School of Nursing and Midwifery

How do we meet the spiritual needs of residents in aged care facilities?

Jodi Smith

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DECLARATION

To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgment has been made.

This thesis contains no material which has been accepted for the award of any other degree or diploma in any university.

Signature: ……

Date: .....

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ABBREVIATIONS AND ACRONYMS

ACSAA Aged Care Standards and Accreditation Agency

AIHW Australian Institute of Health and Welfare

APRAC Australian Palliative Residential Aged Care

CINAHL Cumulative Index to Nursing and Allied Health

DoHA (Australian Government) Department of Health and Ageing

FICA Faith and Belief, Importance, Community, Address in Care Spiritual History Tool

HREC Health Research Ethics Committee

NCLS National Church Life Survey

NPCS National Palliative Care Strategy

PAS Psychogeriatric Assessment Scale

RACF Residential Aged Care Facility

ST Self Transcendence

UK United Kingdom

WA Western Australia

WHO World Health Organisation

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ABSTRACT

Spiritual support is considered essential for the holistic care of clients in residential aged care. It is part of one of the 44 standards that are audited by the Aged Care Standards and Accreditation Agency (ACSAA) (2011a). Despite this there is little documented about what residents would like in terms of spiritual care and there are few examples of good practice in this area.

This thesis presents a study of residents living in a residential aged care facility (RACF) in regional Western Australia. A descriptive and explorative qualitative approach has been applied to examine the spiritual needs of residents. A purposive, theoretical sampling method allowed access to 16 residents living in regional Western Australia. Data was generated by in-depth, semi-structured interviews using the Faith, Importance and Influence, Community, and Address (FICA) Spiritual History Tool as part of the interview guide (Borneham, Ferrell & Puchalski, 2010). Interviews were audiotape recorded, transcribed and coded to ensure confidentiality and anonymity of participants. The findings of this study start to provide an understanding of residents' viewpoints on religion and spirituality and residents' unmet psychosocial needs. The results highlight the importance of individually focused assessment and care for residents.

A constant comparison method of analysis was used to discover three central themes, two of these central themes had subthemes. The themes that emerged from the data to incorporate the perspectives of participants pertaining to spirituality are: *spirituality -I don't know what you mean*; *end of life is no joy at all* and *sources of comfort*. The theme *spirituality -I don't know what you mean* represents the difficulty participants had in translating this term. The theme *end of life is no joy at all* describes the difficulties associated with ageing and living in a RACF. This theme has two subthemes of *losses of later life* and *burden on others*. The theme *sources of comfort* covers the sources of support and comfort identified by participants that helped them cope with the stressors of ageing and institutionalised living. This theme has three

subthemes of: *support from family, ritual and tradition associated with organised religion* and *nature and its cycles*. This study contributes to an understanding of the issues associated with ageing and ways that participants can cope with these issues from the residents' perspective. This study questions the terminology used and provides suggestions for alternate names to identify and care for residents' needs that go beyond the purely physical. The research findings and recommendations from this study have implications for clinical practice, education, management and for further research both in the aged care setting and in the wider community.

1.0 BACKGROUND AND SIGNIFICANCE

1.1 Introduction

In the next two decades the number of older people in Australia is set to rise dramatically (Salt, 2009). A larger population of older people will place increased demand on aged care services and facilities, including RACFs (Australian Institute of Health and Welfare (AIHW), 2012; Haugan, Rannestad, Hammervold, Garåsen & Espnes, 2013). It is also likely that there will be greater expectations for service quality with a newer generation of older people consuming these services (Abbey, Froggatt, Parker & Abbey, 2006). The impact of increased consumer demand and expectations will conflict with health care and RACF providers drive to reduce costs and work more efficiently and effectively while maintaining quality and high standards of resident care. Some authors (Timmins & McSherry, 2012) talk of the potential spirituality has as a panacea in these challenging times to transform organisational cultures, values and attitudes; all of which positively influence the patient and staff experience.

Over the past two decades there has been increasing interest in spirituality and how it impacts on a person's well-being at the end of life. The reason for this burgeoning field of research has been attributed by some to a shifting emphasis from curing to healing in line with an increasing proportion of the population ageing and living with often more than one chronic condition (Adegbola, 2006). Spirituality has more worth for individuals when the medical system is perceived to be unable to meet their needs and the person begins to look toward spirituality for meaning, purpose, hope and understanding (Puchalski, 2004). The spiritual care of those at the end of life is often discussed in the literature however there is limited research regarding the needs of those in residential care facilities and how these needs could be best met.

1.2 Background to the study

1.2.1 Defining spirituality

Spirituality is a nebulous term, although it is often grouped with culture, such as in the Australian Aged Care Standards (ACSAA, 2011a). Alternatively, spirituality is

viewed as a component of culture (Rumbold, 2003), or culture and spirituality are viewed as acting independently (Wright, 1997) For the purpose and scope of this study, spirituality will be focused on and viewed as a part of a broader concept of culture. The following definition of spirituality will be used:

Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature and to the significant or sacred (Puchalski et al., 2009, p.887).

The most common cultural form of spirituality is religion, an institutionalised system of belief, prayer and ritual worship that usually centres on a supernatural god or gods (Eckersley, 2007). Religion and spirituality are seen as closely linked by many writers (MacKinlay & Trevitt, 2010; Moberg, 2010; Rumbold, 2003). Religion usually refers to activities, rituals and rites related to a religious faith like Judaism, Hinduism, Islam or Christianity, while spirituality is a more personal, but not always consciously expressed, sense of connectedness to the world in which we live (Moberg, 2008; Rumbold, 2003). As per the above definition, spirituality does not exclusively involve religion; in fact it does not necessarily include religion at all. Non religious explanations of spirituality include finding meaning in daily activities (Hicks, 1999), a sense of connection to the universe (Carroll, 2001) or as a web of relationships that give coherence to our lives (Rumbold, 2003).

1.2.2 Contemporary context of spirituality

Whilst spirituality is increasingly being discussed in international literature in terms of both aged care and palliative care, it is unclear where it fits in contemporary Australia, which is seen by many as an increasingly secular society (MacKinlay & Trevitt, 2007). Although 73% of Australians stated they believe in a god or a higher being, only 20% attended church at least monthly (Nielsen, 2009). Australians are increasingly describing themselves as spiritual but not religious; they seek spiritual experiences, but typically neither interpret nor express these through conventional religion (Rumbold, 2003). Whilst many of today's aged care clients identify with a

religion (Rumbold, 2003), more and more people are considering spirituality in older age as analogous to a spiritual quest or journey (MacKinlay & Trevitt, 2010; Rumbold, 2003; Salt, 2009).

1.2.3 Use of the term "spirituality"

While there has been plenty of dialogue about the definition of spirituality in the literature, the acceptance and understanding of this term by older persons, including those in RACFs, is largely unknown (Nolan & Mills, 2011). It has been suggested that while many older people are familiar with the term 'religion', there may not be the same degree of comfort with the term 'spirituality' (Nelson-Becker, 2005). The popularity of the word 'spirituality' originated in the 1960s and was associated with 'alternative' lifestyles and 'flower-power' hippies; consequently those born prior to the 1940s may have a narrow and possibly negative understanding of the term (Simmons, 2008). This difficulty in following fashionable terms is compounded with persons with dementia, who find abstract concepts difficult to comprehend (Martin & Fedio, 1983). Nolan and Mills (2011) recommend that spirituality needs to be explained to the older person as being about where one finds meaning and purpose, strength and support for the older person to comprehend and accept the term.

1.2.4 Spiritual care

Whilst the definition of spirituality is contentious, the practice of spiritual care with older people is less so. Studies have shown that older people rate the importance of spirituality more highly than younger adults (Moberg, 2008; Salt, 2009) and that spiritual care is a resource for well-being among older people (Hicks, 1999; van Olphen et al., 2003).

Improvements in health care have led to increased longevity, although increasing rates of chronic illness and mental health issues amongst older people are experienced (Kristjanson, 2006). Increased and improved community services allow older people to live at home for longer, so when people do need RACF accommodation they are frailer, have multiple co morbidities and are more likely to have a cognitive impairment than previous cohorts (Australian Institute of Health and Welfare (AIHW), 2011). Accordingly residents often have complex circumstances that require skilled

assessment and care by their caregivers. Depression is common in RACFs with a recent Australian study suggesting that 50% of aged care residents suffer from depressive symptoms (AIHW, 2011). MacKinlay (2001) states that many residents fail to either thrive or flourish in RACFs as evidenced by loss of appetite, physical and cognitive decline and social environmental impairment. This failure to thrive has been ascribed to a loss of meaning in life and lack of nourishment for the soul (MacKinlay, 2001). There is a growing awareness that spiritual care can help an older person in times of difficulty and complex need in their search for meaning and in guiding their life review (Bloemhard, 2008; Daaleman, Williams, Hamilton & Zimmerman, 2008; MacKinlay, 2001; Nolan & Mills, 2011).

Research into ageing and spirituality is based on a premise of ageing as a journey, as a search for meaning, balance, consolidation and reconciliation (Mowat, 2004). The effects of accumulated losses and grief on an older person's personality and behaviours have been the subject of many theorists. Within Erikson's model of human psychosocial development (1950), the eighth and final developmental crisis entails integrity versus despair, which is resolved by the development of maturity and wisdom, qualities providing well-being (Erikson, 1964). Butler's (1963) theory of life review reveals the importance of assessing older people's feelings and evaluations of the past to promote their current well-being. MacKinlay's (2004) research in the area has specified six spiritual tasks of ageing. These are: to find ultimate meaning, to respond to meaning, to develop self-transcendence, to find final personal meanings, to find relationship (intimacy), and to find hope (MacKinlay, 2004).

Spiritual care has a strong affinity with health care. According to Rumbold (2003):

It begins with attention, offers companionship in exploring issues that arise, encourages a quest for meaning, and continues to support the relationships that give life. Strategies for care will address physical, psychological, social and spiritual aspects of a person's life, and may involve intervention to change his or her circumstances,

assistance in revising a sense of self, or support to re-examine fundamental beliefs. (p. S13)

Similarly, MacKinlay and Trevitt (2007, p. S74) state that "Health care is not just about caring for people's physical needs. Spiritual care is a way of helping older people in their search for hope and meaning, especially as they face issues of grief, loss and uncertainty".

1.2.5 Spiritual care in RACFs

Social and health care policy documents specify person-centred compassionate and dignified care (ACSAA, 2011a; Australian Government Department of Health and Ageing (DoHA), 2011), yet examples of poor care of older people, including neglect, substandard and unsafe practices (DeBellis, 2010) , malnutrition and dehydration (Gaskill, Black, Isenring , Hassall , Sanders , & Bauer (2008) continue to emerge . Focusing on the spiritual care of older people is one of the ways in which person-centred care can be achieved (ACSAA, 2011a; Australian Government DoHA, 2006). National standards recommend that appropriate spiritual care is provided to residents of RACFs (ACSAA, 2011a; Australian Government DoHA, 2006). RACFs must meet each Aged Care Standard set by the Commonwealth Government in order to maintain accreditation (ACSAA, 2011a). Provisions for meeting the needs of the residents' spiritual life are included under *Standard 3 - Resident Lifestyle,* specifically *Standard 3.8 Cultural and Spiritual Life* with the expected outcome being "individual interests, customs, beliefs and cultural and ethnic backgrounds are valued and fostered" (ACSAA, 2011a, p. 2). Despite this, there are limited formal guidelines or suggestions, other than the *Guidelines for a Palliative Approach in Residential Aged Care* (Australian Government DoHA, 2006), available to offer suggestions of how this standard can be met. Within the *Guidelines for a Palliative Approach in Residential Aged Care* (Australian Government DoHA, 2006), chapter 12 is dedicated to spirituality and spiritual care. This section labeled Spiritual Support, lists three guidelines for best practice, namely:

1. "A multidisciplinary aged care team that responds in an open non-judgemental manner to residents' questions regarding spiritual needs, and that involves a chaplain/ pastoral care worker with experience and

knowledge of spiritual issues, is likely to provide appropriate spiritual support to residents, which will enhance their quality of life.

2. A palliative approach supports residents and families to express their unique spirituality. Respecting their privacy and providing an opportunity for them to continue their spiritual practices enhances residents spiritual care and their quality of life , as does spiritual counselling
3. Understanding the resident's current of desired practices, attitudes , experiences and beliefs by obtaining a comprehensive history, assists in meeting the spiritual needs of a resident as does a regular review"

As of 30 June 2010 there were 185,500 residential aged care places (AIHW, 2011). This number is set to grow with the increasing number of older people, (i.e. those over 65 years of age) living in Australia. As a result of improved community programmes, those who are admitted to RACFs (previously known as "nursing homes", or "hostels") have increasingly more complex health and social needs. RACFs are providing end of life care to their residents with increased frequency and are thus more often the place of death for older people (Abbey et al., 2006). The Australian Government has endorsed policy guidelines aimed at promoting the delivery of a palliative approach in RACFs (Australian Government DoHA, 2006). A palliative approach aims to "improve the quality of life for older people with a life-limiting illness and their families by reducing their suffering through early identification, assessment and treatment of pain, and of physical, psychological, social and spiritual needs" (World Health Organisation, 1990, p.1). Aged care and palliative care have many commonalities, most obviously the imminence of death and changed circumstances associated with illness. Spirituality is a popular concept in palliative care; its presence and practice is seen as positively influencing quality of life and health (Australian Government DoHA, 2006; Herman, 2001; Hicks, 1999; Kristjanson, 2006; Thomson, 2000; Tuohy, Brown & Smith, 2005).

Spiritual care is probably the least understood and most neglected aspect of residential care (Cobb, 2001). Historically, RACFs have addressed spirituality by

providing religious based church services and there are many RACFs that cater exclusively for specific cultural and religious groups (ACSAA, 2011b). Whilst church based organizations own RACFs throughout Australia, a growing number and diversity of residents requires that spiritual needs (in a wider context than purely religious) are clearly identified and strategies put in place to meet them. Challenges to providing spiritual care in a RACF include: how to respectfully assess the spiritual needs of residents and respond positively, how to maintain and promote the residents' sense of dignity, how to provide spiritual support to residents with cognitive impairment (Kristjanson, 2006) and how to provide balanced support to residents who request religious or other spiritual support without offending/limiting co-residents (ACSAA, 2010).

1.2.6 Spiritual care in RACFs

The Guidelines for a Palliative Approach in Residential Aged Care (Australian Government DoHA, 2006), state that spiritual assessment should be a continuous process and should begin on patient admission. Asking a resident what religion they belong to is not an adequate assessment of spiritual needs (Australian Government DoHA, 2006). The RACF's care team needs to consider whether a resident identifies with some form of spirituality and the ways they choose to practice their beliefs (Australian Government DoHA, 2006). The Guidelines for a Palliative Approach in Residential Aged Care (Australian Government DoHA, 2006, p155) propose the following recommendation in respect to spiritual assessment:

"Understanding the resident's current or desired practices, attitudes, experiences and beliefs by obtaining a comprehensive history, assists in meeting the spiritual needs of a resident , as does a regular review."

Common spirituality assessments include spirituality scales (Moberg, 2010; Wallace & O'Shea, 2007), spiritual histories (Puchalski & Romer, 2000), questionnaires, interviewing schedules and spiritual care scales (Moberg, 2010; Wallace & O'Shea, 2007).

1.3 Significance of the study

With older people becoming a rapidly growing segment of the total population, the need for high quality residential aged care that meets both agency and residents' standards is set to grow accordingly. This research will increase the understanding of RACF residents' spiritual needs and contribute to efforts aimed at improving quality care within a residential aged care context. Implications for practice will be discussed and directions for further research in this area will be provided.

1.4 The purpose of the study

The purpose of this study is to explore and describe the experiences of residents of RACFs in terms of their spiritual needs. A qualitative method of inquiry was selected due to the paucity of literature pertaining specifically to the residents' experiences and perceived spiritual needs. Qualitative methods permit the topic to be thoroughly examined while not being hampered by preconceptions (Marshall & Rossman, 2006). With qualitative research, the emphasis is on a holistic understanding (Marshall & Rossman, 2006). This differs to quantitative research methods that involve the classification of characteristics of interest. A descriptive exploratory approach has been applied to facilitate a thorough exploration of the residents' subjective experiences (Marshall & Rossman, 2006).

The key research question for this study is: what are the spiritual needs of residents in RACFs? The specific objectives of this study are as follows:

1. to explore and describe aged care residents' understanding of the meaning and importance of spiritual care,

2. to explore factors identified by residents as enhancing or inhibiting spiritual support, and

3. to identify ways in which the RACF can better respond to the expressed spiritual needs of its residents.

1.5 Conclusion

This chapter has provided the background for this study. The National ACSAA's recommendations that appropriate spiritual care is provided to residents were outlined and the quandary that there are little practical examples on how this should be done was raised. The nebulous nature of the term spirituality has again been highlighted, and examples were provided for the terms 'spiritual care' and 'spiritual assessment'. The application of spiritual care and spiritual assessment in RACFs was also discussed. Some possible issues with terminology have also been identified. The significance of the study has been stated and the purpose of the study together with study objectives outlined. The following chapter presents findings from a literature review which will focus on the spiritual needs of residents in RACFs.

2.0 LITERATURE REVIEW

2.1 Introduction

This chapter outlines the research related to the main subject areas of the study, beginning with a discussion of the literature regarding the role of spirituality and spiritual care in RACFs from a current viewpoint both internationally and within Australia. The perspectives of nurses, volunteers and residents on the meaning and importance of spirituality on residents are also explored. Difficulties with defining and measuring an abstract concept such as spirituality and the difficulties older people in RACFs face in conceptualising and in expressing this concept are explored and discussed. The chapter will close with a discussion of the gaps in the literature in this area.

The first stage of the literature review involved a wide-ranging literature search to locate as many papers as possible which might be suitable for inclusion. Four electronic databases (CINAHL, Medline, PsychINFO and Google Scholar) were searched, using search terms devised in consultation with a librarian; a number of papers which had been recommended by colleagues were examined; and a hand search of reference lists from relevant papers was conducted. The search was initially carried out between July and October 2008 and then updated between March and August 2013. Papers were only included if they were published in the English language and if they were considered current (i.e. from 1 January 2000 onwards). Details of the search strategy are shown in Table 2.1. A total of 8132 papers were identified.

Table 2.1

Search strategy for literature review - stage one

Search strategy	Number of papers identified
An electronic search of :	
CINAHL (Cumulative Index to Nursing and Allied Health),	9
Medline	1048
PsycINFO	7148
Google Scholar	23700
Papers recommended by colleagues	19
Total number of papers excluding overlaps	8132

The second stage of the literature review consisted of limiting papers according to inclusion criteria. These criteria are listed in Table 2.2 and the results of the ensuing search using these criteria are available in Table 2.3.

Table 2.2

Search inclusion criteria

Papers published in the English language
Papers published from 1 January 2002 onwards
Research papers
Papers in which all or most of the participants studied were 'older people' aged 65 years or over, and/or their families and /or carers
Papers examining in-patient care in a RACF
Papers examining spiritual care as a focus for people in RACFs

In order to assist the clinician to rate a body of knowledge by evaluating the strength of types of evidence under review, various authors and/or organizations have created levels or hierarchies of evidence. An example of an evidence categorization model was developed by Melnyk and Fineout-Overholt (2005). It includes seven levels and rates them from strongest (Level I) to weakest (Level VII) (Melnyk & Fineout-Overholt, 2005). The more powerful the evidence, the higher the chance that it is valid and relevant for a particular clinical problem (Melnyk & Fineout-Overholt, 2005).

Therefore, in clinical practice, stronger types of evidence would have the most clout and carry a higher chance of being effective for a particular problem. The studies tabled rated between a Level VI and Level VII on the hierarchy of evidence scale as proposed by Melnyk and Fineout-Overholt (2005). Therefore the evidence from the studies reviewed was low in the scale in terms of strength. Studies that were found to include only a small number of participants (n= 3) (De Bellis, 2010); those not published or peer reviewed (Bloemhard, 2008; Hall & Sim, 2005; Nolan & Mills, 2011) and those with limited description of their methodology were rated VII. The total number of papers identified when the search inclusion criteria were applied was 15 (see Table 2.4). Where there was duplication of relevant articles from sources, the article was allocated to the location where it was first found.

Table 2.3

Rating system for the hierarchy of evidence (adapted from Melnyk & Fineout-Overholt, 2005, p. 10)

Level	Research qualities
I	Systematic review or meta-analysis of all relevant randomized controlled trials (RCTs), or evidence-based clinical practice guidelines based on systematic reviews of RCTs
II	Evidence from at least one well-designed RCT
III	Evidence from a well-designed controlled trial without randomization
IV	Evidence from well-designed case-control and cohort studies
V	Evidence from systematic reviews of descriptive and qualitative studies
VI	Evidence from a single descriptive or qualitative study
VII	Evidence from the opinion of authorities and / or reports of expert committees

Table 2.4
Final papers found

Literature sources	Number of papers identified
An electronic search of :	
CINAHL(Cumulative Index to Nursing and Allied Health)	2
Medline	3
PsychINFO	2
Google Scholar	1
Google	2
Papers recommended by colleagues	3
Reference lists examined and followed up	2
Total number of papers:	15

Whilst there is a plethora of literature focusing/looking at/discussing spirituality generally, limited literature was found about the topic of spirituality in RACFs. Even less literature was found related to Australian RACFs. Most of the research considered spiritual care for residents from the perspectives of staff and /or volunteers (Bloemhard, 2008; Hall & Sim, 2005; Orchard & Clark, 2001; Tuohy et al., 2005), with some studies including a smaller sample of residents in addition to a larger cohort of staff (Nolan & Mills, 2011; Wilkes, Cioffi, Fleming & LeMiere, 2011). Daaleman et al. (2008) questioned family members of deceased residents to find out about their spiritual care in long term care facilities.

The literature identified focused on the following main themes:

- characteristics of spiritual care,
- spirituality and hope,
- barriers to spiritual practise,
- the importance of education of staff in spirituality, and
- providers of spiritual care in RACFs.

A summary of each major paper and its findings is given in Table 2.5 below.

Table 2.5

Conclusion of research findings in the areas of spirituality and residential aged care

Authors	Year of Publication	Sample	Type of research	Study Aim	Study Findings	Limitations	Rating
Orchard and Clarke	2001	RACF managers in the UK. Surveys were sent to 1522 RACFs. Response Rate 42% N=644.	Quantitative: descriptive study using survey	To provide an overview of spiritual care in RACFS	Managers had a broad understanding of spiritual care, RACFs had a responsibility for providing spiritual care, and the need for spiritual care grew when residents were dying. 73% of RACFs surveyed had called in someone from a Christian faith to help care for a dying resident. 14% had asked for assistance from other faiths including Judaism, Baha'ism and Humanism.	Surveyed only RACF managers who might have a vested viewpoint. The questionnaire was comprised primarily of closed ended questions which may have limited respondents in their description of this care.	VI
Tuohy	2001	Residents recruited from 9 RACFs N=62 Southeast Florida, USA	Quantitative: quasi-experimental, descriptive design	To discuss findings about spirituality that emerged from a larger study examining factors related to hope among institutionalised elders.	A significant positive correlation was found between spirituality and level of hope (r D :733; P D :000). The correlation between level of hope and connectedness with others was not found to be significant.	The scale used was comprised of closed ended questions regarding the composition of spiritual care and hope, which may have limited respondents in their description of this care.	VI
Tuohy et al.	2005	Nurses, care staff and physicians working in four RACFs in Florida, USA. N=25	Qualitative phenomenological approach	Explored spiritual care for dying RACF residents from the perspective of nurses, care staff and physicians	Described spiritual caring as deep personal relationships, holistic care and resident support. They felt that spiritual care could enhance end of life care in RACFs.	The data found was unable to be generalized and it was difficult to eliminate researcher bias. The lack of generality of data found and the difficulty to eliminate researcher bias. 25% of the sample was from a religiously sponsored RACF which would also bias the sample.	VI
Wallace and O'Shea	2007	Long-term residents living in two faith-based (one Jewish, one Catholic) RACFs in the United States, N=26	Quantitative: descriptive using surveys	To investigate perceptions of spirituality and spiritual care among older nursing home residents at the end of life.	Residents had a "moderately high" view of aspects of spirituality and spiritual care. Interventions that residents identified that nurses could use to support spirituality included: arranging visits for religious personnel, showing kindness, spending time listening to residents and showing respect for residents' needs.	Sample was limited to faith based facilities which could bias the sample to a higher level of recognition and meaning of spirituality and spiritual care. The instrument used mainly closed ended questions which may have limited respondents in their description of this care.	VI

Authors	Year	Sample	Type of research	Study Aim	Study Findings	Limitations	Rating
Daaleman et al.	2007	Family members of 284 decedent residents from a stratified sample of 100 residential care facilities in 4 US states N=284	Mixed, retrospective quantitative analysis of ratings scales used with families of the deceased as well as open and closed question interviewing (quantitative and qualitative)	To describe the sources of support, the structure and processes of spiritual care in long term care, and examine the relationship between these components and family ratings of overall care	Most decedents (87%) received assistance with their spiritual needs and those who received spiritual care were perceived by family members to have had better overall care (3.59 vs. 3.25, P 0.002). Family ratings of care ratings were higher for those who received spiritual support or care from facility staff when compared with those who did not (3.76 vs. 3.49, P 0.001) and better care was associated with the facilitation of individual devotional activities (3.87 vs. 3.53, P 0.001).	It used a retrospective design, which carries the possibility of recall bias in areas, such as the determination of cognitive impairment in decedents. The use of surrogate respondent reports questions the validity; the interview was comprised primarily of closed ended questions regarding the composition of spiritual care, which may have limited respondents in their description of this care.	VI
Wilkes et al.	2011	18 pastoral care workers and 11 (including two family members) older people in two RACFs in Sydney, NSW	Qualitative descriptive approach using semi-structured in-depth interviews	To define characteristics and meaning of pastoral care from the perspective of older recipients, their family members and pastoral care workers	The defining characteristics of pastoral care that emerged from the analysis of transcribed interviews were: a trusting relationship, spiritual support, emotional support and practical support. The role of the pastoral care worker was seen as spiritual guide, confidante, and emotional and practical supporter acting within a trusting relationship.	Small sample, most of the respondents (18/39) were pastoral care workers who would assumedly give a skewed perception of their role	VI
Haugan et al.	2013	N=202 cognitively intact nursing-home patients in mid-Norway	Quantitative: quasi experimental, descriptive. Instruments used were the self-transcendence scale, and the Functional Assessment of Cancer Therapy General (FACT-G) Quality of Life questionnaire	To investigate the interrelationships between self-transcendence and nursing-home patients' physical, social, emotional and functional well-being	That there was a significant influence of nurse–patient interaction on nursing home patients' level of hope	Researchers assisting participant to fill in questionnaire may have added bias. Also the questionnaires were quite long which may have introduced bias to an easily tired RACF resident. Also, the cross-sectional design does not allow a conclusion regarding causality. The sample was a good size *N*= 202.	VI
Bloemhard	2008	Practitioners in aged and palliative care in regional New South Wales and Queensland Australia N=26 (focus groups N=20, interviews N=6)	Qualitative: grounded theory using focus groups and interviews	Explored how spiritual care was understood and experienced by a group of practitioners	Spiritual care as being important and involving religious practices such as praying or bible readings and non-religious activities such as talking about dying, comforting touch or reminiscing. Spiritual care which involved qualities and attitudes that were clearly felt or recognized by the participants as special. Barriers to spiritual practices included lack of time and lack of training.	Small sample, sampling attracted those with strong positive opinions regarding spirituality in aged care and focus on religion in spiritual care participants were self selected on basis of interest in the area	VII

Authors	Year of Publication	Sample	Type of research	Study Aim	Study Findings	Limitations	Rating
Brotherhood of St Lawrence Hall & Sim	2005	16 RACFs in metro Melbourne, Australia nominated between one to four staff/ volunteers to attend focus, total numbers of focus group participants is not clear	Qualitative using focus groups with staff and volunteers	How a variety of RACFs addressed issues of spirituality and pastoral care for their residents, residents' families and staff, and how these facilities perceived best practice in spiritual care	Showed identification and assessment of a person's spiritual state and spiritual needs were influenced by the knowledge and understanding of facility staff. In turn, assessment guided the development of resources and provision of spiritual care. The authors suggest that there is a potential for inconsistency and inaccuracy in the identification and assessment of spiritual needs in aged care	Limited numbers in focus groups. Restricted area of sampling. Most facilities (12/16) were affiliated with a religious organization. Staff and volunteers nominated by the organisation were asked to attend focus groups. Research not published and/or peer reviewed	VII
Nolan & Mills	2011	A low level RACF in Bendigo, Australia. Questionnaires N=31 N=9 plus focus group N=3	Qualitative using interviews: open ended questionnaires and focus groups with residents and staff	To develop and deliver a model based on a view of spirituality including, but not focusing on religion	Researched a range of models of spirituality education, consulted stakeholders, then developed and evaluated a model of spirituality education	Research not published and/or peer reviewed. Participants were self selected on basis of interest in the area.	VII
De Bellis	2010	Adelaide, Australia residents in one RACF N=3	Qualitative case study method	To collect and analyse data on the nursing care for three highly dependent residents	Documentation of residents' spiritual needs did not accurately reflect residents' choices nor current routines	Limited number of case studies limits generalisability Spiritual care was but one element of care evaluated .	VII
MacKinlay & Trevitt	2010	N=113 Residents in RACFS in ACT and NSW,AUS	Mixed qualitative information from in-depth interviews, transcribed reminiscence sessions and observer journals and quantitative from a behavioural scale pre and post sessions	To examine whether spiritual reminiscence in small groups could enhance quality of life and improve meaning in life for the participants	Spiritual reminiscence allowed participants to talk about important relationships and connect with others in their aged-care facility, and assisted them to find meaning in life in the present, and develop strategies to accept changes of later life, including losses of significant relationships and increasing disability.	Results are not clear. 2 /6 themes (namely growing older: vulnerability and transcendence and meaning in life) were explored in the article. Results of behavioural scales taken before and after not included in this article. Unclear if residents benefited from small group work or spiritual reminiscence specifically	VII
MacKinlay & Trevitt	2006	N=113 Residents in RACFs in ACT and NSW, AUS	As above	As above	As above	Results are not clear only 2 /6 themes were explored in the article. As above	VII
Trevitt & MacKinlay	2006	N=16 Residents in RACFS in ACT and NSW, AUS	Mixed as per above. This article seems to focus on qualitative information gained from this research	To examine whether spiritual reminiscence in small groups could improve resident quality of life & meaning in life	Themes relate to relationships, loneliness, family, and attendance at worship and how these combine to give a sense of purpose, humour and insight into their illness and living circumstances	The article clearly states that the analysis has not been completed and the themes discussed are emerging themes. As above	VII
MacKinlay	2002	N= 24 independent living older adults; N=12 Residents in RACFS	Qualitative, using a grounded theory approach using in-depth interviews	To examine spirituality amongst these groups	Themes identified were; ultimate meaning in life for each person, the way they responded to meaning, self-sufficiency versus despair, moving from provisional to final life meanings , relationship versus isolation in ageing and hope versus despair	This article features material from two separate studies. The exact methodology for both is unclear in this article.	VII

2.2 Characteristics of spiritual care

There seems to be a consensus in the literature that RACFs have a responsibility for providing spiritual care to residents (Bloemhard, 2008; Daaleman et al., 2008; Orchard & Clarke, 2001; Trevitt & MacKinlay, 2006; Tuohy, 2001; Tuohy et al., 2005) and furthermore that spiritual care could enhance end of life care in RACFs (Daaleman et al., 2008; Haugan et al., 2013; Trevitt & MacKinlay, 2006; Tuohy, 2001; Tuohy et al., 2005). Whilst some of the literature focuses on the religious aspect of spiritual care for residents (Orchard & Clarke, 2001; Wilkes et al., 2011), Bloemhard (2008) reported that this could involve both religious practices such as praying or bible readings and non-religious activities such as talking about dying, comforting touch or reminiscing. Likewise, Wallace and O'Shea (2007) documented both religious and non religious interventions that nurses could use to support spirituality including: arranging visits for religious personnel, showing kindness, spending time listening to residents and showing respect for residents' needs, supporting friendships, supporting need for forgiveness, playing music and facilitating time with nature. Tuohy et al. (2005) described spiritual care more broadly and psychosocially again including holding hands, being with, listening and sharing the experience, comforting touch, helping patients die with dignity, nursing care skills, and controlling pain as well as sharing love and caring words, validating the person's life, assuring the person they would be remembered, and giving permission.

Other ways that spiritual care is provided that were documented in the literature included: religious services, bible groups, visits by religious personnel for Holy Communion, provision of external items for worship (e.g. rosaries), statues and quiet reflective spaces for prayer and worship (Bloemhard, 2008). Bloemhard (2008) found participants described spiritual care as a particular relationship with clients, which involved qualities and attitudes that were clearly felt or recognized by the participants and residents as special. Wilkes et al. (2011) also described the resident / provider (pastoral) relationship as a particularly trusting relationship, offering spiritual support, emotional support and practical support.

MacKinlay and Trevitt (2007; 2010) have found that spiritual reminiscence groups for people with dementia benefited participants. MacKinlay and Trevitt (2010) allocated 113 people with dementia to groups for periods between six weeks and six months. The qualitative and quantitative data collected showed that life story work with an emphasis on spirituality helped develop stronger relationships between staff and residents and allowed for discussions about meaning to take place. Talking about previous religious and spiritual events gave both carers and older people a chance to review spiritual needs and develop new friendships with, and a knowledge of, each other (MacKinlay and Trevitt, 2010). However whether these positive effects were due to increasing socialisation and the therapeutic process of the group itself versus the content of spiritual reminiscence is unclear and the research may have benefited from a control group for comparison purposes.

In Daaleman et al.'s (2008) study, family ratings of care were higher for those who received spiritual support or care from facility staff when compared with those who did not and better care was associated with the facilitation of individual devotional activities. Most decedents (87%) received assistance with their spiritual needs and those who received spiritual care were perceived by family members to have had better overall care (3.59 vs. 3.25, $p < 0.002$). Decedents in this study who received spiritual care were perceived by family members to have had overall better care in the last month of life. Yet the distinction between spiritual care and overall nursing care is not clear and the authors themselves question what elements of spiritual care relate to overall care.

In summary the characteristics of spiritual care as looked at by the literature reviewed are broad, if not global. There is significant overlap with nursing care and this would be expected with good holistic person centered care, however the boundaries between the two appear non-existent. The spiritual provider relationship with the client shares common ground with "therapeutic relationships" as explored in nursing and psychological literature. There are limited studies documented in this area.

2.3 Spirituality and hope

As previously described in chapter one of this paper, issues such as physical illness, disability, loss of function and social deprivation are common in many older people and more so in residents of RACFs (Haugan et al, 2013; MacKinlay, 2007). As also documented previously, depression is common in RACF residents (AIHW, 2011). For these reasons hope is a desirable commodity in RACFs. Researchers have seen hope as an important attitude to measure and promote in RACFs (Haugan et al., 2013; Tuohy et al., 2005; Tuohy, 2001). In a quantitative study, Haugan et al. (2013) investigated the interrelationships between self-transcendence and (cognitively intact) nursing-home residents' physical, social, emotional and functional well-being

According to the authors ST is "a well-being maker", "a process of change striving for new and deeper understandings of life, meaning and acceptance of self, others and the life situation" and "a powerful coping mechanism involving adaptation to physical emotional and spiritual distress (Haugan et al., 2013, p. 3). They found caring qualities of the nurse–patient interaction may influence patients' hope, and thereby affect patients' well-being, positively or negatively. Consequently, improving caregivers' interaction skills and competence can lead to a strengthening of hope and thus better quality of life among RACF residents.

Tuohy (2001) found a significant correlation between spirituality and hope, when spirituality was measured using a modified Spiritual Perspective Scale (SPS) and when hope was measured by using both the Herth Hope Index (HHI) and a rating from the participant on a scale from zero to 10 (indicating no hope through to filled with hope).

2.4 Barriers to spirituality practice

A number of barriers to spirituality practice have been identified by the literature. Bloemhard (2008) and Hall and Sim (2005) identified a range of attitudes and a variety of reasons for the reluctance of staff to provide basic spiritual care including: lack of

time, work overload, lack of training in the area and a lack of confidence in matters of spirituality, as well as concerns that documentation of patient/resident concerns may give rise to ethical issues such as breach of confidentiality and trust placed in them by the resident. In addition, many staff may consider that spiritual care, as they understand it, lies outside their area of responsibility. Institutional barriers including industry difficulties in attracting and keeping skilled staff, barriers to training staff including staffing and workload issues as well as cost, an increasing cultural diversity amongst residents and staff and cross cultural issues also contribute to the capacity and capability of staff to provide spiritual care in aged care practice.

Wallace and O'Shea (2007) identified that varying spiritual beliefs and lack of education and experience with spiritual care are barriers to nurses implementing spiritual interventions. They further proposed that providing spirituality education and experiences during nursing educational programs has the potential to increase nursing competence in this area. In addition, spiritual in-services may be appropriate for enhancing spiritual care in long-term care facilities. This view of the need for better training regarding spirituality, both undergraduate and within facilities, is supported by Bloemhard (2008), Hall and Sim (2005), Nolan and Mills (2011) and Tuohy et al. (2005).

2.5 The importance of staff awareness of and education about spirituality

An Australian study by Bloemhard (2008) explored how spiritual care was understood and experienced by a group of practitioners in aged and palliative care in regional New South Wales. Focus groups (n=20 participants) followed by in-depth interviewing of six participants, were used to source the data for the study. The self-selected participants were from a variety of locations, including RACFs, palliative care and aged care services. All participants were identified as being interested in spirituality. This study found participants felt spiritual care was important and identified spiritual care as including both religious practices (such as praying or bible readings) and non-religious activities (including comforting touch or reminiscing).

Another Australian study by the Brotherhood of St Lawrence investigated how their own facilities and a variety of external for-profit and not-for-profit RACFs (n=16) addressed issues of spirituality and pastoral care for their residents, residents' families and staff, and how these facilities perceived best practice in spiritual care (Hall & Sim, 2005). They conducted focus groups with staff members and volunteers at each separate RACFs. Each facility group expressed a variety of views and understandings of spirituality, spiritual care and pastoral care. Similarly to Bloemhard's study (2008) the findings showed identification and assessment of a person's spiritual state and spiritual needs were influenced by, and ultimately depended on, the subjective knowledge of and understanding by facility staff. In turn, assessment guided the development of resources and provision of spiritual care. Hall and Sim (2005) suggested that there is a potential for inconsistency and inaccuracy in the identification and assessment of spiritual needs in aged care. This paper was published by the organisation concerned (Brotherhood of St Lawrence) and it is not clear if this research has been peer reviewed.

A three person case study of residents in an accredited Australian RACF completed by De Bellis (2010) confirmed the risks of inaccurate assessment of residents' spiritual needs. She found that nursing staff articulated knowledge about the religious and spiritual needs of their residents, however, these were fabrications created by the nursing staff arising from documentation only (De Bellis, 2010). These case studies looked at a range of identified issues of which spirituality was only a part. However, this research is important to the research questions in that it documents real life cases in which spiritual assessment and care can go wrong.

The Healthcare Chaplaincy Council of Victoria Inc. (Nolan & Mills, 2011) completed a pilot project, titled 'Spirituality in Aged Care – education and training for staff and volunteers in residential aged care'. This study was not published, however was found on the internet. This project investigated a range of models of spirituality education and, using questionnaires, interviews and focus groups with residents, volunteers and staff, developed and delivered a particular model based on a view of

spirituality encompassing but not solely focusing on religion. As well as pre and post education testing, this project incorporated resident interview (n=9) in the development and assessment of the resources and one focus group (n=3). This research has relevance to the research questions in that it is an Australian study that has been undertaken in a RACF and asked residents about their perceived needs in regards to spirituality.

2.6 Providers of spiritual care in RACFs

The literature reviewed highlights the need for a variety of providers of spiritual care in RACFs. These providers include both in-house and external providers. Chaplains and pastoral care workers have been considered the traditional providers of spiritual care (MacKinlay, 2008; Wilkes et al., 2011). Chaplains and pastoral carers are employed to tend to the residents' spirituality in many religiously affiliated RACFs across Australia (Wilkes et al, 2011). The inclusion of either a chaplain or pastoral care worker in an aged care team is advocated in the Australian Department of Health and Ageing and Australian Palliative Residential Aged Care Project and National Health and Medical Research Council (Australia) and National Palliative Care Program (Australia) (2006) to facilitate a palliative approach that considers each resident's spiritual care needs. The aged care team may perceive increased spiritual needs at times near to death and readily seek assistance from people who are well trained in the area of spirituality (Orchard & Clark, 2001). In a recent study conducted in the United Kingdom (UK), 73% of residential facilities surveyed (n = 1,500) had requested the external assistance of someone from the Christian faith to help care for a dying resident (Orchard & Clark, 2001). Fourteen percent had called in support from other faiths, such as Judaism, Baha'ism and Humanism. These findings also point to the relevance of access to chaplains and pastoral care workers for residents at end of life.

However, unless the resident wants spiritual support, a visit from a chaplain/pastoral care worker can be considered an intrusion. Daaleman et al. (2008) found that the spiritual care that was associated (by family members) with better overall

care, was delivered by facility staff not clergy nor chaplains, and was focused around individualized devotional activities, rather than more organized religious services.

MacKinlay (2008) tells of a move for "newcomers" to take on roles in spiritual care– nurses, doctors, social workers, diversional therapists, and others. She felt that these newcomers to spiritual care were still learning what the role entails; research and practice were moving together in emerging territory and suggested that even for clergy, the role may be extending as more research is conducted and findings incorporated into practice. Orchard and Clark (2001) also identified concerns about the ability of some staff to deliver spiritual care in a broader context than just religion.

Personal carers make up over half of the workforce within RACFs and have the most personal contact with residents (King, Mavromaras, Wei, et al., 2012). As such personal carers are well situated to provide spiritual care. Whilst there is mention of the training need (Bloemhard, 2008) and appropriate training models for all RACF staff (Hall & Sim, 2005; Nolan & Mills, 2011), there is a paucity of literature on the role of the personal carer as a potential provider of spiritual care.

2.7 Conclusion

The literature suggests spiritual care should be considered as broad, incorporating religious practices as well as caring relationships and other practical nursing and communication skills. The recommended deliverers of this spiritual care are also diverse with nursing, care staff, leisure and therapy staff being mentioned as providers, as well as the traditional providers of chaplains and external clergy. The barriers to care staff providing care in this area are seen as lack of time, work overload and lack of training and confidence in the area. The literature illustrates the need for staff to be educated and skilled in identifying residents' spiritual needs as well as having high level communication and caring skills. The evidence base suggests that a therapeutic relationship with carer/s that inspired trust and hope, reminiscence, and meaningful rituals all help the process of coming to terms with ageing and change.

In conclusion there has been limited research generally into the spiritual needs of residents in RACFs from the residents' perspective and also into what residents see as barriers to achieving their spiritual needs. Nil peer reviewed literature into the Australian RACF residents' perspective of their spiritual needs was identified. Most research into the phenomena of spirituality in RACFs has asked staff what residents' needs are in this matter. It is important that the residents' perspective of spirituality is investigated. This study will begin to address the spiritual care of people living in RACFs by assessing their spiritual needs and what they see would assist them to meet these needs.

3.0 RESEARCH METHODOLOGY

3.1 Introduction

This chapter discusses the methodology used to conduct this research project. The purpose of the study is described together with the rationale for the choice of approach. The approach used, the study setting, participant sampling and recruitment, data collection and data analysis is then outlined.

3.2 Research design

In contrast to the positivist scientific quantitative research, qualitative research comes from a naturalistic paradigm that views reality as multiple, subjective and as individually constructed (Polit & Beck, 2006). Qualitative research methods use means of data collection and analysis that involve the gathering and interpretation of words as opposed to numbers (Polit & Beck, 2006; Sandelowski, 2000). Qualitative methods are useful to researchers studying social experiences and behaviours because they allow opportunities to listen and observe the participant in their usual environment in order to understand and interpret the narrative data being collected (Speziale & Carpenter, 2007). This methodology provided the means for exploring individuals' experiences, thoughts, feelings and stressors providing insight and in depth understanding of the phenomenon. Moberg (2010, p. 107) states that qualitative methods are "exceptionally suitable" for studying spiritual phenomena.

The purpose of qualitative research has traditionally been to describe, explore and explain phenomena of interest (Marshall & Rossman, 2006). The purpose of this study was threefold:

1. to explore and describe residential aged care facility residents' spiritual needs,
2. to explore and describe barriers and enablers of spiritual practice, and
3. to explore the potential to enhance spiritual practice in RACFs.

As already indicated in the previous chapter, all of these phenomena are inadequately reported in the literature. The purpose of this study best fits both a descriptive and exploratory approach as outlined in Table 3.1 below.

Exploratory research is beneficial for finding patterns and exploring new concepts that have not been researched previously (Marshall & Rossman, 2006). Sandelowski (2000) recommends descriptive approaches to research if the phenomenon is inadequately defined or conceptualised. This approach is also useful when a phenomenon is not well researched or understood, by allowing for explanation and interpretation of the data, rather than simple descriptions of the phenomena (Sandelowski, 2000). Spirituality is a difficult concept to define, hence the importance of a descriptive approach. A descriptive exploratory approach was considered appropriate given the paucity of literature in the area and the quest for resident perspective.

Table 3.1

Matching research questions and purpose *(adapted from Marshall & Rossman, 2006, p. 33).*

Name of approach	Purpose of study	General research questions
Exploratory	To investigate little understood phenomena To identify or discover important categories of meaning To generate hypotheses for further research	*What is happening in this social programme in terms of spiritual care for the residents?* *What are the salient themes patterns or categories of meanings for residents?* *How are these patterns linked with one another*?
Descriptive	To document and describe the spiritual needs of RACF residents	*What are the salient actions, events, beliefs, attitudes and social structures and processes occurring in this phenomenon?*

3.3 Study setting

The study was conducted over a 19 month period from November 2011 to May 2013. The researcher recruited participants from one private RACF in regional Western Australia. The facility has 86 beds and has been operational since 2001. It offers a range

of services including high care, low care and dementia specific support. This site was chosen as it was unique in the area in that it provided a range of care level services and was not affiliated with a religious organisation. It was hypothesised that having a mix of low care and high care residents would allow for less dependent participants with higher cognitive abilities. The fact that the RACF was not affiliated with a religious organisation meant that there would be a more diverse sample of participants in terms of spirituality needs. At the time of the study, the facility housed 86 residents, whose average age was 86 years and average length of stay just over two years (D. Harrison, personal communication, July 17, 2013).

3.4 Sample

3.4.1 Participants

Purposive sampling was initially used to recruit participants for this study. This method allowed the researcher to select participants who had knowledge of the phenomenon of interest, were able to meet the inclusion criteria and could provide information rich data by reflecting and articulating their individual experiences (Polit & Beck, 2006; Speziale & Carpenter, 2007). The purposive sampling technique allowed for as diverse a sample as possible by selecting participants from a cross section of ages, identified religious associations, time spent at facility, educational background, underlying morbidities and gender.

Social and demographic information was collected via a verbalised questionnaire, completed with the client prior to the interview. See Appendix F. Data were collected in four main sessions (8 November 2011, 5 December 2011, 30 March 2013 and 29 May 2013). The delay in holding the last two sessions was due to the researcher taking maternity leave in 2012. After each session of information gathering, the data were checked for key themes and discussed with two experienced researchers. As categories emerged, participants were added to the sample to increase diversity in ways that would strengthen the emerging theory (Glaser & Strauss, 1967). Glaser and Strauss (1967) refer to this as theoretical sampling. Recruitment took time to complete due to the theoretical sampling method used. It was difficult to locate persons from

different religious backgrounds, educational background and /or with varying spiritual beliefs due to the relative homogeneity of residents in these respects.

3.4.2 Inclusion criteria for participants

Inclusion criteria were: a resident of the facility for longer than three months, able to communicate their needs and wants in conversation and willing to participate in the study. As participants needed to reflect on and be willing and able to share detailed experiential information about their perceptions of spirituality, they needed a good understanding of English. The capacity of a person with dementia to consent to the research was assessed by the facility's Registered Nurses by indicating whether the resident may be suitable for inclusion due to being able to communicate clearly in conversation. Registered Nurses were chosen for this task because they had a good clinical understanding of their residents together with a good knowledge of their residents' language and cognition skills. The Registered Nurses were informed that participants with a maximum Psychogeriatric Assessment Scale (PAS) score of 15 or less, indicating nil to moderate dementia, were included (Jorm et al., 1995). Each resident had a PAS score documented in their medical records because it is a requirement for aged care accreditation and each was also assessed individually at the time of the interview, to determine their level of communication and comprehension skills.

3.4.3 Exclusion criteria for participants

Exclusion criteria were: those unable to communicate basic wants and needs. For completeness, residents with dementia were not specifically excluded. Given that some estimates suggest as many as 59% of RACF residents have dementia (AIHW, 2011) this would be excluding the majority of the population and therefore findings would not represent the needs of the majority of residents. Many people with dementia have been found to be able to express feelings and describe lived experiences (Wilkinson, 2002) and participate in spiritual reminiscence (MacKinlay & Trevitt, 2010). Each person was assessed individually to determine their level of communication and comprehension skills. It was expected that people with mild to moderate dementia would be able to comprehend the questions and to express their wants and needs clearly (Wilkinson, 2002) and thus be able to participate.

One potential participant was excluded from this study despite a PAS score of 15, due to not being able to communicate clearly in conversation. Refusal or reluctance to participate in a research project by a person with dementia and/ or their family member or legal guardian was respected. One potential participant was excluded from the study following the request of a legal guardian.

3.4.4 Recruitment

All residents of the facility who met the inclusion criteria were initially considered as possible participants in this study. Recruitment was completed in a number of steps. Firstly, participants were informed about the study via newsletters and at resident meetings and asked if they wished to participate. Secondly, senior nursing staff in each of the three main sections of the facility were asked which residents would meet the inclusion criteria and be willing to participate. The residents identified were approached and invited to participate in the study by these senior nurses. All interested residents were given an information pack and a verbal explanation and were required to sign a declaration of informed consent. It was made clear to the residents that participation was entirely voluntary and that they could withdraw consent from the study at any time without prejudice. The residents were also assured that their confidentiality would be maintained and that their participation or non participation would not affect their care in any way. Participants were asked to complete the written consent prior to the researcher arranging an interview.

Families were informed of the study via mail and/ or face to face, to ensure all concerned parties were aware and to protect those residents with moderate dementia who were particularly vulnerable. Family members of participants with a diagnosis of dementia were required to complete a declaration of informed consent as well as the resident, to ensure all parties were fully aware of and supported the residents' participation. This joint consent was required prior to the interview taking place. Two of the participants had a diagnosis of dementia and had family members complete consent forms. Finally, further participants were approached using a theoretical sampling

echnique where initial analysis of data guided the researcher to subsequent specific data sources (Strauss & Corbin, 1990).

Sampling continued until theoretical saturation was reached. This refers to the threshold at which gathering more data about a theoretical category reveals no new concepts or theoretical insights about the emerging theory (Strauss & Corbin, 1990). After data collection from participant 13 it was judged that no new core concepts or categories were emerging and that the data collected had reached “saturation” at this point (Strauss & Corbin, 1990). Three more interviews were carried out to check saturation. Strauss and Corbin (1990) suggest that saturation is a "matter of degree" and that there will always be the potential for "the new to emerge" the more researchers analyse their data. Instead, they conclude that saturation should be more concerned with reaching the point where it becomes "counter-productive" and that if "the new" is discovered it may or may not add anything to the overall story, model, theory or framework (Strauss & Corbin, 1990). They admit that sometimes the problem of developing a conclusion to their work is not necessarily a lack of data but an excess of it. Speziale and Carpenter (2007) suggest interviewing participants from a variety of backgrounds, age ranges and cultural environments to maximise the likelihood of discovering the essence of the phenomena researched and thereby achieving data saturation. Given the population being researched was a RACF in rural Western Australia, the age ranges and cultural environments were limited.

3.5 Ethical considerations and informed consent

This was a low risk study, with participants asked to discuss their perceptions of spirituality in the residential aged care setting. This sort of conversation is part of the routine clinical assessment and review of residents needs, and no undue distress was expected or found. Ethical approval was obtained from Curtin University Human Research Ethics Committee (15 November 2011, HR88/2011), and this approval met the requirements of the RACF. The main ethical issue related to participant anonymity. Data were de-identified and data analysis was conducted so that participants could not be

identified. The names of participants were replaced with pseudonyms to maintain privacy and confidentiality.

The interviews were conducted in a private place, by an interviewer who is an experienced therapist. Participants were monitored and none of them showed any visible signs of distress or reported distress during or following interviewing. A research journal was kept by the researcher to note participant responses and relevant observations made during interview.

3.6 Data storage

Data will be kept in electronic storage that is password protected in a secure university database. All original documentation related to this study (i.e. signed consent forms) will be stored for five years after publication in a secure location in the School of Nursing and Midwifery at Curtin University. At the conclusion of the five year storage period all documents will be shredded and disposed of according to National Health and Medical Research Council guidelines. Audio tapes were wiped at the conclusion of the project. Participants' identities will be kept anonymous in all further presentations or publications.

3.7 Data collection

Following the suggestion of Strauss and Corbin (1990) data collection and data analysis occurred simultaneously, so that the emerging results were able to guide further data collection. Gathering, managing and interpreting data occurred concurrently. Interview recordings were transcribed as soon as possible to allow for early data analysis.

3.7.1 Semi-structured interviews

Qualitative data were collected through semi-structured tape–recorded interviews. Semi structure interviewing was used which employs written questions as a guide in order to achieve some consistency of data, but allows for exploration of topics

that emerge during the course of the interview (Taylor, Kermode & Roberts, 2006). Interviews are used widely throughout qualitative research studies because they provide an extended opportunity for the participant to share ideas, experiences and feelings about a particular subject (Rubin & Rubin, 2011). This approach to interviewing was chosen to investigate the participants' own unique experiences and reflections regarding their needs and thoughts regarding spirituality (Burns & Grove, 2011).

Burns and Grove (2011) advocated the use of a natural setting or location for a descriptive study. All but one of the interviews occurred in the residents' room, the other one being conducted in an interview room. Interviews were conducted face to face at a time convenient for participants. Each interview lasted between six and 62 minutes, with an average of 24 minutes. The interviews were transcribed verbatim. The interview questions followed an interview protocol. The final interview guide consisted of 15 questions (Appendix E), including the FICA Spiritual History Tool, which contains 11 open ended questions (Puchalski & Romer, 2000). The FICA was created for use by health professionals to assist them to recognise and address the importance of spirituality in patient care. Permission was obtained to use the FICA in this research project. The FICA is based on four domains of spiritual assessment: the presence of faith, belief, or meaning; the importance of spirituality on an individual's life and the influence that their belief system or values has on the person's health care decision making; the individual's spiritual community; and interventions to address spiritual needs (Borneman, Ferrell & Puchalski, 2010). Four additional questions explored whether the RACF meets residents' expectations regarding spiritual care provided, residents' perceptions of barriers and enablers of spiritual support and how the individual defines spirituality. Demographic information was gathered from participants prior to the interview (Appendix F).

Some lead in discussion together with a definition of spirituality was provided within the introduction of the interview in order to provide some "settling in" time for participants and to provide some examples of the term so that the participants had a better understanding of what was being asked of them (as per recommendations of the

Ethics Committee). The definition given was as follows "*One definition of spirituality is that which relates to or affects the human spirit or soul as opposed to material or physical things. Spirituality is also seen as what brings joy hope and meaning to your life. You might see spirituality as being linked to religion or it may be something else."*

The constant comparison method was used and so the analytical process began during data collection as the data already gathered was analysed and shaped the ongoing data collection. This continuous analysis has the advantage of allowing the researcher to go back and refine questions, sample theoretically and pursue emerging avenues of inquiry in further depth. Consequently the interview questions weren't always asked in the same order, allowing the researcher to refine questions when required or explore participant responses further when needed.

3.8 Data analysis

Prior to the analysis of the semi-structured interviews, data from audio-taped interviews were transcribed verbatim in Microsoft Word version 2007. The data were transcribed by a transcriptionist and transcripts were checked randomly by supervisors. Personal identifiers were removed from transcripts and replaced with "name".

The constant comparative method of data analysis was used, whereby data were simultaneously collected, coded and analysed (Strauss & Corbin, 1990). Initially the researcher read each of the interview transcripts to ensure they contained the same information as the audiotapes. The transcriptions were then read line by line several times to become familiar with the data. Then key phrases, words and ideas found in the text were analysed and arranged into categories. This process of identifying, naming, categorizing and describing phenomena found in the text is referred to as "open coding" (Strauss & Corbin, 1990). Coding was commenced manually to get a feel for the data and interview transcripts were then open coded using NVivo version 9 software (QSR International, 2010), to identify and label common themes (Strauss & Corbin, 1990). Themes were refined and arranged into categories and subcategories. Coded segments

from the interviews were accessed for axial coding. This coding involved putting the data back together again in new ways by making connections between the coded categories and subcategories. Examples of the coding process are outlined in Table 3.2.

In-vivo coding, where participants' own words form category names, was used as a method of staying true to the data. The constant comparison method was used to look for statements and themes and thus guide further data collection. This method allowed the researchers to explore the information collected in the data, determine if there were any gaps and modify interview questions or sampling accordingly. The interviewer's coding was checked by ongoing discussion with supervisors. The researcher used the qualitative analysis computer software NVivo version 9 to achieve the different stages of constant comparison analysis.

3.9 Maintaining the rigour of the research process

The goal of rigour in qualitative research is to accurately depict study participants' experiences (Speziale & Carpenter, 2007). Four criteria are used to describe the processes that are used to measure trustworthiness of data (i.e. rigour, namely credibility, transferability, dependability, and confirmability) (Lincoln & Guba 1985; Speziale & Carpenter, 2007). Throughout the study, rigor of the analysis was ensured by applying the four criteria (Speziale & Carpenter, 2007).

3.9.1 Credibility

Credibility is demonstrated when participants recognise the reported research findings as their own experiences (Speziale & Carpenter, 2007). Activities increasing the probability that credible findings will be produced include prolonged engagement, persistent observation, peer debriefing, and member checking (Lincoln & Guba, 1985). Prolonged engagement is the investment of sufficient time by the researcher to achieve certain purposes: learning the "culture", testing for misinformation introduced by distortions either of the self or of the respondents, and building trust (Lincoln & Guba, 1985).

Table 3.2

Examples of the coding process

Transcript	Open Coding	Axial Coding	Selective Coding
No I've worn out why it was important and then I've learnt to live with it and live by it you know keeping all the rules and so on that you have to keep everything you believe in. Ah and um just that I'm getting to be so old now that it's sort of I wonder whether it's worth it.	Worn out why it was important, belief, rules, ritual rules to live by is it worth it now? Despair	Belief, prayer or despair, meaning	Comfort and meaning from the tradition of religion
Well when they shut you in a room and go away and forget all about you for hours on end I pray for someone will come and they always do.	Loneliness, isolation, prayer for help, result	Prayer or despair Comfort from prayer	Comfort and meaning from the tradition of religion
If you can sort of pray and that you believe that you might help, helpful and ah you can pray for ah others you know that are there. But I think if you have got a belief in God then ah you're not as likely to ah sort of despair	Help others by prayer, belief in god means you are not as likely to despair	Belief, prayer or despair	Comfort and meaning from the tradition of religion
Spirituality oh I don't really know anything about it what well I never think of spirituality I don't know what you really mean by it you know.	Spirituality I don't know anything about it. I never think of it. I don't know what you mean by it	Spirituality what is it?	Spirituality what is it?
Because what else is there you get your food to eat and everything else here and there is no life anywhere there's no you know you're not part of anything and you my eyes are gone so I can't see to study. And so end of life is no joy at all.	No joy, losses, basic needs met but no meaning/connectedness, no life anywhere	Prayer or despair, loss of meaning and connectedness	End of life is no joy at all
And that was a Catholic church they had three different services a different one every week. And everyone has you can go to the lot if you like but it has three different churches for people who are dedicated to it and all that sort of thing. I've got nothing against it	Variety of church services offered. You can go to all. Choice of church service to meet people's needs. Not against other religions.	Church services at facility, access	Access
Well yes it does because you're always aware that. He knows all about you… And you just say I'm finding it hard to cope with certain problem and I, I can get comfort out of that.	Aware, hard to cope comfort	Comfort from religion	Comfort and meaning from the tradition of religion

Transcript	Open Coding	Axial Coding	Selective Coding
I feel there is something that I think a person joining a church is more of a social thing. I mean you belong to a church you belong to a social group don't you. That's how I feel about church's I think you should be able to go to any church you wanted. I don't know whether I've got the wrong [unclear].	Social aspect of organised religion. Choice of church	Comfort from religion	Comfort and meaning from the tradition of religion
Well I think your faith has a great deal to your improvement. And confidence I think yeah I've always thought that in life hhmm.	Faith = confidence + personal improvement	Meaning and self improvement structure from religion	Comfort and meaning from the tradition of religion
Because it the end of your life there's not much you know left to do that's new you're just at the very end and you're worn out. And that's why I'm trying to do a bit of with (Name) help um do a bit of review of what I really believe in right now	End of life, nothing to do, worn out, review of beliefs	Beliefs, lack of meaning/ purpose	Life review
At night you know it was kneeling you know before you get into bed and say your prayers and um. That was two prayers that I used to say and I said them the other night not that I'm ah a madly religious person but	Prayers at night time tradition, ritual, return to ritual/comfort?	Tradition, comfort	Comfort and meaning from the tradition of religion
Yes I'm very sad spiritually what's going on in the world and surround and my surroundings I'm very disappointed.	Disappointment with what is going on locally and globally Despair	Prayer or despair	Life review
You know [unclear] that much that ah you know when we were little everybody always went to church.	Church as social tradition/social connection	Tradition/ ritual/social	Comfort and meaning from the tradition of religion
Church well when I can....Um I've got that way that um I don't have a drivers license I don't drive a car now....Um so its taxi's or transport.	Physical access makes it hard to get to church/ losses	Access/ barriers	Access
…Oh sometimes I, I don't pray down on my knees so much because I can't get up	Physical ability to pray, access	Access/ barriers	Access
..you know you got a tractor and you know plough up the ground and then you know you rake it and you know to clear it and....You know bush and all that and so forth you know we did that	Farming cycles, bush, nature important	Tradition/ ritual/ beliefs, association to the land	Comfort and meaning from the tradition of religion

It is imperative therefore that the researcher spend enough time becoming oriented to the situation. Prolonged engagement also requires that the investigator be involved with a site sufficiently long to detect and take account of distortions that might otherwise creep into the data. The researcher must first deal with personal distortions. The researcher had been an employee of the RACF that the research took place for a

period of 10 years. The researcher worked at the RACF as an Occupational Therapist and was given the task of assessing residents' spiritual needs and putting these results into care plans. Bracketing interviews were held with the researcher's supervisors to bring into awareness the researcher's subjectivity, assumptions and vested interests in undertaking this research and to consider how these may impact on the researcher's interviews with participants, also to enable the researcher to perform a thematic analysis on the transcript and to make transparent the researcher's reflexive practice in the hope of lending rigour and credibility to the research (Finlay, 2008).

The mere fact of being an external observer draws undue attention to the researcher, with its subsequent overreaction (Lincoln & Guba 1985; Speziale & Carpenter, 2007). In this study, the researcher did spend sufficient time in the site (a period of 19 months) in addition to the time spent at the facility previously as an employee, which enabled her to become oriented to the situation. This time period was due to an extended time frame for data collection for the study because of two lots of maternity leave taken during this time. Peer debriefing by regular monthly meetings and feedback with supervisors assisted credibility by discussion of alternative approaches, and others who are responsible for the work in a more supervisory capacity may draw attention to flaws in the proposed course of action. The meetings also provided a sounding board for the researcher to test her developing ideas and interpretations, and probing from others helped the researcher to recognise any biases and preferences. Peer scrutiny of the project was assisted by a presentation to peers. Member checks for credibility were unable to be used given the difficulties many participants had in describing the subject matter. Data triangulation is used to check and establish validity by analyzing a research question from multiple perspectives (Patton, 2002). Data triangulation involves using different *sources* of information in order to increase the validity of a study (Patton, 2002). Data triangulation was used by approaching Staff members at the RACF to validate categories and themes to ensure that the ideas discussed were accurately captured. To address the criterion of confirmability, theoretical decision making was documented using a reflective journal and field notes to provide a decision trail for audit purposes.

3.9.2 Transferability

Shenton (2004) states that it is the responsibility of the investigator to ensure that sufficient contextual information about the fieldwork sites is provided to enable the reader to make decisions about how transferable a study's results may be to different contexts. It is also important that sufficient substantial description of the phenomenon under investigation is provided to allow readers to have a proper understanding of it, thereby enabling them to compare the instances of the phenomenon described in the research report with those that they have seen emerge in their situations (Shenton, 2004). In this study, the study methodology including data collection and analysis was described as accurately as possible to allow evaluation of the transferability of the results. When evaluating transferability it is important to consider that spirituality is a cultural phenomena and this study describes the perspectives of older rural Western Australians from one particular RACF.

3.9.3 Dependability

In this study the interviews with the participants were kept as similar as possible by using an interview format and the FICA scale. Another researcher independently coded three of the interview transcripts into matching themes. Dependability was also aimed for by having study supervisors regularly monitoring during the analysis period and providing feedback.

3.9.4 Confirmability

The dependability criterion is linked closely to the confirmability of the results. Confirmability was also aimed for with the in-depth description given of the methodology used.

3.10 Conclusion

This chapter has described the study design to gather information about RACF residents' perceived spiritual needs. Specifically, a qualitative descriptive exploratory design was employed to find out more about this little researched perspective. The reason for using purposive sample initially then using theoretical sampling was explained as well as the utilisation of semi-structured interviews. Study procedure and

data analysis were detailed, including examples of the coding process used in data analysis. Ethical considerations and approval to conduct this study were also discussed in this chapter. Efforts made to contribute to rigour in this research have been explained. The next chapter will report on the results of the data collected from these interviews.

4.0 RESULTS

4.1 Introduction

This chapter provides demographic details of the participants together with findings and interpretations of the qualitative data gained from interview transcripts. The objectives of this study were to explore and describe aged care residents' understanding of the meaning and importance of spiritual care, to investigate factors identified by residents as enhancing or inhibiting spiritual support and to identify ways in which the RACF can better respond to the expressed spiritual needs of its residents. In conducting constant comparison data analysis, the results that were achieved were different than what was expected when comparing them to the research objectives identified. The three overall themes identified were:

1. *spirituality-I don't know what you mean,*
2. *end of life is no joy at all,* and
3. *sources of comfort.*

These themes are represented in the diagram in Table 4.1 below. One of the overarching themes has sub-themes and all themes have sub-categories; which build on the theme. Data extracts have been embedded in the chapter as "in vivo" examples of the analysed data.

4.2 Demographic data

The biographical data of the varied group of participants interviewed for this study as illustrated in Table 4.1 are broadly representative of residents in the RACF.

Table 4.1

Demographic profile of the sample

Demographic factor	Category	Number of participants (N=16)
Gender	Male	8
	Female	8
Age	64-74	2
	75-84	4
	85-94	9
	95+	1
Length of stay in months	Less than one year	4
	One to two years	3
	Two to five years	4
	Over five years	5
Educational level attained	Primary school	2
	Secondary school	12
	Undergraduate degree	1
	Doctorate	1
Country of birth	Australia	11
	United Kingdom	3
	Estonia	1
	Italy	1
Marital status	Married	3
	Widowed	8
	Divorced	3
	Separated	2
Religious affiliation:	None	1
	Church of England	10
	Roman Catholic	3
	Uniting Church	1
	Church of Christ	1
Main medical condition:	Arthritis	8
	COAD	3
	Cardiac	4
	Low vision	1

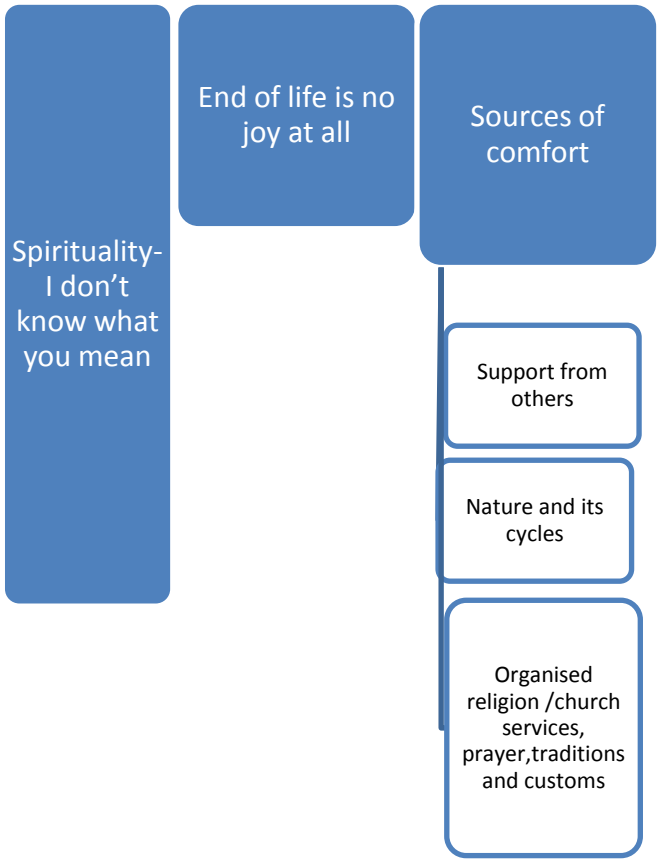
Although presence of dementia was not an exclusion criterion, no participants had such a primary diagnosis. Most participants (87%) had at least a secondary school

education. Although purposive sampling sought a variety of religious beliefs and or non beliefs, most participants (94%) identified with a Christian faith. Only one participant identified themselves as an "atheist"; and they also called themselves a Lutheran.

The interview times varied with a range from six minutes to 62 minutes. The median interview length was 24 minutes. The mean interview length was 24 minutes. During the shorter interviews, participants were not able to be engaged in longer open ended questions or conversations. Reasons for these shorter interviews will be explored in the next chapter.

Figure 4.1

Themes and sub-themes



4.3 Themes identified

4.3.1 Theme 1: Spirituality - I don't know what you mean

Central to this theme was that spirituality was a difficult term for all the participants to use and define. Spirituality as a term and as a concept was not something that participants appeared to have had experience with. They were not used to using the term and were not familiar or comfortable with it. This is evidenced by one of the participant's responses: "Spirituality oh I don't really know anything about it what well I never think of spirituality I don't know what you really mean by it you know" (Barbara).

Despite the researcher having read out a definition of spirituality prior to the interview, eight (50%) of the participants were unable to answer the question, "how would you define spirituality?". Responses to this question are tabled in Table 4.2 below and included the following response from Anne: "define what?".

Table 4.2

Participants' views on a definition of spirituality (n=16)

Participant views	Number of participants
Unsure	8
A belief system	2
To do with religion	2
Spirituality is a very individual thing	4

A further 25% of participants described the individual nature of spirituality in a very ambiguous way. As one participant stated: "It's not something that anyone can give you, you've got to find it yourself your own level and that's, that's how it is with me anyway" (Ethel).

Even the participant who self identified as an atheist spoke of religion as key to spirituality. In terms of defining spirituality, 12.5% participants defined spirituality as being associated with religion. Similarly, the remaining participants described spirituality as beliefs or a set of rules to live by. As one participant stated:

> Belief is necessary, it doesn't matter what you believe in. You can believe in that chair there if you feel like it but look after it and cherish it that chair. Or a rock, or a tree, or even a young lady (Albert).

Another participant had a thoughtful definition:

> I think it's a belief in something that causes your actions to change. Ah it's a kind of measurement of, of what you see and hear in life ah you measure having to measure against and say that's okay or not okay (Margaret).

During the body of the interview all participants referred to spirituality as religion. In response to the FICA question: "what are your spiritual or religious beliefs?", most participants (63%) answered with their church denomination. 12.5% of participants answered nil, 6% believed in nature, 12.5% believed in god and one had "no firm thoughts" on spirituality or religion. Alternatively some participants identified with Christianity however declared not knowing anything about spirituality. For example Anne responded, "well I believe in god I suppose is kind of importance and [unclear] … I don't know anything about spirituality ... ".

Some participants who described themselves as being religious during their lifetime spoke about how they were presently questioning beliefs that they had held strongly in the past. For example:

> No I've worn out why it was important and then I've learnt to live with it and live by it you know keeping all the rules and so on that you have to keep everything you believe in. Ah and um just that I'm getting to be so old now that it's sort of I wonder whether it's worth it (Margaret).

Some participants were not interested in the questioning. These interviews (19%) were the shortest of the group. These participants answered "yes", "no" or one word answers to the questions asked and did not respond to probing. Some participants did not find the questioning important. For example: "Religious beliefs? Well to use my dad's term I'm a Callithumpian" (George).

In conclusion, most participants had difficulty with the abstract nature of the term "spirituality". Most participants linked spirituality with religion and struggled with defining the term. None were able to describe it in the broader terms used commonly in the contemporary literature. Accordingly, participants also had difficulty in identifying barriers and enhancers for spiritual care.

4.3.2 Theme 2: End of life is no joy at all

Participants spoke about how ageing and having to live in residential care was a difficult and stressful experience. Participants talked about the negative effect on their mood from the accumulated losses associated with aging including: loved ones, independence, homes, choice, freedom, purpose, physical and sensory ability, hobbies and their communities. Participants showed sadness, disappointment and anger when discussing these losses. All participants agreed that there were times that they felt despair and helplessness and required hope and help to cope with these feelings.

Participants, while generally positive about the care provided to them, found living in a RACF a hardship. Of particular concern or stress to them was the predictability of the RACF routine, and the lack of spontaneity, joy and "life". These thoughts are expressed by the following participant:

> Because what else is there you get your food to eat and everything else here and there is no life anywhere there's no you know you're not part of anything and

you my eyes are gone so I can't see to study. And so end of life is no joy at all (Margaret).

The frustrations and difficulties of living in a RACF are summed up by another participant: "Oh there are times when I could burn it down" (Betty).

Participants spoke about how they felt trapped physically, by physical impairment and environmentally. Participants compared living at the RACF to being imprisoned, as stated by Harry: "Said I should … have gone to jail they get a toilet each in there" and Anne: "Being in residential care is not very nice really".

Participants talked about how often the decision to move into care was forced upon them rather than it being their choice. They also talked about how moving from their family home of many years into one room at the facility was very difficult. They spoke about how physical and sensory impairments had limited their independence, their choices and their living environment to the point that they needed full care and did not have a choice in where they lived. There was generally a feeling that participants felt they did not have control over their lives. This is reflected in Frank's response: "The reason I'm in here is because of these things you know. But I needed um because if you were having a blackout and um you had to have some sort of care you know and ah".

Another participant spoke of the losses of independence, choice and his home:

Moving into this place. Oh it was a terrible disappointment to me I had a lovely house over in [another town] and ah I had to sell that I couldn't look after myself and I didn't like that at all (Bill).

Participants also spoke about having lost their purpose, meaning and excitement for life. Participants often expressed hopelessness with their situation. Participants talked about having lost their importance and about not having anything useful to contribute to society anymore.

Ah I'm no longer as competent and useful as I used to be (Frank).

` Well they're very good here but I'm not very contented with it; I want to be out doing things which I can't do (Bill).

Because I have lost a lot of the excitement of that there was when I was 21 (Margaret).

Loss of meaningful occupation and role was experienced by several participants. Participants talked about withdrawing from others. For example, one participant said: "Most of the days I spend here in this room watching the television or things like that" (Bill).

Participants spoke about how their physical and sensory impairments made it hard to do everyday tasks and hobbies. They also talked about their inability to participate in activities that previously gave them pleasure. The loss of independence, community access and mobility was also regularly spoken about:

> But in [name of town] you could do that I had a gopher there and you could drive around the town. Um go and do my banking you can't do it here can't get around ah um the town here that you can in [name of town] (Bill).

Likewise, loss of driver's licences and cars meant that the people were much less independent in where and when they could do things. For example, Keith said: "Yes well I can't drive the car I think I could if they'd let me but I don't want to hurt somebody else" (Keith).

The multiple, accrued losses of later life were seen as particularly difficult to deal with. This was a strong sub theme that emerged from the data. Participants spoke of losses of life partners, purpose, jobs, friends, war mates and colleagues. One participant spoke of how she felt:

> I think so um because what this is the end of things you know there is no other thing really left to do anymore. You even can't have friends very much because

they fizzle off and um they die you know. And they go and it's the end of things (Margaret).

Many participants (50%) spoke about how their relationships with others who had died were still incredibly important to them:

Oh well used to me inspiration my earthly inspiration was my husband but he died unfortunately (Betty).

I think about the hereafter and I know [name] is waiting there for me (Shirley).

And ah we kept together we had 58 years yes and I I'm, I'm I suppose I missed her that was worst the worse thing of the lot. She died eight years ago and she and I, I miss her. Yes that was a tragedy that she had, finished up with bowel cancer, terrible thing. But we had a wonderful life and we were fairly prosperous I suppose (Bill).

Despite being around many others in the facility, participants often spoke of their loneliness. There was a perception from them of their lack of connectedness to others and the community. Participants spoke about how they felt isolated, even disconnected from others. This was true for both relationships in the general community and within the facility. They talked about how they felt it difficult to talk to and connect with others in the facility due to theirs' and others' disabilities. An 86 year old participant spoke of observing co-residents disability with negativity:

And ah there are a lot of people who probably older in years but they're I don't seem to mix with them so well. … we go down for meals and we just sit there and nobody talks so all you can do is just ah eat your meal and get out. There's one of them she's an old girl and ah I get on well with her as much as anybody I make her laugh and ah. There's a chap opposite me well you can't hear a damn word he says well because I'm partly deaf now. And there's another woman

she's there and you, you talk to her and you say excuse me you know what was that and she says "Oh forget it."… .. (Bill).

Participants talked about difficulty with coping with obvious disability, theirs and others. Participants found the prospect of increased disability very stressful. For example:

… Ah well when the time comes I can't you know find the mouth where I put the spoon of food in there take me down to Middleton Beach and point it towards Michelmas Island and I will swim to that island. Well I'm not going to get there I can't swim but [laugh] that's not the point. And then I find out that knowing my luck there the bloody water the tide will have changed and bring me back (Albert).

Another similar theme identified was the concern of being a burden to care staff and one's family. Participants dreaded being seen as a burden or requiring total care. For example:

I come here for three weeks [unclear] this will do me and here I am. I don't want to be ah burden to my family the family is here I got twin daughters and ah one daughter's family is there (Albert).

A related, common sub theme that occurred regularly with participants' was that ill health and disability was a frequent barrier to both quality of life and support for quality of life. For example:

I've had this rotten something or the other you know you cough and cough and choke....And ah oh when you're down you're down you can't do anything and everything makes you mad (Barbara).

..I don't pray down on my knees so much because I can't get up (Frank).

I can't walk anymore see (George).

4.3.3 Theme 3: Sources of comfort

The issues raised in theme two highlight the need for support and comfort for residents. Residents' discussions of sources of support in their experience of living in a RACF highlighted that the most important resources were family supports, comfort from religion and relationships with nature (Figure 4.1).

4.3.3.1 Support and comfort from family

All participants reported that support from their families was key to their personal well-being. They nominated family members, usually spouses and or children, as being very important to them and that these relationships brought comfort and joy. Participants reported that the RACF made families feel welcome and that family and friends were welcome to attend activities.

These family relationships were important both present and past. For example:

> I'm convinced that we'll meet again; it would seem such a terrible waste of a whole lifetime if you didn't…and we got married right at the end of the war got married and three weeks later I was on a troop ship coming home and 12 months later she was on a bride ship coming out [laugh]. She was a wonderful girl we had a good life we, we ah we got along very well and we were quite prosperous in our own life (Bill).

My children, I, I see the children and my happiness with children, well, my happiness (Ethel).

> Value, well I think having my family and I've had a lovely family unfortunately I did lose two in later life. But ah I think having a nice family and nice home hhmm (Barbara).

Connections and support from staff and volunteers was another theme regarding what gave participants comfort and hope. For example, one of the participants said, "And ah the girl in charge of this one or lady in charge of it, she said 'You only get to

hug every second morning,' she comes around and gives you a hug every second morning (Harry)."

Interestingly, on three occasions residents did not identify that other aspects of their lives were of importance and meaning to them. For instance, Fred stated that his family gave meaning to his life and nothing else, however the nurse in charge of that section told the researcher that he enjoyed opera music and listened to it daily. Likewise, the registered nurse in charge informed the researcher that both Clive and Anne were artists and that their works of art were displayed on the walls of their room, however neither person identified that painting, drawing or art appreciation was important to them.

4.3.3.2 Comfort from religion

As stated previously, living in a RACF was challenging for all participants. Most (69%) agreed that their religious beliefs helped them to cope with day to day life at the RACF. Eve for example, said that, "I hope it has helped me a bit" and Frank thought that "It probably has, has helped me from um giving way to ah what do you call it despair".

Participants reported they gained meaning and confidence from religious teachings. For example, Frank said:

> Well this is what's taught in religion and so on it's about um ah being truthful doing good ah good to other people not being ah stealing or anything like that. Because of, of the fact that if you're stealing or ah, ah having sex with someone else's wife or anything like that you know that it's sinful. And that would go against you.

Furthermore there was the acknowledgement that religion shaped your beliefs and moral systems on what was wrong and right. Margaret said:

> Well hhmm with religion you know what is right and wrong or what you believe is right and wrong. It might be different to different people but it is you what religion is all about surely wouldn't you say?

Another strong theme was a belief in God as ever-present. This notion of a familiar, parental, homely presence was comforting. For example:

> God's always near me ….Well yes it does because you're always aware that he knows all about you ... And you just say I'm finding it hard to cope with certain problem and I, I can get comfort out of that (Shirley).

No I, I accept that I'd just accepted it. It's not a big [whoof] type of thing it's just there's something quietly that's always there like your mother (Betty).

Well oh yes its quite always when I've been away for a while I walk into the church I feel I'm home (Anne).

Whereas God is everywhere [laugh](George).

Six participants reported that they felt comforted by prayer and that they used it to ask for strength or support from God. Prayer was also used to ward off going to hell for eternity. Participants talked about the meditative effect of prayer as being beneficial to them and also described the routine or ritual of prayer (for example, before bed). For example Frank said:

> Well I pray and ah I ah um hope that when I pass out that I will not go to hell. If you can sort of pray and that you believe that you might be help, helpful and ah you can pray for ah even others you know that are there. But I think if you have got a belief in God then ah you're not as likely to ah sort of despair … or get too depressed.

Many participants (n=7) reminisced about past traditions of attending Sunday school and church on Sundays. For many Church and Sunday School were important local social and family events and were remembered with fondness by participants. For example:

Used to go to church all the time there was Sunday School when I was little you know (Keith).

> That's right oh I mainly go to church well I started going with my wife she likes to go. And that's alright and all the children went while they were at school I don't know how they go now but um well its there if they want to go to it they can go to it. I feel entitled too; I support the church (Harry).

> I've gone along to church I was brought up by a Catholic family my, ah mother and father they used to believe in, God I think and ah mum used to pray yes, yes. In fact ah she used to say "Oh [name] means God" (Frank).

I was a good boy when I was a boy I used to go to Sunday School (George).

> The church has gone to the pack I reckon ah there's lots of things we used to do they don't now. They don't have a Sunday School that's a really dreadful thing (Betty).

Participants were all aware of the church services offered in-house at the RACF and visiting church members. They were well informed about these and felt positive about them. The wide range of church services at the facility was acknowledged by participants, even if the resident chose not to attend them. As one resident stated:

> And that was a Catholic church they had three different services a different one every week. And everyone has you can go to the lot if you like but it has three different churches for people who are dedicated to it and all that sort of thing. I've got nothing against it (Harry).

Another participant spoke about how the priest could be asked to visit sick people for Holy Communion:

> Oh I haven't been here long enough but they came and told me that there would be Mass down there in the hall and ah and I wasn't able to go. So they said that they would ask the priest to come up here and give me communion, so I take it that's what they do for everybody (Shirley).

Well ah there's you can go to mass here…..I have a lady that comes here every Sunday to give me Holy Communion (Margaret).

No I think they do very well, they try to um allow facilities to have um church services here you know (Barry).

Life review was an important aspect for some participants. Participants talked about how they "measured up" in terms of their religious morals as being an indicator of their life success. For example:

> And if you know what I mean but I'm not a um I think I've been a reasonable Catholic if you know what I mean. Gone to church, I think I've been honest in my dealings with people. Well this is what's taught in religion and so on it's about um ah being truthful, doing good ah good to other people, not being ah stealing or anything like that. Because of, of the fact that if you're stealing or ah, ah having sex with someone else's wife or anything like that you know that it's sinful. And that would go against you (George).

> I've always felt that I've been a pretty reasonable person, I've always thought of myself as being a good guy really…I think I've, I've I'm lacking in some things I feel I've ah haven't done as much really for my kids that sort of thing. Although they've all been put through a good school and that so (Barry).

For some the notion of someone with a religious background assisting with their life review was important. For example, Margaret said, "Because it's the end of your life there's not much you know left to do that's new you're just at the very end and you're

worn out. And that's why I'm trying to do a bit of, um oh with [name] help um do a bit of review of what I really believe in right now" (Margaret).

4.3.3.3 Seeing nature/ observing the seasons /cycles

Not surprisingly, given the rural location of the sample, many participants (n=5) identified that nature was important to them. Participants enjoyed the gardens around the facility and going on bus trips. For some, nature and the seasons gave meaning and structure to their lives:

> Well in, in one sentence I believe in nature full stop (Albert).

> You know which you know you got a tractor and you know plough up the ground and then you know you rake it and you know to clear it and....You know bush and all that and so forth you know we did that (Keith).

For other participants nature and the land helped shape their lives and their families. For example:

> […] and I said, "But you don't have the faith in god that we have." And, and [name] when he came over here and he saw the sandy soil and he thought oh I don't think you can farm on this. But then he went to what they called a pilot farm and that was um out at well they called it Cape Riche at the time and he said to the chaps that came with him. He said, "When they open up land here that's where I want; right next door to this," because they'd found the trace elements and this man had Lucerne growing right up to the mudguards on his car. So [name] realised um with his life time on the land and being going to do the agricultural college had a pretty fair idea. And um so he, he kept on writing to me and say if this is what Western Australia is they can have it. And then when he went out to this pilot farm and saw what they could do with trace elements, he came back to Melbourne and I had to meet the night bus up to New South Wales. And he said to me, "We've prayed for guidance and I feel that this

is the guidance we've prayed for. If we don't take this we'll have to answer for it on judgement day, but the decision is yours" (Shirley).

Participants spoke of the enjoyment they got from observing nature. For example Barbara said:

> And we had a farm which ah on weekends we used to go out to the farm and we had a lot of enjoyment there. Looking at the wildlife hhmm, the kangaroos and the, and I was almost bitten by a tiger snake how was that.

4.4 Conclusion

The chapter has presented the findings from the demographics and qualitative data collected on the phenomenon of residents' perceptions of their spirituality needs in RACFS. The findings from data analysis did not align with the research objectives proposed. Participants generally had difficulty defining spirituality and were unable to enunciate their needs in relationship to the term. They were, however, able to clearly state what things caused them stress or discomfort and discuss sources of comfort during the interview. Three dominant themes were found in the data analysis and were categorized under the headings of *spirituality- I don't know what you mean, end of life is no joy at all* and *sources of comfort*. Two of the themes had sub-themes. Together the themes contained issues that have implications on how spirituality should be assessed and provided for in RACFs in rural areas. These will be addressed in the Discussion/ Conclusion chapter which follows.

5.0 DISCUSSION

5.1 Introduction

This study has explored how one RACF meets the spiritual needs of its residents. In this chapter the findings are examined in relation to relevant literature. Also described are the limitations of the study and recommendations for service delivery, education, management and for future research are provided. Finally, conclusions from the study's results are presented.

5.2 Difficulties with terminology

These findings were unique among studies regarding spirituality in RACFs in that they are based on participants' own perceptions of not only their spiritual needs but also their interpretation of the meaning of spirituality. The outcomes of this study were not wholly expected in that participants had such difficulty in defining spirituality and relating to spirituality as a concept that the core research questions are left largely unanswered. The key research question for this study was: what are the spiritual needs of residents in RACFs? The specific objectives of this study were:

1. to explore and describe aged care residents' understanding of the meaning and importance of spiritual care,

2. to explore factors identified by residents as enhancing or inhibiting spiritual support, and

3. to identify ways in which the RACF can better respond to the expressed spiritual needs of its residents.

What this study did find was: (1) spirituality is a term that is not 'user friendly' for the population sampled; (2) that participants consistently substituted religion, and specifically Christianity, for the term spirituality; and (3) the participants' understanding that spirituality equates to religion is quite different to how the term is used consistently within contemporary literature, namely that spirituality is much broader than only religion, something that is more universal.

Considering studies conducted in settings other than RACFs, Hermann (2001), in her study of dying patients' spiritual needs in a hospice setting (n=19), found similar results to this study. Two participants did not know what spirituality meant and most participants identified it with religiosity. The mean age of her sample was 72 years, which is similar to that of the participants of this study. Likewise, when five patients (n=22) also from hospice and acute trusts (providing hospital services) were asked about their understanding of 'spirituality' by McSherry et al. (2004), all were unclear about the meaning of spirituality and considered it to be synonymous with religion. This study also found that in contrast to the understanding of the patients, the staff all had uniformly broad contemporary definitions of spirituality. Conversely, Nolan and Mills (2011) found with a focus group using a very small sample of three residents of RACFs, they were able to identify their spiritual needs. These results imply that any attempt to precisely define what constitutes spirituality may be fraught with difficulty.

The discrepancies that appear to exist between the groups studied emphasises the ambiguity and subjectivity that surrounds the concept of spirituality. Therefore, whilst policy makers and professional regulatory bodies should be commended for attempting to draw attention to, and raise awareness of, this important dimension of peoples' lives through legislation, they must refrain from making assumptions with regard to what constitutes spirituality for the individuals concerned (McSherry et al., 2004). The findings of this study show that some groups of people do not identify with the term or readily articulate what they perceive spirituality to be. Nolan and Mills (2011) state that when spirituality is explained as being about where one finds meaning and purpose, strength and support, then an older person can readily accept the term. However, this contention was not supported by these findings. The FICA instrument consists of a set of questions designed to invite patients to share their religious or spiritual beliefs and history to help identify spiritual issues (Puchalski et al., 2009). Yet participants were unable to distinguish between spirituality as religion and something broader than this. There is a move to remove religious language from spiritual assessment to avoid religious connotations (Atchley, 2009) however this study and those by Hermann (2001)

and McSherry et al. (2004) would suggest that to do so with an older population would be problematic.

5.3 Accounting for difficulties with terminology

A possible reason for the finding that participants were unable to define or use the term spirituality includes the abstract nature of the term creating difficulties in comprehension for people with cognitive loss. Recent research indicates that more than 50% of RACF residents have dementia (AIHW, 2011). People with dementia experience limitations in their ability to think in abstract terms, because impairments to the frontal lobe of their brains impact on their ability to focus on one thing or maintain interest long enough to make judgments, future plans, and decisions (Mendez & Cummings, 2003). So, perhaps it is not surprising that this sample had difficulty responding more broadly to the term spirituality which is abstract in nature.

An alternative theory for why spirituality was not a user friendly term for the participants is that it is unfamiliar. Spirituality is a more recent term and one not widely used by people of the generation of our participants. The mean age of participants was 83 and they were part of the generation known as "The Veterans" who were influenced by living through the Great Depression and World War II (Sherman, 2006). This generation is said to have a greater sense of seniority, respect for elders and people of authority than subsequent generations (Simmons, 2008). Spirituality may have negative connotations for most of our participants associated with the anti-government, anti-war, free love movement of the 1960s and 1970s (Simmons, 2008). The Veteran generation is more likely to save and to not waste resources, respect authority figures and have been active church members (Simmons, 2008). This is consistent with the finding that participants were generally unable to express their spiritual needs unless in a religious context. The rural nature of this sample may also have enhanced this view of spirituality even further (National Church Life Survey (NCLS), 2013). Rural church goers are older than the national average and more likely to have been born in an English speaking country (National Church Life Survey (NCLS), 2013). More than half of rural churches

are either Anglican or Uniting (National Church Life Survey (NCLS), 2013).The historical and cultural background of the participants is key to deciphering these results. The sample is largely western and Christian and hence it is not perhaps surprising that the sample would equate spirituality with religiosity.

Most of the literature reviewed focuses on staff and volunteers' perceptions of the meaning of spirituality, spiritual care and spiritual needs of residents. When compared to the findings of this study there is some overlap but it is very obvious that staff have a vastly different viewpoint of what spirituality is than the residents. Indeed, regulatory authorities and policy makers are presumably from a different generation to those being cared for and as such have different views on what is spiritual care and how it should best be provided. Bloemhard (2008), McSherry et al. (2004) and Nolan and Mills (2011) all talk about the differences between staff meanings of spirituality and those of their care recipients. Given the differences and the increasing multi-cultural fabric of staff in residential aged care, there could be difficulties in staff interpretations of spirituality and how they assess and provide spirituality to people in their care. Once more, plain descriptive terminology would be best used here for ground roots staff to guide individualised client care.

5.4 Residents' needs identified

It seems from the results that Thomas's three plagues associated with residential care living, namely (i) boredom (ii) loneliness and (iii) helplessness (Brune, 2011), are present in the RACF studied. Residents consistently told stories of feeling disconnected and isolated from others and the community. This isolation was related to both environmental access issues but was also self imposed by residents (e.g. "Most of the days I spend here in this room watching the television or things like that"). This need for connection with others fits into MacKinlay's (2004) spiritual tasks of ageing, primarily to find relationship (intimacy), to develop self transcendence, to find hope and meaning and to respond to meaning. The importance of meaning to residents was recognised, residents frequently talked about how they could no longer do what they wanted to do.

Consistent with the literature pertaining to spirituality for older people is that participants told of the intense stress of actual, or expected disability and loss. Furthermore, in dealing with these cumulative losses, the participants told that they needed the support of their families and the support religion offers. They also expressed that nature gives them comfort and meaning. Whether these issues are spiritual (MacKinlay, 2008) or psychosocial (Paley, 2008) depends on which school of thought one belongs to. However they are labeled, they need to be addressed by care staff in a clear and accountable manner.

Another common theme related to what gave meaning and comfort to participants was ritual and the familiar. Many older people had experienced Sunday School and church, even if they had little contact now. These traditions, social customs and rituals were reported by participants to have been important to them both in the past and the present. It is often presumed that people tend to become more religious with increasing age, and it is widely acknowledged that older people are more likely to believe in God and attend church services than younger people (NCLS, 2013). Gender is also implicated in religiosity, as women are more likely to believe in God, more likely to go to church and more likely to pray than men (Nielsen, 2009). In Australian RACFs there is a higher population of females than males, with more than double the number of females (about 114,600 females to 47,700 males (AIHW, 2011)). This study had an equal number of participants from both genders, so was a non-representative sample in this respect.

Participants typically identified with the rituals of organised religion, including church services, communion, prayer and special calendar events such as Christmas and Easter. Residents enjoyed being able to attend church services at their facility and liked that a church representative would visit them if needed, or regularly for communion if requested. Those that did not identify with being religious also recognised that these services provided support to others who did. Importantly they did not feel that they were expected to go to church services if it was not what they wanted. Trevitt and MacKinlay (2006) and MacKinlay (2008) explored issues of religiosity with care home (the name

for RACFs in the UK) residents with dementia and found that religious activities were particularly important to them. This is consistent with the findings from this study in that participants remembered the familiar routines of night time prayers, Sunday School and church, fondly and with importance, both as a social outing and to guide their behaviour and values. The idea that the familiar, together with ritual and routine is important, is consistent with literature on what activities are meaningful for those with dementia. Church rituals, including singing well recognised hymns, the order of service and communion, have meaning and symbolic values to participants (Goldsmith, 2002). They are also well rehearsed activities that for some may become automatic routines.

MacKinlay (2008) discussed the notion that spirituality/spiritual care is multifaceted and included among other things: music, art, relationship with others, links with nature, caring, touch, and dance. However, the participants in this study generally did not identify these needs as spiritual even though the arts in the form of opera music for one resident and art for another were indicated as important and confirmed by nursing staff as exceedingly important and meaningful for the people concerned. Exceptions to this are the meaning and spiritual importance of nature and family to people, which were recognised by most participants. Whilst these things may be very important to people, the participants viewed and categorised them as "what they were", not as part of their spirituality. This indicates that the language used has to be plain, descriptive and readily understandable to accurately assess and provide for peoples' holistic needs in RACFs.

5.5 A framework of residents' needs and possible responses

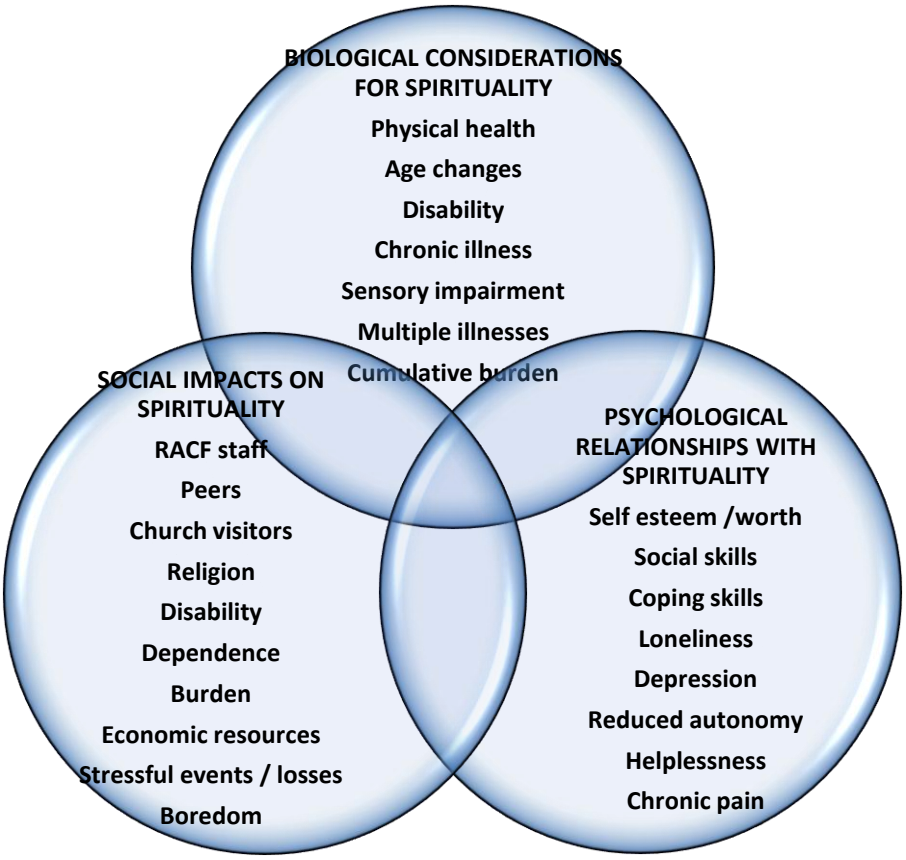
The findings of this study also contribute to the abundant literature regarding caring for older people that stresses the necessity of providing person-centered care that responds to the individual's needs (Brune, 2011). From the study findings we understand these needs to include those relating to religion, socialisation, the love of nature, music, art and/or family meaning. Multiple diverse factors were indicated as contributing to stress and discomfort within RACFs living. A model is proposed to accommodate these diverse multifactorial issues and to indicate the way they impact on the older person in care.

The bio-psycho-social model helps to itemise some of the needs that residents have specified and how these needs can be addressed. A holistic representation such as this model, may facilitate a deeper understanding of the complexity and magnitude of the issues residents face. Engel's (1980) biopsychological model of health is proposed as a framework to assist in the assessment of how the spiritual needs of an older person in a RACF can be identified and responses considered. This framework is represented in Figure 5.1 below.

Biological concerns fit with what participants have told about deteriorating physical health, disability, sensory impairments and multiple health issues. The psychological concerns also reflect the data obtained from participants pertaining to self esteem and worth, social skills and coping skills, loneliness, depression, reduced autonomy and helplessness. The social issues outlined by participants were: both disability of peers and their own disability, religion, dependence, boredom, and fear of being a burden on others. The participants addressed these issues by: religion, being in nature, and support from family and support from staff of the RACF. In summary the bio-psycho-social model accommodates the multiple, complex spiritual needs identified by participants.

Figure 5.1

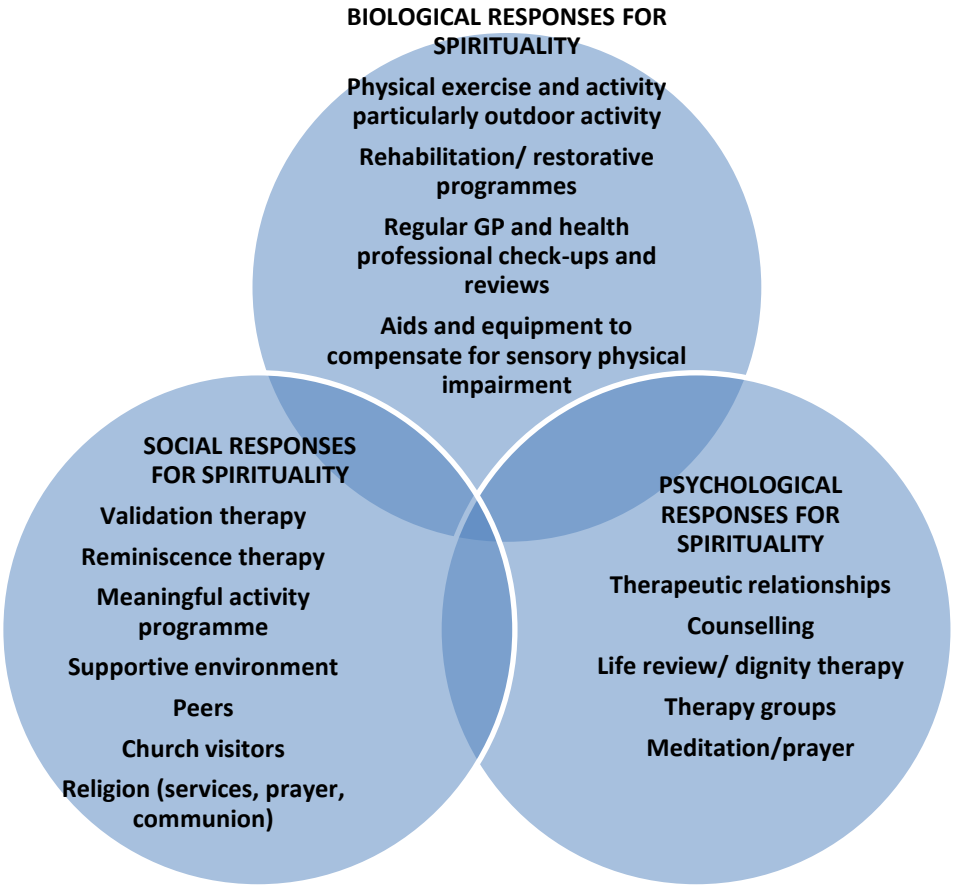
The bio-psycho-social model of health as applied to spirituality and RACF residents (adapted from Engel, 1980)



The complex issues relating to spirituality facing the older person in care make assessing spiritual needs and attempting to meet these needs very daunting. The bio-psycho-social model provides a framework for considering the impact of biological, social and psychological factors on the older persons' health. It can be used to both frame the needs and address them once deconstructed into the categories of biological, social and psychological as shown in Figure 5.2. This model will assist care staff involved in assessment and care planning to understand and appreciate the multitude of 'spiritual' needs and the interplay between these, related to the older person in care. This model provides a comprehensive structure to guide care staff involved in assessment and

care planning in their efforts to address these needs in a targeted, coordinated way, tailored to the individual. This framework attempts to de-mystify the elements of spiritual needs of RACF residents and offer concrete options for addressing them. The care interventions indicated in Figure 5.2 are possible responses to the needs identified by the participants as a whole. Care interventions for individuals would need to be individually planned in line with their assessed needs. The limitation of this model would be in its application as for many recommended practices in health and aged care, workforce and labor, training and associated time away from the floor and costs to service and staff.

Figure 5.2
The bio-psycho-social model of health as applied to possible responses to residents' identified spiritual needs (adapted from Engel, 1980)



5.6 Limitations of this study

This study is limited because it was a small study with a small study sample. Although purposive sampling is appropriate in the case of an exploratory study such as this, the main restriction of qualitative research and this method of sampling is the inability to generalise findings (Polit & Beck, 2006; Speziale & Carpenter, 2007). As the findings are from one rural facility only, results may not be able to be generalised to RACFs in general. However, the findings of this study can serve as a basis for further research in this area.

Another limitation was that although attempts were made to exclude potential participants with severe cognitive impairment, it became clear from the interviews and from reading the transcripts that many participants had cognitive losses without a formal diagnosis of dementia. However, because at least 50% of RACF residents are likely to have similar PAS scores (AIHW, 2011) these difficulties would be common among RACF residents. In this study it was considered that the viewpoints of those with dementia are just as important as those who do not have dementia and as such the limited data collected from residents about spirituality may reflect the cognitive awareness of many RACF residents.

Recruitment of participants was difficult for three main reasons. Firstly, some people found discussing their religious beliefs a deeply personal matter and thus were unwilling to participate. Secondly, theoretical sampling was required to ensure that participants were recruited on the basis of emerging themes and therefore, recruitment was directed to this end. Thirdly, the length of stay at the facility studied is quite long and so there was only a limited sample to work with, given the low turnover rate.

A small percentage of interviews (19%, n=3) were not lengthy, however given the nature of the participants this was to be expected (Robertson & Hale, 2011) advocate a typical minimal interview time of six minutes plus 30 minutes preparatory “warm-up time” to establish a relationship with the older person, develop rapport and

promote storytelling). The limited interview time with these three people may mean that they had either limited information to divulge on the topic and/or that the researcher was unable to get to the core of the issue.

The homogeneity of the sample was also a limitation of this study in that all of the participants came from a Western, Christian background. Repeating the study in other settings may provide more culturally diverse participants and hence different understandings.

5.7 Recommendations

5.7.1 Implications for clinical practice

Implications for care practice for residents in RACFS can be derived from the three major themes that emerged in this study:

Spirituality: I don't know what it means has implications in terms of the language used to both assess and provide services within the standards that are audited by the ACSAA (2011a), and also, the context within which people's psychosocial needs are considered. Essentially, spirituality equates to religion for the population sampled and to read anything further into this is not generally possible, appropriate or necessary. Therefore the recommendation for clinical practice is for clinicians to use plain language including religion as an example of spirituality and church services as an example of how their spiritual needs may be met with the people over 75.

End of life is no joy at all tells the story that there is much to be done to improve participants' experiences in terms of psychosocial needs in RACFs. This is consistent with other literature in the area (Brune, 2011; De Bellis, 2010; MacKinlay, 2008). The participants in this study clearly wanted to remain involved in life, the community and their families. Sensory and physical disability cause considerable grief to people and so treatment, aids and equipment and other compensatory strategies to alleviate or reduce the impact of such disabilities would have a great positive effect on the residents; it would help, for example, with their ability to participate in self-care and hobbies. As a further example, grief related to accumulated losses is often raw in this population and yet grief counseling is poorly resourced for older people and rare in RACFs.

Finally, *sources of comfort and support* concerns a further important area for participants. Residents identified with the rituals of organised religion including church service, communion, prayer and special calendar events (e.g. Christmas and Easter). Family and friends were consistently identified as solid sources of support for participants. Nature and the outdoors were also identified as being an important area of comfort for participants. It is important for RACFs to provide regular, daily if possible, opportunities for residents to take part in outings and outdoor activities. Similarly RACFs need to offer regular church services, at least weekly, and also special events for religious occasions e.g. Christmas and Easter. RACFs need to provide a welcoming environment for family and friends to be able to visit as much as possible and to join in activities with the residents.

The findings of this study generally support the *Guidelines for a Palliative Approach in Residential Aged Care- Spiritual Support* (Australian Government DoHA, 2006 p 155). The first guideline pertaining to spirituality is supported by the findings when spirituality is viewed broadly to include nature, family and friends as well as religion. Participants spoke of how much quality of life they gained from family and friends and being around nature, even though they did not associate these aspects of life as "spiritual". Consequently the multidisciplinary aged care team members involved in assessment of residents' spiritual care needs will need to have skills to recognize the meaning and importance individuals place on, for instance, family and nature. Assessing aged care team members also need to be cognizant of the effects of accumulated losses on the individual and provide support appropriate to the individual. Whilst participants did not refer directly to the need for a chaplain / pastoral care worker (not surprisingly so as the RACF sampled did not have a specific pastoral care worker), the fact that some residents requested support and spiritual guidance from church members and significant others to guide their life review reinforces this guideline.

Likewise, the second guideline is supported by the findings. The participants sampled were largely a heterogeneous group (from primarily western Christian

backgrounds) and so there was much commonality in regards to spiritual practices that residents felt provided them with support and comfort (Mass, church services, celebrating significant religious occasions) and thus enhanced residents' quality of life.

In particularly the third guideline about spirituality that recommends a comprehensive history assessment and regular review of a resident's spiritual practices, attitudes, experiences and beliefs supports the findings of this study. The FICA was useful in identifying a personal spiritual history, beliefs, practices and needs. Residents described that their needs for support and beliefs did change with time, hence regular review of needs is warranted.

In summary the RACF involved supported the religious needs of clients by providing, promoting and making religious services accessible, including church services, communion and church visitors. They also supported the residents by encouraging family and friends to visit and spend time with them including attending activities together. The facility also provided opportunities for residents to spend time outdoors, go on bus trips and make visits to beaches, open spaces and farms. Grief counseling or outlets for expression of grief may help residents with their expressed losses. Maximising residents' sensory and physical abilities would also assist with supporting them in their time in the RACF. The findings also generally support the *Guidelines for a Palliative Approach in Residential Aged Care* recommendations pertaining to spiritual care (Australian Government DoHA, 2006 p 155).

5.7.2 Education

The lack of a clear definition for *spirituality* and hence the terms *spiritual care* and *spiritual needs*, leads to implications for health worker education. Aged care workers including pastoral care workers, nurses, therapy staff, leisure and lifestyle workers and personal carers have been found to have a far different and often broader view of what spirituality is than that described by the participants in this study (Bloemhard, 2008; McSherry et al., 2004; Nolan & Mills; 2011). This may lead to misunderstandings and miscommunications between care staff and residents, poor assessment of clients needs and poor care planning that is not person-centered. There also needs to be links between

what is outlined in guidelines (such as Australia) DoHA and APRAC Project and National Health and Medical Research Council (Australia) and National Palliative Care Program (Australia) (2006) as well as aged care worker, nursing and allied health guidelines regarding teaching related to spirituality, need to consider what spirituality typically means to residents (as described in some detail earlier). The bio-psycho-social model could assist aged care workers and educators by providing a framework for considering the impact of biological, social and psychological factors on the older persons' health. The limitation of this model would be in its application, with difficulties in RACF workforce training, associated time away from the floor and costs to service and staff.

5.7.3 Management

The implications for management from this study's findings are that participants are generally happy with the care and services they receive from the RACF. The issues that emerged are:

(1) managers need to be aware that spirituality is often a contentious and not clearly understood term when it is used in an assessment context. Participants in this study did not identify with spirituality and in the main equated it to religiosity;

(2) managers also need to be aware that there is an overlap in what comprises 'care' and what comprises 'spiritual care', and the provision of the latter should not necessarily be limited to religious representatives; and

(3) managers considering introducing staff education related to spirituality and spiritual assessment should consider the relevance to contemporary practice of spirituality as a term and its understanding as a concept, to all concerned.

5.7.4 Research

This research raises further questions regarding the categorisation of services falling under the umbrella term of spirituality, its assessment and provision of spiritual services to residents in RACFs as recommended by industry guidelines. Of particular

interest are the implications of using terminology that is neither recognised nor familiar with this age group. Also of interest is how care staff assess spiritual needs as required under industry guidelines against their own particular cultural and spiritual background. It would be interesting to find out how staff at this facility viewed spirituality and what they perceived the needs of residents were in this respect and see how it compared and contrasted with the views of residents.

Another key question for further research is how could these needs be better classified, identified and evaluated? The FICA was effective for this sample, in that it identified that participants had religious needs. However, this assessment tool was developed in the USA, for an American population. The USA is widely acknowledged as the most religious of the industrialised nations, in contrast to the increasingly secular Australian society. It would be interesting to explore what generic or unique tools are being used within aged care in different care contexts (e.g. community, centres, home based care) as well as RACFs.

A further research question generated by the findings of this study is: what differences exist between different populations in regards to spirituality and spiritual care? For example, would the Baby Boomer and Generation Xs and Generation Ys have different understandings of spirituality and how could such needs be met (e.g. as measured by the FICA instrument)? Would they respond differently to the question "how would you define spirituality?"? Given that the present research was undertaken in a rural regional RACF it would be interesting to see if the findings were different in metropolitan RACFs. Further research is essential to determine if the use of more concrete language and specific questioning would assist staff to better meet the psychosocial needs of people who live in RACFs.

5.8 Conclusion

This research has identified many difficulties experienced by people who live in a RACF, with participants expressing their frustration with coping with the multiple and accrued losses of older age including finding meaningful roles and joy. Spirituality has

been touted as a support mechanism for older persons aimed at helping to develop meaning and purpose in life and hope. The participants, while not identifying with the term spirituality as such, or being able to identify their spiritual needs, were able to clearly state what provided them with support and comfort and relief from stress. Sources of comfort and meaning included: family and friends, the customs and traditions of religion and nature. Participants did not recognise these sources of support as spiritual, but were generally very happy with the support they received from the RACF in terms of religious services and care. Those interviewed were best able to describe the supports they needed using concrete language and terms they were familiar with (e.g. church, family, nature).

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Every reasonable effort has been made to acknowledge the owners of copyright material. I would be pleased to hear from any copyright owner who has been omitted or incorrectly acknowledged.

APPENDICES

Appendix A

Curtin University

Memorandum

To	Dr Ruth McConigley, School of Nursing and Midwifery
From	A/Prof Stephan Millett, Chair, Human Research Ethics Committee
Subject	Protocol Approval **HR 88/2011**
Date	14 September 2011
Copy	Ms Jodi Smith School of Nursing and Midwifery Professor Duncan Boldy School of Nursing and Midwifery Graduate Studies Officer, Faculty of Health Sciences

Office of Research and Development

Human Research Ethics Committee

TELEPHONE 9266 2784
FACSIMILE 9266 3793
EMAIL hrec@curtin.edu.au

Thank you for providing the additional information for the project titled "*How can we meet the spiritual needs of residents in aged cared facilities?*". The information you have provided has satisfactorily addressed the queries raised by the Committee. Your application is now **approved**.

- You have ethics clearance to undertake the research as stated in your proposal.
- The approval number for your project is **HR 88/2011.** *Please quote this number in any future correspondence.*
- Approval of this project is for a period of twelve months **14-09-2011** to **14-09-2012**. To renew this approval a completed Form B (attached) must be submitted before the expiry date **14-09-2012**.
- If you are a Higher Degree by Research student, data collection must not begin before your Application for Candidacy is approved by your Faculty Graduate Studies Committee.
- The following standard statement **must be** included in the information sheet to participants:

  This study has been approved by the Curtin University Human Research Ethics Committee (Approval Number HR 88/2011). The Committee is comprised of members of the public, academics, lawyers, doctors and pastoral carers. Its main role is to protect participants. If needed, verification of approval can be obtained either by writing to the Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University, GPO Box U1987, Perth, 6845 or by telephoning 9266 2784 or by emailing hrec@curtin.edu.au.

Applicants should note the following:

It is the policy of the HREC to conduct random audits on a percentage of approved projects. These audits may be conducted at any time after the project starts. In cases where the HREC considers that there may be a risk of adverse events, or where participants may be especially vulnerable, the HREC may request the chief investigator to provide an outcomes report, including information on follow-up of participants.

The attached **FORM B** should be completed and returned to the Secretary, HREC, C/- Office of Research & Development:
When the project has finished, or

- If at any time during the twelve months changes/amendments occur, or
- If a serious or unexpected adverse event occurs, or
- 14 days prior to the expiry date if renewal is required.
- An application for renewal may be made with a Form B three years running, after which a new application form (Form A), providing comprehensive details, must be submitted.

Regards,

Associate Professor Stephan Millett
Chair Human Research Ethics Committee

APPENDIX B

SCHOOL OF NURSING AND MIDWIFERY

INFORMATION SHEET FOR PARTICIPANTS

Study Title: How can we meet the spiritual needs of residents in aged care facilities?

Research team:

- **Ms Jodi Smith:** Masters Student, Curtin University.
- **Dr Ruth McConigley:** Senior Lecturer, School of Nursing and Midwifery, Curtin University.
- **Professor Duncan Boldy**: Research Advisor, School of Nursing & Midwifery, Curtin University.

About the project:

Little is known about what residents in aged care facilities need in terms of spiritual care. The researcher is writing on behalf of Curtin University. The researcher is a Masters student at Curtin University and this research project is part of this course requirement. We are writing to request your involvement in this study. We would like to speak with you today about what your spiritual needs are and how this facility could best meet your needs.

What will I have to do?

I would like to ask you some questions about your spiritual needs. I would like to talk to you for 30 – 45 minutes, at a time and location that is convenient to you. If you agree to participate in the study and return your consent form in the enclosed envelope, I will contact you to arrange a time and place to meet. The interview will be audio-recorded if you agree to that. The interview will be typed out and the information you provide will be analysed. The results of the study will be used to write a report which may be published in professional journals. All information that you provide will remain anonymous. You are free to decide whether or not you want to participate in this study. If at any time you wish to withdraw you are free to so without prejudice.

Will I be paid to participate in the study?

You will not be paid to participate in this study. However, it will not cost you anything to participate.

Are there any risks involved?

There are no risks involved with your participation in this project. In order to maintain your confidentiality your name will be removed from all information which will be kept and stored securely.

The aged care facility that you reside at has kindly approved for us to conduct this research project at their premises. The care you receive from the aged care facility will not be affected whether you choose to participate in this study or not. The views that you express will remain confidential from the aged care facility

What if I need more information?

If you have questions about the study at any time you can contact Jodi Smith on 9266 1766 or j.smith2@curtin.edu.au. Alternatively my supervisor Dr Ruth McConigley can be contacted on 9848 1303 or r.mcconigley@curtin.edu.au.

Concerns or complaints?

This study has been approved by the Curtin University Human Research Ethics Committee (Approval Number HR88/2011). The Committee is comprised of members of the public, academics, lawyers, doctors and pastoral carers. Its main role is to protect participants. If needed, verification of approval can be obtained either by writing to the Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University, GPO Box U1987, Perth, 6845 or by telephoning 9266 2784 or by emailing hrec@curtin.edu.au;

Any complaint you make will be treated in confidence and investigated, and you will be informed of the outcome.

APPENDIX C

SCHOOL OF NURSING AND MIDWIFERY

CONSENT FORM FOR PARTICIPANTS

Study title: How do we meet the spiritual needs of aged care residents?

I have been given clear, written information about this research project and have been given time to consider whether or not I wish to take part.

- I understand and accept the nature of the project which has been explained to my satisfaction.

- I understand that my interview will be audio-taped and typed out.

- I know that my participation in this project is strictly voluntary. I know that I have the right to withdraw at any time.

- If I have any questions about the project or about being a participant, I can call Jodi Smith on (08) 9266 1766 or j.smith2@curtin.edu.au

- I know that I can contact the Research Ethics Officer at Curtin University on (08) 9266 2784 if I wish to discuss any aspects of the program on a confidential basis.

- I agree to participate in this project. I have been assured that my identity will not be revealed while the program is being conducted or when the program is published.

Participant's name: _____

Participant's signature: _____

Date: .....

Please keep a copy of this form for your records.

APPENDIX D

SCHOOL OF NURSING AND MIDWIFERY

CONSENT FORM FOR PARTICIPANT'S NEXT OF KIN

Study title: Meeting the spiritual needs of aged care residents

I have been given clear, written information about this research project and have been given time to consider whether or not I wish my family member to take part.

- I understand and accept the nature of the project which has been explained to my satisfaction.

- I understand that the interview will be audio-taped and typed out.

- I know that my family members' participation in this project is strictly voluntary. I know that they have the right to withdraw at any time.

- If I have any questions about the project or about being a participant, I can call Jodi Smith on (08) 9266 1766 or j.smith2@curtin.edu.au

- I know that I can contact the Research Ethics Officer at Curtin University on (08) 9266 2784 if I wish to discuss any aspects of the program on a confidential basis.

- I agree for my family member to participate in this project. I have been assured that my family member's identity will not be revealed while the program is being conducted or when the program is published.

.....

Participant's NOK Name Participant's NOK Signature

Date: .....

Please keep a copy of this form for your records.

APPENDIX E

SCHOOL OF NURSING AND MIDWIFERY

Interview guide

Little is known about what residents in aged care facilities need in terms of spiritual care. We would like to speak with you today about your spiritual needs and how this facility could best meet your needs. We will talk to you about your faith, your beliefs and how important spirituality is to your life. We also want to ask you about if you feel you belong to a community based upon your spiritual beliefs, and how your spiritual needs can be best met by the facility you live in.

One definition of spirituality is that which relates to or affects the human spirit or soul as opposed to material or physical things. Spirituality is also seen as what brings joy hope and meaning to your life. You might see spirituality as being linked to religion or it may be something else.

FICA reprinted with permission from Dr Christina Puchalski:

FICA

F: FAITH AND BELIEFS

1) What are your spiritual or religious beliefs?

2) Do you consider yourself spiritual or religious?

3) What things do you believe in that give meaning or value to your life?

I: IMPORTANCE AND INFLUENCE
1) Is spirituality important in your life?

2) How does spirituality affect how you view your problems?

3) How has your religion/spirituality influenced your behaviour and mood since you have been living in residential care?

4) What role might your religion/spirituality play in resolving your problems?

C: COMMUNITY
1) Are you part of a spiritual or religious community?

2) Is this supportive to you and how?

3) Is there a person or group of people you really love or who are really important to you?

A: ADDRESS
1) How would you like to address these spiritual issues in your care here?

Additional questions:

1) How well do you think this facility looks after your spiritual needs?
2) What things help you meet your spiritual needs?
3) What things stop you from meeting your spiritual needs?
4) How do you define spirituality?

APPENDIX F

SCHOOL OF NURSING AND MIDWIFERY

Demographic questions

Are you? ☐ Male ☐ Female

What is your age (years)? _____
How long have you lived at this facility?_____

What is your marital status?

- ☐ Married / defacto
- ☐ Not married
- ☐ Widowed

Highest level of education achieved

- ☐ Primary school
- ☐ Secondary school
- ☐ Bachelor/ undergraduate degree
- ☐ Other……..

What religion, if any, do you identify with?_____

What is your main health condition?_____

Where were you born?_____