**“LET MY SPIRIT ALWAYS SING”: A DESCRIPTIVE STUDY OF HOW
FOUR ELDERLY REST HOME RESIDENTS VIEW SPIRITUALITY
AND SPIRITUAL CARE AT THE END OF LIFE.**

by

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ABSTRACT

Over the last twenty years spiritual care has become recognised increasingly as an important component of holistic care, care that nurtures the spirit as well as addressing the person's physical and psychosociocultural needs. This descriptive, qualitative study, believed to be the first of its kind conducted in a New Zealand setting, focuses on spirituality issues of a spiritually vulnerable group of people, older people in residential care. From this group of people I recruited four Rest Home residents who were prepared to talk to me about their spirituality, spiritual needs and how their spirits were nurtured, the role of care staff in providing spiritual care, and their satisfaction with the spiritual care they were being offered. They were also asked to predict their spiritual needs as they were dying, their wishes for spiritual care in the perideath period, whether they had communicated these wishes to anyone, their views on advance planning to ensure these wishes would be met, and their comfort with the research process. The research data was collected from semi-structured, audiotaped interviews that were later transcribed.

The spirituality of all participants had a strongly Christian focus that was revealed in the ten themes to emerge from a modified application of Colaizzi's analysis technique. The first themes to emerge were God as the focus of spirituality, God in control, the importance of relationship, and the purpose in life: serving God. Changes in spirituality with age, spirituality and residential care, and spiritual care: whose responsibility? were also identified as themes, as were end of life spirituality, planning for spiritual care, and the participants' satisfaction with the research process. All were able to articulate their spirituality, were generally satisfied with the spiritual care they were receiving, and had views on the spiritual care they wished to receive in the perideath period. Moreover, the participants trusted their families and the care staff to ensure that these wishes would be honoured.

Recommendations are made for improving the spiritual dimension of care, and for further research. Similar research, for example, should be carried out in different residential care settings, especially in the “for profit” sector. Research should also be undertaken to gauge the awareness care staff have of residents’ wishes for spiritual care in the perideath period.

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Finally, I must acknowledge with gratitude my Heavenly Father, who holds me firmly in the palm of His hand, and in whom I put my trust. Thank you!

A DEDICATION

A hymn on growing older, *Let my spirit always sing* (Murray, 1996) has informed the title of this thesis and is included with the permission of lyricist, Shirley Erena Murray, and composer, Professor Jenny McLeod. It articulates many of the sentiments expressed during the interviews and is a fitting tribute to the extraordinary women, Jane, Songbird, Steep, and Theresa who participated in the study, and who trusted me sufficiently to share on such a deep and personal level, the treasures of their spiritual selves.

Let my spirit always sing

HYMN ON GROWING OLDER

① WINTERING ♩ = 104 Jenny McLeod

1. Let my spi-rit al-ways sing, though my heart be win-ter-ing,
2. Though my bo-dy be con-fined, let your word en-gage my mind,

⑤

though the sea-son of des-pair give no sign that you are there, God to whom my
let the in-ner eye dis-cern how much more there is to learn, see a world be -

⑩

days be-long, let there al-ways be a song.
co-ming whole in the win-dow of the soul.

last time

3 Let your wisdom grace my years,
choose my words and chase my fears,
give me wit to welcome change,
to accept, and not estrange,
let my joy be full and deep
in the knowledge that I keep.

4 Let my spirit always sing,
to your Spirit answering,
through the silence, through the pain
know my hope is not in vain,
like a feather on your breath,
trust your love through life and death.

Shirley Murray

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**SETTING THE SCENE FOR A STUDY
ON SPIRITUALITY AND SPIRITUAL CARE**

This study, believed to be the first of its kind in a New Zealand setting, has the potential to improve the spiritual care provided for older people in a residential care setting. It is a qualitative, descriptive study that explores the spirituality and spiritual care issues of four older people living in a Rest Home. This chapter provides the backdrop for the study, initially describing the spiritual challenges that may be faced by people as they age. The Services for Older Persons' environment in New Zealand and how spirituality and spiritual care fits into this context are then described. I also endeavour to position myself as researcher into this environment, and explain why I am particularly interested in this dimension of care. The study central to this thesis is then outlined and the seven research questions clearly identified. Finally, an overview of the remaining chapters is provided.

Spirituality and ageing

For many people in mid-life, their sense of who they are is linked inextricably with what they do, the roles they assume in society, the value placed on these roles by others, and their perception of their success in these roles. Furthermore, the urgency of everyday life and the competitiveness of the workplace may mean, for some, little opportunity to explore what gives their lives meaning aside from these roles. When the balance between these roles is altered, as it is when the person retires and the focus moves from career or paid work, to activity in and about the home or in the community, some older people begin to question the worth, not only of their current situation, but of their past and future as well. MacKinlay (2001a) suggests that as the older person becomes more frail and the physical effects of the ageing process prevent them from being able to do many of the things they did in the past, simply "being" may become more important than "doing" as issues involving meaning are appraised and conclusions drawn

as to their worth. This is particularly so in the Western world where the concept of retirement originated. Jewell (1999) reminds us that, in many other cultures, older people continue to contribute to the economy of the family and community in which they live, up until the time they die. As a result, they continue to hold on to the sense of their own value.

The terms ‘third age’ and ‘fourth age’ are commonly used to refer to the period towards the end of life. The third age refers to the seventh and eighth decades, while the fourth refers to the remainder of one’s life (Jewell, 1999). The majority of those in the third age continue to enjoy reasonable health and lead active and fulfilling lives. However, as they face the challenges of a physically ageing body, their ability to achieve essential wellness incorporating wellness of the spirit and the psychosociocultural domains rests in their ability to transcend or rise above the chronic diseases or physical disabilities they may be experiencing (MacKinlay, 2001a). This may pose a significant challenge when disability, for example, impacts on the older person’s “personhood” as it relates to their identity and self-esteem. Jewell (1999) warns that this is even more likely in a society that tends to be ageist and marginalising of older people, making them feel that they are a burden on the rest of society. Even for the majority of elderly people in the Western world who retain comparatively good health, the reduction in their ability to contribute to the financial security of the household, as has already been noted, may similarly impact on their sense of “personhood”.

I argue that older people, reflecting on their lives past, present and future, can no longer avoid the fundamental existential, spiritual questions which younger people often shrug off with the attitude, *why worry, that’s a lifetime away!* Jewell (1999) suggests that as we age we consider the existential questions, *What is life really all about?* and *What will it be like to die?* Furthermore, I suggest that our own personal philosophies and belief systems would also have some bearing on the nature of the questions we might ask ourselves. From a Christian faith perspective, I may grapple with questions such as, *Is there anything after death?* and *Does God really exist, and if he does, will he give me credit for trying my best in this life?* as I recognise that I am in the last years of my life and seek to find final meaning. Some people, myself included, may draw on their faith

backgrounds to eventually make sense of their lives, yet we cannot assume that older people who had a deep and unquestioning faith commitment in earlier years will face death with welcoming confidence and an aura of serenity. Speaking from many years of experience as a Minister of the Church, and Chaplain to a large Aged Care provider organisation in the United Kingdom, Jewell (1999) cautions that these people are just as likely to experience deep and serious doubt as the end of their life approaches, as those who have never had a faith. He notes that many will now confess to believing far less than they did in their earlier days. Furthermore, the prospect of diminishing faith as death approaches is recognised by some older people even as they continue to retain a strong faith in health. For example, an older friend of mine with a deep awareness of her own spirituality recently shared with me her contemplation of her own death: “I would like my own death to be like some of those I’ve witnessed as a nurse – calm, joyful, with a glimpse of heaven that I can reach out to as I make my transition from life to death. Deep-down however, I’m not totally sure that my death will be like that, that I won’t be anxious and afraid when I’m on my own death bed.” I suspect that for all of us, there is that element of uncertainty.....

Jewell (1999) suggests that older people face death from one of two perspectives and that this shapes their spirituality as they age. The first involves older people wanting to seek reconciliation with others, with their God, and with themselves so that they can die at peace. The second perspective entails a search for integrity and wholeness that transcends the physical dimension. Pulling together the threads of their lives and making sense of the whole as best they can is part of this process.

Older people in New Zealand

An ageing population

Compared with OECD (Organisation of Economic Cooperation and Development) countries, New Zealand has a young population with only 11.5% of people aged over 65 years in 2001. The proportion of older people is expected to rise however, up to 13% in 2010 and then even more rapidly to 22% by 2031 and 25% by 2051 (Ministry of Health, 2002b). Increases in the numbers of Maori

and Pacific older people will be particularly significant over the next 50 years, with a 270% increase in the proportion of Maori aged over 65 years and a more than 400% increase in the proportion of Pacific people in this age group. Other ethnic minority populations, for example Asian, while also relatively young at present, are projected to increase significantly (Ministry of Health, 2001). It should be noted, however, that while projected increases of older Maori in the general population will be significant, gains for Maori health lag behind those of Pakeha (white New Zealanders, typically of European descent), and the gap is widening in the life expectancy of the two groups (Reid, 2003). Durie (1998) asserts that when links between health, power, economic prosperity, fair representation, control, and autonomy are laid bare, then the Treaty of Waitangi, the founding document of the partnership between Maori, as tangata whenua (people of the land), and the British Crown, is seen to have major significance for the health of Maori.

Older New Zealanders in residential care

Of the 11.5% of the population in New Zealand over 65 years of age in 2001, 1.8% of those in the age group 65-74 years were living in residential care settings. In the group 75–84 years, 5.9% were in residential care. This percentage escalated for the “old old” that is, the group aged 85 years and over. Of these, 27% resided in residential care environments because their physical or mental frailty prevented them from being able to live independently in the community. In 2001 this group comprised 29,100 New Zealanders but is expected to increase significantly, particularly between the years 2010 and 2040 (Ministry of Health, 2002a). Although older people may be healthier for longer into the future and the Ministry of Health is not expecting the proportion of elderly requiring residential care to increase significantly above the 1.8%, 5.9% and 27% already stated, the numbers of elderly people in this situation will increase because of the rapid growth in the number and proportion of older people. This situation will impact significantly on the cost of health and disability support services, inevitably increasing the pressure on health funding.

Now and in the future, the significant number of older people living in residential care is a justification for inquiry into the specific needs of this group, including

needs relating to the spiritual dimension. The multicultural nature of the general population provides for diversity across all facets of daily living. The rise in the Pacific Island and Asian populations adds a further dimension to how spirituality is understood in New Zealand. I suggest that as more older people enter residential care, individual staff members will need to develop a broader understanding of spirituality and spiritual care and realise that as with any aspect of care, a “one size fits all” package is not appropriate when assisting someone to meet their spiritual needs. The above notwithstanding, however, Maori and Pacific Island peoples prefer to care for their elders at home and generally, from my experience, it is only those with moderate to late dementia and those requiring continuing care who are admitted to residential settings. I suggest that as the principle of tino rangatiratanga (Maori sovereignty, self determination and self-actualisation), promised in Article Two of the Treaty of Waitangi (Durie, 1998) is implemented more fully, Maori will establish a broader range of services to meet the care needs of their kaumatua (older people) for whom the spiritual dimension of care will be very important. The spiritual dimension as understood by Maori will be discussed in more detail in the next chapter.

It is my personal view that if the funding body does not understand and/or value the spiritual dimension of care, justification will be made for factoring it out of the range of services they will be prepared to fund. Support for the spiritual dimension might be found in a clause of a contract or a standard which must be met but without its cost being recognised and incorporated into the price for service that is paid to the provider. I suggest that this has already started to occur. In the late 1990s, one Regional Health Authority in New Zealand paid a slightly higher daily rate to providers of residential services for older people if they had a chapel on site. However, with the advent of a national contract and a consistent price paid to all providers, this price differential was abandoned.

The residential care industry in New Zealand

O'Brien (1999) suggests that a residential care setting for older people has a number of defining characteristics. To begin with, the average age of residents in care is in excess of 80 years. Most are widowed or single, and women outnumber men by approximately 3:1. Many have arthritis and/or cardiovascular disease,

and many have at least some degree of dementia. Moreover, many have impaired hearing or vision or both, and most require some assistance with the activities of daily living. Although writing about the United States experience, the same might apply in the New Zealand setting and probably in the remainder of the Western World.

In New Zealand, the public health sector has devolved residential care services for older people to private providers. Two categories of providers compete to provide residential services for older people and across the nation both have approximately 50% of the sector business. The first category, the “religious and welfare” providers, generally have linkages to church groups or charitable trusts. Although they are deemed “not for profit” organisations, the reality is that they endeavour to make a profit to enable them to grow their businesses. The “for profit” providers are the second category. They run their businesses as commercial enterprises. Increasingly, large companies are operating the “for profit” sector, with many sites throughout the country. Both categories receive government funding in exchange for service provision, although residents are means tested and have to pay for their own care until their financial resources have been depleted to the Government threshold for funding assistance.

There are four levels of residential care in New Zealand. A Rest Home (termed Hostel in Australia, Residential Care Home in Britain, and Assisted Living or Community Based Residential Care Facility in the United States), accepts frail older people who need assistance with many of their activities of daily living. A Continuing Care Hospital (termed Nursing Home in both Australia and Britain, and Skilled Nursing Facility in the United States), accepts residents who require 24 hour registered nursing input and are too dependent to be cared for in a Rest Home. The third level, Dementia Care, provides dementia specific care in a secure environment. The residents who meet the criteria for this service have advancing dementia and require a secure environment to manage their wandering tendencies. The fourth level is Psychogeriatric Care, catering for older people with significant challenging behaviour issues who cannot be managed appropriately in the dementia care setting. Facilities providing care at levels one

to three may also offer respite care for older people being cared for in the community, thereby allowing time out for their fulltime carers.

Continuing Care Hospitals in New Zealand must have a registered nurse on duty 24 hours per day. Rest Homes and Dementia Units, however, are not required to provide this although there must be adequate registered nurse input to carry out the care planning activities of each resident, supervise and train the staff, and be responsible for the medication management within the Facility. Care workers provide the greatest “hands on” input into service delivery. While some have had minimal training, many others have formal, nationally recognised qualifications in caring for and supporting older people. Furthermore, the current contract between the Ministry of Health and Providers of Dementia Specific Services require that all care workers complete specified training within a certain time frame of commencing employment. When “care staff” are referred to in this thesis, I am referring to both nurses and care workers.

The importance of spiritual care?

The admission of an older person into a residential care facility is, in my experience, a time of stress for him or her. After weeks or months of failing health, and uncertainty about such things as the appropriateness of the decision to go into care and whether or not their health might improve sufficiently to allow them to retain at least some degree of independent living, they must grapple with the admission process, meet new people, become accustomed to a different environment, and cope with people asking endless questions. Questions about spiritual needs are frequently overlooked, however, yet spiritual issues may be especially significant for people in crisis. Marcoen (1994) argues that questions pertaining to spirituality often arise on a conscious level during critical life periods when previously available sources of wellbeing are unavailable. It is likely many older people experiencing a number of losses on both the physical and social fronts will start to question the meaning of their lives in the period leading up to and then following their admission into residential care. The ignoring of unsatisfied spiritual needs can have serious consequences for the resident’s total wellness.

The researcher

I acknowledge the particular perspectives I bring to this study with my personal background, and the relevance of the spiritual domain to my own life. For many years I expressed my spirituality exclusively within a religious framework. Now, although I remain committed to the faith of my fathers, I celebrate my own spirituality more broadly by including my relationship with self, others, my environment and with God. My spiritual self is nurtured within these relationships and I have clear views on how I would want this nurturing to continue when and if I can no longer advocate for myself at the end of my life. These I have made known to family and friends and trust that they will be honoured if my life ends in circumstances where spiritual care is possible.

My personal definition of spirituality has developed over time and has been influenced by the reading I have done in recent times. Definitions provided by Lloyd (2004), Ross (1997b) and Speck (2002), referred to more fully in the next chapter, were the most convincing and have had most impact on the framing of my own. I define my spiritual dimension as the integral essence that causes me to seek relationship with myself, others, the environment, and a power outside of myself, enabling me to rise above the immediate and find purpose and fulfilment, hope, faith in self and others, the will to live, and eventually to find existential or ultimate meaning in life. For some people, as with me, the beliefs, rituals and practices of a religious creed nurture their relationship with God who they perceive as that power outside of themselves. For others whose spirituality is humanistic in nature, the power outside themselves with whom they seek relationship may be, for example, the environment, a guiding philosophy, or another individual or group of other people (Burnard, 1988; Elkins, 1988).

Experiences which fostered an interest in the spiritual dimension of care

My 35 years as a nurse and more recently the eight years spent in management of Older Persons' Residential Care Services provided me with a number of experiences bringing me to the conclusion that on the whole, spiritual care is poorly provided for. I include here a sentinel anecdote from my professional experience that had a part to play in shaping this view:

In my role as Senior Manager of Clinical Services in a large provider organisation, I was responsible for staff development and was often called upon to facilitate in-service training sessions in Rest Homes or Continuing Care Hospitals. Sessions on spirituality and meeting the spiritual needs of residents were often requested, and during one training session a care worker shared an anecdote of a situation that had occurred several days earlier. A resident was found unconscious in the bathroom having had a severe cerebral vascular accident and died several hours later, in her own bed at the Rest Home. The family were called and several adult children and grandchildren chose to come and maintain a vigil at her bedside as she struggled through her final hours. From all accounts the resident and her family received appropriate physical and emotional care during this time – her airway was monitored and maintained, she was turned regularly, her mouth was kept moist and her hygiene requirements were attended to. The family were offered refreshments, additional seating and space, and the opportunity for as much private time with their mother as possible.

This scene is common in a New Zealand Rest Home. Some residents may be transferred to acute care but an increasing number of relatives request that their loved one be allowed to die in the place that has become their home. What concerned me (and the staff member who initiated the discussion), was that during the course of that day the staff member had enquired of the family whether they wished the priest to be summonsed. The response of the resident's son was a very clear: "No thanks very much! We are definitely not having any of that." As a result, the staff complied with the expressed wishes of the family – ignoring the fact that the resident was a devout, practising Catholic. During the five years she had been resident in the Rest Home she had retained her links with Catholicism and with as many of its practices as possible, given the limiting

effects of her increasing frailty. I believe that for this woman, her life's practices pointed very clearly to what her end of life wishes would be: to have the priest at her deathbed to administer the final rites of the Church which had sustained her for some eighty five years. From this incident, I learnt that the answers to the questions: "who is the client?" and "for which client must the nurse advocate first and foremost?" are not always clear-cut, especially when the patient him or herself is no longer able to express their wishes, and the wishes of the family are in conflict with the presumed wishes of the patient. The staff attending the in-service training session hotly debated the issue. A number of people, including the Manager, argued that the family was just as much a client as was the resident herself, especially since it was the family in that situation who paid for their mother's care. Eventually, most agreed that staff should be aware of the interventions required to meet all the needs of their residents, and are in fact empowered to implement these when required. Calling the priest to the resident should have been seen in the same light as calling the doctor and family, and gaining permission should not have been deemed necessary.

From my experience, many care staff are unsure about just what constitutes spirituality and spiritual care. During the many in-service education sessions I conducted on the spiritual dimension of care, I noted that most staff equated spirituality solely with adherence to some religious ethos. This narrow view was also reflected in the Care Plan, the guide to individualised client management, where the obligatory section pertaining to spiritual needs seldom contained more than a comment on whether or not the resident attended the "in-house" church service. Generally, the staff I encountered in the Older Persons' Services Sector did not recognise spiritual need; and even if they did would see it as being the exclusive domain of clergy, and themselves having little or no responsibility in this area.

In 2001 I received the Christian Healthcare Trust Study Award to travel to Australia and Britain to study the delivery of residential services for older people, specifically the spiritual dimension of care. I observed that in comparison with my experience of New Zealand, some religious and welfare providers of older persons' services in the United Kingdom seemed to place greater

importance on the spiritual dimension of care. This was reflected in the extensiveness of their documentation guiding spiritual care, spiritual care practices at site level, and staff understanding about the importance of providing this aspect of care. It was also interesting to note that the Scottish Executive had recently written guidelines for the spiritual care of patients in National Health Service organisations (Scottish Executive, 2002). From this increased awareness of the importance of spiritual care in the health sector per se, I can only assume that the quality of spiritual care for nursing home and residential residents in Scotland will continue to improve. But what do elderly residents think? Do they believe that their spiritual needs are being met appropriately?

The residents' perspective

If, for the most part, elderly people in residential care are satisfied with the spiritual care they receive, then maybe staff understanding and how the care plan guides it become less important. Spiritual need is defined as a lack of any or all of the elements required for spiritual wellness: meaning, purpose and fulfilment in life; the will to live; and belief and faith in self, others and God. Spiritual care involves making arrangements for the provision of interventions to address patients' spiritual needs (Ross, 1997b). Although I knew of no specific research into spirituality issues of older people in New Zealand, I was aware of a Scottish study carried out by Ross (1997a) in Edinburgh, revealing the views of older hospitalised clients that nurses failed to address their spiritual needs. Earlier studies, while not focusing specifically on older people, concluded that spiritual needs arising for individuals during periods of hospitalisation were only partly addressed, or not at all, especially by nurses (Stallwood-Hess, 1969; Kealey, 1974; Martin, 1976). These studies all supported the view that nurses could have a role to play in providing spiritual care by such actions as listening to their clients, "being there", and facilitating the referral of clients to spiritual directors. Unfortunately, many participants in the aforementioned studies believed that nurses were too busy to be concerned with such things. Other studies have indicated that nurses feel unprepared to provide spiritual care, signalling to nurse educators and curriculum developers the need to incorporate more of this

important aspect of care into basic nursing education programmes (Chadwick, 1973; Piles, 1986; Narayanasamy, 1993; Ross, 1996). There is also evidence that people want support when they are dying. A Gallup Poll (Gallup, 1997) indicated that people wish to have support to become spiritually at peace as they are dying.

The study

The aim of the study

The specific aim of the study was therefore to explore the spirituality of four older people in residential care, and the meaning that had for them at the end of their lives.

The research questions

The study centred around seven research questions:

1. How do four elderly people in Residential Care perceive their spirituality and how this has changed as they have aged?
2. Do the study participants have spiritual needs?
3. If so, do they believe these are being met, and by whom?
4. Do the study participants have specific wishes for spiritual care now and in the perideath¹ period?
5. Have they communicated these wishes to anyone?
6. Do the study participants have views on how they can ensure their wishes for spiritual care in the perideath period will be honoured?
7. Have the study participants been at ease talking about their spirituality and intimate end of life issues?

A description of the study

Spirituality and spiritual care issues of older people in Rest Homes was the focus of this study, and it was from this group of people I recruited four residents who were prepared to talk to me about their spirituality, spiritual needs and how their

¹ I define the perideath period as that period from when death is imminent ... maybe days, hours, or minutes prior to death, during or at the time of death, and immediately after death. This later period is culturally determined by the eschatological belief system of the individual.

spirits were nurtured, the role of care staff in providing spiritual care, and their satisfaction with the spiritual care they were being offered. They were also asked to predict their spiritual needs as they were dying, their wishes for spiritual care in the perideath period, whether they had communicated these wishes to anyone, their views on advance planning to ensure these wishes would be met, and their comfort with the research process. A descriptive, qualitative methodology was employed. The research data was collected from semi-structured audiotaped interviews that were later transcribed. A modified Colaizzi method of data analysis was used to identify and describe the emergent themes (Colaizzi, 1978). The significance of the study was its uniqueness to a New Zealand Rest Home setting, and its potential for raising awareness in the health sector of the importance (or unimportance) of spiritual care.

The next chapter presents an overview of the literature reviewed in order to shape the present study and refine the questions to be answered. Gaps in the literature that might be filled by ongoing research are also identified. Chapter Three describes the methodology chosen, and a summary of research findings is presented at the beginning of Chapter Four which goes on to explore the themes to have emerged from the data analysis phase. Ten themes emerged, five discussed in each of Chapters Four and Five. Chapter Six discusses the implications of the study findings for funders and providers of services for older people, nurses, care workers and support staff, and for spiritual care at the end of life. The limitations of this study are also acknowledged in this chapter, and recommendations for further research are made. Chapter Six ends with a reflection on the research process and some concluding remarks.

SPIRITUALITY AND SPIRITUAL CARE: THE LITERATURE

Since the late 1980s the body of research on spirituality per se and spiritual care has increased so much that one might be forgiven for surmising that it has become fashionable to study, write and publish in this expanding area of human concern. Reviewing published research and commentary in this field enabled me to refine the research questions. The object of this chapter is to specifically highlight the literature that led to the research questions identified in Chapter 1. Literature relating to the importance of spirituality for Maori, and spirituality as a component of nursing theory is also reviewed briefly.

My sources included books, full-text journal articles accessed from the electronic databases (CINAHL, Proquest, Cochrane Library, and Expanded Academic ASAP), conference proceedings and journal articles. Key-words used in the electronic database searches included “spirituality”, “spiritual needs”, “spiritual care”, “spiritual care and nursing”, “spirituality and ageing”, “spirituality and older persons”, “spiritual needs and elderly”, “spiritual needs and residential care”, “spiritual needs and long-term care”, “spiritual needs and dying”, “spiritual care and dying”, “spiritual care and nursing homes”, “advance directives”, and “advance directives and spiritual care”.

Understandings of spirituality and spiritual dimension

There are many definitions of spirituality, a concept which is, to many, subjective, unique, universal, mysterious, complex, personal, sensitive, and private (McSherry, 2002). A common theme to emerge, however, was that religion and spirituality are not synonymous – many people are deeply spiritual without adhering to any particular set of religious beliefs or ideals. Spirituality is a broad term within which religion is one aspect, and together or separately they provide a framework for interpreting the things that happen, and for coping with

life (Davidhizar, 2000). Blockley provides further clarification: “Both religion and spirituality involve a sense of meaning and purpose in life, provide a source of love and relatedness, and help keep believers in relationship to the unknown and unknowable” (2001, p.15). She goes on to explain the distinction made in the literature between the two terms, making it clear that the beliefs or practices of a church or other organised religious institution relate specifically to “religion”.

Aside from the distinction between spirituality and religion, there are diverse understandings of spirituality and the spiritual dimension : Elkins and Hedstrom take the view that spirituality is a humanistic phenomenon, the word being derived from the Latin *spiritus*, meaning “breath of life”, and is “a way of being and experiencing that comes about through awareness of a transcendent dimension and that is characterised by certain identifiable values in regard to self, others, nature, life, and whatever one considers to be the Ultimate” (1988, p.9). Ross defines the spiritual dimension as “that element within man, from which originates: meaning, purpose and fulfilment in life; a will to live; belief and faith in self, others and God, and which is essential to the attainment of an optimum state of wellbeing, health or quality of life” (1997b, p.11). Speck (2002) has a similar understanding. He suggests that spirituality is a search for existential or ultimate meaning within life experience, with reference to power other than self. He asserts that this belief/power can help a person transcend the ‘here and now’ experience and establish hope. Speck suggests that the word ‘God’ may be used to describe that power but it may often be less specific, involving terms like “higher power”, “forces of nature”, or “powers within the universe”.

Finally, the retired Australian geriatrician, Dr Murray Lloyd, shared with me his understanding of spirituality in a personal communication in 2003, prior to it being accepted for publication:

Spirituality is the part of our life experience that is processed by the human spirit. The human spirit is the centre of energy that works to give continuous meaning to our lives and nourishment to our inner being. By surveying and appraising our connections with the environment and in relationships, it creates dialogue within ourselves’ through which we

privately weigh up the meanings of deeper aspects of life experiences, - visible and invisible – positive and negative – past, present, and future. For many, a relationship with a life force represents an important and challenging part of this process (Lloyd, 2004).

The common threads to emerge from these understandings may connect spirituality to religion, but not necessarily so. Spirituality as a source of strength, enabling a sense of purpose and meaning in life, facilitating peace with oneself, a feeling of security; inner strength, searching, coping, hoping, relationship, and connectedness emerge from the definitions above and are some of the threads also identified by Narayanasamy (2001) in his exploration of spirituality. Individuals experiencing a state of spiritual wellness, irrespective of whether or not they have a religious faith, can experience all of these.

Each of the views of spirituality identified above was applicable to this study, but as indicated in Chapter One, those of Ross (1997), Speck (2002), and Lloyd (2004) impacted most significantly on how I understood spirituality throughout the project. Influenced by my own worldview, and by the way my own understanding had been shaped by an exploration of the literature, the writings of these scholars found particular resonance with me.

Spiritual needs

Spiritual needs are described in the literature from either a negative or positive perspective: when a negative stance is taken, the focus is on deficit or the lack of some essential ingredient for optimal wellness. As indicated in Chapter One, Ross, for example, defines spiritual need as “a lack of any or all of the following which are required to produce spiritual wellbeing: meaning, purpose and fulfilment in life; the will to live; belief and faith in self, others and God” (1997b, p. xv). When a positive perspective is taken, however, needs are understood as the requirements of wellness. The well-known hierarchy of needs as described by Maslow in DiCaprio (1974) is an example of this. When needs are identified in this manner, the question might be asked as to whether these needs are being met?

In their Judeo-Christian approach to spirituality, Shelly and Fish (1988) have listed three spiritual needs: the need for meaning and purpose, the need for love and relatedness, and the need for forgiveness. The work of Highfield and Carson (1983) also acknowledges specific spiritual needs. These nurse researchers explored the understandings that some surgical nurses have of spiritual issues and concluded that the needs for meaning and purpose in life, to give and receive love, hope and creativity (all identified as spiritual needs) had to be met if the individual was to achieve optimum wellness. Narayanasamy (1991) represents a further broadening of the boundaries of spiritual needs. He identifies the following needs which must be met for optimal spiritual wellness, the last four being particularly relevant to the provision of holistic nursing care: the need for meaning and purpose, for love and harmonious relationships, forgiveness, a source of hope and strength, creativity, trust, expression of personal beliefs and values, expressions of God or deity, and the need for spiritual practice.

Several studies, all in the United Kingdom, reported such spiritual needs as search for meaning, peace and prayer (Chomicz, 1984; Simsen, 1985, 1986, 1988) and I was interested to discover whether similar spiritual needs would be identified in the present study.

Spirituality, Maori, and Maori health

Given that the present study would be undertaken in a New Zealand Rest Home, I believed it was important to gain some understanding of how spirituality is perceived by Maori. Although, as indicated in Chapter One, fewer Maori enter Rest Homes compared with pakeha New Zealanders, the ageing population will eventually see larger numbers of older Maori in need of residential care services. Spirituality has long been recognised by Maori as an integral component of an individual's being and indeed health, and since 1982 has been represented metaphorically as one side of a four sided house (whare tapa whā). The whare tapa whā model was developed to represent the contemporary Maori way of thinking (Durie, 1998). The four components, taha wairua (spiritual), taha hinengaro (mental), taha tinana (physical), and taha whānau interact, and are all

seen as necessary to ensure strength and equilibrium. Taha wairua, the spiritual dimension, is believed by many to be the starting point for health. As Durie explains, it is understood by Maori to be “one’s capacity for faith and wider communion and acknowledges that health is related to unseen and unspoken energies” (1998, p. 69). Knowledge of one’s cultural identity is fundamental to spiritual wellness, and whakapapa (genealogy) and tikanga (customs) are part of this.

In accordance with the broader understanding of spirituality, Durie (1998) makes clear that the spiritual dimension includes religious beliefs but is not synonymous with them. Belief in God is a reflection of wairua (spirit), but so too is relationship with aspects of the environment such as the mountains, lakes, rivers and land, all of which have special spiritual significance.

From the perspective of this study, the spiritual beliefs of Maori are particularly relevant. Durie (1998) explains that as the deceased person’s spirit lingers in the space between this world and the spirit world, Maori feel the spiritual presence not only of their loved one, but of their ancestors as well, enabling them to derive a sense of continuity with their past. This accounts for the urgency with which Maori need access to the body of their deceased as soon as possible after death, especially if for some reason they have not been able to be present at the time of death.

Spirituality and spiritual needs in ageing

MacKinlay (2001b) studied the spiritual dimension of older people living independently in the community. Her findings were further tested in in-depth interviews with older people in residential care settings. Spiritual developmental tasks were derived from the themes to emerge from the data, the accomplishment of which would allow the individual to achieve wholeness. Identifying what brings ultimate meaning, finding appropriate ways to respond, transcending disabilities and loss, searching for final meanings, finding intimacy with God and/or others, and finding hope, were the spiritual tasks identified. Both Leetun

(1996) and MacKinlay (2001b) argue that the spiritual dimension should continue to grow until the time of death, and MacKinlay (2001b) suggests that as people move closer to death and can no longer avoid the reality of their own mortality, achievement of these spiritual tasks becomes a matter of urgency for them.

Researchers have acknowledged that spirituality is an important factor in personal wellbeing and indeed the mental health of older people (Highfield, 1992; Levin and Taylor, 1993; Levin, Taylor and Chatters, 1994). Indeed, Marcoen argues that if an older person has a spiritual outlook on life “they are better able to cope constructively with the vicissitudes of life” and will feel secure into advanced old age (1994, p. 521). Leetun (1996) warns, however, that for some people their spirit may be lost as a result of functional decline that causes their sense of identity and connection with others to be threatened. Krach, DeVaney, DeTurk and Zink (1996) support this view.

Krach et al, (1996) included spiritual assessment in a study involving older people living in a United States community setting. The Spiritual Wellbeing Scale (SUBS) was developed for the purpose. Concurring with the research of Burkhardt (1994) which suggested that the primary theme of spirituality is that of relationship – with self, others and God, Krach et al. found that participants identified relationships with other people, particularly family, as being important in assisting them to find meaning and purpose in life. They also noted that many participants saw positive attitude, self-determination, and prayer as being important for coping with chronic illness, pain, and other difficulties. Although the study by Krach et al was set in the community, I suggest that these findings may be relevant in residential care settings as well. For those people for whom life is centred on visits from family, and for those striving to make sense out of the infirmities of later life, positive attitude and nurturing relationships are all-important.

Spirituality, spiritual needs, and meeting the spiritual needs of older people in residential care

Bland Trice (1990) warns that older people in residential care are at greater risk of feeling that life has lost its meaning for them. She suggests that the reason for this may lie in the notion of personal devaluation, discussed earlier by Storlie (1982). Storlie suggests that as older people endeavour to conform to society's expectation of the elderly, a process of personal devaluation occurs which is particularly evident in residential care environments where personal autonomy may be altered or removed. Loss of control over an ailing body and activities of daily living, as well as the removal of useful activity, contributes further to this, resulting in spiritual distress. Brown (2001), writing about older people in residential care, provides indicators of spiritual distress and makes recommendations to nurses for strategies to manage this.

In a 1991 study undertaken by Pardue, long-term care patients' perceptions of their spiritual needs were identified and compared with the perceptions the chaplains in the same setting had of the spiritual needs of their patients. Significantly, the chaplains' views differed markedly from the views of the patients themselves (Pardue, 1991). The reasons for this discrepancy were unclear but Pardue had two suggestions: that chaplains did not spend long enough in nursing homes to be able to adequately assess residents' spiritual needs, and that chaplains often failed to recognise the spiritual distress of residents still adapting to residential care, presuming them to be in a state of spiritual well-being already. Consequently, inappropriate or inadequate pastoral care may have resulted.

In another study, Ross (1997a) invited ten older people in an Assessment Unit in Edinburgh, Scotland, to give their views on issues pertaining to spiritual need and spiritual care. Eight admitted to having experienced spiritual need at some time during their lives, six while in hospital. The types of need experienced related to religion, meaning, love and belonging, morality, and death and dying.

All participants agreed that staff in the Unit could have met their spiritual needs more appropriately.

A question arising for me at this point is whose responsibility is it for spiritual care? Do pastoral care workers have primary responsibility for this, and to what extent are nurses and other care staff expected to take responsibility for meeting patient's spiritual needs? Do recognised theories of nursing acknowledge the spiritual dimension?

Spirituality in nursing theory

Many nurse theorists make either direct or implied reference to spirituality and spiritual care in their models of nursing and other writing. Calabria (1990), Cook (1913) and Widerquist (1992) have all written on Florence Nightingale's spirituality that was focused on devotion to God and evident in her writings. She believed that God had created laws that gave order to the universe. Nightingale eventually applied these laws to nursing, stating that nursing was obliged to place the patient in the best possible condition for Nature (God) to act (Nightingale, 1946). In writing about Florence Nightingale's view of holism, Torres (1990) suggests that Nightingale saw humankind as multidimensional and as a consequence of this a person could not experience physiological illness without their psychological, social and spiritual components being affected as well. Watson (1999) also stresses the importance of the spiritual dimension. Drawing on the work of Levin (1993), she argues that for over a century, research has demonstrated a statistical association between spirituality, variously defined, or religiousness and various health outcomes. She also suggests that nurses are better able to sustain caring-healing relationships if they foster their own spiritual practices with prayer, meditation, yoga, or imagery practices (Watson, 1999). Neuman (1989) considers the spiritual variable to be an intrinsic element of the whole, whether the individual acknowledges or develops it or not. In her view, the spirit controls the mind and the mind, either consciously or unconsciously controls the body either positively or negatively. Neuman clearly believes that spirituality is a vital component of nursing, and calls for careful spiritual needs

assessment to inform interventions that promote spiritual health, encompassing hope and the will to live, or at the end of life, peace and acceptance.

It would seem then, that since its earliest days, nursing has been concerned with body, mind, and spirit, and its body of knowledge has developed accordingly. Ellerhorst-Ryan (1985) argues, however, that nurses' knowledge of the human spirit has lagged behind. In practice, nurses still tend to view the spirit as primarily concerned with religious practices and often relegate any spiritual care that needs to be given to the chaplain (Carpenito, 1983; Highfield and Carson, 1983; Sodestrom and Martinsonk, 1987). But what about clients? Do they believe that nurses and other care staff have some responsibility for spiritual care? I was unable to find any research or other literature to answer these questions and so I signal them as possible avenues for exploration in the future.

Wishes for spiritual care at the end of life

I found only one study that reported people articulating the spiritual care they hoped to receive in the perideath period. A 1997 survey conducted by the George Gallup International Institute asked people of all ages to look ahead into the future and imagine the kind of care they would like to receive in their dying days. Spiritual care was revealed as a common theme among the majority of participants who thought it important to have someone help them to become spiritually at peace (Gallup, 1997).

Advance directives in residential care settings

An Advance Directive is a document setting out the person's preferences about future treatment they would want to have or wish to refuse if they were in a condition that prohibited them from making their views known (Age Concern, 2001). The document should be reviewed and amended over time if necessary, to ensure that changes in medical technology are taken into account and that they still reflect the person's wishes.

The Self-Determination Act of 1990 in the United States required all nursing homes and hospitals to discuss health care directives (living wills) with each new admission (Herman, 2002). Moreover, court decisions in the United States and in Britain have led to an understanding, at least in these countries “that advance directives can be legally effective as regards refusal of treatment if properly drafted and if they apply to the situations that arise” (Age Concern, 2001). However, this situation may not necessarily be applicable in New Zealand where there is currently no statutory authority for advance directives and the legal standing of them when they do exist is yet to be tested.

There were conflicting findings in the literature over whether people understand the concept of advance directive. Hague and Moody (1993) surveyed 137 adults and noted that 57% to 79% were familiar with many of the elements involved. On the other hand, in a somewhat later study, Schiff (2000) questioned 74 medical inpatients and learned that 82% had never heard of advance directives or even living wills. Of the 13 who stated that they had heard of them, only four defined them correctly. Other studies found that residents in residential care settings believed that clinicians and their families were responsible for the end of life decisions and that they themselves had very little say (Palker and Nettles-Carlson, 1995). Moreover, they did not see the need to document end of life care wishes, trusting that others would act in accordance with their wishes (Winland-Brown, 1998).

The concept of advance directives in the studies cited above related specifically to patients’ preferences for physical treatment options in the event of their being unable to advocate for themselves. With the exception of the writings of Herman (2002), I noted a paucity of advance directive literature including spiritual care. Herman comments that advance healthcare planning provides an occasion for considering the spiritual aspects of living, ageing and dying, and also for addressing “the challenges of diversity and the various beliefs and cultural practices about health and wellness, as well as illness and death” (2002, p. 233). Herman is concerned, however, that the process of gaining an advance healthcare directive, particularly with frail elderly approaching death, is often handled as a “procedural checklist, without consideration of the spiritual implications inherent

in discussing end of life” (2002, p. 228). He urges those who are assisting others with making advance directives to consider the spiritual dimension, suggesting that when this component is taken into account, end of life planning becomes more than merely a routine. It is a ritual involving activities which serve a profound purpose and to which symbolic meaning is attached. Moreover, he suggests that such a ritual can maximise self-determination for the elderly at a time when they feel most vulnerable.

Although both should be considered in advance health care planning, the spiritual dimension must be distinguished from the religious. For the most part, the religious component is more easily quantified and involves details concerning selection of ministers, funeral arrangements, burial/cremation requests etc. The spiritual dimension on the other hand is not so clear-cut and requires that a degree of trust exists between the older person and the professional assisting them with making the directive. Spiritual questions might include the meaning of life and death, the significance they give to their body and the mode of its disposal, and the sanctity of their internal organs in relation to organ donation. To assist the process of comprehensive advance health care planning, the University of Minnesota Department of Continuing Education has developed a tool that includes specific questions about physical, spiritual and religious wishes (Herman, 2002).

Shaping the research questions from the literature

The questions to be answered in this study were designed to either determine the relevance of what had arisen in the literature to a New Zealand setting, or to attempt to fill identified gaps. Much has been written about spirituality, and many people have attempted to define the concept, including the three scholars, Ross (1997), Speck (2002), and Lloyd (2004) mentioned above. The growing body of literature on spirituality and ageing points to the development of a very specific spirituality as people grow older, and as has already been noted, Jewell (1999), MacKinlay (2001) and Krach (1996) identify characteristics of spirituality in older people and their spiritual developmental tasks. The first

question, therefore, was designed to confirm the findings of these scholars in a New Zealand setting:

1. How do four elderly people in Residential Care perceive their spirituality, and how has this changed as they have aged?

Ross (1997), Storlie (1982), Bland Trice (1990), Pardue (1991) and Uhlman and Steinke (1985) have all suggested that for varying reasons, older people in residential care might be at risk of not having their spiritual needs adequately met. Research of Chomicz (1984) and Simsen (1986) had also signalled this to be the case for patients in orthopaedic, medical and surgical wards in Britain. I planned to explore the notion of whether the study participants perceived themselves as having spiritual needs, and whether they believed these were being met while in the Rest Home environment. I referred earlier in the chapter to some of the literature attesting to the responsibility care staff have for providing spiritual care, and I queried whether residents, or in this case research participants, would see it in the same way. This influenced the framing of my second and third research questions:

2. Do the study participants have spiritual needs?

3. If so, do they believe these are being met, and by whom?

Given the paucity of research on spiritual care at the end of life, I was curious to know whether some older people in Rest Homes perceived spiritual care as being important, and whether or not they saw it as being something they would plan for. Therefore, the fourth, fifth, and sixth research questions were shaped as follows:

4. Do the study participants have specific wishes for spiritual care now and in the perideath period?

5. Have they communicated these wishes to anyone?

6. Do the study participants have views on how they can ensure their wishes for spiritual care in the perideath period will be honoured?

A question that arises from my own professional background but which hasn't been identified in my literature search, concerns the difficulty older people might have in discussing their spirituality, especially the spiritual issues they consider might arise as they approach the end of their lives. I suspect that for some, death is a taboo subject and any exploration of this requires considerable sensitivity. I was anxious to learn whether some, or all of the study participants had become ill at ease during the research process, in spite of agreeing to take part. The final question therefore was:

7. Have the study participants been at ease while talking about their spirituality and intimate end of life issues?

To conclude, much has been written about spirituality and this chapter provided only a brief overview of some of the literature relevant to the present study. What is evident is that spirituality is an important component of holism, and spiritual wellness an essential ingredient of health. As people age and move into the final chapter of their lives, their spirituality takes on a different focus as they seek to find final meaning. Coping with the infirmities of old age may precipitate spiritual distress for some, and those in residential care are particularly at risk. Although nurse theorists argue that spiritual care that aims to prevent or address spiritual distress is a component of nursing, many nurses fail to incorporate it into their practice. What was unclear from my review of the literature, however, was whether older people in residential care saw nurses and care staff as having a role in spiritual caring, and whether they were able to articulate their wishes for specific spiritual care in the perideath period. The next chapter describes how the present study, designed to explore spirituality issues and implications for end of life spiritual care, was undertaken.

SPIRITUALITY STUDIED: METHODOLOGY AND DESIGN

This chapter describes how the study was conducted. Issues involving the rigour and congruence of the project are addressed, as well as ethical considerations. The method of data collection, and the interview questions designed to capture this data are then outlined. The chapter then goes on to describe the research setting, how the participants were selected to take part in the study, and to introduce the participants. Finally, an overview of how the data was analysed is provided.

Designing the study**Justification for a descriptive, qualitative study**

As the size and scope of the study precluded using a phenomenological or grounded theory approach, I came to the view that a descriptive technique would be most appropriate for finding answers to the research questions shaped by my review of the relevant literature. Parse describes the descriptive method as a mode of inquiry originating in the social sciences. “It is a method which yields findings based upon conversations and observations ... which focuses on discovering the meaning of an event in time” (1985, p. 91). By using this method I hoped to be able to uncover the participants’ perception and interpretation of their reality and how this impacted on their behaviour. Polit, Beck and Hungler suggest that the strength of this methodology is to provide an “accurate portrayal of the characteristics of persons, situations or groups and the frequency with which certain phenomena occur” (2001, p. 643) since it requires the researcher conducting the descriptive investigation to observe, count, describe, and classify.

The descriptive method does have limitations. It seeks to describe phenomena rather than to offer more classically scientific explanations of cause and effect (Polit, 1991). Nevertheless, Harrington (1993) used the descriptive method

effectively in her study of registered nurses' perceptions of spiritual care. In her methodology section she makes the following point:

No research is conducted in an intellectual vacuum and there are explanations to be found within the data themselves – in the understandings, meanings, and values inherent in the data, and therefore in the attitudes and motivations inherent in the data. These are explanations of a different kind from scientific explanation and, while they are offered more tentatively and provisionally, with only the descriptive data themselves to serve as warrant to their validity, they are valuable nonetheless (p.26).

Harrington goes on to warn that the explanation for the descriptive data should be given with caution and with an indication of other variables that might impact on it. With regard to the present study for example, a categorical statement that older people are able to articulate their spirituality would be fraught with the potential for criticism since a number of variables may have impacted on this conclusion being reached, not the least of which would be participant bias. Nevertheless, I chose to apply a qualitative, descriptive methodology to this study because of its congruence with the research questions and the scope of the study. From the outset, I hoped that the importance (or lack of importance) of the spiritual dimension in the lives of four elderly Rest Home residents would be revealed, and that subsequent researcher would use the study as a platform for more extensive explorations of spiritual need and spiritual care of older people at the end of life.

Rigour

Koch (1996) suggests that there is a lack of consensus around the notion of rigour in qualitative research but warns that the legitimacy of knowledge is dependent upon the researcher demonstrating that the study is trustworthy and believable. In her view, the researcher must select the criteria appropriate to the study to demonstrate this. For the purposes of this study I selected the four criteria of Lincoln and Guba (1985) to guide the research process and facilitate the rigour of the project. Credibility, dependability, confirmability, and transferability are these criteria and their appropriateness for judging the trustworthiness of this study will now be explained.

Credibility

Credibility refers to “confidence in the truth of the data” (Polit et al., 2001). Not only does a project need to be carried out in a way that is believable, but steps need to be taken to demonstrate credibility (Lincoln and Guba, 1985). The authors suggest a number of techniques for demonstrating credibility, and from these I chose prolonged engagement, member checks, and researcher credibility.

Although I spent no more than three hours in total with each participant during the investigation, prolonged engagement was achieved through the intensity and intimacy of the interaction that resulted from the nature of the area of concern, allowing sufficient time for data collection.

External checks on a study may be made through peer debriefing and member checks (Polit et al., 2001). To “member check” my research findings I returned my initial findings and interpretations to the participants and noted their reactions. All four participants agreed with my findings. Lincoln and Guba (1985) suggest that member checking is the most important strategy for establishing credibility although Polit et al. (2001) warn that one can never be totally sure that the participants are not agreeing with your findings merely to be seen as cooperative.

Data source triangulation also demonstrates the credibility of a study. Denzin (1989) and Polit et al. explain that triangulation “provides a basis for convergence on the truth” (2001, p. 313). When several perspectives are used, flawed information is more likely to be distinguished from information that is true. Some degree of data source triangulation was possible in this study because although the participants were similar on one level, i.e. their spirituality was focused on their belief in God, they represented four diverse backgrounds and faith experiences.

Dependability and confirmability

Dependability is the second criterion for assessing the rigour of qualitative research. Polit et al. (2001) argue that there can be no credibility without dependability, data that remains constant over time and over variable conditions.

Dependability in this study was achieved by “inquiry audit” (Polit et al., 2001) consisting of scrutiny of the data and supporting documents by my academic supervisor, and through the thesis examination process. Dependability is closely related to confirmability, the third criterion for assessing rigour, and is the objectivity or neutrality of the data to the extent that two or more independent reviewers would agree as to its relevance and meaning. Ultimately, this would be assessed through the thesis examination process.

Transferability

One cannot necessarily assume that any aspects of this study can be transferred to other individuals or populations. Nevertheless, Lincoln and Guba (1985) identify transferability as the fourth criterion for assessing rigour, and Koch (1996) clarifies the concept by explaining that transferability is dependent upon the extent to which two contexts are similar. To meet this criterion, Lincoln and Guba warn that the onus is on the researcher to provide sufficiently descriptive data in the research report to enable the reader to decide whether the data can be applied to other contexts. Taking up a concept originally described by Geertz (1973), Lincoln and Guba describe this data as “thick description” that provides “a rich and thorough description of the research setting and the transactions and processes observed during the inquiry” (1985, p. 316). Nevertheless, Sandelowski and Barroso (2002) caution researchers to avoid excessive detail, numerous quotes, and lengthy case studies, with virtually no interpretation or explanation.

Auditability

In addition to the four criteria identified above, I adopted a fifth: auditability of events, influences and actions of the researcher. Koch (1996) suggests that this criterion is also important for establishing the trustworthiness of a research project since it requires the availability of a decisions paper trail to clarify the research process. Essentially, this chapter describes the theoretical and methodological decisions of the study.

A final point I would make in defence of the rigour of the study involves truthfulness of the participants’ responses. When a researcher wants to know how

people perceive a phenomenon or what they believe, the most direct way of finding out is simply to ask them. Face to face interviews do just this, but they are not without certain weaknesses. I was mindful, for example, of the warning by Polit et al (2001) as to the validity and accuracy of interview responses, although they concede that researchers often have no alternative but to take for granted the fact that most participants have been frank in their responses. They warn readers of research, however, to be aware of the potential biases in data from interview responses that may be less than truthful. Nevertheless, I trusted the information from the four participants in this study. Their sincerity and integrity was apparent to me as I got to know them on a deeper level, facilitated by the subject matter of the interview.

To be credible, dependable, confirmable, transferable, and auditable, research must also be ethical.

Ethical considerations

Any research has the potential for harm, and for the study participants their physical, psychological, emotional, spiritual, social, and financial wellbeing may be put at risk (Roberts and Taylor, 1998). In this study, I identified as most likely the potential for emotional and spiritual harm. The participants revealing more than they intended to, for example, and spiritual disquiet occurring as an aftermath of an interview process requiring their intense existential focusing were anticipated. I recognised the need to protect the participants' rights throughout the research process and identified four ethical concepts as being most applicable to this study: self-determination, informed consent, privacy, and confidentiality.

Self determination

This concept acknowledges the rights of people to determine their own actions. This study involved the participants' right to participate or otherwise after full disclosure of the project had been given to them. Not only did people have the right to refuse to take part, they also had the right to withdraw at any time and

without penalty. This was explained to the potential participants during my first meeting with them, and was included in the Participants' Information Sheet (Appendix 2).

Informed consent

In research, this is the voluntary agreement of the participant to take part in the study. There are two components to this process, the giving of information and the gaining of consent. The prospective participants were given written information to consider prior to deciding whether or not to participate. This information (Appendix 2) identified me as the researcher, the purpose and nature of the study, the right to refuse to participate and to withdraw at any time, the right to have a support person with them during the interview, my responsibilities as the researcher, potential benefits and risks of the study, and the measures to be taken to protect their privacy and confidentiality. Because many older people have impaired vision, the information was provided in an accessible format with a large point-size font.

The Rest Home chaplain made the initial approach to prospective participants and briefly explained the study. Residents who expressed interest and an initial willingness to take part were then given the Information Sheet and Consent Form (Appendix 3) to consider. After they had had time to consider the information they had been given, i.e. at least two days, the chaplain returned for their tentative decision. If they still wished to participate, an appointment was made to meet me for the first time. At this first meeting, as well as to establish rapport, I answered any questions they had about the study and again stressed their right to refuse with no penalty and to withdraw at any time. Anticipating that some older people have hearing difficulties, I spoke clearly during my explanations, faced them at all times, and checked that they had understood. If they still agreed to take part, an appointment was set up for the interview. At the outset of this second meeting I ascertained their continued willingness to participate, had them sign the Consent Form, and reiterated their right to withdraw. Although all were invited to have support persons present during the interview, none chose to do so.

Privacy

It was made clear to the participants before the interviews, their right to disclose only what they felt comfortable with sharing. Conducting the interviews in their bedrooms where the conversations could not be overheard also ensured physical privacy of three of the participants. The participant who preferred to be interviewed in a small lounge room claimed to be claustrophobic in her bedroom and did not mind the fact that people walked through the room during the interview. I felt somewhat uncomfortable about this, having concern that her privacy was at risk. Nevertheless, she insisted she was happy with this situation and indeed the few people who passed through the room did so without lingering.

Confidentiality

Because several staff members and I knew the identity of the participants, I recognised my obligation to keep their research data confidential to avoid their being compromised. Pseudonyms are used in the written report to identify the participants, and any other information that might potentially identify them, specifically excluded. Confidentiality would be protected by safely storing the audiotapes and transcripts in a lockable cabinet in my office. The participants were reassured of the confidentiality of their information both verbally and in writing at the outset. The staff with knowledge of the participants' involvement were also cautioned as to the importance of confidentiality, including not disclosing their Rest Home's involvement with the study. Moreover, the Rest Home and location are not named in this thesis, and neither will they be in any subsequent writing.

Ethical approval process

Formal ethical approval was sought from an Ethics Committee accredited by the Health Research Council, a statutory body set up by the New Zealand Government to oversee issues involving healthcare ethics. Approval for the study was granted after I agreed to return the transcripts to the participants for validation. Originally, I had planned not to return the transcripts to the participants, influenced by Wells (1994) who casts doubt over the validity of making such comparisons. Amongst other criticisms he suggests that participants will vary their responses according to the circumstances in which they are given,

making consistency of response impossible. Nevertheless, returning the transcripts to the participants for checking was a requirement for Ethics Committee approval, and once I amended the application to accommodate this, the approved application was then lodged with the Victoria University of Wellington Ethics Committee.

Method of data collection

The data-gathering phase of the research process comprised single, semi-structured, audiotaped, interviews encouraging a free flow of words and ideas in response to the questions asked, while at the same time keeping the participants on track. I had planned to make field notes of the participants' nonverbal communications and anything else I considered relevant. When the time came, however, I did not do this for fear of interfering with the rapport established with each of the participants.

The purpose of the interviews was to obtain from the participants their descriptions of their spirituality and spiritual needs, and their prediction of spiritual care wishes at the end of life. In order to obtain this information I asked several predetermined questions to ensure that similar territory was explored with each participant and the research questions could be answered. These questions, tested and refined during a "pre-test interview" with a colleague were mostly open-ended and therefore could not be answered merely with a *yes* or *no*. I believed that the interviews should proceed as the worldviews of the participants unfolded, and as the researcher, I was attentive and open to what was being shared, and listened closely for meaning so that I could ask questions relevant to what had already emerged (Fielden, 2003). As indicated in the previous chapter, exploring the spirituality of older people as they approach the end of their lives is an exercise requiring considerable sensitivity, so having flexibility within the method to let things happen as they would was preferred.

The interview questions

The questions I asked were designed to enable me to answer the research questions, which in turn had been shaped by my review of some of the spirituality, and spiritual care literature.

The first question, *“Do you have any way of making sense of things that happen to you?”* was suggested by Speck (2002), designed to open up the individual’s spiritual domain without restricting it to a religious framework.

My second question was: *“What sources of support or help do you look to when life is difficult?”*

The answers to these opening questions positioned the main focus of the participants’ spirituality. I was then be able to use carefully worded probes, determined by the course of the conversation, to encourage them to talk more deeply about their spirituality and spiritual needs, what it meant for them at that time, and the spiritual care they saw as appropriate for them then. Some of the probing questions included: *“So you were brought up in the Christian faith...does that mean that God is an important part of your life and how you make sense of the things that happen to you?”* and *“Is there anything else that nourishes your spiritual life ... (I would wait for a response, and if necessary offer a prompt) ... music, for example?”*

The third question, *“Has your understanding of your own spirituality changed as you’ve got older?”* was influenced by MacKinlay (2001a) and Jewell (1999) and designed to establish whether the participants had insight into how their spirituality had altered as they had aged. Probes to allow for a deeper understanding included *“Has your relationship with God changed as you’ve got older?”* and *“Since you’ve been in the Rest Home has your spirituality changed in any way?”*

Based on evidence that some health service users considered that their spiritual needs were not always addressed while in hospital settings (Ross, 1997a), I was interested to learn whether the participants felt their spiritual needs were being

met at the facility, and also whether the participants saw the care staff as having any part to play in this. Consequently, the fourth, fifth, and sixth questions were as follows: *“Have you any specific spiritual needs now?”* *“Do you think your spiritual needs are being adequately attended to here?”* and *“Do you think the staff here have a part to play in your spiritual care?”*

The seventh question was: *“Looking ahead now to the time when you are actually dying, do you imagine you will have specific spiritual needs and wishes for spiritual care at that time?”* A probe I used then was *“What about just after you have died and before your body is laid to rest, is there any spiritual care you would want then?”* This was justified as a key concern in the absence of evidence that this question had been asked in any previous study.

The eighth question, *“Have you told anybody, or written it down anywhere, about the spiritual care you want at this time?”* arose from the absence of research evidence making connections between advance directives and spiritual care at the end of life. I was interested in whether these participants had communicated their wishes for end of life spiritual care, if indeed it was found that they did have wishes of this nature. If the participants did have wishes for end of life spiritual care and had not communicated these wishes to anyone, I used a probing question, *“Is there anything you might need to do now to ensure those wishes are honoured when the time comes?”* in an attempt to ascertain whether they considered, or saw merit in, including spiritual care in an advance directive.

The final phase of the interview involved the returning of the conversation to the present. I used recapitulation probes to encourage the participants to reiterate their perception of where they were at, at that time, before engaging them in light conversation aimed at drawing them completely back into the here and now (Gordon, 1980). I asked the participants, for example, to tell me about events they were looking forward to in their activities programme, trips in the facility van they would enjoy when the weather became warmer, visitors they were expecting, what was going to happen next on Coronation Street etc.

The literature suggests that many healthcare professionals are not comfortable discussing spirituality issues (Clark, Cross, Deane, and Lowry, 1991; Davidhizar, 2000; Gibeau, 1995; Leetun, 1996; Murray, 1995; O'Malley and Menke, 1988; Ross, 1997b). I was unclear, however, whether service users found it similarly uncomfortable answering questions about such issues. My ninth and final question: *“Have you felt comfortable talking to me about these issues?”* enabled me to clarify this as it related to the present study.

I was concerned that some participants, even those with a prior interest in spiritual issues, might experience some degree of spiritual disquiet after the interviews. As an experienced nurse of older people, I closely monitored their body language throughout the interview and was prepared to stop the interview immediately and return the conversation to the “here and now” if any signs of discomfort were noted. The senior staff member on duty, knowing that the interview had taken place, also monitored the participants for signs of disquiet afterwards. Although provision was made for the chaplain or another person of their choice to visit if necessary, none of the participants felt the need for this. In fact, all reported enjoying the experience.

At the end of the interview I invited the participants to contact me through the Rest Home staff if, upon reflection, they wished to change or add anything to our taped conversation. Although this proved not to be necessary, I also indicated to them that a second interview could be carried out if they felt a single interview had not done justice to the intensely deep and personal issues they had shared.

The research setting

The research setting was a religious and welfare Rest Home as described in Chapter 1. Located in a New Zealand city, it was owned by a specific religious group although accepted clients of any religious faith or none. The facility was set in spacious and well tended grounds with seating areas affording privacy for residents. Each resident had their own bedroom and there were several lounge rooms and a conservatory where they could entertain guests or engage in the

planned activities of the Home. A chapel was also available for residents and staff and Catholic and Protestant services were held there regularly.

Recruitment and selection of participants

My justification for choosing four participants was the manageability of data for an MA(Applied) thesis, the short time-frame to complete the project, my expectation that the information would be of sufficient depth and richness, and the expectation that the findings would not necessarily be directly transferable to a larger group of people. I hoped that “thick description” would lead to readers making the transfer to their own experience or practice settings if they wished (Lincoln & Guba, 1985).

A purposive sample was selected for this study. Polit et al. (2001) explain that purposive sampling is based on the assumption that the researcher’s knowledge of the group and phenomenon under investigation allows him or her to hand pick cases to be included in the sample. My study involved the hand selection of participants who were thought to be knowledgeable and articulate about the areas of concern and who met the criteria for selection. Whilst this very subjective method of sampling did not provide for assessing whether the older people selected were typical of their peers, the sample comprised participants who effectively represented a view of the phenomena under study, the spirituality and spiritual needs of older people in residential care.

The criterion for participant consideration was that they were “least vulnerable” (McKinlay, 2001). They were judged by the facility staff, and themselves, as being able to stand up to the research process, meet with the researcher, answer questions and reflect deeply on their own spirituality. Elderly people likely to fit the criteria were those who: were not judged to be dying imminently and in a reasonable state of health; were lucid and cognitively intact with no indications of even early-stage dementia; did not require the services of an interpreter; were able to sustain a conversation for up to an hour; were known to have concerns with the meaning of life, death, and/or beliefs as evidenced by behaviours and routines such as conversations with others on spiritual matters, prayer schedules,

attendance at chapel services etc.; were willing and able to articulate these; and were free enough to express their inner feelings (Smucker, 1996).

Since approval to access a potential research setting is a pre-requisite of gaining formal ethical approval for a study, I wrote to the Manager of the Rest Home where I hoped to be able to recruit participants, providing her with an overview of the project and its aims, and requested permission for access (see Appendix 1). Once permission had been granted I met with the Manager, answered any queries she had about the project and, as already outlined in the section relating to informed consent, requested that she or some other person nominated by her, in this case the chaplain, make the initial approach to residents who might meet the criteria for inclusion in the study: residents who would be information-rich data sources (Polit et al., 2001). Recognising the possible vulnerability of these prospective participants and the fact that I would be a stranger to them, I believed that an initial approach from someone they knew and trusted would be more appropriate (Fielden, 2003). The chaplain and manager compiled a list of some dozen residents who met the criteria for inclusion in the study. Six were approached and four agreed to meet me. These residents were eventually the four participants in the study. Prior to meeting them for the first time, I met with the staff, gave them a brief overview of my background, the project, ethical considerations, and the need for them to monitor participants after the interviews for signs of disquiet and the possible need for referral to the chaplain or nursing staff.

The participants

All four participants were pakeha women of European descent in the fourth age of life, i.e. aged over eighty years. At the beginning of the interview I invited them all to choose pseudonyms for identification purposes in the event of direct quotes from their transcribed interviews being used. Consequently, each chose a pseudonym that had a particular meaning for them without increasing the risk of their identification.

Theresa was a 91-year-old retired primary school teacher who had enjoyed a long teaching career in a number of towns and cities in the country. She was brought up in the Catholic faith to which she remained steadfast. Theresa never married but was well supported by her faith community. She derived a great deal of pleasure from classical music, engaged in the activities of the facility, and was an expert in the growing of household plants. At the time of the interview, Theresa had been a resident of the facility for 10 years.

Jane was 91 years old. Accompanied by her mother, she had come to New Zealand from England years earlier. As a State Enrolled Nurse, then as a Midwife, Jane held three midwifery positions in New Zealand before accepting the position of Manager of a Rest Home and Continuing Care Hospital for older people. She held this position for a number of years.

Jane was a Congregationalist until the age of twelve when she joined the Baptist Sunday school. In later life she became and remained a Presbyterian.

Jane never married but had nephews in New Zealand, one living nearby. At the time of the interview she had been at the facility eleven years. Jane was an avid reader and contributed in a number of ways to the Rest Home community.

Songbird had her 92nd birthday the week of her interview. Although she had been resident at the facility for eighteen months, Songbird claimed not to have adjusted to life in the Rest Home and yearned for her former life of independence.

Songbird was married and widowed twice. Just prior to my first meeting with her, one of her sons had died suddenly and another had died several years earlier. This was very difficult for Songbird to accept because for her, her family was all-important and she lived for their visits, phone calls, faxes and letters. Songbird was mentally very capable but had impaired vision and hearing which distressed her. She was frequently frustrated by her attempts to have meaningful conversation with those residents with early stage dementia.

Originally a Salvationist, Songbird became an Anglican and continued to be an active member of the Anglican community for as long as she was able.

Steep was the youngest of the four at 87 years of age. She had been at the Rest Home for 6 months. Steep was brought up as the eldest daughter in a Catholic family, being required to assume some of the responsibilities of the household. She continued to adhere to the beliefs and practices of the Catholic faith.

Steep's family prevented her from marrying when she wished to do so in her late teens and she remained single until almost age 40. Steep had a long career as a shoe and fashion wear buyer for large department stores and derived great satisfaction from this and from her interactions with others she came in contact with in the course of her work.

Steep had a number of nieces and nephews and considered one niece in particular to be her "daughter". This person lived nearby and visited frequently. Steep also received other visitors several times each week, having retained her friendships with many people in the community.

After having recruited the participants and conducting the interviews, the next phase in the research process involved an analysis of the data contained in the transcripts.

Method of analysis

After the interviews had been conducted, the tapes were carefully transcribed in a manner that captured emphases, reflective pauses and other non-verbal nuances. This process enabled me to become very familiar with the data and begin to appreciate its true richness. Each interview produced 15-20 pages of transcript. In keeping with the Ethics Committee requirements, I returned the transcripts to the participants for verification once these had been completed. I increased the font point size to allow for ease of reading, but even so, a participant with very poor vision required me to read hers aloud to her. All four agreed substantially

with what they had said in the interviews and asked only that I altered minor aspects relating to their use of grammar. Ironically, when the time came, Wells' (1994) prediction of participants varying their responses was unsubstantiated.

The analysis of the data for this study was guided by the descriptive, seven stage research methodology developed by Colaizzi (1978). Although used primarily in phenomenological research, I adapted the process in order to analyse the data from the descriptive research design of the current study. The stages of Colaizzi's method are as follows:

1. Transcription of taped interviews, and repeated reading of transcriptions to gain a feeling for them.
2. Extraction of significant statements
3. Clarification of the meaning of, and categorisation of significant statements
4. Organisation of formulated meanings into clusters of themes
5. Integration of these results into a comprehensive description of the phenomena being studied
6. Formulation of an exhaustive description of the phenomenon in as clear a statement of identification as possible
7. Validation of the findings with the participants (Polit et al., 2001)

Since the study was descriptive rather than phenomenological, I combined Stages 5 and 6 because together they offered a logical process for integrating emergent themes that could then be formulated into a description of aspects of the participants' perception of their spiritual dimension.

After transcribing the taped interviews (Stage 1), returning them to the participants for verification and making the amendments as necessary, I reviewed the research aims, objectives and questions. Roberts and Taylor (1998) emphasise the importance of the researcher being absolutely clear about what they are looking for in the data prior to attempting the analysis phase. Next, the transcriptions were read one by one, six times in total so that I could become totally familiar with the content and get a sense of the whole. I then sectioned off the components of the transcripts dealing with each of the questions put to the

participants and deal with each question separately. As I reread the data pertaining to the specific question, significant statements began to emerge (Stage 2). Drew suggests that when a passage in a transcript stands out “it does so because it signifies inherent meaningfulness for the reader” (1999, p.270). She goes on to explain that statements of significance that arise in the awareness of the researcher as they read transcripts do so “because our implicit understanding of the phenomenon we are studying is what allowed us to see it as a research topic in the first place” (1999, p.270). The explicit statements of significance were sought first by searching for key words (Roberts and Taylor, 1998). These were underlined and flagged in the margin. Implicit statements of significance, bearing a less obvious resemblance to what I was looking for, were eventually recognised and similarly underlined and flagged.

Colaizzi’s Stage 3 involved the in-depth examination of the significant statements, and from this the development of a categorization scheme that was used to sort the data. Within the nine areas of spirituality to be explored, underlying concepts and clusters of concepts were searched for in the significant statements, and were eventually formulated into categorization headings and subheadings if they lent themselves to a categorisation process. The categories and subcategories of responses to be identified are summarised in Table 1 at the beginning of the next chapter.

The next phase in the data analysis process involved scrutinizing the data and allocating codes to text passages or phrases linked to the categorization headings or subheadings, and bringing together sections of text pertaining to specific codes under specific categorization headings. With only four transcripts to manage, I did this manually rather than employing a data analysis computer package. At this point, Stage 4, the reorganised data was searched for patterns and structure that connected the thematic categories, and the formal themes of the data were identified.

Up to this point, each individual transcript was dealt with in this way. Stage 5/6 required, however, that the emergent themes from each of the four transcripts be combined, commonalities and natural variations identified, and an exhaustive

description of the phenomenon in question provided. Ten themes emerged in the data analysis process, and these were returned to the participants for their reaction and comment (Stage 7) once they had been fully described. Again, influenced by Wells (1994), I did not plan to do this initially. My review of the research theory literature, however, convinced me that the implementation of Colaizzi's Stage 7 would give the project more credibility. This final stage in the analysis process is also referred to as member checking (Lincoln and Guba, 1985). The participants, in fact, were very interested in, and agreed with the preliminary findings when I returned these to them.

I believe that the attention to detail in planning this study, and the measures taken to ensure credibility, dependability, conformity, transferability, and auditability facilitated the integrity of this project. The qualitative descriptive methodology chosen allowed for appropriate data to be collected, enabling the research questions to be answered. Chapter Four summarises the categories and subcategories of responses recognized in the data, and both Chapters Four and Five identify and describe, in the participants' voices, the themes to emerge from the in-depth exploration of the areas of concern.

SPIRITUALITY AND SPIRITUAL LIFE

In the previous chapter the methodology and an account of how the study was conducted were presented. Chapters Four and Five give voice to the participants and present the findings as they relate to their spirituality and spiritual life, and spiritual care and spiritual planning in the Rest Home environment respectively. Nine aspects of spirituality and spiritual care were explored: the participants' perception of their spirituality, their spiritual needs and how their spirits were nurtured, the role of care staff in providing spiritual care, the participants' satisfaction with the spiritual care they were being offered, their prediction of their spiritual needs as they were dying, their wishes for spiritual care in the perideath period, whether they had communicated these wishes to anyone, their views on possible actions to ensure these wishes would be honoured, and their comfort with the research process.

Ten emergent themes were identified from the data: God as the focus of spirituality, God in control, the importance of relationship, the purpose in life: serving God, changes in spirituality with age, spirituality and residential care, spiritual care: whose responsibility?, end of life spirituality, planning for spiritual care, and participant satisfaction with the research process. Clearly, for the participants of this study, religiosity and spirituality were closely intertwined. From the outset, I acknowledge that the Christian outlook of the participants invested the emergent themes with a set of values that could be expected to change if a non-Christian view was included.

The findings, as they relate to the nine aspects are summarised in Table 1, indicating categories and subcategories where the data lent itself to a categorisation process.

Table 1: Summary of research findings

Aspects of spirituality explored	Response Categories	Response Sub Categories
1.0. Perceptions of spirituality	1.1. God as focus of spirituality	1.1.1. Image of God 1.1.2. God's role in their lives 1.1.3. Responsibility to God
	1.2. Importance of relationship	1.2.1. With God 1.2.2. With family 1.2.3. With people outside the family 1.2.4. With God's creation
	1.3. Changes in spirituality with ageing	
	1.4. Changes in spirituality since being in care	
2.0. Nourishing spirit and spiritual needs	2.1. Identified spiritual needs 2.2. How spiritual needs are met 2.3. Challenges to meeting spiritual needs	
3.0. The role of staff in providing spiritual care		
4.0. Participants' satisfaction with spiritual care		
5.0. Prediction of spiritual needs in the perideath period		
6.0. Wishes for spiritual care in the perideath period	6.1. As they are dying 6.2. After death 6.3. Funeral wishes	
7.0. Communication of wishes for end of life care		
8.0. Possible actions to ensure wishes would be honoured		
9.0. Participants' comfort during the research process		

This chapter examines the first five themes: the focus of spirituality, God in control, importance of relationship, the purpose in life: serving God, and changes in spirituality with age. Excerpts from the participants' narratives are used to illustrate or clarify the themes, and where appropriate, reference is made to the relevant literature.

Direct quotes from the participants' transcripts are italicised, and for auditing purposes identified by abbreviation for name, page and paragraph numbers.

JA is the abbreviation for Jane

TH for Theresa,

ST for Steep

SO for Songbird.

A quotation identified as JA 4-3 for example, is taken from the third paragraph of the fourth page of Jane's transcript.

Underlined script indicates participant emphasis.

God as the focus of spirituality

The spirituality of each participant was dominated by her relationship with God, as understood within the Christian context. This did not surprise me since although the facility accepted older people of any faith or none, it was associated with a specific Christian church.

Images of God

A number of different images of God emerged in the data, and as explained by Greeley (1973), the circumstances of their lives, and in particular their childhood upbringing, as well as their culture, moulded the images they brought with them into old age. MacKinlay (2001a) suggests that even among Christians of various denominations, differing images are likely to exist and this was borne out in this study. The participants saw God from different angles:

I regard Him as my Heavenly Father, and He's all my life. I couldn't do without Him. SO 1-8

Jane saw God as her leader, her support and the determinant of the path of her life:

In 1965 I changed from a Baptist to a Presbyterian. Now, I would say that I changed, but looking back, I was led to change [pause] and I can see how God was moving me around until He got me in the place where He wanted me, which eventually was (last place of employment). I really felt it was the work He wanted me to do. JA 2-3, 3-5

Theresa believed that she belonged to God.

You belong to God, and it is God who arranges your life. Although perhaps you don't understand what is happening to you or what has happened to you, God is there and he wills that [pause] He may not will it, but He allows it to happen to you [pause] God is love and He loves us, and nothing can happen to us without His knowing – whether it's crosses or ill health [pause] that is all in God's plan for us so you take it as coming with His permission... TH 1-5

Theresa also talked of God's presence:

You feel that He is with you, and you can just turn to Him like He was with the apostles in the boat [pause] and sometimes you forget that He is asleep in your little boat, your barque, but He is there, just as He was with the apostles in their barque. Then, if you turn to Him, He will calm the storm or whatever it is within you. TH 3-1

Not all images related to an intimate and personal God. Although both Songbird and Theresa obviously had relationships with a deeply personal God, they also had images of His being “out there” and more aloof:

I believe God is almighty.

SO 3-6

and Theresa, recognising God as creator:

I saw a book the other day with gorgeous mountains in it [pause] our own mountains, and they were just so beautiful, the power, the might, showing Almighty God's power in all things.

TH 4-7

Unlike the other three participants, Steep gave little indication of how she saw and understood God, giving the impression that it was in relationship with others that real meaning in life was found for her. She acknowledged God as creator, however:

I've always been fond of gardening, and the flowers and birds [pause] I always think that God has more or less created all these things.

ST 6-5

Only one of the participants gave any indication of belief that God would one day judge her:

I hope that when I do go to heaven I will be given credit for trying, even when I've stumbled over and done a lot of things I shouldn't have done.

SO 9-6

MacKinlay (2001a) suggests that if God is seen as a punitive God, the concept of punishment is seen as part of life, and in fact the individual may see no way of overcoming the “wrongs” of their past, fearing what they understand may follow death.

God in control

Three participants expressed views of God being in charge and in control of their lives, confirming that for them, God was the focal point of their spirituality and who gave ultimate meaning to their lives. Being led by God according to His ultimate plan and in His time featured prominently in Jane's comments:

...you realise that it's all in His plan and what He has planned. He is going to do it whether you say "yeah or nay" [pause] but you come through it in the end.

JA 13-7

For two of the participants, God being in control also extended to His determining when their life's work was over and they could die:

For some reason He has kept me alive for so long [pause] there must still be some work or something I have to do.

TH 14-7

Jane recalling a near death experience that proved not to be her time to die:

I actually knew that I was at the gates of heaven and a voice said "not yet", and I came to [pause] the first thing I said (to the hospital staff) was, "I told you not to bring me back" [pause] but, there again I could see afterwards that it obviously was not the time [pause] well, if God still has something for me to do then I'm willing to stay and do whatever it is that He wants me to do.

JA 11-5

Songbird recalled the premature death of her daughter-in-law:

I said to my son "I think that God must have a special something that only (the daughter in law) can do" [pause] It's hard to explain really, but the feeling I had about her, there must have been some job that only she could accomplish for her people (the daughter-in-law was from a different ethnic background).

SO 14-7

Songbird was able to derive meaning for herself through her belief in God being in control.

The importance of relationship

MacKinlay (2001a) points out that relationship is an important part of being human, as the human spirit longs for connection with others. Grovier (2000) includes *relationship* in what he describes as the “Five R’s” of Spirituality, along with reason and reflections, religion, and restoration. He argues that relationship with self, God and others is central to spirituality and may be expressed vertically towards God or horizontally towards others.

Relationship with God

In talking about their relationship with God, the participants shared their mechanisms for communicating with Him, and how they perceived God communicated with them.

I spend a great deal of time in prayer, and I think that it's in prayer that I go right to the top [pause] and I can talk to God about whatever's happening.

JA 5-1

The scriptures also nourished Jane's spirit and she read the Bible for some time each night prior to retiring.

Jane was often called upon to read the scriptures during the services conducted in the Rest Home chapel.

Towards the end of the month, I read what I'm going to read on the Saturday for the Anglican communion, and get that really into my mind so I have an idea of what God is trying to say [pause] and I try and get it over to the people that are listening [pause] but I really like to get the reading into myself first, before I can pass it on to somebody else.

JA 6-3

Theresa also spoke of the importance of scripture for her:

...if you are reading the Gospel you are in direct communication with Our Lord, and the Old Testament too – there are a lot of readings there that bring you very close to God. TH 3-7

Theresa suggested that a relationship with God was not always easy, and to maintain an ongoing connection she had to strive constantly to meet her own objective of having Him at the centre of her being:

It's like a walk with God, and you try in your own poor human weakness to let it be God alone in your mind and heart and will [pause] which is not possible all the time, because you can't have God in your mind all the time [pause] but that is the objective because God is the only one. To achieve this there must be much prayer. TH 1-7

Songbird saw her relationship with God as being similar to a father/daughter bond and suggested that God wanted people to ask for help:

When I am in trouble I think of God as my father. He knows what's happened to you [pause] He knows what's wrong but I think He wants you to ask Him. He doesn't want to impose His will on you [pause] He wants you to ask Him, then He's got your full cooperation. SO 3-6

Traditional practices were also seen as important to relationship with God:

We lived in the country and didn't have much [pause] it was all through the depression and we didn't have much in the way of learning about our faith. My mother was very good [pause] we always said our prayers every night [pause] I think we said the rosary every night and I think we went to Mass about once a week [pause] and then in those days we had someone come out from town to give us catechism. ST 5-8

The rituals of the Church were significant for Theresa. She recalled her teaching days during the polio outbreak in New Zealand in the 1940s:

I remember once I had some children in school and the polio was about – it was just about finished but they were back at school. I used to sprinkle them with holy water as my old teacher used to do. The priest laughed about it and I said, “well, not one of them got polio anyway!” Those are the old practices they say now, but I think some of them are coming back...

TH 8-1

The above excerpts bear out MacKinlay's suggestion that as disability encroaches on the lives of older people, decline in church attendance is offset by increased engagement in non-organisational activities such as prayer, scripture reading, and watching religiously based television programmes (MacKinlay, 2001a).

Relationship with family

Relationship with family and others was particularly important for Steep. She focused on significant events and people from her past, relationships that influenced the path that her life would take and to which she continued to contribute meaning. Although she did not have children, Steep talked about a niece who was very important to her:

...she's my special one, she's like my daughter.

ST 7-11

Jane was acutely aware of the fact she had little family since most had died, but appreciated the contact she had with a nephew who lived locally:

I have one nephew who lives here and comes to visit me every Thursday morning. He takes Bible in Schools up at (name of school) and while he is nearby he comes to visit me.

JA 14-10

Songbird recognised God as the focal point of her spirituality, but it was her relationship with her family, similarly reported in the studies of Chomicz (1984)

and Ross (1997a), that infused the most tangible meaning into her human life. She lamented the effects of ageing on this and also the fact that a son had recently died:

I've lived for my family and there's nothing left now is there, at 92?

SO 4-1

I reminded her of her grandchildren who visited, wrote or faxed regularly:

Oh yes, they're priceless to me [pause] they're priceless. No, they come up (to visit). They've been very good. They're priceless! SO 4-3

...now and again they send me a card, a Mothers' Day card or a birthday card, on the wrong date [pause] but it comes, it comes! SO 12-8

Songbird stated that love was an essential ingredient of family life. She remembered an encounter she had had with a Jehovah's Witness visitor who suggested that there was no love in the world:

...and I said, "look", I said, "there's love in my home", I said, "and if all parents taught their children the true meaning of love there would be plenty of love in the world!" SO 5-1

I concluded that each of the participants deeply valued the fact that significant family members respected their faith traditions, even when they themselves were of a different tradition or none:

...even though my husband wasn't a Catholic he was very good with the church [pause] always helped a lot. ST 5-6

...my Dad wasn't a Catholic but he made sure he went when there was Mass [pause] but he did turn a Catholic, a wonderful event in our lives about three years before he died. It was really great! ST 11-3

Songbird, talking about her late husband:

He had a belief in God, and I would say an unshakable belief in God, but he didn't show it [pause] he didn't ever talk religion or anything. Now and again he'd say he knew what he was doing wrong, but he wouldn't say any more than that.

SO 2-5

Relationship with people outside the family

All of the participants considered relationships with other people to be important. For example, all appreciated their association with like-minded people.

Theresa spoke about a fellow resident who had died, grieving for a relationship that had been meaningful for her:

There are times when I miss (name) very much, because we could talk about things and we'd know it would go nowhere else. If we were a bit grumpy about things we could just say it.

TH 10-13

Steep in particular appeared to value relationship with others and indicated that she had made the most appropriate choice when selecting the Rest Home she was eventually admitted to:

I was quite pleased I came here because I knew quite a few people, about half a dozen I would say. In (the other Rest Home she considered), there were two people I knew but they couldn't remember me or anything...

ST 13-2

Jane also recognised the value that others added to her life at the Rest Home:

There are some wonderful people in (the Rest Home) that I wouldn't have known if I hadn't come here. We can talk about spiritual things [pause] I don't know that you could do that in every Rest Home [pause] I'm pretty sure you couldn't...

JA 7-9

She spoke about a special relationship she had had with another person with whom she had been able to share deeply:

(Name) was a very good person to talk to. She would never talk much about her own spiritual life but you couldn't be in her company for long before realising that that was at the bottom of all that she did. JA 5-3

Theresa considered why God had kept her alive for 92 years, speculating that her unfinished work might involve interaction with others:

...if you can give even a smile or lend a helping hand where you can, if you can, and perhaps just a smile or say a little word, or do some little thing for someone... TH 14-9

Relationship with God's creation

Relationship with God's creation provided another dimension that was considered important in bringing additional meaning to their lives. Both Steep and Theresa talked about their sense of relationship with God's creation.

A chapel service had been held shortly before the interviews to farewell a large Puriri tree that was to be felled in the grounds:

Recently we had a service to prepare to say goodbye to the tree [pause] we thanked God for it [pause] and remembered how the insects had lived in it and how all the other kinds of birds had enjoyed it. We thanked God for the singing of the birds that was heard in the tree. But now its time was over and it was giving itself up to be used by the wood carvers.

TH 5-7

As well as recognising God's creation in nature, Steep identified gardening as an activity that had given her life meaning, i.e. a spiritual activity:

I've always been fond of gardening, and the flowers [pause] I always think that God has more or less created all these things. ST 6-5

Theresa, in acknowledging God's creation in the world around her:

I think I'm an earth person. I love all creation. It's God's gift to us and so therefore you can admire the beauty of his creation. It's beautiful! Sometimes when you go for a walk out there and see the tiny, tiny little flowers, and yet they are so beautifully formed [pause] and you see God's wonderful creation even in the animals. You know, our pussy [pause] I often thank God for Gingey! He's quite soothing when you give him a little stroke. I often thank God for Gingey and all his antics. He often goes into the chapel and does all sorts of antics to get the sun onto himself and I'm sure Jesus must laugh [pause] I don't think he's doing any harm in there! So I love all creation [pause] the mountains [pause] when you think of them, the beautiful mountains [pause] aren't they gorgeous!

TH 4-5

Music was also very important to Theresa:

Music is very dear and I get a lot of enjoyment out of classical music. I think it plays a big part in my spirituality. I can find music very moving [pause] there is something in beautiful music that is tranquillising and makes you feel more peaceful. I can be very moved by music. I always have been, even as a little girl. I hear beautiful music and I can cry, and it's rather embarrassing at times.

TH 3-9/4-1

Music as a spiritual element is reported in MacKinlay's (2001) study of the spiritual dimension of older adults living independently in the community. It is argued that each individual has an internal world of beauty that can be viewed through a window of music, poetry, or nature.

MacKinlay (2001a) cites a 1982 study conducted by McCready and Greeley which describes how they had identified a series of triggers for deep spiritual experiences, or a sense of "otherness" beyond or greater than the individual concerned. These triggers, listed in the order of frequency mentioned are: listening to music, prayer, the beauty of nature, e.g. sunsets, moments of quiet

reflection, attending a church service, listening to a sermon, watching little children, reading the Bible, being alone in church, reading a poem or novel, childbirth, sexual lovemaking, one's own creative work, looking at a painting, and physical exercise. As evidenced in the excerpts above, a number of these triggers were reported by participants of the present study as being meaningful for them in terms of their spiritual dimension.

The purpose in life: serving God

Three of the four participants were very clear that ultimately they were in the world to serve God.

From my analysis of the data, a five-step process for serving God emerged: discerning God's will, having faith and trust in God's will, carrying out God's will, prayer and praise to God, and the perception of failing God on occasion but having faith in His forgiveness.

Discerning God's will

The first step involved discerning God's will for them. Songbird explained the importance of this:

That's our job, to somehow get vision [pause] you know how you hear of people who suddenly realise what they should do, and to me that's a kind of answer to prayer.

SO 15-1

Songbird also explained that this discernment could be reached through the scriptures:

My schoolteacher said to me on the last day of school, "anything that happens to you in your life, any trouble or difficulty you get into, you go to the Bible. You will find the answer there". I've never forgotten that.

SO 4-5

Faith and trust in God

The second step involved having faith and trust in God and accepting His will for them:

I can talk to God about whatever is happening and can pick up an answer more often than not [pause] if you don't see the answer but have faith, you know that having told God what the problem is, He is going to take care of it [pause] that gives you a great sense of peace in your mind.

JA 5-1

Theresa saw faith as being crucial to facing up to death:

We just have to have faith and know we've got to meet it. Dying is one thing we can never get out of. We might have got out of many things in our lives but we've just got to face that one, no matter how great a person is...

TH 14-3

Theresa suggested that since suffering comes from God, not only should one strive to rise above this, but in fact praise and thank God for it.

Doing God's work

The third step of the process to emerge involved doing God's work and living life according to His will.

Whilst Jane saw her need to enter residential care as God protecting her, she also recognized her role in serving Him in that environment:

...I like to think that it's not all one sided, that I can still do things for Him, that he leads me to speak to people, the residents and the staff. And I can take part in the services we have here...

JA 4-3

Songbird was sure that each individual had a unique role to play in the service of God:

God definitely has plans for us all. Whatever they are, I've always had the feeling He's got a job, work for us all, and a duty for us all to attend to somebody, somewhere.

SO 19-4

Songbird saw that her primary role had been that of homemaker and mother. The sharing of her faith with others was also important and she admired others who did the same. Although she did not embrace the teachings of her Jehovah's Witness visitors, she respected the faith and courage of a particular Jehovah's Witness man with a severe stutter who came visiting:

...the only one I ever thanked for coming [pause] he came to my back door and he had such a terrible stutter he never got a word out. I was standing up at the top of the steps you see, so what I did, I came down the steps, took his hand and thanked him very much for coming in with a message [pause] I thought that if anybody could go through that to help me, I'm very grateful to them. And he never said a word [pause] he never got a word out.

SO 5-1

Although Steep did not explicitly acknowledge that involvement in church organisations and activities was serving God, the fact that she mentioned this involvement on several occasions may have indicated this. Involvement of family members in church activities was also important to her:

(Name of niece) does quite a lot there (at church). She helps with the First Communicants and she does reading and all that sort of thing there [pause] I used to do bits and pieces like greeting and Offertory [pause] but I never did reading. I didn't think I was good enough... ST 13-8

Prayer and praise to God

The fourth step in the process involved prayer and praise to God, including offering up the events of the day to God in prayer.

Theresa admitted to frustration by sometimes having her prayer time interrupted. She conceded however that:

The thing that interrupted you is your prayer, and in order to be charitable, to give a hand to someone else, that is prayer for you, because in the morning you make the Morning Offering. TH 2-1

Trips in the Rest Home van to local parks could also focus prayer because:

If you have an outing, if you go to (name of local park), there are things there that you can praise God for [pause] there is the animal life, birds on the lake, the beautiful trees and the flowers [pause] so there's an opportunity there for praying and praising God for His creation.

TH 6-9

Jane described her prayer list of 167 people including all the residents of the facility and staff, and how she prayed for each one individually twice daily:

...there's a strange feeling between myself and God, that I'm asking Him to watch over them, and it's all in the name of Christ because He said "whatever you ask in my name, I will do it" [pause] I always bring that into my prayers before I've finished, knowing that what I have asked will be done in God's own way, in God's own time... JA 9-5

Jane's commitment to pray for others was possibly motivated by her desire to continue to contribute into old age. Speck (1995), in commenting on the place of prayer and scripture reading in Pastoral Care, recalled a paralysed woman he had met as a hospital chaplain. She yearned for the opportunity to contribute, so he supplied her with the first names of people who needed prayer. The woman subsequently included these people into her own prayer, reaping personal benefit from the knowledge that she was indeed contributing to others.

Perceptions of failing God, but faith in forgiveness

The final step involved the participants' recognising the occasions when they believed they had failed in their responsibility to God, faith in having been forgiven by God, and their resolve to persevere. MacKinlay (2001a) writes that an important aspect of finding final meaning in life is being able to acknowledge

guilt and wrongdoing and recognise the need to seek forgiveness. She warns that unresolved guilt is a heavy burden for individuals to carry and they may require spiritual intervention to rectify the situation to ensure their continued spiritual and emotional growth.

Theresa recognised her failings when contemplating the remainder of her life's journey, but had faith in God's mercy and forgiveness:

Well, nobody's perfect, are they? I think that now, (for her remaining years), you should try to live as you should [pause] I'm sure He's all love and mercy and compassion.

TH 13-6

Songbird, freely acknowledged her failings and resulting remorse:

Well I try to do my best and I apologise for when I don't, when I haven't done the right thing [pause] and like everybody else I make mistakes and get my hair in a knot over nothing...

SO 1-10

Steep disclosed that she seldom read the Bible:

I've got a Bible up there (on her bookshelf), but I'm afraid I haven't read it very much. It wasn't the one I wanted her (the niece) to bring [pause] I had two, I had another newer one that I wanted her to bring but I don't know what's happened with that [pause] I can't go and get it myself.

ST 14-3

Steep reported occasional doubts brought about by tragedy and failure on her part to understand how a loving God could allow such things to happen. In referring to a recent media report, she observed:

Sometimes, I suppose like everybody, you think, "how could that be?" Sometimes I have my doubts about things [pause] we all think that surely God wouldn't have put people on fire?

ST 5-4

Changes in spirituality with age

Although scholars of ageing do not agree that older adults necessarily become either more or less involved in spiritual or religious issues (Bianchi, 1995; Burt, 1992), the participants of this study all stated that their spirituality had changed as they had got older. The following excerpts illustrate how the participants perceived that their spirituality had changed as they had aged.

I would say that my faith has grown. I think when I was young I just accepted things as they happened, and at first I liked to go to church just to take part in the services, to sing the hymns... JA 6-7

Steep expressed her sense of being liberated from some of the more formally observed practices of her faith:

I'm not as, you know [pause] I'm not as faithful. I don't mean that I don't believe in God, but I know that I don't have to be so strict about doing things. I can't get to Mass because we only have Mass once a week here [pause] you don't have to be in a church praying to be with Our Lord. You can still be with Him when you're on your own somewhere, walking or [pause] we have a service here once a month for the Anglicans. I go to that and feel that they're much the same as we are [pause] I can go to their services and feel that it's almost the same as ours. ST 6-7

Songbird described how her relationship with God had changed as she had aged:

I think I've felt a more restful relationship [pause] not a feeling of His being in authority over me, even though I know He still is. And I've felt more in tune with it. When you're young you sort of pray in desperation, don't you? But as you get older, you learn to accept and ask for vision and direction or whatever to see what's really happening, for guidance in whatever it is you've got to go through. SO 5-3

Songbird believed that as she had grown older she felt more confident in voicing her beliefs:

Well, I think you get a bit more outspoken [pause] when you're young you often speak quickly without thinking, but as you get older you think a little longer about what you have to say... SO 4-9

Songbird's poor vision and deafness resulted in her spending a significant amount of time sitting and reminiscing on her life and spiritual journey:

I think that sometimes I have a sense of wonderment, (when reflecting on her past life) because I don't think it's in our power to understand the Almighty God and His ways [pause] we can try, but I think it's quite beyond us. You put your own understanding on something but it may not be the right one! SO 19-2

Theresa agreed that her spirituality had altered with age and like Songbird, sensed a freer spirituality:

It's certainly different, and becoming freer [pause] and perhaps you could say, becoming more casual with God. You talk more openly with Him. TH 3-3/3-5

Theresa's experience concurs with MacKinlay's (2001a) conclusion that as individuals age, they engage, often somewhat apologetically, in less formal prayer. Theresa also described how God's position relative to hers had changed, and that in contrast to her younger days, she recognised that she was now totally responsible for maintaining her relationship with God:

...there were strict times for prayer and we would meet together for prayer, but in the more modern days you are responsible for saying your own prayer [pause] but perhaps in the older days God was out there, He was further away from you. But now, God is more with you, as it were...

TH 3-1

Theresa acknowledged that as she had aged, the practices of the church had also changed and she saw herself as belonging to both the new and old church. To illustrate this, she referred to a bottle of Lourdes' water she had, an "object of faith" of the old church:

I've got a bottle, We did have great faith in those things [pause] we still do, really [pause] but it's a different kind of spirituality that modern people have to ours. We are part of the modern but we are also part of the old.

TH 8-3

Theresa's spirituality took on a new meaning but it did not mean discarding the old.

I came to the conclusion that for these older women, the change in their spirituality related mostly to their changing perception of their relationship with God, and in keeping with the view of Seymore (1995), a deepening of their personal spirituality and progression of their faith practices from obligation to commitment. Two of the women expressed a much freer and more casual relationship with God, less bound by a feeling of needing to comply with the old rules and rituals of the church. A feeling of God being more "inside" was also considered by them to be a product of their ageing.

An examination of the themes emerging from the data relating to the participants' spirituality per se and how this had altered over the years, revealed a spirituality for each of them based on a Christian understanding of God. Each of the participants was able to articulate their spirituality, particularly the images they had of God, and reported a freeing up and broadening of their spirituality with age. The concept of relationship was seen as fundamental to spiritual wellness, particularly relationship with God, family and others and with God's creation. In accepting the importance of Christianity in their lives, the participants recognised their responsibility for serving God. A five-step process for this was identified involving the discernment of God's will, placing faith and trust in God's will, implementing God's will by doing His work, offering prayer and praise to God, and recognising the occasions of failing God but at the same

time having faith in His forgiveness. The next chapter will present and illustrate the remaining themes identified, those relating to the participants' spirituality and spiritual needs in the residential care setting, and their wishes for spiritual care in the perideath period.

**SPIRITUAL CARE AND SPIRITUAL PLANNING IN THE
REST HOME ENVIRONMENT**

This chapter focuses on the residential care environment and the participants' experience and perception of spiritual issues therein. Five themes are examined: spirituality and residential care, spiritual care: whose responsibility? end of life spirituality, planning for spiritual care, and participant satisfaction with the interview process.

Spirituality and residential care

The participants had individual views of whether their spirituality had altered since being admitted to care. Jane did not believe that her spirituality had undergone any change:

I wouldn't think so, not really, because it (spirituality) was pretty well established [pause] I mean, I was about 80 when I came here. JA 7-5

Steep admitted that since entering the Rest Home she had started to think about her own death:

Well, I'd never thought about it...but now I've thought about dying [pause] I can't imagine myself really dying, but I know I will... ST 7-7

Once Theresa had entered the Rest Home she had a sense of wanting more in the way of spiritual nourishment. When I asked whether anything had changed for her spiritually since she had been admitted, she responded:

Perhaps there is just the feeling that you'd like a bit more. You see, I've been used to retreats, silent retreats – and you feel sometimes that things are not deep enough... TH 5-5

Songbird did not consider that her spirituality had changed since entering residential care, but she had had to find alternative ways of accommodating her relationship with God as a result of the worsening sensory acuity with old, old age:

I can't say that it (spirituality) has changed. I've seen it in a different way, you know [pause] and I can't quite explain that either except that I can't hear what they're saying half the time, and I can't read what's written, so I'm sort of just sitting here listening to music or whatever...

SO 6-3

Having time for prayer and scripture reading was important for Theresa. In response to my query regarding her current spiritual needs she replied:

Well, I would say that I should perhaps spend more time in prayer and more time in spiritual reading, or reading the Bible [pause] or the New Testament, and spending more time with God, even if it's only to sit with God in the chapel.

TH 6-7

Steep's inability to attend daily and especially Sunday Mass, created for her an unmet spiritual need:

I'm sad to miss Mass [pause] I really miss Sunday Mass... ST 10-7

Being aware of God's love was identified by Songbird as a spiritual need although it had always been important to her. When I enquired about her current spiritual needs, she indicated that she was able to meet this need:

I think just by praying and talking away...

SO 7-5.

Prayer was used by all participants to meet their spiritual needs, in keeping with published evidence that prayer was the most universally identified religious practice with both Eastern and Western religions (O'Brien, 1999). For many Maori too, karakia (prayer) is integral to their culture. Whether based in a

religious framework or in recognition of another older Maori deity, karakia enable the individual to rise above the challenges of daily life and step onto a more elevated spiritual plane where one-ness is achieved with their ancestors, the environment, and with the spiritual powers (Durie, 2001).

I referred earlier to Jane's sense of obligation to pray and to praise God, and in order for her to be able to accomplish this without interruption she carefully planned her day:

I usually wake up between five and half past, and I make a point of getting out of bed and shutting the door. I put the light on and get back into bed and pick up my prayer card... JA 8-8

She then described how she prayed for all 167 people on her prayer list, each one in turn. Essentially, Jane was able to meet her own spiritual needs and as demonstrated by earlier excerpts, scripture reading, contact with like-minded people, and the opportunity to discuss spiritual issues with them were also important for her.

The Participants had differing degrees of connection with the chapel. Jane did not mention it specifically as being important for her, but access to the chapel was important for both Steep and Theresa whose spiritual dimension was supported by simply being able to spend time there:

The chapel's always there and I can go in [pause] sit in it and pray. ST 10-1

Theresa, in acknowledging that she needed to spend more time in the chapel:

I should spend more time with God, even if it's only to sit with God in the chapel. TH 6-7

The chapel was not important for Songbird. In fact, she saw it as a barrier to her connection with God:

It's something I can't do, just sit in the chapel [pause] I think I seem to need company. If I sit by myself I feel afraid [pause] I'm not in communion with God at all. I'm sitting in a building, and I can't do it. I suddenly find I've closed myself off somehow [pause] it's not the same. To me it's morbid [pause] I can't get in touch with God that way. SO 6-5

Songbird was able to meet some spiritual needs through reminiscence. Since her failing vision did not allow her to read, and her deafness created difficulty for her in conversing with others, Songbird spent a lot of time sitting and reminiscing about the past, present and future. Reminiscence is common in old age when individuals, shaped by their life experience built continuously over the years, and in seeking meaning for their perceived future, review and reframe the meanings previously placed on the events of their past. MacKinlay suggests that it is a developmental task of old age and “in particular of the spiritual dimension” (2001a, p.78). She suggests, moreover, that meanings are reframed and modified right up until the point of death. I asked Songbird whether she tried to make some sort of sense out of the past as she reminisced:

I don't know whether I would try to make sense of them [pause] you wonder why, but I do reminisce a lot. SO 18-13

The challenges of meeting spiritual needs in a residential care setting

For the most part the participants indicated that their spiritual needs were being met, either by themselves or with the assistance of others. However, the residential care setting also posed some challenges for them in meeting these needs, especially when the timing of planned activities conflicted:

We have rosary through the week but I don't always get to it. If we have something on in the leisure lounge, well [pause] we don't always get there (to rosary) because its at half past eleven and sometimes things go over the time... ST 9-10

Mass being said only on Thursday each week was also an issue for Steep although she appreciated alternative arrangements that were made for Sunday worship:

I'm sad to miss Sunday Mass [pause] but (name) takes Exposition. She does the prayers and puts on a couple of hymns [pause] otherwise we wouldn't have anything. ST.10-7

(Exposition of the Blessed Sacrament is a Catholic ritual where the Body of Christ, in the form of bread, is displayed to provide a focus for worship).

For a person accustomed to attending daily mass, the inability to do so might precipitate significant depression, a reality for many older people in care as they adjust to the losses being faced. Swinton (2001) explains how many people in the midst of, and as a result of depression, are intellectually incapable of grasping and holding onto their faith and rely on the non-cognitive elements of ritual and symbols to make a spiritual connection. For these people, and also for those with dementia, church services with the familiar hymns and the sacraments are extremely important. Even in an informal environment like a Rest Home, an act of worship provides for the participants a link to their faith community and as Swinton writes, seems to “transcend the boundaries of their intellectual struggles over truth” (2001, p.129). However, in spite of not having frequent access to the Mass, Steep gave no indication of being depressed. I was impressed, in fact, by her very positive outlook and her expectation that she would have many years ahead of her.

At times, Theresa found that the busy routine of the facility did not allow for the time she felt she needed for prayer and other activities related to her spiritual dimension:

The lack of time can be a problem [pause] mind you, you don't always have to take part (in the activities of the Home), and sometimes I don't [pause] but you feel that when these things are programmed for you, its for your own health TH 5-7, 5-7

Songbird's visual and auditory impairment challenged her ability to meet some of her spiritual needs.

What I would like, if anybody had the time and the patience, would be to have someone read the scriptures to me [pause] sometimes I'd like to hear the scriptures read. I can't see to read them myself [pause] I don't think I've even got a Bible with me. They do read the scriptures here of course, but it's just that I can't hear them.

SO 8-7

Songbird was also challenged by what she perceived as a "generation gap" between her and the staff.

The staff does their very best. They are very good and they do their very best. But there is a difference between older experience and younger experience. They don't always get it, if you know what I mean – it couldn't be any other way really because a younger person couldn't know what you've seen..

SO 7-7

Of the four participants, Songbird had experienced the greatest challenge to her spiritual dimension as a result of being admitted to residential care. Her admission was obviously very much against her wishes. I asked whether she still had a sense of continuing to grow spiritually.

No, I can't say that because I have wished to die before now [pause] I thought I was losing my mind. I couldn't think, I couldn't sleep, I wanted to be done with everything that poured on me [pause] life seemed to be one big burden [pause] The family decided it was time for me to come here, you see. I was too old to look after myself [pause] and at first you feel like you're being deserted [pause] but you know you're not being deserted, you know that it's the right thing to be done because I was getting dangerous [pause] I was catching my cuffs on fire with the gas and one thing and another...

SO 16-6

In spite of having devoted grandchildren and regular contact with family members, Songbird was struggling to come to terms with a number of losses associated with old age and admission to residential care. Mobility, vision, hearing, her independence, and then most recently the death of her son were the most obvious losses she was grappling with. I suggest that Songbird was experiencing at least some degree of spiritual distress, a concept defined by both Burnard (1987) and Carpentio (1983). Burnard describes it as “the result of total inability to invest life with meaning. It can be demotivating, painful and can cause anguish to the sufferer” (1987, p. 377). The last transcript excerpt illustrates the anguish Songbird felt after being admitted to residential care. Carpentio suggests that spiritual distress may disturb one’s belief system. She describes spiritual distress as “the state in which the individual experiences or is at risk of experiencing a disturbance in his belief or value system that is his source of strength or hope” (1983, p. 451). As a result the individual may experience inner turmoil, conflict and confusion, a state described by the Carmelite mystic, St John of the Cross, as “the dark night of the soul” (McSherry, 2000).

The lack of real companionship from other Rest Home residents made it especially difficult for Songbird to adjust:

...it isn't easy because there is no real companionship. When you are in a family you are all one with the other, but in here they don't talk sense, a lot of them [pause] and you can't sort of get along, you can't cope with it sometimes [pause] but it has made me more tolerant of others. SO 17-11

During the process of reflecting on the data I was compelled to consider the extent to which the coping mechanisms of these women had been assisted by their faith. Dein and Stygall (1997) suggest that there is evidence, especially among older people, that religious belief is positively correlated with physical health and wellbeing, and that religion is a significant cultural force in their lives.

Jane, Theresa and Steep gave no indication of failing to cope with their circumstances. For Jane, her situation was God’s will for her and she accepted

this without question, and years earlier Theresa had embarked on a lifelong journey with God that was not yet over. For these two women certainly, their beliefs continued to provide meaning for their challenges of old age. Steep was also supported by her beliefs. Having access to the chapel and Mass, even if only on Thursdays, contributed positively to her wellbeing. Songbird poignantly described her earlier distress from having no option but to enter residential care. In keeping with the research findings of Hall (1994) who identified how HIV patients maintained hope during crises, Songbird's steadfast faith possibly contributed to her emerging from this dark period in her life.

Spiritual care: whose responsibility?

In Chapter Two I argued that nurses should have some responsibility for spiritual care and made reference to the fact that the spiritual dimension is included in the writings of many nurse theorists who consider it to be an integral aspect of the nurses' role. All the participants did not share this view, however. The Rest Home employed Catholic and Presbyterian chaplains and Jane, Steep and Theresa believed that they had the primary responsibility for spiritual care. Songbird, however, suggested that all staff had responsibility for assisting residents to meet their spiritual needs by being loving, caring, cheerful and positive:

Everybody is so kind, and wanting to be helpful [pause] and they do their best to put the bright side forward. I think (staff help to meet spiritual needs) just by keeping a cheerful attitude to you [pause] I think that they help you keep a balance.

SO 7-11

It was also important for Jane that the staff were loving and caring people although she did not specifically relate this to spiritual caring:

The majority of the staff would be Christian [pause] they are sympathetic to the things we believe in [pause] we really have a very good staff, very loving and caring people.

JA 8-2

In contrast, Steep thought:

They are a very busy lot I think, without having to do anything like that [pause] but sometimes they tell you when Mass is on, or other services. They might just come by and see if you were going and remind you. Sometimes they take people down to the services in the wheelchairs...

ST 16-6

Theresa also saw the staff in a more supportive role.

Seeing that people were brought to religious services, which they do. I think that would be more or less their role [pause] and they do that very well.

TH 19-7

And in an advocacy role:

If anything wasn't right they would see to it that it would be put right [pause] they would never deprive you if they saw that something wasn't right. You can also ask them for help if necessary (to meet spiritual needs).

TH 18-4, 19-9

The Christian ambience of the Rest Home, based on the values of the owners and facilitated by the people there, was also significant for Jane:

Right from the beginning the Home was owned by (name) and their Christian beliefs have built the place up. You feel it as you come in [pause] you are surrounded by Christian people with Christian beliefs and you know that God is in this place.

JA 7-9

Overall, the participants were satisfied with the spiritual care offered at the Rest Home. As indicated earlier, Songbird believed that the staff did their best to provide care in a manner that nurtured her spirit, but:

...in a way I say that I hate being here [pause] because it's not home, that's all. There's nothing wrong with the Home. It's me... SO 3-10

and Jane:

That is one thing I miss here [pause] we do get lots of services, but what we don't have is a Sunday service [pause] but I can get by on Praise Be (a programme of hymns screened on Sunday morning television) and my own prayer time. JA 6-9, 8-4

Unfortunately, as a result of a shortage of clergy in the district and the Sunday commitments of those that *were* available, a Sunday service at the facility was impossible. While Lay Ministers could conduct some services, only a priest could celebrate the Mass for the Catholic residents, and he was only available for this on Thursdays. This situation, commonplace in residential care services for older people, is criticised by Bruce (1998). She argues that this underlines the residents' second-class status and loss of individual identity resulting from admission to residential care.

Theresa implied that her own particular needs were not being entirely catered for:

The spiritual needs of most people are dealt with because we do have services [pause] we have an open communion sort of service, and recently we had a service to prepare to say goodbye to the tree... TH 5-7

Her earlier comment about wishing for deeper spiritual nourishment led me to believe she did not see herself as a typical resident in Rest Home.

End of life spirituality

All participants had total confidence in the notion of life after death and, as described in the literature, had thought more about this as they had aged. Both MacKinlay (2001a) and Jewell (1999) suggest that as people age and can no longer deny the reality of their approaching death, contemplation of this is more likely, and from this, feelings of uncertainty may emerge. Songbird's comment illustrates this very clearly:

Well, I think everyone needs some assurance [pause] I think there is always a little bit of fear at the thought of death [pause] I've read something about people who talk of going through a black tunnel which seems to have stayed with me, but I think that like everybody else I have a small fear of dying. You wonder, Will you have the strength? Have you got it right? Have you been the Christian you thought you were being?

SO 8-3, 8-5

Reassurance was perceived by Songbird as an important spiritual need at the end of life:

I think that I'd like assurance that I've tried [pause] I'd just like to feel hope that I'd be given credit for trying to be what I think I should be.

SO 9-6

Songbird also saw that having a sense of being in communion with God was important. I asked whether she would like to have scripture read to her as she was dying:

No, because to me the Bible is man-made, in a language and a time we don't understand. I'd sooner have the feeling that I had direct communion with my Heavenly Father, to be going towards Him.

SO 9-4

For Jane's part, she could not understand why anyone with a faith in God would fear death:

We had one lady here that was a great friend of mine. And would you believe, she had been a Sunday school teacher and she was scared to die. Frightened, absolutely! She used to talk to me and I used to try to help her to see that she was going from here to the hereafter and that it would be Jesus who would take her from (Rest Home) to heaven. JA 9-7

Receiving the Last Rites of the Catholic Church was the spiritual care of preference at the end of life for Theresa and Steep:

Well, I feel I would like the Rites of the Church, and I'd like them before I got too stupid to realize I was receiving them [pause] but that's in God's hands, really. I mightn't get the chance, but I would like the Rites of the Church [pause] I've got great faith in the priest's blessing and I would like that if it's God's will. TH 7-5

Steep's response to my question regarding specific spiritual care at the end of life:

I'd like to have the priest with me, certainly [pause] I can't really imagine myself dying [pause] I haven't got to that stage where I can imagine myself dying [pause] but I know I will... ST 7-9, 8-3

All four participants hoped that family and other significant people would be with them as they died. Jane, who was content to leave her end of life spiritual care in God's hands, acknowledged that a close nurse friend was going to be there to support her when her time came:

I do know that (name) will be with me [pause] she has told me that, and she is also told any time I am sick, and she comes up. The nurse here is our go between. JA 10-9

Theresa assumed that those who were significant in her life would be praying at her bedside:

...but I wouldn't want them praying loudly all the time, but I would like them to pray [pause] and perhaps sit quietly praying. I don't think I'd like a lot of noise around me, but I'd like to be assured of people's prayers...

TH 7-5

Songbird also presumed that her family would be there:

...not praying, just sitting there. I think the time for prayers is over. When my son was dying [pause] it's the family custom to get around and hold hands, and they just repeat their names and the dying person repeats them after them [pause] but it comes to an end you know, and they all go out together...

SO 9-10, 10-3

But the above notwithstanding, Songbird wanted to die peacefully:

I think I'd rather go out quietly, the quieter the better [pause] no hymns or anything.

SO 10-9

End of life rituals associated with the Catholic Church were part of Theresa's heritage and aspects of the spiritual care she expected to receive herself:

I hope that they would sprinkle the holy water [pause] music, I wouldn't mind that at all, and I think they would do that [pause] Vivaldi, perhaps. Some of those, very softly, and some of the hymns of the church because they say your hearing is the last to go. I wouldn't mind if they lit a candle but I'd be quite content with prayers.

TH 8-1, 9-2/4

Theresa was the only participant to suggest her carers might play music as she was dying. There is increasing evidence however, that music has considerable therapeutic value in calming "terminal agitation", the restlessness often associated with the dying process (Dowling Singh, 1999).

According to the custom of the facility, Theresa expected that she would lie in the chapel for a period and then, the evening before the funeral, a service would be held:

We have these symbols of opening the Bible you've used. We generally have a service, a liturgy and reminisce about the things that have happened. TH 10-5

Death, for Songbird did not mark the end of her requirements for spiritual care either:

...you would want them to commit you to God's care [pause] you'd want that I think, when you can't speak for yourself. SO 10-13

Songbird was content to leave her funeral arrangements up to her family:

I don't want to say. They've asked me and I said I'd leave that to them, they can decide [pause] they can decide what you have [pause] as long as they commit you, your soul and spirit to God when the time comes [pause] but the body is nothing, is it, after that? SO 11-1

Although Theresa planned to document certain aspects of her funeral service, she also had trust in others to “do the right thing”:

I know they would do all in their power to make it a very satisfactory funeral. I wouldn't have any worries about that... TH 10-5

Planning for spiritual care

Jane had had conversations with her nephew and a Funeral Director about her funeral arrangements and had chosen hymns and had specified where the service would take place. Even Steep, while continuing to voice her inability to imagine herself dying, had planned her funeral:

I've told her (the niece) just to be simple, and I told her I didn't want a eulogy. We picked out some pallbearers too [pause] I'm going to be cremated and then I'm going to go in the rose garden with him (her husband) and have a rose over me [pause] but I can't imagine myself dying...

ST 8-5

Jane had arranged that a friend would be with her at the time of her dying and would support her appropriately. The other participants had taken it for granted that their families and those caring for them in their last days would ensure that spiritual care appropriate for them would be implemented:

I've just taken it for granted they (priest and family) will be there.

ST 8-7

No, I haven't discussed it, I think they would know [pause] I think they would know...

SO 11-7

The participants did see some value in making their wishes known, however:

I think there would be a point in talking it over. I think it's something that should be mentioned. It's a big event, shall I say, in your life [pause] you've come to the end of your life. Yes, I think it would be a good thing to talk it over with your family.

SO 11-9

But as far as taking any action to ensure her wishes would be honoured:

No, I think I'd trust my family enough to be sure that they would carry out my wishes.

SO 11-11

However, Songbird had been more forthright in making her wishes for end of life physical care known:

They asked me in the hospital if I wanted to be revived again? And I said "No, never". When I die I die, and I don't want to be revived!

SO 11-3

Steep conceded that it would be wise to talk to family about her wishes:

*When my brothers died we've been with them all around the bed [pause]
I've just taken that for granted, I suppose.* ST 8-9

She was somewhat ambivalent about further actions she could take, but her involvement in the study caused Steep to consider this further. When I returned with the transcript for her to read, she informed me that she had spoken to her niece to ensure that the latter understood what her wishes were.

Prior to her involvement in the study, Theresa had not documented wishes for any end of life care, spiritual or otherwise. She began to rethink this, however:

After my funeral service is written out, I might say that I want to be buried with my rosary beads I have in the chapel, because they were my mother's. And I would like the picture over there to go somewhere in (the Rest Home). TH 9-11

In speaking generally about the notion of formally written advance directives for spiritual care, Theresa agreed that staff should attempt to discern and document people's wishes for this dimension of care at the end of life:

...because some people don't think about that, do they [pause] I mean about themselves [pause] or they might want to talk to someone and not be able to say what they want. TH 12-5

She warned that not everyone would necessarily be consistent with their requests.

Jane's view:

As far as (the Rest Home) is concerned, the people that would be talking to you would be the two chaplains, and especially if you were sick and if they thought that you were likely to die, either of them, I know, would talk to you about the things that matter. JA 12-5

In conclusion, the participants expressed diverse views of how their spirituality was impacted on by infirmities of old age and by the Rest Home environment in particular. Where appropriate, reference was made to relevant literature to clarify and substantiate the research findings. The participants agreed that at least in part, their spiritual needs were being met, even if they had to plan their day to accommodate spiritual activities such as prayer and scripture reading.

Although prior to the study the participants may not have consciously considered the spiritual care they wanted at the end of life, they had clear views on what they wanted at this time when asked, and had taken it for granted that those caring for them would do the right thing. Although all four participants saw the merit in having conversations with family or significant others about these wishes, three did not see any reason to document them, such was their level of trust in those who would be making the care decisions for them when the time came.

To conclude the chapters in which the themes to emerge from analyses of the participant's interview transcriptions were examined, the final theme relating to their comfort with the research process is briefly illustrated:

Participant satisfaction with the research process

I was especially concerned with their comfort during the section of the interview that focused on end of life care.

*I'm not a person that really is one to talk about things like that [pause]
but I've really felt quite comfortable about it, thank you very much.*

TH 17-1

*Yes, yes absolutely! I've felt very comfortable! You wouldn't have chosen
to do your thesis on a spiritual subject if it didn't mean anything to you at
all [pause] and I've felt that from the beginning.*

JA 14-8

Although I had identified the potential for the participants to experience some spiritual disquiet after the interviews and had arranged for staff to monitor this, none of the participants were troubled by the process and all claimed to have enjoyed the experience.

The next chapter will address the significance of this study, with implications and recommendations for providers of residential care services for older people.

**RESEARCH CONCLUSIONS, LIMITATIONS,
IMPLICATIONS, AND RECOMMENDATIONS**

This chapter presents the conclusions of the study and acknowledges its limitations as well as its significance. The task is then to describe how the study may be used to benefit service delivery, in this case the spiritual care of older people in residential settings, and to inform professional practice. Implications for funders and providers of services for older people, nurses, and care workers and support staff in the Services for Older Persons' Sector are discussed, along with implications for spiritual care at the end of life, and for nursing research in the future. A reflection on the research process is then presented. A brief overview of the study and some closing observations draw the project to a conclusion.

Research conclusions

The two previous chapters discussed the research findings as they related to the ten themes to have emerged from the study. Reference was also made to relevant literature to clarify and substantiate the research findings. I concluded that God, perceived and understood in many ways by the four participants, was the focal point of their spirituality, and that their spirituality was very important to them. In their view, God was in control and everything that happened, even suffering, was part of His ultimate plan. Although God was central to the participants' spirituality, gifts from God in the form of His creation helped to nurture their spirits. Relationship was also an integral component of spirituality for them: relationship with God, family, other people, and God's creation.

In accepting that they belonged to God and that He directed and led them, the participants acknowledged their responsibility to lead their lives in accordance with His will. They also recognised their human tendency to sometimes fail in this.

For Theresa, Songbird and Jane in particular, the centrality of spirituality to their being indicated to me that their holistic wellness depended on spiritual wellness, especially when considered against the backdrop of age related frailty. This conclusion was in keeping with the body of evidence in the literature for spiritual wellbeing and positive health outcomes. With ageing, the participants experienced changes in their spirituality. All reported a freer spirit and a deeper sense of “God within”, not experienced in their earlier years.

Although the participants in this study articulated a spirituality understood within a Christian framework, as the literature revealed, spirituality may be shaped in many ways and other residents may have perceived it very differently. For three of the participants, admission to residential care brought with it some alteration in spirituality and specific spiritual needs which were met in various ways. Rest Home routines or the residential care environment per se either helped or hindered the meeting of these needs, impacting on the participants’ overall satisfaction with the spiritual care provided. Although the chaplains were considered to be primarily responsible for providing spiritual care, the participants agree that the care staff contributed in an advocacy role and by demonstrating positiveness, love and caring in their interactions with those they cared for.

While the participants may not have articulated these in the past, they envisaged themselves as having specific spiritual needs at the end of life and had clear views about how these needs might be met. Only one of the participants acknowledged the merits of documenting directives for spiritual care in the perideath period. The other three had complete confidence that their families and carers would ensure that their wishes would be honoured, but all had had conversations with family members about funeral arrangements.

Finally, discussing spirituality and spiritual care around the time of their own death might be difficult for some. Nevertheless, the participants in this study demonstrated that when sensitivity was maintained, open discussion about these issues was possible.

Limitations of the study

The size, scope and methodology of this study pose significant limitations on the value of its findings and the extent to which they can be used to inform significant change across the wider Services for Older Persons' Sector. Even though the data was rich and revealed the participants' perception of the issues in question, the fact that it came from only four participants suggests that the findings cannot be transferred to a larger group.

The research setting was a religious and welfare Rest Home owned by a church organisation. This posed another limitation on the study since one cannot assume that participants in a purposive sample of older people from a "for profit" facility would respond similarly.

Although this was not predetermined, a Christian framework provided the spiritual focus for each of the participants. Again, this limited the applicability of the findings to a broader group since people of different creeds and spiritual perspectives might have responded quite differently.

Gender and ethnicity might also have posed limitations. All four participants were women of white European origin. Men, and men and women from other ethnic backgrounds may have seen spirituality and spiritual care issues in a different light.

A final limitation to acknowledge here involves the method of data analysis. With hindsight, I would use another strategy for analysing the data. The modified Colaizzi method was very cumbersome for the data I had to analyse, and of the nine areas explored, only three were able to be categorised, and of these, only two lent themselves to sub categorisation (see Summary of research findings at the beginning of Chapter Four). Ten themes emerged from this data analysis phase, and considerable difficulty was experienced confining my discussion of these.

Significance of the study

The above notwithstanding, I contend that the study and its findings are significant for the advancement of knowledge of the issues of concern, especially since it may be the first in a New Zealand Rest Home setting to explore spirituality and spiritual care issues. The study may also have been the first ever to explore the notion of advance planning by older people in residential institutions for “end of life” spiritual care.

The study provides an indication that at least four older people perceive spiritual care at the end of life as important for them. It contributes to nursing knowledge by providing an indication of what some people need to achieve a “good death”. Furthermore, the study has a contribution to make to the “end of life”, legal, and theological discourses, and contributes to the theoretical frameworks in which chaplains practice. Finally, the study provides the groundwork for wider research into spiritual care at the end of life and may form the basis of a more substantial study into the spiritual needs of older people.

Implications for service delivery and professional practice

I suggest that implications have emerged from the study for funders and providers of services for older people, nurses, care workers and support staff, for the end of life spiritual care of older people themselves, and for nursing research in the future.

Implications for funders and service providers

The significance of spirituality and spiritual care has implications for all funders of services for older people to recognise its importance in funding contracts, and to factor the provision of spiritual care into funding formulae. Similarly, the study findings may serve to remind providers of services for older people that attention to this dimension of caring is a client right and therefore an obligation on the part of the provider. Moreover, the findings may suggest to them that appropriate spiritual care may impact on the profitability of their businesses as

well. Maximising the total wellbeing of residents by including care of their spirits as well as their bodies may have positive implications for both medical and pharmaceutical costs.

The Rest Home where the study was conducted resourced forty hours of chaplaincy input per week. All four participants identified the chaplains as the primary providers of spiritual care, and the question remains as to whether they would perceive an absence of this care if chaplains were not employed at the facility. Forty hours of chaplaincy input per week is significantly higher than that provided in most other organisations. Although pastoral care services are commonplace in hospitals, hospices, and even in industry, many providers of residential services for older people do not appreciate its value as a component of their service delivery (Hudson and Richmond, 2000; Vance, 1997). Vance suggests that there are three main reasons for this: ignorance of what pastoral care really constitutes, facility managers' lack of understanding of the value of pastoral care, and cost (Vance, 1997). "We can't afford to fund that!" is a commonly heard cry in the Services for Older Persons' sector in New Zealand, but Vance argues that the other reasons are more influential in the lack of commitment to this aspect of service. I suggest, however, that the findings of this study indicate that where providers resource significant chaplaincy input, clients may feel that, for the most part, their spiritual needs are being catered for. For this reason, I urge service providers to consider the inclusion of significant chaplaincy input as an investment, rather than merely as a cost.

Implications for nurses

Although the study participants saw the chaplains as being responsible, they did recognise that the staff had a role to play. Theresa, in particular noted that the registered nurse would advocate for her if her spiritual needs were not being met, implying that nurses must have some knowledge of spirituality and spiritual care to be able to do this. From its earliest days, the nursing profession has recognised the spiritual dimension, and this study provides further evidence that for some people, spirituality is the integrating factor that makes them who they are. The literature continues to suggest, however, that some nurses do not give equal standing to spiritual care compared to physical care, and in fact might

disregarded it all together. I suggest that the findings of this study may remind nurses of this component of holistic care.

As with all aspects of care, spiritual care begins with assessment of need. Gone are the days when a “one size fits all” package of care is deemed acceptable (Ministry of Health, 2002c). Since the advent of the nursing process and even earlier, nurses have understood that the care they deliver must be based on a comprehensive assessment of the client’s actual and potential problems, i.e. their specific needs. Ideally, from this assessment a fully integrated, individualised, goal oriented, client-centred plan of care is developed, involving the client and their family, and all members of the multidisciplinary team (Ministry of Health, 2002c).

As was noted in Chapter One, staff rarely have qualms about enquiring into intimate details relating to physical functioning and yet may feel uncomfortable about questioning clients about spirituality issues. The findings of this study suggest, however, that if sensitively undertaken by an interviewer, older people may be happy to disclose the aspects of their lives which give meaning to them and to inform the care planning process of their wishes for spiritual care up to and beyond the end of their lives. Nevertheless, my experience in the Services for Older Persons’ Sector is that many nurses have little understanding of spiritual assessment beyond noting down a resident’s religious preference in the “Religious Denomination” box of the Care Plan. Hudson and Richmond suggest that a comprehensive assessment of spiritual needs includes a wide range of issues, from the narrowly defined preferred religious affiliation if any, “to a broader understanding of the resident’s wishes and dreams, fear and anxieties affecting the whole of life” (2000, p.138). These authors also caution that a resident’s spiritual needs are likely to change over time so that, as with the Care Plan as a whole, regular review is mandatory. A person who declared themselves free from spiritual needs on admission, for example, may develop different needs as time progresses, especially when and if they begin to contemplate the reality of their own mortality for the first time.

Recognising and facilitating interventions to manage spiritual distress is a dimension of spiritual care, and one that has implications for nursing practice. In spite of the literature warning that older people in residential care are particularly at risk of this, only Songbird appeared to have a degree of spiritual distress, precipitated by her difficulty settling into the Rest Home environment and the recent death of her son. As noted in Chapter Two, Brown (2001) discusses indicators of spiritual distress and makes suggestions for how nurses may meet the spiritual needs of older people in residential care settings.

This study has a further implication for nursing. The questions it raises may stimulate further inquiry and nursing research that extends the body of nursing knowledge on spirituality and spiritual care, and in particular the spiritual care of older adults at the end of life. The recommendations for further research will be discussed later in this chapter.

Implications for care workers and support staff

Most care staff employed in residential care services for older people are care workers who work under the supervision of registered nurses. The findings of this study have implications for them as well. Each of the participants in one way or another voiced affirmation of the way in which the care staff were caring, cheerful, and positive, attributes that engendered trust on the part of the participants, and in Songbird's voice, "allowed them to keep things in balance". The earlier explication of relevant literature revealed that meaning and purpose, love and harmonious relationships, forgiveness, hope and strength, trust, and the opportunity to express personal beliefs and engage in spiritual practices are spiritual needs (Narayanasamy, 2001), which I argue may be considered within the framework of daily care giving. Interactions between the older person and their carers may either promote or break down the sense they have of love, trust, meaning in life, hope and strength.

Jane indicated that an ambience conducive to nurturing the spirit was important for her, and I suggest that all staff have a role in fostering a warm, caring, and welcoming environment where holistic care of a high standard is encouraged and supported by management. Positive interpersonal staff relationships, unhurried

attention to detail, and apparent concern for one another, create such an ambiance. In contrast, staff disharmony and a blinkered orientation to the task at the expense of expressions of caring, result in the opposite.

The ambience of the facility also impacts on the willingness of friends and family to visit, identified in the study as being important for the broader spiritual wellbeing of Songbird, Jane, and Steep. However, visiting a relative in a residential care environment is difficult for some. Having to acknowledge that their loved one is becoming frailer is not easy and the family member may already be experiencing feelings of guilt that they themselves are not caring for the older person in their own home. Moreover, the sights and occasionally the smells of such environments are disturbing for many and sadly, from my experience, some family members stop calling after an initial period of “duty” visiting. Staff can do a great deal to ensure the facility is a place where visitors feel at ease. Not only should open visiting be encouraged, but steps taken to promote a “family friendly” environment. Tea making facilities to enable the resident to share a “cuppa” with a relative, invitations to regular meals extended to visitors who happen to be visiting at this time, allowing family members to participate in care giving if this is the resident’s and their wish, ready access to staff so that family members can discuss concerns, and a room where family can have time out when sitting with a dying loved one, are all examples of an environment which welcomes visitors and encourages them to return.

Two of the participants, Theresa and Steep, indicated that at times the Activities programme encroached on the time they may have spent attending to their spiritual needs. This finding has implications for staff, and in particular the Activities Coordinators/Diversional Therapists who should be mindful of the extent to which they provide persuasive encouragement to residents to attend the planned activities programme. Older people need time to be able to reflect on and make final meaning of their lives. Some also must have space to engage in other activities that nurture their spirits. And yet, as was stated by the study participant Theresa, some may feel obliged to go along to an activity in recognition of the effort put into the organisation of such activities. Many residents enjoy the planned activities but others are less enthusiastic. I believe it is very important to

determine the true activities preferences of the residents and then to respect these. Over the years, a number of older people, anticipating the time when they might require residential care, have commented to me, “Lord, save me from the bingo players!” or words to that effect. Activities, utilizing all five senses, need to be meaningful for the residents and provide them with opportunity for nurturing their spirits.

A final implication of this study for care staff involves ensuring that the needs of *all* residents are met. Most residential care facilities have a number of residents with varying degrees of dementia. For those not similarly effected, this situation can pose a great challenge as was voiced by Songbird. At times even their sense of safety can be threatened when those with dementia wander at night and/or intrude on their personal space. Like Songbird, they may also feel spiritually isolated by not having others nearby with whom they can engage in conversation. It is important that staff are mindful of and manage this situation appropriately. In most countries, residential care services management have a statutory obligation to ensure that the residents are receiving the care they need. Where their condition has changed and they can no longer be cared for in the Rest Home environment (for their own safety and/or to maintain the rights of others), management are required to initiate the process to have them moved to a more appropriate level of care. This does not always happen when it should. Family may put pressure on facility management to allow the resident to stay in the environment that has become familiar for them. Rest Home management may also be reluctant to transfer the more dependent resident. Some may genuinely believe they can accommodate the older person’s increasing dependence, while others are more motivated by the financial implications of an empty bed in the facility. Nevertheless, the issues must be carefully weighed up and decisions to transfer or retain residents made in the best interests of all concerned. Of course, the wishes of the older person themselves should be sought where possible, and taken into account.

The above notwithstanding, the spiritual needs of older people with dementia must also be considered. Appropriate activities that nurture the spirits of this group must be incorporated into the routines of the facility.

Implications for end of life spiritual care

The study participants all had clear views about the spiritual care they wanted as they were dying but none had shared these wishes with others. Two of the four *had* nevertheless, spoken to family members about specific funeral arrangements. Jane had even gone so far as to pay in advance for her funeral, and discuss the arrangements with a funeral director and the minister she had chosen to conduct the service in the Rest Home chapel. As for the spiritual care they wanted as they were dying, however, the participants were content with the fact that their families and those caring for them as they died would somehow know what they would want and ensure the appropriate spiritual care was given. The question remains, though: do staff and family actually know what the older person's wishes for spiritual care at the end of life would be? Family members might know but can they necessarily be relied on to implement these wishes in all cases? The family members of the participants would probably honour their wishes provided they knew what their relative wanted, but from my own experience, as described in Chapter One, this is not always the case. Jane believed that the chaplains would have a conversation with residents approaching death and the details of their wishes for specific care would be made known at that point. Theresa, on the other hand had a different view. In a conversation near the end of the interview, she conceded that it would be wise to document these wishes, particularly in a facility without pastoral care/chaplaincy input.

Walter (1996) suggests that there are three approaches to spiritual care of the dying. One is the *religious* approach where facility staff, motivated by compassion, try to minister to a person's identified religious needs. The second, or *ecclesiastical* approach delegates all responsibility for the meeting of religious needs to ordained clergy. The third approach, identified as the *spiritual* approach, involves whatever a dying patient considers as meaningful to his or her life. Maybe it is wishful thinking to hope that if staff of residential care facilities for older people knew what their clients wanted at that time in their lives, a blend of all three models could be utilised. But how might care staff discover what a resident would want?

Addressing such issues would require considerable sensitivity on the part of the nurse, and should certainly not be part of the “clerking in” on admission process. In so saying however, most service providers enquire of new residents or family members their preferences for funeral directing firm and burial or cremation in the event of their death. The Statutory Authority in New Zealand also requires that even in the Services for Older Peoples’ Sector, information be sought of the clients’ views on resuscitation and other active strategies for preserving their lives. In such a climate, it may be easier to address spiritual care issues at the end of life, compared to earlier days when death was certainly a taboo subject for many. Of the many Care Plan formats I have viewed in New Zealand, none have made provision for noting residents’ wishes for spiritual care at the end of life, advance directive documentation focusing exclusively on resuscitation decisions. If staff are to be made aware of residents’ wishes for end of life spiritual care, I contend that it needs to be documented. Figure 1 provides a suggested format for documenting such wishes and may be incorporated into the comprehensive Care Plan.

<p><u>Request for care at the time of dying:</u></p> <p>Family/Significant others present: N ☐ Y ☐</p> <p>Specify: _____</p> <p>Clergy Present: N ☐ Y ☐ Specify _____</p> <p>Last Rites and/or other Sacraments: N ☐ Y ☐ Specify _____</p> <p>Rosary/Other Prayer: N ☐ Y ☐ Specify _____</p> <p>Reading of scripture/Other: N ☐ Y ☐ Specify _____</p> <p>Music: N ☐ Y ☐ Specify _____</p> <p>Touch/massage/holding hands: N ☐ Y ☐ Specify _____</p> <p>Other care? _____</p> <p>Wishes for specific care of the body: _____</p>
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Figure 1 Care at the time of dying

Nevertheless, as with all aspects of the older person's plan of care, advance directive information (including that for spiritual care), should be reviewed at regular intervals. People may change their minds over time and this needs to be noted.

Implications for nursing research

As I indicated earlier, this study will have limited applicability to other settings although excerpts from the interviews were included in Chapters Four and Five not only to provide evidence of the participants' views, but in the hope that readers engaged in providing residential care services for older people might find some resonance with their own practice settings. Nevertheless, this study indicates a need for more extensive research into spirituality issues of older people in residential care, to validate or disprove the findings of this study, and to add to the body of knowledge of this important dimension of care. The aspects that lend themselves to further research stem primarily from the limitations of the study identified earlier, and I include four for consideration:

Firstly, similar studies involving older people, including men, from different faith backgrounds and none, different cultural backgrounds, and set in the "for profit" sector should be carried out to compare the findings with those of this study. In recognising the importance of the spiritual dimension to Maori, kaumatua should also be included in these studies.

A second suggestion is for a similar study set in an organisation with no formal chaplaincy or pastoral care service. This could provide an indication of whether or not the participants' satisfaction with the spiritual care being offered was directly influenced by the very significant chaplaincy input noted in this study. If there was no chaplaincy input, would the participants be similarly satisfied? How would they then perceive the role of the care staff in providing this dimension of care?

The participants of this study had faith that their families and those caring for them would implement their wishes for spiritual care in the perideath period. But do staff and family members necessarily know what these wishes are if they

haven't been told? To determine this, a two-stage study involving older people, then family and staff, is a third suggestion for further research.

Finally, another study might also include a review of the older persons' Care Plans in search of directives to guide their spiritual care whilst resident at the facility and at the end of their lives.

A reflection on the research process

Overall, I believe that the research process employed to investigate the topic of concern, i.e. the spirituality of four older people in Rest Homes and their spiritual care issues in the perideath period, was appropriate, although there were challenges with each phase. There is a large and growing body of literature on spirituality and related issues, and the challenge here was to use some of what was known to refine the research questions. Throughout the process, and even as I near the end, I have an acute sense of not having read enough, that I have only skimmed the surface of this vast area of human concern.

The data-gathering phase of the project was the most enjoyable. The participants, and extent to which they were prepared to share with me such deep, personal, and beautiful treasures, made me feel very humble. Indeed, if this thesis has any strength, it is in the voices of the four women – voices which, if necessary could stand alone as a testimony of older people who have achieved integrity in old age and who are at one with their God.

Conclusion

This descriptive study, the first of its kind in New Zealand as far as I am aware, explored issues of spirituality involving older people resident in a Stage Two Rest Home. Four women ranging in age from 87 to 92 years were interviewed. Their perception of their spiritual dimension was investigated, and the participants shared how this had altered as they had aged. Their wishes for spiritual care in the perideath period were also explored.

Older people in residential care are a group particularly vulnerable to spiritual pain. The many losses they have experienced in the last years of their lives may impact on their ability to find final meaning in their lives and to grow spiritually until they draw their last breath. Care staff who understand and value this dimension of care can assist residents to address their spiritual needs. I call for Provider organisations to give serious consideration to including significant chaplaincy or pastoral care input into their service.

The Health and Disability Sector Standards in New Zealand demand that residents' beliefs and values are valued and supported, but do Rest Homes and Continuing Care Hospitals provide spiritual care for all residents? There is a danger that providers, even those with religious affiliation, think that they have "done spiritual care" because they have made provision for church services at the facility and have even employed a "token" pastoral care worker or chaplain a few hours per week. While these are important for some residents, they may do little to nurture the broader spirituality of many others. Care staff do, sometimes inadvertently, provide spiritual care by being caring, kind, compassionate, and good listeners - yet greater awareness of how these attributes fit into the context of spiritual care might increase their effectiveness as spiritual carers.

It is my hope that this study might raise the profile of spiritual care, convincing some providers of residential services for older people that effective and appropriate care of the spirit can be facilitated, providing residents with a song that surely enables their spirits to always sing until the end of their lives, in spite of the challenges of their wintering years. The commitment of staff to this dimension of care is vital however, particularly the commitment of senior management who must be prepared to resource and drive it, and also to model its principles in their dealings with residents, families and staff.

APPENDICES

Appendix 1: Letter to Rest Home Manager

Title
Address of Researcher

Date

The Manager
(Name of Rest Home)

Dear Manager

I am employed as xxxxxxxxxxxx Currently, I am enrolled in the Masters programme at the Graduate School of Nursing and Midwifery, Victoria University of Wellington and am about to undertake the research for a two-paper thesis. The focus of my study will be the perception elderly Rest Home residents have of their spirituality at the time of the study, their wishes for spiritual care then and at the time of time of their death, and their views on how they could ensure these wishes would be honoured. Although only four residents will be involved in the study, I hope that readers of the research currently employed in the Aged Care sector will come to a deeper understanding of the end of life spiritual dimension and as a result be in a position to facilitate better spiritual care for some of their clients.

Once I have gained approval from the xxxxxxxxxxxx Regional Ethics Committee I will need to recruit four participants in total and am seeking your consent to invite some of your Residents to be part of the study. If you agree in principle to my having access to (Name of Rest Home), I will ask permission from you to involve your Chaplain and Activities Coordinator in identifying residents who meet my criteria for selection. My criteria for participant consideration are that they are judged by you and your staff as being “least vulnerable”: they would be able to meet with me, answer questions and reflect deeply on their own spirituality. Residents likely to fit the criteria will be those who are not judged to be dying imminently, are lucid, do not require the services of an interpreter, are able to sustain a conversation for at least an hour, are known to have concerns with the meaning of life, death, and/or beliefs, and are willing and able to discuss these. I believe that you and your Care Manager are best fit to judge which residents would meet these criteria and if you are able to identify

such residents, I would ask you or some other person designated by you to make the initial approach. If they are willing to speak to me, formal introductions could be made at that point.

Prior to engaging the resident in the research, an overview of the study would be given to them in the form of an information sheet, and full, written informed consent sought. An appointment would also be made with them for a single, in-depth interview, lasting approximately one hour. I envisage the interviews taking place between May and July 2002, and either on a Saturday or Sunday to accommodate my working week. Although I live in (name of city), much of my time is spent out of the city. With the resident's permission I will also inform the Chaplain (or any other person you or they might consider appropriate) of the interview appointment so that they can visit afterwards to talk through any issues that have arisen for them. Although I would not expect this to happen for participants willing to participate in a study of this nature, deep personal sharing for some may possibly cause the surfacing of long buried emotions and uncertainties that might need to be dealt with.

In many Aged Care organisations, the spiritual dimension of care receives much less priority than the physical or even psychosocial domains. I am asking for your approval for me to access four residents at your facility for research which I hope will make a difference to this very important aspect of care

Thank you for considering this request.

Yours sincerely

Judy Brown

Appendix 2: Prospective Participants' Information

Thank you for agreeing to hear more about my study. You will already have heard a little bit about it from the person who asked you if you would be willing to speak with me. I want to reassure you from the outset that becoming involved will be entirely your choice. This information sheet will provide you with a little bit of background information about my research and me.

I am a registered nurse employed in a management role of an organisation, xxxxxxxxxxxxxxxx that provides Rest Home and Hospital care for elderly people. I am also studying for a Masters (Applied) degree in Nursing at the Graduate School of Nursing and Midwifery, Victoria University of Wellington.

This year I am doing the research that will form the basis for my thesis. This research will be conducted in (name of) Rest Home. My particular interest is in aspects of care other than the physical component. I am interested to know, for example how people make sense of things that happen to them and what sources of support or help they look to when life is difficult. As people approach the end of their life I'm also interested to know whether they have wishes for specific care at the time of their death.

The title of my study is: How four older people living in Rest Homes view their spirituality and spiritual needs, and their wishes for spiritual care now and as they are dying

This study will involve my listening to four people living in (name of Rest Home) talk about how they see some aspects of their spirituality and spiritual needs.

I am inviting you to be part of this project. In particular, I will be interested to hear your views on the following:

What spirituality means to you.

How you make sense of what happens to you

The spiritual care you have or would wish to have now you are living at the Rest Home.

The care you would wish to have when you are close to death, dying, and just after death, and whether you have told anyone about these wishes.

What you can do to ensure your wishes are honoured.

Prior to having this conversation with you, I will explain the research to you in detail, and ensure that you understand what it involves. Only then can I invite you to be part of the study. If you agree, I must obtain from you your written consent.

After you have given your consent to participate in the study, I will make an appointment at your convenience to come and listen to your views on the above. I expect the interview to last for about an hour and I will tape it, providing you are comfortable with this. After the interview I will write down our taped conversation and bring it for you to read and amend as you see fit. If you wish, you may also hear and alter our taped conversation.

The interview will be carried out in a place of your choice where your privacy can be ensured. Confidentiality will be maintained at all times and you will not be personally identified in any discussions I have with any other person or in my writing. The tape of our conversation and any notes will be either returned to you or destroyed after the research has been completed and the regulatory time period for retaining research materials has expired.

I appreciate that the subject of my research may be very personal for some people. As the researcher, I will endeavour to be as sensitive as I can. If you would like to have a family member or other person with you during the interview, you are very welcome to do so. Sharing deeply about very personal things may cause some people to feel slightly troubled. If this is the case with you, I can stop the interview immediately. If you wish, I could also arrange for someone of your choice to visit afterwards to check how you are.

After the interview you may decide you want to clarify something you said or add to your story in some way. If you make this known to the staff, they will contact me and I'll return to see you. Alternatively, you may call me yourself. My contact details are below.

All research involving people must have ethical approval. The xxxxxxxxxxxxxxxxxxxx Regional Ethics Committee has given approval for me to conduct this study. After I have heard your views on these aspects of your spirituality, I will analyse what you have said very

carefully and hopefully come to a deeper understanding of “end of life” spirituality and spiritual care.

Thank you for taking the time to consider this. It is important to me that your choice to participate is an informed decision. If you have any further questions regarding this study, I will be delighted to discuss these with you.

My contact details are:

Judy Brown
(Address)
(Phone Numbers)
(Email Address)

Or, you may contact my Supervisor:

Dr Joy Bickley Asher
Senior Lecturer
Graduate School of Nursing and Midwifery
Victoria University of Wellington
Phone: 0800 108 005
Email: Joy.BickleyAsher@vuw.ac.nz

Appendix 3: Informed Consent Form

Research Title: How four older people living in Rest Homes view their spirituality and spiritual needs, and their wishes for spiritual care now and as they are dying

Researcher: Judy Brown
(Address)
(Phone Numbers)

I give my consent to being interviewed by Judy Brown about my spirituality and spiritual needs, what my wishes for spiritual care are now and at the end of my life, and my views on what I can do to ensure these wishes are honoured. The interview is part of a study that may lead to a greater understanding for some people of “end of life” spiritual need and spiritual care.

I agree to being interviewed at (name of Rest Home) at a time convenient to me and in a place of my choosing where privacy can be assured. Furthermore, I understand that the interview will be taped and will last approximately one hour.

I understand that I was selected to participate in the study on the grounds that I was judged by staff and myself as being able to stand up to the research process and able to talk freely and deeply about my spirituality, and issues relating to the end of my life.

I have been given ample time to consider my involvement in the study, and the consent I give is entirely voluntary. I also realise that I can withdraw from the study at any time without my care being adversely affected.

I have been told that the information I give will be shared with no person other than Judy Brown’s academic supervisor. Even then, I will not be personally identified. Furthermore, I understand that I will not be identified in any research report or thesis.

I am aware that neither my participation nor non-participation in this study will influence any health care services provided to my family or me in the future.

I understand that the study may result in a deeper understanding of the meaning of “end of life” spiritual need and spiritual care for some people, but I personally will not receive any direct benefits from my participation other than the opportunity to talk and share my ideas.

I appreciate that this study has been approved by the xxxxxxxxxxxxxx Ethics Committee and understand that I can contact them to discuss concerns on Phone No: xxxxxxxxxxxx. I also know that I can contact Judy Brown if I have additional questions about the study.

Date: _____ Research participant’s signature: _____

Researcher’s signature: _____

Ethics Committee Letterhead

Appendix 4: Ethics Approval Notification

C/- Ethics Committee Address

3rd June 2003

Judy Brown
Position Title
Address

Dear Judy

A **descriptive study** of how four older people living in a Rest Home view their spirituality and spiritual needs, and their wishes for spiritual care now and as they are dying.

(Name of Region) Ethics Committee Reference 03/024

Regarding your ethics application. We thank you for your letter of the 14th of May and confirm ethics approval for your study.

The above study has been given ethical approval by the (Name of Region) Ethics Committee under the processes set out in the national application form for ethical approval of a research project guidelines for completion May 2002.

ACCREDITATION

The (Name of Region) Ethics Committee is accredited by the Health Research Council and is constituted and operates in accordance with the operational standards for Ethics Committees March 2002.

REPORTS

It is the investigator's responsibility to forward a report to the Committee.

GENERAL

All correspondence, protocol amendments, SAE reports and the final report should be forwarded to the (Name of Region) Ethics Committee.

It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any health care provider within whose facility the research is to be carried out. Where applicable authority for this must be obtained separately from the appropriate manager within the organization.

We wish you well with your research.

Yours faithfully

(Name)
Chairperson

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