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# The care that shines from within: the role of spirituality in aged and palliative care : A qualitative study that explores how spirituality informs care-giving to the elderly and dying in home and residential care in a regional area on the Mid North Coast of New South Wales

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# ‘The care that shines from within’: The role of spirituality in aged and palliative care

***A qualitative study that explores how spirituality informs care-giving to the elderly and dying in home and residential care in a regional area on the Mid North Coast of New South Wales***

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**Submitted as a requirement for the degree of**
**Master of Arts**
**Southern Cross University,**
**Coffs Harbour, Australia 2006**

I certify that the work presented in this thesis is, to the best of my knowledge and belief, original, except as acknowledged in the text, and that the material has not been submitted, either in whole or in part, for a degree at this or any other university.

I acknowledge that I have read and understood the University's rules, requirements, procedures and policy relating to my higher degree research award and to my thesis. I certify that I have complied with the rules, requirements, procedures and policy of the University (as they may be from time to time).

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Date: 20-03-2008

## Synopsis

The importance of spirituality in relation to mental well-being and physical health is currently well regarded in the academic literature. Therefore spiritual care is now considered an important aspect of holistic healing practices. However, research is showing that most health care providers do not feel competent or confident in this area of care. In this thesis I explore how spiritual care is understood and experienced by practitioners in aged and palliative care in a regional area on the coast of New South Wales. The 26 participants, whose insights and experiences are depicted in this thesis, were very happy to be involved in this qualitative research project, because they felt that they now had the opportunity to explore spirituality and spiritual care.

The participants in this research describe spiritual care as involving *doing* in the form of religious practices, such as praying or bible readings and non-religious activities that were seen as spiritual such as talking about dying, touching people or reminiscing. Additionally, they also commented about spiritual care as a special way of *being* with clients, which involved qualities and attitudes that were clearly felt or recognized by the participants as special. Not necessarily labeled as spiritual care, this special way of being was described as not being separate, but being an integral part of the daily acts of caring such as feeding a patient or preparing them for a bath. Participants found it often difficult to elaborate on what made such an interaction spiritual or how to describe the quality of these interactions as there

seemed to be no familiar language to share the experiences of spirituality and spiritual care. Additionally, participants commented quite regularly that, although spiritual care was seen as important, there were many factors that inhibited these practices. In reflecting on these issues I put forward that, although the practitioners in this research are familiar with spiritual care, the most important contribution to encouraging health care providers to feel more confident is to continue conversations about spiritual care to increase competency in a non-denominational spiritual discourse in aged and palliative care.

# Acknowledgments

This thesis would not have been written without the help of many people. Much time was spend away from my partner, my family- in particular my grandsons Matthew and James as well as my intimate friends. I am grateful that they kept loving me and accepted my absence not as disinterest in their well-being, but as an important journey that was enriching our life in different ways. Many thanks in particular to my partner Aloka who has lived with me in many years of studying before and this time again offered comfort, cups of tea and countless hours of discussion and proofreading.

After a long discussion about the role of spirituality in dying I asked Dr. Jean Griffiths to be my supervisor. She agreed and included Dr. Stuart Hase as my co-supervisor. I appreciate their clear directions and academic advice at times of need and their confidence in my ability to work independently. I thank Jean and Stuart for their faith in me during this arduous journey of gathering raw data and forming these into a research narrative that was sound. I thank to Professor Colleen Cartwright from ASLaRC (Aged Services, Learning and Research Centre) for facilitating and advising the 'Postgraduate Research in Ageing Support Group', which brought together students from different disciplines to whom I also extend my gratitude for their collegial support. I would like to thank Dr. Kath Fisher, who generously offered to read the final draft of this thesis; she became my critical friend and offered vital feedback in those last stages. Of course, final drafts are followed by final, final drafts and I once again thank Dr. Jean Griffiths for the fine-tuning or what she called 'going over it with a fine toothcomb'.

Somebody asked me that if I had still a year to live, would I finish my thesis? The answer is yes, because for me the research process was a meditation on spirituality, dying and ultimately living. I thank all those who contributed in any way; the people I met over a life time and the many academics, sages and wise people whose valuable references adorn this thesis. I thank the trees for the paper, the

ocean for washing away my tiredness and, not in the least, I thank those wonderful people who participated in the research and gave their time, their thoughts and showed me how they, as healthcare professionals engaged in ‘the care that shines from within’.

# Table of content

**SYNOPSIS** ..... **II**

**ACKNOWLEDGMENTS** ..... **IV**

**TABLE OF CONTENT** ..... **VI**

**PROLOGUE** ..... **1**

AN INTEREST IN SPIRITUAL CARE ..... 1

**CHAPTER 1 INTRODUCTION** ..... **3**

**1.1 INTRODUCTION** ..... **3**

**1.2 CONTEXTUAL ISSUES** ..... **3**

1.2.1 A CONFUSING PARADOX ..... 3
1.2.2 SPIRITUALITY AND AGEING IN CONTEMPORARY SOCIETY ..... 5
1.2.3 MODERN RELIGION AND POSTMODERN SPIRITUALITY ..... 6

**1.3 THE SPIRITUAL DIMENSION OF CARE IN CONTEMPORARY SOCIETY** ..... **7**

1.3.1 POLICIES AND CODES OF CONDUCT ..... 7
1.3.2 A MEDICAL MODEL ..... 8
1.3.3 A COMMUNITY HEALTH MODEL OF CARE ..... 8

**1.4 AIM OF THIS THESIS** ..... **10**

1.4.1 RESEARCH QUESTION ..... 10

**1.5 SIGNIFICANCE OF THE STUDY** ..... **11**

**1.6 PARTICIPATION** ..... **12**

1.6.1 ETHICAL CONSIDERATIONS ..... 13

**1.7 LIMITATIONS AND BOUNDARIES** ..... **13**

1.7.1 A FOCUS ON SECULAR SPIRITUAL CARE ..... 13
1.7.2 DIVERGENT VIEWS ..... 14
1.7.3 A SMALL SAMPLE ..... 14

**1.8 STRUCTURE OF THE THESIS** ..... **15**

**1.9 CONCLUSION** ..... **17**

**CHAPTER 2 LITERATURE REVIEW** ..... **18**

**2.1 INTRODUCTION** ..... **18**

**2.2 LOCATING THE FIELD OF SPIRITUALITY** ..... **19**

2.2.1 DEFINITIONAL ELUSIVENESS ..... 20

**2.3 RELIGION AND SPIRITUALITY; WHAT IS THE DIFFERENCE?** ..... **22**

2.3.1 RELIGION ..... 23
2.3.2 SPIRITUALITY ..... 24

2.3.3 Differences and Similarities ..... 25

**2.4 UNIVERSAL QUALITIES ..... 26**

2.4.1 Spirituality as meaning-making or purpose ..... 26
2.4.2 Spirituality as relationship or connection ..... 27
2.4.3 Spirituality as generativity or vital life force ..... 29
2.4.4 Bringing it all together ..... 30

**2.5 DIFFERENT APPROACHES TO UNDERSTANDING SPIRITUALITY ..... 30**

2.5.1 Locating the spiritual ..... 31

**2.6 PASTORAL, SPIRITUAL OR HOLISTIC CARE? ..... 33**

2.6.1 Being of service ..... 34

**2.7 MODELS OF SPIRITUAL CARE-GIVING IN PALLIATIVE CARE, NURSING AND SOCIAL WORK ..... 35**

2.7.1 Palliative care ..... 35
2.7.2 Spiritual care in nursing ..... 37
2.7.3 Spiritual care in social work ..... 38

**2.8 SPIRITUAL PRACTICES, ASSESSMENTS AND INTERVENTIONS ..... 40**

2.8.1 Spiritual assessment ..... 40
2.8.2 Spiritual interventions ..... 42
2.8.3 Mutuality in spiritual care ..... 43

**2.9 IMPEDIMENTS TO SPIRITUAL CARE ..... 44**

2.9.1 The research question and the key elements of spiritual care ..... 46

**2.10 CONCLUSION ..... 46**

**CHAPTER 3 METHODOLOGY ..... 48**

**3.1 INTRODUCTION ..... 48**

**3.2 THEORETICAL FRAMEWORK ..... 49**

3.2.1 Aim of the research ..... 49
3.2.2 Qualitative research ..... 49
3.2.3 Social constructionism ..... 50
3.2.4 Radical and weak social constructionism ..... 51
3.2.5 Rationale for choosing social constructionism ..... 53

**3.3 DATA-GATHERING METHODS ..... 54**

3.3.1 Focus groups ..... 54
3.3.2 In-depth interviews ..... 55
3.3.3 Methods of Strategic questioning and Appreciative inquiry ..... 55
3.3.4 Initial questions in the focus groups and interviews ..... 56
3.3.5 Time, recording and member checks ..... 57

**3.4 PARTICIPANT SELECTION AND SOURCES OF INFORMATION ..... 58**

3.4.1 Participation ..... 58
3.4.2 Selection of focus group participants ..... 59
3.4.3 Selection of in-depth interview participants ..... 61
3.4.4 Documents ..... 61
3.4.5 Research journal ..... 62
3.4.6 Locating the research participants ..... 62

**3.5 ANALYSING THE DATA: A GROUNDED THEORY APPROACH ..... 63**

3.5.1 THE CODING OF THE DATA ..... 65
3.5.2 KEEPING TRACK OF THE PROCESS ..... 65
3.5.3 OPEN CODING ..... 66
3.5.4 AXIAL CODING ..... 66
3.5.5 SELECTIVE CODING ..... 67

**3.6 RIGOUR AND TRUSTWORTHINESS ..... 68**

3.6.1 CONSTRUCTIVE PROCEDURES: ANALYTIC RIGOUR ..... 69
*3.6.1.i Triangulation ..... 69*
*3.6.1.ii The role of the researcher ..... 70*
*3.6. 1.iii Reflexivity ..... 71*
3.6.2 EVALUATIVE PROCEDURES: CREDIBILITY AND TRUSTWORTHINESS ..... 72
*3.6.2.i Goodness ..... 73*
*3.6.2.ii A dynamic relationship ..... 73*
*3.6.3.iii Theoretical sensitivity ..... 74*
*3.6.4.iv Faithfulness ..... 74*

**3.7 ORGANISATION AND REPRESENTATION OF THE RESEARCH FINDINGS ..... 75**

**3.8 ETHICAL ISSUES ..... 75**

3.8.1 CONFIDENTIALITY AND ANONYMITY ..... 76

**3.9 LIMITS AND BOUNDARIES OF THE RESEARCH ..... 76**

3.9.1 FOCUS ON THE ELDERLY AND DYING ..... 76
3.9.2 RELIGION ..... 77
3.9.3 DIRECTION OF THE RESEARCH ..... 77
3.9.4 REPRESENTATION OF THE DATA ..... 78
3.9.5 GENERALISING THE FINDINGS ..... 78

**3.10 CONCLUSION ..... 79**

**CHAPTER 4: CONCEPTUALISING SPIRITUALITY ..... 80**

**4.1 INTRODUCTION ..... 80**

**4.2 WHAT IS SPIRITUALITY? ..... 80**

4.2.1 SETTING THE SCENE ..... 81

**4.3 CONNECTION ..... 82**

4.3.1 REACHING OUT ..... 82
4.3.2 BEING PRESENT ..... 83

**4.4 MEANING-MAKING ..... 85**

4.4.1 AN EXISTENTIAL SEARCH ..... 85
4.4.2 A BELIEF IN GOD ..... 87
4.4.3 SPIRITUALITY AND RELIGION ..... 89

**4.5 THE ESSENCE OF BEING HUMAN ..... 92**

4.5.1 VITAL PRINCIPLE ..... 92
4.5.2 A WAY OF LIVING ..... 94
4.5.3 DEVELOPING SPIRITUAL MATURITY ..... 95
4.5.5 TRANSCENDING LOSS ..... 97

**4.6 THE COMMON GROUND ..... 98**

**4.7 CONCLUSION ..... 100**

**CHAPTER 5 SPIRITUAL NEEDS: PERCEPTIONS AND BELIEFS ..... 101**

**5.1 INTRODUCTION** ..... **101**
**5.2 SIGNIFICANCE OF SPIRITUALITY TO CARE** ..... **102**
**5.3 THE NEED FOR CONNECTION** ..... **102**
5.3.1 THE NEED FOR COMPANIONSHIP ..... 104
**5.4 THE NEED FOR MEANING-MAKING** ..... **105**
5.4.1 THE NEED TO MAKE SENSE OF A LIFE LIVED ..... 106
5.4.2 THE NEED TO MAKE SENSE OF DYING ..... 107
5.4.3 THE NEED FOR A TRANSCENDENTAL BELIEF ..... 108
5.4.4 THE NEED FOR FORGIVENESS ..... 109
**5.5 RELIGIOUS NEEDS** ..... **111**
5.5.1 THE NEED FOR RELIGIOUS RITUALS ..... 112
5.5.2 THE NEED FOR PASTORAL CARE ..... 113
**5.6 ARE SPIRITUAL NEEDS UNIVERSAL?** ..... **119**
**5.7 CONCLUSION** ..... **122**
**CHAPTER 6 SPIRITUAL CARE: A WAY OF BEING** ..... **124**
**6.1 INTRODUCTION** ..... **124**
**6.2 APPRECIATING WHAT IS ALREADY THERE** ..... **125**
6.2.1 SPIRITUAL CARE INVOLVES REMINISCING ..... 126
6.2.2 SPIRITUAL CARE AND POETRY ..... 128
6.2.3 SPIRITUAL CARE AND MUSIC ..... 129
6.2.4 SPIRITUAL CARE AND TOUCH ..... 132
6.2.5 WHAT SPIRITUAL CARE IS NOT ..... 135
**6.3 PRIVILEGED MOMENTS: BEING PRESENT** ..... **136**
6.3.1 'NON-DOING' ..... 137
6.3.2 WITNESSING PAIN AND SUFFERING ..... 140
**6.4 CONCLUSION** ..... **143**
CHAPTER 7: FACTORS THAT INFLUENCE SPIRITUAL CARE ..... 144
**7.1 INTRODUCTION** ..... **144**
**7.2 TIME PRESSURES AND LACK OF HUMAN RESOURCES** ..... **145**
7.2.1 A LACK OF INSTITUTIONAL SUPPORT ..... 147
**7.3 LACK OF APPROPRIATE TRAINING** ..... **148**
7.3.1 A MISSING PIECE OF THE PUZZLE ..... 149
7.3.2 LACK OF APPROPRIATE SKILLS, PERSONAL ATTITUDES AND QUALITIES ..... 151
**7. 4 SPIRITUAL CARING AS SELF-SUPPORT** ..... **154**
7.4.1 MAINTAINING A POSITIVE ATTITUDE ..... 154
7.4.3 PREVENTING BURN-OUT ..... 156
**7.5 CONCLUSION** ..... **159**
**CHAPTER 8 REFLECTIONS AND CONCLUDING REMARKS** ..... **160**
**8.1 INTRODUCTION** ..... **160**
**8.2 DOMINANT NARRATIVES IN THIS RESEARCH** ..... **161**
8.2.1 BLURRING THE BOUNDARIES OF THE DIFFERENT RELIGIONS ..... 161

8.2.3 APPRECIATING WHAT IS ALREADY THERE ..... 162
8.2.3 DIFFERENT MODELS OF SPIRITUAL CARE ..... 162
*8.2.3.i A medical mode of spiritual care ..... 162*
*8.2.3.ii A wellness model of spiritual care ..... 164*
*8.2.3.iii Reciprocity and self-support ..... 164*

**8.3 THE YIN AND YANG OF SPIRITUAL CARE ..... 165**

8.4.1 COMMON GROUND ..... 166

**8.4 DISCOVERING A LANGUAGE FOR EXPERIENCE: ..... 167**

8.4.1 HELPING YOU TO HELP MYSELF ..... 169

**8.5 FURTHER RESEARCH OPPORTUNITIES ..... 169**

**8.6 ON A PERSONAL NOTE ..... 170**

**8.7 CONCLUSION ..... 171**

**ATTACHMENT A (ON UNIVERSITY LETTERHEAD) ..... 174**

**ATTACHMENT B (ON UNIVERSITY LETTERHEAD) ..... 176**

**ATTACHMENT C (ON UNIVERSITY LETTERHEAD) ..... 179**

**ATTACHMENT D (ON UNIVERSITY LETTERHEAD) ..... 181**

**ATTACHMENT E (ON UNIVERSITY LETTERHEAD) ..... 183**

**REFERENCES: ..... 187**

# Prologue

## An interest in spiritual care

> Religiousness is not something to be believed in, but something to be lived, something to be experienced… not a belief in your mind, but the flavor of your whole being (Osho, 1988: 30).

For as long as I can remember, I have been interested in the big questions about the nature of our existence and my place in it. Surely, there was more than I was led to believe and the quote above epitomised my search. I wondered about myself, my relationships to others, to the earth and to the universe. Brought up as a Protestant, I rejected formal religion in my early 20s and embraced the heady mix of Existentialism in the early 1970s; I read the French philosopher Jean-Paul Sartre and attended encounter groups modeled on Fritz Perls' Gestalt therapy. Not finding the answers there, I turned to Eastern philosophies in my late 30s, met the Indian guru Bhagwan Shree Rasjneesh, later known as Osho, and formally became a sannyasin; a spiritual seeker. In my 40s I attended many meditation retreats and continued to read widely in the hope to find some definitive and authoritative answers. Now, in my late 50s, I am no longer interested in universal truth claims and embrace a postmodern spiritual eclecticism. I find myself inspired by the philosophy and practices, rather than the religious expressions, of Buddhism.

I have visited ashrams and churches, worshipped nature and walked ancient pilgrim paths; I marvel at the differences and the similarities of these different spiritual

expressions, whilst enjoying and embracing them all. I have found great joy, peace and support in my spiritual journey. In this thesis I have extended my personal passion into a public inquiry about the role of spirituality in aged and palliative care. I have learned much from listening to practitioners and the title of this thesis comes from a participant who summarised so clearly what I have been searching for. She simply said that spiritual care is the 'shining from within'.

In this thesis the voices of the participants are woven into a research narrative about spirituality and spiritual care. My own reflections on the research are added in the final chapter, but also are represented in the selection of words of wisdom from mystics, saints and poets from very different spiritual traditions. I dedicate this thesis to what Lincoln and Guba (2003: 273) describe as 'human flourishing' expressed in the traditional Buddhist blessing of 'may all beings be happy'.

# Chapter 1 Introduction

## 1.1 Introduction

This chapter will introduce the purpose, design and structure of this qualitative Masters by Research project, which is concerned with spirituality and care-giving in aged and palliative care. The aim of the thesis will be explained and it will be discussed how the research question developed over time as a result of the information that was gathered. Contextual issues about ageing and dying will be discussed in relation to the need for spiritual care. The research methodology will be introduced and in conclusion an overview of the structure of this thesis will be given.

## 1.2 Contextual issues

In this section I will explain the background issues that relate to care-giving and the role of spirituality.

### 1.2.1 A confusing paradox

Although spirituality may be timeless, the focus in this research will be on the care of the elderly and dying, because in developmental psychology, Eastern philosophy and tribal societies, old age and dying is often seen as a the ultimate time for integration, spiritual maturation and wisdom (Beirne, 2002). Approaching the later stages of life has traditionally meant to step into a position of authority, wisdom and respect; into a time of

plenitude. In contrast, old age and dying in contemporary Western culture present an increasingly confusing paradox. On the one hand, we are given images of what successful ageing should look like, mostly symbolised in pictures of youthfulness, health and expansion. On the other hand, there are the physical realities of loss of status in society, diminishing life force, as well as sickness, loss of loved ones and impending death; images that threaten and potentially could destroy the dominant views of the ageing self and more importantly, life's purpose.

From a postmodern perspective, our sense of self and who we perceive ourselves and others to be is mediated through our physical being, our embodiment in the world (Merleau-Ponty, 2001 in Maclachlan, 2004). However, Wilber (1991) points out that there are two ways to understand our embodiment: in purely physical, objective terms of cause and effect or in subjective terms of location, meaning and purpose. Maclachlan (2004) adds that different cultures place different values on body images and people's self evaluation, e.g. the idealisation of youthfulness in contemporary Western culture.

Media images and cultural messages about who we are in the world have important implications for contemporary ageing and dying; the diminishing sense of physical and mental capabilities, coupled with growing social invisibility must influence our understanding of self. This situation is exacerbated if the older person is forced to move into institutional care. Furthermore, the process of losing ground in old age is further compounded by having to confront the greatest existential challenge: one's own mortality and the death of loved ones. Maclachlan (2004: 5) describes this predicament in the

context of contemporary illness and disability as ‘not simply a breakdown of mechanical functioning, but a disordered way of being in the world’.

### 1.2.2 Spirituality and Ageing in contemporary society

Despite ‘the inevitable vicissitudes of old age’ (Mowatt 2004: 48) contemporary society also provides new opportunities for growth and a sense of relative mental and emotional well-being. For example, the ‘baby boomers’- those born in the 1940s and 50s, have revised ideas of old age in the light of health, mobility and community engagement. Modern technology, such as computer technology and internet access, is also providing a sense of participation and connectedness with the world. On a very different level, religious and spiritual connectedness is increasingly rated as a very important support base for older adults; not necessarily as the traditional refuge in times of need, but also as a source of inspiration for living the later stages of life more fully and contentedly (George, Larson, Koenig & McCullough, 2001; Levin & Chatters 1998; MacKinlay, 2001a; Moberg, 2001). Furthermore, it is said that spirituality allows people to ‘transcend their current feelings and circumstances, enabling their well-being to be maintained’ (Kirby, Coleman & Daley, 2004: 127). Therefore it is not surprising that older adults, especially those who experience ill health and frailty, are turning to their spiritual roots to seek solace and adjustment. Interestingly enough, this does not necessarily mean that the elderly are embracing orthodox religions for their sustenance and support (Coleman 2004).

### 1.2.3 Modern religion and postmodern spirituality

Traditionally, support and meaning in an 'otherwise unpredictable universe' was provided by a meta-narrative of a 'transcendental God' who was wholly 'Other' and beyond (Ward, 1998: 15). However, in modern times, science endeavoured to replace 'myth with materialism' and to cast aside 'the shackles of dogmatic religion, superstition and irrational beliefs' (Spretnak, 1997: 37). No longer considered as valid and scientific knowledge, modernism demystified religion and spirituality was considered not relevant science (Tacey, 2000). At the same time, the churches emptied themselves out into the shopping malls, which may do little, especially in old age, to provide the relative security of religious or spiritual beliefs.

Paradoxically, it may have been one of postmodernism's by-products to reaffirm spirituality as an existential and personal quest rather than 'the search for a universal truth claim' (Kvale, 1995: 19). A postmodern understanding of spirituality relates to subjective personal meaning-making in 'the deepest dimension of human existence' (King, 1998: 96). Despite the current 'religious fragmentation', 'spirituality, not as an idea or concept, but as a praxis… a perennial human concern which entails encounter with self-transcendence' is again widely accepted (King, 1998: 97). This is reflected in the growing patchwork of writings in the academic literature, which accepts and celebrates spiritual differences and embraces eclecticism. Similarly, statistics show that, although fewer people turned to organised religion for meaning and purpose, a majority of adults in Australia profess to have an interest in spirituality (Tacey, 2003).

## 1.3 The spiritual dimension of care in contemporary society

### 1.3.1 Policies and codes of conduct

The interest in holistic and spiritual care is also demonstrated in various policies and codes of conduct in the human services and nursing. For example, the new Code of Ethical Standards for Catholic Health and Aged Care Services in Australia connects ethics with a 'spirituality of healing', which embraces 'the reality of human experience', albeit within the context of a predominantly Christian framework (Ranson, 2002: 75). A publication by the Australian Government Department of Health and Ageing (2004: 131), however, is more eclectic and states that 'spiritual counselling and support are essential to a palliative approach'. A Scottish spiritual care policy makes a distinction between religious care to be 'delivered in the context of shared beliefs, values, liturgies and faith community, usually by a chaplain' and spiritual care consisting of a 'one-to-one relationship to offer counsel support and comfort that is person-centred and makes no assumptions about religious affiliation' (Lanarkshire NHS Board, 2003: 2). Traditionally, the domain of the clergy, spiritual care is nowadays considered integral to contemporary nursing and involves, amongst other things, developing meaningful relationships (Milligan, 2004: 163). The essence of a holistic nursing practice involves attention to the 'physical, psychological, social and spiritual' needs of clients (Theis, Biordi, Coeling, Nalepka & Miller, 2003: 48).

According to many authors, more attention and value must be given to holistic care and the role of spirituality in healing and care-giving (Berggren-Thomas & Griggs, 1995;

Burke, 1999; Cohen, Wheeler & Sheier, 2001). Many studies declare that people who have a spiritual orientation have a greater resilience in coping with life's difficulties (Kirby, Coleman & Daley, 2004; George et al. 2000), especially in the later stages of life. In one study it was found that most nurses believe in the 'efficacy of spiritual practices and beliefs' and that those were 'healing factors that should be offered to clients who ask for it'. (Grant, 2004: 40). The expectation that nurses should and could provide spiritual care is reflected in hospital and nursing home guidelines and policies, but how spiritual care could be integrated in health care is still open to debate.

### 1.3.2 A medical model

A few voices warn that the revival of spiritual and pastoral care for support in old age and dying is usurped by the medical model of care, which is problem or deficiency-based (Kellehear, 2002; Rumbold, 2002). Even a superficial overview of the academic literature reveals that the language of research in spirituality is often clothed in clinical terms such as assessment, interventions and practices, which are seen as beneficial for the clients (Hodge, 2004; McEwen, 2004; McSherry, Cash & Ross, 2004; Soerens, 2001). These terms are embedded in a medical model of evidence-based practices and point to spiritual care that is deployed as yet another technology of healing, which is administered to the patient by an expert, be it chaplain, nurse or spiritual carer. It needs to be asked, however, whether the medical model is conducive to the nature of spiritual care.

### 1.3.3 A community health model of care

Kellehear (2002: 172) proposes an alternative model of spiritual care based on the public health approach, 'which targets health and quality of life'. This involves less of a reliance

on an expert stance in spiritual care, than ‘participation and mutual exchange’, which protects ‘the honour and integrity of a person's social identity and social self-image’ (Kellehear, 2002: 173). Spiritual care from this perspective is less concerned with disengagement from life, but focuses on a ‘continuing engagement with life’, which includes being part of a network of socio-emotional support (Rowe & Kahn, 1997: 437). However, upon closer exploration it becomes obvious that the medical and public health models of spiritual care ‘are not antithetical but complementary’, because different client needs may call for different approaches; for example, a prayer may at times be more appropriate than deep reflection and inquiry into the meaning of the current situation (Kellehear, 2002: 172). From a community health perspective spiritual care is everyone’s business and is often best located in the client’s ‘usual social world’ (Kellehear, 2002: 170). In home care, nursing homes and hospitals the usual social world of the elderly and dying often include health care providers, hotel services and other care givers; professionals who are competent in their usual roles but, as the literature confirms, are often not well prepared for the role of spiritual care (Narayanasamy, 2004).

The current interest in spirituality as an important factor in holistic care needs to include careful consideration of the different discourses that influence policies and practices of spiritual care. The section above examined the theoretical approaches to spiritual care; the first seeing it as something you bestow onto others, the second perspective suggesting that spiritual care is what happens between people when they engage in meaningful interactions. In the next section I will explain how this relates to the aim of the research.

## 1.4 Aim of this thesis

This research project explores the way in which spirituality is understood and how it informs care practices in aged and palliative care industry. The study took place in a regional area on the coast of New South Wales and involved 26 practitioners, who worked in residential and home care. The aims of the research are:

1) To explore how practitioners in palliative and aged care understand spirituality.
2) To inquire into how this understanding informs the practices and strategies of spiritual care-giving.
3) To identify impediments to meeting the spiritual needs of clients in aged and palliative care.

This research project focuses on spirituality and spiritual care-giving. It also aims to discover more about how health care providers can support their clients' spiritual needs and concerns in the context of old age and dying.

### 1.4.1 Research question

The following research question was derived from the aims of the research and further developed to accommodate the emerging themes:

How does spirituality inform care-giving to the elderly and dying in home and residential care?

This question, I believe, was sufficiently open-ended and non-directive to support the exploration of existential and person questions about the nature of spirituality and the significance of spiritual care in the context of the later stages of life.

## 1.5 Significance of the study

In the current neo-liberal political climate, social and health care services are often struggling to provide sufficient assistance to the public, giving diminished funding and government support. As a result there is often less time, less money and less staff to provide care in all sectors of the human services, including aged care and palliative care. At the same time there is increasing knowledge of and pressure to provide holistic services, which means caring above and beyond the bare essential biophysical and socio-psychological needs to include the spiritual needs of clients.

Despite the postmodern assertion of the fragmentation of spirituality and the demise of orthodox religious practices, most of the academic literature originates in England or America has strong Christian overtones (Kirby, Coleman & Daley, 2004: 124; George et al, 2001; Moberg, 1997). Although the research coming from Australia focuses more on what Tacey (2000) calls ‘The New Australian Spirituality’, it is still concerned with

‘form’ rather than with the ‘mystery’ of a subjective, non-religious spirituality. Tacey (2000: 226) asserts that a spirituality of ‘creative spirit’ would be ‘a headache for institutions’. George et al. (2000: 114) argue that research into the lived experience of spirituality ‘is the most-ignored dimension of spirituality’. Berggren-Thomas and Griggs (1995: 5) add that little original, secular, non-religious research has been undertaken in Australia that focuses on supporting and ‘enhancing the individual’s unique spiritual journey’. The academic literature abounds with research exploring the importance and function of spirituality in relation to care giving. However, there are fewer studies that focus on how practitioners in the field understand, experience and carry out these practices.

## 1.6 Participation

In this thesis, care-givers in a mostly rural region in Northern NSW Australia, speak about their experiences, their practices and their constraints in relation to spirituality and care-giving. Three different focus groups met twice: The first focus group consisted of 8 practitioners who were working in local nursing homes. The second one consisted of 4 participants in palliative care and the third one involved 8 participants who were interested in volunteering as spiritual care-givers. Most participants were female, over 30 years of age and were all interested in spirituality. Focus groups were utilised because they can provide an ‘insight into the range and depth of opinions, ideas and beliefs’, which generates information through reflective interaction (St John, 2004: 421). To solicit divergent views, I also conducted a total of 6 in-depth interviews with people who

were seen as playing an important role in coordinating or administering spiritual care; these involved a chaplain, two ordained nuns, two senior practitioners in aged and palliative care and a spiritual care coordinator. These people were chosen at the recommendation of focus group practitioners and key people in the aged and palliative care industry.

### 1.6.1 Ethical considerations

This research project received approval from the Ethics Committee of Southern Cross University. All participation in the research was entirely voluntary and informed consent was sought and given in every instance. Research participants knew that they could withdraw their consent at any stage and that their privacy and confidentiality was strictly guarded and respected in line with university policies.

## 1.7 Limitations and boundaries

Discourses on spirituality are multi-disciplinary and multi-layered; it plays an important role in theology, philosophy, anthropology and history, to name the most obvious sources of inspiration. This thesis focuses on only a small area as explained in the following section.

### 1.7.1 A focus on secular spiritual care

Although the religious literature has contributed greatly to the debate on current issues of spirituality, this thesis intends to put the spotlight firmly on non-religious spiritual care from a lay practitioner's perspective and particularly how they understand the praxis of

spirituality in aged care and palliative services. However, from the research data that were collected and analysed, an unexpected focus on religious care performed by the clergy and practitioners alike emerged. Interestingly, the ecumenical approach of this pastoral care made it unnecessary to accentuate differences between religions and religious movements other than where necessary or appropriate, for example, when mentioning a religious source in the literature review or the origin of a specific practice. Similarly, if research participants wanted to expand on their particular religious or spiritual views, which may have contributed to their understanding and application of spiritual care, this has been included.

### 1.7.2 Divergent views

Participation, by the very notion of being voluntary, attracted many people with strong interests and mostly favourable opinions about the role of spirituality in aged and palliative care. Although I looked for different perspectives, especially in the in-depth interviews, it was difficult to find people who disagreed with including spirituality into the practice of care. In the end, all the participants agreed with the notion that providing spiritual care was an important aspect of aged and palliative care. This limitation is acknowledged and will be further discussed in the chapters dealing with the findings.

### 1.7.3 A small sample

Although the topic-and my interest in it, could easily encompass the world, this qualitative research is restricted to a small sample of 26 participants. Furthermore, the research is concerned with subjective accounts, story telling and lived experiences; it is well-established that qualitative findings cannot be generalised or transposed to other

social situations. However, I hope that the research narrative will inspire and inform the reader to explore their own life world; this is an invitation to the readers to engage with this material in a responsive fashion.

## 1.8 Structure of the thesis

The structure of the thesis comprises two distinct sections; the first section is concerned with how the study was conceived and executed; the second section concerns the findings and discussions.

The first section of this thesis includes this introductory chapter, which introduces the researcher and discusses the aims, objectives and the limitations of this research project. It also discusses the significance of the research and explores some of the contextual issues. Chapter 2 provides an overview of the literature on spirituality; its definitions and its relationship to care-giving in the fields of nursing, palliative care and social work. This chapter is quite lengthy because how spirituality is represented in the literature will, to a great degree, influence how spiritual care-giving is conceptualised in the field. Chapter 3 presents the theoretical framework and will locate the researcher in the chosen perspective of social constructivism. Additionally, this chapter will also explain the methodological issues: Participation, data gathering methods and the grounded theory approach to data analysis is discussed and justified. This chapter concludes with exposing the limitations and ethical considerations of the research project.

The next section concerns the findings and discussion. Although the focus is on the research participants' experiences and stories, there will also be some discussion of the findings in relation to the literature to achieve a contextualised picture of the wider landscape of spiritual care-giving. Chapter 4 focuses on how spirituality is understood by aged and palliative care professionals, religious office bearers and volunteers. This chapter shows that for some of the participants, religion seemed to be an overriding principle in their understanding of spirituality, for others spirituality was experienced as a part of their daily living. Chapter 5 explores how spiritual care is conceptualised and what the perceived purpose and function of this perspective on care is in a context of old age, infirmity and dying. It is discussed that the two overarching themes that ran through all the samples were the need for connection or relationship and the need for meaning-making. That the latter often seems to involve a focus on religion and beliefs will also be discussed. Chapter 6 expands on this with a focus on how spiritual care is experienced and practiced. It will be shown that reminiscing, listening to music and even daily acts of care can be seen as spiritual especially when they are infused with a special way of 'being present'. Across the board, participants identified similar impediments to spiritual care; in some cases suggestions were made about how these problems could be improved or overcome. These themes are discussed in chapter 7. The concluding chapter 8 gathers the different strands and themes; thereby providing further discussion and insights into how an inclusive language of spiritual care could be developed. This chapter also provides some suggestions for further research.

## 1.9 Conclusion

The introductory chapter has set the scene for the research interest, which involved an exploration of the contemporary contextual issues in relationship to ageing and spirituality. I argued that although religion may play an important role in traditional understandings of spirituality, there is an increased interest in non-denominational spirituality. The aim of this thesis therefore is to explore how the understanding of spirituality influences practices in aged and palliative care. The research involved 26 mainly self-selected, voluntary participants who were all working in that field in various functions. The limitations and boundaries to this research were set and a short overview of the structure of the thesis was provided. The next chapter continues to place the research in a context by reviewing current issues and related themes in the literature.

# Chapter 2 Literature review

> Looking back at my own experiences they all converge towards a kind of insight to which I cannot help ascribing some metaphysical significance. The keynote of it is invariably reconciliation. It is as if the opposites of the world, whose contradictoriness and conflict make all our difficulties and troubles, were melted into unity (James 2002: 94).

## 2.1 Introduction

Whilst immersing myself in the literature I remained open to what James so insightfully describes in the quote above: Despite the different perspectives and divergent approaches I found again and again an unmistakable 'keynote of reconciliation' in the current literature on spirituality and spiritual care. This keynote is concerned with the recognition that spirituality involves healing, wholeness and unity.

This chapter consists of two sections. The first part provides the context of the research through an overview of how spirituality is conceptualised in the academic literature and how difficult it is to establish a final and irrefutable definition of spirituality. Many authors, therefore, prefer to explore the attributes most commonly assigned to spirituality such as meaning-making, purpose and connection. It will also be discussed that in much

of the literature the boundaries between spirituality and religion are somewhat unclear. The second part of this literature review focuses on the research question and concerns spirituality in relation to care-giving for the elderly and dying. It will be argued that a positive correlation between religion, spirituality and well-being is well established in the literature. The debate on what spiritual care encompasses, however, and the best means of providing spiritual care or who should responsible for that care, is much less conclusive. These issues will be discussed in some length as it will be shown that the way in which spirituality is understood will have important ramifications for the delivery of care.

## 2.2 Locating the field of spirituality

Currently, there is an interest in and a focus on spirituality in many academic disciplines, as well as in the popular and esoteric literature. Although I have used some quotes from the popular and esoteric literature that I consider important and relevant, the following review mainly concerns the academic literature. In that field, even an initial perusal indicates that much of the literature focuses on defining spirituality or is concerned with confirming the benefits of spiritual care. It seems that much less attention is given to spirituality as a lived experience or how the spiritual beliefs and values of health care providers influence the professional practice of caring. It is this area that caught my interest and consequently my research question focuses on this perceived gap in the literature.

### 2.2.1 Definitional elusiveness

Currently there is a lively debate in the academic literature about how to define spirituality and some authors argue that the definitional 'objectification of spirituality' (Beringer, 2000: 158) would have the benefit of 'a scientific approach to teaching and applying its principles' (Goddard, 1995: 810). Many authors, such as Beringer (2000), Griffin (1988), and Reed (1992) make compelling claims to delineate what should or could be seen or not, as 'spiritual'. For example, it is important to acknowledge that 'psychological and emotional health may include spiritual well-being, however are not synonymous' (McSherry, 2000: 41). The following two definitions, which are used quite regularly in the literature, state that spirituality is:

> The ultimate concern, the basic value around which all other values are focused, the central philosophy of life- whether religious, antireligious or nonreligious- which guides a person's conduct, the supernatural and nonmaterial dimensions of human nature (White House Conference on Aging, 1971: 3 in Moberg, 2001: 10).

> A quality that goes beyond religious affiliation, that strives for inspiration, reverence, awe, meaning and purpose, even in those who do not believe in God. The spiritual dimension tries to be in harmony with the universe, strives for answers about the infinite and comes into focus when the person faces emotional stress, physical illness or death (Murray & Zenter, 1989: 259).

McSherry and Draper (1998: 683), however, contend that ‘conceptual clarity’ or ‘unity of theory’ would be difficult to achieve, because such subjective mental concepts and social constructs as spirituality escape by their very nature a definitive definition, as illustrated in the following quote:

> Any working definition of the spiritual experience comprises value judgments- saying, in effect, spiritual experience is this or that, but not something else. The selection of criteria is necessarily subjective, arbitrary and personal (Bash, 2000: 14).

Winslow (2005) agrees that it may be impossible to define spirituality and argues that it is therefore more productive to say that ‘spirituality defines you’. In the esoteric literature spirituality is often denoted as ‘a mystery to be lived’ (Osho, 1989:15). Stanworth (2002: 193) adds that spirituality is more ‘easily recognised than explained’. Goddard (1995: 810), however, points out that there is an abundance of descriptors, which seem to capture the many particular, intensely personal, as well as the ‘universal qualities, which transcend individual experiences’ of spirituality in a relatively inclusive way. The experiential nature of spirituality is hinted at in a substantive, often used quote:

> The sacred is what distinguishes religion and spirituality from other phenomena… The sacred is the common denominator of religious and spiritual life. It represents the most vital destination sought by the religious/spiritual person, and it is interwoven into the pathways many people take in life (Hill & Pargament, 2003: 65).

According to Beringer (2000: 168) this appreciative view, where each individuals understanding is honoured, is esoteric and quite unsatisfactory and it would be difficult to apply this fuzzy understanding of spirituality in the practice of health care. Spirituality as a subjective experience is allowed to carry a different meaning for each person, thereby encouraging the unique expression of one's personhood (Jewell 2004). Yet, few accounts of spirituality seem to explore the experience of spirituality or more precisely the *quality* of that experience, rather than *how* the experience can be categorised or labeled (Mauk & Schmidt 2004; McBee 2003; Stanworth 2002). Finally, Garcia-Zamor (2003: 355) contends that, although 'spirituality is mutable and diverse', from a position of dialogue and accepting plurality/diversity, it is possible to create a common language from which a fruitful discourse can be established. One of the first tasks of this language may consist of delineating the differences between religion and spirituality.

## 2.3 Religion and spirituality; what is the difference?

Before moving into a more in depth review about the different approaches to spirituality in the current literature, it is important to distinguish and delineate the areas of spirituality and religion, two related fields, which are often used indiscriminately and interchangeably (Hodge, 2001; George et al. 2000). More specifically, most of the literature, especially from America, is based on a predominantly Christian worldview. McSherry et al. (2004: 938) agrees that discourses of spirituality are often influenced by religious perspectives. The lack of differentiation between religion and spirituality may also account for ambiguity and role confusion for health care providers. For example,

Narayanasamy and Owens (2001) ask under what circumstances can a nurse or aged care practitioner deliver spiritual care and when is it more appropriate to call the clergy? For these reasons I believe that it is important to contrast spirituality and religion to provide a clearer understanding about the 'common ground' between them and the differences.

### 2.3.1 Religion

The root of the word religion comes from the Latin word 'religare' and means binding together or bringing back to the roots (McSherry, 2000: 24). Religion is commonly understood as a 'comprehensible, organised and relatively closed system' (George et al, 2000: 104) of shared beliefs and practices by a defined group of people (Berggren-Thomas & Griggs, 1995; Hume, Richardt & Applegate, 2003). Religion and culture are often closely interwoven as they are both concerned with shared practices and beliefs. Religion is the formal expression of one's beliefs and is as such the 'outward practice of a spiritual understanding' (Kirby, Coleman & Daley, 2004: 125). Furthermore, religions prescribe the social organisation of a group by a clear 'value system or moral code' (Goddard, 1995: 810). The 'collective reinforcement' of these morals, codes of conduct and rituals install a sense of belonging, identity and security for their followers (Kirby, Coleman & Daley, 2004: 126), which makes religion attractive to those who want clear guidelines, explanations and rules for living (George et al. 2000: 104). Religion is usually mediated by the clergy and Handzo and Koenig (2004) argue that their pastoral role is fairly undisputed in aged and palliative care.

### 2.3.2 Spirituality

The root of the word spirituality also comes from the Latin and 'spiritus' means 'breath' or 'air' (McSherry, 2000: 25). In common language, expressions such as 'being spirited' or 'having spirit' denote this quality of animation, enthusiasm and movement together with our experience of that. Following that line of argument, the spiritual is understood as the 'creative energy' and an 'animating force' within a person (Fry, 1997: 6). Spirituality is mostly equated with an existential search for purpose, connection and 'what it means to be human' (Miller, 1999: 35). Similarly spirituality is an important part of one's life review; a task which, in developmental psychology as well as in the Indian philosophical tradition, is most commonly assigned to the elderly (Thornstam, 1999).

Spirituality, however, extends far beyond the mundane concerns of daily living as McSherry (2000: 25) claims it is the 'unifying and integrating dimension of being that includes the experience of transcendence and the mystery of the holy'. According to Garcia-Zamor (2003: 355), this dimension includes notions of 'respect for the sacred, love of beauty and interaction of the divine in human destiny'. From this perspective spirituality is considered as a transcendental force that all particular religions and beliefs can subsume, because it can move a person forward beyond the narrow boundaries of their existence, with its conventional, culturally determined thoughts and actions (Berggren-Thomas & Griggs, 1995; Patel & Giorgio, 2005).

### 2.3.3 Differences and Similarities

Religion and spirituality are obviously not mutually exclusive. It can be argued that both are complementary to each other and both are concerned with 'at-onement' by seeking connection and finding meaning to transcend aloneness and separation. Religion and spirituality share an interest in the sacred or divine dimensions of life and how to transcend life's inevitable difficulties and sufferings (George et al, 2000:103). Furthermore, both are concerned with morals, behaviours and practices, however, Benner (2002: 103) points out one distinction when he argues that religion provides prescriptive and mostly *extrinsic* guidelines, whilst spirituality is concerned with living by *intrinsic* guidelines, which are chosen from experience rather than being determined by doctrines.

Although spirituality can be an essential part of any religion it is a much wider and more encompassing concept and therefore it is much harder to define. Spirituality does not necessarily include a belief in a God, articles of faith or a commitment to a set of rituals and moral codes (George et al, 2000). Additionally, one can also belong to a religion simply by following its prescribed rituals and dogmas mechanically, without engaging in a spiritual life. Although spiritual experiences can be mediated by religious leaders, such as priests or gurus, in spirituality the emphasis is on one's personal, experiential life world. This will be described in greater detail in the next sections.

## 2.4 Universal qualities

Instead of definitions, many authors make reference to the attributes, functions and themes to capture the nature, qualities and manifestations of spirituality (Bambery, 1997; George et al. 2000; Walter, 1997). Three overarching themes are mentioned most frequently in the literature, which makes it possible to establish what Stanworth (2002: 192) describes as 'analogies of experience across cultural or religious boundaries'. These themes are concerned, firstly, with the existential human need for meaning-making and purpose; secondly, with building significant relationships and connections and, thirdly, with spirituality as the life force. Each of these themes will be explored in more detail in the following sections.

### 2.4.1 Spirituality as meaning-making or purpose

Jung (1934/69: 415) states that 'the lack of meaning in life is a soul-sickness whose full extent and full import our age has not yet begun to comprehend'. Similarly, Tillich (1967: 11) is quoted often as saying that meaning-making is the 'ultimate spiritual concern' and the 'existential character of the religious experience'. According to Dokecki, Newbrough and O'Gorman, (2001: 497) spirituality is a 'personal quest and journey, which explores what is involved in becoming human' and MacKinlay (2001: 118) adds that it is the 'essential dimension which brings meaning to life'. It is what makes us 'distinctively human' and involves 'a way of living that promotes awareness of meaning in life' (Hume, Richardt & Applegate, 2003: 21). According to Ellor, Netting and Thibault

(1999, in Watkins, 2001: 134) the ‘reflexive nature of meaning-making’ supports a ‘unique personal style’ of ‘finding, creating and expanding personal meaning’.

Frankl (1984), psychiatrist and survivor of the Holocaust, found that reflective meaning making in the face of adversity is essential in order to cope with suffering. It is suggested that the ‘placebo effect of hope and meaning’ is supporting people through difficult times (Bakerslee, 1998 in Gotterer, 2001: 188). Furthermore, finding meaning and ‘shelter’ or refuge in spirituality can diminish one’s fear for the suffering life can bring, including that of death and ageing (Young-Eisendrath, 1996: 93).

### 2.4.2 Spirituality as relationship or connection

Meaning and purpose are often defined in relation to connections with other people and the theme of relationship or connection is mentioned frequently and the following quote shows its importance:

> We need to feel that no matter what our experiences and circumstances, we are respected and unconditionally accepted. We all need basic human kindness; the reliable presence of another person, someone who is willing to be in regular contact with us for the duration of our journey through suffering (Longaker, 1997: 54).

Most of the literature agrees that spirituality encompasses a meaningful relationship or connection with the other: with other human beings and with God or a Higher Being (MacKinlay, 2004; McSherry 2000; Moberg, 2001). It is the ‘search for those moments

where we feel deeply connected with the web of life and the world seems to make sense' (Rumbold, 2003: 12). The relational dimension of spirituality involves a 'deepening of our love, a decentering of the self, to see others as ends in themselves' which involves not closing off and defending one's sense of self, but the ability to be being open and vulnerable (Faver, 2004: 243). According to Mearns and Cooper (2005: 48) the relational depth of these interpersonal encounters is therapeutic by its very presence. Tacey (2000: 17) adds that this way of relating is emotionally satisfying and therefore 'transformative and complete'. Furthermore, meaningful connections and relationships with the other contribute to 'a sense of emotional and physical well-being' (Kirby, Coleman & Daley, 2004: 125)

However, it is not only with other human beings or God that we are connected; according to Dokecki et al. (2001: 499) it 'is found in all relations and relational realms; spirit connects and unifies'. Garcia-Zamor (2003: 354) explains this as being 'interconnected with self and others/nature'. Described as 'relational spirituality' Faver (2004: 241) argues that this connection is experienced as intrapersonal, which means feeling at home with oneself, whilst it also includes the interpersonal and transpersonal, the latter describing the ability to extend our sense of self to include all of the universe. Carroll (2001: 6) describes this as at-onement or a feeling of peace with 'all that exists in the universe'.

This section shows that meaningful relationships with others and, for many, with God are an important facet of spirituality. These connections are comforting and contribute to a sense of well-being; they can uplift the spirit despite life's inevitable suffering.

### 2.4.3 Spirituality as generativity or vital life force

The translation of spirit is breath and according to Fuller and Strong (2001: 201) spirituality is that which animates us; it is 'the fire inside of us' and our fundamental life force. Fox (1983: 274) agrees by stating that 'to be spiritual is to be alive, to be capable of moving and being moved'. Spirituality supports and maintains a creative and fulfilling life even in old age (MacKinlay: 2004; Moberg, 2001), because it enhances a 'person's engagement with life by deepening an appreciation for the struggles and joys of life' (Miller, 1999:640). Spirituality involves an enthusiasm, literally, 'being full of God' thereby 'infusing the ordinary with a sense of the holy' (Beringer, 2000: 162). Therefore spiritual enthusiasm is often expressed in poetry, music, art and stories (Goddard, 1995; McSherry, 2000).

Many authors, when talking about the generative force of spirituality, mention a sense of being at ease with oneself and a feeling of peace with the world (Canda & Furman, 1999; MacKinlay, 2004; Moberg, 2002). These authors also denote the positive correlation between having a spiritual or religious affiliation and mental, emotional and physical well-being. McSherry (2000: 35) adds that spirituality infuses a sense of hope, forgiveness and trust. These spiritual strengths or 'inner resources' contribute to being fully human and are therefore a 'necessary component' of health and well-being (Moberg, 2001: 12; Watkins, 2001: 134).

### 2.4.4 Bringing it all together

Despite spirituality being mentioned ubiquitously in the literature and in current policy making about practices of caring, this overview shows that spirituality remains a deeply ineffable and subjective concept, which is open to a wide variety of explanations and understandings. All aspects of human behaviour and interaction can be infused with the spiritual, often as part of the search for meaningful connections and making sense out of one's life experiences.

One of the most confounding contemporary issues, however, is that there is often not a clear differentiation between spirituality and religion, especially in the American academic literature. This has important implications for understanding and providing appropriate and culturally sensitive spiritual care, especially in a globalised, more materialistically oriented life world. These issues will be discussed in the following section, where the focus will be on how spiritual care-giving is represented in the current palliative care, nursing and social work literature.

## 2.5 Different approaches to understanding spirituality

It is important to delineate the different approaches to spirituality within the literature, because of the implications for spiritual care-giving. The following section explores the difference between spirituality as something that is experienced within and spirituality that is mainly experienced as an outside force.

### 2.5.1 Locating the spiritual

Some authors make a distinction between what Carroll (2001, 6-7) calls spirituality as the 'within' and the 'without'. Others denote similar themes but talk about the vertical and the horizontal relationship; the above and the below; also described as extrinsic and intrinsic spirituality or theistic and non-theistic spirituality (Dokecki et al 2001). The perspective of the 'without' acknowledges spirituality as a 'one-dimensional relationship with a higher reality, Higher Self or God outside oneself' (Reese, 2001: 157); transcendence of this earthly life is sought through worship, practice and ritual. This theistic view of spirituality is very dominant in the American literature on spirituality (Crowther, Parker, Achenbaum, Larimore & Koenig, 2002; Moberg, 2001) and assigns the role of spiritual care to an expert or professional pastoral carer, such as the clergy or other 'intermediaries of the Other' (Theis et al. 2003:50). Although this approach is closely related to religion and theology, theistic spirituality does not necessarily affiliate itself to religion, but is similarly 'seeking theories of the divine' and 'theistic images of Godhead' (Benner: 2002: 1).

In contrast, in the spiritual tradition of the 'within' there is a desire to 'directly experience and realize the holy' within oneself (Beringer, 2000: 162). The acknowledgment of God in all things or 'pan-en-theism' subscribes to the lived experience of the divine and interrelated nature of all existence (Fox, 1983; Tacey, 2003). The direct experience of spirituality is often described as mystical or ecstatic; a transcendental feeling of being at one with the universe (Ochs, 1997). The spirituality of tribal and indigenous societies, including the Australian Aboriginal, has long recognised the interconnectedness of all

life. Tacey (2000: 255) argues that this ‘radically democratic and immanental [sic] style of spirituality’ is now quintessentially Australian. From the perspective of the ‘within’, an ‘expert stance will not be effective’ and spiritual care can be given by anyone who is skillfully concerned with the lived experience and aware of the faith context of their client (Rumbold, 2003: 12).

Another important distinction that impacts on spiritual caring concerns the understanding about the place of spirituality in personhood: spirituality can be seen as a component of the whole person as in the physical, the psychological, the social and the spiritual. There are many references in the nursing literature to holistic care that encompasses and integrates all aspects of the human experience (Hudson & Richmond 2000; McEwen 2004; Milligan 2004). This view implies ‘that all dimensions of our lives are all equally important’ and are interacting with each other (Reed, 1992: 351). Described as spirituality in the ‘broader sense’ by Griffin (1984: 4), spirituality as a component of the self tends to relegate the sacred, and thus spiritual care, to special occasions and special rituals (Beringer, 2000). This view is fairly common in the nursing literature and could, according to McSherry, (2000: 49) contribute to reducing the whole human being -and thereby also spiritual care, into ‘manageable, mechanistic units’ delivered on demand by experts in the field.

Griffin (1988: 4) contrasts this ‘broader sense’ of spirituality with a ‘stricter sense’: spirituality is seen as the essence, ‘the foundational force, which animates the bio-socio-psychological dimensions of a person’. McSherry et al. (1998: 688) agree and suggest

that spirituality is so ‘intimately interwoven with and fundamental to our existence that it cannot be separated or segregated from any other dimension’. Carson (1989: 23) adds that spirituality ‘pervades and unifies body, mind and emotions’. Therefore, the spiritual is seen as the ‘core of one’s being, the essential part’ (Goddard, 1995: 810) or ‘the ground of one’s being’ (Joseph, 1988: 44, in Carroll, 2001: 7). From this perspective, spiritual care is part of all interactions with clients, but should also involve close ‘collaboration with clergy to support the spiritual needs’ (Theis et al. 2003: 49). The following sections examine the different roles and current issues in relation to spiritual care.

## 2.6 Pastoral, spiritual or holistic care?

Milligan (2004: 163) is concerned that the boundaries are blurred between the practice of spiritual care, pastoral care and the experience of an integrated holistic practice of nursing. Traditionally spiritual or pastoral care was administered by the clergy and some authors argue that even today the role of the clergy is paramount (Handzo & Koenig, 2004). The pastoral role of the clergy in holistic care is not disputed and is usually well defined in the literature. The very word ‘pastoral’ denotes its Christian origins with the image of the good shepherd caring for his flock (Confoy, 2002).

Contemporary nursing literature, however, reveals a shift from an emphasis on pastoral care to a non-religious spiritual care, the latter being essential in a holistic approach to client care (McGrath, 2002; O'Brien 2003; Robinson, Kendrick & Brown 2003; Taylor, 2002). Confoy (2002: 29) argues that the current revival of spirituality is still seen as ‘a

ministry' with religious 'overtones' and a focus on what she calls 'pastoral care workers'. McSherry et al. (2004: 935) agree that there is confusion and lack of clarity in the health professions about spiritual care and they believe that 'no one size fits all'. The following section explains the historical legacy of this confusion.

### 2.6.1 Being of service

Models of care-giving in the Western world originate in religious service and charity; the question why one should care beyond any 'contractual obligations' involves 'extrinsic and intrinsic moral, ethical' convictions and religious commitments (Bradshaw 1997: 15-20). In fact, most religions involve 'a code of conduct' based on commandments of living an ethical life within the context of the origins of that religion (Burnard, 1997: 41). Choosing to become a caregiver is therefore often informed, even today, by moral, spiritual or religious motivations (Lips-Wiersma, 2002: 497). From this perspective, care is seen and understood as a moral imperative and is always 'specific and relational'; thus it cannot be context-free or value-free (Benner & Wrubel, 1989). Prescriptive morals and values have in the past, however, accounted for negative images of these services and may even now hinder the inclusion and integration of sensitive spiritual care in work place practices. The following sections explore how the contemporary literature in nursing, palliative care and social work integrate and represent spirituality and spiritual care-giving.

## 2.7 Models of spiritual care-giving in palliative care, nursing and social work

Literature searches showed three areas of care-giving that are particularly concerned with spiritual care; palliative care, nursing and social work. They are discussed in the following sections in an order that shows the prominence of spiritual care in the respective literature.

### 2.7.1 Palliative care

Palliative care is concerned with providing as much comfort and relief as possible to patients in the last stages of a terminal illness. In no other domain of health care provision has spirituality been given so much attention as in the palliative care literature.
An extensive review by Flannelly, Weaver and Costa (2004: 570) reveals that more than 18 % of the recent literature addresses spirituality and religion, which are seen as 'indispensable components' of palliative care. Similarly, a publication by the Australian Government states that:

> Spiritual counselling and support are essential to a palliative approach and may help to give access to rites and rituals that offer symbolic meaning to residents (Australian Government Department of Health and Ageing, 2004).

It is well recognised in the current palliative care literature that, apart from religious rituals and symbolism, the function of spiritual care involves providing opportunities for meaning-making and deep connection (Confoy, 2002; Good, 2003). This is not surprising, because a life-threatening illness disrupts the normal patterns of living and

precipitates a new urgency to make sense of these experiences (Mauk & Schmidt, 2004). Some educational text books on death and dying now include chapters on spirituality; others are wholly devoted to spiritual care in the face of death (for example Reoch, 1997; Singh Dowling, 1998). These authors concur with Hudson and Richmond (2000: 169) who claim that holistic palliative care needs to involve ‘culturally appropriate care and spiritual sensitivity regarding death and old age’. Rumbold (2002: 195) describes ‘dying as a spiritual quest’ and from this perspective, the goal of spiritual care is ‘to witness, empower and validate the spiritual quest' (Victoria Hospice Society, Cairns, Thompson & Wainwright, 2003: 3).

Kubler-Ross’ ground-breaking work *On Death and Dying* in 1978 has been followed by many other academic publications that mention the importance of spiritual care at the end of life. Many studies argue that spirituality and religion can be a source of great strength in old age and dying (for example, Kirby, Coleman & Daley, 2004; MacKinlay, 2001b; Moberg, 2001). However, much of the literature, especially from the U.S.A, is based in a Christian tradition (George et al. 2000; Moberg, 2001) and I found that much less is written in the academic literature about the Buddhist perspective on death and dying. For example, in 1992, Sogyal Rinpoche wrote *The Tibetan Book of Living and Dying*, which offers the insights into the last stages of life, compiled from centuries of practices into seeking enlightenment about the nature of life and death. Similarly, work by Geshe Kelsang Gyatso (1999) highlights the many alternative and little explored ways of preparing for one’s own death and of giving spiritual care in the face of death and dying.

I have mentioned these sources here because I believe that the Buddhist literature could offer valuable perspectives on the role of spirituality in palliative care, not in the least because they are acknowledging death as a natural part of life (Longaker 1997). It is interesting to note that Queensland Palliative Care is collaborating with Buddhist palliative care organisations through joint meetings and conferences. Palliative care is part of the field of nursing and it is therefore not surprising that spirituality also plays a role, albeit less pronounced, in more generalist nursing practices.

### 2.7.2 Spiritual care in nursing

An overview of the general nursing literature also shows an increasing interest in spiritual care. This is evidenced by the numerous journal articles and books that prioritise spirituality as an essential component of holistic care-giving in nursing (for example Brykczynska, 1997; Davidhizar, 2004; Don, 2004; O'Brien 2003; Taylor, 2002). However, McEwen (2004) asserts that despite ubiquity in the academic literature, spirituality as an important component of care it is not well presented or taught as part of the nursing education, despite the fact that in survey of 270 nurses, Grant (2004: 39) found that ‘spiritual care could produce certain effects in patients’ as:

> Almost every nurse believed that spirituality could give their patients inner peace, strength to cope, bring about physical relaxation and self awareness, and help them forgive, connect and cooperate with others (Grant, 2004: 39).

Research also shows that although most nurses feel that spiritual care is part of their role, many feel that they lack understanding of how to put this into practice (Narayanasamy & Owens, 2001; Grant, 2004). Similarly, there is confusion about the boundaries between spiritual and religious care and consequent ambiguity about who is responsible for spiritual care (Handzo & Koenig, 2004).

However, from the above literature review it is clear that, despite the confusion about the nature of spirituality, there is a vivid interest in promoting spiritual care in nursing practices. However, historical practices, role division and lack of clarity may account for less enthusiasm for including spiritual care in social work practices and this is discussed in the next section.

### 2.7.3 Spiritual care in social work

The social work literature has been slow to adopt spirituality as a valid concern for their practice. A new textbook edited by Alston and McKinnon (2005) *Social Work: Fields of Practice* devotes only one paragraph to discussing spirituality, stating that this may be 'important to the future for social work' (McMahon, 2005: 81). The omission of spirituality in much of the literature is often attributed to old images of 'value-laden care' by religious charities or, equally important, the overriding concern of social work with 'evidence-based practice' (Rice 2002: 310).

In the current social work literature, however, there is little indication of religious overtones and spirituality is generally seen as being concerned with existential issues such as meaning-making and the human need for belonging and connection (Carroll

2001; Reese 2001). Furthermore, Rice (2002: 209) proposes that spirituality and social work are both concerned with promoting 'the growth of the individual and the greater good of the community'. As in nursing and palliative care, therefore, some authors advocate that holistic care in social work practices 'must include the spiritual dimensions of client problems' (Canda & Furman, 1999: 46). Research shows, however, that social workers are not likely to address spirituality with their clients, unless working in a hospice environment. Reese (2001: 158) concludes that there is:

> a lack of social work training in this area, an inability to define spirituality according to current social work literature and an inability to identify major spiritual issues (Reese, 2001: 158).

Canda and Smith (2001) points out that the focus on culturally appropriate support in social work has brought home the need to address religious diversity, as well as non-religious expressions of spirituality. He continues to say that social work has traditionally been at the forefront of creative and client-centered practice and this should now also include 'spiritually sensitive social work practice' (Canda & Smith, 2001: 135).

This section of the literature review shows that there is a general agreement in the palliative care and nursing literature and to a lesser degree in the social work literature that care-giving should be extended beyond the familiar bio-psycho-social needs and includes caring for the spiritual wellbeing of the client. How this is envisaged and could be achieved is discussed in the following section

## 2.8 Spiritual practices, assessments and interventions

The social work literature focuses more on the philosophical aspects of spirituality. In the palliative care and nursing literature, however, the practical application of spiritual care is often discussed in relation to two specific areas: the assessment of spiritual needs and the provision of these needs (George et al. 2000; Levin & Chatters, 1998). These two issues will be discussed in the following section in general terms, because of the similarities present in the literature of the different professions.

### 2.8.1 Spiritual assessment

Government papers, nursing home policies and many academic articles agree that spiritual assessments are necessary in order to deliver appropriate care. McSherry (2000: 37) explains that a 'spiritual assessment looks for signs of spiritual well being and or spiritual distress'. According to Hodge (2001: 203) a spiritual assessment consists of two parts and includes a spiritual or religious history as well as an inventory of the strengths and resources in a client's life. A publication of the Australian Government Department of Health and Ageing (2004) states that:

> Understanding the resident's current or desired practices, attitudes, experiences and beliefs assists in meeting their spiritual needs (Australian Government Department of Health and Ageing, 2004: 2).

In many organisations the spiritual assessment is part of the intake interview and often is restricted to a series of questions about religious practices and preferences. However,

many authors suggest that this is not enough and encourage using more descriptive and narrative methods (Berggren-Thomas & Griggs 1995). Furthermore, Hill and Pargament (2003: 71) warn that 'spiritual assessment tools' are not necessarily 'stable constructs' and that it is not unusual to find, especially in the later stages of life, changes and/or development in spiritual and religious coping. This is also poignantly illustrated in the following quote:

> The process of measuring is a coarse one, and extremely imperfect when applied to a living object. A living thing cannot be measured by something external to itself; it must be measured, it must provide its own gauge. This gauge, however, is highly spiritual... (Goethe, in Kaplan, 2002: 159)

Others disagree and, for example, Hodge (2004: 41) describes a comprehensive set of assessment tools, which should be conducted by 'spiritually competent' workers. These competent workers, according to Handzo and Koenig (2004: 1242), are the doctors, who should be responsible for 'spiritual assessment as part of overall assessment', whereas 'spiritual distress' should be attended to by the experts, such as the clergy and professional spiritual counsellors. Taylor (2000: 103), however, argues that a spiritual assessment is a team effort and, apart from the usual intake information, should be compiled in an ongoing fashion with a focus on story telling and reminiscing. It is at this intersection of assessment as story telling that the boundaries between assessment and intervention are blurring.

### 2.8.2 Spiritual interventions

Spiritual interventions can involve simply listening, laughing or physical touching and McGrath (2002: 55) agrees that spiritual care often involves the ‘quintessential of the ordinary’. Other interventions are more ritualistic; they involve prayer and meditations or sacred and religious practices such as the last rites and communion (O'Brien, 2003). Specific religious rituals performed by the clergy are not a concern here. However, it is important to note that some religious practices such as prayers are often also provided by health care practitioners. Soerens (2001: 107) points out that ‘primary health providers need to be able to offer patients numerous non-religious spiritual care interventions’. These interventions invariably encompass communication skills such as listening (Milligan, 2004), supportive talking (McGrath & Clarke, 2003), reminiscing (Bickerstaff, Grasser & McCabe, 2003), silence (McGrath & Clarke, 2003) and the ability to ask gentle probing questions (O'Brien, 2003). Initiating meaningful connections also involves touch (Brykczynska, 1997), music (Salmon, 2001; Hays & Minichiello, 2005) and poetry reading (Charles, 2004). Traditional religious interventions include praying or reading the bible (Grant, 2004) and interventions inspired by Eastern religions and philosophies may include meditation and visualisation (Taylor, 2000).

Other areas of spiritual care involve the ability to be involved in teamwork, to network or to refer on where appropriate (McGrath, 2004; Milligan 2004). In all cases, the role of the care giver is to encourage and support clients, where appropriate, into using their own, personal ‘conceptual and moral resources… to face the limitations and challenges of

being human' in old age and end of life issues (Henery, 2003: 556). Theis et al. (2003: 47) summarise this by stating that it is important to nurture a 'positive attitude'.

### 2.8.3 Mutuality in spiritual care

It is interesting to note that although very supportive of the client's need, much of the language of spiritual care-giving in the literature is based on a one-way medical model of deficiency and ill-health and uses terms such as 'spiritual assessment', 'spiritual distress' or 'spiritual intervention'. For example Cohen, Wheeler and Scheier (2001: 32) warn that 'the question of whether religious and spiritual beliefs improve outcomes is misplaced:

> [they are] not a form of medical treatment, and should not be used for extrinsic ends… the real issue is not whether religious or spiritual commitments improve patients' health, but rather whether physicians inquiries into such commitments honor patients as persons… as a whole and integrated person (Cohen, Wheeler & Scheier, 2001: 32).

Some Australian academics are developing an approach to spiritual care that is less interventionist and is based on 'mutuality', 'reciprocity' and 'interaction' (Kellehear, 2002: 271; Rumbold, 2002: 14). This would involve a practice which is 'founded on values, knowledge, and skills that promote the dignity of all persons and spiritual paths, religious and non-religious' (Canda & Furman, 1999: 35). This view of spiritual care makes it possible and invites care-givers to relate to their clients on an equal footing, not as spiritual experts but as human beings who share a spiritual connectedness. According to van Hooft (2002: 49), 'caring is the fundamental ontological relationship between two

subjectivities- not objects'. From this perspective spiritual care is not something you do *to* someone, but something you do *with* someone (Kellehear, 2002: 173).

A model for this care could be found in Buber's explanation of the 'I-Thou' relationship, where the other is not the object of our business, but is genuinely seen as a whole (holy) person in their own right and accepted with 'non-possessive love and reverence' (Tschudin, 2003: 198). Chochinov, Hack, Hassard and Kristjanson (2004: 136) have developed an approach to care that affirms 'a state of being worthy, honoured and esteemed', which preserves the dignity of the client, whether infirm, ill or dying. This quality is also reflected in the Indian greeting of 'Namaste', which translates as I greet godliness or the divine in you, and in humanistic counselling. Developed by Rogers (1969: 282-3) humanistic counselling stresses the importance of unconditional positive regard for and acceptance of the client as a worthy human being under all circumstances.

## 2.9 Impediments to spiritual care

There is no doubt that health care is concerned with providing the best care possible and the abundance of literature on the subject indicates that nurses affirm the 'efficacy of spiritual care' (Grant, 2004: 39) and should at least be knowledgeable about these matters. Yet, research consistently shows that practitioners find it difficult to identify and attend to the spiritual needs of patients (Milligan 2004). Although nurses in the palliative care field may seem more knowledgeable about spiritual issues than other care givers according to McGrath (2004: 5), there is still a sense of 'being uncomfortable' with

delivering this care. Furthermore, there is some confusion about who is responsible for spiritual care, despite Doka's (2000: 113) assertion that the 'responsibility for spiritual care is shared' by all members of the care team, which include the clergy where appropriate. An English study of 115 nurses conducted by Narayanasamy and Owens (2001: 477) concluded that 'spiritual care is largely unsystematic and delivered haphazardly' using 'limited traditional therapies like prayer and religious approaches'.

The literature in palliative care, nursing and social work all report concern about the lack of formal education and training in spiritual care (Canda & Furman, 1999; McGrath 2004; Hassad, 2000; McSherry et al. 2004). According to these authors, most of the training in spirituality is done as an elective or on the job, if at all. Wright (2000) states that training in spiritual care, both in educational institutions and the workplace, is haphazard and often optional. Spiritual training should involve communication skills (Culliford, 2002), counselling skills (Curtis & Glass 2002), values and ethics (Taylor, 2002), knowledge about religions and philosophy (Lamb & Thomson, 2001), self awareness and self reflection (McBee 2003). Kimble (1995: 171) draws attention to the fact that spirituality really involves 'a life-long process of encountering, reflecting on, responding to and developing insight' into the nature of life.

Mauk and Schmidt (2004) agree that spiritual care-giving involves a certain 'readiness and preparation' which implies a 'recognition' and 'experience' of spirituality, coupled with the willingness and ability to provide this care. Spiritual training therefore must involve experiential learning and the concept of spiritual development and spiritual

maturity. Kaplan (2002: 159) concludes that social and spiritual competency needs to be 'cultivated', which by its very nature requires that the trainer or educator needs to have information *and* experiential knowledge in these matters.

### 2.9.1 The research question and the key elements of spiritual care

This literature review showed me that spirituality is no longer considered an eccentric pathway to wholeness or enlightenment; it is no longer considered an alternative or esoteric religious practice. Spirituality is now also sparking the interest of practitioners, policy makers and the academic world; literature abounds and spirituality is increasingly being included as an accepted part of health care. To summarise, the academic literature makes ample reference to spirituality in relation to health and well-being. Despite the fact that most authors extol the importance of spiritual care, I found a distinct lack of research into how spirituality is understood by health care providers and how understanding influences the experience and practice of spiritual care in the field. This thesis is exploring the experience, language and care relating to spirituality in health care, with a focus on the experiences of the care givers in aged and palliative care.

## 2.10 Conclusion

This literature review showed that spirituality is of great concern for contemporary care-giving and can no longer be seen as the exclusive domain of religious experts and the clergy. However, there is considerable overlap between religion and spirituality and some

of the American literature uses both terms interchangeably. Furthermore, it is difficult to establish an authoritative definition of spirituality, because it is such an ineffable and subjective concept. Notwithstanding these complexities, the literature agrees that there are many common themes and distinctions that support a shared discourse. Spirituality involves the ultimate search for meaning, purpose, connection and transcendence; it is often seen as a personal quest, which takes on special importance and urgency in old age and infirmity. Consequently, the role of spiritual care is seen as essential in aged care and palliative care. Despite this acknowledgement the disciplines of nursing, palliative care and social work have recognised that practitioners in these fields are not very well prepared for this task. Although this chapter provided a general overview of how spirituality and spiritual care is addressed in the academic literature, further references to the literature will be included in the chapters that describe and discuss the findings. This practice is in line with the chosen research methodology, which is discussed in the next chapter.

# Chapter 3 Methodology

> Questions of meaning rest on metaphysical assumptions and cosmological issues such as God, spirit, other-worldly realms and ontological and epistemological questions e.g. 'What is the Ground of Being?' (Beringer, 2000:158).

## 3.1 Introduction

As the quote above shows, spirituality, meaning making and epistemological questions cannot easily be separated and in this chapter I will outline how the research was conducted, following Marshall and Rossman's (1999: 24) guidelines for presenting a qualitative research methodology. To begin with, the overall approach or theoretical framework, which underlines this small scale research project, will be explained. The data gathering methods are described in detail and are followed by an introduction to the research participants. How the samples and sources of information were selected and how the ensuing research data were analysed is of great importance; this is described in a section that also discusses the trustworthiness of the research. Finally, this chapter concludes with an overview of the ethical considerations and limitations of the research design.

## 3.2 Theoretical framework

### 3.2.1 Aim of the research

Chapter 1 explained that this study is concerned with spirituality, spiritual care and ageing. The research project's aim is to answer the following question:

> How does spirituality inform care-giving to the elderly and dying in residential and home care?

I chose the context of caring for the elderly and dying, because old age and dying are often seen as the ultimate time for integration, spiritual maturation and wisdom (Beirne, 2002: 138). I assumed that spiritual needs are therefore more pronounced in old age and thus spiritual care is more relevant. However, the research focus is not on client needs but on the experiences of the care givers. It is their understanding and their practices of spiritual care, which form the narrative of this thesis and in the next section I discuss how this narrative is represented.

### 3.2.2 Qualitative research

It is well-established that qualitative research is eminently suitable for research in the social sciences, because it embraces a subjective and holistic worldview (Lincoln & Guba, 1985). I have chosen a qualitative research design, because it can portray 'the complexity and variations of the lived experience' (Browne, 2004: 626). According to Braud and Anderson (1998) and Smith (2001) qualitative research can also reveal the

esoteric, interpersonal and even transpersonal aspects of human existence. Qualitative reports are particularly interested in 'interpreting how meaning is constructed', because, as Wilber (1998: 40) states, human beings are 'condemned to meaning'.

### 3.2.3 Social constructionism

For this research, I argue that social constructionism provides a relevant theoretical framework, because this approach is respectful of participant voices and appreciative of local knowledge (Crotty, 1998). At this stage it may be important to note that there is, at times, a lack of clarity in the literature regarding the two related theoretical frameworks of social constructionism and social constructivism. According to Schwandt (1998: 241) social constructivism examines 'the processes of knowledge construction' from the perspective of individuals creating their 'knowledge claims' from external, relatively stable constructs or schemata. In contrast, social constructionism looks at the 'collective generation of meaning as shaped by conventions of language and other social processes', in other words, knowledge is not an individual property but is created by people in interpersonal processes that are fluid, relative and subjective (Schwandt, 1998: 241). Goldenberg and Goldenberg (2004: 322) add that social constructivism is 'rooted in the biology of cognition' whereas social constructionism' is concerned with 'language system, relationships and culture we share with others'.

According to Bluff (2005:144) social constructionism is fluid and responsive, 'whilst familiar to those who are immersed in its discourse'. The foundational philosophical dimension of social constructionism poses that all our knowledge of the world is created through 'interpretive interactionism' (Denzin, 1989: 19). This means that shared

understanding of the world is co-created through dialogue, interpretation and meaning-making in an interactive fashion (Schwandt, 2003). This approach to knowledge construction is particularly relevant in relation to this research project, as the literature review revealed that the field of spirituality is not clearly demarcated or defined. The inclusive approach of social constructionism allows a 'range of understanding, voices and storied variations' (Lincoln & Guba, 2003: 273), which invites mutuality, collaboration and multiple perspectives.

Furthermore, the ontological position of social constructionism is that our perception of the outside world is mediated through our understanding and interpretation (Rapley, 2003). This means that we cannot perceive the world as it is and therefore cannot make any knowledge claims, which are absolutely true. Rapley (2003: 14) continues to say that we cannot 'impose a monologic, theoretical resolution upon the essentially dialogical activity'. Bakhtin (1984: 9) adds that such truth claims would show 'disrespect for the unfinalized nature of dialogue'. Lincoln and Guba (2003: 274) reinforce that there are 'no permanent unvarying knowledge bases for truth claims', which is an ontological position that is shared in most qualitative research approaches in the social sciences.

### 3.2.4 Radical and weak social constructionism

Taking this reasoning further, Rapley (2003: 15) continues that 'radical constructionism' claims that there is no 'reality', and therefore no shared experiences. Schwandt (2003: 307) however, argues that a 'weak' social constructionism makes it possible to co-create a shared understanding or discourse by limiting it to a defined context or environment. A weak social constructionism is flexible enough to accept that the subjective nature of

human existence necessarily creates ‘multiple realities, or multi-universes’ (Kanuka & Anderson, 1999: 9), which is a position that I believe is well suited to explore an emerging, contemporary understanding of spirituality. Importantly, a weak social constructionism concurs with my own understanding of how we create our life-world.

Although social construction is concerned with how we understand our life-world and how we create meaning, during this research I learned that this perspective can also invite narratives and truth claims that confirm rather than question the social reality of a particular group. I learned that discussions in focus groups often focused on Western views on spirituality; in other words it favoured narratives about spirituality that brought to the fore the traditional Christian approaches to spiritual care, whilst paying less attention to other or non-religious approaches to spirituality.

One of the greatest contributions of postmodernism is its relentless questioning of all narratives and theoretical explanations (Batchelor 1998: 4). Postmodernism focuses on the ‘social and linguistic construction’ of any social practice and emphasises cultural and contextual factors which determine ‘the meaning of the lived world’ (Kvale, 1995: 21). This is especially relevant for discussions about spirituality, which over long periods of history has been monopolised by prescribed ways of knowing, such as the dominant religious doctrines (Batchelor 1998: 97). Therefore, a postmodern perspective allowed me to ask important questions about the nature of what Bluff (2005: 156) calls the ‘content of social reality’, in this case about the nature of taken for granted practices and regulations related to spirituality and health care provision for the aged and dying.

### 3.2.5 Rationale for choosing social constructionism

Taking into consideration the postmodern concern, as outlined above, I believe that social constructionism allowed me to explore the rich, multi-dimensional and intensely subjective interpretations of spirituality. I concur with Schwandt (2003: 307) that there is a shared understanding, a 'meaning realism' that can be used to communicate and co-construct a shared discourse of spirituality. In weak social constructionism, as well as in spirituality, it is assumed that those who come from differing 'faith communities' could transcend these contextual differences through an intersubjective or interfaith dialogue. Wilbers (1998: 7) observes that you have to experience, or be immersed in the spiritual life to appreciate its rich complexity. I have chosen the following quote, because it reflects my own position so eloquently:

> We know a thing only by uniting with it; by assimilating it; by an interpenetration of it and ourselves… Wisdom is the fruit of communion; ignorance the inevitable portion of those who 'keep themselves to themselves' and stand apart, judging, analyzing things which they have never truly known (Underhill, 1915 in Wilbers, 1998: 7)

Social constructionism is concerned with a reciprocal inquiry, which appears as a 'profoundly spiritual concern' , according to Lincoln and Guba (2003: 273), who continue to say that it involves a deep interest in the 'freeing of the human spirit'. These authors argue that it is important to come to a place 'where the spiritual meets social inquiry' by including the less tangible aspects of the human experience, because it would contribute to 'human flourishing'. These statements affirm the match of the chosen theoretical

perspective and the aims of my research, which is to conduct a reciprocal inquiry into spiritual care. In the next section I will discuss the methods to achieve such an inquiry.

## 3.3 Data-gathering methods

In this research two different data-gathering methods that are consistent with the theoretical framework of social constructionism have been chosen; focus groups and elite interviews. These will be explained in the following sections.

### 3.3.1 Focus groups

In the first phase of data collection I chose to use focus groups, because I believe that they would facilitate the development of a rich, interactive picture of how the participants of each of the samples understood spirituality and spiritual care-giving in relation to their particular beliefs and experiences. Focus groups are often utilised in research in the health and social sciences, because well-facilitated focus groups can sustain a discussion of a single topic for 'a considerable period of time' (Putcha & Potter, 2004: 8). This is an important factor in discussing issues, such as spirituality that are not often talked about.

The chosen research perspective of social constructionism is well matched with the interactive nature of focus groups, because the first is concerned with the contextual and 'interactive nature of meaning-making' (Crotty, 1998: 54) and the latter invites a 'dimension that goes beyond individual interview data' (St. John, 2004: 420). Thus, focus groups provide an excellent opportunity for reflective interaction with others who may have complementary or different views on an issue. As discussed before, participants in

this research were self-selected and the focus groups consisted of 4-8 participants; a number which maximises personal contributions and effectiveness of these groups, according to Kitzinger (1995: 28).

### 3.3.2 In-depth interviews

After the focus groups were concluded, in-depth interviews were conducted with two key persons in the field in each of the research samples. These interviews can provide valuable information according to Marshall and Rossman (1999: 113), because participants are chosen on the basis of a ‘leadership position in the field’. Putcha and Potter (2004: 8) concur that focus groups are often complemented with individual interviews to explore diverging views or to expand on already existing information. Additionally, face to face interviews can provide what Geertz (in Neuman, 1997: 347) called a 'thick description', because they provide an opportunity for focusing and expanding on a particular aspect of significance.

### 3.3.3 Methods of Strategic questioning and Appreciative inquiry

In the focus groups and interviews I took great care not to ask leading questions, nor to make suggestions, which could influence the interviewee's responses. Where possible, I have used Peavey's (1995: 90-95) guidelines for strategic questioning, which encourages reflexivity by creating common ground, whilst showing respect and openness for other people's opinions and deep listening. Strategic questioning invites exploration of different solutions and suggestions, because it employs open-ended and naive questioning, which does refrain from judging and evaluating the responses (Peavey, 1995: 92). Strategic

questioning is appreciative because it focuses on the acknowledgment of strengths and resources that may already be available.

Appreciative inquiry, according to Ludema, Cooperrider and Barret (2001: 189) shows a validation for tacit knowledge and local expertise, thereby acknowledging already existing practices. Lincoln and Guba (1985: 197) assert that tacit knowledge is ‘an indispensable part of the research’, and needs to be made explicit. Appreciative inquiry also invites ‘new voices’, ‘expanding circles of dialogue’ and ‘focuses attention towards the most life-giving, life-sustaining aspect of organisational existence’ (Ludema et al. 2001: 191). In this research many participants were already engaging in spiritual care and an appreciative approach to inquiry sets out to honour and bring to the fore these practices, whilst also exploring new opportunities and different aspects.

### 3.3.4 Initial questions in the focus groups and interviews

As is usual in social constructionism, the interviews were planned as discursive interactions and unstructured interviews. However, at the beginning of the first focus group and/or interview I asked some questions to set the scene:

> What comes up for you when I use the word spirituality?
>
> What does spirituality mean for you?

These questions were followed by an exploration of the role of spirituality in the participants’ lives and how their understanding influenced their practices of care-giving. These conversations were often circular, in that spiritual understanding, professional

practice and the insights and impediments to giving spiritual care were intimately linked and therefore the focus would often shift from one to the other in a matter of minutes.

Sometimes, other issues for discussion were offered to provide direction, to develop rapport with the participants and to obtain an understanding of the areas of inquiry. This could easily be seen as me shaping the inquiry in my role as a facilitator, but the following questions and ideas were held lightly and only used as guideline:

- What do you see as major sources of spiritual support for you or your clients?
- In which way are you involved in discussing or otherwise engaged in meeting your clients' spiritual needs?
- If engaging in this work, how well do you feel you are prepared and trained for this?
- How is this part of your work acknowledged and supported?

As is usual in qualitative, subjective research the development of these questions and themes was often guided by the participants' explorations, whilst I occupied the role of facilitator by keeping the conversations on track.

### 3.3.5 Time, recording and member checks

The focus group meetings took approximately two hours and the interviews one hour. The interactions were taped and eventually transcribed verbatim. Research participants

received a copy of the transcripts to invite further comments and feedback to increase consistency and coherence prior to data analysis. How participants were selected is described in the following section.

## 3.4 Participant selection and sources of information

Rapley (2003: 33) stresses that an important factor in scientific research is to clearly denote how participants are selected and 'which voices may be given privilege' or, in contrast, which voices may not be heard. Participation in this research was entirely voluntary and by self-selection.

### 3.4.1 Participation

With the exception of the third sample, the research was conducted in a regional area in NSW. The population is spread out over several small towns and here are a few hospitals and many nursing homes, but no residential hospice in the area. The third sample was conducted on location in Queensland and the reasons for including this sample will be explained later.

As a qualitative Masters thesis the scope of this research is relatively small and involved in total 26 people. Through self-selecting, 20 people chose to attend the three different sets of focus groups (8 people in the first set, 4 in the second set and 8 in the third set). In addition, I conducted elite interviews with another 6 persons. In all cases the participation was entirely voluntary. In the following sections it will be explained how participants became involved in the research.

### 3.4.2 Selection of focus group participants

The first research sample comprised 8 self-selected participants from local nursing homes and aged care services. These participants responded to invitations to participate disseminated by Directors of Nursing, who were informed by the researcher about this project at one of their regional meetings. Prospective volunteers were given an introductory letter (see attachment A, letter to health services providers) and an information sheet (see Attachment B, information sheet). The letter was followed up by a phone call a week later to confirm attendance at the 2 sequential focus groups that I had planned: 2 directors of nursing, 3 nurses, 2 assistant nurses and one social worker offered their participation. All participants who volunteered to participate were female, over 40 years of age and most of them had worked in the aged care industry for more than 5 years.

The research conversations in the first sample revolved around a rather Christian perspective on spirituality. It is often recommended to extend the initial research sample to different settings, to enrich the emerging themes (Appleton & King, 1997; Kitzinger, 1995). Glaser (1992: 102) confirms that often ‘groups are chosen as they are needed rather than before research begins’. In this research, I chose to include other samples to increase the width of perspectives on spirituality and spiritual care beyond the predominantly Western worldview. Bluff (2005: 151) agrees that it is not unusual that the emerging themes dictate further ‘progressive focusing’ and further sampling.

To complement the perspective of the first set of focus groups, a key person in the local aged care industry recommended that I approach a hospice service, which advertised that spiritual care played a central role in their practice. This Buddhist organisation, which is located in an urban centre in Queensland, welcomed involvement in the research and I conducted two focus groups with four self-selected participants; two were social workers, one was an ordained nun and the other a registered nurse. Again all participants were female, over 40 years of age and apart from the nurse, these participants had a long term background in social work.

The third sample, which was included to further enrich the emerging narrative, consisted of a newly formed group, who were setting up a non-denominational, non-religious volunteer 'spiritual care' service in the local area. They had heard about my research and invited me to become involved in their project, whilst at the same time giving me wholehearted permission to use their interactive learning process for my research. This group consisted of 8 members and we also met two times with the aim to clarify the mission statement for their organisation; this also involved exploring the meaning of spirituality and spiritual care. Apart from two males, the other members of this group were also female; age ranged from late 20s to mid 70s. Professional status included two palliative care workers and a counsellor, two old age pensioners and three members who were at the time unemployed.

### 3.4.3 Selection of in-depth interview participants

The three samples also each included two in-depth interviews with participants who were chosen on the recommendation of senior people in their field. The interviewees were, where possible, selected in a responsive fashion; that is to complement or disconfirm already collected data, as is recommended by Morse (1991: 129). As with the focus groups, interviewees received a letter (See Attachment C – Letter to interviewees) and an information sheet about the research (Attachment B), which indicated the expectations and clearly stated the voluntary nature of the involvement in the interviews.

In total, 6 interviews were conducted; 5 interviewees were female and 1 was male; ages ranged from mid 40's to mid 60's. Two of the interviewees were senior nurses, one was a social worker and also included were, following strong recommendations of senior professionals in the industry, a chaplain, an ordained nun and a spiritual care coordinator who were all involved in aged and palliative care ministry. I decided to include these voices, despite my personal interest in non-religious spiritual care, because the religious aspects of spiritual care continued to emerge from the data.

### 3.4.4 Documents

Background information in the form of public documents, such as pamphlets and information brochures that described the aims, objectives and codes of conduct were collected from the three samples that were involved in the study. These sources of data were relevant, because the documents contained contextual information about what Lincoln and Guba (1985: 277) call 'the natural language of that setting'. In the case of

this research project, it showed how these organisations positioned spirituality and spiritual care in their discourse. That information became, where appropriate, part of the conversations or was used to triangulate the data collected from the participants.

### 3.4.5 Research journal

From a postmodern, social constructionist perspective there are no pure data; data are the product of a 'complex, interactive process between already existing knowledge, contextual issues and the participants in these interactions' (Appleton & King, 1997: 14). This perspective locates the researcher squarely *in* the research narrative; the insights of the researcher are recognised as just another voice in the field. In the introduction, I stated my interest in this research and gave a short overview of my spiritual journey and beliefs. Janesick (2003) agrees that, because qualitative research is subjective, it is essential to keep a reflective journal. Reflexivity is, according to Lincoln and Guba (2003: 283) the ability to 'critically reflect on the self as researcher' and I have used my journal to record my personal learning about the research process, as well as my feelings and thoughts about the data collection and developing themes, as is recommended by Janesick (2003). Complementing the data of the focus groups, interviews and document analysis, I have used my diary as the fourth source to be considered whilst writing the thesis.

### 3.4.6 Locating the research participants

The names of the other research participants have been omitted to ensure anonymity. To maintain a sense of consistency and familiarity with the conversations, I have identified direct comments and quotes from the focus groups using the following codes:

F1:1- first sample, first focus group

F1:2- first sample, second focus group

F2:1- second sample, first focus group

F2:2- second sample, second focus group

F3:1- third sample, first focus group

F3:2- third sample, second focus group

The quotes from the interviews follow a similar pattern; IV1 relates to the first interview conducted, IV2 to the second and so on.

From the very beginning this research has also been a uniquely personal journey and I have used the subjective, first person in this thesis, where appropriate, to acknowledge my own inferences. Crotty (2005) points out that the notion of the objective scientist is not supported by social constructionism and would be maintained by using the third person, which contradicts the subjective nature of qualitative studies.

## 3.5 Analysing the data: A grounded theory approach

According to Browne (2004: 629), all data analyses comprise a 'systematic, comparative and analytical process of interpreting research data'; however, how this process is conducted depends on the epistemological assumptions underlying the research. Parsons and Brown (2002) argue that research reliability depends on a clear definition of the

methodology and in the previous sections the epistemological foundations of this research were outlined and described in detail.

According to Bluff (2005), social constructionism is well matched with a grounded theory approach to data analysis. Developed by Glaser and Strauss (1967), grounded theory refers to an emergent process of gathering and analysing data in a constant comparative fashion, which means that theory develops 'through the continuous interplay between analysis and data collection' (Leedy & Ormrod 2005: 160). I read and reread the transcripts of all the focus groups at several stages during the research to immerse myself in the data.

Grounded theory can be 'generated initially from data' or 'elaborated and modified' upon existing data according to Strauss and Corbin (1998: 161). In this research it is clear from the literature review in Chapter 2 shows that this research project builds on a wealth of existing data pertaining to spirituality and spiritual care. Grounded theory, however, is 'creative and dynamic', according to Browne (2005: 627) and '*must* include the perspectives and voices of the people whom we study' (Strauss & Corbin, 1998: 160). In the chapters on the findings I have quoted extensively to make known the perspectives and voices of the research participants; for further clarification and illumination I also have illustrated these narratives with relevant references to the existing literature on spirituality, as is an accepted practice in grounded theory according to Strauss and Corbin (1998).

### 3.5.1 The coding of the data

In analysing the data I have followed Tuetteman's (2003: 12) observation that the essential element of the comparative, grounded approach to data analysis is the 'open coding' of the data. She continues that another aspect of grounded theory can take place at any stage of the research process and involves a constant comparative analysis of the emerging themes (Tuetteman, 2003: 12). The process of analysis is generative, which means that a 'progressive focusing' occurs; this continuous sorting and coding of the data eventually results in the forming of a clear research narrative (Van Maanen, 1997: 79).

### 3.5.2 Keeping track of the process

Browne (2004: 635) states that the first step in coding is to become very familiar with all the research data, including the notes, memos and journal entries to ensure what Strauss and Corbin (1998: 173) call a 'questioning, questioned and provisional' approach to all, including the authors' own voice. According to Miles and Huberman (1994: 72) personal reflections and notes are 'one of the most powerful sense-making tools' as they expose links, insights and 'momentary ideation based on the data'. This analytical process should be performed during data collection, sorting and analysing itself (Strauss 1987: 127). Like any of the other data, memos should be coded, sorted and eventually develop into substantial categories and emerging theories (Bluff 2005). During the entire research I kept a journal, which recorded my thoughts, impressions and discussions with critical friends. Whilst emerging myself in the data I also kept track of my thoughts and discoveries by comments in the margins, scribbling memos or highlighting particularly important connections.

### 3.5.3 Open coding

Strauss and Corbin (1990: 63) have described the procedures of coding and analysing as the ‘process of sticking conceptual labels to distinct phenomena’; a process that, according to these authors, involves ‘ the data being broken down into discrete parts, closely examined and compared for similarities and differences’. Leedy and Ormrod (2005: 141) agree that the aim of coding is to establish ‘commonalities’ across the various data and to arrive at clearly defined categories and sub-categories. I have used highlighters, colour-coded stickers and memos to identify the categories and themes that were emerging from the interviews.

Open coding was applied to all the data; they were sorted in particular concepts or ideas, which were considered, especially in the beginning, provisional, as is recommended by Browne (2004: 635). Strauss and Corbin (1990: 64) remind us that care needs to be taken that the process of open coding needs to be 'systematic, credible, consistent '. For example, in the initial stages of the research, spirituality was often understood in terms of a connection or relationship with God, thus ‘connection with God’ and ‘beliefs’ emerged as provisional, but consistent themes.

### 3.5.4 Axial coding

After the initial sorting and coding of the data in emerging themes and categories, I applied ‘axial coding’, which is described by Strauss and Corbin (1990: 65) as a process of constant comparison, analysis and connection building between the developing categories and themes. Axial coding, according to Leedy and Ormrod (2005: 141) seeks

for links between the contextual issues and categories by ‘moving back and forth’ till the data are ‘refined’. For example, despite the different religious beliefs and non-religious understandings of spirituality, ‘meaning-making’ became a prevalent theme across all categories.

### 3.5.5 Selective coding

The final stage of the analysis consisted of selective coding, which according to Appleton and King (1997: 15) moves beyond description to the ‘essential meaning of the construction’. Leedy and Ormrod (2005: 141) describe this stage of the research as ‘the story unfolding’ and ‘the development of a theory’. This non-linear and iterative process, which is inherent in grounded theory, resulted in a research narrative that embraces an inclusive understanding of spiritual care despite different perspectives and approaches to spirituality. More particularly, in the chapters on the findings I have argued that the unfolding research story finds a synergy between spiritual care as active involvement and at the same time as being quietly present with the other. I was very pleased with these insights, which were only emerging in the later stages of the research as such formed a rewarding outcome.  However, it needs to be remembered that, although Strauss and Corbin (1990: 66) talk about ‘saturation’ of the data, the findings from this research are open-ended, which means that from a social constructionist perspective, these outcomes are inconclusive and open ended.

## 3.6 Rigour and trustworthiness

The ‘complex, interrelated choices made in knowledge gathering and integration’ involve subjective choices which ‘invariably inform the outcomes’ (Kanuka & Anderson, 1999:2). In quantitative research the reliability of the research rests on outcomes, which are valid and true when they can be replicated and generalised. In contrast, Avis (2005) argues that validity and replicability are not relevant criteria in qualitative research, because knowledge is always local and subjective. Furthermore, Schwandt (2003: 306) explains that in social constructionism truth claims are always contextual and fluid.

Therefore, Avis (2005: 13) recommends that the criteria of validity and replicability be replaced with ‘internal consistency and credibility as an authentic description’, in other words for the trustworthiness of the experiences of those participating. Beck (1993) adds that rigour complements trustworthiness, because it denotes the thoroughness used in all aspects of the research process. Rapley (2003: 105) agrees that the quality of research depends on ‘the analytic rigor’ and ‘persuasiveness of argument’, to which (Morse, Barrett, Mayan, Olson & Spiers, 2002: 2) add that ‘without rigor, research is worthless, becomes fiction, and loses its utility’. Morse et al. (2002**:** 4) distinguish between a ‘constructive procedure’ of rigour in data collection and analysis, which needs to be complemented by an ‘evaluative (post hoc) procedure’ to ensure trustworthiness of the final research narrative. The following sections will use this framework to explain firstly issues of rigour, followed by a section on trustworthiness of this research.

### 3.6.1 Constructive procedures: Analytic rigour

According to Beck (1993: 263) rigour refers to the transparency in participant selection, purposive sampling, data collection and data analysis. Because participant selection and sampling have been discussed previously, the following sections will focus more on rigour in data collection and analysis.

#### *3.6.1.i Triangulation*

Many writers have recommended triangulation, which is the use of different methods, such as interviewing, participant-observation and group work, as well as using different sources of information, to increase rigour in qualitative research (Costello 2003; Fine, Weis, Weseen & Wong, 2003; Thurmond 2001). Triangulation has been used extensively in this research in the form of different sources of information, different methods of data collection and different theoretical samples. I used all three methods of triangulation to achieve what Reinharz (1992: 194) describes as 'multi-method is like casting a wide net to learn as much as possible'.

After the first focus group I became aware that the local, self-selected participants in this research came from a perspective on spirituality that was predominantly based in Christianity. Therefore, I chose three different sources of information to avoid bias and prejudice. Similarly, the elite interviews were conducted to provide a different angle from that of the focus group. My research journal and documents supplied by the participants also became important sources of additional information.

However, Thurmond (2001: 257) warns that although ‘triangulation might enhance the completeness and confirmation of data’, these methods do ‘not strengthen a flawed study’. Although agreeing with this statement, I believe that in this research project triangulation was effective because it provided new points of view and a wider perspective by including, but also moving beyond a perspective of spiritual care that is based in an interventionist model of care to a perspective that includes within that model an approach to care as a way of being present.

#### *3.6.1.ii The role of the researcher*

Strauss and Corbin (1998: 63) argue that grounded theory invites the researcher to immerse him or herself in the process of data gathering and meaning-making, rather than being a dispassionate observer. In relation to this, Morse et al. (2002**:** 2) make an obvious but sometimes overlooked point that ‘research is only as good as the investigator’ and they pose that research rigour depends on the openness, reflexivity and creativity of the researcher.

It will be recalled that Wilber (1998:7) postulates that intimate knowledge of the rich and complex world of spirituality is required in order to engage in research in this field. This, of course, does include both theoretical knowledge and practical, lived experience of spirituality. Being in that position, my intimate knowledge implies passion, which according to Braud and Anderson (2001: 21) could produce preparedness and ‘theoretical sensitivity’, but could equally imply an attachment to a certain way of thinking and researching, or what Rapley (2003: 72) calls a ‘standpoint’.

Therefore, I took care not to impose my ‘standpoint’ or to come from an ‘expert stance’ when facilitating the groups or conducting the interviews. I agree with Regher (2000: 200) that such ‘bias, research interest and propaganda’ decreases research reliability. Another way of avoiding bias is to acknowledge researcher interests by making intimate knowledge an explicit part of the research so that the reader is well informed (Janesick 2003). Thus the standpoint, when declared, becomes a valuable contribution of ‘the values, preconceptions, preferences and frailties’ of the researcher in constant interchange with new information and data (Rapley, 2003: 104).

In this regard, my research journey certainly took some unexpected twists and turns; for example, my initial interest in non-denominational spirituality was initially quite compromised by some of the participants’ religious, predominantly Christian perspectives on spiritual care. Similarly, at times I needed to bracket off my familiarity with a language of non-religious spirituality, when participants were struggling to find words for experiences that were outside their normal vocabulary. When this language eventually emerged in later samples, I also needed to question my own assumptions about the nature of spiritual care as new perspectives were offered.

#### *3.6. 1.iii Reflexivity*

Reflexivity plays an important analytic role in grounded theory according to Lincoln and Guba (2003: 283). Yeomans (1995 in Vidovich, 2003: 77) succinctly describes reflexivity as a dialogue between 'researcher, -process and - product'. Avis (2005: 8) points out that ‘reflexivity can increase research relevance and fidelity to subject matter’ in qualitative

research. Reflexivity therefore implies sensitivity and responsiveness towards the participants as the main players in this process, as has been shown in my ability to bracket off my own perspectives on spirituality. However reflexivity in this research also applied to the way participants explored their expanding understanding of spirituality and spiritual care, especially when engaged in the dialogical conversations in the focus groups.

Van Maanen (1997:17) qualifies rigour as 'being courageous in reflective awareness', which he describes as constructing 'a full interpretive description whilst being aware of complexity'. It certainly took some courage for me to reflect on my own preferences as I wrongly judged the initial explorations of spirituality in the focus groups as predictable and conventional. In the data analysis I also had to admit that careful analysis of the data showed many more synergies between religious and non-religious perspectives on spirituality than I had initially anticipated. These complementary approaches eventually merged into a research narrative that featured a much wider and more inclusive understanding of spiritual care.

### 3.6.2 Evaluative procedures: credibility and trustworthiness

Trustworthiness relates to the credibility of the research and is, as Morse et al. (2002: 4) point out, largely a post hoc, evaluative procedure. However, it can also be argued that maintaining trustworthiness is relevant at all stages of the research as will be shown in the following sections.

#### *3.6.2.i Goodness*

One way of achieving what Chiovitti and Piran (2003: 430) call the 'goodness of the research' involves letting 'participants guide the inquiry process'. For example, in this research the initial focus on religion and a belief in God was not anticipated, but participants brought these issues to the fore, time and again. Chiovitti and Piran (2003: 430) add that it is also important to use 'the participant's actual words' in the final document. Apart from member checks, where the participants read the transcript and were invited to make further comments, the goodness of the research was also enhanced by extensive quoting from the original sources. Although both strategies have been applied in this research, it needs to be acknowledged that such procedures or checks do not necessarily increase the reliability of the research but could instead provide post-hoc justification for the findings (Morse et al. 2002: 6).

#### *3.6.2.ii A dynamic relationship*

However, a lack of external validity does not mean that qualitative research cannot be reliable or be capable of verification, which is according to Morse et al. (2002: 9) the process of 'checking, confirming, making sure and being certain'. For example, Morse et al. (2002: 10) propose that it is necessary to ensure 'a dynamic relationship between sampling, data collection and analysis, thinking theoretically and theory development'. In this research this is evidenced by the inherent congruence and coherence between the theoretical framework of social constructionism, the inclusion of different samples, the grounded theory approach to the data and finally the emerging research narrative of an inclusive understanding of spiritual care.

### *3.6.3.iii Theoretical sensitivity*

Therefore, another important evaluative feature in grounded theory is what Glaser (1978) calls ‘theoretical sensitivity’. As discussed before, my own theoretical perspectives and epistemological assumptions, as well as those of the research participants were gently questioned and revised by private and public reflection on the research process, the interpretation of the findings and the relevance of these outcomes to community practices. Private reflexivity conducted through my use of a journal and extensive memos, which shed light on my intra-personal dialogue, thus became a part of the analytical process and this too adds to the trustworthiness of the research, according to Chiovitti and Piran (2002: 430).

### *3.6.4.iv Faithfulness*

The above sections described the trustworthiness and rigour applied to this research. Another term for these criteria that is used in the literature is credibility or faithfulness; Beck (1993: 264) states that credibility is achieved if the description of the phenomenon is ‘vivid and faithful’ and adds that the participants in the research, practitioners in the field, but also the reader need to be able to recognise ‘the described experiences’ in the research narrative ‘as their own’. I will need to leave the reader to judge the trustworthiness of this last requirement.

## 3.7 Organisation and representation of the research findings

In this research a wide net was cast to capture some of the diversity and the richness of such a complex issue as spirituality in relation to care-giving. Each of the three different samples involved in this research was quite distinctively different. Therefore, initially, it seemed logical to write up the research as three mini-case studies; each in a separate chapter. However, in the process of axial and selective coding, it became obvious that despite the differences, there were many synergies and commonalities.

Therefore, after a few failed attempts to represent each case separately, it became obvious that the research narrative would be much clearer when the distinctive themes were organised in different chapters. This decision did not eliminate the differences from case to case or, equally valid, they did not extinguish the differences from person to person. In fact, as the analysis progressed it emerged that the divergent views were often more clearly located between persons, rather than between the different samples. I will expand on these and other matters in the chapters which discuss the findings.

## 3.8 Ethical issues

The research was approved by the Southern Cross University Ethics Committee (See attachment E). All participants were provided with a letter of invitation, an information sheet and an informed consent form (See attachment A, B,C and D). The introductory

letter and information sheet outline the involvement and clearly state the voluntary nature of the participation in the focus groups and interviews. The participants were asked to sign a consent form at the beginning of the focus group session and interviews and, as is recommended by Christians (2003), again were informed of their right to withdraw at any time (see attachment D, consent form).

### 3.8.1 Confidentiality and anonymity

However, Christians (2003:217) also warns that it is not always possible to guarantee anonymity as 'pseudonyms and disguised locations are often recognised by insiders'. Confidentiality and anonymity of all participants was at all times considered to the best of my ability by omitting any information which identifies the participants in the focus groups and the elite interviewees or their organisations. For that reason the data from the tapes and transcripts have been analysed in relation to themes and perceptions and at that stage all names were omitted. The tapes and transcripts are stored under lock and key for five years and thereafter will be destroyed. Subsequent to the research, there will be no further access to the data at any time.

## 3.9 Limits and boundaries of the research

### 3.9.1 Focus on the elderly and dying

I have chosen to focus on spiritual care for the elderly and dying, because I believe that the quality of care-giving in this stage of life is often infused with great spiritual significance. Nursing homes and palliative care services often mention spirituality in their codes of

conduct and information brochures, making it therefore a salient part of the care giver's work environment. The lack of attention to other age groups does not mean that spirituality has no place in care-giving to young people or middle aged clients. However, some of the findings in this thesis may not so relevant for other populations or other care situations.

### 3.9.2 Religion

Participation in the research was entirely voluntary and the self-selection process limited, up to a degree, the variety and diversity of voices. For example, all participants said that they were interested in the concept of spirituality and spiritual care-giving, which made it difficult to find divergent or opposing views. However, in the first set of focus groups some participants professed to have a fairly strong Christian orientation, even if they did not attend church regularly. The second set comprised health care providers in a Tibetan Buddhist palliative care service and it came as no surprise that their lineage or worldview was strongly influenced by Buddhism. The third theoretical sample involved volunteers, who were less outspoken about their religious affiliation but in general embraced the 'love thy neighbour' message of both Christianity and Buddhism. Therefore, I acknowledge the absence of the voices of outspoken atheists or members of other religions or spiritual worldview in the research.

### 3.9.3 Direction of the research

As is usual in a grounded theory approach to data analysis, themes emerged and were expanded and built upon during the process of data collection. Although I had not planned to explore the religious expressions of spiritual care, this became a fairly

dominant theme from the very start of the first focus group. This factor determined to a degree the direction of the research and influenced the process of participant selection, both in terms of self-selection and in recommendations for key interviews, for example despite my initial focus on non-religious spiritual care a chaplain and a two ordained nuns were involved in the research.

### 3.9.4 Representation of the data

Apart from member checks and the inclusion of extensive quotes, the analysis and final research narrative is by necessity my work and I could therefore not avoid what according to Lincoln and Guba (2003: 284) is ‘the crisis of authority’ or ‘the crisis of representations’. My involvement in selecting and placing those voices in the text reveal what Regehr (2000: 197) calls the problematic nature of 'speaking for others' and representation when writing a research narrative. I have, however, tried to the best of my ability to tell some of what these authors call ‘the storied variations’ about spirituality in relation to aged and palliative care-giving.

### 3.9.5 Generalising the findings

This research is limited in scope and is not meant to present a general overview of the subject matter. The research involved 26 participants and was conducted in a relatively small regional area in the North of NSW, with one sample which was located in a metropolitan area in the Southern part of Queensland. The findings of this research cannot be generalised, but as in all qualitative research, my aim nevertheless was concerned with, what Lincoln and Guba, (2003: 284) call ‘expanding the range of understanding’.

Therefore I hope that the research narrative engages readers to explore their own position in relation to spiritual care-giving.

## 3.10 Conclusion

The first part of this chapter explained that social constructionism offers a compatible theoretical framework for exploring spirituality and spiritual care, because it does justice to the multi-faceted, complex and personal nature of such an inquiry. Social constructionism proposes that our knowledge about the world is created through dialogue and interpretation; it therefore rejects notions of objective truth claims. This is important because how spirituality is understood depends on personal beliefs and contextual issues, including those of the researcher. The second part of this chapter concerns the methodology; this included the application of a multi-method approach using focus groups, elite interviews, documents and the research data. Participation, it was shown, was self-selected and entirely voluntary; as a result it was difficult to find divergent voices that negated the dominant narratives of spiritual care-giving. A grounded theory approach to data analysis, it was argued, was deemed compatible with the chosen theoretical framework of social constructionism. Having given an overview of the current literature on spirituality in the previous chapter and explained the main research methodology and argued my reasons for it in this chapter, the following chapters are concerned with the findings of this research.

# Chapter 4: Conceptualising spirituality

## 4.1 Introduction

This chapter outlines the research participants' understanding of spirituality in three overarching themes that emerged in most conversations. The first theme involved spirituality as a search for meaning and purpose; the second theme showed how spirituality was expressed as the yearning for connection with others; the third theme concerned spirituality as the innermost, underlying essence of being human. In many of the conversations spirituality was closely linked with beliefs and religious perspectives; it often involved seeing spirituality as the relationship with God or a Higher Being. For others spirituality was the guiding principle that determined their values and ethics. It will be shown, however, that despite the different understandings, beliefs and practices, common themes ran through many of the conversations about spirituality.

## 4.2 What is spirituality?

As mentioned in chapter 1, the aim of this research project was to investigate how spirituality informs care-giving in aged and palliative care. I decided that is was very important to start any discussion about spirituality by exploring what it meant for the participants involved in this research.

### 4.2.1 Setting the scene

Most participants in this research had, as became obvious from comments that were made in the various sessions, a keen interest in exploring these issues. Some would express this as: 'being spiritually oriented, I feel it's a great opportunity to learn more about myself' (F3:1); others would say that 'it is good to talk about this in a group (F1:2)' or 'I came along because I am interested in this [spiritual care-giving]' (F1:1).

As a starting point, participants were asked about their personal experiences and beliefs about spirituality. Therefore, all the interviews and focus groups invariably started off with questions such as: 'How do you understand spirituality?' and 'what does spirituality mean for you personally?' or 'what are your experiences of spirituality?' These questions were always met with a great deal of reflection, discussion and exploration with the other members in the focus groups. Similarly, interviewees paused before they answered and often needed considerable time to ponder these questions.

Three major themes arose from most of these conversations: firstly, spirituality was repeatedly equated with the human need to feel connected; secondly, spirituality involved the search for meaning and purpose; finally, spirituality was experienced as lying at the core of being human. It will be recalled that these themes were also identified in the academic literature, because of their ability to transcend the different definitions, spiritual orientations and religious perspectives.

## 4.3 Connection

For all participants, spirituality foremost involved being connected with others. ‘Being connected’ had two distinct components: the first encompassed an active reaching out to connect, or at least the ability to respond to other persons reaching out to you; the second component involved being present to that connection, the ability to have the experience of that connection.

### 4.3.1 Reaching out

For most participants spirituality as ‘a genuine dialogue and meeting’ involved that which ‘reaches out to connect’ (F1:1) or meant ‘having a connection with self and others’ (F1:2). Connecting meant ‘that you are accepting of everybody and every living creature’ (F2:1). It was described by one participant as an ‘interconnectedness with others’ (F3:1), which for yet another participant involved ‘moving beyond self-interest’ (F3:2). This understanding of spirituality was mentioned across all three samples, regardless of what religious or spiritual beliefs were adhered to. As one participant explained:

> Whether it is a religious tradition or a spiritual tradition that’s recognised or if it’s something that’s deeper within; it’s really being connected with and that can be through nature or through music or through philosophy as well as through recognised religions. It’s certainly different than just formal religion (F2:1).

Faver (2004: 241) uses the term ‘relational spirituality’ and explains that this perspective rests on the ability ‘to *recognise* [my italics] the interconnectedness with the other,

whether this is God, self, nature or fellow human beings’. This is quite poignantly expressed in the following quote:

> The preliminary, yet essential step in establishing the possibility of a genuine, dialogical connectedness is a 'turning' of my whole person to the other, in order to better engage this person. This 'turning toward the other' is inevitably a momentary turning away from being preoccupied with my self. This 'turning toward' is far more encompassing than what is ordinarily meant by 'attending'. It is viewing the other in his/her unique 'otherness' - which is different from me and any of my needs (Hycner & Jacobs, 1995: 15-6).

When asked, however, to describe the nature of relational spirituality, it was difficult for some of the participants to find the words to distinguish a spiritual way of connecting from more mundane meetings, because ‘it is something that you don’t talk about so much; it is something that you feel’ (F3:1).

### 4.3.2 Being present

In the later focus groups, participants seemed to be more at ease describing these feelings or with exploring the nature of these connections. They often used a vocabulary of spirituality that focused on ‘being present to what is’ (F3:2), because ‘when I am really attending to what is present, then there is a sense of spirituality’ (F2:2). Another participant obviously felt very strongly about this by saying that:

> Being present is my religion, to be more clear in the moment. And that gives you an incredible flexibility, because with that presence and compassion, it becomes a natural thing [spirituality]; you don't force that (IV2).

Thus, spirituality 'means to have awareness and presence in what I am doing' (F2:1). This language of spirituality as 'being present to each moment', echoes some of the Buddhist practices of mindfulness, where attention is focused on what is present 'here and now' (Levine 1997: 34). Some of the participants qualified being present with having 'very deep connections' (F2:2) and suggested that it was not about what or who we are connecting to, but about how the feeling of being in deep connection was experienced as illustrated in the following quote:

> Everyone has a different description of what we are connecting to, and words are often failing; I find it indescribable, but when I am connected I am grounded, I am available to my own energy, I am inexhaustible; such a feeling of joy and peace and yet I am connected with everything… it is really big for me, I had a few strong experiences in my life and they let me see the possibility, the potential that we have to be connected continuously in our life (IV2).

This participant continued to say that this feeling occurred when you were 'physically, mentally, emotionally and spiritually present (IV2)'. Other participants described it as 'really more being than doing' (F3:1) and 'the ability to be with whatever is' (F2:2). Thus, spirituality involves the process of being present without entertaining preconceived ideas. It also involved having no expectations about the nature of this

meeting. Tacey (2003: 41) argues that these intimate connections are spiritually nourishing and an antidote to ‘existential isolation and loneliness’. This has important implications for spiritual care and will be examined more closely in chapter 6, because many participants spoke about ‘being present’ as the underlying nature and quality of any practice of spiritual care.

## 4.4 Meaning-making

Meaning-making was mentioned often and persistently and often involved conversations about religion and beliefs. For most participants their spiritual beliefs gave meaning and direction to their lives.

### 4.4.1 An existential search

Spirituality as a way of connecting was for most participants intertwined with what was meaningful or important in their lives. McGrath (2004: 5) talks about the importance of ‘maintaining an intimate connection with life and making sense of it’ and King (2004: 135) agrees that these real connections with significant others help clients ‘to create deeper meaning’. Participants, no matter what their religious background or beliefs were, often commented upon the importance of meaning-making as a spiritual search:

> I see spirituality as a search people have for making meaning in life (F1:1).

> [Spirituality] involves helping to find out who I am… a journey of discovery (F3:2).

Taylor (2002: 11) affirms that spirituality is concerned with 'issues in life in terms of ultimate meanings and values' and that was echoed by a participant, who felt that, for her, meaning-making involved something 'deeper':

> I think living in a meaningful way, living in accordance with something that is deeper than our normal day-to-day actions and activities, working from a base that's deeper than our usual business (F2:2).

Thus, meaning-making involves making sense out of one's experiences and finding out what is valued most in one's personal life. Spirituality was expressed as:

> … The person's deep-rooted meaning of life; the values which stem from their heritage, environment, family and beliefs. It is what gives them their directions in life and is probably… becoming the seed for their own aspirations and purpose in life (IV4).

It was interesting to note that sometimes, when speaking about what spirituality meant, participants would use the third person; 'what gives *them* [my italics] directions' and at times there was little distinction between the understanding, the needs and the practice of spirituality, because it all involved 'living a meaningful life' (F2:1).

For some of the participants the search for meaning also involved the more esoteric questions about the meaning of life or what the theologian Tillich (1967) calls the the most important or ultimate concern. One participant described this as being 'about meaning-making and exploring what is unspoken and untouched (F3:1). That which is

‘unspoken and untouched’ involved the very prominent sub-theme of meaning-making within the context of religion and beliefs. Predominantly present in the first set of focus groups and in some of the elite interviews, meaning-making was for these participants intrinsically connected to a belief in God or a Higher Being.

### 4.4.2 A belief in God

In the first focus groups and interviews when asked what spirituality meant, some participants were quick to answer that ‘spirituality means to me to believe in God’ (F1:1) or ‘involves a relationship with God’ (F1:1). For others it meant that ‘basically I’m a Christian’ (F1:1) and one participant commented that:

> I think your religious beliefs are just part of your spirituality, there are a lot of people… every one has a spirituality, whether they realise that or not, it is just the case of helping people to see that… and a lot of people express their spirituality in a religious way (IV4).

Others shared that spirituality was ‘a search people have for a meaning in life and for me that involves a relationship with a Higher Being, with God’ (IV3) or meaning-making involves ‘a strong religious belief’ (F1:2). For some of these participants, this perspective on spirituality held important images about how relationships with others were structured and how it influenced their life:

> A Christian should be a practising person each day: they should be practising what they believe (F1:1).

Carroll (2001: 6-7) defines ‘spirituality as connection with a higher reality, the without’ and this relationship with a Godhead is ‘a gift to a receptive person by the Holy Spirit’. It was interesting to note that many participants agreed with spirituality being defined as:

> Something that is bigger than you… a Higher Being or God… which was more important than the business of every day living (F1:1).

This ‘something bigger’, however, can take many forms as is clear from the proliferation of religions and beliefs in the world, which one participant described as:

> There are many pathways to God that is how I see spirituality (F1:2).

A participant, who visits local nursing homes to perform religious services, explained in the following excerpt from an interview a similar understanding of spirituality:

> Participant: I see spirituality as a search people have for a meaning in life and for me that involves a relationship with a Higher Being, with God. I am the chaplain here in the [name withheld] and I am also an ordained Anglican Priest, and I also work part time in the parish, doing normal parish stuff in an Anglican context.
>
> Question: You talked before about your spirituality being grounded in your belief in a Higher Being and how that supports your meaning-making. Can you separate your belief in God from meaning-making and spirituality?

> Participant: I would find it hard, because for me meaning is through a relationship with God and most people who profess to have no faith or no religion still would believe in a Supreme Being. There are very few people who don't believe in a Supreme Being; even if they don't call it God or whatever, whether they see that Supreme Being as in nature or in creation, most people at least acknowledge a Higher Being (IV3).

Described by Dokecki et al. (2001: 504) as 'theistic spirituality', the relationship with God or a belief in a Higher Being played a major role in this research. This came as a surprise, because my initial research interest was in non-religious spiritual care. However, as is usual in exploratory research, developing themes determine to a degree the focus of the research and therefore this theme was explored further.

### 4.4.3 Spirituality and religion

As discussed above, in the first set of focus groups the theme of meaning-making in relation with God was quite strong. Therefore I asked participants to explore the differences between God, religion and spirituality. Some participants shared that:

> I do not like the word 'religion'… it conjures up… back in the olden days when people used to go to church and the minute they stepped out of church they were no longer a Christian. I prefer to say I am a 'Christian' [instead of religion] (F1:1).

> I don't go to church now, but I still do believe that there is a God or something there that looks over us (F1:1).

Thus, for many of the participants who believed in God, the search for meaning was located in their relationship with a Higher Being and was not necessarily found in organised religions or 'the church'. This was clearly stated in the following:

> You don't have to come from a religious faith; it is about people finding what is meaningful for them (IV1).

> Religions are these kinds of structures whereas spirituality is more personal (F2:1).

> God is not the problem but the formal religion in their life hasn't answered their questions, or they did not know enough about it, and so the only time that they dip their toe in the water is at birth, marriage and death (IV4).

Nevertheless, in the focus groups where theistic spirituality played an important role it was sometimes difficult to hear a dissenting opinion or differing voices. Henery (2003: 554) confirms that theistic spirituality is often located in the 'Judeo-Christian dominant world-view' and would 'leave little room for others'. This was evident in one focus group where different views were expressed quite strongly:

> Person 1: That's what we are looking for in our spiritual lives, we are looking to be uplifted, to be inspired, to have some sense that whatever word we want to use – God is looking after us, God is there for us, Goddess or cosmic energy or whatever word we want to use; that we are connected with that Being and that Being cares about us. I guess, I don't have a view that God is male… I need to express more collectively that

> God is female, so that's important to me. I don't think that a male God – the one that I was brought up to believe in or to worship, had a lot to say to me as an adult…
>
> Person 2: Other than this feminist thing I can relate to what you are saying…
>
> Person 3: [Spirituality is] something that you can have regardless of which religion… It is something that underlies everything, it is your very nature and I believe that you can be spiritual without belonging to any group or denomination…
>
> Person 4: (quite forceful) I've got very simple beliefs and spirituality means to me to believe in God (F1:1).

As I discussed in the literature, it is difficult to define spirituality, because it is such an intensely personal and subjective concept. I also revealed that two different lines of thinking about spirituality involved the within and the without. Fox (1983: 89) argues that 'the idea that God [however understood] is out there is probably the ultimate dualism' and calls this a 'subject-object relationship to God', which externalises spirituality as a search for meaning and connection in the 'without' or with the 'ultimate Other'. These different perspectives have important ramifications for how spiritual needs are perceived and how spiritual care is delivered to clients, as I will show in chapter 5 and 6.

## 4.5 The essence of being human

Spirituality, as discussed above, was seen, firstly as a connection or relationship with others and, secondly as involving the search for ultimate meaning. A third theme emerged from many conversations and concerned spirituality as the essence of being human. Pope John Paul expresses this in the following quote:

> A human being is a single being: Unique and unrepeatable (Pope John Paul II in Hayward, 1984).

Thus, spirituality is the vital principle, the essence of each living being and yet is different and unique in every single person.

### 4.5.1 Vital principle

Spirituality as the essence of being human was seen by one participant as ‘a vital principle of every living creature’ (F1:1), which according to another participant involved everything she did:

> I feel very strongly that spirituality is a way of life, our every day existence... (F3:1).

This theme again ran through all the conversations, no matter what background or religious orientation participants subscribed to. It was explained by one participant as the very nature of things:

> I think what we're surrounded by is spiritual in nature and the nature of nature and the nature of humans and our interactions and connections; and if we look at it long enough, close enough, meditate on it; that is spiritual (IV5).

For another participant it meant that there was no real separation between self and what she called 'the spiritual life', as she said that 'it is the essence of who I am' (F1:1). According to Carroll (2001: 7), this perspective on spirituality can be described as the 'within', because it 'pervades and unifies body, mind and emotions' and is therefore experienced as 'the fundamental nature and soul of existence, which is seen in everything that exists'. This was described by participants thus:

> I feel that it [spirituality] is always below the surface (F3:2).
>
> [Spirituality is] Life's work (F3:1).
>
> Spirituality *is* you; it is your essence, your being' (F1:1).

These views affirmed a perspective on spirituality as an intrinsic part of being human. Therefore you did not 'have to be involved in any religion' (IV1) to experience a sense of spirituality or as one participant explained:

> Everyone can practice spirituality – you don't really have to be involved with a religion – be it Christian or Buddhist or whatever it is. That's my feeling – I think it's something, as you say, that comes from within and people can work upon it and I think it is a way of expressing your feelings for others, for life and for God with anything you do. That's what it means to me (IV1).

Rumbold (2002: 16) confirms that there is currently a shift away from the traditional role of the external authority in Western religious and spiritual observance to a more 'self-reliant spirituality'; in other words, a shift to a spirituality that is within. This changed perspective was also noticeable in most of the focus groups and interviews. In the next section I will show that participants agreed that a more self-reliant spirituality is also concerned with bringing into practice what is being preached.

### 4.5.2 A way of living

The shift to spirituality as within, however, is not a new concept for those research participants with a background in Buddhism, because:

> [There is] a lot of emphasis on taking responsibility for all of your own actions in Buddhism and the whole philosophy of Karma, cause and effect, means that you have to take responsibility; and although other religions also focus on qualities… that are within, there's not the same responsibility that's given to you for all of your actions and thoughts (F2:1).

Some of the participants in this research agreed that they were working in aged and palliative care because it gave them, amongst other things, the opportunity to practice kindness and compassion. One participant, in particular, saw her work as a way of practicing her spirituality:

> It informs your actions through kindness and compassion and that's what it has become for me- it places my compassion in a context and gives me a way to develop my compassion… it gives me a way to develop insight in my loving and kindness, my empathy, it's not about me, which is really nice and it has given me so much scope to developing as a social worker, hugely. It's no longer about me; it's so nice (IV1).

The comment that 'it is not longer about me' refers to a move away from a level of individualism, which is central to Western thought. In contrast, many Eastern philosophies are concerned with overcoming personal desires and egocentrism (King, 1998: 7).

### 4.5.3 Developing spiritual maturity

In Buddhism, spiritual qualities need to be developed through right action and right thought. Spiritual development, some participants agreed, 'is a journey of discovery' (F3:1) which comes more to the fore when growing older. One participant equated ageing with becoming 'wiser'; it was seen as an opportunity to become more aware of the self as a spiritual being:

> What gives me the greatest joy is to touch that vital principle [spirituality] because I am old and wise now and I think I'm a bit more in touch with my spiritual inspiration (F1:1).

The journey of coming in touch meant for one participant that you had to 'find' your spirituality as it wasn't something that was automatically there:

> You know you were talking about having to find your own spirituality; how I feel about that is that I have to constantly remember my divine essence and that is by developing the high aspects of myself. I think as soon as we acknowledge that we have a dark essence within I feel that we have more understanding of human nature, so now in my 50s I acknowledged that I can be bad tempered, I can be a bitch, I can be jealous and possessive and all those things; and as soon as I acknowledged it though, I feel as if I have more to give and more compassion (F1:1).

A developmental view of spirituality denotes a model of self which is 'unfolding in a predetermined sequence, the speed of which is influenced by contextual issues' (Reed, 1992: 350). A participant commented upon this as follows:

> I think spirituality kind of leads you, if you become interested in spirituality and if you are getting older or dying that is one of the times when people do get very interested in spiritual issues. I think that leads you to thinking about spirituality, it leads people to seeking a spiritual path (F1:1).

Bickerstaff et al. (2003: 159) mention that in developmental theory older people are invited 'to expand boundaries of time and self-interest into a maturity'; this means that there is an opportunity to transcend the inevitable issues one has to face. The discussion in Chapter 2 also revealed that there is a lively discourse about spirituality in the palliative care and nursing literature. Reed (1992: 351), for example, argues that spiritual development is not necessarily a 'mechanistic model' that is linear and predictable, but a 'dialectic process', which is accelerated when facing death. It was therefore not

surprising that right from the start of this research, in the very first focus group, in-depth conversations evolved about the significance of spirituality in the face of death and dying.

### 4.5.5 Transcending loss

Spirituality is important in old age because it can support people in finding peace amidst the inevitable process of loss of abilities and diminishing life force. Research by Bickerstaff et al. (2003) found that spiritual maturity supports the process of coping with loss and grief. Similarly, one participant agreed that for her it concerned 'finding the strength to face life's problems: Not giving up' (F3:1).

For many of the participants spirituality was vitally important and intrinsically connected to the last stages of life; in fact, it was seen by some as a practice for when the time of dying would come. This practice would make it possible 'to die with a virtuous mind' which is 'absolutely beneficial' (F2:1). Therefore spirituality became more significant in old age and dying, because it helped to transcend loss:

> Death and dying are almost seen as an opportunity and it is something that we're working towards and that it's just very much a part of life. And so all the things we are doing in this life are all about preparing for that (F2:2).

Longaker (1997: 24) in *Facing Death and Finding Hope* describes death as 'an opportunity', which has 'a rich potential for our own growth and change'. This is consistent with the findings of this research, for example:

> Looking at unfinished business, and issues of forgiveness and regret, maybe guilt and how you can resolve all of that so that you can die in peace (F3:2).

> [Spirituality is] a way of experiencing, understanding and coping with being alive and coping with the certainty of facing an inevitable death (IV5).

Zohar and Marshall (2000: 14) agree and conclude that 'spiritual intelligence' is the 'wisdom to be able to live with the uncertainty of living' and one could add of dying; spiritual beliefs and practices can contribute to coming to terms with the reality of a finite existence in an uncertain world.

## 4.6 The common ground

Despite the different orientations and perspectives on spirituality, there seemed to be a common theme running through all these insights. This common theme is exemplified in the following quote by H.H. the Dalai Lama:

> Whether one believes in religion or not, we are all seeking something better in life. So, I think the very motion of our life is towards happiness (H.H. Dalai Lama, 1998: 13).

Participants in this research agreed that the purpose of spirituality, whether it was expressed as connection or as meaning-making, was ultimately concerned with 'finding peace'. One of the participants, a social worker, expressed that very definitely:

> Well I think for me personally apart from my commitment to Buddhism, spirituality is sort of a deep sense of contentment and peace within. It's got nothing to do with anything else (F2:2).

Other comments similarly included references to spirituality as bringing a sense of accomplishment, acceptance and joy:

> Now I am older I find more comfort and peace in my spiritual life… it is a sense of joy… no matter what I am doing (IV1).

> When I am connected I am grounded, I am available to my own energy, I am inexhaustible, such a feeling of joy and peace and yet I am connected with everything (IV2).

Similarly, whether participants saw their spirituality as intrinsically religious or as a non-denominational path, the common ground seemed to be that their sense of spirituality was intimately connected to a way of being in the world that promoted being more present, more accepting and more connected. In conclusion, for all participants spirituality increased their sense of well-being or contributed to what King (2004: 133) calls 'human flourishing'.

## 4.7 Conclusion

This chapter explored how spirituality was understood by professionals and volunteers in aged and palliative care. Three distinctively different themes emerged and the first one was described as relational spirituality and involved a connection with the other, which could be God, other human beings or nature. The second theme involved making meaning out of one's life, which for some was connected to their religious beliefs. Despite the different beliefs and experiences, most participants agreed that spirituality also involved a certain approach, a certain attitude to being in the world. This formed the third theme, which discussed spirituality as the essence of being human; it was expressed as a way of being or, more specifically, a way of being present. Common ground was found in the fact that for all participants, spirituality was a way of life that, especially when growing older, offered the possibilities of peace and joy. In the following two chapters it will be shown that the way that spirituality was experienced personally had important implications for how the client's spiritual needs were perceived and how spiritual care was practiced.

# Chapter 5 Spiritual needs: perceptions and beliefs

> *There is a vague restlessness of the soul yearning for a genuine meeting with others* [author's italics]… It is as if the capacity for genuine dialogue and meeting has been lying dormant, in wait, for someone to seek out the real self.
>
> Hycner (1991: 65)

## 5.1 Introduction

In the previous chapter I described how the research participants explored their perceptions of spirituality and the central themes that emerged were about spirituality as connection and meaning-making. These themes are expanded upon in this chapter, because how spirituality was understood by the research participants influenced to a great degree their perceptions of the spiritual needs of their clients. Participants discussed the importance for clients to maintain and practice the different religious beliefs and faith orientations, which, they agreed involved close collaboration with the clergy. Non-religious needs focused on making sense out of the life lived and staying in a network of meaningful connections. Finally, some concerns are raised regarding the perceptions that all clients would have spiritual needs.

## 5.2 Significance of spirituality to care

It is well established in the literature that there is a positive correlation between personal wellbeing and spirituality or religion (Coleman 2004; Loewenthal, 1995; Griffith & Griggs 2001). The renewed interest in providing care that includes spirituality is not always clearly distinguished from religious care, which was also evident in this research. Although I was interested in discussing non-religious spiritual care, many of the research participants repeatedly returned to their particular belief or faith to describe what they considered a significant spiritual need. As a result, a religious discourse at times dominates the development of the themes and narratives in this research regarding the spiritual needs of clients in aged and palliative care.

## 5.3 The need for connection

Many participants said that a significant function of spiritual care would involve ‘providing intimate connections with a client’ (F1:2) and therefore, spiritual care-giving would predominantly be concerned with building meaningful relationships and maintaining connections. One participant expressed this as follows:

> It is just like reaching out and thinking of others; if you think the basis of what makes people happy is feeling that somebody loves you and cares about you, then it becomes important to figure out how you can put that in practice with everyone (F1:1).

The need for love, according to H.H. the Dalai Lama (2002), is the most important need for every human being. For the participants in this research this love was expressed as being in touch with another human being:

> Yes, building those bridges is the most important thing, if you can build a bridge so we can see at least that it is common to all people (F2:2).

The human aspect of care, the building of bridges, can easily be overlooked in the current social climate, according to McSherry (2000: 6,) who draws attention to the danger of 'dehumanising and impersonal care in our modern society'. Participants agreed with the statement that a 'spiritual focus would make all the difference' (IV4). Another participant supported this view:

> That's right, we're not going in to just do the showers and do all the physical stuff, and we're not going in to help people be Buddhists, but we're going in to kind of support and connect and to build relationships with people (F2:1).

This connection, most participants agreed, really 'helped to be in a good way with clients' (F1:1), because 'they still know that you are with them, even if they don't react or cannot talk anymore' (IV4).

> 'I see it in myself. Its everywhere I go. Each one of us. Looking for connection' (Miten, 2005).

Miten (2005) calls his song, from which the line above was taken, ‘Looking for connection’ and this is for me a powerful reminder of the need for connection. A content analysis of popular songs would provide a plethora of themes related to the need for a meaningful relationship. Yet, for older people in our society the ability to be in connection is often severely hampered, because of illness, isolation and contextual issues; therefore the relationships with care-givers are often very important (King, 2004; MacKinlay, 2004). This is very powerfully expressed in the following story:

> I remember a couple of months ago one of the gentlemen, one of our residents, was in the hospital in the psychiatric ward and I went to see him and… he held out his hand… and I held out my hand, and he just gripped it and we sat there for a quarter of an hour without saying a word… and then I said: ‘It is probably time for me to leave now… you are getting tired’ and he said: ‘thanks for your coming, it was inspirational’ and I thought…. I did not say a word… but I know what you mean (IV4).

This excerpt from an interview describes how you can connect even when there are no more words and when there is no trace of trying to do something special or spiritual other than just being present in a significant connection.

### 5.3.1 The need for companionship

Connection involves companionship and for one participant this meant that ‘spiritual care is about being a companion’ (F3:1). Thus, an important spiritual care function is, what McGrath (2002: 55) describes so clearly, the importance of optimising ‘the individual’s

capacity to stay with the meaningful network of intimate connections'. A participant of a focus group pointed to the 'intimate' quality of such a connection:

> It is an intimate situation and caring is like that (F1:1).

Stern (2004: 172) describes these 'person to person encounters' as 'a shared feeling voyage' and Krishnamurti adds that:

> Only in relationship can you know yourself, not in abstraction and certainly not in isolation (Krishnamurti, in Hayward, 1990).

It was not possible to find a divergent view on the issue of connection; all participants agreed that being in relation was the essence of spiritual care. Without a connection there could not be spiritual care and relational spirituality therefore denotes the primacy of the human need to be in connection (Fuller & Strong 2001; Levin 2003; McSherry et al. 1998). Similarly without a connection to others, nature and the world, as well as for religious people a relationship to God, there would be little meaning to life.

## 5.4 The need for meaning-making

I discussed how participants spoke often about how spirituality gave meaning to their lives and how their spiritual beliefs supported them in times of difficulties and grief.

Similarly, participants agreed that their clients needed to find meaning in old age and dying.

### 5.4.1 The need to make sense of a life lived

The need for connection and relation is complemented by the need to explore and understand the meaning of the life lived so far or, more immediately, the meaning of their present situation:

> A mixture of concepts but the central thing would be… facilitating, enabling the individual to recognise and experience… the depth and meaning of their lives…. the achievements that they have made in their lives (F1:2).

It seems that these two main themes of meaning-making and connection are strongly interrelated and another person agreed that spirituality "really, I guess, just being able to help people find what is meaningful' (IV1). It would be hard to explore a person's core events and beliefs, without establishing a safe and secure relationship and vice versa:

> I try to bring that out in people and talk about issues that are related to that and once you get past the initial, once you go into that, people tend to respond. (F2:2)

MacKinlay (2001) describes this need for meaning quite poignantly in the title of one of her articles: *Ageing and Isolation: Is the Issue Social Isolation or Is It Lack of Meaning in Life?* King (2004:125) agrees that the main aim of spiritual care is 'making connections

to create deeper meaning'. This need, according to most participants, became even more pronounced in old age and dying.

### 5.4.2 The need to make sense of dying

Most participants agreed that clients needed a feeling of trust before they were willing to share their innermost longings, doubts and fears. These conversations often involved exploration of feelings and meanings about the end of life and the process of dying. One of the participants drew attention to the sensitive nature of these discussions:

> I always ask permission, I say is it alright if we speak openly [about what was going on] and I have only ever had one person say no and she was too scared. But I ask permission to talk about things openly and then sometimes I ask them if it is ok if we talk about death and dying and whatever (F2:2).

Henery (2003: 550) agrees that it is important to explore 'questions of personal meaning in relation to death, suffering and loss'. A participant shared that she often encouraged these conversations:

> [It is important] to be available to listen and maybe to ask gentle questions in order to help the person who maybe doesn't express or explore how they feel or what the meaning of life is for them at a particular time in their life, particularly when they are ageing or when they are dying, is to be able to help them express what the meaning is for them or for them to be able to explore what it means for them to be dying and what their belief is –whether that is perhaps going to heaven or Jesus or God or perhaps something else entirely different (IV3).

McGrath (2002: 50) noted in her research that many people who were experiencing serious illness did not turn to religion to make meaning of their situation, but explored their predicament with ‘an openness or sense of wonder about the possibilities of a transcendent realm to life’.

### 5.4.3 The need for a transcendental belief

As shown above, conversations about spiritual needs and care in this research project often revolved around issues of death and dying. Participants said that spiritual needs were greater in the last stages of life, because clients would try to find meaning to the big questions. This often involved exploring beliefs:

> Even though people may not want the ‘cross’ you know or any kind of overt religious ritual… but especially if people are facing real hardship and death, then some spiritual questions will be there… unless they’ve got a very clear belief of OK when I stop breathing I’m dead and it doesn’t matter… but most people have this sense that something continues on (IV3).

> And for people that are dying, the reassurance of a life to come is very comforting especially for people with a deep faith, they see that it is just the crossing to the next life (IV1).

Religious beliefs allow people to ‘transcend their current feelings and circumstances, enabling their well-being to be maintained’ (Kirby, Coleman & Daley, 2004: 127), which is also addressed in the following statements:

> If somebody has a clear path in any religion and it is taking you to your goal that is the best thing, it is a protection for you in your old age (F2:1).

> They [family]… were all very happy because they believed that the spirit of this woman was going to heaven and she [the dying person] said: ‘how can people face death without that belief?’ She said: ‘I just couldn’t do it... I really don’t know how they can handle the torment and the pain of approaching death without the belief’ (F1:1).

Most of the participants were especially interested to support the process of dying and, as expected, transcendental beliefs were mostly seen in relation to religion and faith.

### 5.4.4 The need for forgiveness

Exploring meaning, especially when death is imminent, can unlock feelings of regret and spiritual pain about issues that have not been resolved. The need for forgiveness was seen as an important theme in relation to meaning-making and a participant shared that:

> Meaning-making involves looking at unfinished business and issues of forgiveness and regret, maybe guilt and how you can resolve all of that so that they can die in peace (F3:1).

According to Mauk and Schmidt (2004: 12) ‘patients at the end of life may need assistance in resolving old differences’ with significant others in their life. The following example supports the importance of that practice:

> She needed some support because she was kind of reflecting on her life, all the things that she regrets and we talked about that and we talked about the good stuff as well… to help her change what is going on in her mind; you feel regret and you kind of make a resolution (F2:1).

Resolution at the end of life is important and may result in the ‘internal release of emotions attached to past experiences’ (Mauk & Schmidt, 2004: 12); in other words it may lead to forgiveness and letting go. A chaplain saw that as a big part of her role:

> At the end of their life instead of feeling like their lives were not very good, they could have done better, all that guilt, they may be thinking ‘I’m not too bad you know’ (IV4).

The following comments from another participant also support the need for resolution and acceptance:

> I feel that if you have an opportunity with an older person to explore an issue, to have a good cry or a laugh that will give an opportunity for resolution (IV3).

Participants in this research agreed that spiritual care's main tasks were; to offer meaningful relationships and to create opportunities for meaning-making. It was shown that this involved exploring and finding answers to questions that go beyond the issues of daily living and touch on values, meaning and finding a sense of peace in life and death.

> And in that context it is a very short jump to say 'is there anything in your life that is causing you concern… or you are not proud of?' Sometimes you do get people that are looking at their life as a waste of life and you know that there is something there, and you have to move really sensitively (IV3).

Participants commented often that they felt that it was very important for their clients to look back at their lives with acceptance and pride. They said that 'peace of mind would come from the ability to forgive and accept' (F2: 1) and suggested that a significant spiritual need was that of 'coming to a resolution and reconciliation' (F2: 1). McSherry (2000) concurs that the ability to find a place of forgiveness and letting go is one of the important spiritual tasks in old age.

## 5.5 Religious needs

As mentioned before, religion played a more pronounced role in this research than I had anticipated and some conversations focused predominantly on the religious needs of their clients. In this section I discuss the need for religious rituals, with most participants agreeing about the importance of the role of the clergy in this aspect of spiritual care.

### 5.5.1 The need for religious rituals

For some participants there was a deep connection between their personal spiritual beliefs and the way they perceived the spiritual needs of their clients. Some participants, who professed to have a strong religious affiliation, shared that they would sometimes get involved in conversations about religion and beliefs. For some it meant that 'the way I live, the way I speak should be showing that I am a person of God' (F1:1) or 'it's spiritual care, because I see the motivation [Buddhist precepts] before I go in' (F2:1). Religious beliefs also played a prominent role for one participant who said that:

> It is my duty as a Christian to tell people about God- but not to slam it down their throat... because spirituality means one thing to me and that's believing in God and living the way he wants you to (F1:1).

The duty to talk about religion was connected to having a clear path:

> Spiritual care is very much about moving or seeing things or having a perspective bigger than where you come from before, so it is not… using your own store of experiences; it is like transcending… looking for something outside of your experiences, so if you don't have someone giving you religious guidance you can only go as far as your thoughts take you (IV1).

Spiritual care was seen by these participants as clearly involving religious practices, such as:

> Saying a prayer with someone, even to say the Lord's Prayer with them, I think, is probably something that some people would appreciate (F1:2).

Although these religious rituals were derived from the respective religion, there was also willingness to remodel and accommodate these practices to suit the client's needs, for example:

> When we were talking about her higher power her higher power is God, so I kind of remodeled a Buddhist practice which is in essence using the purification capacity of the Buddha. So, when she visualised her higher power, it was God; she was visualising the white light coming to her as from God's heart. So it was still meaningful for her and she still got the Buddhist idea of doing that kind of practice (F2:2).

Spiritual care from a religious perspective was often performed by lay people; for example, participants mentioned 'prayer' (F1:1) and 'some of the nurses would read from the bible' (F1:1), others talked about 'visualisations' (F3:1), 'Buddhist teachings' (F2:2) or 'scripture readings' (F1:1). Rumbold (2002: 7) agrees that religious spiritual care is often delivered by lay people and research by Grant (2004: 37) confirms that nurses often see spiritual care as limited to familiar approaches like prayer and other religious activities.

### 5.5.2 The need for pastoral care

As shown above, many of the participants admitted that they did not shy away from engaging in religious activities. They, however, also expressed that the role of the clergy

was imperative and that they would strongly support their involvement in spiritual care. This concurs with the observation that religious spiritual care involves having an expert stance and the clergy embodies the authority and knowledge to administer this (Herman 2002). This view is also supported by the following:

> Someone may ask 'what do you think will happen to me when I die?' I usually would say… 'Well, this is what I believe…' but I recognise that people have different beliefs, but when they ask me directly I can say 'this is what I believe…' I have people who say to me that they don't believe that there is an afterlife… all I can then say is that I believe differently (IV3).

> That's really crucial, that's like you're coming from a place, which is not just your ideas. So it's kind of safe for someone. So they were saying that it's the responsibility of the religious traditions to find ways of keeping their paths relevant (IV1).

For many participants the status and authority was one of the hallmarks and prerogatives of the clergy, because they can give counsel and expand on articles of faith expressed in the following ways:

> Because of the power of his presence and status [the religious representative], she liked having that conversation with a religious person. She felt comforted through his prayer and his presence as a religious minister (F1:1).

> I have the wisdom and the blessings to pass on and I can do that because I am not working from your own individual beliefs, but from a lineage (F2:1).

> What people usually ask, particularly if they are close to death, is for the rites of the Church. It is important for them [the patients] to have a spiritual person there to pray for them or do whatever is important in their own religion, such as the anointing of the dying, so that is really important (IV3).

The following excerpts from an interview with a chaplain expand on the importance of religious ritual and church services in nursing homes:

> Chaplain: I do the services there [the nursing homes] and I find it really interesting, I've been doing them now for four years and when I just started doing them, I must admit it was thrust upon me, it was not my choice to do these services, but I have developed a real passion for it.
>
> And there are a lot of people in nursing homes and hostels that are still totally mentally alert too, but physically incapable. So, for them to take church to them, when they can't get to church, is really important.
>
> At one point in the service I said 'the lord be with you' and she came straight back with the immediate response and said 'and also with you'. So, it awakened something in her, there was something in her that was still responding. There are times that we sing a hymn during the service that obviously strikes a cord somewhere in there and you see someone with the tears rolling down their face and you can just go and give them a hug. People, when you come down with the sacrament, who you think are really not quite with it, but their hands go up because they know exactly what to do. Maybe it is the white robe they see or whatever, but there are still those spiritual responses that come out of the rituals they are used to, and there is still that connection (IV3).

As I expected, there was no disagreement about the importance of providing access to the clergy and religious services for clients who were brought up in a particular faith community. The need for religious ritual, performed by an office bearer, was seen by all participants as very important. However, it seemed that it was less important which religion was attended to than having the opportunity to take part in a religious ceremony at all as is illustrated in the following quotes:

> Catholic or Anglican or whatever, I think everyone was confused as to what she [Mum] was… but when Dad died suddenly she said to me 'I am so glad we had communion together a few days before he died' (F1:1).

> There was a lady that died not long ago and she was a Presbyterian and the Presbyterian minister comes to the home three times a year unless he's called and we asked her if she would like him to come because she was dying and she said no she didn't want him to and we had the Catholic church every Tuesday afternoon and if she was in the lounge she would always ask to go to her room because she didn't want to be at that service and a week before she died I asked her if she wanted to go to her room and she said she wanted to go to the service and I told her it was a Catholic service but she still wanted to go so I took her over and she died not long after that. But she was happy to go to that service although all those years she wanted to go out when the Catholic service was on. Sounds like almost a sense of knowing she was coming to the end and being at the service gave some comfort (F1:1).

Coming from a place of religion or a belief system however did not mean acting exclusively from that perspective and it was important in spiritual care to have a sound knowledge about the different religious contexts, because:

> An understanding and respect for all religions is important because once you've got that you can see the common threads and that for me is where spirituality lies. It is the common thread between all religions and faiths (IV4).

An ecumenical approach to spiritual care involves looking for 'common threads' and strives to transcend religious differences; this approach to pastoral care is now more common, according to Rumbold (2002: 3). The following excerpts also denote the need for finding the common ground in spirituality and religion:

> If you don't hold on to those kinds of [religious] practices then you can water it down to get something that everybody can accept… They've kind of made it that you don't really talk about anything religious because as a pastoral care giver you're supposed to be there for people from all different faiths, so… you kind of become a companion (F2:1).

> She [patient] talks about a visit from a pastoral carer who happens to be a Christian priest, I think, or minister from some denomination, I'm not sure which and she said 'we hardly ever talk about religion; I don't even know what that is, but whenever he comes, he finishes by just holding my hand and he says a prayer and I'm really comforted by that'. So for me this priest is providing spiritual care (F1:2).

This was confirmed by a local chaplain who had observed that for many of her clients 'the denomination barriers are not as important as they used to be' and offered the following example:

> I had a Catholic person one day, actually she wanted communion before an operation, so I said 'sure, I'll ring the Catholic priest to bring you communion', she was a dear old soul in her eighties and she said 'Oh dear, you can give me communion, can't you?' And I say 'it's all the same for me if it is for you', but I often make that offer, so they can access someone from their own religion (IV3).

The willingness to adapt ritual to the client's needs was equally clear in the interviews with participants from a Judeo-Christian worldview or a Tibetan Buddhist background. Confoy (2002: 23) agrees that a 'multi-faith' approach is more common these days and she believes that spiritual care can transcend 'religious dogma in pursuit of ultimate goodness'. Spiritual sensitivity was highly valued by religious office bearers and the lay care-givers alike; it was interesting to note that all the religious representatives said that they avoided guiding people. For example, a chaplain said:

> I have deliberately adopted what some people would call a low key approach in contrast to say the [name withheld] who come in with all guns blazing to look for people that can be saved and I don't think that is the way to do it. You come in as a friend and you make yourself available. And if it feels appropriate I may ask 'do you want me to pray for you or may I give you a blessing?' But I would never do that without asking permission (IV3).

The religious office bearers who participated in the research all agreed that their role in spiritual care-giving was very important and that they would be very happy to adapt their rituals and ceremonies to the needs of the clients. Rumbold (2002: 5) agrees that spiritual care has evolved from religious teachings to 'ecumenical chaplaincy' to now also including non-religious, non-specific supportive relationships. This inclusive view indicates that spiritual needs are common to all people and this will discussed in the next section.

## 5.6 Are spiritual needs universal?

When talking about spiritual needs with participants sometimes the question came up regarding whether all clients have spiritual needs. In the literature, the position presented often is that spiritual needs are universal. Similarly, many participants believed that everyone has spiritual needs, regardless of their religious upbringing, past experiences or current situation. It is therefore not surprising that participants in this study felt that the spiritual needs of clients should be assessed and acknowledged. A nurse in palliative care said that a spiritual assessment of clients was routinely done in her field:

> In fact these days we do things [spiritual assessment] – like end of life issues and we actually ask them if they want to see a minister or a priest; so you basically have an idea what people might want if they are preparing for death (IV6).

Although spiritual needs were often equated with religious needs, at the same time participants said that 'everyone has spiritual needs'. This is clearly expressed in the following:

> Well, I come from the belief that everyone has deep spiritual needs and also has a deep spiritual essence and I try to speak to that, I try to bring that out in people and talk about issues that are related to that and once you get past the initial, once you go into that, people tend to respond. I ask people if they have any particular religious affiliation or tradition that they are connected with, even if they don't have a formal connection I still have the assumption that they have spiritual needs; that's part of how I operate and how I would approach working with them (IV4).

This participant believed that everyone has spiritual needs, which may not always be very clearly expressed or even experienced as such, but nevertheless were considered as spiritual needs. Similarly, the following observation expressed expectations about the spiritual needs of older people:

> And when you look at the retirement villages now; they have bowling greens and swimming pools and a place where you can play your card games. But there's nothing there for that group of people as a community to do meaningful things and or there's no opportunity for them to do spiritual things either. If they want to go to a church or whatever they have to get their family to take them out and I think it's quite interesting as a reflection of what we [Western society] think is important you know? (F2:1).

The view that everyone has spiritual needs is contested by Walter (2002: 24) who argues that this would reflect the caregiver's perspective rather than representing the actual needs of the recipients. However, it could be argued that Walter's assertion refers to spiritual needs that are being equated with religion, ritual or special practices. Such spiritual care may not always be welcomed or needed, no matter how well-intended. Indeed, one participant found that:

> I don't think we talk about religious stuff or spiritual stuff as such but we certainly talk about, you know... I am thinking of one particular man whose really not willing to go there [religious or spiritual stuff] but is very troubled and frightened and we all spent time talking with him, and each of us in our own way. I think we all do that (IV4).

While for some these conversations did not carry the label of spirituality, they are certainly intended to support the client to explore their predicament in a meaningful way:

> I've got an interest there to explore that but not necessarily to push my ways on to anybody else but to be open and there with them through whatever they are going through (F2:2).

Participants often described spiritual needs quite loosely to include any of the client's needs that involved 'that what they are going through' (F3:1). Similarly, the chaplain said that it was often more important to be 'a friendly face' than to focus on 'special' spiritual needs:

> For some people I am the only one to visit them, apart from those who poke and prod and give them an injection. So, then I might just be talking with them about what they are watching on TV or the book they are reading and just make contact (IV3).

Although the above quote doesn't seem to refer to spirituality at all, for many of the participants spiritual needs often found their expression in the very mundane, every-day activities with clients, such as reminiscing, listening to music or looking after a client's physical needs. It could be argued that Walter's (2002) assertion that not all clients are interested in spiritual care may refer predominantly to what Milligan (2004: 162) calls a 'blanket approach' to spiritual care of a more religious nature.

In this research, however, spiritual care often included attention to religious observance and ritual, but was more importantly equated with the need for meaningful connections, which made every-day activities precious. Participants were not able to recall situations where spiritual care in the form of a meaningful connection or relationship was refused by a client.

## 5.7 Conclusion

In this chapter I discussed how the spiritual needs of clients in aged and palliative care were perceived and showed that participants mostly agreed that the purpose of spiritual care was to provide opportunities for meaning-making in safe person-to-person connections. I also revealed that meaning-making was often equated with exploring religious practices and beliefs and many lay care givers said that religious rituals such as

prayer or discussing the meaning of life and death in the light of a specific belief system were important components of their spiritual care-giving. At the same time the role of the clergy was seen as important and that there was considerable overlap in roles as both lay persons and clergy were involved in religious and more generalist spiritual care-giving. In the next chapter I discuss the sub-themes that emerged; those that revolve around the skills and qualities which, accordingly to the participants, effectively made these interactions spiritual.

# Chapter 6 Spiritual care: A Way of Being

## 6.1 Introduction

This chapter focuses on how participants believed that they were providing spiritual care to meet some of those needs. I will discuss that some of these practices involve activities such as deep listening, touch and sharing music. An important part of the exploration in this chapter concerns the fact that spiritual care can involve action and services, but more importantly it seems to concern the way in which the client is approached. Roger's (1980/1995) quote below embodies the sentiment of this special relationship.

> How my inner spirit may sometimes reach out to touch the inner spirit of the other and the therapeutic relationship transcends itself and becomes a part of something larger (Carl Rogers, 1980/1995: 129).

In this chapter I present the common thread which runs through the research findings; the understanding that spiritual care is determined by the attitudes and qualities of being *with* the client, rather than something that is done *for* or *to* the client.

## 6.2 Appreciating what is already there

Many participants reported that they were drawn to the research because they felt that they were already providing spiritual care and wanted to know more about it. This appreciative view is supported by Milligan (2004: 170) who in his research also found that nurses were already involved with what he called ‘relatively unspecified but all the same essential, intuitive’ spiritual care activities. He found that health service providers needed ‘to be shown which of the roles they already play’ in spiritual care-giving. This was also commented upon by a participant in this research, who keenly observed:

> Sometimes you only realise later on how important that moment was (F1:1).

The analysis of the data in this research clearly showed that participants were already involved in non-religious spiritual care practices and four broad themes or activities emerged. The first theme concerns activities that involve meaning making, reminiscing and life review; the second theme of spiritual care practices involves reading inspirational texts or poetry reading; thirdly it includes listening to music that lifts up the spirit and brings back memories; and lastly it involves making connections that are physical such as touching or giving a cuddle. The common thread that runs through all these practices were that they all involve ‘spending time’ (F3:1) and ‘giving attention’ (F3:1) or ‘being a quiet presence’ (F2:1). Participants saw these all these activities as being part of spiritual care-giving and I discuss these in the following section.

### 6.2.1 Spiritual care involves reminiscing

> It is as though he listened
>
> and such listening as his enfolds us in a silence
>
> in which at last we begin to hear
>
> what we are meant to be
>
> (Lao-tse, 499 BC, in Rogers 1980: 41)

All participants in this research were interested in facilitating their client's spiritual well-being and this always involved 'listening' (IV3) to what was important for the client. For some that involved listening to the client's stories and exploring the past, often in the hope of finding 'positive achievements and joys' (F1:1) to come to a place of 'pride or contentment' (IV4) with the life that had been lived. The quote from Lao-tse that begins this section illustrates beautifully how this listening could be seen as spiritual care. Taylor (2002: 268) describes this special way of listening as 'listening to the spirit' and states that reminiscing and story telling are important spiritual tasks. Many participants agreed that it was important to 'be a good listener (IV6) or 'to share stories (F3:1). For one of the participants, what he called 'deep listening' was a big part of his spiritual care:

> I look at their personal history, and often you can walk in their room, and around their bed there is their history, it is in the ships on the wall or the fish being dragged in, or a tennis racket over their shoulder or…it is the family, and that is the starting point, where I get to talk about with them. And as soon as you do that, you see the sparkle in their eyes, their eyes light up. [But sometimes] you can walk into a room and there is nothing… and that is something you can start with as well… it is a harder job, but it tells you something

> too. And a lot of it could be… grieving, or … a fractured life, a fractured marriage, children that have grown up and abandoned them, [it] could be a lot of things… but it is the walls around in their room where I start…and get them to talk about that (IV4).

This participant agreed that a life review could bring up painful and difficult issues, but saw these as an opportunity for the client to resolve some of these old hurts and disappointments in his or her life. Exploring the past, he continued is important, because:

> In that process, they themselves will come up with issues. I often ask them 'what is the thing you are most proud about in your life, what is your greatest achievement in life? And it could be like 'raising my family' or 'coming to Australia' (IV4).

Doka (2000) argues that there is healing power and spiritual value in the telling of one's story, especially if the listener is attentive and interested. McSherry (2000: 117) agrees that spiritual care involves having good interpersonal skills and points out that Carl Rogers in his later years drew attention to the spiritual quality of deep listening (McSherry, 2000: 57). According to one participant this way of listening involved:

> Cleansing the lens to see the world and the experiences that come up more clearly… so that we are more able to see the innate goodness in self and others, in all beings (F3:2).

Another participant also pointed out that it would be important to bring out the positive experiences in a client's life, so they could look back with satisfaction:

> And I think for older people … there's a sense of being a burden to everyone; 'why can't I just go you know, leave my life?' And I think it's really important to find one thing that they can be pleased about as they reflect back on their life, helping them to rediscover the importance of those things (F2:1).

Bickerstaff et al. (2003: 159) agree that moving into a nursing home could be 'very soul destructive' and usually involves 'a loss of identity'; these authors suggest that amongst other things 'structured reminiscence therapy' would restore a sense of self and thereby be spiritually nourishing.

### 6.2.2 Spiritual care and poetry

According to some participants, inspirational poetry or readings that were significant in one way or another for the client could also be spiritually uplifting. A spiritual care coordinator related how much of his work involved triggering old memories and past experiences that were meaningful for the client:

> In particular I believe that imagery can stimulate memory and recall… it becomes like an exercise, in fact a lot of that is tucked away in the long term memory but it can get to the short term memory with a bit of work and that is very much the area where spiritual care comes alive (IV4).

Fuller and Strong (2001) describe the awakening of the spiritual as 'alive moments'- moments that are significant and present; this is quite literally, explained in the following excerpt from an interview:

> I look for responses in their life, and often poetry is one of the good things to start with, I've got some great poetry sources there… but you need to look at it according to the needs of each individual… a wonderful one there is 'Memorial Day', with the 11th of November coming up I'll tend to use that in the memorial session. Henry Lawson, Banjo Patterson…. John Williamson… marvelous poetry that they relate to… I can recall reading some poetry to a group over here, and I read 'My Country' and there was this old lady at the end of the table with her head on her chest and it appeared that she was not listening, but when I finished her head came of her chest and she said 'Dorothy MacKellar'. So, she picked up every word and it obviously brought her back to something that was deeply meaningful for her (IV4).

Charles (2004: 151) points out that 'existential longing' and questions about the meaning of life can be awakened by painting, dancing and poetry and she refers to Elkins (1995: 91) poetic expression that if 'the soul is ontologically thirsty, ... if not met, life becomes barren and dry and the soul begins to die'; therefore the spirit needs to be 'nurtured by love, goodness, truth, beauty and passion'. Poetry was seen as an important source of goodness and for other participants this also included listening to inspirational music.

### 6.2.3 Spiritual care and music

In some focus groups and interviews there were extended conversations about the spiritual properties of music. It was argued that music, like reminiscing, could open doors to the past or simply could uplift or transport someone in times of need or sorrow:

> I think music helps to lift the spirit and perhaps move towards a different way of being. And I think that sublime beauty of music enables people in that situation of dying or in

> despair or not knowing where they might be heading. They can connect with the music and for me that's part of spirituality (F1:1).

The spiritual care coordinator also shared that another of his favourite ways to connect with people was to find a piece of music that would have meaning:

> Some nice music, that could be one way of lifting someone's spirit, making people reminisce, you know, I think music is a great avenue for everybody, it may be sad music, but that may help people grieve, you know. Somebody that might have some idea of what somebody would like or even find out what somebody wants. Or say something like I have got a really nice CD, and I could bring my CD player and maybe we can listen to it together and we could talk about what we got out of that (IV4).

Music was seen as a non-intrusive avenue to support reminiscing, for exploring meaning or getting in touch with feelings. Research by Hays and Minichiello (2005: 267) confirms that music can bring a person 'in touch with a personal sense of spirituality'. One of the outstanding qualities of music is that it can touch the soul without words and therefore music could play an important role, according to participants, when communication was no longer possible or when life was ending. Participants suggested that it could become a catalyst for a meaningful connection:

> Person 1:When this man was dying last weekend and he loves music – because I like singing and playing guitar – and I said to him next time I come I'm going to bring my guitar and sing and he said he would love that. Well next time, he had died! So, I'm

> thinking I would really like to carry my guitar in my car when I'm visiting people and sing for them.
>
> Person 2: Well, you can also use CDs. I used those with my husband and also Mum last week – I got out some really nice classical music and played it for quite a few hours of the day. It is soothing – even if they can't hear anything else they can hear that. I mean I can imagine – I haven't asked Mum if she could hear it, because she's in denial that anything happened to her but that's beside the point. Yes, I think music is great.
>
> Person 3: I think [music] takes the quietness off the room, you know, and makes the atmosphere more warm (F1:1).

O'Brien (2003: 135) adds that spiritual care from a Christian perspective can involve the use of sacred music as well as prayer, scripture readings and rituals. Similarly, in the Buddhist tradition the use of mantras and chanting is considered beneficial and healing (Rotem, 1996). Contemporary, non-religious therapeutic approaches include music therapy, which according to Salmon (2001: 142) 'allows the expression of human emotion' thus supporting a process of meaning-making, healing and integration.

In this section participants described how reminiscing, music and poetry all involve a reaching out to connect with another person on a spiritual level. Music, particularly, can touch people without words and most participants, at one time or another, similarly mentioned that 'to be in a spiritual way with a client' (F1:1) was very much concerned with touch

### 6.2.4 Spiritual care and touch

Touch is a vital human need and O'Brien (2003: 15) states that touching is of comfort for the 'physical, emotional and mind-body'. A participant agreed that 'it can just be touch – like that's a spiritual thing too' (F1:1) and someone else commented that:

> Just being there for them really, even just to be able to touch people, sometimes even a hug (if you ask them if they'd like that), doesn't have to be talking, it can be actually showing your feelings towards them, their grief, sometimes they are grieving because they are getting old, not only have they lost their loved ones but also sometimes families don't support them (F1:2).

Touch is an important human need and Brykczynska (1997: 5) states that touch is a powerful way of showing the client that you are there for them and with them at that moment.

> Some of our residents are very lacking in touch and some don't get any visitors at all so a lot of the time it is up to the staff to get in touch (IV6).

Touch could be many things, from the simple touch of a hand to the more intimate gestures such as giving a hug, as is illustrated in the following quotes:

> A smile – you just sit and hold their hand and let them tell what their aches and pains are and they feel a lot better after that too because they have shared their thoughts with

> you – you don't always have to hug them – just a smile is very important to some people (F1:1).
>
> With my job which I absolutely love, as draining and as stressful as it can be, the moments I enjoy most are those ones, as you were saying, without the words; you just sit there and touch the person (F1:1).
>
> It's an intimate connection with somebody. If you put your hand on someone there is perhaps that instant connection where you are showing someone your care or your love, so I think that you could call that spirituality if you wanted to (F2:1).

To test the veracity of this idea, I asked in a focus group whether anyone ever refused a hug and there was a resounding 'no' from most voices. Someone explained that 'I think sometimes now we ask whether they like to be touched only because of all this stupid legality' (F1:1) and that was a great shame, because 'that touch is like bringing us together' (F1:1):

> I found that when somebody needs a hug and you're not sure whether you should hug them or not; I often ask them if they would like to hug me and if they hug me you can respond (F1:1).

However, some participants said that not everyone wanted to be touched:

> If you put your hand on someone there is perhaps that instant connection where you are showing someone your care or your love so I think that you could call that spirituality if you wanted to… but not everyone would want to be touched (F1:1).

> Some people actually say 'we are not a touchy family' and I think there's some vibes there, but I think if the time came that they needed to be given a little bit of empathy, I don't think [that] they probably would resist (F1:1).

Participants agreed that touch could be intrusive and needed to be approached with great sensitivity. For example, 'you really sometimes have to ask permission – do you mind having a hug' (IV2). One aspect of touch, however, was that it gave an opportunity to bring spiritual care in all interactions with patients, and one participant commented:

> Spiritual care can happen when you are just with someone, maybe silently sitting or listening or even sometimes when you are doing something together, maybe even something practical, like giving them a drink or wiping their face… it is not just sitting there being spiritual (F2: 1).

> There is often not enough time to sit down and listen, but at least you can be there for them… really touch them… when you are feeding someone or giving them a bath (F2:1).

From this perspective even mundane activities which involved touch, such as washing or feeding a client, could be spiritual. Moore (1994: 219) agrees that spirituality can be 'found and nurtured in the smallest of daily activities', which become thus infused with the sacred.

### 6.2.5 What spiritual care is not

Participants talked about their understanding and experiences of spiritual care and sometimes it seemed difficult to find the words to express their views. In contrast, it was interesting to observe that  there was little difficulty in articulating what spiritual care is *not* [my italics]. For example, most participants agreed that spiritual care always involved 'caring and loving kindness' (F3:1) and listening to the client (F1: 2). Giving advice was not included as is illustrated in the following quote:

> It doesn't actually have to be talking so much, it is just listening. And it certainly should not be advice, because I don't think advice is what you give in a spiritual hearing, so just being there for somebody, even just making a cup of tea… it is just being nice and caring for someone (F1:2).

In one of the first focus groups a lively conversation ensued about not being spiritual, which was seen as 'not being kind, caring and loving' (F1:1) , or at least, '*less caring and loving'* (my italics). There were strong opinions expressed about care givers who were not spiritually oriented, because 'they don't listen and speak *about* them [clients], not *with* them' (F1:1):

> You can see it when they (the aged care workers) are just in it, because it is a job. Not that you would sack them, but you would prefer people who are spiritual because of the

> quality of their care. And those who don't care, who are not interested, eventually leave anyway (F1:1).

These observations were expressed with a general air of displeasure, because 'they [those without a spiritual orientation] don't seem to care much or are not interested' (F1:1). That would be obvious because 'they do not talk to the clients' or 'take no time for giving them anything more than what is needed' (F1:2). This was a problem according to one participant:

> You need that [spirituality]… something inside yourself like love and understanding so that you can give to others and if that was not the case then it would be a worry to be employed in aged care, quite frankly (F1:1).

Spiritual care was thus equated with care that comes from the heart. Participants agreed that health care providers who did not seem to care would not survive for long in the health industry, because their attitude would not only harm the client, it would also not support themselves in a demanding, often exhausting job. In the following section I will expand on spiritual care as something that involves a special way of being present.

## 6.3 Privileged moments: Being present

> The purpose of relation is the relation itself- touching the You. For as soon as we touch a You, we are touched by a breath of eternal life (Buber, 1970: 113).

Some participants commented that touch was much more than the physical act of connecting and talked about the spiritual importance of being in touch with a client. To illustrate these observations, I started this section with a quote from Buber (1970), which emphasises this aspect of touch; it is also interesting to note that he uses capital letters when he talks about the person he connects with. One participant explained:

> Yes, I get in touch… I knock on doors… I visit them all and I just tell them who I am… and then I start talking about what surrounds them… and then in the next couple of months we got to know each other (IV4).

Although spiritual care involves certain activities, as was shown above, most participants agreed that these activities in themselves were not necessarily spiritual, but needed an awareness, a presence. The transition from an ordinary act of care to spiritual care is reflected in the title of a recent nursing book: *Standing on Holy Ground* in which the author agrees that 'to be present with spiritual care' transforms simple acts to 'privileged moments'(O'Brien, 2003: 113).

### 6.3.1 'Non-doing'

Presence is often equated with 'non-doing', an equally complex concept that is explained in the following quote:

> Presence is a difficult quality to define. Yet its absence is readily apparent. More than a 'quality', it is an existential stance. It is bringing all of myself to bear in this moment

> with this person- No other concern is paramount. It is a letting go of all my technical concerns and 'goals'. The only goal is to be fully present -paradoxically a goal that is not achievable by technique (Hycner & Jacobs, 1995: 116).

Non-doing has to do with what we are rather than what we can do and this meant for one participant that:

> It's not what we say or what we do but how we act and who we are, that is so important in the relationship with a patient (F1:1).

Participants commented that all their interactions with clients were ideally underscored by 'who they are' and an 'essence of acting from a place of spirituality' (IV5), because it is 'something inside of us, so that we can give to others' (F1:2). The most important aspect of this perspective on spiritual care was described as a quality of 'being' rather than 'doing' and is illustrated in the following quotes:

> Spirituality underlies everything I am doing (IV2).

> Well, I think spirituality comes from within in any case; it's what you give out many times (F1:2).

According to Mauk and Schmidt (2004: 248) 'the gift of presence, being with a patient in the time of need, can provide a tremendous spiritual benefit' as is also expressed in the following comment:

> If you are there with what is; being present, being accepting- that constancy of being open, then it can actually be a good process (IV1).

Fuller and Strong (2001: 203) stress the important spiritual function of these moments of meaningful connection by calling them 'sacred'. One participant expressed that being present is not always easy:

> I'm thinking, it [spiritual care] is about being in the here and now with that person; and that is not always easy, because… you know we have our problems… we have our worries and we're always distracted, you know (F1:1).

Another participant also drew attention to the fact that it is more than just being physically present:

> It is a process. That's probably what it is: Being present and not being in the way. When we talked before about being in the way that basically meant: Letting our judgment guide whatever is spiritual or not (IV5).

According to Welch and Wellard (2005: 9) being present means to be able 'to dwell in the patient's subjective world', whilst also being at home to oneself; it means to be aware of the intersubjective world. Stanworth (2002: 192) agrees that presence means to be attentive to 'the value of shared human experiences', which demands an 'awareness that transcends common interpretations'. Therefore being present is an active, reciprocal process as expressed by one participant:

> Better at being in the world, definitely. My experiences in life was that I was very cut off all the time, so for me to find a way to function effectively, yes that is one way, but that functioning is only coming out of an internal functioning. The more I create awareness and situations for awareness in my life the more I love and nurture the person that I am and accept and stop judging and all of those things. So then you have a basis to get real in the world… a basis that all people can relate to. Some people feel that, if you are present; and I certainly feel that, that I am not running away or that I am not reacting (IV1).

Being present with awareness, as described above, is reminiscent of Humanistic values and overtones: In his book 'A Way of Being' Carl Rogers (1980: 129) looks back at 'the foundations of a person-centred approach' and concludes that being truly present is one of the most important conditions for 'profound growth and healing'. He warns though that these are not tools of the trade, or a means to an end, but being present, truly connecting with another human being is an end in itself.

### 6.3.2 Witnessing pain and suffering

Truly connecting and staying present is also called 'witnessing' in the Buddhist tradition. Glassman (1998: 33) describes witnessing as maintaining a deep level of awareness of self and other in the present moment: It means having the ability to sit compassionately and quietly with the pain, with the grief and with the joy someone is experiencing without the need to make things better or taking away the suffering. This was beautifully described by one participant:

> Sometimes, when someone is in pain or uncomfortable, there is nothing you can do, you are just sitting there and you feel so helpless…. But it is the helplessness where we need to be with, just sitting in it, rather than *doing* some spiritual care… just being with that person when they are going through their pain [my emphasis] (F2:2).

The ability to be present makes a huge difference as described by one participant:

> The difference I have seen between a nurse sharing a difficult routine with compassion [in the context of spirituality] and someone who doesn't have that… the difference is huge, and I know what sort of care I like… I'd like a person that was more present to my feelings (IV1).

Jenkins (2002: 124) argues that spiritual care involves a mutuality, which is explained as 'the sharing of vulnerability' and being present to 'the intensity of moment'. This sentiment is also expressed in the following:

> Spiritual care is recognising and being present with that person. With all their doubts, all their fears, whatever, just being there with them. And that can be expressed in all different ways; it's just being there with them on the day, their companion (F2:2).

Carl Rogers (1980/1995, p. 129), quoted at the beginning of this chapter, describes very movingly how 'his inner spirit may sometimes reach out to touch the inner spirit of the other'. He considered such a transcendental meeting of great therapeutic value because the 'relationship transcends itself and becomes a part of something larger'. Some of this magic is described in the following:

> I know that this one woman in this nursing home and I held her hand quite regularly and it was easy; it made her cry once because it was such a magic thing for her (F1:1).

Spiritual care thus involves the ‘magic’ of being in touch and being present with a client. Brykczynska (1997:13) asserts that this care involves ‘to protect and honour’ and quotes Buber (1970) who sees these attributes and qualities as ‘essentially an education of character' rather than a skill to be learned. From this perspective spiritual care does not demand expert knowledge or a special position and Kellehear points out that everyone can deliver spiritual care, who can:

> Sustain ongoing community involvement, understand spiritual traditions, and can stand in the tension of spiritual health and spiritual distress as experienced by the individuals themselves... maybe social workers, chaplains, but also nurses (Kellehear, 2002: 176).

Kellehear (2002) points out the paradoxical nature of spirituality; apart from the tension between doing and being there is also a contradiction between the need for training in spiritual care and the need to maintain a non-expert approach. Spiritual care thus involves qualities that were quite poignantly summed up in the very first focus group by a participant who said this about spiritual care:

> It is a caring that’s shining from within (F1:1).

It may be that part of the difficulty with finding a language of spiritual care involves the complexity of describing ‘the shining from within’. This attitude or approach to patient care demands qualities of awareness that go beyond and above the doing aspects of practical support, empathic understanding or religious care. Especially in the later parts of the research, participants seemed to express that being truly present could be the most accurate way of describing any practice of care that is infused a sense of spirituality.

## 6.4 Conclusion

In this chapter I discussed how participants commented that, apart from religious observances, spiritual care-giving involved reminiscing and story telling, reading poetry and sharing music. Sometimes a meaningful connection was established without words and many participants said that it was important to touch or hug patients. Physical touch conveyed being in touch with the other and even ordinary activities such as washing or feeding a client could become spiritual. While these activities may not be not sacred or spiritual in themselves, the key ingredient that distinguishes these practices as spiritual involves the ability to be truly present with the client without judgement or preconceived ideas. Spiritual care therefore involves an aspect of what in this chapter is described as a ‘non-doing’, which involves being present in any care activity with deep empathy, mutuality and immediacy. This quality of being present with clients is most poignantly described by one participant as ‘the shining from within’. Despite these keen observations and the general interest in spiritual care, the next chapter reveals that participants also commented on the factors that influence the delivery of spiritual care.

# Chapter 7: Factors that influence spiritual care

> You know the first thing I was taught as a social worker was that my job as a social worker was to try and understand 'a map of the world of the person' with whom I was working. And for me now I think if your going to do that and don't address issues relating to spirituality then it's the most incomplete map of the world, you cannot understand someone's map of the world until you've talked to them about spiritual matters, what gives their life meaning. What is meaningful to them?. It is absolutely very integral and I now look back and I can't believe we never talked about it, that we never named it. (Research participant)

## 7.1 Introduction

In this chapter I discuss the factors that influence the ability to deliver spiritual care, which involves what in the above quote is called, completing 'the map of the world of the person'. In order to deliver the best care possible, which involves the complete map of the person, the most obvious impediment entails lack of time and resource restraints, while others include the nature of the organisational culture, lack of experience or lack of education and training. Other potential barriers to providing spiritual care that were raised involve lack of self-awareness, personal attitudes and beliefs as well as burn-out. No matter whom I talked to, these themes emerged without probing, in spite of the often very divergent experiences, contextual circumstances and belief systems of the participants.

## 7.2 Time pressures and lack of human resources

In the literature review I mention that over the last decades spirituality has increasingly been seen as an important aspect of holistic care-giving; for example, several recent nursing text books deal exclusively with spiritual care (O'Brien, 2003; Robinson et al. 2003; Taylor, 2002). Paradoxically, at the same time there are increasing pressures within the health industry to do more with increasingly less available resources. Apart from the Tibetan Buddhist organisation, whose members told me that they had access to private financial support, time and funding were a major problematic issues as is illustrated in the following quote:

> Time is a major issue, because government funding for the nursing homes has become much less now, there is no time to sit down with clients and give them attention, or even a nice long chat. There are fewer nurses and it is really mostly whilst doing the work of caring for the patient's physical needs that spirituality can be expressed (IV1).

There seemed to be a real shortage of personnel, especially in the nursing homes. Some senior participants were particularly bothered with this situation and expressed that in very strong words:

> It is all [aged care] dollars; it is all driven by money (IV6).

> I've been in the situation where you're sort of pressured to get so many people in a day; because that's the funding (IV2).

In the previous chapters it was shown that spiritual care would involve, amongst many other things, story telling and reminiscing. These very time consuming practices could easily be relegated to the area of non-essential care in a corporate approach to aged and palliative care. Lack of time to sit down with clients seemed especially prevalent in conversations with staff from nursing homes and other government funded organisations such as Home Care:

> The paperwork in nursing homes in particular has overwhelmed the job, the hands on time has just shrunk and shrunk (IV6).

> Where I came from [a nursing home] was very big and the focus can easily get lost in things like budgets and meeting outcomes and all those sorts of things and the actual meaningful side of the work is lost (F2:1).

The difficulties that these practitioners were facing did not seem to derive from lack of interest, but were often the result of work pressures impacting on the participants as evidenced in the following quotes:

> In the institutionalised climate I was just too exhausted and I couldn't implement it [spiritual care] because of the time schedules… it is really impersonal (IV2).

> There is not enough time for spirituality and spiritual care; it is not part of your workload, it is not part of the work-description even though it is implicit in the ethical framework of aged care (F1:1).

Despite the interest from health care providers and current government policies regarding the importance of spiritual care in aged and palliative care, participants agreed that the main impediment to spiritual care was not having the time to sit down with their clients. These observations are in line with many other research findings that confirm that lack of time is the major problem for health care providers (Jenkins 2002; Taylor 2002).

### 7.2.1 A lack of institutional support

Notwithstanding funding issues and tighter schedules, some organizations, by the very nature of their leadership or religious affiliation, were interested in creating a culture or climate where spirituality was nurtured. In these institutions spiritual care was considered as an important part of the overall care plan, as is shown in the following observations:

> In the Catholic institutions I have worked in people were often working there because of their religious orientation to outward service… In a way it would be almost easier to work or be in an organisation whose culture is embedded in a religious or spiritual background, would it be Catholic or Buddhist, than in a secular culture (IV2).

> There's a very strong wish to be able to build the spiritual care component of [name withheld] and so there's a movement towards that and I don't know that some of the other services and organisations have such an emphasis on spiritual care or see the value of it in the same way (F2:1).

These quotes came from participants who were currently working in organisations with a religious or spiritual focus, but had also worked in non-religious institutions. In the following excerpt from an interview organisational support for spiritual practice was clearly expressed:

> For example we have a weekly meditation group here and the fact that there is meditation going on in the building has an effect on the energy of the building. Some of the staff come to the meditation as well as people from outside and that has an effect on relations within the staff and how the whole system of [name withheld] goes ahead (F2:2).

Such observations confirm Grant's (2004) findings that a supportive organisational culture enhances the overall expression and practice of spiritual care. Kaplan (2002) points out that there is a dynamic interplay between the needs of the clients, the professional's interest in spiritual care and the restraints or opportunities within a given organisational culture. It could, therefore, be argued that a lack of organisational support could pose another significant challenge to discussing and implementing spiritual care practices.

## 7.3 Lack of appropriate training

Lack of time and organisational support were seen as significant impediments to spiritual care. Related to this is the concern about the lack of understanding and training in spiritual care. Many participants commented that spirituality and spiritual care had not

been part of their formal education as nurses or social workers. Similarly, they had not received on-the-job training in spiritual care.

### 7.3.1 A missing piece of the puzzle

Some of the participants said that they had volunteered for this research project because they did not really know 'what spirituality is all about' or wanted 'to learn more about it' (F1:1). Other participants felt they were better informed, yet agreed that, although they had received some exposure to the socio-cultural issues their clients may be facing, in their formal training and education (apart from religious representatives) there was no training in spiritual care:

> You know the first thing I was taught as a social worker was that my job as a social worker was to try and understand 'a map of the world of the person' with whom I was working. And for me, now I think if your going to do that and don't address issues relating to spirituality then it's the most incomplete map of the world. You cannot understand someone's map of the world until you've talked to them about spiritual matters, what gives their life meaning. What is meaningful to them? It is absolutely very integral and I now look back and I can't believe we never talked about it [in university], that we never named it (IV1).

Mowatt (2004) agrees that spiritual care training is rather an exception and that spirituality is not included in the curriculum of most formal education and training programs. One participant was at the time of the study involved in writing a training manual for staff and volunteers. She said that although 'the biggest part of what we are

doing is going to be Buddhist spiritual care' it would be 'quite possible to translate across' (F2:1):

> The pastoral care training that you receive now if you go to university to get that training is Christian based. And so this [training] will be generic in that the terminology… well… that you don't have to be Buddhist to do it… you don't have to believe that, but the philosophical tenets that underlie it will be Buddhist (F2:1).

One of the problems with spiritual care training in a formal setting seems to be the difficulty to deliver training from a neutral perspective; there was either a Christian or a Buddhist focus and while some spoke about a 'generic training', this would often involve 'teaching about the different religions' (IV3) or be 'Christian based' (F2:1). Hassad (2000: 6) points out that training in spiritual care should be holistic and 'respectful of religious and cultural background', but none of the participants in this research had ever been part of a non-denominational training in spirituality. However, it was interesting to hear that a local Catholic organisation had recently appointed a spiritual care coordinator; in an interview he shared that his role was to 'look after the spiritual, not the religious needs of the residents and to some degree staff' (IV4). Furthermore, he was also asked to initiate non-religious spiritual care training for the staff and he commented that:

> I think it is a big challenge to train the staff…and also out there [in the university], for example, in nursing courses; to train them in coming to terms with what spiritual care involves and I think that would be a great area to have an input into (IV4).

During the research project I had some informal conversations with coordinators of volunteer organisations (National Association of Loss and Grief; Silent Visitors; Tweed Palliative Care Service). These organisations were providing education programs for their volunteers, which involved practical knowledge and communication skills, but also included training in awareness of spirituality of religion. In speaking about these training programs, coordinators repeatedly stressed that they were attentive and at times selective about the personal attitudes and beliefs of their volunteers. Coordinators of these training programs all said that they did not want to include people who had strong religious or spiritual beliefs. Hudson and Richmond (2000: 11) agree that there is a real 'danger to overstep boundaries' when providing spiritual care. Personal attitudes and beliefs are issue that also needs to be addressed in spiritual care training for professional practitioners.

### 7.3.2 Lack of appropriate skills, personal attitudes and qualities

Participants who were involved in delivering training programs stressed that an important part of the training was experiential and included personal growth or self-development issues:

> One of the things we used to do in the program was to get people to look at their own issues; we looked at crisis and death and dying and issues of grief and I think as people are able to work through their own issues that relate to that, then there is a natural compassion that comes out. So that's one way (IV5).

In the previous chapter, being present to your client's issues was identified as important and that you needed to be able to put your own problems to the side. According to one participant, it was important to know your own issues in order for your judgments and values not to get in the way of being present:

> Awareness of their own values about death and dying; being aware of their own spiritual values to kind of develop an understanding of spirituality in general but also so that they're not imposing their own values on other people, but heightening awareness so when they go into somebody's home they are alert to the cues that they were talking about spiritual matters… and how to engage people in a way that doesn't shut down the conversation but opens it up so that people have a real opportunity to talk about that (F2:1).

Thus, it seemed that spiritual care training needs to involve practical communication and counselling skills and at the same time needs to devote time to awareness training and the development of personal qualities. The spiritual care coordinator summed it all up when he said:

> Well, qualities and values and education, if you can bring those three together and the person has the willingness to grow or to develop you can grow a beautiful human being. We all have the potential in the beginning; we just have a lot of obstacles in our mind that prevent that very deep compassion from coming out. But we certainly have the potential for it. We just have a lot of obstacles in our mind that prevent us from getting there (IV4).

Wasner, Longaker and Borasio (2005) agree that self-reflection and awareness of one's own issues in regards to ageing, dying and spiritual needs should be important components of any training program in spiritual care. Furthermore, Means and Cooper (2005: 36) state it was only possible to develop connections at 'relational depth', if one had experientially developed the personal qualities of deep empathy and compassion.

Empathy, being present and deep compassion point to certain attitudes and qualities rather than to acquired skills and some participants pointed out that such a perspective on spiritual care would be 'hard to teach; it is something that you either have, or haven't got' (F1:1). A participant who was also involved in training staff shared that:

> We looked for those qualities developed in people and basically we looked for people who had been through the mill and come out the other side- that was the best teacher, when they'd been through the crisis in their own life then they understood crisis, and they understood inner pain and grief and they developed that emotional maturity and spirituality within themselves and that's the quality we looked for. Then someone with a piece of paper doesn't necessarily have that (F2:2).

However, these qualities could be developed within the framework of experiential teaching and would be best taught by example; participants suggested that 'you could model it' or even 'show how it works' (F1:1). One participant gave a clear example in the following statement:

> I think… someone like the Dalai Lama or Mother Theresa: Their whole being and their whole way of being is an example of those qualities working and so they then draw people to their own belief system and that way of thinking… and people then voluntarily want to become like that… so I think that's a way of teaching that can be very powerful (IV1).

Modeling would involve practical applications such as showing that 'even some of the more aggressive clients calm down when you are around' (F1:1) and 'aggressive clients often react a lot better, when you approach them with loving kindness' (F1:1). 'It is teaching by example' and you can then 'explain how this works and why being kind and empathic is helpful for the client' (IV1). Interestingly what is helpful for the client could also be helpful for the care-giver, as will be discussed in the next section.

## 7. 4 Spiritual caring as self-support

Many conversations focused on the needs and benefits of spiritual care for the clients. In the later samples some participants talked about how their spirituality supported them in their work. A positive attitude, therefore, was seen as mutually beneficial for the practitioner and for the client.

### 7.4.1 Maintaining a positive attitude

Sometimes even workers that cared deeply would close themselves off from what was happening, because working in aged care and palliative care was 'very strenuous', (F1:1) 'demanding' (F2:2) and could be 'emotionally draining' (IV2). With the combined

pressures of being understaffed, lack of organisational support, lack of training and the strenuous nature of the job it would sometimes be difficult to maintain a caring, giving and positive attitude. At times, practitioners commented that sometimes ‘it is just easier to close off’ (F2:1) or ‘to laugh things away’ (IV4) and a participant commented that:

> It is not feeling, on a level it was just functioning, almost robot like, yes the very opposite to presence (IV2).

For some the most difficult situation in nursing homes and palliative care was how to cope with the inevitable death of their clients. Unacknowledged grief or lack of time to grieve was an issue also:

> Death is a big issue, a spiritual issue, and an unavoidable part of working in aged care. There is the search for meaning and the inevitable sadness if one of the clients dies. But it is still traumatic for the others, and for the nurses too and often there is not enough time to give to mourning and the process of grief, other than the memorial service maybe. And there is often no time to attend the service or even to go to the funeral (F1:2).

One of the participants felt that making light of it seemed to be one way to cope with the pressures of the profession, as is expressed in the following quote:

> I recognise the nursing profession as an earthy profession and I can understand that because in order to stay sane they’ve got to be able to laugh about the… very mundane and ordinary things of life… however, in the process of laughing are they laughing about

> themselves… each other… or at someone else. That is a big difference, and you can sometimes walk into a room and the joke is about something which is really… about an individual… whereas… I feel like saying there… 'Hey, not good enough'. In saying that, I also understand the need to be able to laugh (IV4).

Although distancing oneself from the situation may at times help to handle a difficult situation, it did not seem a satisfactory solution in the long run, because it would diminish a positive attitude towards work, towards clients and ultimately towards oneself. A participant was concerned that closing off could even result in accidents:

> I think a lot of physical injury could be avoided, accidents and incidents happen because of unawareness and because of the pressure of time, there is no taking it slowly or playing; it is just even more difficult to work with presence and awareness in those pressured situations. In fact, such an attitude, it was shown before, would not be spiritual and, thus, it would really be the opposite of giving good spiritual care. At the same time, some participants observed that this strategy also affected the practitioner and could contribute to burn-out (IV4).

The issue of burn-out was mentioned at several occasions and for some participants there was a relationship between burn-out and lack of spiritual self-care and this is discussed in the next section.

### 7.4.3 Preventing burn-out

Burn-out is a serious problem in health care and one participant, in particular, was quite outspoken about the importance of preventing burn-out:

> Participant: And the biggest thing in caring work is doing that, preventing burn-out. People are giving and giving and giving and not renewing their energy.
>
> My question: does that mean that you are aware of that?
>
> Participant: Absolutely, I mean that if I am unconscious, I am quickly aware of the consequences. I can feel tired and exhausted and not wanting to be there basically. And, the response of clients is really quite different too. I mean if you are calm, if you are peaceful, that transfers also to the client, it works both ways (IV2).

This excerpt from an interview shows that burn-out can have serious consequences for both parties; it does harm to oneself as much as it disadvantages the client. According to this participant, who was passionate about self-care, having an active spiritual life protected her from burn-out:

> To process it [a hard time at work] at home, often with active meditations: that gave me the opportunity to come back each morning fresh… and I don't think that there are many of those skills available to people in the aged care industry (IV2).

This participant found that an active spiritual life was for her a source of personal strength in a job that could be very demanding. Spiritual self-care was mentioned by a few participants only and most of these were working in palliative care. For example, another participant revealed that:

> My work with the dying is often exhausting in that people when they reach that stage in life, they are often throwing off a lot, energetically they are shedding a lot of emotions; they are people that are in pain and there can be a lot of anger and frustration. If you can adapt to their energy by just being present, then it is actually not draining. Then they feel that you are not judging them or not wishing that it was different with them and it gives them an opportunity to explore their situation. It is a way of acceptance… so it is like a circle, it supports you and it supports the client (IV5).

Culliford (2002: 1436) hypothesises that 'to provide spiritual care affords reciprocal benefit', including the benefit of alleviating burn-out. Kellehear (2002: 167) agrees by stating that spiritual care is not something you 'do *to* others but *with* others' [my italics]. The observations of the participant who was quoted above are also confirmed by Mearns and Coopers (2005: 50) who state that 'relational depth' involves a mutuality in care which enriches both the giver and the receiver, with both parties feeling 'fulfilled', 'satisfied' and 'feeling good'. Another participant commented that:

> There is an intrinsic reward in this, knowing that you are doing the right thing, being virtuous maybe. And there is an extrinsic reward, in the sense that clients are more easy to handle, and then there is sometimes the thank you from the family, a reward that is recognition of all the care [that] is given, especially when a client dies (F1:1).

Jenkins (2002: 124) argues that mutuality in spiritual care can be a 'source of nurturance for both'. Furthermore, research by Wasner et al. (2005: 103) indicates that even just a

training program in spiritual care increased the sense of well-being of those who participated in the training.

## 7.5 Conclusion

In this chapter I showed that while many participants showed great willingness and interest in spiritual care, they felt that they did not have enough time for spiritual care-giving within tight work schedules. Furthermore, there was great concern about the lack of spiritual care training, which needs to involve learning about skills and practices, but, most importantly, also explores and cultivates the personal attitudes and beliefs of practitioners. These issues reveal that there is still a long way to go before spiritual care can become a well-integrated part of holistic care for the elderly and dying. Interestingly, competence in such care has unexpected benefits and some participants indicated how having a spiritual orientation made their work not only more effective, but also sustained them in work that was often hard and draining. Engaging with spiritual care, it was suggested could prevented burn-out.

# Chapter 8 Reflections and concluding remarks

> Whether one believes in religion or not, we are all seeking something better in life. So, I think the very motion of our life is towards happiness (Dalai Lama, 1998: 13).

## 8.1 Introduction

In the previous chapters I organised the findings of this research in major themes, which formed a sequence of images and experiences of spirituality and spiritual care-giving. In this chapter I reflect on these themes and gather the different strands together to form a summative and appreciative image of the research findings. I discuss how some important insights emerged from the participants' differing philosophical, conceptual and religious perspectives that were evident in this research. These insights include a genuine tolerance for difference within the different faith communities and a great willingness of religious care-givers to forego devout conversations in order to embrace the client's need for human connections and companionship rather than religious rites. For all participants impediments to engaging in spiritual care included a lack of training, but even more so a lack of time to attend to the spiritual needs of clients. The most important finding, however, is that spiritual care is not so much a matter of doing, but involved a special way of being with patients that infuses all acts of caring, including the more mundane activities such as washing of feeding a patient. I conclude with the insight that, although

most participants commented that they were familiar with providing spiritual care, they were often not able to find adequate words to describe how spirituality illuminated the everyday acts of care.

## 8.2 Dominant narratives in this research

### 8.2.1 Blurring the boundaries of the different religions

Despite the different contexts and backgrounds, participants in this research demonstrated an appreciative understanding and acceptance of spiritual and religious differences. All participants agreed that the client's spiritual needs would guide their interactions and it seemed fairly common to cross the boundaries of the different belief systems. An example of this comes from the Tibetan Buddhist nuns who modified their rituals to invoke Christian imagery and symbols and the chaplain who spoke about an ecumenical approach to spiritual care. Similarly, it was shown that residents in nursing homes often attended church services that were different from their own orientation and prayers were said with those who did not have strong religious beliefs.

Thus, care-givers were able to adapt rituals, beliefs and religious practices or, alternatively, would refrain from the practices and rituals of their own traditions, to suit the client's needs and beliefs. A chaplain would talk about the family or just be a silent presence with a dying client in the hospital and a spiritual care coordinator in a large Christian organisation talked about Australian bush poetry with nursing home residents. Spiritual care by the clergy and lay people alike would, at times, mean nothing more than

being empathic and supportive of another human being, whilst respectfully leaving religion or beliefs at the door.

### 8.2.3 Appreciating what is already there

From an appreciative viewpoint it was clear that many participants were already engaged in providing spiritual care in many ways. Whether their actions were inspired by religious beliefs or attitudes of kindness and compassion, participants felt that they were providing a quality of care that was spiritual and beneficial for their clients. Brykczynska (1997: 2) suggests that such supportive acts of caring may be fueled by moral imperatives or a 'duty of care' and the participants in this research, similarly, described their spiritual care activities as 'supportive' or 'providing peace of mind'; something that was supplied to meet the client's needs.

### 8.2.3 Different models of spiritual care

#### *8.2.3.i A medical mode of spiritual care*

Some authors argue that spiritual care to meet the client's need, as a means to an end- and, thus, as a therapy of healing, is, however well-intended, primarily based on the ubiquitous medical model of care-giving (Kellehear, 2002; Pesut & Sawatzky, 2006). This is not surprising of course, because this remedial, therapeutic approach is currently the dominant perspective in the health care industry. In this scientific model of cause and effect there is little room for spirituality and religion, because they represent fundamentally different worldviews. McSherry (2000: 7) points out that these are fundamentally different inquiries, because spirituality is 'looking into the heart and

meaning of things and people and science into evidence and control'. Henery (2003: 550) warns that the 'new interest in scientifically defined spirituality' does not necessarily embrace 'the personal human capacity for individual freedom and meaning-making', but could easily become another 'technology of healing'. Kellehear (2002: 171) is also concerned that spiritual care could be usurped by an interventionist, expert approach, which means that something that is in essence innate and personal, could become another 'clinical specialism' based on needs, deficiencies and problems. He makes this distinction quite clear by saying that in the medical model:

> Spiritual care is something that we dispense, something that we do *to* others rather than something we do *with* others, because this is part of what we all do [my italics] (Kellehear, 2002: 171).

Participants in this research project also described spiritual care from a predominantly medical perspective. Assessment of spiritual needs and planned interventions needed to become part of the overall care plan and spiritual caring was seen as *a practice* or service, something you did, whether it involved praying, listening to music or acknowledging someone's humanity in small acts of kindness. Such an approach assumes that nurses and other care givers, who were adequately trained could provide for the spiritual needs of their clients. According to Pesut and Sawatzky (2006: 131), however, a medical model of spiritual care would be 'ethically problematic', because it could result in a 'systematic' and 'prescriptive approach to spiritual care' that includes 'spiritual judgment', prescribed interventions and possibly 'undue influencing of clients'.

#### *8.2.3.ii A wellness model of spiritual care*

In contrast to the medical model, some participants in this research made reference to a different approach to spiritual care that involved on a special way of being with patients. This approach to spiritual care was described as reciprocal and as involving a personal, authentic connection, which recognises the other as a spiritual person in their own right. Described as a wellness model of spiritual care, the focus is on a person's strengths and their unique network of connections, beliefs and values. I was very interested in these conversations, because such an approach to spiritual care concurs with my own beliefs. From this perspective spirituality is concerned with a person's lived experience; it demands 'the courage to step into the unknown' and the willingness to respect the other person on a more equal footing (Stanworth 2002: 193). Jenkins (2002: 124) argues that such a perspective involves 'the sharing of vulnerability' and being present to 'the intensity of moment'. This approach to spiritual care is not concerned with an expert approach or spiritual deficiencies, but is interested in the spiritual well-being and inner resources of the client.

#### *8.2.3.iii Reciprocity and self-support*

The medical model relegates spiritual care to being a means to an end, as something that is given or done to someone with a goal in mind. Spiritual care, therefore, may be finite, in short supply or only made available when there is time or energy; in other words its availability is on terms set by the giver. In contrast, some of the participants referred to spiritual care as an end in itself; an interactive way of being that can be applied to every moment or in any situation. In 1968 the Beatles sang: 'And in the end the love you take is

equal to love you make', which clearly suggests a mutuality, which, I argue, is also expressed by the participants in this research.

For these participants spirituality as 'a way of being' supported and sustained them in a job that could at times be very demanding and stressful. In other word, their spirituality supported them as much as it supported the client. Interestingly, mutuality in spiritual care focuses on the practitioner's spiritual well-being, in that, according to Taylor (2002), health care providers need to learn to become more self-aware, to engage in self-reflection and to acquire ability to be present in the moment. These observations are confirmed by research that found that even just training in spiritual care; learning to care in a spiritual way had personal beneficial outcomes for the trainees (Wasner et al. 2005): Nurses who had completed a spiritual care training course had become more aware of their own spirituality and reported higher levels of job satisfaction and wellbeing.

## 8.3 The Yin and Yang of spiritual care

The yin-yang symbol represents ancient Chinese wisdom proclaiming that polarities always carry the seed of their opposite; white contains the seed of black and vice versa. Similarly, the two positions described in this chapter may seem to come from very different angles, however, the yin yang metaphor applies equally here. Spirituality as a means to an end would not be effective if it didn't carry the seed of spirituality as an end in itself. Vice versa, spirituality as an end in itself can and often needs to employ practical and educated means to express itself. A caring relationship that is spiritually meaningful

is therefore not a one-way street, an act of charity and compassion, but becomes a mutually beneficial way of bringing attention and presence to the practice of all health care services: It truly ‘shines from within’ (F1: 1).

The distinctions between doing and being uncovered in this research are not merely semantic; the importance of these differences lies in the possibility of exploring a more secular and non-denominational language of spiritual care. McGrath (2005: 223) argues that this language is informed by ‘values of respect, wonder and reverence’; it is aiming to be respectful of differences and inclusive of religion or spirituality, whilst remaining present and open in the midst of suffering and loss. Kellehear (2002) states that such a language should not be clothed in expert knowledge and deficiencies, but needs to be based in the client’s life world and experiences. A language of spiritual care that is non-religious could present an opportunity for training in spiritual care by being both a vehicle for spiritual/personal self-development and simultaneously an opportunity to learn to care in a more inclusive way. A non-religious language of spiritual care would certainly make it more feasible to include spiritual care training in the curriculum of all health care providers.

### 8.4.1 Common ground

This research project involved participants from different spiritual backgrounds and although not all participants called themselves religious or even practitioners of their faith, most participants professed to either a Christian or a Buddhist orientation. In fact, none were without any belief or faith at all. It was therefore remarkable that the conversations all pointed to one common denominator, which is clearly stated in the

conclusive observations of participants who talked about spirituality as a quality that ‘shines from within’ and was sometimes equated to love. It is not surprising that those feelings were echoed in many ways in the focus groups and interviews. After all, the participants in this research all worked in one or another capacity in aged and palliative care; work that is widely regarded as emotionally challenging and physically draining. Some were volunteers, others had worked as professionals in the field for a long time and, without exception, all spoke with care and love about how to improve their practice to best provide care for their clients. The answer may be that the message of love is present in all religions and all spiritualities. In this research the most pervasive and conclusive explanation of spiritual care is, therefore, that it is not an extra task or burden to be performed, but is to be experienced as a mutually beneficial practice of care for all involved.

## 8.4 Discovering a language for experience:

Spiritual care as a way of being present or as a way of building meaningful relationships was the most prominent theme in this research. In the beginning of the research, when I asked to be more descriptive, participants found it often difficult to verbalise their thoughts or describe the felt quality of spiritual care. It was only in the later focus groups and interviews that the term of ‘being present’ was used to describe the *experience* of spiritual care. Upon further analysis of the data, I discovered, however, that many of the comments earlier on were concerned with attempts to describe the various ways of being present, such as deep listening or holding someone’s hand quietly.

Increasingly used in current nursing literature, the term ‘presencing’, the process of being present, comprises the ability to be physically, emotionally, mentally and spiritually there *with* the client as a person (Taylor, 2002: 90). This means being there for the client without distraction, without expectations and without assumptions; seeing the other person, rather than a patient, a client or a deficiency that somehow needs to be provided for. Participants commented that those moments can involve prayer, physical touch or silence, but that presencing gives a felt quality to that experience, which sets it aside from an interventionist model of care. Pesut and Sawatzky (2006: 235) call this a ‘descriptive approach’ to spiritual care, which does not intervene but ‘makes visible the nurses’ support of patient’s spirituality’.

The language of being present is founded in a rich tradition of religion, spirituality and psychotherapy; it is a familiar concept in the Christian practice of contemplation and the Eastern approach to meditation. Often described as immediacy, being present is also an important component in Gestalt therapy, counselling and many stress relief practices; the therapeutic nature of these ‘alive moments’ is well documented (Fuller & Strong, 2001: 210). Clements (2003: 39) describes this in terms of Buddhism as an ‘engaged presence’ or ‘interrelated presence’.

Presencing thus means leaving your role as a health care provider behind and bringing attention to the *in-between-ness* [author’s italics] that connects you and your client- in that given moment. Thus, presencing is experienced as a reciprocal process; it is no

longer a means to an end but denotes spiritual care as a way of being and an end-in-itself. Kellehear (2002: 169) argues that this approach to spiritual care can invoke ‘the transcendence of meaning beyond the immediacy of suffering’, which is described as a source of ‘hope, courage, acceptance’ for both parties involved.

### 8.4.1 Helping you to help myself

In the previous paragraphs it has been argued that spiritual care is much more than providing a service for someone else. This understanding is most poignantly expressed in the brochure of a volunteer bereavement counselling service, which was set up by one of the participants who had lost her husband in an untimely and unexpected way. In a brochure of the bereavement service there is a startling statement that sums up the findings of this research very succinctly by saying ‘I am helping you to help myself’.

## 8.5 Further research opportunities

This research points to the need for further exploration into practitioners’ experiences of spiritual care as an end in itself, because I believe that it could provide important insights for the future of spiritual care in the health services. Another important area of research involves the possibility that this model of care has as an added benefit that it could reduce or diminish the danger of burn-out for professionals in the health care industry. It is important to note that Wasner et al. (2005) have reported a similar finding, which also denotes the beneficial effects of raising awareness of spirituality in training.

Most participants in this research commented that they had not received any formal training in spiritual care-giving and felt quite ill-prepared and at times confused about the nature and extent of this task. At the time of writing this thesis, there was very little research into the scope, content and effect of spiritual care training programs. As spiritual care is considered an important issue in the aged and palliative care industry, adequate and appropriate formal education and training programs for the health services can no longer be overlooked and further research is recommended.

In this research, a Buddhist perspective on spirituality and spiritual care was presented together with a more conventional, Western perspective. Participants who had an affiliation to Buddhism often seemed to verbalise their spiritual experiences with considerable ease. Buddhism, which could be described as a non-theistic religion, offers rich insights into the experience and practice of spirituality. Furthermore, the language used in the Buddhist literature on death and dying is often surprisingly accessible and non-denominational. There is very little academic research, however, that takes this perspective into account; I believe that such research would be invaluable in developing and enhancing an inclusive and rich language of non-denominational spirituality.

## 8.6 On a personal note

I acknowledge that my orientation towards a Buddhist spiritual philosophy combined with a postmodern perspective of spirituality could be perceived as a possible research weakness or bias. I believe, however, that mostly my spiritual orientation is an

opportunity and strength in this research. In retrospect, at its worst, it favoured a non-theistic approach to spiritual care, which would not focus on religious perspectives and at its best my standpoint enabled me to ask important questions about the prevailing expert nature and means-to-an-end perspective on spiritual care in much of the literature. Described as the medical model of spiritual care in this thesis, this perspective is present in popular conceptions and would also at times prevail in the research data. I believe that the perspective I chose supported an exploration of a community health model of spiritual care, with a focus on with what happens between people rather than how spiritual care can be bestowed onto people. I included in this research voices that are less frequently heard in the academic world, in this case the participants with a Tibetan Buddhist orientation. This moved the focus away from a medical model of spiritual care. I believe that my personal interest made it possible to provide a communicative space where spiritual care could be explored as a reciprocal, inclusive way of being that nurtures human flourishing.

## 8.7 Conclusion

This final chapter brought together the different themes and strands that emerged from conversations about spiritual care in aged and palliative care services. An appreciative view showed that many participants in this research were already engaging in spiritual care, even if they were not so sure about what it all entailed. Broadly, two different models of spiritual care emerged from the findings. The first model is based in the ubiquitous medical model of care, which focuses on spiritually oriented activities and

interventions with the aim to provide a holistic and therapeutic service for the clients. Although well intended, it was shown that this approach is in danger to commodify spiritual care as a means to an end. The other model involved a reciprocal way of being with a client that is spiritual in nature, often expressed as being present and aware in the moment. It was shown that these approaches are complementary and therefore allow spiritual care to be part of the everyday activities of health care service. Such an existential approach to spiritual care requires less of an expert knowledge base and is more concerned with self awareness and the ability to hold the space for the experience of spirituality. However, the research concludes that at present there is little fluency in a nonreligious language of spirituality.

# Epilogue

Three years ago I embarked on this journey of exploration into practices of spiritual care. I had chosen spirituality, because it is the guiding principle in my life and the aged care perspective, because it is one of Southern Cross University's research strength. At that time I was employed by this university as an associate lecturer in the counselling major of the Social Sciences Bachelor degree, a job I would be happy to hold until the time of my impending retirement. Little did I know that the decision to do my Masters would lead to a job I could not even have imagined! A few months ago, I accepted the position of Spiritual Care Project Officer with the Mid North Coast Division of General Practice; my objective is to raise awareness of and competence in spiritual care in aged and palliative care in this regional area of NSW. My years of reading, studying and talking with practitioners about spiritual care have cumulated in an opportunity to actually do what I suggest in my thesis: to run workshops and create training opportunities that enhance already existing practices and connect these with a language of spiritual care that is inclusive and accessible. It has been suggested that there is a PhD in there, but at this stage of my life I am happy to just focus on this precious job. However, I will document my experiences where I can and hope to be able to share important insights through conferences and publications in the spirit of the concluding Traditional Tibetan Buddhist invocation:

: May we dwell in the open heart

May we tend to whatever clouds the heart

May we be awake in this moment, just as it is

May the awakened heart be extended to all things

# ATTACHMENT A (on university letterhead)

**School of Social Sciences**
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**Hogbin Drive, Coffs Harbour 2450**
ABN No. 41 995 651 524
Email: abloemha@scu.edu.au
Phone: 02 6659 3324
Fax: 02 6659 3103

Dear

I am conducting a study, which explores how aged care workers respond to spiritual concerns and issues with their clients, other than those attended to by the clergy. We hope to learn about current practices and possible recommendations for improving these practices. An information sheet (attachment C) providing some more of the background and further information is included with this letter

You are cordially invited to participate in this research project. Your name was suggested in a process called snowballing which started at a meeting of the Directors of Nursing in the Coffs Harbour area. Snowballing means that the DONs or other aged care workers who heard about the project have suggested that you may be interested. Alternatively, you may have heard about the project via an information sheet that was distributed to the DONs for public display in the nursing homes, and have indicated your interest to me.

If you are willing to participate you are required to attend a series of up to 3 focus groups, which will be held at the Coffs Harbour Education Campus to discuss spirituality in an aged care context. The focus groups will consist of 8-10 participants and take about 2 hours each.

All participants will be given the opportunity to refuse involvement in the focus groups at several points:

1) After receipt of the letter and information sheet
2) When arrangements are being made to attend the focus group/interview
3) At the beginning of the focus group meeting, interview itself.

At any time during the focus groups/interviews the participant can refuse further involvement.
Informed consent will be sought by signing a consent form. Implicit in the notion of informed consent is the ability of any participant to withdraw consent at any time during the process

The focus groups will be tape recorded, with the consent of all participants, but no names or identifying information will be recorded or used in the reporting phase of this research. All information is entirely confidential and your anonymity will be ensured.

Because the research is based in action research, general discussion points will be provided initially to develop rapport and an understanding of the area of inquiry, as listed below.

**Initial issues for discussion in the focus groups and interviews.**

How do you understand and experience spirituality?
What do you see as major sources of spiritual support for their clients?
In which way are you involved in discussing or otherwise engaging in meeting their clients' spiritual needs?
If engaging in this work, how well are you prepared and trained for this?
How is this work acknowledged and supported?

I am an academic staff member at the School of Social Sciences, Southern Cross University and will be conducting the research and facilitating the focus groups. Thank you for considering to participate. And I will ring you in the next week to ascertain your interest in becoming involved, and to let you know the date for the focus group. You are free to participate or not as you wish. Please feel free to contact me or my supervisor if you wish to ask any questions. We will be happy to answer any queries you may have.
Yours sincerely,
Anna Bloemhard

**Researcher** Details
Anna Bloemhard
Associate Lecturer, School of Social Sciences, SCU
Tel: 02 66 593 324, abloemha@scu.edu.au
**Supervisor** Details
Ms. Jean Griffiths, senior lecturer, School of Social Sciences, SCU
Tel. 66593 106, jgriffit@scu.edu.au
OR if you have any problems associated with this project, please contact:
Mr John Russell , Ethics Complaints Officer
Graduate Research College, SCU
(02) 6620 3705 jrussell@scu.edu.au

**ATTACHMENT B** **(on university letterhead)**

# RESEARCH PROJECT:

# SPIRITUALITY AND AGED CARE: HOW DO WE CARE?

# INFORMATION SHEET

I am conducting a study into spirituality and aged as part of a Masters by Research in the School of Social Sciences, Southern Cross University, Coffs Harbour Campus.

## The aim of the study is:

1) To identify how carers in the aged services define spirituality.

2) To explore the issues related to meeting the spiritual needs of aged people.

3) To identify strategies and impediments to meeting those needs.

4) To explore the implications for education of aged services workers regarding spirituality.

## Significance

In a predominantly secular world, an increasingly ageing population is facing significant life changes, which may need considerable support and professional care, e.g. moving to a home, loss of spouse, loneliness, decreasing abilities and impending ill-health and death. There is a positive correlation between client coping skills and well-being, and culturally appropriate, spiritual care. Little attention is given in the Australian context as to how aged care workers are to address these important spiritual issues with their clients. Furthermore there is little agreement and understanding what spiritual care encompasses. This research project seeks to provide a better understanding of current local, rural practices in relation to spirituality and their meaning and importance in the aged service industry. Although it is a local study located in the Coffs Harbour region, it is expected that the findings will provide recommendations for key areas of research of global importance.

## Research plan

A series of focus groups and interviews will be conducted over a period of three months. The research will be informed by an Action Research framework, which allows for dialogue and inclusiveness, an important consideration given the multi-disciplinary and multi-layered understandings of the term spirituality. In the focus groups general questions will be asked initially to develop rapport with the participants and an understanding of the area of inquiry. Instead of a list of questions there will be a list of issues, which will be addressed (see Initial Issues for Discussion, below). The task of the facilitator/researcher is to encourage deep listening and collegial feedback and dialogue, whilst at the same time clarifying and summarising the emerging themes.

**Initial issues for discussion in the focus groups and interviews.**

- How do you understand and experience spirituality?
- What do you see as major sources of spiritual support for aged services clients?
- In which way are aged care workers involved in discussing or otherwise engaging in meeting their clients' spiritual needs?
- If engaging in this work, how well are they prepared and trained for this?
- How is this work acknowledged and supported?

**Informed consent and details about withdrawal from the research**

All participants will be given the opportunity to refuse involvement in the focus groups and interviews at several points:

1) After receipt of the letter and information sheet

2) When arrangements are being made to attend the focus group/interview

3) At the beginning of the focus group meeting, interview itself.

4) At any time during the focus groups/interviews the participant can refuse further involvement.

Informed consent will be deemed to have been given when the participants sign the consent form implicit in the notion of informed consent is the ability of any participant to withdraw consent at any time during the process. If participants decide to withdraw consent during a focus group session or interview then this will be respected.

## Confidentiality

Should you decide to participate in this research, your confidentiality and anonymity will be assured in the following way:

The focus groups will take place at the Coffs Harbour Education Campus and be tape recorded but comments will not be attributed to specific individuals nor their organisations during the data analysis or through the writing of the report. From the tape and transcripts, quotations will be used to illustrate developing themes. Thus, the data will be analysed in relation to themes and perceptions and these processes ensure anonymity and confidentiality to all participants. The tapes and transcripts will be stored under lock and key for five years as required, and thereafter will be destroyed.

Thank you for your time and interest in this project. I will ring you in the next week to ascertain your interest in participating in this project. Please feel free to contact me or my supervisor if you wish to ask any questions. We will be happy to answer any queries you may have.
Yours sincerely,

**Researcher** Details
Anna Bloemhard
Associate Lecturer
School of Social Sciences
Southern Cross University
Coffs Harbour 2450

**Supervisor** Details
Ms. Jean Griffith,
Tel. 66593 106,
jgriffit@scu.edu.au

OR if you have any problems associated with this project, please contact:
Mr John Russell
Ethics Complaints Officer
Graduate Research College
(02) 6620 3705
jrussell@scu.edu.au

## ATTACHMENT C (on university letterhead)

**School of Social Sciences**
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**Hogbin Drive, Coffs Harbour 2450**
ABN No. 41 995 651 524
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Phone: 02 6659 3324
Fax: 02 6659 3103

Dear

I am conducting a study, which explores how aged care workers respond to spiritual concerns and issues with their clients, other than those attended to by the clergy. At present, several focus groups are meeting and discussing the issue. We hope to learn about current practices and possible recommendations for improving these practices. An information sheet (attachment C) providing some more of the background and further information is included with this letter. At the meeting on 13th April of the Directors of Nursing I presented this research project and asked for collaboration to broadcast invitations to aged care workers in the field who would like to participate in the focus groups.

Additional to the focus groups, I would like to conduct interviews with some of the key leaders in the Aged Services field to enrich the picture that is emerging from the focus groups. For that reason I was also seeking information at that meeting as to who should be involved in the elite interviews, Your name was mentioned and following the telephone conversation we consequently had**,** this letter formally invites you to participate in the research by way of an interview. The interview may take up to 1 hour in a location at your convenience, either at your work office, or if that is more suitable at the Coffs Harbour Education Campus

With your permission, the interview will be tape recorded, but no names or identifying information will be recorded or used in the reporting phase of this research. All information is entirely confidential and your anonymity will be ensured. A transcript of your interview will be send to you for checking an/or possible comments and additional information. In all cases, the tapes and transcripts will be securely locked away for 5 years, to ensure confidentiality and privacy.

Because the research is based in action research and in a qualitative methodology, general discussion points will be provided initially to develop an understanding of the area of inquiry.

## Initial issues for discussion in the focus groups and interviews.

How do you understand and experience spirituality?
What do you see as major sources of spiritual support for aged services clients?
In which way are aged care workers involved in discussing or otherwise engaging in meeting their clients' spiritual needs?
If engaging in this work, how well are they prepared and trained for this?
How is this work acknowledged and supported?

**Informed consent and details about withdrawal from the research**

You will be given the opportunity to refuse involvement in the interviews at several points:

1) After receipt of the letter and information sheet

2) When arrangements are being made to attend the focus group/interview

3) At the beginning of the focus group meeting, interview itself.

4) At any time during the focus groups/interviews the participant can refuse further involvement.

Informed consent will be deemed to have been given when tyou sign the consent form.

Implicit in the notion of informed consent is the ability of any participant to withdraw consent at any time during the process.

I am an academic staff member at the School of Social Sciences, Southern Cross University and will be conducting the research, the interviews and facilitating the focus groups. Thank you for considering to participate and I will ring you in the next week to ascertain your interest in becoming involved. You are free to participate or not as you wish. Please feel free to contact me or my supervisor if you wish to ask any questions. We will be happy to answer any queries you may have.
Yours sincerely,

Anna Bloemhard
**Researcher Details**
Anna Bloemhard, associate lecturer, School of Social Sciences, SCU
Tel: 02 66 593 324, abloemha@scu.edu.au

**Supervisor** Details
Ms. Jean Griffiths, senior lecturer, School of Social Sciences, SCU
Tel. 66593 106, jgriffit@scu.edu.au
OR if you have any problems associated with this project, please contact:
Mr John Russell , Ethics Complaints Officer
Graduate Research College, SCU
(02) 6620 3705 jrussell@scu.edu.au

## ATTACHMENT D (on university letterhead)

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Phone: 02 6659 3324
Fax: 02 6659 3103

# SOUTHERN CROSS UNIVERSITY
# INFORMED CONSENT FORM for FOCUS GROUPS

## Name of Project: Aged Care and Spirituality: How do we care?

You are invited to participate in a study, which will be exploring how aged care workers approach spiritual concerns and issues with their clients, other than those attended to by the clergy. We hope to learn about current practices and possible recommendations for improving these practices.

Added: You are invited to participate in this research project and your name was suggested in a process called snowballing which started at a meeting of the Directors of Nursing in the Coffs Harbour area, where I presented the project. Snowballing means that other aged care workers who heard about the project have suggested that you may be interested. Alternatively, you may have heard about the project via an information sheet that was distributed to the DONs for public display in the nursing homes, and have indicated your interest to me.

You are invited to participate in a focus group, at the Coffs Harbour Education Campus, which will meet 3 times to discuss spirituality in an aged care context. The duration of each focus group will be 2 hours and a suitable time will still have to be arranged after discussion with all participants. The focus groups will consist of 8-10 participants. Your participation is entirely voluntary and you can withdraw your consent at any time.

The focus groups will be tape-recorded, with the consent of all participants. From the tape and transcripts, quotations will be used for the study. However, comments will not be attributed to specific individuals or their organisation to ensure anonymity and confidentiality to all participants. The tapes and transcripts will be stored under lock and

key for five years as required in the supervisor's office, and thereafter will be destroyed. Subsequent to the research, there will be no further access to the data at any time.

**Possible Discomforts and Risks**
Because the research focuses on spirituality and aged care, there may be a risk that the discussions will touch on an area of human experience that can provoke intense, private and deep feelings and emotions. Although you are able to leave at any time, or invited to withdraw active participation at any time, you may need to consider these risks carefully, when deciding whether to participate or not. Support and debriefing will be part of the nature of the focus groups and in case of distress, will be followed by a personal contact two days after the event. However, if counselling is needed the following persons have agreed to act in this role:
Ms. Johanna Treweeke, counsellor, 66 522 745
Ms. Joanna Johnston, counsellor, 66 593 263

**Responsibilities of the Researcher**
Any information that is obtained in connection with this study and that can be identified with the subjects will remain confidential and will be disclosed only with your permission.

**Responsibilities of the Subject**
(We expect you to discuss openly and provide relevant information, which could affect the value of the research. As stated before, you can withdraw your consent to participate at any time.

**Freedom of Consent**
If you decide to participate, you are free to withdraw your consent and to discontinue participation at any time. However, we would appreciate you letting us know your decision

**Inquiries**
If you have any questions, we expect you to ask us. If you have any additional questions at any time please communicate these questions to us:

**Supervisor Details**
Ms. Jean Griffiths,
Tel. 66593 106,
jgriffit@scu.edu.au

**Researcher Details**
Ms. Anna Bloemhard abloemha@scu.edu.au
Associate Lecturer
School of Social Sciences
Southern Cross University
Hogbin Drive, Coffs Harbour, 2457
tel 0266593324, fax:0266593103

We will be happy to answer any queries you may have.

OR if you have any problems associated with this project, please contact:
Mr John Russell
Ethics Complaints Officer
Graduate Research College
(02) 6620 3705
jrussell@scu.edu.au

You will be given a copy of this form to keep.

*I have read the information above, or contained in a separate information sheet entitled....., and agree to participate in this study. I am over the age of 18 years.*

Name of Subject:

Signature of Subject: Date:

*(Signature of parent or guardian if subject is under 18 years of age)*

Name of Witness (who shall be independent of the project)

Signature of the Witness: Date:

*I certify that the terms of the form have been verbally explained to the subject, that the subject appears to understand the terms prior to signing the form, and that proper arrangements have been made for an interpreter where English is not the subject's first language. I asked the subject if she/he needed to discuss the project with an independent person before signing and she/he declined (or has done so).*

Signature of the researcher:.....Date: .....

## ATTACHMENT E (on university letterhead)

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**Coffs Harbour Education Campus**
**Hogbin Drive, Coffs Harbour 2450**
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Phone: 02 6659 3324
Fax: 02 6659 3103

## SOUTHERN CROSS UNIVERSITY
## INFORMED CONSENT FORM (for Interviews)

### Name of Project: Aged Care and Spirituality: How do we care?

You are invited to participate in a study, which will be exploring how aged care workers approach spiritual concerns and issues with their clients, other than those attended to by the clergy. We hope to learn about current practices and possible recommendations for improving these practices.
You are invited to participate in this research project and your name was presented to me in a process called snowballing in elite interviewing, which means that a previous interviewee suggested your name, or alternatively you volunteered after hearing about the project at a meeting of the Directors of Nursing in the Coffs Harbour area.

You are invited to participate in a personal interview, at the Coffs Harbour Education Campus or a location at your convenience. The interview will take approximately one hour at a suitable time. Your participation is entirely voluntary and you can withdraw your consent at any time.

The interview will be tape-recorded, with your consent and a transcript of the interview will be sent to you for checking and further comments, if you wish so. From the tape and transcripts, quotations will be used for the study. However, comments will not be attributed to specific individuals or their organisation to ensure anonymity and confidentiality to all participants. The tapes and transcripts will be stored under lock and key for five years as required in the supervisor's office, and thereafter will be destroyed. Subsequent to the research, there will be no further access to the data at any time.

**Possible Discomforts and Risks**
Because the research focuses on spirituality and aged care, there may be a risk that the discussions will touch on an area of human experience that can provoke intense, private and deep feelings and emotions. Although you are able to withdraw active participation at any time, you may need to consider these risks carefully, when deciding whether to participate or not. Support and debriefing will be part of the nature of the interview and in case of distress, will be followed by a personal contact two days after the event. However, if counselling is needed the following persons have agreed to act in this role:
Ms. Johanna Treweeke, counsellor, 66 522 745
Ms. Joanna Johnston, counsellor, 66 593 263

**Responsibilities of the Researcher**
Any information that is obtained in connection with this study and that can be identified with the subjects will remain confidential and will be disclosed only with your permission.

**Responsibilities of the Subject**
We expect you to discuss openly and provide relevant information, which could affect the value of the research. As stated before, you can withdraw your consent to participate at any time.

**Freedom of Consent**
If you decide to participate, you are free to withdraw your consent and to discontinue participation at any time. However, we would appreciate you letting us know your decision.

**Inquiries**
If you have any questions, we expect you to ask us. If you have any additional questions at any time please communicate these questions to us:

**Supervisor** Details
Ms. Jean Griffiths,
Tel. 66593 106,
jgriffit@scu.edu.au .....

**Researcher** Details.....
Ms. Anna Bloemhard
Associate Lecturer

School of Social Sciences
Southern Cross University
Hogbin Drive, Coffs Harbour, 2457
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fax:0266593103
abloemha@scu.edu.au

.....

We will be happy to answer any queries you may have.

OR if you have any problems associated with this project, please contact:
Mr John Russell
Ethics Complaints Officer
Graduate Research College
(02) 6620 3705
jrussell@scu.edu.au

You will be given a copy of this form to keep.

*I have read the information above, or contained in a separate information sheet entitled....., and agree to participate in this study. I am over the age of 18 years.*

Name of Subject:

Signature of Subject: Date:

*(Signature of parent or guardian if subject is under 18 years of age)*

Name of Witness (who shall be independent of the project)

Signature of the Witness: ..... Date: .....

*I certify that the terms of the form have been verbally explained to the subject, that the subject appears to understand the terms prior to signing the form, and that proper arrangements have been made for an interpreter where English is not the subject's first language. I asked the subject if she/he needed to discuss the project with an independent person before signing and she/he declined (or has done so).*

Signature of the researcher:..... Date: .....

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