ For this research study, I considered that this sort of open invitation would have been too broad and unspecific for younger participants and hence prepared some ‘prompt’ questions to assist participants tell their story.

The underpinning epistemological and theoretical perspectives discussed above support and emphasise the focus of the research (Mason, 2002): to give young people with cancer a voice about their spirituality and to value their
interpretations and meanings of their spirituality. While this provides a foundational level of safety and integrity for the research, I now outline the specific ethical issues and strategies adopted to address the concerns.

**Ethical considerations**

Research in the past, which has been of an unethical nature with harmful ramifications as a consequence, has influenced social scientists, scientific societies and professional bodies to formulate codes of ethics for the treatment of participants (Judd, Smith and Kidder, 1991). Specifically, the practice standards and code of ethics of the AASW emphasise that social workers should develop research questions and engage in research relationships, which are based on the five basic values of social work practice: human dignity and worth, social justice, service to humanity, integrity and competence (AASW, 1999 and 2003). Addressing ethical issues also supports the integrity of the research and social research commentators such as Bryman (2001), Denscombe (2003) and Judd et al (1991) alert the researcher that ethical considerations should be built into the methodology and research design.

Resolving ethical issues in social research often involves balancing costs and benefits for both the individual and the researcher/research community. Firstly, there is the individual’s right to dignity, privacy and self-determination and secondly, the right of science and society to inquire and to be informed (Judd et al, 1991). This is the most obvious cost/benefit analysis but there are other potential costs and benefits. There is the potential cost to society and future scientific work if the research process adds negatively to society. Examples of this include contributing to “a social climate of suspicion, distrust, or manipulation” or if covert methods are used, it could “turn society against social science and reduce future financial support of
social research” (Judd et al, 1991, p482). On the other hand, the research data might actually directly or indirectly benefit the individual involved, as well as others in the same or similar situation. There is also the possibility that the individual may actually benefit from their participation in the research. They have an opportunity to tell their story and doing so may assist them to clarify unresolved issues. They also have an interested party listening to them and validating their experiences. Thompson (1992), referring to children participating in research, noted that “research activities are typically pleasant, sometimes interesting, and children often learn from their experiences in research and receive affirming responses from the researcher” (p53). The challenge for the researcher is to obtain the desired research data while looking after the individual’s personal interests. I now outline specific ethical issues relevant in this research as well as strategies used to address same, under the following headings: harm to participants, informed consent, invasion of privacy and deception. I conclude with an outline of the ethics approval process for the various institutions involved and organisations responsible.

Harm to participants

The literature forewarns the researcher that there are many ways that the researcher or the research project can inflict harm on the participant, either directly or indirectly and participants can experience harm on a number of different levels. At one end of the continuum, participants may feel that they are being treated unfairly or disrespectfully when the researcher is late for appointments. At the other end of the continuum, participants’ self-respect may be diminished if they are led to be dishonest and commit acts such as cheating, lying or stealing (Judd et al, 1991). In the middle of the continuum and more relevant in this research is the situation where participants experience harm when they are exposed to physical or mental stress, for example, when they disclose inappropriate or unnecessary personal information (Judd et al, 1991).
Immediately the sensitive nature of the research topic (spirituality, which may lead to discussion about life and death, and life-threatening illnesses, which may lead to disability and/or premature death) and the potentially vulnerable population group (young people who may be unwell) alerted me, as the researcher, to employ great care, compassion and sensitivity with my contact with participants and their families, to ensure that emotional or psychological discomfort or unease is eliminated or at least minimised (Valentine, 2007). I used the following strategies to safeguard participants’ physical and emotional safety and to ensure their experience was reasonably positive. In the first instance, participants could engage or dis-engage with the research study as they wished and they could do this without having to deal with me directly. Support workers from the research site acted as intermediaries and distributed the research documents: invitation to the young person [Appendix 1], letter to the parent/carer [Appendix 2], information sheets for young person and parents [Appendices 3 and 4], consents for young person and parents [Appendices 5 and 6] and revocations of consent for young person and parents [Appendices 7 and 8] (the research documents). In this way, interested participants did not have any direct contact with me until they had agreed to participate.

Secondly, I invited participants to have a support person (a peer, a family member, a social worker or a support worker) throughout the study. Similarly, I offered to talk to parents/carers, prior to the research interview to provide an overview of the research and to answer any concerns.

Thirdly, the structure for data collection enabled me to engage, build rapport and provide support to participants and their parent/carer. In the initial telephone conversation, I allowed time (or offered to meet in person), for ‘meet and greet’, getting to know the participant and their parents/carers as well as information exchange. Specifically, I explained the purpose of the research, the participant’s role in the interview, the use of a support person, privacy, as well as acknowledging the difference between this interview and
other types of interviews (that is, it was an opportunity to talk as they wished). Importantly, participants were alerted to the limits to confidentiality in the event that a participant disclosed or indicated that they were unsafe, in terms of hurting themselves or someone else or being hurt themselves by another person. This was also consistent with the policies and practices of the research site.

During the initial contact, I assessed the level of maturity of the participant, with the participant themselves or their parent/carer, so that I could tailor the interview process accordingly. While I planned to initiate the interview with open-ended questions, the brief assessment alerted me as to whether to use ‘prompt’ questions or other communication mediums (for example, drawing, picture cards). During the interview, I provided as much choice as possible to participants (to answer/not answer questions, to control the tape-recorder, to terminate the interview and to read the transcript), and emphasised the phenomenological nature of the research (myself being in the ‘student-learner’ role to learn from the participant as an expert in their life, similar to Coles’ approach [1990]). I also provided light age-appropriate refreshments.

Lastly, I adopted a strengths/resilience-based and phenomenological approach. To this end, I used my experience of working therapeutically with young people in mental health and child protection work. I presented the study, in a non-judgmental, supportive and empathic manner, to the participants as an opportunity for them to share their experiences, beliefs, attitudes and so on about the topic. I emphasised that there were no right/wrong answers and that I was interested to learn from them. While this approach went towards reducing the power imbalance between the participant and myself, as the researcher, the adult/younger-person dynamic remains as do other power differentials (for example, gender, class and ethnicity). Notwithstanding the above considerations, in the event a participant became distressed during or at the end of the interview, I planned
to provide appropriate support, reassurance and debriefing as indicated. I had arranged that I would check-in with the manager at the research site at the completion of each interview and alert her if any participant was unsafe, distressed or of concern and she would then refer as per their policy. In any event, I had anticipated that any distress would not have been outside the normal range of life experiences (for example, of feeling upset or worried about something).

**Informed consent**

It is vital to the spirit and integrity of the research that interested participants are provided with a full disclosure of pertinent information to enable an informed decision (Tymchuk cited in Morrow and Richards, 1996). It is also important that interested participants feel supported to provide their consent for or against participating in an unpressured manner and that they are aware their involvement does not influence their treatment or contact with the referring service. Furthermore, the process of young people being given real choices serves two purposes. It attempts to balance power in the research relationship and it provides an opportunity for the young person to make choices in a safe and supportive setting (Melton, cited in Ireland and Holloway, 1996).

In this study, participants were provided with the research documents by the support worker at the research site. I also discussed confidentiality, anonymity, consent, safety and supports with the participants and their parent/carer in the initial telephone contact. Participants and their parent/carer were also advised about the purpose of the study, the anticipated publication of the findings, and they could terminate the interview at any time. They were also advised that they could control the audio-tape and could choose to answer or not answer questions and they could obtain a copy of their transcript.
**Invasion of privacy**

Participants’ rights to privacy are often violated in one of two ways. In the first instance, they may be coerced into disclosing personal material that they would prefer to keep private or that is not relevant to the study. I was conscious to make a distinction between a counselling interview, which may involve discussion of personal relationships in detail, and this research interview, where personal relationships were not the subject of the study. Secondly, privacy is often denied when participants are not fully informed about their rights with regard to privacy. While this necessarily excludes issues of child protection and public safety, participants were informed about the use, storage and publication of confidential data, that the contents of their interview would not be discussed with other people in their family or the research site, and that identifying information would be omitted, and pseudonyms used, in any publications.

**Deception**

Deception in research can take place in a number of different ways. If participants are not told the truth or passively told only part of the truth, this can lead participants to formulate their own hypothesis (Judd et al, 1991). Similarly, if participants are informed about the research in a biased manner, they may skew their information to support the hypothesis (Bryman, 2001). Judd et al (1991) noted that these actions can diminish respect, violate the expectation of mutual trust, and contribute to a climate of cynicism and mistrust. Furthermore, Thompson (1992) cautioned the researcher to be mindful of the developmental context of the lives of young people, where younger adolescent’s trust in authority may render them more vulnerable to being deceived in research, whereas older adolescents may be more likely to question the researcher’s requests. In this research, participants were provided with an overview of the research study explaining that the purpose of the research is to learn from young people (who have or have had cancer).
about their spiritual beliefs, practices and experiences. As it is an exploratory study, with no hypothesis to be tested, there was no difficulty in being open and honest about the research.

In summary, after weighing up the anticipated risks and potential benefits of conducting research with young people, I considered that adequate steps had been taken to protect the participants’ privacy and safeguard against deception and causing physical and emotional harm. The main safeguards in this research are: that there was complete openness and honesty with participants and their parent/carer about the research, that there was no particular agenda or hypothesis to be tested, that an inter-mediatory person initially mediated between participants and myself, that participants could have a support person during the interview, and that participants could withdraw consent to the research at any time without any ramifications.

The ethics approval process

In November 2006 (stage one), I submitted an Ethics and Privacy Application Form for Research involving Humans to the University of Sydney Ethics Committee under reference number 9643. Approval was initially deferred because the Committee considered a control group of young people without cancer was needed in the research design. The remainder of the suggestions were of a more minor nature, for example, that a separate participant information sheet and consent form be prepared for young people and their parents/carers, that a point be added that the research was part of the researcher’s Doctor of Social Work Degree, and that the points about ‘concerns or complaints’ and ‘further information’ needed to be in ‘bold’ print in the information sheets. The minor amendments were made to the participant information sheet and a response, regarding the control group, was made highlighting the fact that this was a small exploratory study with no hypothesis being tested, with an appropriate methodological approach and
that the addition of a control group fell outside the scope of the dissertation requirement.

Final ethics approval from the University of Sydney was granted in February 2007. This was then followed by an Application for Approval to Conduct Qualitative Research Interviews with patient members at CanTeen (the research site) being submitted in March 2007. CanTeen’s Research and Evaluation Committee subsequently approved the researcher accessing their members in May 2007.

In January 2008 (stage two), I sought modification from the University of Sydney Human Research Ethics Committee as follows: (i) to extend the age for participants from 12-16 years of age to 12-24 years of age (this was consistent with the age range of CanTeen members, this increased the pool of potential participants, and this responded to the young people over 16 years of age who had expressed interest in the research), (ii) to change the number of interviews from three or four to one (as experience had shown that the preliminary information exchange could take place by phone and considerable data could be collected in one interview), (iii) to vary the method of data collection by adding age appropriate methods of communication (weblog and focus group discussion) in addition to face to face qualitative interviewing, and (iv) to change the research title to ‘spirituality of young people with cancer’ to more accurately reflect age-appropriate language for the cohort. This was accepted on 28 February 2008 and the University of Sydney’s letter of approval is contained at Appendix 9. I resubmitted my application to CanTeen in June 2008 and approval was confirmed by email on 14 August 2008. CanTeen’s original letter of approval dated 9 May 2007 is contained at Appendix 10.
Methods

In this segment, I describe my research action plan according to a phenomenological perspective.

The research inquiry

As the focus of this research was exploratory in nature, about the lived experience of young people with cancer, with regard to their spirituality (its meaning and the context, as well as their beliefs, practices, ideas, and experiences), there were no hypotheses to test. I was however, interested to explore whether the following areas were relevant for young people:

(i) whether questions of meaning and purpose interest young people with cancer,
(ii) whether spiritual beliefs have (positive, negative, neutral or mixed) affect on young people with cancer,
(iii) whether young people with cancer experience similar or different spiritual beliefs to their families/significant others,
(iv) when young people started being a spiritual being,
(v) whether a life-threatening illness, like cancer, accelerates interest in spirituality,
(vi) whether demographics (social class, ethnicity or gender) influence young people’s interest in spirituality,
(vii) what form young people’s spirituality takes (belief in a Divine Being, Nature, Universe), and
(viii) how young people express their spirituality (by prayer, meditation, poetry, music, art and so).

These points were used as ‘prompts’ or a guide and were covered in the interview schedule [Appendix 11].
The research design

In the original research design, I planned for in-depth interviewing, with a combination of semi-structured and unstructured interviewing, with the participants aged 12 to 16 years. At the time, I aimed for three to four interviews with each participant, with the first interview typically focusing on rapport and trust building with the participant and, where relevant, their parent/carer and providing information about the purpose of the research and the participant’s role (this is detailed below). Subsequent interviews were to focus on the research content. In the ‘content’ interviews, I planned to start with open-ended questions to invite participants to speak about their experiences and if necessary, use direct or ‘prompt’ questions to compliment the free narrative. Some of the questions/topics in the interview schedule were derived from the research study of Mason et al (2007) and from the “Deep Speak” ‘belief’ cards (designed ‘to stimulate discussion with young people about life’s big questions’) (http://www.innovativeresources.org). If appropriate, participants were invited to draw (and talk about) their ideas and ‘prompt/picture’ cards “Signposts: exploring everyday spirituality” (http://www.innovativeresources.org) were used to generate discussion. The last interview was for completion of the interaction with the participant: an opportunity for debriefing and feedback, for questions to be raised and for delivery of the transcript.

However, in practice, things were different. During my involvement with the first participant, I noticed that much of the rapport building and information exchange took place in the initial telephone conversation, when I introduced myself and the research and arranged a meeting time. Similarly, I found that one lengthy interview of between one and a half hours to two hours covered most of the significant research content. In the follow-up telephone conversation and further in-person meeting, when the transcript was given to the participant, I observed that outstanding questions and/or points of clarification were explored.
At the same time as the initial interviews, there were recruitment issues and new information came to light. I found that there were only a small number of eligible participants to draw upon from the research site and there was minimal response. Additionally, I found that young people aged 18 years and over had expressed interested in the research topic, and consultation with young people, youth workers and research colleagues indicated other methods of communicating may be needed for young people. With these factors in mind, I sought to vary the research methodology. Hence, in the second stage, the research was extended to young people up to 24 years of age (from 12 to 16 years of age to 12 to 24 years of age), the number of interviews was changed from three or four to one, the method of data collection was varied to include focus groups and website discussion, in addition to face to face interviewing, and the research title was changed ‘Spirituality of Young people with Cancer’ (omitting the reference to children).

I consulted widely with regard to the development of the blogsite. I sought technical and ethical advice from the E-Research Consultant, Faculty of Education and Social Work at the University of Sydney and a participant acted as a youth consultant. A safe and appropriate server was found through www.blogger.com as this site could be used for ‘invited readers only’ and an appropriate template, design, colour, fonts were selected with the assistance of the young person consultant and a design consultant. The blogsite entailed developing a title for the blogsite, a description of the purpose of the blogsite, and information about participating in the blogsite as well as including a photo and personal profile of myself, as the researcher/blogmaster and posting an entry to start the blogsite discussion. The front page of the blogsite is contained at Appendix 12. In the end, the blogsite was only used by two participants, with one entry each, and for the most, the data were comparable to that contained in the research interviews. Similarly, the plan of a focus group was abandoned as only one participant expressed interest in it, and it appeared her interest was mostly for social reasons.
The participants

While the original research design was varied to extend the age from 12 to 16 years of age to 12 to 24 years of age, the selection criteria did not change. Participants needed to be at least three months after diagnosis, when they had passed the initial crisis phase, and were starting to cope, live with and make sense of the illness and its treatment. They also needed to be in an emotionally and psychologically stable frame of mind and without current mental health issues. This was to be determined by staff at the research site and/or parents. For participants under 18 years of age, they also needed their parent/carer’s permission to participate. Initially I planned to interview 15 to 20 participants, however this number was reduced to 10 to 12 with the inclusion of the blogsite data.

The research site

The participants in this research study were recruited from CanTeen: the Australian organisation for young people living with cancer (http://www.canteen.org.au). CanTeen aims to support, develop and empower all young people aged 12 to 24 years who are living with cancer, whether they are a young person with cancer themselves, or have a parent or sibling with cancer, or have had a parent or sibling die recently from cancer. It is a peer support program for young people and its members participate in the management of the organisation and guide the educational, social and recreational activities (for example, camps, recreational outings). The members are supported by paid staff and volunteers (including medical and psychosocial volunteers). It was in my capacity as a volunteer that I became involved in CanTeen. CanTeen has 11 offices throughout Australia and I recruited participants from three locations: Australian Capital Territory and Southern New South Wales, Hunter and Northern New South Wales, and Sydney and Central New South Wales.
The recruitment of participants

An opportunistic approach was utilised for accessing participants, via convenience sampling (that is, people who were available or accessible (Bryman, 2001) at CanTeen and who met the research criteria (as outlined above).

In stage one, after ethics approval from the University of Sydney and CanTeen, the research documents were sent to CanTeen and in June 2007, the Division Manager at CanTeen provided a mail out to all CanTeen patient members and a reminder letter was sent in August 2007. As there were only 22 patient members aged 12 and 16 years in the Sydney and Central New South Wales Division, in September 2007, at the suggestion of the Division Manager (and the approval of the CanTeen National Research and Evaluation Manager) the geographic area was extended to the Australian Capital Territory, Southern New South Wales and the Hunter and Northern New South Wales Divisions. Furthermore, in September and October 2007 the researcher did informal recruitment presentations at a CanTeen Recreation Day and Camp. While there was minimal formal response, enthusiastic interest was expressed by young people at an ‘Over 18’s camp’.

In the initial mailout, the invitation to the young person, the letter to the parent/carer and an information sheet was sent. Upon the young person or their parent contacting CanTeen, a full set of the research documents was sent to them. Upon receipt of a signed consent by the young person and their parent/carer, the CanTeen Division Manager then released their contact details to me by email and I made direct contact with the participant and/or their parent/carer and discussed the research and arranged an interview time. In the case of young people under 18 years of age, consent by both the participant and their parent/carer was obtained. In stage two, the research documents were sent to the extended group (all patient members aged 12 to 24 years) and the same distribution process was followed.
Data collection

Bracketing the assumptions, expectations and biases of the researcher

Using a phenomenological approach, the first step in the data collection process is the bracketing of the researcher’s assumptions, expectations and biases. These assumptions, expectations and biases emerged from a range of experiences in my personal and professional life and some of this was briefly discussed in Chapter One. Some of these influences were also based on understandings from a generational perspective, that is, my experiences as a researcher and as a Baby Boomer and unwisely my expectations that subsequent generations would essentially experience similar things. However, as I noted in Chapter Two regarding Gen Y, each generation has a different set of experiences based on the socio-economic/political context of the time.

Firstly, I expected that a diagnosis of cancer would influence young people to be more interested in religion/spirituality or it would increase their practices. I also considered that if young people were not engaged with traditional religion they would be involved with New Age spiritualities. Furthermore, I anticipated that New Age spiritualities would appeal to young people because the concepts and practices were diverse, flexible, accepting and relaxed. I had not recognised, as Mason et al (2007) pointed out, that many New Age spiritual practices require a certain level of income.

Secondly, I thought that young people would be predominantly influenced by their peer groups rather than their parents/families and like previous generations, and in particular Baby Boomers, would be keen to live independently. However, this did not take account of the increased cost of housing and education. Nonetheless, I learned that it was not just a question of economics. I observed that many young people enjoyed the company of their Baby Boomer parents.
Thirdly, I expected that if young people were attached to a particular religious or spiritual path and if they deviated or contradicted themselves with other religious or spiritual sources, that they would experience worry, concern, or perhaps guilt.

Fourthly, I expected that by virtue of their developmental stage in life, adolescence, traditionally a time of wonder and idealism, that young people would have spent time on their own or with their peers reflecting, thinking abstractly, wondering, establishing ideals and ‘looking at the big picture’ of life. Similarly, using a phenomenological approach, I expected that I would interview young people and obtain their ideas, in a free narrative form by asking questions such as, ‘what have you experienced in terms of your spirituality?’ and ‘what contexts or situations have typically influenced or affected your experiences of spirituality?’ (Creswell, 2007) rather than use ‘prompt’ questions I prepared as a back-up. Furthermore, I expected that by virtue of the participants agreeing to participate in the research that they would have had some awareness about their beliefs and practices and had some definite things they wanted to contribute to the research.

Having now bracketed and documented my assumptions, expectations and biases, I now discuss my data collection process. Whilst the data collection methods were varied to include focus group and web blogsite discussion, the bulk of the research data was drawn from in-depth research interviews.

The research interviews: data collection

The research interviews took place in three stages: I conducted the first two interviews in December 2007 and May 2008. Then, after the research was extended to young people over 16 years of age, a further seven interviews took place between September and November 2008, and final two in December 2009 and January 2010. It is interesting to note the significant increased interest in and uptake of the research when the age was extended
from 16 years of age to 24 years of age. The exact reason for this is unclear but I wondered whether it made a difference that the young people aged 18 years and over could decide for themselves and did not need to obtain their parent’s consent. I also wondered whether the research topic appealed more to older adolescents — as noted earlier, young people at the CanTeen ‘Over 18’s camp’ expressed interest in the research topic.

Interviews took place at a range of settings: two at participants' homes, five at CanTeen Offices and two in libraries in the cities of Sydney, Newcastle and Canberra. The interviews ranged from 85 minutes to 155 minutes (most averaging 90 minutes to 105 minutes) in a mostly one-off meeting with follow up telephone and email conversations. In the two interviews that took place in the participants’ homes, one of the parents joined the interview minimally, by offering refreshments and clarifying information, and the other more significantly, by contributing her views and beliefs and gently challenging her daughter’s views.

During the initial telephone contact and at the beginning of the research interview, I reiterated the contents of the participant information sheet. This included the purpose and approach of the research, the roles of the interviewer, interviewee, family member/s, support people, the structure of the interview, and the meaning of participation in the research. I also covered confidentiality/privacy, the risks and benefits of participating in the research, special needs, recording the interviews, field notes and storage of the data. I also checked the participant had read and understood the information sheet and signed the consent form, and advised the participant about feedback, access to the transcript and publication of the research findings. I also welcomed questions from the participant.

When offered the option of ‘prompt’ questions or speaking-as-they-wished, all participants, other than one, opted for the ‘prompt’ questions. This participant immediately proceeded with her thoughts in an excited way as if
she had been waiting for the interview. It should be noted that whilst ‘prompt’ questions or points were used for the majority of the participants, generally the interview flowed in a conversation style, with participants deviating on tangents. Typically an interview started with preliminary information about the research (as noted above) and their involvement with CanTeen. This was followed by background information about their family, friends, school, interests/activities and their cancer experience, before discussion of their spirituality. Only one participant asked about my spirituality and another asked about my cancer experience.

Throughout the interview, I checked with participants as to how they were feeling and coping with the interview. The participants spoke in a positive tone and said that they were enjoying the interview, and that it was something new or different and that they ‘hadn’t thought about this [sort of thing] before’. One participant was tearful during the interview and when asked, she said that she often becomes emotional and that she was coping and wished to continue.

At the conclusion of each interview, I again checked that the participant was safe to finish up and made arrangements for further contact after the interview was transcribed. I posted or emailed transcripts to each participant and at an arranged time, I contacted the participant for discussion of the transcript, for alterations, additions and deletions. Mostly the participants were happy with the transcript of the interview and did not require any changes. However, one participant appeared to have an expectation that the transcript would be similar to a media interview transcript rather than a verbatim transcript. I discussed and supported the participant through this process and explained that I had deliberately included all the ‘uhms’, ‘don’t knows’ and pauses in the transcripts to reflect the level of contemplation in the interviews. At the conclusion of this process, I sent each participant a certificate of appreciation [Appendix 13] and a music or book gift voucher for
between $25 to $30. When the research project was completed, I compiled a summary report for the participants.

The main source of data collection was drawn from the research interviews. However, a small amount of datum was collected in the research web blogsite. I provided some ‘prompt’ discussion points on the blogsite and one participant posted her contribution and another responded, however discussion did not move beyond this level. Consultation from various sources (CanTeen, young people, and other researchers) revealed that young people tend to participate in established blogsites or use sites recommended by their friends or follow links to other sites, rather than using newly created and purpose-developed blogsites. It may also be that the blogsite being ‘for invited users only’, in an effort to provide privacy and confidentiality, may, in fact, have been too restrictive. The focus group did not proceed as interest was only expressed by one participant.

Data Analysis

Data analysis took place in a number of different ways and stages to form a comprehensive and systematic approach. With each participant’s consent, their interview/s was recorded and during the interview or immediately afterwards, I wrote field notes (which included factual information as well as my impressions, observations and ideas). Soon after each interview, I listened to the interviews and made handwritten notes. I transcribed all the interviews and at the time made notes or highlighted in different colours relevant or interesting or significant text. I did a brief/broad manual analysis of data for conference presentations identifying descriptive and important points and using the headings: personal background, cancer diagnosis, spiritual beliefs, practices, ideas, influences, themes, contradictions/inconsistencies, and summary points.
At a later stage, I re-listened to the interviews and/or reviewed the transcripts drawing out the main themes and responses to the ‘research questions’ or my areas of interest. I then reviewed the transcripts and colour coded themes or areas of significance or interest into five main colours: family and background information, cancer experience, coping mechanisms, important points, and spirituality/meaning-making. I used Nvivo 8, a computer-supported qualitative data analysis software program, to assist me to organise and store the data. I entered what I termed the ‘research-related data’ in ‘free nodes’ (single nodes) and the data about the participant’s background, cancer experiences and spirituality in ‘tree nodes’ (nodes that could be sub-divided to create coding hierarchies (Bazeley, 2007) in Nvivo 8 [Appendix 14 contains a list of the Nvivo 8 nodes]. Some of the categorisations of the nodes were generated from the research questions (for example, beliefs, practices) while others were ‘data-driven’ (Braun and Clarke, 2006) or derived from the data itself (for example, worries/concerns, positives (of cancer experience or spirituality), and death and dying). I re-read and checked my coding in Nvivo 8 from each transcript and then I reviewed each node and expanded and condensed nodes as indicated. I also reviewed the small amount of data generated from the blogsite and added that to the Nvivo 8 nodes. Rather than merging various nodes together to form a theme (as suggested by Braun and Clarke, 2006), I made notes of the main points made by the participants in each node and I then clustered the significant statements into categories or units. I often used the name of the node to name these units and the name subsequently became a heading in the Findings chapter.

CONCLUSION

This chapter has focused on the research methodology, beginning with the theoretical influences, the ethical considerations and the ethics approval processes underpinning the study. The research methods section provided a
detailed chronological account of the setting up of the research (the nature of
the research inquiry, the research design, the participants, the research site,
and the recruitment process). This was followed by an outline of the data
collection and data analysis processes, which included a discussion of my
assumptions, expectations and biases about the research study, the
participants, and the data.

With the research methodology now outlined, I shift to the research findings.
From a phenomenological perspective, the Findings chapter contains the
participants’ interpretations of the data and the subsequent Discussion
chapter, contains my interpretations of the participants’ data, including
narratives or essences of the phenomenon studied. The strengths and
limitations of the study are also contained in the Discussion chapter.
CHAPTER FOUR

Findings

INTRODUCTION

In the previous chapter, I outlined my methodological approach to the research study. This involved a discussion of the epistemological and theoretical perspectives that underpin the research study and the ethical considerations employed to protect the participants and the integrity of the research study. I also detailed the research design and the methods of data collection and data analysis.

In this chapter, I report on the findings that have been drawn from a comprehensive data analysis. The material is organised in three sections: firstly, a demographic and descriptive profile of the participants, secondly, the participants’ experience of cancer, and thirdly, the participants’ spirituality. In phenomenological terms, this represents the participants’ interpretations of their experience of cancer and spirituality where all data are valued equally.
SECTION ONE

Demographic and descriptive profile
of participants

The eleven participants who participated in the research study were aged between 13 to 23 years at the time of interview. They consisted of six females and five males and were from the Sydney metropolitan area, the Central Coast, Newcastle, the Hawkesbury River and the South Coast of New South Wales, and Canberra in the Australian Capital Territory. In many ways, the young people interviewed reflected the diversity of Australian society. Participants identified with a number of ethnic backgrounds: Anglo-Celtic, Greek, Asia, European and American, and with a range of religious backgrounds: Catholic, Protestant, Greek Orthodox, and Islamic. Most of the participants lived with their families. Family took many forms — single parent; parents; parents and siblings; parent, step-parent and siblings; and parent, step-parent and half-siblings. One participant lived independently with his girlfriend, one lived half-time with her family and half-time with her boyfriend’s family and another shared with a flatmate. A range of different households is also noted in the literature (SGP, 2008; Wyn and Woodman, 2006). All participants, whether they lived with or separately from their parents, had regular and ongoing involvement with their parents and siblings, which again is consistent with the point made by McCrindle (2006) that young people value their relationship with their families.

The participants attended or had attended public and private schools. These were, variously, single-sex, religious and academically selective, and one participant was home-schooled until high school. Participants were engaged in a number of vocational pursuits: school and voluntary work; school, part-time work and voluntary work; tertiary study and part-time work; full-time...
work; casual work, voluntary work and job-seeking; unpaid work and job-seeking; voluntary work and job-seeking. Those job-seeking or unable to work due to their illness, and one with a young baby, were on income support from the federal government. Participants engaged in or followed a range of interests and activities: the arts (music, art, and dance), sport (basketball, water polo, swimming, soccer, ice-skating, and horse riding), computer games, animals, reading, socialising, camping and involvement in social causes.

In terms of the religious and spiritual histories of participants, three indicated that their parents or families had never been religious, while the remaining eight had had some religious input from their families. Of these, five reported that they had been baptised, six indicated that they had attended church in the past with parents, grandparents, godparents and aunties and one participant had attended church independently of her family’s wishes and practices. Another participant’s family and extended family had been very involved in the church up until his parents abandoned organised religion when he was a small child. The parents of five participants had sent their children to religious schools. Furthermore, three participants had indicated that they had been influenced by scripture at school. Overall, only a small number of participants had quite similar beliefs and practices to their families, and most participants had developed their own perspective, in some cases more ‘religious’ or ‘spiritual’ and in other cases, less so.

Participants had experienced a range of cancers: leukaemia (five), brain (two), lymphoma (one), testicular cancer (one), sarcoma (one) and neuroblastoma (one). From an informal audit (rather than a database analysis) conducted in January 2010, CanTeen staff, in the Sydney area, estimated that the most common cancers that their members experienced were: acute lymphoblastic leukaemia, osteo and Ewings sarcomas, neuroblastoma brain cancer and Hodgkin’s lymphoma. In 2007, the AIHW found that the most common cancers among young people were melanoma.
(30%), Hodgkin’s disease (11%), testis (9%), leukaemia (9%) (followed by thyroid, non-Hodgkin’s lymphoma, bone, brain, connective and soft tissue, colorectal). Unlike the national picture, none of the participants in this study had had melanoma, but otherwise the participants had had the most common cancers identified in CanTeen data and the national statistics. It is interesting to note that while the national figures for testicular cancer and leukaemia were the same (at 9%), this varied greatly with the participants in this study, in that five participants had leukaemia but only one participant had testicular cancer. Perhaps, sensitivity around masculinity may stigmatise testicular cancer more so than other cancers and may mean young men, with this type of cancer, do not present or engage with services and groups that might bring them to the public eye.

While one participant had been diagnosed at 16 months of age and another at almost six years of age, most of the participants were diagnosed during late adolescence (three at 18 years of age, two at 19 years of age and one at 20 years of age), with another two during early adolescence (one at 11 years of age, another at 13 years of age and again at 18 years of age) and only one during middle adolescence (at 15 years of age). This concurs with the statistical data from AIHW (2007), which noted that cancer incidence rates increased with age. Participants were treated with surgery, transplant, chemotherapy and radiotherapy. While three were on ‘maintenance’ chemotherapy, none were currently engaged in active treatment, and most of the participants reported that they had regular scans and check-up appointments with their doctors. The issue of prognosis was rarely mentioned by the participants but on the whole they indicated that the cancer was currently stable. Prognosis is discussed in more detail later in this chapter.

I now provide a summary of each participant, to assist the reader to get in touch with and to personalise the participants. In terms of the protection of their identities, CanTeen staff (who reviewed this section) considered I have appropriately protected them. However, because it is envisaged members of
the ‘CanTeen community’ may view and/or read this document, some detail that is potentially of an identifying nature has been omitted or changed to protect the anonymity of the participants, and of course I use the pseudonym selected by each participant. In most instances, I use the participant’s pseudonym to indicate ownership of a direct quote or idea, but in other instances, I omit this information for confidentiality reasons.

Adam

At the time of interview, Adam was aged 22 years. After attending public schools, he worked in the service industry. He was on government income support and as he was nearing the end of his treatment for cancer, he was job searching, and he was undecided about what he wanted to do following cancer. He lived with his mother, step-father and young step-sister, his twin brother lived nearby independently, and his father and step-mother lived interstate. Culturally, he had an Anglo-Saxon background and his family had never been religious. He had a girlfriend and a wide range of friends through school, work and hospital but preferred his small group of close friends. He was actively involved in CanTeen and in other organisations, doing public speaking and advocating about disability and cancer issues. At 19 years of age, he was diagnosed with leukaemia and had had aggressive surgery, as a result of infections, and extensive chemotherapy.

Anna

At the time of interview, Anna was aged 21 years of age. She had attended a private Christian high school as well as public senior college and was studying environmental science at university and working part-time. Anna lived half-time with her boyfriend and his family and half-time with her parents and young brother and sister. Culturally, she had an Anglo-Saxon/Celtic background and had attended church infrequently as a child. She had a boyfriend and a mixed group of friends from school, college and university
and was interested in art, sport and nature. At 18 years of age, she was diagnosed with a sarcoma cancer and had been treated with surgery, chemotherapy and radiotherapy.

**Bella**

At the time of interview, Bella was aged 13 years and was in year eight at a selective high school in Sydney. She was the only child of Greek parents who were both tertiary-educated and professionals. Her immediate family was non-practising Greek Orthodox while her extended family was practising Greek Orthodox. She had a number of friendship groups through school, family and CanTeen and her interests included music, dance and voluntary work relating to her interest in social causes. At 11 years of age, she was diagnosed with an inoperable brain tumour and was treated with radiotherapy and chemotherapy.

**Emz**

At the time of interview, Emz was a 19 year old young woman who had completed her studies at a public high school and at a Technical and Further Education (TAFE) College and was working full-time in administration. She lived with her mother and step-father and younger brother, and her father and his wife lived in Asia. Her family was from Anglo-Saxon and Asian backgrounds and was influenced by Christianity and Islam. Emz had a long-standing boyfriend, a large group of friends and a small number of friends she could depend on. She was interested in sport, travel, socialising and ‘having fun’. In her final year of high school aged 18 years, she was diagnosed with Hodgkin’s lymphoma and was treated with chemotherapy and radiotherapy.
Georgia

At the time of interview, Georgia was aged 23 years. She had attended a range of rural and urban public and religious schools as well as a private college. She was currently doing casual work and job searching for work that was suitable in light of her ongoing health problems. She was a twin and lived with her parents and younger siblings. Her family was of Mediterranean background and her family identified as Greek Orthodox. She had a range of friends - adult-like and mentors - and wished for more peer-friends. She was interested in soccer and camping and passionate about voluntary work that ‘gives back’. She had had four diagnoses of cancer, firstly a brain tumour at almost six years of age, then again at almost seven years of age and again at 17 years of age and a further tumour at 22 years of age. She had been treated with surgery and radiotherapy.

Lyn

At the time of interview, Lyn was aged 20 years and had attended a public high school and was studying art at university and working part time. She lived with her mother, step-father and younger brothers. Her father and his family lived overseas. Her family was from European, Asian and American backgrounds. She had many friends through family, school and university. Her interests included art, yoga and travel. She was first diagnosed with leukaemia at 13 years of age and she relapsed at 18 years of age and had initially been treated with chemotherapy and later with a blood transplant.

Maree

At the time of interview, Maree was aged 19 years. She had attended public primary and high schools until she left in year nine. She had worked in retail, was currently on government income support and planned to go to TAFE in 2010 to complete her school certificate. Maree had a young baby and lived
with her mother. She had one brother who lived away from home with her extended family. She was from an Anglo background and her family was not religious. Since joining CanTeen, she had made friends; but did not have many other friends. She was interested in animals and sport. Whilst pregnant and aged 18 years, she was diagnosed with leukaemia and treated with chemotherapy.

Marvin

At the time of interview, Marvin was aged 13 years and attended a private Christian high school. He lived with his parents and his older brother lived nearby. He was of Anglo-Australian background, and he and his family were not religious. Marvin had friends from school, Scouts and CanTeen and in particular a few entrusted friends. He was interested in animals, electronic games, music and television and he did voluntary work with animals. He was diagnosed with neuroblastoma (a childhood cancer that grows in the nervous system) at aged 16 months. He had had extensive hospital admissions and medical treatment throughout his life including a bone marrow transplant.

Oscar

At the time of interview, Oscar was aged 20 years. He was home-schooled until he attended a public high school. After school, he had a ‘gap year’ when he worked and travelled overseas and he was enrolled to start university in 2010. He was living away from home. His family comprised parents, older brother and sister and a large extended family. They were all tertiary-educated and worked as professionals. He was from an Anglo-Celtic and European background and had an active Christian upbringing for the earlier part of his life. At school, he had a wide circle of friends including some close friendships but his social circle had decreased since he moved away from home, travelled overseas and had his leukaemia treatment. He enjoyed music, fitness, reading (self-improvement, philosophy, social dynamics) and
travelling. At 19 years of age, he was diagnosed with leukaemia and was treated with chemotherapy.

Steve

At the time of interview, Steve was aged 17 years of age. He was doing his Higher School Certificate (HSC) at a Christian College, having attended public primary and high schools. He had a part-time job and did voluntary work with his church. He planned to go to Bible College in 2009. He lived with his mother, step-father and two younger sisters, his father having died when he was a young child. His family was of European and Anglo-Saxon/Celtic background and they were members of various Christian churches. He had a wide range of friends through school, work and church and his interests included church, sport and playing musical instruments. At 15 years of age, he was diagnosed with mixed germination cell tumours and was treated with surgery and chemotherapy.

Tom

At the time of interview, Tom was aged 22 years. He had attended both private Christian primary and high schools. Prior to the cancer diagnosis, he had been working as a tradesperson and in retail and had started studying and doing vocational training at TAFE. Due to the cancer treatment, he was on government income support and undecided about his work/study in the future. He lived with his girlfriend of some years and his parents and younger brother lived nearby. He had an Anglo-Celtic background and had a Christian upbringing. He had a large group of acquaintances and a small tight group he mixed with regularly and he was interested in fishing, car building, tools, music, learning and reading. At 20 years of age, he was diagnosed with leukaemia and treated with chemotherapy.
In brief, these descriptions of the participants indicate that they had a diverse range of family, cultural, religious and educational backgrounds, they had varied interests and they had different experiences with cancer. Among what they shared were their active and fully-engaged lives, and their value of and support from their families and friends.
SECTION TWO

Participants’ experience of cancer

“barely no scars” (Lyn)

INTRODUCTION

In this section, I report on the participants’ experiences during the three stages of the cancer: ‘the diagnostic stage’, which encompasses the participants’ symptoms leading up to diagnosis as well as their thinking at the time of diagnosis, ‘the treatment stage’, which includes the types of treatment the participants underwent, the effects and the participants’ responses and coping mechanisms to the treatment, and ‘the post-cancer stage’, which covers the effects of the cancer on their lives physically, psychologically and socially. I examine the issue of prognosis, the worries and concerns of the participants with regard to cancer and I conclude with reporting on some of the positive aspects that have emerged from the participants’ experience of cancer.

Although documented in the first section, I firstly reacquaint the reader with brief details about the participants’ experience of cancer. In terms of types of cancers, participants had been diagnosed with brain cancer, leukaemia, lymphoma, testicular cancer, sarcoma and neuroblastoma. At the time of diagnosis they were aged 16 months, almost six years of age, and during early, middle and late adolescence. They had been treated with surgery, transplant, chemotherapy and radiotherapy.
Cancer diagnosis

Symptomatology

At the time of diagnosis, the participants had presented with a range of symptoms, including feeling sick and weak, persistent cold and flu-like symptoms, a lump in the foot, an infected foot, sore legs, a swollen and inflamed testicle, high platelets in a routine pregnancy blood test and having a focal fit. Initially, these regular illnesses and infections that did not respond to antibiotics had meant participants had to undergo further scans and blood tests to investigate for something potentially more serious. In most cases, it appeared the cancers were detected and diagnosed promptly; however, one participant had had such leukaemia-type symptoms as nose bleeds, unusual bruising and anaemia, four years before leukaemia was detected during her pregnancy.

Thinking at the time of diagnosis

In their own individual way, the period immediately after diagnosis was, at the very least, difficult and challenging for participants, but for some it was very complicated, serious and life-threatening. While participants had to wait a period of time for a final diagnosis, most had been alerted promptly to the possibility of cancer. During this time, one participant reported he had not been anxious and had coped by praying and ‘giving it all over to God’, but most responded with shock, disbelief, distress, anger, depression and had experienced difficulty accepting the diagnosis. One participant was alarmed to learn at the time of her diagnosis that her grandmother had died from lymphoma, another was confronted with dealing with a third cancer at 17 years of age, when previously her parents had taken care of things during her childhood. One participant struggled against the advice to terminate her pregnancy and she also tried to hold onto the belief that her symptoms represented a gestational condition. For another, the infection, which was
the initial presentation, was spreading so quickly that he had to undergo immediate and radical surgery to release the pressure and was only given a 50% chance of survival. For all the participants, they were instantly aware that their immediate future life plans would be significantly disrupted.

**Cancer treatment**

*Types of cancer treatment*

The cancers experienced by the participants were mainly treated with surgery, transplant, chemotherapy, radiotherapy, and pharmacological treatments such as steroids and immune therapy drugs. Participants typically underwent treatment for approximately one year. Seven participants underwent surgical procedures that included removal of the cancerous lump, removal of infected limbs and damaged organs, bone marrow transplants and insertion of support pins in the body. Nine participants had undergone chemotherapy either as an inpatient or outpatient, either intravenously or in tablet form and at least three had had or were on ‘maintenance’ chemotherapy. Five participants had been treated with radiotherapy, two participants with bone marrow transplants, either allogeneic (donor) or autologous (own stem cells) transplants, and another two with steroid treatments. One participant had had intensive rehabilitation and physiotherapy and all participants had ongoing check-ups and scans with their oncologists.

*Effects of cancer treatment*

The cancer treatment regimes that were prescribed for participants had an enormous physical-medical and psychological-emotional impact on them. From a physical-medical point of view, as participants underwent chemotherapy and radiotherapy, they experienced sickness, nausea, vomiting,
tiredness, weakness, lethargy, insomnia, sore legs and disordered eating. In particular, one participant had blood poisoning and septicaemia that resulted in an induced coma and removal of limbs, while others reported being ‘in and out’ of hospital coping with the cancer treatment and contracting other illnesses, for example, pneumonia. Similarly, the intense cancer treatment and participants’ suppressed immune system resulted in one participant being immobilised for five months, while another two experienced hypomania whilst on steroids.

Furthermore, participants’ psychological-emotional wellbeing was affected by their ‘normal adolescent life’ being interrupted. Their freedom of movement was restricted as a result of their numerous hospital admissions, they missed significant periods of school, and their compromised immune systems meant they were unable to use public transport or public swimming pools and had to avoid crowds. Their cancer treatment and consequent health also increased their isolation from friends and peers and increased their reliance on parents (at a time when their peers were gaining greater independence) and in some cases, made them feel depressed.

_Coping with cancer treatment_

The manner in which participants coped with their cancer treatment was diverse. Participants felt either their whole family or certain members of their family were very supportive and helpful. It was noted that parents, in particular, would travel great distances regularly to give love and care and they were also appropriate and competent advocates and organisers. However, one participant noted the ‘double-bind’ regarding his mother’s care, “… it was good that Mum was there a lot of the time but you don’t want your Mum, to hang out with your Mum all day every day …” This was also noted by Hynson et al (2003); Pellebon and Anderson (1999).
Participants also indicated that they had called on particular personality traits, for example, being positive and always looking at possibilities, self-confidence and leadership skills learnt at school, and developing an awareness that “… you’re not going to use your full potential of coping …” unless it is needed (Adam). Lastly, participants used a range of activities and interests to keep themselves occupied and entertained throughout the cancer treatment. These included reading, writing a journal, meditating, exercising, eating healthily, learning Latin, surfing the internet, socialising with friends, and doing self-portraits (documenting how she was feeling on the inside).

**Effect of cancer on participants’ lives**

*Physical effects of cancer*

From a physical-medical point of view, cancer and its treatment had some lasting effects on participants. For one participant, who had limbs removed, it had meant ongoing physiotherapy to re-develop strength, mobility and independence. Another participant remarked that he was short for his age and had had pins inserted in his hips, others had muscle weaknesses and cramping at the surgical site. Participants reported continuing symptoms ranging from ongoing tiredness to adverse reactions to hospital smells, large tablets, hospital ‘beeping noises’ and seeing people on drips. Participants’
experiences had meant that they had difficulty playing some sports or walking long distances, that they were not able to complete their school work in time, that they had to drink filtered water (because of damaged kidneys) and that they were not able to ride on certain rides at amusement parks. In terms of the future, one participant mentioned that she was at high risk of developing lung or breast cancer. Indeed the issue of having children came up for both female and male participants, with three young women indicating that either they could not have children or that they may have difficulties having children, while one male participant had donated sperm. Fertility issues were discussed in the recent studies of Abrams et al (2007); Hanson et al (2009); and Vadaparampil et al (2008).

Social and psychological effects of cancer

Cancer had also raised psychological and emotional problems for participants in terms of them missing certain events in their lives, in terms of how they were treated and how they reacted, and in terms of their relationships. Firstly, participants noticed that cancer and its treatment regime had interrupted their normal lives, for example, they missed kindergarten, they missed the HSC examinations, they had to do the HSC over two years, they missed the ‘gap year-off’ between school and post-school studies/work, they had to postpone university studies and cancer interrupted friendship-making at school or post-school.

Secondly, some participants noted they were treated ‘delicately’. One participant noted that, as a child, she had been ‘molly-coddled’ and she said, “... I never really got that childhood where I was just free to do stuff like everybody ... like participating in sports and be an everyday kid.” She also said she was ‘picked on at school’ and had more in common with the ‘minority groups’ but that sometimes other children were “... a bit too understanding, and they wouldn’t leave you alone at times when you kinda wanted to be alone”.
Thirdly, participants’ reactions to cancer varied. One participant said she ‘went off the rails’ and had become very angry and depressed, while another had become hyper-alert to ailments in her body. Another noted that it had changed her perspective on life. She now valued life more, she had become more sceptical about people’s lack of awareness of others and was intolerant of things such as smoking. Participants spoke about ‘living in the present’ or ‘one day at a time’, but at the same time, some had become future-focused. One participant said she wanted to have “kids soon, not too soon, soon enough so that I can see them grow up ...”

Lastly, cancer also affected peer, intimate and family relationships. One participant noted that her father had handled things well but her mother had had a ‘breakdown’. Others noted that some friendships had dropped off with the extended hospital admissions, and another noted that it had been difficult to form relationships, in the way her friends had.

**Prognosis**

Participants did not readily talk about nor offer information about their prognosis, or they appeared unclear about their prognosis or what the word meant. However, they did make comments about where they were in the cancer treatment-recovery process. Two participants in particular noted the seriousness of their situation. The first participant, who had had three cancers, noted that the doctors had told her that her body was ‘tumour-proned’ and therefore her body responded to medical problems with tumours. The other participant had reported that the cancer had been inoperable and although it was stable at the time, the chemotherapy and radiotherapy treatment had only reduced the cancer by half.

A number of participants celebrated anniversary dates from one to seven years in remission, while others noted that scans had been clear, that the
treatment had been ‘successful’ or that they had been given a high recovery rate, that is, 80%. Participants persisted with regular scans and check-up appointments with their oncologists and some participants continued with ‘maintenance’ chemotherapy. There were also ongoing complications as a result of the cancer compromising other aspects of their health.

Although at the time of the interviews, it appeared that the participants’ medical conditions were stable, I wondered whether their hopefulness about their prognosis — in light of the diagnosis of cancer, treatment and complications — was reflective of their youth and ‘generational status’ of being a young people in the twenty-first century, who have a high level of optimism. Optimism, as a recurrent theme, is discussed in detail in the next chapter.

**Worries and concerns about the cancer**

*Fear of relapse*

De Graves and Aranda (2008) noted that relapse could be more distressing than the original diagnosis, due to the increased awareness of the threat of death and greater uncertainty surrounding survival. Cancer in the future — either as a relapse of the same cancer or a new cancer or cancer as a consequence of the cancer treatment — was one of the biggest concerns for the participants. They considered that it would be very difficult to face again, a second time or in some cases, a third or fourth time. Tom put it succinctly:

“I didn’t have a bone marrow transplant, but if I relapse … my brother’s not a match … so they’d have to find me a match, so there’d be all that worrying about that, then actually going through it, it is … quite a traumatic process … It feels like a lot more traumatic than dying I suppose.”
Along the same lines, participants reported being very anxious when they had medical tests and scans, and some were hyper-vigilant about body ailments as this raised the question as to whether it was cancer again and they then revisited their experience of cancer. Others said that they thought about cancer every day and hence they were committed to ‘living in the present’.

Social isolation

While participants noted that friends had been instrumental in their recovery, they also repeatedly mentioned in interviews that they experienced social isolation during the cancer treatment, whether they were in hospital or at home. Adam noted that his friends had been unsure if/when to visit hospital, and at the beginning of his treatment, Oscar had dissuaded friends from visiting until he needed them but by this time, he was too unwell emotionally to initiate contact with friends. He said:

“I’ve always been like a social person ... whereas ... I probably spent 90% of my time with maybe six or seven people ... and now ... I’m almost starting afresh because while I do know some people here and there, I haven’t talked to them for a few years now ...”

Adjustment and change

Participants readily talked about the plans they had before cancer came into their lives and how cancer had changed or interrupted their plans for university study or work, or travel or to have children. Oscar, who had flourished at school both academically and socially and had successfully travelled overseas for many months, felt totally unprepared for the challenge that cancer and its treatment presented, which resulted, at least temporarily, in a loss of confidence and identity. Anna discussed her plans to travel overseas but wondered if she could manage walking long distances and carrying things because some of her bones were brittle and she needed to avoid stress fractures.
Positive outcomes from the experience of cancer

Individual positive experiences

Notwithstanding the worries and concerns outlined above, participants had their own individual positive experiences as a result of cancer. Steve reported that he had grown closer to God, Maree reported she had joined CanTeen, made friends and developed ‘a new lease on life’, and Bella and Tom reported that they felt that through diet and exercise, they had become healthier and fitter. Emz said she learned ‘who her friends were’ and to appreciate them more, and to empathise and stand up for people as needed. In her own words:

“... you appreciate people more ... like at work there’s an old lady on the staff and a lot of people mock her ... and I don’t think that’s right. Like maybe if I didn’t get sick maybe I might be laughing or giggling and stuff.”

Furthermore, Adam had developed many positives from his experience of cancer. After his lengthy hospital admission and many surgical interventions, he regained his self-confidence and independence by joining CanTeen and meeting others in a similar situation. He ‘survived’ by giving back and helping others, and becoming a public advocate and raising awareness about disability and cancer ‘in a normalising and inspiring way’. Oscar acknowledged that while he had had some bad experiences with the steroids, he appreciated the experiences, the new ideas, and the clarity of thought and insight he gained about himself. He was adamant he would not ignore or dissociate himself from the experience or trivialise it as ‘drug-induced’. During her experience of cancer, Lyn had met her father for the first time and she considered she was “a very fortunate person, especially to be 20 and to have been sick twice already and I’m still alive and I have barely no scars ...”
Participants’ striving for normalcy

Along with the individual positive experiences, there was also a general theme of participants striving for normalcy. While cancer can interrupt and at times dominate young people’s lives, not surprisingly, young people do not want their identity attached to cancer and yearn for a normal life. Participants made specific reference to their wishes to be ‘normal’ and to be ‘like everyone else’. When discussing the significance of his spirituality, Marvin shifted the focus to the point that he tries to put the cancer behind him and “I try and live like a normal person.” Similarly, after the cancer treatment Oscar valued regular life:

“I’m only realising the extent of it now ... just how much fun normal life is and how important it is to be doing what I want to be doing ... I’ve discovered a certain sense of freedom ... and make sure I know why I’m doing what I’m doing and enjoy.”

In the same way, Adam appreciated post-cancer life, “I’m in a pretty cosy spot at the moment and I’m still taking that in, getting back to normal, normalcy ...” When discussing friends, he said, “Yes, well normalness would probably be the key, just mucking around with the guys, talking about girls or whatever, like just normal behaviour.”

Georgia indicated she was disappointed she had to do her schooling differently to her brother because she “really wanted to finish school and be like everybody else but I couldn’t and ... had to actually do pathways and do a whole two years of HSC to finish it as per normal.”

Lyn also desired and valued ‘normal’ when she was in hospital having her transplant:

“I was stuck in this isolation place, I had some VRE and so I wasn’t allowed out and had to always be in my room and everyone had to wear
white gowns when they came in. I felt really like sterile and I just wanted to be like normal like everybody else.”

In short, the female participants’ positive experiences related to the actual cancer treatment whereas the male participants’ experiences related to post-cancer life.

Thus far it is becoming evident that participants are more reflective of their generational status and, notwithstanding some learnings through the cancer experience, a ‘cancer victim’ or ‘cancer survivor’ identity is not part of the participants’ life plan.
SECTION THREE

Spirituality of the participants

‘spirituality is like chemotherapy, you have to have it’ (Bella)

INTRODUCTION

During the interviews, by way of introducing discussion about the participants’ spirituality, I inquired about what was important to them. All participants made some reference to people: peer, intimate and family relationships/friendships, in terms of the support they gained from family and friends throughout their experience of cancer and also in terms of enjoyment. The notion of caring was also emphasised with references to respect for self and other people (human rights), looking after animals (animal welfare), nature and the environment. Other aspects mentioned pertained to how they intended to live their life: gratitude for ‘normal life’, personal values, freedom and happiness, positive outlook towards cancer, realistic life plans and goals, and living in the present. Only one participant made a direct reference to his spirituality in terms of living his life for God and according to The Bible. The following themes developed either from my ‘prompt’ questions or they emerged out of the data.

Beliefs, values and interests

While most of the participants believed in a deity or something greater than themselves and used words such as God, Greater Being or Higher Power, or that there was ‘something there’, the nature and strength of the belief varied substantially among the participants. Steve talked about a direct relationship with God, while others spoke of a more distant Christian God. Oscar had his
own definition of God, ‘God as the potential’, to wit: “the potential for what I can become, the potential for where the world goes, the potential for what happens today, tomorrow ...” Tom believed there was ‘something there’ but qualified that there was “no Christian God up there looking on every individual person”.

Two of the remaining participants subscribed to a belief in people. Adam believed in himself and Marvin had faith in the ‘skill of the doctors’ (who had kept him alive). Lyn saw spirituality as ‘caring for self and others’ and Anna rejected the notion of ‘belief in’ and saw spirituality as being about the “way you live your life ... the way you treat other people and things like that.”

Aside from a belief in some sort of entity, there were a range of other aspects that were involved in their spirituality. Adam adopted a positive outlook, subscribed to the notion of ‘giving back’ and had a sense of belonging to ‘his community’, which formed as a result of him being diagnosed with cancer. Marvin struggled between feeling his existence being a matter of luck or not-by-chance but in the end, thought that it was mostly because of his doctor’s successful treatment. Oscar adopted an agnostic perspective and was interested in the ‘laws of the universe’ or universal consciousness rather than subscribing to a Christian God and was interested in Daoism’s concept of:

“... simply being and living in the moment, and letting the world ... take care of you and you ... being a part of the rhythms of life and in that there is no good and bad because in the environment there is no good and bad.”

Oscar also said he was content to sit with opposing views, to wit:

“... being logical, scientific based, like rational thinking, on one hand and then also holding this idea of the possibility of the unknown, random coincidences, the possible presence of God and all that, the kind of things that can’t be explained ... and even though they are totally and
completely different in a lot of ways, I sort of feel as though I can sit with that now.”

Steve believed in The Bible teachings, the prophetic word and that God “has hope, destiny and purpose and a sovereign plan for me in life”. Tom believed in respect for all living things and was interested in the after-life, the supernatural and astral projection into different realms of existence (the state of death and dreaming being other possible “planes of existence”).

Anna believed in respect for living beings: nature, animals and people and she advocated for women’s rights and objected to capital punishment. Bella struggled between identifying with religion or atheism but considered that people, like her, “… need something … to lean on and to fall back on …” [in hard times] and that “… spirituality … it’s something you have to have and … like chemotherapy tablets, you have to take it …”

Emz believed that good and bad things happen and she reported that she had experienced God’s forgiveness. Georgia subscribed strongly to the belief in doing good and being kind to others, which translated to a strong commitment to voluntary work. Lyn also adopted a positive outlook and thought that spirituality was about “how you feel!” and that it connects everyone together. For Maree, the diagnosis of cancer led her to question her religion and the existence of God but she resolved that “everything happens for a reason” and in her case this meant she had made friends by joining CanTeen.

Practices

When the participants were discussing the spiritual practices they engaged in, a number reported they ‘use to’ engage in some traditional religious practices, for example, reading The Bible, saying the rosary, attending church and church groups, and prayer.
Church attendance

While only one participant belonged and was actively involved in church, worship, fellowship, reading and studying The Bible, taking communion, group meetings and church camps, many participants attended church irregularly on occasions such as Easter and Christmas or when sick. Participants were quite open and honest about their reasons for not belonging to or attending church. While Emz believed in and prayed to God, she explained that she had little interest in church attendance:

“Yeah, I think I am strong and I don’t think that I need to go to church for me to want to pray and I don’t need to read The Bible to want to pray and stuff, I can do it myself … I don’t think a lot of people have time … I have other things to worry about than to run to church and whatever.”

Bouma (2006) also noted that Australians find it acceptable to “call themselves religious … but believe that it is not necessary to attend church, synagogue, mosque or temple to be religious” (p36).

Conversations with two participants offer further explanations for their diminished interest in belonging:

Researcher: “Sounds like you’re a curious kind of searcher but not at this stage wanting to connect, belong to a specific group around this?”
Tom: “It’s the same reason I’m not involved in a car club, I just don’t like the politics that revolve around this sort of thing, like presidents and stuff.”

And later on in the interview:

Researcher: “… Would you say that you are a bit on the outside?”
Tom: “I’m on the fringe, yeah I s’pose.”
Researcher: “Do you think you could ever see yourself getting more involved?”
Tom: “Possibly. I mean maybe if I had children or something it might happen, I don’t know. I want to do something else in life or another step but right now I’m sweet.”

And similarly, this quote from Georgia:

“... I do get a bit annoyed at sometimes because people that are very like religious and stick to the one sort of thing like ‘coz I know I have been christened Orthodox but I’ve been at my Nan’s church, I’ve been at my other Auntie’s church and she’s actually Jehovah’s Witness, I’ve been at the Uniting Church where I work and stuff like that so I don’t have any strict, I just believe that ...”

**Spiritual discussion**

Almost all participants considered ‘discussion with others’ an expression of their spirituality. They discussed their spiritual beliefs with people such as family, partners, close friends, teachers, mentors and religious leaders and mostly it was informal, but Steve attended fellowship and group meetings with his church and Marvin discussed his ideas with CanTeen members during CanTeen camp discussion groups.

**Prayer**

Many participants also used prayer in a range of ways: private prayer, prayer at church or during a church service, formal prayer, conversational prayer, prayer of exaltation, prayer of appreciation and prayer for help. Georgia described her experience of prayer:

“Yep, on occasions, like private prayer, yes. I feel that private prayer is a lot better than maybe having to go to an ordinary Mass or Church, yeah, like before when I got sick and stuff like that I have gone into my Church and done private prayer. Uhm privately.”
However, Emz keenly pointed out that prayer alone (which was the basis of her spiritual practice) was not enough to support a person. In her own words:

“... like believing in God and being by yourself praying by yourself and just having yourself praying that’s not going to get you far. You need your friends and stuff, you need your family, they can help you, they can pray for you.”

\textit{Meditation}

Meditation, in many different forms, was also cited as a spiritual practice. For some participants it was a contemplative or reflective experience, as described by Marvin:

“Time on your own in the wilderness ... sometimes I just like being alone ... you just kind of like sitting there and you’re just looking out, like the big city and you’re basically anonymous and it’s just like WOW.”

However, a small number of participants had joined in more traditional meditation where they focused on stilling the mind or mindfulness or sat in lotus position with a candle. Bella described her meditation experience:

“I don’t think it has anything to do with religion the way I meditate ... I don’t see meditation as getting in touch with a Higher Being, I think that it is about getting in touch with myself.”

Bella also identified that it was difficult for her to identify whether meditation was a spiritual practice or otherwise:

“So I actually think in a way that it is spiritual, I am just trying to figure it out now, I sort of think it is like an alternative way of ... praying, I think, in a way, no, I don’t know what I think about it, I don’t know if it is spiritual.”
Volunteerism

“... giving back ... what I do with a lot of my community work ... and I believe that’s the whole Christian thing ...” (Georgia)

About half the participants in this study were involved in some form of voluntary work, which included work with animals, children, the environment, social/recreational/sporting and church groups, social causes and self-help/personal development organisations. In some instances, it was difficult to establish what prompted or motivated the participants’ volunteerism: was it connected or part of their spirituality or as a result of the cancer diagnosis or connected to other extraneous influences such as family. Bella’s involvement in voluntary work pre-dated being diagnosed with cancer and was possibly influenced by her family. She was adamant that her volunteerism was a secular and not religious activity. Georgia and Marvin, who both had been diagnosed when they were very young, had volunteered throughout their lives. Georgia spoke passionately that volunteering and giving back to the community, nature and the earth, was a fundamental and significant part of her life. Steve volunteered in his church community as part of his religious/spiritual involvement, and this pre-dated his being diagnosed with cancer. Whereas Adam’s volunteerism with CanTeen began as a result of cancer and he specifically said that giving back and helping others had helped him. In a similar vein, but perhaps not involving a specific action, Anna also spoke passionately about her interest in nature, animal welfare and human rights.

In contrast to the participants herein, in the national study of Mason et al (2007), the authors looked at the relationship between spirituality and volunteerism, in a broader context of social concern and civic orientation and participation. Specifically, only 29% of their participants did some level of volunteering, and they mainly volunteered in the following areas:

“fundraising/sales (21%) followed by befriending/supporting/listening/counselling (18%), repairing/maintenance/gardening (16%),
Furthermore, Mason et al (2007) concluded that in some instances, young people were involved in voluntary service for social reasons rather than it reflecting their civic values. They also found that the more young people were affiliated with the church, the more volunteer hours they were likely to do in their church community, whilst others were involved in the wider community and young people in their twenties in national and international organisations such as Amnesty International and World Vision.

**Other practices**

Participants also considered activities such as yoga, art, listening and writing music, reading, camping as spiritual practices. Others had broader concepts, such as Lyn, who both defined and expressed her spirituality as “being loving to self and others” and for Adam being connected to ‘his community’ was an expression of spirituality.

**Contemporary spiritual beliefs and practices**

As well as the participants freely discussing their spiritual beliefs and practices, I specifically asked them on a range of topics I had derived from the national study of Mason et al (2007) and the *Deep Speak* ‘belief’ cards (designed to stimulate discussion with young people ‘about life’s big questions’). As my consultations with young people prior to the interviews had indicated that these topics were currently of interest to young people, some topics being age-old (miracles) and others being newer areas
(astrology), for ease of communication, I have called them ‘contemporary spiritual beliefs and practices’.

The majority of participants (66%) disagreed with the idea of ‘sticking to one religion’ as evidenced by Maree’s comment:

“... there are so many religions and they can’t all be right ... they can’t all be wrong either. You’ve gotta just skip through everything and take a bit from here and take a bit from there.”

Even more participants (88%) agreed it was acceptable to ‘pick and choose beliefs’, as epitomised by Adam’s comment, “… whatever works for the individual”. About half of the participants agreed with the idea of ‘definite rights and wrongs’ and they responded from a personal and worldly perspective. Reflecting on themselves, Georgia commented that “sometimes you do the wrong thing and you learn by them” and Lyn said, “I’ve no regrets for anything that I have done ...” However, Anna approached it more broadly with a passionate comment that capital punishment was a definite wrong.

Again, a majority (72%) agreed that they had a ‘special/sacred place’. For some participants, this was in a fairly traditional special or sacred place such as at a cemetery or church, whereas for Tom it was in a regular building where he undertook his favourite activity, car building. Meanwhile for others, it was the beach or the ocean or close to water or a special place in nature overlooking the city or the harbour. Bouma (2006) also noted that nature held special significance for Australians. Emz described her place:

“Yeah there’s a place in [name of suburb] that me and my boyfriend or me and my friends ... would just go there ... and we will just sit there and we’ll just have really good like deep and meaningfuls, like talks and stuff for ages, just about everything, like life and stuff, it doesn’t have to be a church but that’s where we just sit on these rocks ...”
Just over half (60%) believed in ‘the supernatural’ and Tom commented, “I’ve always had an interest in the supernatural, even before I was sick ... I’ve just read books on it ... like astral projection ...” In terms of ‘life after death’, half the participants agreed to it, compared to 31% who believed in reincarnation in the national study. Oscar considered, “if there is anything, it will be so different to what we have experienced ... it almost won’t be the same ...” A large number (63%) reported having had a ‘spiritual experience’ and Lyn described her experience, thus,

“... when I was in hospital having my transplant ... everybody’s worried that you might die ... I remember this really strong like really overwhelming feeling like I didn’t care and that all I wanted to do was be outside and I remember, because I was stuck in this isolation place, I had some VRE and so I wasn’t allowed out ... and everyone had to wear white gowns when they came in, I felt really like sterile and I just wanted to be like normal like everybody else and I remember sitting down on my chair in my room one day and the sun was outside and it looked really nice outside and I wanted the sun on my skin and had this overwhelming sensation that: I don’t care if I was going to die. ... I was really happy with that one moment ... all I wanted was like the sun ... on my skin ... I felt perfect. I had that one moment.”

Only a small number of participants (18%) (compared to 25% in the national study) believed in ‘astrology’. Another two participants were unsure but generally participants were sceptical and did not take it seriously. Emz admitted she read her star sign but that she did not know what it meant and thought “whatever!” whereas Oscar did not discount it because he had not studied it closely. Instead, he said, “I can also see value in anything that makes you think along those lines.” Just under half (40%) believed in ‘psychics’ (compared to 21% in the national study). Oscar considered that “some people were more intuitive than others” while Steve said, “I believe in the prophetic, which is a lot like similar [to psychics].” A small number (27%) (comparable to the national study (25%)) believed it was possible to
‘communicate with the dead’. While Emz said she “would love to do it one day”, Oscar thought that it would not be “in a direct conversation kind of way”. Lastly, there was reasonably significant belief in ‘miracles’ (63%) and some varied comments were made by the participants, mostly of a personal rather than worldly nature. For instance:

    Maree: “Yeah miracles do happen, coz without [baby] they wouldn’t have found the leukaemia, it would have been too late.”

    Marvin: “They are possible because my existence could be a miracle.”

    Emz: “Of course, anyone that has survived cancer thinks it is a miracle.”

    Oscar: “I would believe in miracles … if you’re going to believe in miracles, you’ve also got to believe in disasters.”

**Naming participants’ beliefs and practices**

Participants identified with a broad range of names for their beliefs, practices and experiences. It also seems that prior to the interviews, some participants had not actively or consciously thought about their spirituality, nor named it nor attached it to anything bigger. As Lyn put it, “… to define actually what it [spirituality] was … I always just felt that it was just something” that one just lived and experienced. For these reasons, the following classifications are somewhat nominal. Two participants identified as ‘religious’, a further two as ‘spiritual’, one as ‘spiritual/relationship with God’, two as ‘agnostic/spiritual’, one ‘undecided’, two as ‘no identification’ and a further one as ‘other - identification with values and principles’. Within these classifications, there were qualifying comments such as non-denominational Christian/spiritual and the undecided participant was oscillating between religion and atheism. None of the participants volunteered that they called
themselves ‘New Age’ but some of their interests suggest New Age or alternative spiritualities, for example, astral projection, the supernatural and meditation.

While young people do not typically classify themselves, I made a further nominal classification of the participants’ spiritualities for the purposes of comparing them with the national study of Mason et al (2007). Using the national study’s categories, five participants in this study or 45% could be classified as ‘traditional Christian’, which is very close to the national percentage at 47%, a further three participants or 27% could be classified as ‘New Age’, whereas the national percentage was 17%, and a further three participants or 27% could be classified as ‘secular’, which again is very close to the national percentage at 28%. It should be noted that the authors of the national study categorised their participants as ‘New Age believers’ (8%) if they had three to four beliefs but not involved seriously in any ‘New Age practices’ and ‘New Age participants’ (9%) if they held two or more beliefs and participated in one or more ‘New Age practices’. In brief, it can be seen that except for New Age or alternative spiritualities, the participants herein were very similar to the young people in the national study.

**Exploration of other religions and spiritualities**

Most of the participants’ explorations into other religions and spiritualities concentrated on books, films, researching on the internet, talking to others, attending other churches and religious camps, attending a spiritual walking tour, and experimenting. With regard to the latter, Lyn explained that she wanted to:

“... to understand religion and ... how people go down that path. So for a week I did this test for myself and I was like a Muslim for a week and then I was a Buddhist for another week so ‘Mum I can’t eat pork this week because I’m a Muslim this week’.”
Participants also described instances where they had consulted or read religious books (The Bible, The Koran).

It is likely that exploring other religions and spiritualities reflects the diversity of cultures and religions in some of the participants’ lives. Emz explained:

“it’s easy for me because I have a whole different mixture of everything like I’ve got different ‘natoes’ [nationalities] and religions and ... heaps of my friends are different nationalities ... like none of us are the same, so it’s good.”

Furthermore, participants also indicated that they were curious, adventurous and unafraid to be exposed to more information and experiences. For example, when asked about whether she believed it was possible to ‘communicate with the dead’, Emz eagerly replied, “I don’t know, I’ve never done that. I would love to do it one day.” The conversation at the end of my interview with Bella also demonstrated this point:

Researcher: “... so it leaves you with clearer ideas and things that you can think about further and talk with people about?”
Bella: “I’m really glad, it has given me stuff to go research, so off to research about different [cultures].”
Researcher: “Off to Google by the sounds of things?”
Bella: “Yes off to Google or off to my book again, that book I haven’t looked at it for a while, that book that when I started meditating I had seen it in that book ...”

Influence on spirituality

A range of diverse experiences and people influenced each participant’s spirituality. The influence of family is noted at the beginning of this chapter.
In earlier generations, for example Baby Boomers, gender played a significant role in influencing spirituality. Women were more interested and actively involved in religious pursuits (Mason et al, 2007). Mason et al (2007) found there was no gender differential in their national study and concluded that “… the Boomers are the last generation to retain some clear signs of gender difference in religiosity.” (p308) However, gender played a different role in this study. On the one hand, there did not appear to be significant gender differences. One male participant identified as an active and practising Christian, and at least three female participants were engaged in Christian beliefs of some kind. New Age and secular spiritualities were adopted by both male and female participants. In contrast, the national study by Mason et al (2007) found that more young women than young men were interested in New Age spiritualities. Again, male and female participants were keen explorers of other religions and spiritualities and both male and female family members were influential on participants in terms of their spiritual beliefs and their values.

On the other hand, deeper analysis with the benefit of a feminist lens, suggests that the nature of the female participants’ spiritual beliefs reflected feminist morality and spirituality (discussed in Chapter Two). Anna was concerned about people, animals, and the environment, Georgia was committed to volunteer work, and Lyn believed that spirituality was about caring for self and others. Essentially Anna, Georgia and Lyn were considering their spirituality in terms of relationships, responsibilities and caring.

School scripture

As noted at the beginning of this chapter, scripture at school had been influential on some of the participants’ religious or spiritual beliefs and practices. Maree, who was from a non-religious family, had derived all her
religious input from scripture at school. Tom noted that it had been useful to have good teachers, “… that weren’t old school bashers, they were like ‘oh good point’ … they weren’t those fire-breathing Christians.” And this from Anna:

“I never particularly liked doing religion at school but it was an interesting one because it raised questions on things like capital punishment and abortion and things like that which was very interesting.”

School and personal study

Participants also noted that their study of science at school had influenced or changed their way of thinking but they also researched and gathered information independently from the internet, books (The Secret, The Alchemist, Silent Power and Jonathan Livingstone Seagull), self-help books by Petrea King and Ian Gawler, films (What the bleep do we know?) as well as through informal conversations with peers. Conversations with two participants illustrate the influence of personal study:

Researcher: “… do you have a connection or belief in a God or a Higher Being or … ?”

Anna: I don’t think so. I used to I think when I was younger and then the more that, I guess, experienced life and saw things around me, the less I thought that it was, I don’t know, something was there, but uhm I don’t know whether it’s … because we’ve spoken about this, like with friends and people like that and uhm, I think it might be in general things, I know it is within my friendship group and people I know but I don’t really, I don’t think I know anyone that’s religious, that would say ‘oh yes, I believe in God’ and things like that.

And similarly, from Lyn:

“I think when I was first sick, I suppose you could say that I was religious, but I believed, I was a Christian and then a few years after that was during my remission, I kind of lost that. I didn’t feel, like when you are
studying more and you hear about other people, you become a little bit more ‘oh that doesn’t sit right with me’ what your parents have always told you and you challenge them so I went a different way and I wouldn’t say I was atheist but I just didn’t believe in those sort of things, religious things. And then when I got sick the second time, I told my mum that I didn’t believe in God and she got really angry at me and said that ‘you’re going to regret that’ and she was really upset, I think. She really thought that that’s how I survived the first time, if you believe in God or something, that’s how you survive. But I didn’t see it that way and I told her that that’s what I’m going to do. I don’t believe in the things like that. And she always pushed me to go to church and I really disliked that and I think she saw a different side to me to when I was unwell, she was always there and we had a bit of a conflict about religious things like that. But I feel like it’s not about religion, and spirituality is different to religion. And during when I was in hospital I met some really great people who helped me to understand like spirituality separate from religion.”

The relationship between spirituality and cancer

Influence of cancer on spirituality

For most participants, the development of their spiritual beliefs and practices was not prompted by a diagnosis of cancer, although given that two of the participants were diagnosed with cancer as very young children, it is difficult to disentangle the start of spiritual beliefs and practices from the cancer diagnosis. In any event, Marvin (diagnosed at 16 months of age) noted that his outlook changed in year two when his two friends died of the same cancer as the cancer he had had. On the other hand, most of the participants indicated that being diagnosed with cancer had affected their spirituality or at least their outlook on life in some way. For some of the participants this
change in their spirituality was temporary. Emz reported that when she was diagnosed with cancer, her religious practices changed and she prayed more, she prayed “for help” and she attended church a few times when ordinarily she would not. In a similar way, Tom briefly revisited his Christian beliefs and prayed once, even though “it didn’t do it for me.” However, for Bella, cancer had affected her beliefs, thusly:

“... before I had been diagnosed ... I sort of believed in God, I still pray every night and stuff ... I think that it has strengthened that, and ... as I got better I think that like the connection I had with God sort of broke and sort of fizzled out a little ... I see it as a really selfish thing, because I looked to God to make me better and stuff and as I got better ... I wasn’t as religious, I felt like I was saying, ‘look you have done your service ... I don’t need you anymore’ ... I just had learned more and it had sort of lead me away from looking to God as like the thing ...”

For other participants, the change in their spirituality was more permanent. Steve said that he had grown closer to God, and for Georgia, cancer had prompted her thinking about deeper matters, and she described her experience, thusly:

“I think my sickness has from a young age ... made me think about these things [dying] all the time ... from about 8 or 9, was when I used to start praying ... Even from kindergarten I was always the one who used to say ‘look we’ll go to the Christmas Mass’ ... My family are not religious at all like me. I was always the one who liked to go to church or something ...”

For Oscar, being diagnosed with cancer raised many questions and led to much thinking about higher meaning, his own death, about God and the universe. At the same time, for Maree, cancer had adversely affected her religious beliefs and practices, in that she abandoned her religious practices (attending church, reading The Bible and praying) but not her beliefs. In her own words:
“Before I was diagnosed, I was very religious … I believed a lot about God … I’ve come to think about ‘why has it happened’ like and … considering that there are so many people that do so many bad things … Well I stopped reading The Bible, I threw my Bible out and thought ‘what’s He ever done?’ yeah. I thought God was punishing me for something and then I started going through everything, everything that I’ve ever done.”

For other participants, cancer had changed their outlook on life. Lyn indicated that she became discontented with her friends’ ways of life and became aware that she wanted more in life and hence she started studying and taking notice of what was happening in the world. For Tom, being diagnosed with cancer had prompted him to live more day-to-day and to stop ‘pipe dreaming’.

**Influence of spirituality on cancer**

Participants also noted that their spirituality had changed how they approached the cancer diagnosis and treatment. Despite Bella’s shift away from her connection with God, she said:

“[her belief system] is just something you have the comfort of knowing it’s there … especially … like when I was going through my cancer journey … to have something there … you need it more if you are going through a really hard time.”

Emz’s position was a lot more frank, to wit, “[God] gave me cancer but he’s keeping me alive.” Oscar and Steve’s beliefs meant that they approached their treatment more positively and the prayers of Steve’s religious community kept him ‘happy’ throughout his treatment. For Oscar, his spirituality had added value to his experience of cancer by allowing him time for meditation, spiritual experiences and contemplating the world, life and his beliefs about God.
The relationship of spirituality and death and dying

While there were no specific questions about death and dying in the interview schedule, participants made comments about dying and death either as part of their spiritual beliefs or in relation to the cancer or both. Georgia, who had had three cancers since she was a young child, spoke frequently about death from an abstract and personal perspective throughout the interview. She indicated that she believed in a heaven and possibly an after-life and that she had considered dying as a possibility (since she was diagnosed for the third time at 17 years of age). She said she also had a fear of dying but drew some comfort knowing there would be family ‘waiting for her’. Other participants recognised that death was a possibility as a result of the cancer or the treatment, in particular with two forms of treatment: transplant and steroids, the latter having an adverse affect mentally. Like Georgia, participants had a range of perspectives about an after-life: that there may be an essence of the person that continues on, that a person’s spirit comes back in a new life, that there is a heaven and that one “dies and that’s it or there’s something”.

Worries, concerns and dissatisfactions about spirituality

On an ‘artificial’ continuum, rating satisfaction of spiritual beliefs and practices, participants covered all bases. For many of the participants, their spirituality was uncomplicated and a source of support and resilience. They were comfortable with their beliefs (in God or a Greater Being or that there was ‘something there’) and content with their level of practices or expressions of their spirituality, generally it was functional and they did not wish to change, improve or increase them.
However, for others, their spirituality was a little troubling. Oscar was concerned that he might become distracted with ‘normal life’ and forget his spiritual learnings during the cancer treatment experience, and Steve worried that his occasional doubts about his faith would get in the way of him becoming closer to God and living his life for God.

Whereas, for Bella, her spirituality, both in terms of beliefs and practices, was complex, challenging, brought some discomfort and raised ethical dilemmas. It was also something she was open and honest about and was interested to resolve. In the first instance, Bella indicated she was happy for her family to provide guidance with her beliefs, but she did not want them to influence or put pressure on her. Secondly, Bella seemed to be struggling deciding between Christianity and atheism, and although she thought she was “… a little bit more leaning more towards the atheist side”, she also thought there was “something there” and was unsure whether it was “like God or Buddha”. Thirdly, and following on from this fundamental issue, was Bella’s concern that she was being exploitative, contradictory and inconsistent because after the cancer treatment and her health returned, she had abandoned her relationship with God, which had strengthened during her treatment. She was puzzled with herself that she continued to pray every night (to be consistent), yet she considered it a chore and “weird that I’m praying to God when I don’t actually believe in God so much”. Lastly, Bella appeared to devalue the relevance of her beliefs in her life — “I don’t think spirituality anywhere near the top of the list” — yet she spoke passionately about her beliefs and considered that she:

“... couldn’t live without something to believe in or knowing that something was there...” and she likened religion to chemotherapy “... it’s something you have to have ... like chemotherapy tablets, you have to take it ‘coz ... it kills the bad cells ... but it makes you nauseous and it gives you like constipation and all this other stuff ... there are good things to it and you need it, like if you didn’t have chemo, the cancer would just spread and keep growing and if you didn’t have religion you
would have nothing to look to, nothing to lean on, but all that said, there are still bad things about religion... religion itself causes problems ... it’s the cause of like conflict, cultural conflict and tension and it can also be a cause of war ...”

In the end, it seems Bella’s spirituality is a resource for coping with stress and also a bit of a burden (also noted by Koenig, 2010).

Relevance of spirituality

Some participants rated their spirituality or belief system or outlook on life as very significant as it was connected to “the way you live your life” and “helps to stay happy and positive and unstressed”. Others considered it moderately useful, for example, it made Georgia feel confident there was something after this life that gave her assurance and calmness. Others considered it not useful or irrelevant. Participants were roughly spread across the three points on the spectrum.

CONCLUSION

In this chapter, I have provided a comprehensive report of my findings following analysis of the research data, primarily from interviews with the participants. The data have been presented in a number of ways to maximise the richness of the data and to help the reader engage with the participants and their personal stories. The descriptive profile about each of the participants personalises them while the demographic profile draws out particular characteristics of the participants. The organisation of the data reporting on the participants’ experience of cancer and spirituality focused on the ‘prompt’ research questions and what actually emerged from the data. There appears to be more common threads in the participants’ experience of cancer than in their spiritual experiences, but the themes shared by the
majority of participants are complemented by the individual stories and experiences that demonstrate the uniqueness of the individuals involved in the research. On reflection, the personal interview as the method of data collection facilitated the participants’ individual and unique stories and experiences.

In the next chapter I discuss my interpretations of the participants’ data under five themes. I also characterise the experiences of all the participants into two narratives. Moreover, I discuss lessons drawn from the research study, both from the participants’ perspective and from my own reflections, as well as the strengths and limitations of this research study.
CHAPTER FIVE

Discussion

INTRODUCTION

In the previous chapter, I reported on the participants’ experiences of cancer and of spirituality. In phenomenological terms, this involved identifying the relevant statements that characterised the participants’ perspectives, and clustering them into themes or ‘meaning units’, which were each detailed. Having reported the participants’ interpretations of their experience of cancer and of spirituality, I now present my interpretations of their accounts. Specifically, I look at broad themes or patterns that occur in the data, while at the same time respecting the value of individual stories or differences. My interpretations also relate to previous research on this topic. In some instances my interpretations confirm previous studies and in other instances I bring new material to the body of knowledge on this topic. My discussion focuses on five themes: spirituality as a self-defined concept, spirituality as an evolving process, believing and exploring but not belonging, optimism and individualism. The discussion draws to a close with narratives or essences of the data, the first being a narrative of the spirituality of young people with cancer and the second being a grand-narrative of the lives of young people with cancer. This last step in the phenomenological approach characterises the experiences of all the participants. In the second part of the chapter, I discuss lessons drawn from the research study, both the participants’ perspective and my own reflections, as well as the strengths and limitations of this research study.
Theme one: Spirituality as a self-defined concept

“... I definitely believe in my definition of God” (Oscar)

By the participants agreeing to participate in the research, I had anticipated they would have had some awareness of their spirituality or their ‘higher order’ or ‘big picture’ beliefs. However, in the early stages of conducting the research interviews, when the issue of beliefs arose or I introduced it, there was a range of responses. Participants struggled with either identifying their beliefs or articulating them. In some circumstances they did not subscribe to beliefs of a higher order or big picture. Furthermore, their responses about their beliefs were generally complex and indefinable and they often followed with a narrative about their family’s current position on religion or their family’s religious history or their past experiences as a young child with scripture at school or in reference to their experience of cancer.

Initially, I tried to assist participants to tease out their beliefs, but I noticed these beliefs did not appear to be traditional spiritual or higher order ones. They were somewhat different from the descriptions of spirituality which I had considered (see Chapters One and Two). However, I was keen to adopt a phenomenological approach authentically and to truly understand the social world of the participants. I reached a point where I just encouraged and supported participants to talk about how they made sense of the world and of difficult matters and challenges in whatever way was meaningful for them. At this point, I noticed a shift in the research interviews where participants included things that could be viewed as personal interests or values. At this time, I was also reminded that there was no absolute definition of spirituality. Moreover, it was often viewed as the ‘personal search for meaning and purpose in life’, suggesting it was a personal experience where the meaning may be unique for each person; hence I welcomed their views and insights.

This personal and individual focus continues with many of the participants adopting their own definition and name for their spiritual beliefs and
practices. However, it is possible that if participants had subscribed to organised religion, perhaps their definitions or ideas about their spiritual beliefs and practices would have been more recognisable or well defined. Moreover, as noted in the previous chapter, participants agreed with the notion of ‘picking and choosing’ one’s religious beliefs and practices and not subscribing wholly to any one religion. They applied the same principle to themselves and hence had an eclectic mix of beliefs and practices.

That young people construct and define their own spirituality which may entail an eclectic mix of beliefs and practices selected from various religious traditions, as well as contemporary or New Age spiritual beliefs and practices, has not been readily endorsed in the previous literature. Eckersley et al (2005) noted, without commentary, that Gen Ys are abandoning traditional religions, which endorse belief in a Higher Being and are developing their own meaning-making and embracing “eclectic, hybrid, deeply personal expressions of spirituality” (p39).

Conversely, the authors of the Australian national study, Mason et al (2007), acknowledged in an interview with Rachael Kohn on The Spirit of Things on ABC Radio National on 13 August 2006 that initially they had difficulty with people who defined their own spirituality and “refused the entire notion of the spiritual”. However, the authors acknowledged that they ended up accepting spirituality as “… a way of life, … a world view, … their own set of values and ethics”. Still, it would seem the authors accepted this as part of their working definition of spirituality, and in their various publications, they noted the diverse range of beliefs and practices of young people, identifying young people’s practice of ‘picking and choosing’ beliefs and practices. Moreover, Mason et al (2007) noted that the respondents in a survey conducted by the Australian Young Christian Workers in 2005 saw spirituality as “self-constructed rather than accepted from a religious tradition …” (p35).
However, when interviewed two years later for a Digital Video Disk (DVD) entitled *My Generation* by SGP, Mason et al (2007) had a number of criticisms or concerns about young people’s self-defined spirituality. Firstly, they considered that young people’s ‘shopping at the spiritual supermarket’ and forming their own ‘self-driven authenticated spirituality’ was not adding up to anything and ‘not making a difference to their life practices and experiences’. On this point, it is questionable as to whether previous generations, when the same age as Gen Y, would have had the intellectual capacity and psychological, emotional and social maturity to have formulated a philosophical or ideological foundation for their spirituality (other than joining a particular religion).

Secondly, Mason et al (2007) were concerned about where young people would learn values associated with traditional religion (about community and volunteerism) if they were constructing their spirituality themselves. I question whether traditional religion is the only forum whereby values can be learned and wonder where non-religious people learn these values. What about the influence of peers, school subjects such as ‘Studies of Religion’, the arts, and political and philosophical forums?

Lastly, Mason et al (2007) were also concerned that if society was made up of individual people who did not gather together to promote their causes, then they would be left open to control by large corporations and governments. It may also be just as easy for large corporations and governments to target their wares, products or policies to a generational group that is predictably cohesive and homogeneous in nature.

Moreover, other authors, such as David Tacey, in an interview with Rachael Kohn also on *The Spirit of Things* on ABC Radio National on 20 February 2000 raised concerns about an individual and a solitary spiritual path. In his view, this takes people into narcissistic and somewhat alienated experiences and does not connect people to others, a pathway he considered was unlikely to
stand the test of a crisis. Tacey cited some of his experiences with his students who had advised him that they were on spiritual paths and then later he learned they had suicided. The question is thus raised, that a personal spirituality alone is unlikely to be sufficient to sustain a person. I make three points in response to Tacey’s point. Firstly, participants in this study emphasised that their spirituality was not their only support or resource and that their family, friends and their ‘community’ had been integral in dealing with the cancer.

Secondly, it is worth highlighting that these young people have experienced an enormous personal challenge/crisis: they were diagnosed with cancer at a young age and faced the possibility of death, they have been aggressively treated with surgery, transplant, chemotherapy and radiotherapy and they have ongoing side effects and health issues with which to contend. It would seem that their own version of spirituality is effective for them and has sustained them. Of course, there were fluctuations, with temporary increases and declines in beliefs and practices during the initial diagnosis and throughout the treatment.

This theme is also supported by Possamai’s finding (see Chapter Two) that people use the authority of the inner self to make decisions about their spirituality and that they do not accept a religious ‘set menu’ offered by traditional religions and are more interested in a ‘religion à la carte’ (Dobbelaere and Voyé, 1990 cited in Possamai, 2005).

Lastly, when consulted on this issue, one young person had a qualifying comment, that provided young people spend some time thinking about it, he was not concerned about the lack of philosophical or ideological base.

To conclude this point/theme, I make a brief comment about the participants’ satisfaction with the nature of their spirituality. In general, participants were comfortable and satisfied with their beliefs and practices.
and their level of commitment. While I support the participants’ (and young people’s in general) satisfaction with their spirituality, I question whether or not this comfort and satisfaction may be explained by the fact that their spirituality is not relevant or significant enough or does not rank highly in day to day life.

**Theme two: Spirituality as an evolving process**

“... when I was first sick ... I was religious ... a Christian and ... during my remission, I kind of lost that ... like when you are studying more and you hear about other people, you become a little bit more ‘oh that doesn’t sit right with me’ what your parents have always told you ... I wouldn’t say I was atheist but I just didn’t believe in ... religious things ...” (Lyn)

Along with the previous theme where participants subscribed to their own concept of spirituality, the spirituality of the participants also appeared to be an evolving rather than a static experience. The changes tended to be of a temporary nature, for example, a more intensified belief in God and increased prayer during cancer treatment and decreased religious practices (but not beliefs) after diagnosis because of anger towards God. Rather than significant swings or changes, these alterations were incremental.

Furthermore, these changes in the participants’ beliefs and practices varied over a period of time in their lives, over the cancer treatment and at times, within the research interview. Taylor (1989) (cited in Lovecky, 1998) in referring to young children, argued that spirituality was “a process in which depth of understanding might change over the course of several moments” (p4).

There may be a number of explanations for the fluidity of young people’s spirituality. Firstly, it may reflect that the participants’ involvement in the research was the first time that they had thought about and discussed their
spirituality in any detail, and that some of their ‘spirituality beliefs’ may actually have been constructed in the interview.

Secondly, it may reflect the influence of external sources. Many of the participants indicated that they had become less interested in traditional religious beliefs and practices when they commenced high school and began studying science or learning about other cultures.

Thirdly, it may also reflect that it is a work-in-progress, something that allows for some level of growth or change as they distil issues in their life and consider things that do not make sense or are inconsistent.

Fourthly, it may also reflect that contemporary young people are satisfied with ‘picking and choosing’ from and within various religions and spiritualities. Hence they may not have an ongoing commitment or philosophical or entrenched ideological position that might otherwise deter this practice. It is also possible that this ‘self-selecting’ practice occurs in the adult population, but what might be different is that the young people interviewed were open, honest and unembarrassed by their practice, whereas for others it may be a deeply private and unspoken matter.

Fifthly, it may be that participants use their spirituality as a coping resource and hence draw on it when needed. This latter point is consistent with the findings of Hendricks-Ferguson’s empirical research (2006) on adolescents with cancer, discussed in Chapter Two. The author found that spiritual wellbeing was mostly high during the first two years during diagnosis and treatment, in contrast to hope, which remained consistent throughout treatment. Hendricks-Ferguson (2006) concluded that adolescents use spiritual support as a coping resource early in the cancer experience and decrease their reliance on spiritual support as they come to terms with their illness and shift to peer support. Hart and Schneider (1997) shared a similar view about the use of prayer as a coping resource during cancer treatment.
I want to make a final point about the exception to the majority of participants. While most of the participants differed by degrees in relation to their spiritual beliefs and practices, one participant was oscillating between opposing ends, traditional religion and atheism. Perhaps her inclination was to atheism, as this would be consistent with her learning from science at school and the views of significant people in her life. Yet she was still drawn to a belief in the mysterious, which she cited as important as it offered her some hope and support. I am curious as to whether this belief in the mysterious is influenced by her extended family or whether having cancer leaves her feeling vulnerable, seeking comfort and support. In the same way, this might also have influenced many of the participants to only adopt temporary and/or incremental changes in their spirituality. Hence, in light of their vulnerability as a result of cancer, they were keen to retain at least something of ‘the spiritual’.

Theme three: Believing and exploring but not belonging

“... I don’t think that I need to go to church for me to want to pray and I don’t need to read The Bible to want to pray and stuff, I can do it myself” (Emz)

Along with participants’ own definition or concept of their spirituality, and the fluidity of their spirituality participants tended to believe in God or a Greater Being or that there was ‘something there’. However, most of the participants did not belong to any religious or spiritual group or organisation. Participants were clear and candid in their explanations for not belonging to a religious or spiritual organisation. They did not think belonging was necessary or needed, nor did they like organised or structured groups. They also wanted the freedom to ‘keep their options open’, an expression I borrow from Hugh Mackay (cited in Wolters, 2010), and not be locked into something.

In the national study of young people’s spirituality, Mason et al (2007) noted that the concept of ‘believing but not belonging’ had been discussed in some
form for the last 50 years and was first proposed by Grace Davie (Davie, 1994, 2002, 2004, 2007 cited in Mason et al, 2007) as a European trend. However, Evans and Kelley (2004) (also cited in Mason et al, 2007) came to the same conclusion about other countries including Australia. Critics doubted that people could maintain being truly religious based on belief only, without the communal aspects to religion: church belonging and attendance, and the rituals (Mason et al, 2007). However, in a contemporary sense, church belonging and attendance have to compete with an array of weekend activities: sport, paid work, shopping and family activities. It may also be that the dominance of individualism, discussed later in this chapter, may deter people joining. Nonetheless, many participants reported that the introduction of science in high school was a significant factor in their move away from traditional religion. Interestingly, these changes used to take place at the end of high school when young people were moving out of home and entering university or the workforce (as noted by Mason et al, 2007), but now the changes are happening during the transition from primary to high school.

As noted, while the theme of ‘believing but not belonging’ was discussed in the national study of young people’s spirituality, for the participants in this study, there was another dimension to the concept that describes their spirituality, that of exploration of other religions and spiritualities. Although exploration of other religions and spiritualities was acknowledged by the authors of the national study, it did not seem to be regarded as a key component, as is the case for the participants herein. Hence, the phrase ‘believe and explore but not belong’ would more aptly describe the participants in this study. Again, the exploration of religions and spiritualities is intrinsic in Possamai’s research on postmodern spirituality (discussed in Chapter Two). The other interesting factor with regard to the participants’ interest in exploring other religions and spiritualities is that they appeared confident and unafraid of possible negative consequences, either in this world or the other-world, whereas previous generations approached their religion in
a serious manner and were often conscious of condemnation for heresy and blasphemy.

Theme four: Optimism

“... no point being negative about something, until there is something to be negative about, like there’s always possibilities ...” (Anna)

It would seem that cancer has placed the participants in an unenviable situation. Some have been diagnosed with cancer at a young age and for some, cancer has had a significant impairment on their health and lives (for example, the loss of limbs and damaged organs). Others are currently living with the uncertainty of the cancer (for example, inoperable tumour and relapse). Yet the participants predominantly portrayed a sense of optimism about their health, their lives and their future. For many, their optimism was explicit in their inherent positive outlook, which predated cancer and did not wane during their experience of cancer. Others made specific references to being ‘lucky’ or ‘fortunate’ because the cancer had been diagnosed early and promptly, because there had been positive learning or experience during treatment or their dreams had been fulfilled, or because they were healthy and doing well in the aftermath of cancer.

I want to discuss the participants’ optimism in a broader context but first a cautious comment about their optimism. The participants’ actual cancers were stable at the time of interview. None of the participants was undergoing active treatment for cancer, but rather their medical interventions included: ‘maintenance’ treatment or treatment for cancer-related conditions (bone and renal issues) or follow-up reviews. One could speculate that it may have been a different picture had any of the participants experienced a recent relapse.
Secondly, the optimism may also reflect the participants’ generational status in the life cycle. According to Erickson the main task for young people during adolescence is to establish their identity, by resolving any identity crises and avoiding what he termed ‘role confusion’ (Fowler, 1981). The participants more closely identified with other young people in terms of their positive outlook and readiness to embrace life as they entered adulthood, rather than their identity of ‘cancer victim’ or ‘cancer survivor’. Interestingly, while the research site, CanTeen, is an organisation for young people who have or have had experienced cancer in their life, the participants appeared content to be associated with the organisation, possibly because it is a member-driven organisation that neither dwells on nor avoids acknowledging the existence of cancer in the young people’s lives, yet also promotes hope for the future.

Thirdly, the participants’ positive outlook may also reflect young people’s current social and economic position in society. On the one hand, as it was noted in Chapter Two, the evidence is that Gen Y in Australia accept responsibility for their future (for example, tertiary education expenses, compulsory superannuation, their own health needs). At the same time, they are also keen to embrace the ‘here and now’ (for example, technological devices, music, travel, the pursuit of pleasure) (Eckersley et al, 2005; Wyn and Woodman, 2006) and as considered earlier, Gen Ys are able to balance both aspects (responsibility and ‘living in the present’) because they are flexible, adaptable and undaunted by change, uncertainty and unpredictably. They are used to keeping their options open (Mackay cited in Wolters, 2010).

Finally, the participants’ optimism could also reveal spiritual growth. This is consistent with the empirical research study of Parry (2003) and Parry and Chesler (2005) (also discussed in Chapter Two), which looked at the transformative effects of uncertainty, psychospiritual growth and psychosocial thriving in relation to long term survivors of childhood cancer. The authors advanced two arguments, both of which relate to spiritual growth. Firstly, Parry considered that living and coping with the uncertainty of cancer could
be “a catalyst for growth ... resilience, and optimism” (Parry, 2003, p233). Furthermore, Parry proposed that balancing uncertainties against certainties (for example, their own strength and resilience), can lead survivors to explore deeper issues, such as a belief in a higher power, the meaning and purpose of life. Parry and Chesler’s other argument (2005), along the same lines, is that some survivors experience positive effects or ‘psychosocial thriving’, a term they used to describe changes such as increased psychological maturity and greater compassion and empathy. They considered that psychosocial thriving involved personal agency and empowerment, and a process of looking at deeper spiritual issues such as meaning-making, which augments for spiritual growth.

**Theme five: Individualism**

‘whatever works for the individual’ (Adam)

The above comment in response to the question about whether he agreed with ‘picking and choosing beliefs’, highlights a highly rated value of many of the participants. The participants’ focus on the individual or self, as the locus of control or as the reference point and of importance, can be viewed from two angles. Firstly, from a sociological perspective, the concept of ‘individualism’ can be seen as a characteristic of the social context of the current generation of young people, which has been identified in the literature relating to Gen Y and in particular, by the national study of Mason et al (2007) on young people’s spirituality. Secondly, from a psychological perspective, the concept of ‘inner self’ can be seen as a deeper characteristic of young people’s spirituality. These two points will be discussed in detail below.

In the first instance, we saw in the generic profile of Gen Y (in Chapter Two), that the socio-economic context for young people in contemporary society is variable. It includes the following: high uptake of tertiary education, variable
and insecure work environment, improved health compared to other age
groups and world standards, marriage and children at an older age, living at
home longer, lower rates of home ownership than previous generations,
substantial personal debts, the latest technological equipment and devices,
and greater acceptance of difference and diversity. Within this context, the
authors of the national study on young people’s spirituality (Mason et al,
2007) identified a number of views, attitudes and behaviours that influenced
and supported the ‘label’ of individualism being applied to contemporary
young people. These include young people placing a high value on the
following: the human individual and the inviolability of personal freedom and
autonomy, egalitarianism, truths through personal experience or science, no
definite rights or wrongs and morals relative to the person/situation,
individual rights preferred to law, the individual as self sufficient and
choosing their own values and meaning-making, social participation as a
choice, and personal fulfilment by asserting self. Interestingly, while Mason
et al (2007), had expected to find a theme of ‘individualism’, they were
surprised to discover this was the case for the majority of their participants,
regardless of their denomination and religiosity. In other words, given a
socio-economic climate where one is encouraged to look after ‘self’ with
compulsory employer superannuation replacing the aged pension, where the
pursuit of tertiary education renders a personal debt, where private health,
income and life insurance become the ‘norm’, it is not surprising that
‘individualism’ or focus on self is a dominant feature of young people’s lives.
Nonetheless, Hodder (2007) notes that focusing on self-fulfilment and the
development of the autonomous individual can draw people away from the
community (also Eckersley et al, 2005) and can be a downside to
individualism.

Perhaps individualism is a product of modern materialist consumer society or
perhaps it is a particular characteristic of this generation of young people.
Further still, perhaps individualism is a feature of youth spirituality, wherein
rather than looking outwardly for guidance and support for the deeper aspects
of life, young people turn inwardly and firstly look to themselves. Tacey (2003) shed some light here. As it was noted in Chapter Two, Tacey argued that while people become interested in religion from a conventional extrinsic place (through the church) or from an inward spiritual awakening (based on personal experience), youth spirituality gravitates to inward spirituality. Tacey identified a new model of youth spirituality that is holistic, informal and individual and “the sacred is intimate and close, a felt resonance within the self, and a deep and radiant presence in the natural world” (p70) (for example ecology, nature, the stars, planets and so on). Tacey asserted that by going deep inside oneself to the true self, one discovers God. He cautioned that as long as one did not get stuck in the ‘subjective self’ and moved to inward reflection objectively, then he accepted this as a legitimate pathway to the sacred. This then allows young people to establish a personal relationship with the sacred, without input from the church. Whether young people remain in ‘self’ mode or move beyond this, remains to be seen. In this way, it can be seen that the participants have redefined their concept of God or the sacred, in a way that makes sense to them, taking into account the other influences in their life (for example, science), that support them. However, the participants were not entirely absorbed in their own needs, and they contributed to their family, their friends and their community (church, CanTeen or local). This may demonstrate paradoxes in the participants’ lives (consistent with the findings of Cantrell and Conte (2009) discussed in Chapter Two).

By way of finishing the discussion about individualism and in particular, the point that young people access the sacred through ‘self’, it is interesting to note that this concurs with aspects of my own spiritual journey: reflecting inwards for clarity before connecting outwards.
Synopsis of five themes

In the above discussion I outlined five key themes describing the participants’ approach to their spirituality: spirituality as a self-defined concept, spirituality as an evolving process, believing and exploring but not belonging, optimism and individualism. The question arises as to whether the themes are connected or whether there are commonalities running through them. From the five ‘meta-themes’, one can see that broader concepts or ‘macro-themes’ emerge and centre around the importance and value of self, and the inviolability of personal freedom, choice and flexibility, without commitment and without worry or guilt. These qualities have also been found to be characteristic of Gen Y and articulated in Possamai’s thesis on postmodern spirituality (as discussed in the literature review in Chapter Two).

Interestingly, this study set out to give voice to participants about their experiences and its phenomenological approach both encouraged and valued the viewpoint of the participants. The process gave participants choice and flexibility, for example, to participate in an interview and/or a focus group and/or a blogsite or to have the ‘prompt’ questions or ‘free-narrative’ style interview. In effect, the research process facilitated, validated and replicated the theme of individualism.

Phenomenological narratives of the research data

In accordance with the final step in the phenomenological data analysis process, I provide a narrative of the spirituality of young people with cancer and a further grand-narrative of the lives of young people with cancer. While the first narrative concentrates on the participants’ spirituality, in the second narrative, ‘spirituality’ represents one aspect of the lives of young people with cancer.
Spirituality of young people with cancer

Notwithstanding that the participants were very individual in their overall spirituality, no two being the same, there were enough commonalities between the participants in at least some areas of their spiritual beliefs, practices and experiences to establish a narrative or essence of the phenomenon being studied, the spirituality of the participants. Young people with cancer (in this study) subscribed to their own self-defined concept of spirituality. Their spirituality was influenced by and grafted from their family’s religious or spiritual history and upbringing. It was also derived from an eclectic array of ideas, beliefs and practices, which were selected after some level of exploration of traditional Christian and other world religions and New Age/alternative spiritualities. Rather than their spirituality being a fixed concept, it appeared to be a fluid, ‘work-in-progress’ that was reviewed with life events and challenges, particularly those of a personal nature such as their experience of cancer. They tended to use their spirituality as a resource or coping mechanism. The participants were optimistic about their future and identified with their generational status as a Gen Y young person in the twenty-first century. Moreover, they identified with the ‘connection’ aspect of spirituality and highlighted the significance of their family, their friends and their community.

The lives of young people living with cancer

Young people with cancer can be described as having a number of different characteristics. On the one hand, they felt vulnerable, fearful and worried about the status of their health: the effects of the cancer and its treatment, other illnesses due to their compromised immune system, the tenuousness of remission, and the possibility of relapse and the limited treatment options (for example, transplant compatibility). At times, they felt uncertain about their future, in terms of career prospects, relationships, and having children. They also recognised a level of dependency on their parents with regard to
their current health status but in particular if relapse occurs. Conversely, young people with cancer were open and honest to speak for themselves on taboo topics: spirituality, cancer, death and dying. They recognised they had a certain level of maturity as a result of ‘growing up quickly’ and dealing with complex issues. They were grateful for life, including the ordinariness of life, and felt supported by family, friends, and their ‘community’ (for example, their local or CanTeen community). They were resourceful and called on their spiritual beliefs and practices as a coping mechanism, to be used as needed. They strived for normalcy, identifying with other young people rather than being a ‘cancer victim’ or ‘cancer survivor’. They tended to be resilient with challenges and adversities, and were ‘strengths-oriented’, focusing on the ‘glass half full’ rather than any deficits. They were also optimistic about their future.

Lessons drawn from the research

As the review of the research data draws to a close, I now review the research experience, both the participants’ involvement in this empirical research study and my own reflections and observations drawn from my field notes. This discussion may be useful for future social researchers engaging with similar populations around sensitive issues. The chapter concludes with an exploration of the strengths and limitations of the study.

Recruitment and interview preparation

Initially it was a somewhat difficult and slow process to recruit participants to the research, however, once participants agreed to participate, they engaged with enthusiasm and conscientiousness, and were flexible and generous with their time and energy.
In the pre-interview telephone conversations, I noted that as soon as I repeated the content of the ‘information statement’ to the participants, they better understood the format and the non-threatening nature of the research, and they appeared reassured, relaxed and unconcerned. In particular, I emphasised that there was no specific preparation for the interview but they were welcome to bring notes of points they wished to make and that they could participate with my ‘prompt’ questions or the ‘free narrative’ or both, about their deeper thoughts.

Furthermore, in the brief to more substantial interactions I had with some of the parents of the participants prior to the interviews, no concerns were raised that I could not quickly address and in general, I received a respectful and supportive response. To this end, my past experience as a child, youth and family social worker had raised my awareness about issues parents were likely to be concerned about (for example, transport, time constraints, and physical and emotional safety) and I was able to provide reassuring answers to the parents. It would also be fair to say that the parents, no doubt, approached the research and myself drawing on their experience with, and trust and confidence in CanTeen.

Research site: CanTeen

I am confident that participants’ positive relationship with CanTeen also influenced their decision to participate in the research, either in the name of research itself or as an activity connected to CanTeen. In general, participants valued their involvement in CanTeen, as an organisation with its staff, volunteers, and members, it was high on their ‘priority list’. All participants were CanTeen members but just over half were actively involved in CanTeen activities. They were all aware CanTeen provided recreational activities, a place of friendship, a place to meet others in a similar situation where they would talk about taboo topics and ‘get it out of their system’, and a place for leadership opportunities.
Research interviews

Again, my previous social work experience with children, young people and their families prepared me: given the sensitive nature of the research topic, participants may cancel or be late for the meeting times. However, I found that, other than two appointment times being postponed due to sickness, there were no cancellations or non-attendances and participants kept in contact by email or mobile texting about their movements, leading up to an interview. To this end, I balanced supportive reminder communications against intrusiveness.

In the interviews, I observed that participants generally only took breaks for external interruptions (for example, their mobile phone ringing or someone at the door) rather than because the interview was emotionally or mentally challenging. Throughout the interviews, I inquired of the participants about the progress and pace of the interview (for example, ‘is it what you were expecting?’, ‘do you want to take a break?’). Interestingly, participants expressed their enjoyment and satisfaction, and appeared comfortable with the process, to the point where one participant asked me about my experience of cancer and another about my spirituality. Participants shared their confidences: that they had not talked to anyone about their spirituality, and that they enjoyed the conversation, with a focus or angle, rather than it being testimonial-style. Participants also commented they enjoyed talking to someone ‘outside the circle’ where their responses were valued and validated. Furthermore, one participant, who was doing a research subject in her university course, commented that it was good to be on the ‘other side’ and another came to the interview with notes of points he wished to make. Comments from two participants reflect the positive feedback:

“I enjoy sharing on this sort of medium … you broaden the topic and section them out, I quite enjoy it…” (Adam)

and
“I don’t think that there is anyone that I actually talk to about my spirituality, that’s why I like talking to you now because I am exploring something that is there…” (Bella).

Post-interview reflections

New to the field of research, I think I was unwittingly influenced by the dominant discourse of quantitative research methods. This influenced me to approach the interviews in an objective information-gathering manner, with relatively little input from myself, for fear of inadvertently influencing the participants. However, I recognised that to keep the interview comfortable and the conversation flowing, I needed to employ client-centred ‘counselling-type’ skills: being empathic and non-judgmental, validating and reflecting feelings and content expressed, and summarising. I also adopted a strengths-based approach: drawing on the participants’ strengths and resources for their own empowerment. I also maintained a ‘healthy curiosity’ to elicit further information about the participants’ beliefs, practices, experiences, ideas and opinions and if appropriate, canvassed other interpretations of an event or experience.

During the interviews, I noted that participants did not display discomfort or distress, nor were there reports of this in follow up communications. Some participants found the research experience cathartic, therapeutic, validating, or an exercise in personal development. This point was discussed in the ethical considerations in the Methodology chapter wherein I cited Thompson’s point that children often experience research as a pleasant and affirming activity (1992). While one participant became a little tearful during her interview, when asked, she explained that she was an emotional person and this was ‘normal’ and she was not concerned by it. I also verified this with a CanTeen staff member who acted as the inter-mediatary. As anticipated and discussed in the Methodology chapter, this was in the ‘normal’ rather than the ‘traumatic’ range.
I also noticed that the participants appreciated the interview refreshments, gift voucher, and offer or payment of travel expenses. They also showed interest and engaged in conversation about my youth-friendly audio-taping device (Media Player ‘MP3’), the use of mobile phone texts and email communications, and the blogsite as an additional research tool. These were ‘shared-world’ experiences between myself and the participants.

**Strengths and limitations of the research study**

At the outset of this research in 2006, there was very little data that were current, empirical and Australian, looking at the phenomenon of spirituality for young people with cancer. The large study of Mason et al published in 2007 looked at the spirituality of Australian young people, whereas this study looks at a subset of the population of young people, namely young people with cancer. It was not the aim of this study to specifically compare participants against the wider population of young people, however useful data have emerged. This includes: that young people with cancer are optimistic about their future and are similar to their peers, and that their experience of cancer does not dominate their spirituality, their identity and their outlook on life.

In this study, I collected rich empirical data from eleven participants (six females and five males) aged 13 to 23 years from diverse backgrounds, in terms of their family composition and life, their religious/spiritual background and upbringing, their schooling, their friendships and relationships, and their interests. The research was actively supported by CanTeen, with which participants had a positive relationship and which played a pivotal role in recruiting the participants. The data were collected using a traditional research method, face to face interviewing, within which participants could opt for a ‘prompt’ questions or a ‘free-narrative’ interview.
In terms of data collection methods, I am confident that both the high level of collaboration and the high level of data collection would only have taken place in the safety of a one-to-one environment. A group discussion would not have engaged the participants and gathered the quantity nor the quality of data, as well as the individual interview did. Notwithstanding that participants had the experience of cancer in common with each other, their spiritualities were quite individual and diverse, with some subscribing to atheistic beliefs and others to a belief in ‘something greater than ourselves’. While Gen Ys are renowned for being tolerant of others’ beliefs and positions (Owen, 2005), I doubt that it would have enhanced the data collection process.

A further strength in this research study was the opportunity for critical reflection. In particular, I spent time reflecting on the literature about contemporary young people. I struggled engaging with developmental and stage theories and found them to be limiting, prescriptive and reductionistic. I wondered how the stages and theories could accommodate the complexities of modern life (for example, economic crises, technological advances, diverse human relationships) and still forecast the same universal path ahead (for each generation of young people). Conversely, I found the generational perspective of sociologists such as Wyn and Woodman (2006), more palatable and liberating. They outlined that each generation is situated in a particular period of history and “within its social, political and economic milieu” (p497). Until then, I had envisaged that this generation of young people would somewhat follow or aspire to what I, as a Baby Boomer, had experienced or observed as a young person (education→work→flatting/travel→partnering and so on). The critical reflection process freed me to engage with the participants on ‘where they are at’ rather than ‘where they should be heading’.

Every research study has its limitations, it cannot be all things to all people and even at the beginning, the researcher is often aware of the limitations of
their study. With its strength of being informed by rich empirical data, qualitative or exploratory research is limited in terms of generalisability and hence the findings of this study are unlikely to be representative of the general population of young people. This is a small in-depth study and an opportunistic sample was used. As with voluntary participation in research, the participants were motivated and they were also well in terms of their general health. The gaps in time between the interviews (commencing at the end of 2007 and finishing at the beginning of 2010) reflect the small numbers of CanTeen members eligible to participate in the research and the careful attention that I paid to meeting the eligibility criteria. The last two participants interviewed in 2009 and 2010 had only been diagnosed in the year before their interview. While the age range of the participants spanned early to late adolescence, this added to the range and diversity of the responses of participants. The rich qualitative data are available for other researchers and healthcare professionals to evaluate whether it fits with their practice or experience.

In brief, it can be seen that exploring people’s spirituality remains a sensitive and personal topic, and young people, who have experienced cancer, remain a potentially vulnerable cohort. However, I consider that the methodological framework, using a phenomenological approach as well as the ethical safeguards put in place, assisted in making this an evidently positive research experience for the participants.

CONCLUSION

In this chapter, I have discussed the five significant themes that I have drawn from the research data: spirituality as a self-defined concept, spirituality as an evolving process, believing and exploring but not belonging, optimism and individualism. After each theme was discussed in detail, referring to the
participants’ data and the relevant literature, I discussed connections between the themes. I offered an overall narrative of the spirituality of young people with cancer and a narrative of the lives of young people living with cancer, to complete the phenomenological process. I concluded the chapter with a discussion of the research experience, both the participants’ perspectives and my own reflections as the researcher, and I included the strengths and limitations of the research study.

In the forthcoming final chapter, I explore the participants’ recommendations for health and community professionals and implications for my social work practice, and I conclude the chapter and the thesis with some final words about the research study and the participants.
CHAPTER SIX

Future Directions

INTRODUCTION

In the preceding chapters I have discussed this research study in detail. In the first chapter, I looked at the importance of the topic: the marginalisation of the spiritual dimension in the holistic approach of social work and palliative care, the origins of the research from a personal, professional and socio-political perspective, and I also described the relevant terms: young people, cancer and spirituality. In the second chapter I provided a comprehensive literature review on the three key concepts: young people, cancer and spirituality, and I looked at spirituality in the professional settings of social work and palliative care. I then outlined my methodological approach in Chapter Three. This included the epistemological and theoretical influences on my work, ethical considerations and the methods I used for the data collection and data analysis. The fourth chapter detailed the findings of the research, firstly looking at the demographic and descriptive profile of the research participants and then the data collected about the participants’ experience of cancer and their spirituality. Following the findings, I provided a discussion in the fifth chapter of five themes identified in the participants’ data: spirituality as a self-defined concept, spirituality as an evolving process, believing and exploring but not belonging, optimism and individualism. In accordance with my theoretical approach, phenomenology, I offered two narratives, the first being that of the spirituality of young people with cancer, and the second being that of the lives of young people with cancer. I also discussed the research experience from the participants’ perspective and
myself as the researcher, and this included the strengths and limitations of the research study.

It is now time to bring this research study to a close, and in this final chapter, I examine the participants’ recommendations for health and community professionals and the implications for my social work practice, and I provide concluding comments regarding the research study and the participants.

Participants’ recommendations for health and community professionals

Support

In the research interview, I specifically asked participants whether they had had any contact with social workers during the cancer diagnosis or treatment. I also invited participants’ suggestions for ‘helping professionals’ with regard to spiritual matters and participants answered in terms of what was important to them. Participants reported social workers had helped them with practical matters such as school/work, income support and referral to CanTeen. Adam’s comments provide some useful insight into how young people view helping professionals:

“I guess if anyone had a problem with … where’s the avenues, you’ve got a social worker and a psychologist at the hospital. Social workers are busy and they’re mainly like Centrelink and where you’re at school or the family’s needs, they’re working with everyone in the hospital sense, from my experiences, and the psychologist, I just didn’t want to see, like the big name psychologist, you know you’re seeing this person there must be something wrong with you … ”

However, for Maree, who was diagnosed at her (specialist) doctor’s surgery, it would have been helpful to see a social worker for support:
“... it would have been good to talk to a social worker. Like when I was first diagnosed, I didn’t really understand anything about what was going on and it was all too much shock to my Mum as well coz my Mum was crying because she just didn’t understand why either, so I didn’t really have anyone to talk to for a couple of days.

While some participants recommended emotional support from helping professionals at the time of diagnosis, other participants considered it would be useful to have a young person with cancer visiting newly diagnosed young people to provide hope and support. This recommendation supports CanTeen’s Teen-Link program, which offers this type of support.

Finding information on spirituality

Participants reported that the cancer diagnosis and subsequent treatment had raised questions about the meaning of life, and life and death. At the time they had been interested in talking about their spiritual beliefs, practices and experiences and considered that, had they been asked questions on this topic, it could have helped them sort out their spirituality (in light of the cancer diagnosis). One participant predicted that, at the time of diagnosis, questions about life, death and God will come up for the first time and he considered that helping professionals should expect these questions. He considered that information on finding out about different religions would be helpful, while another participant recommended that ‘developing a relationship with God’, praying and reading The Bible would give people hope.

Communication

There were a number of points regarding communication. One participant recommended that medical teams provide prompt information about the long term effects of the cancer and that treatment plans, possibilities and positives should be the focus rather than discussions about morbidity.
Another participant emphasised doctors’ respect for patients’ wishes. This was in light of his request, regarding a procedure, being ignored, which resulted in him becoming so distressed that he required counselling. His distress was still evident as he re-told his story in the interview. Others suggested that helping professionals should listen and understand, be open and approachable, and prepared to give detailed explanations to questions.

Health/treatment facility

Participants highlighted that young people were not appropriately accommodated in either the paediatric or the adult hospital system. They impressed the need for an adolescent ward or facility that was youth friendly and could provide activities for both young people’s physical and mental wellbeing. Interestingly, a number of the authors in the 2009 Cancer Council Australia’s publication of *Cancer Forum* featuring ‘Cancer in Adolescents and Young Adults’ advocate for an adolescent facility.

Furthermore, the importance of a family-centred model of care for both children and young people, which was mentioned in Chapter Two, was stressed by Lyn in her comment “… it all connects in the end. So what’s going on in your family is just as relevant as what’s going on in your body”.

A point about continuity of care was recommended in Tom’s comment that he would have preferred the same health professionals looking after him throughout his diagnosis, treatment and follow-up review.

Implications for social work practice

The wisdom, insights and experiences that the participants shared in this research study, as well as my own experiences as a researcher, have influenced my clinical practice as a social worker in palliative care. These
insights and ideas can also be considered by others. Outside the domain of my current clinical practice, I intend to be an advocate for resources and changes relevant to young people’s needs.

_Social work practice_

I have become more attentive to the importance of including questions about a client/patient’s spirituality as part of my social work assessment and not to assume that their spirituality will be the same as their family. I have also become more aware that deeper issues about spirituality and meaning-making can arise at any stage during the life-threatening illness trajectory or life itself. As I noted in Chapter Two, social workers have often been reluctant to raise spiritual matters because they felt ill-equipped or fearful they might impose their own views. With the benefit of this research experience, and specifically learning from the participants that they call on their spiritual beliefs, practices and experiences in times of stress and use them as a resource tool, when needed, this has given me more avenues to explore the spiritual dimension with clients/patients. When asking clients/patients about their supports, I often ask questions such as ‘do you have a religious or spiritual following/practice that supports you?’ (with the last few words indicating the reason for the question). Cobb (2003) also offered a good (purposeful) question: “are there things we need to know about your faith/spirituality/religion that would help us in caring for you?” (p142). Alternatively and more generally, I might ask ‘other than the areas I have asked you about, would there be any other things that would be important for me to know about you?’ All in all, it has been helpful to learn that a client/patient’s spirituality may be a fundamental part of their being and existence or it may be more simply a support mechanism or a coping tool.

My awareness has also been heightened about balancing practical tasks alongside the emotional support/counselling aspect of clinical social work. Obviously it is important to assist clients/patients with practical issues such as
income support, and often during the process of attending to these tasks, rapport, trust and connection develops between the client/patient and the social worker, but it is equally important to continue to offer support and invite client/patients to discuss deeper issues, such as the making of meaning and making sense of difficult matters.

Furthermore, as part of my social work practice, I intend to share my learnings from the research experience and on the research topic with other social workers and healthcare professionals, and with community organisations such as CanTeen. I envisage this happening in a number of ways. I will continue to emphasise to social workers I supervise, as well as social work students on placement, the usefulness of a comprehensive social work assessment and practice that includes attention to the spiritual dimension. I also intend to continue to present my research in clinical and research forums in my work in oncology and palliative care. Not only will I share the research findings, I also intend to highlight the usefulness of clinical social work experience in social research, for example, for engaging with participants around sensitive issues.

Adolescent welcoming environment

I intend to look for ways to make the clinical environment within which I currently work more youth friendly and welcoming to both the client/patient and their siblings and friends. While monetary resources are always limited and something like a young people’s social/recreational room may not be possible, there are some inexpensive and simple ways of making the environment more welcoming, such as ensuring that the furnishings, colours, and wall furnishings are youth friendly or at least appropriate for all ages and including brochures and flyers relevant for young people, for example CanTeen.
I support the participants’ recommendation for an adolescent hospital ward, appreciating that adolescence is not just a transitional period from childhood to adulthood, but rather a distinct stage in the life cycle. This may be becoming more relevant as the period of time for adolescence or an adolescent lifestyle has perhaps increased with young people studying and living at home longer, and delaying marriage and children.

**Dissemination of information**

Given the significance of friends in young people’s lives and the importance of peer support, as well as the incidence of social isolation occurring during cancer treatment, it could be useful to design an information leaflet that informs young people what to say and do when they have a friend with cancer. This could be distributed widely in schools, hospitals, community health centres, youth centres and so on. This is something I intend to discuss with CanTeen.

**Policy and resource implications**

Given that some young people will receive news of a diagnosis of a life limiting illness such as cancer from their general practitioner or a medical specialist, I consider it would be useful to have a professionally trained person available to provide emotional support and counselling. I am conscious that hospitals have support services such as social workers, however, patients outside the hospital system often do not have easy access to this resource. However, some general practitioner surgeries currently employ social workers (and other counsellors) to provide counselling for a whole range of issues and perhaps general practitioners need to involve these counsellors from the initial diagnosis. Unfortunately the Medicare funding for this is currently under threat.
Further research

During the course of this research, I became aware of other gaps in the literature. As noted above, the families of young people with cancer are an integral part of their life, both living with and recovering from cancer. Siblings are ‘peer-like’ and often play an enormously important role in the treatment and recovery process (for example, for bone marrow transplants). However, sometimes siblings’ needs are sidelined while the focus is on their brother or sister with cancer. Further research looking at the spirituality or meaning-making of siblings of young people with cancer may also shed light as to how health and community professionals can improve access to and support for these young people.

Conclusion

I now bring this exciting, innovative and rewarding research study to a close. As noted at the beginning of this thesis, the focus of this research study was to give young people, who have or have had cancer, a voice about their spiritual beliefs, practices and experiences. This was prompted by the absence of current empirical data in Australia. The phenomenological approach to the study facilitated the gathering of rich data from eleven young people (in a researcher-learner and participant-expert setting). To some extent, the research data relate to or is confirmatory of other recent studies (Hendricks-Ferguson, 2006, 2008; Mason et al, 2007; Parry, 2003; Parry and Chesler, 2005). The five identified themes (discussed in the previous chapter) – spirituality as a self-defined concept, spirituality as an evolving process, believing and exploring but not belonging, optimism and individualism - also bring new material and a different angle.

Reflecting on the eight research questions, it has become clear that, particularly when asked, young people are interested to talk about spirituality
and how they make meaning in life. This in itself is a compelling reason for social workers and palliative care clinicians to ensure that the spiritual dimension is included in their holistic approach to care. Secondly, the research data revealed that the participants’ spiritual beliefs tended to have a positive effect on them, possibly because they selected their own beliefs, practices and level of commitment. There were however both positive and negative fluctuations during diagnosis and treatment. Thirdly, only a small number of participants had similar beliefs and practices to their families, and most participants had developed their own perspective. Fourthly, it was difficult for participants to pinpoint when their spirituality began, and it tended to be connected to events like a young friend’s death from cancer, rather than a particular age. Fifthly, a cancer diagnosis did not of itself prompt interest in spirituality, but the cancer diagnosis often prompted a temporary change in their spirituality. Sixthly, social class, ethnicity and gender did not appear to influence the development of spirituality. Seventhly, the nature of the participants’ spirituality was diverse, both theistic and non-theistic beliefs, and similarly, the spiritual practices were just as diverse, ranging from traditional practices such as prayer to volunteerism.

A last word about the participants involved in the study. The young people seem to live a paradoxical existence (and Cantrell and Conte, 2009 also discuss the paradox of childhood cancer survivorship). On the one hand, they have endured both physically and emotionally challenging experiences with the diagnosis and treatment of cancer. Furthermore, by their membership and involvement in CanTeen, they do not wish to ignore these experiences. On the other hand, they also continue to identify and relate to their peers as their main focus, rather than ‘victim of cancer’ or the like and they live with incredible optimism about their life and their future. Adam’s inspiring words capture the sentiment of the participants’ outlook on life and the future:

“... I guess I’m passed that stage of ... you know being self-conscious or people looking at you or not going to expect things of you or something.
Like I feel now that I have a lot to offer, and through all I’ve been through and I’ve done and like I’m not afraid to, I guess, to tell that to people.”
Reference List


Parry, C. (2002). *The psychosocial experiences of long-term survivors of childhood cancer across the lifespan.* University of Michigan, USA.


QSR International Pty Ltd. (n.d.) Nvivo 8 computer-supported qualitative data analysis software.


Appendices List

1. Invitation to young person
2. Letter to parent
3. Information sheet for young person
4. Information sheet for parents
5. Consent for young person
6. Consent for parents
7. Revocation of consent for young person
8. Revocation of consent for parents
9. The University of Sydney Human Research Ethics Committee’s final approval dated 28 February 2008
10. CanTeen’s original approval dated 9 May 2007
11. Interview schedule
12. Blogsite front page
13. Certificate of Appreciation to research participants
14. List of Nvivo nodes
Invitation

- Are you a young person aged 12 to 24 years?
- Are you living with a diagnosis of cancer?
- Do you have beliefs that help you figure out difficult things in life?

If yes, then you are invited to join a new research project about young people’s beliefs, practices and experiences of spirituality. Spirituality may be about a religion or it may be about the way people make sense of life and understand why things happen.

Participating in the research will mean being part of a group and/or website blog discussion and/or being interviewed by a University of Sydney researcher, Jenny Broadbent, who is also a social worker working with young people. You can participate as freely as you wish or she may ask questions and you can answer as many or as few as you wish.

Do you want to be involved or find out more?? You can:
- read the attached information sheet
- talk to your parent (if under 18 years of age) and/or Claudia Lennon at CanTeen (02 9382 1563) who will arrange for us to make contact.

Look forward to hearing from you.

Jenny Broadbent
Tel: 02 9515 9905 (W-F)
Mob: 0407 733 223
Appendix 2

The University of Sydney
Faculty of Education & Social Work

Research Study: Spirituality of Young People Living with Cancer

Jenny Broadbent
c/- Dr Lindsey Napier
Faculty of Education and Social Work
University of Sydney
Tel: 9515 9905 (Wed-Fri) Mob: 0407 733 223

Dear Parent/Carer (of young people under 18 years of age)

My name is Jenny Broadbent and I am conducting this research study, *Spirituality of Young Living with Cancer*, as part of my Doctorate of Social Work with the University of Sydney. My supervisors are Dr Lindsey Napier (tel: 02 9351 4168) and Dr Fran Waugh (tel: 02 9351 4207).

Your child is invited to be part of a study about young people who are living with cancer. With your child's help, we hope to learn more about young people's beliefs, practices and experiences about spirituality (which might be expressed in a religion or in other ways).

I have attached an information sheet, which sets out important information for you and your child to know. I will also go over this in more detail in our first contact.

If your child would like to participate in a group discussion and/or website blog discussion and/or being interviewed by myself, and you agree with this, please contact Claudia Lennon, Division Manager at CanTeen on 02 9382 1563 and she will arrange for consent documents to be sent to you. After consent documents have been signed and returned to CanTeen, this will authorize your contact details to be given to me so that I can contact you directly.

If you would like to talk to me about the research, I can be contacted on 02 9515 9905 (Wed-Fri) or Mob: 0407 733 223. You can also talk with Claudia Lennon at CanTeen (02 9382 1563).

Yours sincerely

Jenny Broadbent
Appendix 3

The University of Sydney
Faculty of Education & Social Work

Research Study: Spirituality of Young People Living with Cancer

Information sheet for the young person

Purpose of the research
To learn and understand more about the spiritual and religious beliefs, ideas, practices and experiences of young people living with cancer, which will contribute to better care for young people living with cancer.

People involved in the research
• the research participant – the young person
• the support person – a parent / carer or support worker / CanTeen staff who will provide support during the research and who can be at the interviews
• the researcher – Jenny Broadbent (this research forms part of the researcher’s Doctorate of Social Work Degree)
• the researcher’s supervisors – Drs Lindsey Napier and Fran Waugh at Sydney University

Participation in the research
You may take part in any one or all of the following:
• in-person interview – the first contact (usually by phone) will take about 10-15 minutes and this is to provide information and ask/answer questions about the research and ‘to get to know one another’. The interview itself will take about 1-1.5 hours and you can talk freely about the topic or the researcher will ask some questions that may help you to talk about your ideas, beliefs, practices and experiences. The last contact (by phone or in person), about 20-30 minutes, is to debrief, ask questions, give feedback and read the transcript
• group discussion – similar to the in-person interview, except that it will be with other young people in the same situation as yourself
• website blog discussion – this will involve the researcher forwarding you a website blog address/link by email to an email address nominated by you. You can use another name and the researcher will start with some discussion topics for comment and response. Only young people in the same situation as yourself will be invited to take part.

The interview and discussion group will take place at a CanTeen office or another location that is safe, quiet and private and agreed by participants. At any time in the research, you can change your mind about taking part in the research and deciding for or against being part of the research study will not change your connection with CanTeen.
**Risks and benefits of doing research**
- People involved in research tell us that being part of research involves time; that it can be inconvenient; that it can be a bit embarrassing and sometimes it can make people feel upset or worried.
- People also tell us that taking part in research can give people a sense of satisfaction or increased confidence and sometimes talking about things to an outside person can help clarify or sort out things.

**Confidentiality / privacy**
The information from the interview or group discussion or website blog discussion will not be passed on to anyone else, but if a young person is unsafe, by law, the researcher has to report this.

**Notes and taping the interview**
- With permission, the researcher will audiotape the interview/group discussion and write notes.
- You can turn the tape recorder on/off and/or read the notes at any time.
- You have the right to answer/not answer questions.

**Feedback and publication of the results**
- Transcripts will be made of the interview and group discussion and you can read your part of it.
- A summary of the research findings will be made available to you.
- Any information about you or your family will be confidential and only non-identifying material will be published and another name other than your real name will be used.
Information sheet for the young person

Storage of the information
All papers, tapes, disks etc will be stored securely at the University of Sydney and are only accessible by the researcher and her supervisors and after seven years will be destroyed.

Reimbursement of travel costs
This is available at 50 cents per kilometer or on production of transport receipts

Special needs
Where possible these will be provided

Further information
When you have read this information, Ms Jenny Broadbent will discuss it with you further and answer any questions you may have. If you would like to know more at any stage, please feel free to contact Dr Lindsey Napier on (02) 9351 4168 (telephone) or Dr Fran Waugh (02) 9351 4207 (telephone) or Jenny Broadbent on (02) 9515 9905 (telephone Wed-Fri) or 0407 733 223 (mobile).

Concerns or complaints
Any person with concerns or complaints about the conduct of a research study can contact the Senior Ethics Officer, Ethics Administration, University of Sydney on (02) 9351 4811 (telephone); (02) 9351 6706 (facsimile) or gbriody@usyd.edu.au (email).

All this information will also be explained in detail in our first contact.
Information sheet for the parent / carer
(only for young people under 18 years of age)

Purpose of the research
To learn and understand more about the spiritual and religious beliefs, ideas, practices and experiences of young people living with cancer, which will contribute to better care for young people living with cancer.

People involved in the research
- the research participant – the young person
- the support person – a parent / carer or support worker / CanTeen staff who will provide support during the research and who can be at the interviews
- the researcher – Jenny Broadbent (this research forms part of the researcher’s Doctorate of Social Work Degree)
- the researcher’s supervisors – Drs Lindsey Napier and Fran Waugh at Sydney University

Participation in the research
Your child may take part in any one or all of the following:
- in-person interview – the first contact (usually by phone) will take about 10-15 minutes and this is to provide information and ask/answer questions about the research and ‘to get to know one another’. The interview itself will take about 1-1.5 hours and your child can talk freely about the topic or the researcher will ask some questions that may help your child to talk about their ideas, beliefs, practices and experiences. The last contact (by phone or in person), about 20-30 minutes, is to debrief, ask questions, give feedback and read the transcript
- group discussion – similar to the in-person interview, except that it will be with other young people in the same situation as your child
- website blog discussion – this will involve the researcher forwarding your child a website blog address/link by email to an email address nominated by your child. Your child can use another name and the researcher will start with some discussion topics for comment and response. Only young people in the same situation as your child will be invited to take part.

The interview and discussion group will take place at a CanTeen office or another location that is safe, quiet and private and agreed by participants.

At any time in the research, your child can change their mind about taking part in the research and deciding for or against being part of the research study will not change their connection with CanTeen.
Research Study: Spirituality of Young People Living with Cancer

Information sheet for the parent / carer

Risks and benefits of doing research
- people involved in research tell us that being part of research involves time; that it can be inconvenient; that it can be a bit embarrassing and sometimes it can make people feel upset or worried
- people also tell us that taking part in research can give people a sense of satisfaction or increased confidence and sometimes talking about things to an outside person can help clarify or sort out things

Confidentiality / privacy
The information from the interview or group discussion or website blog discussion will not be passed on to anyone else, but if a young person is unsafe, by law, the researcher has to report this.

Feedback and publication of the results
- transcripts will be made of the interview and group discussion and your child can read their part of it
- a summary of the research findings will be made available to your child
- any information about your child / family will be confidential and only non-identifying material will be published and another name other than your child’s real name will be used

Notes and taping the interview
- with permission, the researcher will audiotape the interview/group discussion and write notes
- your child can turn the tape recorder on/off and/or read the notes at any time
- your child has the right to answer/not answer questions
Storage of the information
All papers, tapes, disks etc will be stored securely at the University of Sydney and are only accessible by the researcher and her supervisors and after seven years will be destroyed.

Further information
When you have read this information, Ms Jenny Broadbent will discuss it with you further and answer any questions you may have. If you would like to know more at any stage, please feel free to contact Dr Lindsey Napier on (02) 9351 4168 (telephone) or Dr Fran Waugh (02) 9351 4207 (telephone) or Jenny Broadbent on (02) 9515 9905 (telephone Wed-Fri) or 0407 733 223 (mobile).

Concerns or complaints
Any person with concerns or complaints about the conduct of a research study can contact the Senior Ethics Officer, Ethics Administration, University of Sydney on (02) 9351 4811 (telephone); (02) 9351 6706 (facsimile) or gbriody@usyd.edu.au (email).

Reimbursement of travel costs
This is available at 50 cents per kilometer or on production of transport receipts

Special needs
Where possible these will be provided

All this information will also be explained in detail in our first contact.
Consent Form for Young Person

I, ____________________________________ of __________________________
____________________________________________ telephone _____________________
email address ________________________________________________
give my consent (please tick)
o to be interviewed in person
 o to participate in a group discussion
 o to participate in a website blog discussion
organized and run by Jenny Broadbent with regard to her research looking at the spiritual or religious beliefs, practices and experiences of young people living with cancer.

I have received the invitation and the information sheet. I understand that:
• I am participating in the research on a voluntary basis and I can discontinue at any time without this affecting my involvement with CanTeen,
• it will be a confidential interview or group discussion or website blog discussion,
• only non-identifying material will be published, and
• I have a right to read the researcher’s transcript and the summary of the results.

In any publication of the research, I would like to be known as __________________________
(a name other than your real name).

I further understand that the researcher is obliged, by law, to report any child protection concerns with regard to young people under 18 years of age.

I am aware that if I have any questions, I may contact Jenny Broadbent on Tel: (02) 9515 9905 (Wed –Fri) or Mob: 0407 733 223 and she will answer my questions or I can discuss the research with Claudia Lennon, Division Manager at CanTeen on Tel: (02) 9382 1563.

I give permission for my contact details to be given to Jenny Broadbent.

_____________________________         ___________________ ________
Your signature      Signature of witness
______________________________  ___________________ __________
Please print name     Please print name
_____________________________         ___________________ ________
Date       Date
(Note: For young people under 18 years of age, your parent/carer has received a separate form)
The University of Sydney
Faculty of Education & Social Work
NSW 2006 Australia
Tel: +61 2 9351 4038

Research Study: Spirituality of Young People Living with Cancer

Consent Form for Parent / Carer
(only for young people under 18 years of age)

I, ___________________________________________ of ___________________________________________
_____________________________________________ telephone ______________________________

give my consent for my child ____________________________ aged ________ years
(please tick)
  o  to be interviewed in person
  o  to participate in a group discussion
  o  to participate in a website blog discussion

organized and run by Jenny Broadbent with regard to her research looking at the spiritual or religious beliefs, practices and experiences of young people living with cancer.

I have received the covering letter and the information sheet. I am aware that:
• my child’s participation in the research is on a voluntary basis and my child can discontinue at any time without this affecting his/her involvement with CanTeen,
• it will be a confidential interview or group discussion or website blog discussion,
• only non-identifying material will be published, and
• my child has a right to read the researcher’s transcript and the summary of the results.

I further understand that the researcher is obliged, by law, to report any child protection concerns.

I am aware that if I have any questions, I may contact Jenny Broadbent on Tel: (02) 9515 9905 (Wed –Fri) or Mob: 0407 733 223 and she will answer my questions or I can discuss the research with Claudia Lennon, Division Manager at CanTeen on Tel: (02) 9382 1563.

I give permission for my contact details to be given to Jenny Broadbent.

_____________________________________________  ______________________________
Your signature                                           Signature of witness

_____________________________________________  ______________________________
Please print name                                         Please print name

_____________________________________________  ______________________________
Date                                                   Date
(Note: your child has received a separate consent form)
Revocation of Consent Form for Young Person

I, ___________________________________________ of ________________________________
_____________________________________________ telephone ____________________________

revoke my consent to be interviewed and/or to take part in a group discussion or website blog
discussion organized and run by Jenny Broadbent with regard to her research looking at the
spiritual or religious beliefs, practices and experiences of young people living with cancer.

I understand that participating in the research was on a voluntary basis and I do not wish to
continue with the research.

I further understand that discontinuing with the research does not in any way jeopardize my
involvement with CanTeen.

I am aware that I can contact Jenny Broadbent on Tel: (02) 9515 9905 (Wed –Fri) or Mob:
0407 733 223 and she will answer my questions or I can discuss the research with Claudia
Lennon, Division Manager at CanTeen on Tel: (02) 9382 1563.

__________________________________________  ________________________________
Your signature                                  Signature of witness

__________________________________________  ________________________________
Please print name                                 Please print name

__________________________________________  ________________________________
Date                                              Date

(Note: For young people under 18 years of age, your parent / carer has received a separate
revocation of consent form)
Revocation of Consent Form for Parent / Carer  
(only for young person under 18 years of age)

I, __________________________________________ of __________________________________________
____________________________________ telephone __________________________________________

revoke my consent for my child ______________________________ to be interviewed and/or to take part in a group discussion and/or website blog discussion organized and run by Jenny Broadbent with regard to her research looking at the spiritual or religious beliefs, practices and experiences of young people living with cancer.

I understand that participating in the research was on a voluntary basis and my child does not wish to continue with the research.

I further understand that discontinuing with the research does not in any way jeopardize my child’s involvement with CanTeen.

I am aware I may contact Jenny Broadbent on Tel: (02) 9515 9905 (Wed –Fri) or Mob: 0407 733 223 and she will answer my questions or I can discuss the research with Claudia Lennon, Division Manager at CanTeen on Tel: (02) 9382 1563.

____________________________________  ____________________________
Your signature                                    Signature of witness

____________________________________  ____________________________
Please print name                                  Please print name

____________________________________  ____________________________
Date                                               Date

(Note: your child has received a separate revocation of consent form)
Appendix 9

Human Research Ethics Committee  
www.usyd.edu.au/ethics/human

Senior Ethics Officer:  
Gail Briody  
Telephone: (02) 9351 4811  
Facsimile: (02) 9351 6706  
Email: gobiody@usyd.edu.au  
Room 313, Level 3, GII Teachers College – A22

Human Secretariat  
Telephone: (02) 936 9309  
(02) 936 9308  
Facsimile: (02) 936 9310

The University of Sydney  
NSW 2006 Australia

28 February 2008

Dr L Napier  
Faculty of Education and Social Work  
Education Building – A35  
The University of Sydney

Dear Dr Napier

Title: An exploratory study of spirituality of children and young people living with cancer

Ref No.: 9643

The Executive Committee considered your request dated 16 January 2008 (see attached) to modify the above protocol. The Executive Committee found that there were no ethical objections to the modification/s and therefore recommends approval to proceed.

Chief Investigator / Supervisor's responsibilities to ensure that:

(1) All serious and unexpected adverse events should be reported to the HREC as soon as possible.

(2) All unforeseen events that might affect continued ethical acceptability of the project should be reported to the HREC as soon as possible.

(3) The HREC must be notified as soon as possible of any changes to the protocol. All changes must be approved by the HREC before continuation of the research project. These include:-

• If any of the investigators change or leave the University.
• Any changes to the Participant Information Statement and/or Consent Form.

(4) All research participants are to be provided with a Participant Information Statement and Consent Form, unless otherwise agreed by the Committee. The Participant Information Statement and Consent Form are to be on University of Sydney letterhead and include the full title of the research project and telephone contacts for the researchers, unless otherwise agreed by the Committee and the following statement must appear on the bottom of the Participant Information Statement. Any person with concerns or complaints about the conduct of a research study can contact the Senior Ethics Officer, University of Sydney, on (02) 9351 4811 (Telephone); (02) 9351 6706 (Facsimile) or gobiody@usyd.edu.au (Email).
(5) Copies of all signed Consent Forms must be retained and made available to the HREC on request.

(6) It is your responsibility to provide a copy of this letter to any internal/external granting agencies if requested.

(7) A report and a copy of any published material should be provided at the completion of the Project.

Yours sincerely

[Signature]

Professor D I Cook  
Chairman  
Human Research Ethics Committee

cc Dr Fran Waugh, Faculty of Education and Social Work, Education Building – A35, The University of Sydney

Encl:  
Modification request dated 16 January 2008  
Invitation Letter  
Dear Parent/Carer Letter  
Information sheet for the young person  
Information sheet for the parent/carer  
Consent Form for Young Person  
Consent Form for Parent/Carer  
Revocation of Consent Form for Young Person  
Revocation of Consent Form for Parent/Carer
9th May 2007

Ms Jenny Broadbent
7 Nicholson Street
Tempe NSW 2044

Dear Jenny

Re: An exploratory study of spirituality of children and young people living with cancer – Broadbent, J.

I am pleased to inform you that CanTeen has approved your protocol on the above study.

It is the chief investigator’s responsibility to ensure that:

1. You notify CanTeen at the completion of the study and submit a final report, including final results. Further, CanTeen is to be provided with a copy of all publications that arise from the research;
2. CanTeen is notified as soon as possible of any changes to the protocol. All changes must be approved by CanTeen before continuation of the research project;
3. All serious and unexpected adverse events are reported CanTeen within 7 days;
4. CanTeen is provided with a progress report every 6 months with the first progress report due on the 9th November 2007.

Address all notifications and progress reports to the National Research and Evaluation Manager.

Approval is valid for 2 years from the date of this letter. Your approval will therefore expire on the 9th May 2009. If you have any questions, please do not hesitate to contact me on (02) 829 66513.

Yours Sincerely

Dr. Pandora Patterson
National Research and Evaluation Manager

cc. Ms. Anne Senner, Chairperson, Ethics and Young People Sub-Committee
Interview Schedule and questions

Demographic and general information

Pseudonym ______________________ Code No __________________________
Age __________________________ Gender _____________________________

Family structure / household (parents, siblings, extended family, pets, share house/flatting, relationship)
__________________________________________________________________

Cultural background _______________________________________________

Friendships/Relationships _____________________________________________
__________________________________________________________________

School and year (Public / Private / Religious)
__________________________________________________________________

Tertiary study (University or TAFE) and year_____________________________

Work (full/part time, voluntary)_________________________________________

Activities / interests / sports ___________________________________________
__________________________________________________________________

Type of cancer ______________________ When diagnosed ________________
Treatment __________________________________________________________
Questions

Warm-up / getting-to-know-you question

Would you like to talk about what life has been like living with the cancer?
_Prompts - at the beginning, currently, before the cancer (how did you cope with stressful things)_

What is important / special / sacred to you in life?
_Prompts – family, friends, interests_

Introducing questions about spirituality

_You know we’re here to talk about your spiritual or religious beliefs, ideas, experiences or practices._
_Spirituality can mean different things to different people. Here’s some ideas about spirituality:_

- it can be about searching/finding/understanding the meaning and purpose of life,
  - how people find meaning in their life,
  - how people make sense of things,
  - how people explain difficult things to themselves/others
  - how they figure out difficult things
- it can be about being connected to places or things
  - to yourself
  - to others who are important in your life (eg. family)
  - to groups or communities (eg. religious)
- it can be about being connected to something greater than one’s physical body and day-to-day life (eg. God, a greater being, a creative force or the universe)
- it can also be about belonging to a religious group or community

Introducing free narrative

1. Would you like to talk about
   - what comes to mind / what you believe in spiritually/religiously / when you are thinking on a deeper level
   - when you are thinking / feeling spiritual or trying to make sense / understand what is happening to you or in the world or understanding the unknown?
1. Are there specific things that you believe in that help you figure out difficult things?
Prompts – God / Higher Being / Life Force / Universe; teachings of holy books (Bible etc.), life after death, good and evil, heaven and hell, reincarnation, angels and demons

Some people say that there are specific things they believe in..............

2. Do you belong to a particular religious tradition? Or Is there a name you give for this or others call it?
spiritual/personal beliefs, nature, universe, higher power, mixed

Some people belong to a specific religion or spiritual group....................

3. When did you first starting thinking about this?
Prompts – before / after diagnosis, before / during / after treatment

For some people, there is a specific time or event when their spiritual/religious beliefs/practice started...

4. Do you remember what or who got you started thinking like this?
Prompts – talking to someone (child, young person, adult, spiritual leader), reading

5. Some people attend church / temple / synagogue / mosque / other religious / spiritual place, is this something you do? If so, how often? On your own or with others?

6. Some young people say that they pray/use prayer.
Is this something you do? If yes, when do you do it?
Prompts – all the time, at stressful times, when nothing else works

7. Are there other ways you express it / use it?
Prompts – through art, music, writing, poetry

8. Do you talk to others about it? If yes, who -
Prompts – friends, support group, parents, family, religious/spiritual leader

9. Who talks to you about this? Where do these ideas come from?
1. How **helpful / significant** has your spiritual/religious beliefs been in living with the cancer?
   Prompts – very helpful, reasonably helpful, not helpful at all
   (on a scale of 1-5; 1 being the lowest and 5 the highest level of helpfulness/significance)

   Some people say that God cares about us…
   Some people say they speak/relate to God personally …

   Do your (spiritual) beliefs impact/assist with the **uncertainty of cancer**?

2. **What things** have been helpful?
   Prompts - support from religious/spiritual group/community, sense of meaning/purpose, belief or connection with something bigger/higher power; prayer; religious/spiritual practices

13. **General questions**

   • do you think one should stick to one religion?
   • do you think it is okay to pick and choose beliefs?
   • do you think there are definite rights or wrongs?
   • do you believe in the supernatural? (beyond nature)
   • do you believe in miracles?
   • do you believe in astrology?
   • do you believe in communicating with the dead?
   • do you believe in psychics?
   • do you have a place that is special or sacred?
   • do you believe there is life after death?
   • have you ever had something you’d call a spiritual experience?

14. **Recommendations for the helping profession?**

15. **Finishing up questions**
   What’s been the best thing that you have talked about?
   Are you okay to finish up/go home/feel safe/comfortable?

16. **Future meetings**
   • Would you like to meet again? If so, what sort of things would you like to talk about?
   • From here, I will type up a transcript of the interview and then arrange to get it to you for your comments, additions/deletions
   • You can also join the blog discussion or group discussion (if indicated)
Enlarged text

Spirituality of young people with cancer
This site is for young people aged 12-24 years who've had or have cancer; who may belong to CanTeen, the Australian organisation for young people with cancer; and who wish to share their spiritual beliefs or practices or experiences.

Being involved in this blogsite
This blogsite forms part of Jenny’s research degree (at Sydney University), looking at the ‘spirituality of young people with cancer’. This link was sent to you after Jenny received your consent (and parent's if under 18) to participate. You can participate in the research in 3 ways: you can be interviewed in-person or in a group or you can post here. You can post anonymously and use a made-up name; you can stop posting at any time without this affecting your involvement with CanTeen; and only non-identifying material will be published. This blogsite is copyright and belongs to Jenny but always own your comments and you can withdraw them at any time. If you would like to be interviewed in-person or be part of a group, you can contact Jenny on 02 9515 9905 or 0407 733 223 or Claudia at CanTeen on 02 9382 1563.

Saturday, June 14, 2008
Ideas about spirituality
Spirituality can mean different things to different people
Here's some starting points:
- it can be about the search for meaning and purpose in life or making sense of life
- it can be about being connected to places or things; to yourself, to others who are important in your life, or it can be about groups
- it can be about connecting to something greater than your physical body and day-to-day life (eg. a greater being, a creative force or the universe)
- it can also be about belonging to a religious group or community

Here are some questions to help you get started:
- What do you think spirituality is about?
- What does spirituality mean to you?
- How would you describe your spirituality?

Nota by Jenny in post 14 1 2008

Appendix 12
Certificate of Appreciation

Awarded to

In recognition of your participation in the research project

Spirituality of Young People with Cancer

And special thanks for your generosity with time and enthusiasm and your courage and commitment to openness and honesty throughout the interviews.

Best wishes for a happy and healthy future.

March 2008

Jenny Broadbent
Tel: 02 9515 9905 (W-F)
Mob: 0407 733 223
Nvivo 8 nodes

Research – free nodes
- Connections to literature or previous research
- Interview field notes
- Participants’ recommendations
- Participants’ research experience
- Phenomenological narrative/s or essence/s
- Research site: CanTeen
- Research themes

Personal background – tree node
- Age at interview
- Ethnicity
- Family
- Friends
- Income
- Interests
- Live with
- Location of home
- Miscellaneous
- Pets
- School
- Tertiary study
- Work – full time, part time, voluntary
- Work background

Cancer experience – tree node
- Age at diagnosis
- Diagnosis time
  - Symptoms
  - Thinking
- Effects of cancer
  - Non-physical
  - Physical or medical
- Miscellaneous
- Prognosis
- Treatment
  - Coping with treatment
  - Effects of treatment
  - Type of treatment
- Type of cancer
- Year of diagnosis

Spirituality – tree node
- Beliefs or deeper thoughts
- Broad themes
- Contradictions or inconsistencies
- Death or dying
- Exploration of other religions and spiritualities
- Impact of cancer on spirituality
- Impact of spirituality on cancer
- Important in life
- Influences on beliefs
- Contemporary spiritualities
  - Astrology
  - Communication with the dead
  - Definite rights and wrongs
  - Life after death
  - Miracles
  - Pick and choose
  - Psychics
  - Special or sacred place
  - Spiritual experience
  - Stick to one religion
  - Supernatural
- Positives
- Practices
- Religious history
- Religion on family
- Relevance of spirituality
- Start of spirituality
- Talk to re: spirituality
- Worries