Minimising the impact of depression and dementia for elders in residential care

Final Report

Rev. Prof. Elizabeth MacKinlay AM PhD FRCNA
Prof. Tracey McDonald PhD FRCNA
Rev. Dr. Alan Niven PhD
Mrs. Frances Russell
Ms. Dorothy Seidel Hooke

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Members of the research team:

Rev. Prof. Elizabeth MacKinlay AM PhD FRCNA, Chief Investigator
Prof. Tracey McDonald PhD FRCNA, Associate Chief Investigator
Rev. Dr. Alan Niven PhD, Site coordinator
Mrs. Frances Russell, Site coordinator
Ms. Gabrielle Brian, Research coordinator and program author (until July 2009)
Ms. Libby Byrne AThR ANZATA, Program author
Ms. Keryn Traversi RMT, Program author
Mrs. Joan Jennings MA(SD), Program author
Ms. Dorothy Seidel Hooke, Research coordinator (from October 2009)
Mr. Arrigo Dorissa, Research assistant
Dr. Kylie Nolan PhD, Research assistant
Ms. Justine Curran, Research assistant
Mr. Kevin Teo, Research assistant
Mrs. Heather Dewar, Research assistant
Ms. Elisabeth Larsen, Research assistant
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Executive Summary

Research aims and objectives

The aims of the project were:
1. to develop a successful prevention approach that will
2. improve the quality of life for elders in residential care by
3. minimising the levels of depression among people with dementia in residential aged care facilities
4. maximising morale and
5. maximising cognitive potential in elders in residential care.

In accordance with these aims, the programs developed as a part of this prevention approach were intended to:

- Reduce the levels of depression in those older people with dementia and depression through participating in the group work programs, and therein improving their quality of life through maintaining or reducing the rate of cognitive decline, and
- Facilitate spiritual expression and growth among older people in residential care, thereby contributing to resident quality of life and maximising morale.

In order to accomplish these aims, the following objectives were identified:
1. introduce participants to specially designed programs designed to increase communication with people who have dementia;
2. explore how meaning and quality of life can be achieved by and for people who have dementia;
3. explore the concept of personhood and respect for persons with dementia;
4. develop effective strategies to improve quality of life for those with dementia;
5. help families and staff to find meaningful ways to interact with persons who are experiencing communication difficulties in dementia;
6. evaluate the effectiveness of the programs used;
7. modify the programs based on the evaluations;
8. publish the programs for use in residential aged care facilities; and
9. publicise the programs widely through conferences, workshops, training, websites and email distribution.

The extent to which these aims and objective have been met:
Objectives 1, 2, 3, 4, 6, and 7 and have been fully met. Objective 5, to help families

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2 A previous version of this report did not contain the results from the prayer and meditation program as this program was still ongoing; it has since been completed, and all results are included herein.
and staff to find meaningful ways to interact will be achieved in the next phase of training and implementing the recommendations.

Objectives 8 and 9 will be the next achievements, once the programs have been redesigned. We have the findings of the study evaluations ready to be incorporated into the programs.

**Study design**

This was a mixed methods study, based on the assumption that it would be necessary to use quantitative data to establish base line and changes in scores across the 18 week study of the trial of the programs with 3 month follow up, of art, music, pastoral care and prayer and meditation, in small groups with people with dementia. The small group process was to examine ways of using these modalities as a means of touching into meaning and the spiritual dimension for people with dementia. To determine what was actually happening in the small groups, qualitative data was used so that analysis could be made of group interactions, facilitator style and participant responses.

**Sample**

The study consisted of 99 participants (male=22; female=77). The study began with 99 participants, 17 withdrew during the course of the program, 6 deceased while the program was running or before the three month follow-up data was collected, and 76 completed the study. The average age was 86.24 (84.45 for males, SD 6.7, and 86.79 for females, SD 5.6). 83.8% of participants were Australian born.

The research team anticipated 50-80 participants, divided into small groups. Thus the final number of participants (99) exceeded the numbers planned.

In some cases, the pre-test data were unable to be collected due to issues of such as limited verbal ability, hearing and visual difficulties, etc. A decision was made by the research team that such participants could still be included in the research program if facility staff felt they could benefit from the program. Obviously the lack of data from these participants means that they were not included in the statistical analysis for those measurements; they were included in the qualitative data collection.

**Data collection**

The demographic data and results from the ACE-R (cognitive status), PGC Morale Scale and GDS tests have been analysed using PASW 17.0. Qualitative analysis was conducted using grounded theory process. All qualitative data (session transcripts, observation journals and facilitator journals) have been analysed with NVivo8.

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3 Dates of birth were not obtained for 5 of the female participants, so average age is calculated based on the available data.
Quantitative Analysis

Quantitative analysis was performed on all programs except the prayer and meditation group, since there was only one group of participants in this group and only four of six completed the program. This means that quantitative analysis was performed on the data from 72 of the participants.

Reliability analysis found the following reliability scores for the measures as follows:

ACE-R = .902, GDS = .789, PGC Morale Scale, with agitation = .747 attitude toward own ageing = .629 lonely dissatisfaction = .737

GDS broken down by allocation to treatment condition: With all programs except the art program, the mean scores for depression decreased from measurement session 1 to measurement session 3. At the 3 month follow-up (measurement session 4), scores increased in all programs, but not to the initial values. It should be noted that whilst the art program shows an increase from measurement session 1 to session 2, this is affected by the small sample size.

Significant reduction of depression levels in the pastoral care groups: A within-group analysis on the pastoral care group only, comparing testing session 1 with testing session 3 on the GDS showed that this comparison is significant (p<.05), and shows that this group decreased significantly in their GDS scores between these time points.

PGC Morale Scale: The PGC Morale Scale measures positive morale. Three modes of morale are measured, agitation, attitudes towards own ageing and loneliness. There was decreasing morale in regard to agitation in the ‘no treatment’ group (with very small numbers) across the 4 measures, while the treatment conditions show morale to be fairly stable across the measurement sessions. Treatment groups improved across the attitudes to own ageing, while the ‘no treatment’ group declined. There was little apparent difference in the loneliness scale in all conditions.

Qualitative data analysis

Analysis found that the small groups, particularly in art and music, were used mainly as activities for the enjoyment of participants, with a focus on ‘doing’. There was little interaction at a spiritual level. We found marked differences in the amount and quality of communication from the participants in the different groups, particularly across the pastoral care groups, as there were five groups and we were able to examine these five groups at multiple sites with different facilitators to tease out critical factors in the group process. These differences were not related to cognitive levels of the participants.

The most important theme that emerged as being accountable for group differences in communication by the participants was that of facilitator style. This was irrespective of cognitive level of the participants. We believe this to be an important finding of this study. It cuts right to the core of what it means to be human and what it means to have dementia and still be human. Simply basic person centred care would assist greatly, and it is possible to establish communication at deep levels with people who have dementia, despite their cognitive levels. Person centred care can be extended to take account of the spiritual and emotional, as was seen in the pastoral
care groups. Communication is about emotions, non-verbal communications and spirituality as well as cognitive processes.

Some reasons for the focus on doing rather than connecting with the participants could be:

- Lack of preparation in skills of person centred care
- Lack of self awareness and confidence as a facilitator (relating to training needs)
- Lack of knowledge latest scholarship of the ageing process, and therefore what to expect as possible ways of being in later life
- Lack of knowledge of dementia and the characteristics of the person who has dementia and therefore, what may be possible for them in communication and understanding

**Recommendations**

An extensive number of recommendations, both program-specific and for the field of aged care, have been made as a result of the findings of this study. The overall recommendations made are as follows:

1. Activities in aged care for people with dementia can lower levels of depression in dementia.
   
   **Recommendation:** People with dementia are able and should be given the opportunity to participate in activities of their choice in residential aged care.

2. Clear distinctions need to be made between entertainment and quality programs giving benefit and meaning to the lives of people with dementia. Too often an activity is ‘done’ because it has always been done, or it is something to distract the residents from the daily existence in the facility. Sometimes, it may be just as important for older people simply to sit quietly and contemplate.
   
   **Recommendation:** Staff in aged care develop a new philosophy of seeking to find what is important in the lives of older people that acknowledges the wholeness and individuality of the person and their needs for connection with others.

3. Staff working with people who have dementia and with older adults need to learn about the ageing process and about the characteristics of people who have dementia. Too often staff work with myths and assumed knowledge about ageing and dementia and do not have the opportunity to learn new ways of seeing the possibilities of ageing and dementia, based on recent scholarship and research.
   
   **Recommendation:** Staff require knowledge of relevant research of ageing, aged care and dementia for improving practice in caring for these people.

4. Assessment of meaning in life, values and beliefs are important areas of inquiry to establish appropriate quality care for people with dementia.
   
   **Recommendation:** People with dementia should be assessed to establish where they find meaning, and their values and interests, before assigning them to particular groups. They need to have choice.
5. Groups for people with dementia need to be small. Previous research has shown clearly (MacKinlay and Trevitt 2006) that, depending on communication difficulties, the groups may even need to be as small as 3 people. With not so marked communication difficulties, it is possible to work effectively with up to 6 people in one group, but no more. In larger groups, the people with dementia are lost and find it difficult to focus on competing stimuli. Staff levels would need to reflect this change. The changes to depression levels may offset the extra costs of group facilitators.

Recommendation: Small group work with people with dementia be available in all aged care facilities.

Recommendation: Staff trained to facilitate small group work.

Staff reported positive changes in behaviour among some group participants that lasted during the intervening week. There may be other benefits, including economic benefits and raised staff morale from group participation relating to staff time in care when groups are being run in a facility.

Recommendation: Further study to be undertaken to investigate economic benefits and staff morale related to the conduct of such programs.

6. Meaningful activities will make an even greater difference in both depression levels and in morale of the participants. It is not simply being in a group that makes a difference.

Recommendation: Meaningful activities to be designed for people with dementia.

7. Working with people who have dementia may be challenging. Yet using principles of person centred care can make an enormous difference to the quality of life for people with dementia and also for those who care for them.

Recommendation: Training programs to be designed and implemented widely to effectively train workers in aged care to provide person centred care.

8. Death and dying are facts of being older and must be a real part of the agenda when caring for people who have dementia and for older people. How death and dying are dealt with will have enormous effects on these elderly people as they face their own dying.

Recommendation: Training programs contain relevant content and training in working effectively with people who are dying and those who live with them.

9. The culture of aged care needs change. Many of those who work in this industry, in low paid positions, have a sense of their own inability to make change. A focus on a medical model of care is too narrow a focus in an area where people desperately need to be recognised as human beings first, and have appropriate care of their medical conditions second. That is not to say that good care of medical conditions is not needed, but that the focus has to be on the person first. These requirements are already in the Aged Care Standards for Australia (Pringle 2010), but are often not fully addressed. This will start to change the climate of the whole industry.
Recommendation: Effective training in person centred care be implemented throughout the aged care industry.

10. Spiritual well-being is a basic requirement for resilience and hope among older residents of aged care. This is a relatively new component of care. It is a new paradigm that can well be developed across disciplines. Training in this area goes even further than person centred care.

Recommendation: Education and training programs be developed to take account of the latest research in spiritual care.

11. Recruiting for this study found that there are few people with the appropriate qualifications available now.

Recommendation: Urgent attention be given to preparing practitioners to work in art, music and pastoral care with older people and especially for equipping them to work effectively with people who have dementia.

12. If there is a shortage of suitably qualified people in the major Australian cities then remote and rural areas of Australia are even more deprived of people who can provide this care.

Recommendation: Special training programs be developed and made available to people working with people who have dementia in rural and remote areas.
1. Introduction to the project:

1.1. Issue and rationale

By intervening to minimise the levels of depression, it is believed that the effects and severity of dementia in elders will also be reduced. This will positively affect the quality of life for elders in residential care; ease the demand on health services and lessen the burden on the Australian health budget. Programs that seek to engage in meaningful ways with people who have dementia may be one means of alleviating the effects of depression.

Many programs are used in residential aged care, and in the wider community, but little is known about their effectiveness. It is a fact that such programs are generally conducted as an activity that will be one of enjoyment but fail to address the more fundamental issues that these people experience. Programs chosen and designed for this project were in music, art, pastoral care and prayer and meditation. These programs were chosen as they are often used in practice, and these modalities are considered to provide a means of tapping into spirituality and life meaning, which in turn can assist people with dementia to find hope in the presence of dementia (MacKinlay 2006). Therefore, this research sought to move beyond the activity, to attempt to engage more deeply with these people with dementia. This research project sought to develop and evaluate high quality programs for residents with dementia that could then be modified on the basis of the evaluations and published and marketed for use in residential aged care facilities, and the wider community. Education and appropriate training of workers in aged care is a continuing issue, with low levels of funding and training that often is based on tradition, rather than evidence based research. Therefore a problem for numbers of aged care facilities, and for those who conduct programs for older people in the community, is the provision of well qualified care providers. It is recognised that not all aged care facilities will have ready access to qualified professionals like music therapists and art therapists, whether due to funding or location. The programs developed as a part of this project would not replace the skills and knowledge of such professionals, but they could be delivered by the facility staff and, when necessary, referrals for particular residents could then be made to these professionals. The programs to be published will contain training material that can be used in train the trainer programs and even by aged care workers in remote regions to develop skills in these areas.

1.2. Research aims and objectives

The aims of the project are:

1. to develop a successful prevention approach that will
2. improve the quality of life for elders in residential care by
3. minimising the levels of depression among people with dementia in residential aged care facilities
4. maximising morale and
5. maximising cognitive potential in elders in residential care.
In accordance with these aims, the programs developed as a part of this prevention approach are intended to:

- Reduce the levels of depression in those older people with dementia and depression through participating in the groupwork programs, and therein improving their quality of life through maintaining or reducing the rate of cognitive decline, and
- Facilitate spiritual expression and growth among older people in residential care, thereby contributing to resident quality of life and maximising morale.

In order to accomplish these aims, the following **objectives** were identified:

1. introduce participants to specially designed programs designed to increase communication with people who have dementia;
2. explore how meaning and quality of life can be achieved by and for people who have dementia;
3. explore the concept of personhood and respect for persons with dementia;
4. develop effective strategies to improve quality of life for those with dementia;
5. help families and staff to find meaningful ways to interact with persons who are experiencing communication difficulties in dementia;
6. evaluate the effectiveness of the programs used;
7. modify the programs based on the evaluations;
8. publish the programs for use in residential aged care facilities; and
9. publicise the programs widely through conferences, workshops, training, websites and email distribution.

2. **Background and Literature Review:**

2.1. **Dementia in Australia**

According to the Australian Bureau of Statistics (2009), the proportion of the population aged 65 or older has increased from 12.7% in 2003 to 13.2% in 2008. The proportion is predicted to be at 14.0% in 2011 and rise to 17.2% by 2021 (Australian Bureau of Statistics 2009). From 1999 to 2008, the number of deaths due to dementia and Alzheimer’s disease has increased by 138% (Australian Bureau of Statistics 2010). Mental health disorders, in which dementia is included, have been identified as a National Health Priority Area. In 2008, “dementia accounted for 89% of deaths due to Mental Health Disorders” (Australian Bureau of Statistics 2010, p.9). In 2008, the third leading cause of death was dementia and Alzheimer’s Disease (Australian Bureau of Statistics 2010). According to one source, from 2000 to 2050 the number of Australians with dementia is predicted to increase by 327% (Alzheimer’s Australia 2008); Jorm et al (2005) give a slightly more conservative estimate of 241%.

2.2. **Depression and dementia**

Kasahara et al (2006) suggest there is a case for prevention of depression and intervention during pseudo-dementia coinciding with depression, and show that
depression is a risk factor in the onset of dementia. A 3-year study divided 114 patients with mild cognitive dysfunction into two groups based on “whether or not they also showed depressive symptoms” (Kasahara et al 2006, p.129). The study found that “dementia developed in 33% of the patients with no depressive symptoms, but in 85% of the patients with depressive symptoms” (p.129). This corroborates the finding of a 5-year follow-up study of life events and survival in dementia by Butler et al (2004), “the only psychiatric or social factor associated with poor survival in dementia was depression” (p.702). It appears that intervention against depression may provide one of the answers to improving well-being for Australian elders, particularly those in residential care.

In a study of older Australians, Pirkis et al (2009) found that approximately 8% of older Australians had clinically significant depression (which was defined as a score of 10 or higher on the PHQ-9, moderate depression or higher). In their study, however, only a small number of respondents were in institutional settings (206 respondents out of a total 22,251) (Pirkis et al 2009). In contrast, Fleming’s (2001) study into depression in residential care in Australia suggested that 40-60% of residents are experiencing depression. In a more recent study of residents in aged care facilities, Snowdon and Fleming (2008) found 40% of residents in high-care and 25% of residents in low-care were rated as depressed on the Cornell Scale for Depression in Dementia (CSDD). It should be noted that the CSDD has been validated for use in subjects with and without dementia, and the study included residents with dementia as well as those who did not have dementia (Snowdon and Fleming 2008). It is possible that those people who have dementia and are depressed may be more likely to require residential aged care and to require this earlier.

Gruber-Baldini et al (2005) have argued that “depression is under-detected and under-treated in nursing homes, especially among residents with dementia. … Depressive symptoms were more than twice as common … for patients with dementia” (p.50).

Identifying methods and approaches that impact depression and onset of dementia could have significant effects on Australia’s health system and ageing population. Jorm et al’s (2005) Australian study suggests that “delaying the onset [of dementia] by 5 years would decrease prevalence in 2050 by 44%” (p.959) and that “even a 6-month delay would reduce prevalence by 6%” (p 959). Jorm et al (2005) believe that “even modest prevention efforts could lessen the impact” (p.959). Considering the cost of this disease burden is one thing, but translating these costs to real life for those with dementia (and their carers) projects a frightening image for Australian elders.

### 2.3. Spirituality, depression and dementia

Spirituality may be defined in many ways. One definition of spirituality is:

That which lies at the core of each person’s being, an essential dimension which brings meaning to life. Constituted not only by religious practices, but understood more broadly, as relationship with God, however God or ultimate meaning is perceived by the person, and in relationship with other people (MacKinlay 2001, p.52).

One way to understand spirituality is to consider how this concept may be
worked out in every day existence by humans. We can consider that spirituality is mediated through: relationship, the environment, the arts and religion (MacKinlay 2006).

**Relationship:**
Humans long for relationship and deep connections with others. Life meaning for most people is found through relationship. For many this comes through family, life partners, children, and in some cases, deep friendships. In many faiths, life meaning is centred on God. For people of some other faiths and people of no religious background, life meaning through relationship with other humans becomes the first priority.

Relationship can be seen to have both a spiritual and a psychological focus. The spiritual focus goes to the depths of what it means to be human, to the connections that bring life and hope, even in adversity. It is possible to connect deeply and therefore to connect at the spiritual level with people who have dementia (Hughes, Louw and Sabat 2006; MacKinlay and Trevitt 2006.)

**Environment:**
There is wonder in our world, in our environment, in the whole of the created order. Who has not responded to the beauty of a sunrise, or sunset? Or perhaps responded to the beauty of a flower, or the sense of walking in a forest, or being by the ocean, or perhaps, being or working in a garden? There is a sense of awe about these connections, something that takes us out of the immediate and transports us to another plane. The natural environment provides connecting points between individuals and communities of different faiths and cultures. Environment relates to both the natural and human made environments, for example, through the wonder of the gothic cathedral, or temples, shrines and mosques.

It has even been found (Ulrich 2000) that people in intensive care need less pain relief where there is some connection with nature, for instance, being able to see out of windows. So, it is possible that the built environment can also work to make it difficult for people to connect with their natural environments.

**The arts:**
Poetry, art, music, drama and dance. All these modes of expressions and appreciation help to transport people to another level of being. Sometimes, it is the person with dementia who responds deeply to one of these modes – in a sense of human ‘being.’ The arts are a way of connecting with symbol and ritual and meaning. We often express the deepest things of life through symbol. Some things are too deep to be just spoken about, but they may be sung, or painted, or danced, or spoken in poetry. Again, that human sense of awe can be better expressed through the arts. In our deepest times of need, in tragedy, in joy, in love, symbols can connect us with the spiritual and with our God. The arts take humans across faith and cultural barriers to a place where we can connect as humans, in a broader sense of being.

**Religion:**
Religion is a way of connecting with the spiritual. It cannot be separated from the spiritual dimension, or it becomes a nothingness. In fact, in a well functioning religion, it takes in all of the ways of mediating the spiritual; relationship with God and others, responding to the environment, through creation (remembering who we are as part of the whole creation), and of the arts through ritual, liturgy, music, poetry, drama and art. Religion provides the means of worship, of community and a
structure for the working out of human spirituality. Prayer and meditation connect with Ultimate meaning. Good worship should bring a sense of awe, rather than entertainment. Worship is not simply for human enjoyment but is about connecting with the Ultimate, with God (MacKinlay 2006).

Fleming (2002) argues that “those elderly people in residential care with a healthy spiritual life are less likely to be depressed than those who have an empty life or occupy themselves with activities” (p.113). Lack of life meaning, which lies at the core of the spiritual dimension, is a critical factor in depression, and elderly people with dementia are more likely to lack life meaning. However, diversional activities are given more emphasis than spiritual care. If residential aged care facilities would shift their focus from diversion to engagement, spirituality and spiritual practices could be supported, and ultimate meaning could be addressed. By engaging with the person and recognising his/her individuality, his/her spiritual well-being may be fostered and encouraged (Ryan, Schindel Martin and Beaman 2005). Strategies identified by Ryan, Schindel Martin and Beaman (2005) to affirm personhood and encourage spirituality include communication, sharing life stories (reminiscence), and assisting with participation in religious life. These strategies acknowledge personhood and assist in creating relationships between carers and the individuals with dementia.

Searching for meaning, finding hope, finding intimacy (with God and/or others), and transcending loss and disability are “spiritual tasks of ageing” (MacKinlay 2002, p.139). The importance of relationship (intimacy, or connectedness) for people with dementia is emphasised by Hughes, Louw and Sabat (2006): “people with dementia have to be understood in terms of relationships, not because this is all that is left to them, but because this is characteristic of all our lives” (p.35). It is through relationship and the process of connecting with others, that is, moving beyond the questions of ‘does she recognise me?’, moving through transcending the losses and disabilities of failing cognitive function to connect with the person who has dementia, rather than the disease of dementia (Kitwood 1997). When an individual is depressed or has dementia, it may be difficult for him/her to find meaning.

2.4. *What does it mean to be human and to have dementia?*

The move from ‘doing’ to ‘being’ in ageing (MacKinlay 2001, 2006), sometimes termed ‘gerotranscendence’ (Tornstam 1999/2000, 2005), is an important part of the process of ageing. As the physical body declines in strength and mobility, the person is thrown back to a realisation that their identity can no longer be based on their abilities to achieve physical outcomes, but a new struggle begins to redefine the person as a human being, or a human becoming. In a society that affirms doing over being, this is a difficult phase for many older people. This process of loss and increasing disability that so often accompanies ageing may itself be a trigger for loss of meaning and depression. If meaning can no longer be found in doing, then some would say, there is no meaning in life. However, according to Jones (2001), real meaning “resides neither in doing nor in having, but in the integrity of life drunk deeply, intrinsically, thankfully” (p.106).
Finding meaning in dementia becomes an important process for the well-being of these people; their very vulnerability, through the loss of cognitive functioning, render them more likely to be stereotyped and de-valued as persons of worth in the eyes of people in the wider society, with the commonly held assumption that there is no meaning in dementia. On the contrary, life still has meaning, and the questions are to be asked, where does that meaning lie? Finding meaning in the face of ageing, of loss, of disability, of dementia, in fact, in any circumstances is critical to human well-being and flourishing (Frankl 1984). Lesser (2006, p.59) states that even in severe dementia, self awareness may be damaged but identity is not destroyed. Further, Murphy (2006, pp.137-183) maintains that memory does not truly capture all of what is required to secure personal identity. What is missing from the person in dementia? It could be argued that memory, maybe anticipation, rationality, intellectual, and political capacities may be missing to various degrees. But what remains is important; self-awareness, self-transcendence, creativity, moral capacity and perhaps social, aesthetic and religious capacities. These latter capacities are all associated with emotional and spiritual aspects of being human.

So how are we to understand the person with dementia? Tom Kitwood’s work has been fundamental to changing paradigms of the understanding of personhood. His much quoted definition of what it means to be a person is pivotal to the newer understandings of the person with dementia: “a standing or status bestowed upon one human being by others in the context of relationship and social being. It implies recognition, respect and trust” (Kitwood 1997, p. 8). This places the person in a position of ‘relational encounter’ with others (Swinton 2008), with the onus on others to reach out to the person with dementia. This is contrary to the biological views of the person that would argue that the ‘person’ no longer exists in dementia. It is with this view of the ‘person’ that Kitwood has ascribed to, that we set out to examine how personhood might be affirmed and supported in the experience of dementia.

It is on the basis of these understandings of the spiritual and emotional capacities of older people and, especially, people with dementia and depression, that this project was designed to facilitate connections with these people in support of their well-being. The programs were especially planned to use art, music, pastoral care and prayer and meditation as ways into the spiritual, and therefore as ways of connecting with people whose cognitive function was compromised.

2.5. Art therapy

Basting has written of “People who have edited themselves into silence for fear of saying the wrong thing, or shut themselves down to avoid contact they cannot understand” wondering if they might be able to “use the arts to reconnect with themselves and the people who care for them.” (Basting 2006, p.16) It is well recognised that people with dementia can participate in a range of creative activities (Smith 2010) rather than being passive recipients of entertainment. Engagement with art was trialled in a project of using National Gallery of Australia (NGA)
personnel specially trained to work with people with dementia in discussing artwork at the gallery. The participants actively engaged in this six week activity (MacPherson et al 2009). They found good interaction with participants during the sessions, but no lasting benefit from the program, and it is noted that while the study was conducted over only six weeks, the program is continuing with new participants and may be extended to other galleries. Often programs are conducted short term, and it seems that often people with dementia need longer term support. A recent pilot study has confirmed literature findings of benefits of art therapy for people with dementias including Alzheimer’s disease (Rusted, Sheppard & Waller 2006). In comparison with a recreational activity group, participants in the art therapy group showed a continual upward trajectory in responsiveness, which included mental acuity and sociability. In contrast, the recreational activity group showed an initial improvement over the first 10-20 weeks (of a 40 week program) which was followed by a steep decline to a level below baseline results. (Rusted, Sheppard & Waller 2006).

The expression of creativity “reinforces essential connections between brain cells, including those responsible for memory”, encourages emotional resilience, and promotes positive outlook and well-being (Hannemann, 2006, p.61). Creative activities, like those engaged in art therapy, may also decrease experiences of isolation and depression (Hannemann 2006).

2.6. Music therapy

The role of music in a person’s life is not just one of hobby or enjoyment, but the connection to music may occur on a deeper level. In interviews conducted with 38 Australians aged between 60 and 98 years of age, Hays (2005) found individuals identified a connection between music and self-identity, stimulation, and well-being. Music therapy has been used with dying patients as a form of musical life review, a means to explore emotions, and in alleviating pain and anxiety (Hogan 2003). Music can connect to one’s implicit memory, unconscious memory that is not language based (Johnson and Johnson 2007). With dementia, understanding and using words may be difficult, and triggering implicit memories; music, outside the realm of words, can connect an individual with those implicit memories and emotions (Johnson and Johnson 2007).

For those with dementia and depression, the benefits of music may have a profound impact. A Taiwanese study on a preferred music listening intervention (where music involved is selected based on participants’ preferences) for elderly residents in a long-term care facility with dementia and anxiety found that, after 6 weeks of 2 sessions a week, there was a statistically significant decrease in measured anxiety; in the control group, whilst there was a decrease in anxiety, it was not statistically significant (Sung, Chang and Lee 2010). A study of community based older adults in Hong Kong found a statistically significant decrease in levels of depression in the experimental group, who listened to 30 minute sessions of music over a period of 4 weeks (Chan, Chan, Mok and Tse 2009). In various studies, it has been shown to relieve depression and anxiety (Sorrell and Sorrell 2008). Music therapy has been used with dementia patients to decrease agitation and improve memory (Sorrell and
It has been found to promote “positive effects in mood and socialization of patients diagnosed with dementia” (Wall and Duffy 2010, p.112).

2.7. Pastoral care

The isolation and exclusion experienced by those with dementia may be exacerbated by such acts as talking about the person with dementia (rather than to the person), or placing value on cognitive functioning over self-worth and personhood (MacKinlay 2002). Pastoral care of an elderly individual, in particular one with depression or dementia, can involve exploring an individual’s sense of ultimate meaning and acknowledging the individual’s core of existence (MacKinlay 2002). Provision of pastoral care should take into account the spiritual development of the individual in addressing these tasks and tailored to assist that person in their individual needs, which may include depression and dementia (MacKinlay 2002).

Often pastoral care has been delivered on a one-on-one basis, seeing this as a very personal activity and process. Baker (2000) examined the effectiveness of individual pastoral care for people with depression in residential aged care. Using a chaplain for regular weekly sessions for six months, he found that in the treatment groups, compared with the control group, intentional pastoral care, nurturing the spiritual dimension, may reduce the prevalence and degree of depression. Although this work was with individuals, it was assumed that pastoral care could also be effective with small groups, as well as with individuals, and that this may be tested with people who have dementia. This could have added benefits of supporting more people at once, and helping the participants to form friendships with others within the aged care facility. Based on the work of spiritual reminiscence with small groups of people with dementia (MacKinlay and Trevitt 2006) where it was found that participants in the small groups responded well to the work of spiritual reminiscence, it seemed appropriate to use small groups in this study too. In that study, benefits were seen to include mutual support between group members, a willingness to share in a trusting environment, and the development of new friendships over the weeks of group involvement. Further, the participants wished to continue meeting after the completion of the study.

2.8. Prayer and meditation

Prayer in people’s lives has been researched from many different perspectives. Research has been carried out on the efficacy of intercessory prayer, with mixed results (Masters, Spielmans, and Goodson 2006; Roberts, Ahmed, Hall and Davison 2010) and criticism (Dossey 2008; Dossey and Hufford 2005; Masters 2005). Jantos and Kiat (2007) discuss four mechanisms by which prayer may provide health benefits: relaxation response, placebo, expression of positive emotions, and prayer as a ‘channel for supernatural intervention’. They stress the importance of further study into the positive health benefits of prayer and argue for recognition of prayer as a resource in “coping with pain and illness and improving health and general well-being” (Jantos and Kiat 2007, p.S53). In a small study (50 participants) of elderly Americans, Dunn and Horgas (2000) found that the majority (84%) used prayer as a coping mechanism. Whether or not prayer is effective, it is used by elderly individuals as a means of coping, and, as such, medical professionals should
acknowledge the role of prayer in their patients’ lives (Narayanasamy and Narayanasamy 2008). Marston (2001) argues that residents of nursing homes who are frail and physically limited in their movement and activity may use prayer as a meaningful activity through which they may find meaning in their lives. The role of prayer in the lives of people with dementia would, like those without dementia, be that of coping, benefits for health, and meaningful activity, but there is an added dimension of symbol and ritual in prayer. For those with dementia, as it progresses and individuals begin to experience difficulty communicating, “symbol and ritual can communicate what is of ultimate meaning and value to people with dementia” (Hide 2002, p.84). The acts undertaken during rituals can connect individuals with their memories and their experiences of the divine (Hide 2002). The practice of meditation takes many forms. Some, like Zen meditation, transcendental meditation and mindfulness meditation, have origins in Eastern religions and cultures (Ferguson, Wilemsen, and Castañeto 2010). Christian meditation, such as contemplative prayer and centering prayer, use similar techniques, grounded within Christian influences (Ferguson, Wilemsen, and Castañeto 2010). Studies have found that meditation practices may have both psychological and physiological benefits (Lindberg 2005; Seeman, Dubin, and Seeman 2003). In a study of 27 older adults (65 years or older) suffering from lower back pain, use of mindfulness meditation for 8 weeks resulted in participants reporting a reduction in pain, improvement in the ability to pay attention, and improvement in quality of sleep (Morone et al 2008). In a study of 73 residents of aged care facilities, divided into 4 groups (Transcendental Meditation, mindfulness training, relaxation, and control/no treatment), Alexander et al (1989) found that participants in the Transcendental Meditation and mindfulness groups felt they were better able to cope with inconvenience and felt less old. A small study (14 participants) conducted in a nursing home found that practising meditation techniques (including deep breathing methods, guided imagery, and sensory awareness) with residents with dementia found a statistically significant decrease in agitation amongst residents who participated in the meditation program as compared with the control group (Lantz, Buchalter, and McBee 1997). Benefits of meditation for individuals with dementia include decreased agitation, increased relaxation, and reduction in anxiety and depression (Lindberg 2005).

3. Research Plan:

3.1. Development of programs

At the outset of the study, professionals and academics in the fields of art therapy, music therapy, pastoral care, and prayer and meditation were approached and asked to develop programs in their fields that would engage with the spirituality of elders with dementia. Group sessions were designed to facilitate spiritual expression, explore meaning in the process of dementia, and optimise spiritual growth. In developing these programs, the authors needed to take into account the effects of dementia and depression, including anxiety states. For example, as the music programs were to be conducted at a site providing care to war veterans, considerations had to be made in regard to Post Traumatic Stress Disorder (PTSD) and possible negative reactions that could be triggered by some types of music.
The following programs were developed:

_Art_. This program was designed by an ANZATA\(^5\) Registered Art Therapist, Libby Byrne. The actual program was facilitated by recreational activities officers (RAOs)\(^6\) and pastoral carers. The program seeks to find ways of blending the experience of creativity and spirituality through the making of art. As Mary Daly states, “It is the creative potential itself in human beings that is the image of God” (Daly 2009, n.p.); this program seeks the image of God in its participants and allows them the opportunity to develop their sense of self, engage with their spirituality, and share their stories through the process of art making. The facilitator was to use the art as a vehicle to engage in conversation with the participants. Participants were encouraged to participate in various forms of art expression such as painting, drawing, collage, air-dry clay, etc., that were intended to stimulate spiritual expression, reflection, discussion and growth. Spirituality does not necessarily involve religion but encompasses the spiritual nature residing within all human beings. Prompts of artwork created by the program author were also used to stimulate conversation and reflection on the topics presented. Topics in the art program include safe spaces, favourite things and people, abundance, potential, life experiences, and dreaming images.

_Music_. Two separate programs were designed by a music therapist, Keryn Traversi. Both types of programs, listening and participation, may be conducted by trained RAOs or pastoral carers. In the listening program, stimulus music is presented to participants who then may be engaged in appropriate discussion and/or activity that facilitates spiritual expression, reflection and growth. Though it was intended as a listening program, participants were encouraged to sing along with the songs if they wished, and song lyrics were provided. The participation program engaged participants in various forms of musical expression and experiences towards facilitating spiritual expression, reflection and growth. In the participation program, participants have the opportunity to play instruments in accompaniment to the recorded musical pieces. Songs chosen for the programs include war time songs, songs from musicals, and other songs popular from the 1930s to 1950s.

_Pastoral Care_. This program was designed by an academic, widely experienced in the field of pastoral care with people who have dementia, Gabrielle Brian. It was designed to be conducted by facility chaplains or pastoral care staff. It addresses themes of gratitude and blessings, images of God, peace and forgiveness, hope and expectation, joy and happiness, and strength and faith. The content encompasses various ways of engaging with meaning in life, including use of materials from nature (meaning from the environment), use of songs (meaning from music), and pieces of artwork (meaning through art). The sessions encourage reflection not only on meaning in life, but on life experiences.

\(^5\) ANZATA is the Australian and New Zealand Art Therapist’s Association. Professional membership involves a rigorous application that requires a Master’s level of qualification. Registration with ANZATA is an important reflection of the level of qualification of the Art Therapist who has designed the program.

\(^6\) Aged care facilities have a variety of titles for this position, including recreational activities officer (RAO), lifestyle coordinator and diversional therapist (DT). Throughout this report, they will be referred to as RAOs.
Prayer and Meditation. This program was designed by the assistant director of the Campion Centre of Ignatian Spirituality, Joan Jennings. The premise of this program is allowing the facilitator and group members to journey together in prayer. It acknowledges a ‘wilderness’ experience of dementia, where sufferers may face isolation in their situation, and allows for the prayer to guide those with dementia as well as the facilitator. The themes in the program are adapted from themes identified in Joan Chittister’s (2003) book, Scarred by Struggle, Transformed by Hope in a dynamic of the transition from struggle to hope. Six stages of struggle were identified: fear, darkness, powerlessness, vulnerability, exhaustion, and scarring. Six stages of hope were identified: courage, faith, surrender, limitations, endurance, and transformation. These stages seem especially relevant for people with dementia. While people with dementia, as it progresses, may not be able to respond to cognitive group activities, they can engage with emotional and spiritual concepts (Hughes et al 2006, MacKinlay 2006, MacKinlay & Trevitt 2005). Each session uses music, prayer material, and visual prompts. Each session also has a time of sharing for participants to reflect on the themes and their life experiences.

3.2. Site coordination

As the research was carried out at multiple sites, coordination of the research was managed by site coordinators. For Churches of Christ Community Care, in Melbourne, Reverend Dr. Alan Niven coordinated the two sites. At RSL LifeCare Sydney, Frances Russell was the site coordinator. Frances Russell is the Research Assistant to the Professor of Ageing, Dr. Tracey McDonald, who was an associate chief investigator for this project. For the sites in and around Canberra, a member of the research team at the Centre for Ageing and Pastoral Studies (CAPS) acted as site coordinator. Each of the site coordinators assisted the chief investigator in preparing the sites for implementation of the programs. Once the programs began at the sites, the roles varied at the different sites. At the Churches of Christ Community Care facilities, the staff and research assistant took a large role in coordination of sessions and correspondence with the research team in Canberra, while Rev. Dr. Niven was instrumental in maintaining contact with and updating the Churches of Christ Community Care board, whereas Frances Russell, at RSL LifeCare, maintained her role of coordination between the facility (including staff and research assistants) and the research team in Canberra. The variance in the roles of the site coordinators was due to a number of factors, including numbers of staff involved in the project, number of groups at the facilities, and facility support available.

3.3. Research sites and a summary of their involvement

This research was carried out at seven sites in two states and the ACT with the support of the following organisations from the not for profit sector:

Churches of Christ Community Care, Melbourne. Permission was obtained from this provider in 2007. Work began with Churches of Christ Community Care in Melbourne, and the chief investigator visited the organisation and provided an orientation to the team. As a part of the orientation, practical issues such as rooms, space, materials and staffing were addressed, as well as recruitment of
participants and ethical considerations, which will be discussed later in further detail. Four research groups were conducted at two of their facilities; two art groups and two pastoral care groups. 

**Anglicare Aged Care of Canberra and Goulburn.** Permission was granted in 2008 to use their facilities. Three groups, two pastoral care and one prayer and meditation, were conducted at three of their facilities. The prayer and meditation group was late in commencing, due to serious illness of the research coordinator and the time needed to recruit a replacement. There is a shortage of suitable qualified people to work in this field. Staff liaisons were identified in each facility so that communications between the facility and research team were optimised. 

**Calvary Retirement Village, Canberra.** Approval for the study to be undertaken at this aged care facility was granted in 2008. One pastoral care group was conducted at their facility. 

**RSL LifeCare, Sydney.** Permission was obtained in 2009 for research groups to be conducted in their facilities. Eight groups of participants were recruited for music programs, four listening groups and four participation groups. 

Each of the sites provided in kind support such as: 

- Providing a quiet place for the group(s) to meet each week 
- Ensuring that a chaplain, pastoral carer, or Recreational Activity Officer (RAO) (as required for the particular program) was available for each weekly session and to assist in the set up of the group sessions, bringing the group members together and assisting with closure of the sessions each week. 
- Provision of necessary office space, computer, use of fax and phone at clinical sites, if needed. 

4. **Methodology:**

4.1. **Study Design**

This was a mixed methods study, based on the assumption that it would be necessary to use quantitative data to establish base line and changes in scores across the 18 week study of the trial and follow up (at three months post study) of the programs of art, music, pastoral care and prayer and meditation in small groups with people with dementia. The small group process was to examine ways of using these modalities as a means of touching into meaning and the spiritual dimension for people with dementia. To determine what was actually happening in the small groups, qualitative data was used so that analysis could be made of group interactions, facilitator style and participant responses. 

4.2. **Sample**

The study consisted of 99 participants (male=22; female=77). 11 participants in the art program (male=2; female=9); 20 in the music-listening program (male=8; female=12); 23 in the music-participation program (male=7; female=16); 32 in the pastoral care program (male=5; female=27); 6 in the prayer and meditation program (male=0; female=6); and 7 with no intervention (male=0; female=7). Whilst the
study began with 99 participants, 17 withdrew during the course of the program, 6 deceased while the program was running or before the three month follow-up data was collected, and 76 completed the study. The average age was 86.24\(^7\), (84.45 for males, SD 6.7, and 86.79 for females, SD 5.2). 13.1% of participants (n=13) had completed primary school or less. 31.3% of participants (n=31) reported partial secondary education (up to Intermediate) as their highest level of education; 22.2% (n=22) had completed secondary education (up to Leaving); 16.2% (n=16) had completed training in a trade; 12.1% (n=12) had completed an undergraduate diploma or higher; and 5.1% (n=5) did not report their highest level of education. 83.8% of participants were Australian born. 25.3% (n=25) of participants identified themselves as Anglican/Church of England; 18.2% (n=18) of participants identified themselves as Catholic; 4% (n=4) as Methodist\(^8\); 13.1% (n=13) as Presbyterian; 4% (n=4) identified themselves as part of the Uniting Church of Australia; 1% (n=1) as Seventh Day Adventist; 2% (n=2) as Baptist; 1% (n=1) as Jewish; 5.1% (n=5) were classed as other as they identified a personal theology that drew on multiple denominations; 8.1% (n=8) identified themselves as having no religious affiliation; and religious affiliation was unknown for 18.2% (n=18) of participants.

4.3. Ethics

Ethics approval was granted by the CSU Ethics in Human Research Committee (Protocol number 2008/022). In addition, each aged care organisation involved approved the project through their ethics committees and/or boards. A full ethics application was required for research at Calvary Retirement Village; approval was granted by the Human Research & Ethics Committee of Calvary Health Care ACT. Anglicare Aged Care of Canberra gave permission through their Research, Evaluation and Development Unit. Permission was granted by the CEO of Churches of Christ Community Care. At RSL LifeCare, permission for research was granted by the CEO.

As the study worked with a vulnerable population, ethical considerations were made as to the recruitment of participants. Because these are vulnerable adults, the research staff did not recruit study participants; the aged care facility staff, who know the residents in their care, approached potential participants, ensuring that they were in no way pressured or coerced into becoming part of this study. Facility staff were trained by the researchers in ways of recruiting study participants that would in no way put any perceived pressure on these people to participate. In addition, as it could be uncertain in some cases whether participants were able to fully understand their giving of consent, their legal guardian, or specified relative also gave consent, if either the potential participant or the guardian did not consent, then the person was not included in the study. The facility staff gave out the forms and collected them. It was only when the research staff received the completed consent forms that they made contact with the participants.

\(^7\) Dates of birth were not obtained for 5 of the female participants, so average age is calculated based on the available data.

\(^8\) Some still identified as being Methodist even though this denomination has not existed in Australia since the institution of the Uniting Church of Australia in 1977.
At one of the sites, after having been briefed by the research team on the requirements for the consent forms, the staff only collected consent forms from legal guardians/nominated relatives, not the residents. The ethical guidelines for the research require that we treat all participants as people of dignity and worth; therefore, it was a requirement that all participants should sign the consent forms, and that we would make no assumptions as to who ‘knew what they were doing’ or not. The research team then asked the staff to go back and obtain signed consent forms from the residents before we would proceed. This raised the issue of ethical implications of consent and impact on person centred care. The ethical obligation that the research team had, which facility staff seemingly did not understand, was to the potential participants. The decision to participate rested with the residents. The determination of capability in giving consent was not to be assessed by the research staff or the facility staff, and consent was to also be obtained from legal guardians/nominated relatives.

4.4. Recruiting

Initially, the inclusion criteria for the study were as follows:

- Resident of the partnership aged care facility
- Consent from resident and his/her legal guardian or specified relative has been obtained
- Mini-mental state examination (MMSE) score of less than 24 (MacKinlay & Trevitt 2005)
- GDS\(^9\) score of \(\geq 5\) (Yesavage, Brink, Rose, Lum et al 1983)
- Completed spiritual assessment interview has provided a positive indication regarding the resident’s suitability to participate in group work
- Resident interest and agreement to participate
- The resident will have sufficient stamina to participate in the 50-minute group, and be most likely to attend every group
- The resident will be able to speak and understand English

These selection criteria eliminated a number of possible participants, reducing the possible pool of participants.

Taking into account the work of Shiroky, Schipper, Bergman, and Chertkow (2007), who demonstrated that individuals may have dementia and have a high MMSE score, residents with an MMSE score of higher than 24 were allowed into the study if they had a diagnosis of dementia. Numbers of participants were anticipated to be delimited based on residents’ levels of depression and concurrent cognitive decline or dementia. In practice, it was not possible to exclude all participants whose GDS scores were less than 5; and a number of those who consented to participate were subsequently found to have lower GDS scores, and the decision was made to include them.

For the study, the research team anticipated inclusion of 50-80 participants, divided into small groups. Thus the final number of participants (99) exceeded those planned.

\(^9\) It was decided to use the GDS scale rather than the Cornell Scale, as the GDS requires direct participant answers, rather than observation of the person. The validity of the GDS, short form that was used in this project is well substantiated.
In some cases, the pre-testing data were unable to be collected due to issues such as limited verbal ability, hearing and visual difficulties. A decision was made by the research team that such participants could still be included in the research program if facility staff felt they could benefit from the program. Obviously the lack of data from these participants means that they were not included in the statistical analysis for those measurements.

4.5. Program and facility staff

The programs required the involvement of facilitators, research assistants, and facility staff. Each site varied in regard to the background of the persons involved in the research, based not only on the type of program delivered but also staff availability and training at each site. Trainings were conducted at each site for members of staff who were to be involved with the research program. The trainings covered the aims and objectives of the research, testing information, the details of the specific programs to be carried out at that particular site, and the responsibilities of all those involved.

4.5.1. Research assistants

Research assistants were recruited specifically for this study by the research team and employed by Charles Sturt University. Research assistants were not existing members of staff at the facility where research was being conducted. As such, they did not previously know the participants, but they came to know the study participants with whom they worked over the eighteen week period of weekly sessions. Research assistants were trained to work effectively and consistently such that the data would be reliable across groups and settings. The majority of the research assistants had background in research; many also had prior experience working with older people. The role of the research assistant in the sessions was that of observer, not participant. The duties of the research assistant included observing and recording non-verbal interactions during the sessions, audio recording the sessions, and administering quantitative testing to participants at testing periods.

4.5.2. Facilitators

The facilitators for the different programs had varying backgrounds. For two of the pastoral care groups, the program author and site coordinator (who was a member of the research team at CAPS) acted as facilitator. In other cases, pastoral care staff at the respective sites facilitated sessions. The facilitator for the art program sessions was a chaplain for Churches of Christ Community Care, though she initially was not a chaplain at the facility where the art programs took place. For the music programs, the facilitators were RAOs within the facility, who were of varying backgrounds, some had no formal qualifications, and others had backgrounds in professional fields, like IT. The choice of facilitators at each site was made based on academic preparation, clinical experience of working with people with dementia, and availability. As this study was trialling programs for use in aged care facilities that may not have ready access to professionals like music therapists and art therapists, the facilitator needed to be representative of the type of staff that would be available at a typical aged care facility. However, the research team wanted to ensure that the
facilitators did have appropriate training and experience, when possible. By using staff that would likely be used for such programs at aged care facilities, like RAOs for the music group, the study encountered the types of obstacles that are common to aged care facilities, like conflicting duties and interruptions during sessions.

4.5.3. Facility staff

Initial interdisciplinary meeting

Three interdisciplinary meetings were held prior to commencement of the program in Melbourne. The first two were between members of the team in Melbourne (December 2008 and January 2009), and the third included the chief researcher and research coordinator from Canberra as well as the Melbourne team (March 2009).

Strategic Impact: emerging themes at that stage of the research were identified through the initial team meetings:

1. The value of collaboration between University, Theological College and Aged Care sector (not for profit denominational aged care) provided an excellent entry into the process that would engage in reflective practice in working with art and spiritual care.
2. The meeting presented an opportunity for all care providers to share and recognise their anticipated and particular contributions to the project.
3. There was a complementarity of skills that still respected differences that emerged through dialogue between spiritual care providers, chaplains, lifestyle coordinators, the art therapist and research assistant (psychologist).
4. The meeting between the on-the-ground team and the Canberra team, in consultation with the creator of the art program, not only ironed out a few procedural wrinkles, but it also helped us all to catch and renew the vision of the whole program.
5. The collaborative process provided great momentum around the themes of reflective practice, interdisciplinary care and dialogue, and a stronger sense of community.

Meetings were held at the other sites prior to commencing the projects at each site. At each meeting, research staff from the coordinating team and the principal researcher were present.
As mentioned previously, facility staff were trained and responsible for the recruitment of participants based on their familiarity with the residents. As well as facilitating some groups, it was expected that pastoral care staff would play an important part in this project by being available for referrals of people who could benefit from one-on-one support and pastoral care. It was assumed that there was a close link and effective communication between the RAO, the research assistant and the pastoral care team. It was important that any participant in the study who wished to speak with someone from pastoral care was referred as soon as possible. Nursing staff were made aware of the project and to report any concerns they might have about any of the residents involved in the project. Staff were made aware of the topics discussed within the groups, but not of the content, as this remains
confidential to the group. This was important as group members could raise issues with staff following sessions, and where staff were aware of the topic, they would be able to more effectively respond to the needs of the residents.

4.6. Process of research

Once consent was obtained from residents and their guardians/relatives, potential participants underwent assessment to determine their eligibility for the study. Program schedules were determined among facilities with respect to staff availability and existing facility activities. Programs were then scheduled and conducted. The groups for each program met weekly for a period of eighteen weeks. A three month post study testing was done, making the whole study a total of 30 weeks. Data were sent back to the research team at CAPS for analysis.

4.6.1. Data collection

Testing was conducted prior to the beginning of the program, at 9 weeks (mid-program), 18 weeks (end of program), and 3 months after the end of the program. Tests administered were the ACE-R Australian version (Versions A, B, and C, with A administered pre-program and at the 3-month follow-up), Philadelphia Geriatric Center (PGC) Morale Scale (Lawton 1975), and the Geriatric Depression Scale (GDS): Short Form. At one site, RSL LifeCare, due to limited staffing and time constraints, the full ACE-R test battery was not administered to all participants at mid-program testing; in those cases, only the MMSE (which is made up of select questions from the ACE-R) was conducted. Assessments for each group were conducted by their respective research assistant and then scoring was double-checked by a member of the research team at CAPS to maintain consistency. All scales used in this study have moderate to high reliability, and have been shown to have appropriate construct validity. In addition to these measures, on the first measurement occasion, participants completed a demographic questionnaire, and a Level 2 Assessment of Spiritual Needs of Older Adults (MacKinlay 2006) was conducted with each participant (with the exception of some who were highly agitated or displayed severe language problems that prevented them from participating in the interview, in the perception of the interviewer). The findings from the spiritual assessment were used to enable program staff to gain a better understanding of the participant and their spirituality and where they found meaning in life. The use of the Level 2 Assessment of Spiritual Needs of Older Adults (MacKinlay 2006) was intended to aid in identifying which programs would suit the participants. It was initially planned that each site would offer multiple program types, and participants could be assigned to a specific program based on where they found meaning in life. However, when the programs were being implemented, it was found to be not practical for more than one or two programs to run at each site, so it was no longer possible to assign participants to a specific program but only to the program/s that was/were running at that site.

Each session was audio recorded and transcribed. The research assistants observed the sessions and kept a journal of interactions and non-verbal behaviours during the sessions. In some cases, the facilitator kept a journal of his/her responses to the program and reflections of the group process.
4.6.2. **Data analysis**

The demographic data and results from the ACE-R, PGC Morale Scale and GDS tests have been analysed using PASW 17.0. All qualitative data (session transcripts, observation journals and facilitator journals) have been analysed with NVivo8. Qualitative analysis was conducted using grounded theory (Morse & Field 1995; Strauss 1987; Strauss, & Corbin 1990). A member of the research team coded each group week by week, coding themes as they emerged. Once coding was completed, the chief investigator examined the coding and worked further on the emerging themes.

4.7. **Timeline**

The general planned timeline for programs was as follows:

**Month 1**
- Receive approval from site for involvement in the research study
- Recruit participants
- Inform staff of program
- Collect consent forms from residents and their legal guardians/nominated relative

**Month 2**
- Commence data collection: pre-testing and participant interviews

**Month 3**
- Commence program-to run 18 weeks

**Month 5**
- Mid-program testing (after 9 weeks)

**Month 7**
- End of program testing (18 weeks)

**Month 10**
- 3 month follow-up testing

Thus, the participants were followed for a total of 30 weeks. At some sites where multiple groups were running, the programs were staggered depending on staffing availability. The timeline needed to be adjusted in some cases for various reasons, such as public holidays, research staff illness, outbreak of illness among residents in the facility, facility outings. For two of the groups, an art group and one of the pastoral care groups, the sessions only ran for 17 weeks. For one of the art groups, one week had to be cancelled due to an outbreak of illness at the facility. The pastoral care group combined two themes into one session as one week needed to be cancelled due to research staff unavailability and could not be rescheduled due to Christmas holidays and the transfer of the chaplain (who acted as the facilitator) to another city.

4.8. **Issues of methodology/limitations**

In the cases where participants were unable to be tested due to anxiety, verbal limitations, hearing and/or visual disabilities, and where they refused to complete a test, data are missing and thus unable to be included in the quantitative analysis. Such individuals were not excluded from the program based on the decision that the degree of illness, ability and wellbeing (as influenced by their dementia) should not
prevent them from participating in a program in the likelihood that they might benefit from it. In such cases, it would have been beneficial to also have an observer depression scale, such as the Cornell Scale for Depression in Dementia (Alexopoulos et al 1988), as one of the testing measures.

Due to illness of one of the research staff, necessitating retirement, only three sets of tests, rather than four, were conducted for one of the pastoral care groups, thus the 3-month follow-up results are unavailable for that group.

In regard to the testing instruments used, whilst the GDS has been validated in numerous studies (Watson and Pignone 2003), it has been criticised for its poor detection of depression in ‘old-old’ adults (75 and over) (Watson et al 2004); the vast majority (approx. 96%) of our study population fit in this category. With dementia patients, a limitation of the GDS is that responses are given by the person being assessed, in which the level of cognitive functioning must be taken into account (Fleming 2002). Debruyne et al (2009) found the 30-item GDS to be “a reliable screening tool for depressive symptoms in MCI [mild cognitive impairment] but not in AD [Alzheimer’s Disease] patients” (p.556). Isella, Villa and Appollonio (2001) found the GDS-15 to have 79% sensitivity amongst patients with mild to moderate dementia; it should be noted that in their study, the GDS-15 yielded no false-positives, only false-negatives.

The ACE-R has been validated (Mioshi et al 2006), but the original ‘lower limit of normal’ scoring was only given for individuals up to the age of 75. Larner (2007) reported on a completed clinical study of the ACE-R in a sample of 100 patients with a mean age of 60.9 and range 24-85, all with cognitive disorders of some type. His findings show that the ACE-R has excellent sensitivity, and that test specificity and positive predictive values may be improved by using lower cutoffs (recommends 75 as specificity is >0.9), age was found to have relatively little effects. Scoring tables for the ACE-R have been updated to include information up to age 79, but as there were limited controls aged 80 and above, that age group was not included (E. Mioshi, personal correspondence, 28 May 2010). The criticisms of age and dementia in the reliability and sensitivity of the GDS and ACE-R testing should be taken into account when interpreting the results.

5. Results:

5.1. Quantitative

The results of the quantitative analysis are presented in two sections: overall, which compares results across interventions, and pastoral care, which examines the differences within the pastoral care groups. As the pastoral care program was the only program to be run at multiple sites with different facilitators, the researchers felt it important to examine the data from the pastoral care program broken down by group. Given the small numbers in each group, only descriptive analysis is possible.

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10 Note the prayer and meditation group was not included in the quantitative data analysis due to only one group of four participants being conducted.
5.1.1. Overall

Overall, there were 99 participants that participated in the study; 17 withdrew during the course of the study, and 6 deceased, with 76 completing the study. In the control group, 7 started, 5 withdrew, and 2 completed. Of the 5 that withdrew, 2 refused to continue testing, and 3 were unavailable for further assessment. In the art program, all 11 participants that started the program also completed the program. However, testing was complicated in the art program, as the number of participants tested each time ranged from 5 to 8, and a number of them were determined to be unable to test for a variety of reasons, including anxiety and verbal disability. In the music-listening program, 20 participants began the program; 1 withdrew, and 19 completed the program. The 1 participant that withdrew refused to be tested. For music-participation, 23 participants began the program, 4 withdrew, and 3 died, with 16 participants completing the program. Of the 4 that withdrew from the music-participation program, 1 was transferred to another facility, and 3 refused to continue participation in the sessions and testing. In the pastoral care program, 32 participants were initially in the program, 5 withdrew, 3 deceased, and 24 completed the program. The 5 that withdrew from the pastoral care program stopped coming/refused to participate for a variety of reasons, which included not returning after falling ill, lack of interest in the program, and not being able to give the time commitment for the scheduled time of the sessions. Of those who completed the program, 4 were not tested at any point, and 1 was not tested at the last testing session. This occurred due to reasons such as anxiety, agitation, significant thought disorder and verbal disability during testing, as reported by the research assistant. In the prayer and meditation program, 6 participants began the program, 2 withdrew, and 4 completed.

5.1.1.1. Reliabilities

Reliability analysis found the following reliability scores for the measures as follows:

- ACE-R = .902 (excellent)
- GDS = .789 (good)
- PGC Morale Scale
  - Agitation = .747 (acceptable)
  - Attitude toward own ageing = .629 (low, usually .7 is seen as the cut-off for “acceptable”)
  - Lonely dissatisfaction = .737 (acceptable)

The reliability analysis indicates that with the exception of the PGC “attitude toward own ageing” subscale, that all of the measures were performing well in the current sample. It is noted that the “attitude toward own ageing” subscale will have more measurement error in the scores. An analysis of the items did not indicate that the reliability could be improved by dropping any items. The scale is used, but the greater probability of error is acknowledged in analyses and conclusions using this scale.
5.1.1.2. **ACE-R**

Table 1 shows ACE-R results by intervention across the 4 measurement sessions. For the two music programs and the control group, as mentioned previously, the full-ACE-R was not conducted at the second testing session, only MMSE. It is a pity that the whole measurement was not undertaken, to give the broader picture available from this well tested instrument. Given the standard deviation, there is not significant change (improvement) shown in these results. The cutoff point suggested by Larner (2007) is 75/100. All these scores are considerably below that. It is noted that those measured in the art group have a much lower entry point, and continued to decline on the ACE-R, than any of the other groups, but note the small numbers tested in the art group.

**Table 1. ACE-R: Results by Intervention**

<table>
<thead>
<tr>
<th>Intervention</th>
<th>ACE-R Session 1 Mean</th>
<th>ACE-R Session 2 Mean</th>
<th>ACE-R Session 3 Mean</th>
<th>ACE-R Session 4 Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Intervention</td>
<td>46.0000</td>
<td>44.5000</td>
<td>44.0000</td>
<td></td>
</tr>
<tr>
<td></td>
<td>N 7</td>
<td>2</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Std. Deviation 20.33880</td>
<td>28.99138</td>
<td>38.18377</td>
<td></td>
</tr>
<tr>
<td>Pastoral Care</td>
<td>42.8929</td>
<td>42.5417</td>
<td>43.8947</td>
<td>43.5000</td>
</tr>
<tr>
<td></td>
<td>N 28</td>
<td>24</td>
<td>19</td>
<td>16</td>
</tr>
<tr>
<td></td>
<td>Std. Deviation 19.19556</td>
<td>19.07874</td>
<td>20.09946</td>
<td>23.28376</td>
</tr>
<tr>
<td>Music Listening</td>
<td>42.6000</td>
<td>43.2000</td>
<td>42.6316</td>
<td></td>
</tr>
<tr>
<td></td>
<td>N 20</td>
<td>20</td>
<td>19</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Std. Deviation 19.45413</td>
<td>22.23937</td>
<td>24.87348</td>
<td></td>
</tr>
<tr>
<td>Music Participation</td>
<td>46.9130</td>
<td>49.0000</td>
<td>51.4375</td>
<td></td>
</tr>
<tr>
<td></td>
<td>N 23</td>
<td>19</td>
<td>16</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Std. Deviation 19.36002</td>
<td>19.19780</td>
<td>16.88774</td>
<td></td>
</tr>
<tr>
<td>Art</td>
<td>20.8750</td>
<td>17.7143</td>
<td>17.8000</td>
<td>12.8571</td>
</tr>
<tr>
<td></td>
<td>N 8</td>
<td>7</td>
<td>5</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Std. Deviation 17.29110</td>
<td>12.41926</td>
<td>12.07063</td>
<td>10.09007</td>
</tr>
<tr>
<td>Total</td>
<td>42.1047</td>
<td>36.9355</td>
<td>43.1846</td>
<td>41.7833</td>
</tr>
<tr>
<td></td>
<td>N 86</td>
<td>31</td>
<td>65</td>
<td>60</td>
</tr>
<tr>
<td></td>
<td>Std. Deviation 20.06638</td>
<td>20.52468</td>
<td>21.14082</td>
<td>23.66224</td>
</tr>
</tbody>
</table>

5.1.1.3. **Geriatric Depression Scale**

Table 2 shows the average total scores for GDS broken down by allocation to treatment condition (allocation was not random as, logistically, only one or two treatments could be run at any one site). With all programs except the art program,
the mean scores for depression decreased from measurement session 1 to measurement session 3. At the 3 month follow-up (measurement session 4), scores increased in all programs, but not to the initial values, with the exception of the art program.

Geriatric Depression Scale (GDS) scores show a gradual decline across the sessions of measurement of this study.

**Figure 1. GDS**

![Graph showing gradual decline in Geriatric Depression Scale scores](image)

Figure 1 shows the total score on the Geriatric Depression Scale across the four measurement occasions. There is a steady decrease in depression, as indicated by this scale, from initial values (Session 1) to Session 3. There is an increase in mean depression from Session 3 to Session 4, but not to initial values.

A within-group analysis on the pastoral care group only, comparing testing session 1 with testing session 3 on the GDS showed that this comparison is significant (p<.05), and shows that this group decreased significantly in their GDS scores between these time points. The comparison was not done for testing session 4 as group A was not tested at that point.

It should be noted that whilst the art program shows an increase from measurement session 1 to session 2, this is affected by the small sample size. The changes in mean scores in the ‘no intervention’ group should be viewed with caution, as there was a 71% drop-out rate from this group.
Table 2. GDS: Results by Intervention

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Depression Total Score Session 1</th>
<th>Depression Total Score Session 2</th>
<th>Depression Total Score Session 3</th>
<th>Depression Total Score Session 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Intervention</td>
<td>Mean: 3.6667</td>
<td>Mean: 6.0000</td>
<td>Mean: 3.0000</td>
<td>Mean: 10.0000</td>
</tr>
<tr>
<td></td>
<td>N: 6</td>
<td>N: 2</td>
<td>N: 2</td>
<td>N: 2</td>
</tr>
<tr>
<td></td>
<td>Std. Deviation: 3.38625</td>
<td>Std. Deviation: 2.82843</td>
<td>Std. Deviation: 0.00000</td>
<td>Std. Deviation: 0.00000</td>
</tr>
<tr>
<td>Pastoral Care</td>
<td>Mean: 4.9600</td>
<td>Mean: 5.3750</td>
<td>Mean: 4.2727</td>
<td>Mean: 4.2500</td>
</tr>
<tr>
<td></td>
<td>N: 25</td>
<td>N: 24</td>
<td>N: 22</td>
<td>N: 16</td>
</tr>
<tr>
<td></td>
<td>Std. Deviation: 3.88887</td>
<td>Std. Deviation: 3.97615</td>
<td>Std. Deviation: 3.14993</td>
<td>Std. Deviation: 3.43511</td>
</tr>
<tr>
<td>Music Listening</td>
<td>Mean: 4.7500</td>
<td>Mean: 4.2000</td>
<td>Mean: 3.4000</td>
<td>Mean: 4.1053</td>
</tr>
<tr>
<td></td>
<td>N: 20</td>
<td>N: 20</td>
<td>N: 20</td>
<td>N: 19</td>
</tr>
<tr>
<td></td>
<td>Std. Deviation: 3.00657</td>
<td>Std. Deviation: 3.45802</td>
<td>Std. Deviation: 2.70283</td>
<td>Std. Deviation: 3.05314</td>
</tr>
<tr>
<td>Music Participation</td>
<td>Mean: 4.8571</td>
<td>Mean: 4.7368</td>
<td>Mean: 4.3684</td>
<td>Mean: 4.8125</td>
</tr>
<tr>
<td></td>
<td>N: 21</td>
<td>N: 19</td>
<td>N: 19</td>
<td>N: 16</td>
</tr>
<tr>
<td></td>
<td>Std. Deviation: 3.32093</td>
<td>Std. Deviation: 2.97848</td>
<td>Std. Deviation: 3.14838</td>
<td>Std. Deviation: 3.22942</td>
</tr>
<tr>
<td>Art</td>
<td>Mean: 4.7500</td>
<td>Mean: 6.4000</td>
<td>Mean: 7.0000</td>
<td>Mean: 5.8333</td>
</tr>
<tr>
<td></td>
<td>N: 8</td>
<td>N: 5</td>
<td>N: 5</td>
<td>N: 6</td>
</tr>
<tr>
<td>Total</td>
<td>Mean: 4.7625</td>
<td>Mean: 4.9571</td>
<td>Mean: 4.2059</td>
<td>Mean: 4.7119</td>
</tr>
<tr>
<td></td>
<td>N: 80</td>
<td>N: 70</td>
<td>N: 68</td>
<td>N: 59</td>
</tr>
<tr>
<td></td>
<td>Std. Deviation: 3.47593</td>
<td>Std. Deviation: 3.62534</td>
<td>Std. Deviation: 3.18841</td>
<td>Std. Deviation: 3.72804</td>
</tr>
</tbody>
</table>

Of the 80 participants assessed in Session 1 (Table 3), 48.75% were classified as “depressed”, with 13.75% scoring within the moderate to severe range. It should be noted that some participants were said to be unable to complete the pre-entry tests due to cognitive status and other participants gave incomplete answers during the GDS (e.g. would not give a definite ‘yes’ or ‘no’ in response to a question); in such cases, those incomplete scores have not been included in the analysis for GDS scores in the measurement session in which this took place.

By the final session (Table 6), 37.5% of those in the Pastoral Care intervention were classified as mildly depressed or above (from an initial 52% in these categories), 42% for music listening (from an initial 40%), 50% for music participation (38.1% initially), and 33% for Art (50% initially). The depression scores for art went down from 60% at session 3 to the final measurement of 33%. However, the numbers for the art program were small, with 11 total in the program, and only five were scored at measurement session 3 and 6 at measurement session 4. So, little can be made of these findings for the art group. It should be noted that it is problematic comparing initial with final percentages over all programs as this does not take into consideration “drop-out” rates (described above), nor the systematic causes that may underlie these, for instance, participants who continued in the groups, but could no
longer be tested. These results of themselves provide important information for program evaluation.

Table 3. GDS: Severity of Depression-Session 1

<table>
<thead>
<tr>
<th>Intervention</th>
<th>No Intervention</th>
<th>Pastoral Care</th>
<th>Music Listening</th>
<th>Music Participation</th>
<th>Art</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression Session 1</td>
<td>None</td>
<td>3</td>
<td>12</td>
<td>11</td>
<td>11</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Mild</td>
<td>3</td>
<td>8</td>
<td>8</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Moderate</td>
<td>0</td>
<td>4</td>
<td>0</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Severe</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>6</td>
<td>25</td>
<td>20</td>
<td>21</td>
<td>8</td>
</tr>
</tbody>
</table>

Table 4. GDS: Severity of Depression-Session 2

<table>
<thead>
<tr>
<th>Intervention</th>
<th>No Intervention</th>
<th>Pastoral Care</th>
<th>Music Listening</th>
<th>Music Participation</th>
<th>Art</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression Session 2</td>
<td>None</td>
<td>1</td>
<td>11</td>
<td>12</td>
<td>10</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Mild</td>
<td>1</td>
<td>7</td>
<td>6</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Moderate</td>
<td>0</td>
<td>5</td>
<td>2</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Severe</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>2</td>
<td>24</td>
<td>20</td>
<td>19</td>
<td>5</td>
</tr>
</tbody>
</table>

Table 5. GDS: Severity of Depression-Session 3

<table>
<thead>
<tr>
<th>Intervention</th>
<th>No Intervention</th>
<th>Pastoral Care</th>
<th>Music Listening</th>
<th>Music Participation</th>
<th>Art</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression Session 3</td>
<td>None</td>
<td>2</td>
<td>10</td>
<td>14</td>
<td>11</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Mild</td>
<td>0</td>
<td>10</td>
<td>4</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Moderate</td>
<td>0</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Severe</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>2</td>
<td>22</td>
<td>20</td>
<td>19</td>
<td>5</td>
</tr>
</tbody>
</table>
Table 6. GDS: Severity of Depression-Session 4

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>59</td>
</tr>
<tr>
<td>Depression Session 4</td>
<td>31</td>
</tr>
<tr>
<td>None</td>
<td>2</td>
</tr>
<tr>
<td>Mild</td>
<td>16</td>
</tr>
<tr>
<td>Moderate</td>
<td>19</td>
</tr>
<tr>
<td>Severe</td>
<td>16</td>
</tr>
<tr>
<td>Total</td>
<td>59</td>
</tr>
</tbody>
</table>

5.1.1.4. PGC Morale Scale

For interpretation of scoring on the PGC Morale Scale, the scale measures positive morale, thus the higher means translate to show higher morale. Three modes of morale are measured, agitation, attitudes towards ageing and loneliness. The agitation measure measures the level of anxiety in participants, thus higher anxiety means lower morale and a lower score. There was decreasing morale in regard to agitation in the ‘no treatment’ group (with very small numbers) across the 4 measures, while the treatment conditions show morale to be fairly stable across the measurement sessions (Figure 2). Treatment groups improved across the attitudes to ageing, while the ‘no treatment’ group declined (Figure 3). There was little apparent difference in the loneliness scale in all conditions (Figure 4).
Figure 2. PGC Morale scale: Agitation

Figure 3. PGC Morale Scale: Attitude to own ageing
5.1.2. Pastoral Care

It is important in comparing the different groups in the pastoral care program to be aware of the levels of entry into the groups as well as data at the different testing points across the study. Of the five groups in the pastoral care program, Group A had much lower ACE-R scores at entry and higher GDS than any of the other groups. It must be noted that these marked differences need to be considered in relation to initial conditions, test administration and test scoring. The same staff administered tests for the most part within the two groups of group A and C. It is also important to be aware of the communication style and other factors that may affect the degree and quality of participation of the group members within the groups. Because of the differences between the groups and because we wanted to know what effective communication looked like, we examined differences of the different group facilitators to see if there were any differences of style and strategies that might influence the measured outcomes for the groups. In this analysis we have attempted to tease out variables that might explain the differences found in the quantitative data. The analysis of this examination is reported in the qualitative analysis section. It is noted that in some groups a number of the participants, mainly Groups D and E, were not tested (decision of RA that they were too cognitively compromised to be tested), but took part in the weekly sessions. Thus, by the final time of testing all pastoral care participants, 16 were tested out of the 24 who completed the program.

5.1.2.1. ACE-R

For cognitive function the following results were found:
Table 7. ACE-R Results for Pastoral Care Groups across Sessions

<table>
<thead>
<tr>
<th>Group</th>
<th>ACE-R Session 1 Overall Score</th>
<th>ACE-R Session 2 Overall Score</th>
<th>ACE-R Session 3 Overall Score</th>
<th>ACE-R Session 4 Overall Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>Mean</td>
<td>26.0000</td>
<td>28.4000</td>
<td>35.0000</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>5</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Std. Deviation</td>
<td>7.87401</td>
<td>8.01873</td>
<td>16.97056</td>
</tr>
<tr>
<td>B</td>
<td>Mean</td>
<td>45.8333</td>
<td>52.8333</td>
<td>50.2000</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>6</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Std. Deviation</td>
<td>10.83359</td>
<td>15.71517</td>
<td>18.49865</td>
</tr>
<tr>
<td>C</td>
<td>Mean</td>
<td>45.4000</td>
<td>40.1667</td>
<td>38.2000</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>10</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Std. Deviation</td>
<td>22.60875</td>
<td>23.91164</td>
<td>26.22403</td>
</tr>
<tr>
<td>D</td>
<td>Mean</td>
<td>51.4000</td>
<td>48.8000</td>
<td>49.2000</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>5</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Std. Deviation</td>
<td>22.34502</td>
<td>20.26573</td>
<td>20.52316</td>
</tr>
<tr>
<td>E</td>
<td>Mean</td>
<td>42.5000</td>
<td>38.5000</td>
<td>38.0000</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Total</td>
<td>Mean</td>
<td>42.8929</td>
<td>42.5417</td>
<td>43.8947</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>28</td>
<td>24</td>
<td>19</td>
</tr>
<tr>
<td></td>
<td>Std. Deviation</td>
<td>19.19556</td>
<td>19.07874</td>
<td>20.09946</td>
</tr>
</tbody>
</table>

Note: Group A was not tested at the three month post test.
Numbers in the individual groups are too small for testing for significance, and this can only be done for the whole of this program. However, there are interesting trends in the scores; Group A started with very much lower scores than any of the other groups, a mean of 26 while other groups all had means of 42-51. In all groups but Group B, ACE-R declined across the times of testing; however, the mean for Group B increased by the second testing and remained stable thereafter. Group E shows an average decline over the course of the program and an increase as the three month follow-up, almost to the entry testing level. Can any of this be attributed to the effects of the group sessions? It is interesting that examination of the transcripts and journals for each group show that participants in Group B were empowered to speak more freely than other groups, except perhaps for the Group A (which had a very different starting point, the lowest of all ACE-R scores). Thus it can be seen that
group participation is not dependent on the cognitive levels of the group members, if Group A is considered. The groups that declined in ACE-R scores had markedly less communication from the participants, although ACE-R starting scores had been comparable. An important aspect of this study was to examine the communication styles of facilitators.

5.1.2.2. Geriatric Depression Scale

Table 8. GDS Scores for Pastoral Care Groups across Sessions

<table>
<thead>
<tr>
<th>Group</th>
<th>Depression Total Score Session 1</th>
<th>Depression Total Score Session 2</th>
<th>Depression Total Score Session 3</th>
<th>Depression Total Score Session 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>Mean</td>
<td>9.0000</td>
<td>10.0000</td>
<td>5.2000</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>5</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Std. Deviation</td>
<td>2.73861</td>
<td>1.58114</td>
<td>2.58844</td>
</tr>
<tr>
<td>B</td>
<td>Mean</td>
<td>6.0000</td>
<td>4.5000</td>
<td>5.0000</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>3</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Std. Deviation</td>
<td>5.56776</td>
<td>3.27109</td>
<td>2.73861</td>
</tr>
<tr>
<td>C</td>
<td>Mean</td>
<td>4.1000</td>
<td>4.6667</td>
<td>3.8000</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>10</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Std. Deviation</td>
<td>3.44642</td>
<td>3.88158</td>
<td>3.96232</td>
</tr>
<tr>
<td>D</td>
<td>Mean</td>
<td>2.6000</td>
<td>3.4000</td>
<td>3.4000</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>5</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Std. Deviation</td>
<td>2.96648</td>
<td>4.56070</td>
<td>4.21900</td>
</tr>
<tr>
<td>E</td>
<td>Mean</td>
<td>3.5000</td>
<td>3.5000</td>
<td>3.5000</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Std. Deviation</td>
<td>2.12132</td>
<td>.70711</td>
<td>2.12132</td>
</tr>
<tr>
<td>Total</td>
<td>Mean</td>
<td>4.9600</td>
<td>5.3750</td>
<td>4.2727</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>25</td>
<td>24</td>
<td>22</td>
</tr>
<tr>
<td></td>
<td>Std. Deviation</td>
<td>3.88887</td>
<td>3.97615</td>
<td>3.14993</td>
</tr>
</tbody>
</table>

The numbers in Table 8 are small, so only descriptive analysis is possible. On average, all groups showed some increase from Session 1 to Session 2 (although this was not true for Group B). On average, there was a decrease across subsequent sessions, except for groups D & E, where the scores continued to increase. Group A
stands out as being markedly different from the other groups. However, on face value, this group was considerably higher in their depression scores than other groups in the initial session, but was closer to other groups by Session 3, with their depression levels falling. There were no Session 4 results for this group.

5.1.2.3. PGC Morale Scale

Changes across sessions for the three subscales of the Morale Scale are shown in the following Tables (9, 10, 11). As with the total morale scores, the subscales (agitation, attitude to own ageing, and lonely dissatisfaction) remained fairly consistent.

Table 9. PGC Morale Scale: Agitation for Pastoral Care Groups

<table>
<thead>
<tr>
<th>Group</th>
<th>PGC Agitation Session 1</th>
<th>PGC Agitation Session 2</th>
<th>PGC Agitation Session 3</th>
<th>PGC Agitation Session 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>B</td>
<td>Mean</td>
<td>4.0000</td>
<td>4.5000</td>
<td>4.6000</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>3</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Std. Deviation</td>
<td>1.73205</td>
<td>1.37840</td>
<td>1.14018</td>
</tr>
<tr>
<td>C</td>
<td>Mean</td>
<td>5.5000</td>
<td>5.5000</td>
<td>5.6000</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>10</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Std. Deviation</td>
<td>.70711</td>
<td>.83666</td>
<td>.89443</td>
</tr>
<tr>
<td>D</td>
<td>Mean</td>
<td>6.0000</td>
<td>5.4000</td>
<td>5.6000</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>5</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Std. Deviation</td>
<td>.00000</td>
<td>.89443</td>
<td>.89443</td>
</tr>
<tr>
<td>E</td>
<td>Mean</td>
<td>5.5000</td>
<td>6.0000</td>
<td>6.0000</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Std. Deviation</td>
<td>.70711</td>
<td>.00000</td>
<td>.00000</td>
</tr>
<tr>
<td>Total</td>
<td>Mean</td>
<td>5.4000</td>
<td>5.2105</td>
<td>5.3529</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>20</td>
<td>19</td>
<td>17</td>
</tr>
<tr>
<td></td>
<td>Std. Deviation</td>
<td>.99472</td>
<td>1.08418</td>
<td>.99632</td>
</tr>
</tbody>
</table>

Results for Group A were not available for these analyses.
Table 10. PGC Morale Scale: Attitude to Own Ageing for Pastoral Care Groups

<table>
<thead>
<tr>
<th>Group</th>
<th>PGC Attitude to own ageing</th>
<th>PGC Attitude to own ageing</th>
<th>PGC Attitude to own ageing</th>
<th>PGC Attitude to own ageing</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Session 1</td>
<td>Session 2</td>
<td>Session 3</td>
<td>Session 4</td>
</tr>
<tr>
<td>B</td>
<td>Mean</td>
<td>3.0000</td>
<td>3.6667</td>
<td>2.4000</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>2</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Std. Deviation</td>
<td>.00000</td>
<td>1.50555</td>
<td>.89443</td>
</tr>
<tr>
<td>C</td>
<td>Mean</td>
<td>2.6000</td>
<td>2.8333</td>
<td>3.0000</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>10</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Std. Deviation</td>
<td>1.71270</td>
<td>2.13698</td>
<td>1.87083</td>
</tr>
<tr>
<td>D</td>
<td>Mean</td>
<td>3.2000</td>
<td>3.8000</td>
<td>3.0000</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>5</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Std. Deviation</td>
<td>1.64317</td>
<td>1.30384</td>
<td>2.34521</td>
</tr>
<tr>
<td>E</td>
<td>Mean</td>
<td>3.5000</td>
<td>3.0000</td>
<td>4.0000</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Std. Deviation</td>
<td>2.12132</td>
<td>2.82843</td>
<td>1.41421</td>
</tr>
<tr>
<td>Total</td>
<td>Mean</td>
<td>2.8947</td>
<td>3.3684</td>
<td>2.9412</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>19</td>
<td>19</td>
<td>17</td>
</tr>
<tr>
<td></td>
<td>Std. Deviation</td>
<td>1.55973</td>
<td>1.70654</td>
<td>1.67595</td>
</tr>
</tbody>
</table>
Table 11. PGC Morale Scale: Lonely Dissatisfaction for Pastoral Care Groups

<table>
<thead>
<tr>
<th>Group</th>
<th>PGC Lonely Dissatisfaction 1</th>
<th>PGC Lonely Dissatisfaction 2</th>
<th>PGC Lonely Dissatisfaction 3</th>
<th>PGC Lonely Dissatisfaction 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>B</td>
<td>Mean</td>
<td>4.0000</td>
<td>4.0000</td>
<td>5.2000</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>5</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Std. Deviation</td>
<td>.70711</td>
<td>.63246</td>
<td>.83666</td>
</tr>
<tr>
<td>C</td>
<td>Mean</td>
<td>5.2000</td>
<td>3.8333</td>
<td>3.8000</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>10</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Std. Deviation</td>
<td>1.61933</td>
<td>1.94079</td>
<td>2.28035</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>5</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Std. Deviation</td>
<td>2.38747</td>
<td>2.34521</td>
<td>2.38747</td>
</tr>
<tr>
<td>E</td>
<td>Mean</td>
<td>6.0000</td>
<td>6.0000</td>
<td>6.0000</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Std. Deviation</td>
<td>.00000</td>
<td>.00000</td>
<td>.00000</td>
</tr>
<tr>
<td>Total</td>
<td>Mean</td>
<td>4.7727</td>
<td>4.1579</td>
<td>4.5882</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>22</td>
<td>19</td>
<td>17</td>
</tr>
<tr>
<td></td>
<td>Std. Deviation</td>
<td>1.65994</td>
<td>1.67542</td>
<td>1.87279</td>
</tr>
</tbody>
</table>

5.2. Qualitative

The qualitative results section has been broken down by program, for ease of reference. As these programs examine meaning and well-being for people with dementia using art, music, pastoral care, and prayer and meditation, there are some similarities between content of programs. The qualitative analysis of each program is reported separately, with commonalities being discussed at the end.

5.2.1. Art program

The aim of this project was to find other ways of connecting with the spiritual dimension, especially for people with dementia. This is based on the model MacKinlay (2006) explored of ways of mediating spirituality. Art was chosen in response to critique of the method of spiritual reminiscence that it focused too much on words and would not connect with many of these participants. However, this project appears to show that it may be more difficult to use art for connecting deeply than to use spiritual reminiscence unless facilitators have adequate training and a high level of self awareness.

Main roles of facilitators shown in the group sessions were:
To guide the art process (objective 1 for whole project)
To affirm the participants (objectives 3, 4)
This is compared with the project objectives which were to:

1. introduce participants to specially designed programs designed to increase communication with people who have dementia;
2. explore how meaning and quality of life can be achieved by and for people who have dementia;
3. explore the concept of personhood and respect for persons with dementia;
4. develop effective strategies to improve quality of life for those with dementia;
5. help families and staff to find meaningful ways to interact with persons who are experiencing communication difficulties in dementia;
6. evaluate the effectiveness of the programs used;
7. modify the programs based on the evaluations;
8. publish the programs for use in residential aged care facilities; and
9. publicise the programs widely through conferences, workshops, training, websites and email distribution.

It did seem difficult to go that extra distance to engage in the ‘prayer language’ envisioned by the art therapist in her design for these sessions.

The following remarks are prefaced by the acknowledgement that statistical findings from this project see the participants’ levels of depression diminishing over the period of the 18 week intervention (with a three month post test) over all four programs, however, in the small art group of 11 participants the levels of depression were shown as rising from a mean of 4.7 at pretest to 7 at test 3, and returning to 5.8 at the post test. It is important to note that there were only 11 in this group; only 8 were initially tested due to low cognitive function and only 6 could be tested post test.

When compared with previous findings in spiritual reminiscence with people with dementia (MacKinlay & Trevitt 2006), it is suggested that this program appeared to be conducted more within the focus of an activity, which is valid within its own right, rather than as a program that would use art as a way of connecting into the spiritual and life meaning with these people.

In this project, it seems that it was often difficult for the facilitators to use the art as a means of connecting deeply with the participants. Often the program theme was subsumed into the ‘doing’ of the art work. There were times when the remarks initiated by participants were lost, as the focus kept returning to the ‘doing’. As a result, participants were not seen in the transcripts to be able to initiate their own comments, and they often responded with very few words, following complex questions from facilitators, mostly requiring yes/no answers. It was also noted that some facilitator assistants were too ready to ‘do for’ the participants, rather than leave them to do their own work. These vulnerable people find it hard to react against these behaviours. Even so, participants like Peter, a man who was quite aggressive early in the program, over the duration of the weekly sessions became calm and, although he obviously liked to work independently, did allow staff to assist him at times.

At times, there was hardly any input from participants, for example, Lucille, in week 04 of the program. In the journal it notes the participant says she is confused, but

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12 Pseudonyms are used throughout this report.
this is taken out of context, as the participant does use that word, but it is about which mask belongs to her, not that she is saying she is confused.
For the art program, it is important to recognise that a variety of sources of data are needed to give a good idea of what is happening within the group. While transcripts of verbal communications within a group can capture a great deal, especially in a spiritual reminiscence group, because of the ‘doing’ aspect of this program of art, other means of data collection are heightened in importance. The research assistant (RA) observation journal sheds light on group interactions and comments from participants that are sometimes lost in the art groups as people are talking over each other at times. Two other means of data collection were used with the art groups. First a valuable exercise of post session reflection between the RA and group facilitator; this was audio recorded and transcribed. The remaining means of assessment was suggested by the RA, a psychologist, who set in place a set of faces emotion in a range of happy, sad, anxious, confident, feeling good, and confused, which could then be rated on a scale of one to five. The faces exercise did not seem to be helpful as it was conducted during the session, at the start and just before the session ended, participants were usually asked – do you feel happy, or sad, or confused etc. It could be that these faces were suggestive to participants as to how they should feel about the group, rather than as a measure of how they felt.

Responses from the facility staff
The differences in comparison between the analysis of the data collected and the perception of those involved in the actual programs raise a number of questions. Some valid points were made by the staff regarding analysis. They suggested videoing sessions to pick up information not provided by either audio recording or from research assistant non-verbal behaviours. In practice this would be expensive, and may limit the number of sessions available. The facility staff noted that some topics needed to be carried over a longer period of time, and it is important that facilitators of such groups would be responsive to participants’ needs. Comments on reminiscence by facilitators show that reminiscence can be understood differently and done at different levels, about events remembered, or about the meaning of those events. It may be easier to stay with facts than to go to non-concrete examples. Yet often people with dementia will respond more to emotions than to cognitive aspects of memories. Expectations of staff may guide the responses of participants. (see comments on speed of communication in this study at sections: 5.2.1.1 and 5.2.4.2. Communication style of facilitator - across all programs in relation to comments of participants ‘losing the moment’ below)

The following remarks were made by facilitators and chaplains involved in response to the completion of the art program and may be helpful in the conduct of further art programs.
• The response of participants was a joy to observe, but impossible to capture body language/response/facial expressions without a video\textsuperscript{13}. On entering the room and seeing other participants seated one participant exclaimed “look, it’s the family”.

• Another time constraint involved running the program within the strict schedule within an aged care facility. This required the “pack up” at times prematurely to get the participants to lunch. Another interruption involved the necessary medical checks i.e. blood tests from visiting pathologists and on one occasion the daughter of a participant arrived to visit but sat quietly while her relative continued in the program.

• The participants reflected on the paintings (although abstract) i.e. orange balls in painting, “look like peaches”. We noted that those residents with a high level of dementia tended to “lose the moment” if they were required to reflect too long.

• Reminiscence. All participants reminisced about their work. One such discussion followed after the painting of coloured stripes by the participant. The participant declared she had painted a door. When asked “what is behind the door” she explained in great detail, room by room, the family home in England where she grew up.

The facilitators gave anecdotal accounts of effectiveness of the sessions as follows:

• Expressing what words cannot. One participant, who spoke only occasionally, painstakingly drew a “battle ship” from memory. His time in the Navy from aged 14 was an important part of his life and brought him meaning.

• Participants were able to release emotions. Staff comment on improved mood of the participants after the art program was common.

• Alleviate emotional stress and anxiety. One participant stated he liked being in the group as he “wasn’t told what to do” and that it was a “quiet place”.

• Discover new meaning, which helps with boredom/emptiness, relief from fear.

• A sense of humour was shared by both participants and facilitators.

• Generated energy, participants were often playful and lively. As a result the Lifestyle Department increased Art content in their program due to the observed positive outcomes.

• Finding joy, creating, and communicating in a meaningful way all contribute to physical & spiritual health.

• Increased self-esteem, sense of well-being and pride usually shown by a smile or the intensity of the way the participants wanted to finish their art piece. Relationships were formed, interaction, laughing, sharing. Participants complimented each other on their work.

• Group support for both the participants and the facilitators working in this collegial way.

\textsuperscript{13} Note: non-verbal behaviours were to be recorded by the RA in the journal of each session, and these recordings were designed to capture the behaviours that staff were concerned about.
The main themes identified from the data were:
Communication style of facilitator; relationship/connectedness; identity; group atmosphere/environment; engagement in group activities, and meaning in life.

5.2.1.1. Communication style of facilitator

a) Communication style of facilitator
Often questions were closed questions, eliciting yes/no answers. There was a lot of conversation by the facilitator and with other personnel, for instance the assistants and the research assistant, but in comparison, little with the participants, except comments and questions directly asking about practical aspects of the art work, for instance colours and technique. When compared with previous programs conducted with people with dementia of similar levels of cognitive status (MacKinlay and Trevitt 2006), the participants in this program did not speak nearly as much (see section on spacing of communications in the pastoral care program report).
The following interaction demonstrates a variety of things going on at the same time within the group, with attempts being made by the facilitator to engage with participants, an assistant to the facilitator focusing on the activity, and the themes being lost in the process:

“Lucille: *14 mistake
Art Facilitator: No, there’s no such thing as a mistake, no, not with this. * creative. Does that make sense?
Lucille: It’s *.
Facilitator: What you sometimes think - yes. I know in life sometimes * we think we make mistakes but sometimes *.
Assistant Facilitator (AF) 4: Let’s find some shells here.
Facilitator: Have you had that happen?
Lucille: No.
Facilitator: Haven’t you?
AF 4: Yeah, I’m *.
Facilitator: * because we all make mistakes *.
AF 2: * on to that one.
AF 4: Look at this one, there are some nice shells.
AF 5: * don’t they? Or did live in them. See them down here?
Facilitator: Are you?
??: Yes.
Facilitator: Yeah. It’s hard, isn’t it?.
AF 5: So now we’ve used it like a shell as a decoration.
Facilitator: If it helps * talk together.
Lucille: I think * don’t know what I do *.
AF 4: Which shells would you like?
Facilitator: Sometimes people understand *frustrated can help because then they * can help you.

14 In the transcripts, when a word or phrase is unclear/inaudible, it has been marked with an asterisk (*).
The above interaction from the transcript shows the complexity of communications within a group session. It would have been helpful to have video recordings of these sessions, as it was challenging to sift out what was happening at times. However, it was not practical to use video within this long program due to resources available to the project. In the circumstances it was certainly important to use all available data sources for analysis, and by analysing all data sources, we believe that it has been possible to come to a reasonable evaluation of what was happening within the groups.

b) Use of themes
Themes were not followed through as much as was originally planned. It was difficult to see why the themes in the design were not followed as they were broad themes, easy for the people with dementia to respond to them. The program was intentionally designed with themes that would help to develop a ‘new prayer language’ with these people who have dementia, rather than simply to engage with a program of ‘art therapy’. In other words, the aim was to facilitate spiritual connections rather than to be an activity per se.

Very little in the way of spiritual themes were identified. Why is that so? Analysis of the transcripts shows that little in the way of deep conversation was present in the group sessions. Spiritual themes were not often raised or followed through by the facilitators, and questions were usually of a ‘yes’ ‘no’ nature. This is seen in the following example from art group 2, Week 12 Transcript. Note that in this example, the participant’s initial response is not followed through, and the depth of response is lost in what follows:

Olive: It's God.
Facilitator: It's what?
Olive: God.
Facilitator: God? That's very interesting. Walter. Does anyone else have any ideas about this?
AF5: What do you see, Walter?
Walter: A whirlpool.
AF5: A whirlpool?
Facilitator: Maybe a bit like the windy whirlpool that blew you over the other day.
Walter: Yes.
Facilitator: It does, yes. All of you, there's no right or wrong. It's just interesting that art is something that when we see it we have our own ideas and our own interpretation. Which is so important, isn't it, when we do art. Because it's something from within the artist that's put on paper. And that's what you're going to do today. And here's another one from our artist Libby, who has done lots of swirlly. And this has got words on it as well. So we can see that one as well. That's got lots of words. But again it's like swirling, isn't it?
Walter: Yes.”
One example that seemed to touch deeper was from the Life of the Soul theme, where the interchange was as follows:

“Facilitator: So I’m just looking at some of the words, now, if you remember this painting by Libby, she called it The Life of One Soul. That’s very deep, isn’t it? Very deep title, The Life of One Soul.
Constance: That’s true. That is true. Yeah, that is true.
Facilitator: So what do you think about when you think – what do you think of the title? What do you think about that, The Life of One Soul?
Constance: * It’s about another think.
Facilitator: It’s about another think, is it?
Ruth: We’ve got to have a bit of a mouth open there.
Facilitator: Yeah, it’s a big one, isn’t it? It’s quite a deep statement, isn’t it, this title. But she has some words that might help us on the side. She’s actually on the side of her painting has written a quote and it says, “God is in us everything”.
Ruth: Everything. Yes.
Facilitator: “But God is nowhere as much as God is in the soul”.
Ruth: Lovely.
Facilitator: And then it says, “There where time never enters, where no image shines, in the innermost and deepest aspects of the soul. God creates the whole cosmos, the whole universe.”
Ruth: Lovely.
Facilitator: It’s lovely.
Ruth: It is.”

The above interchange was using the painting for the session to connect with deep things, of the soul and God. Analysis of this examined the words used to elicit responses from the participants and the following points are made: The participants were asked to ‘think’ about the painting, perhaps they could have been invited to respond to the painting, ‘how did they feel as they looked at it?’ We suggest that the skills of the facilitator are important in assisting these people with cognitive difficulties to engage with the art. Engaging at the emotional level may be more fruitful, for both participants and facilitator. In this context, it is noted that often people with dementia paint in abstract form, and it is suggested they can also respond to ‘abstract’ paintings.

If the facilitators used the themes and suggested line of questions designed by the art therapist, this may have helped to connect with the spiritual. Remembering days at the beach and questions like, did they remember having a bucket and spade, may pass the time but certainly do not assist in going deeper! See the following excerpt from one of the art group sessions.

This is taken from the theme for week 3 in the art program, “my favourite things”, which was to be explored with the following prompt: “who we are and what is important to us. What are the things that we hang onto? How is it that these things hold meaning for us?” From previous research, we have evidence that these types of questions and reflections should have elicited spiritual conversation. The following was in the transcript:
“Facilitator: So when we think about our lives when you were little, you remember things you said like going to the beach. Did you have a bucket? Did all of you have a bucket and spade at the beach?
Constance: Oh yes.
Ruth: Yes we had a bucket and spade.
Facilitator: Did everyone have a bucket and spade? Constance, did you have, Lucille, did you have a bucket and spade when you went to the beach?
Lucille: Oh yes.
Facilitator: Peter, did you have a bucket and spade?
Peter: Yes.
Facilitator: Yes. And Martha, did you have a bucket and spade when you went to the beach? So all of you have that in common.
Ruth: Did you have a bucket and spade too darlin?
Constance: And gas in the car going down.
Facilitator: And gas in the car, well it needed to get you there didn’t it. Gas in the car going down. There you go. Wasn’t that fun? And were you excited about going to the beach? Was it something different for you all to do?
Constance: I think it was. We were always…
Facilitator: Yeah, because I’ve noticed a lot of you have chosen things like shells. And then Martha, yours is very, yours is different, so that reminds you maybe of your village as well. And I’m looking at what Peter is doing. He is being really creative.
Ruth: That’s nice
Facilitator: And with your patterning *. 
AF 5: * that’s lovely.
Facilitator: You’ve got all different unique patterns.
Ruth: It is nice, isn’t it?
Facilitator: It is amazing what you can do isn’t it? Isn’t it amazing what you can do with a fork?”

What happened to result in this superficial interaction? First, the questions were not asked as they had been presented by the art therapist. Second the conversation was kept on the surface, about practical memories from childhood, and the type of questions did not allow for the participants to go deeper. This meant that spiritual themes did not emerge.

c) Peter: challenging communications and behaviour
One particular participant, Peter, was followed through in the weekly sessions, in the early sessions he was reported to be aggressive and agitated, making sexually offensive remarks, and not wanting to attend the sessions. He later came at his own wish and became a regular participant.
The facilitator tries to find a way to connect with Peter, particularly by asking questions like the following: “What can we do that would make you feel happier?” We actually can’t ‘make’ someone ‘happy’; is it possible that the goal was to ‘make’ the participant happy? Perhaps it wasn’t even the piece of art that he was referring to in the following conversation:
“AF6: That’s nice
Peter: No.
Facilitator: What do we need to do to it?
Peter: Nothing.
Facilitator: We’ve got another minute or two just to finish up.
Peter: No.
Facilitator: You don’t want to do anything else. You think it’s complete now. You’re happy with it.
Peter: No, I’m not happy.
Facilitator: You’re not happy. What can we do that would make you feel happier? Can you think of anything? You know what I think sometimes you’re a bit of a perfectionist. What do you think about that idea?
Peter: No.
Facilitator: No, you don’t think sometimes … is it hard sometimes to look at something and think ‘Well that came from me,’ what do you think of it, the fact that you made that yourself?
Peter: Pathetic.
Facilitator: You think it’s pathetic.”

On another occasion, later in the weekly sessions, Peter was complimented for his work by the facilitator: “Yeah, because I’ve noticed a lot of you have chosen things like shells. And then Martha, yours is very, yours is different, so that reminds you maybe of your village as well. And I’m looking at what Peter is doing. He is being really creative.”

The following is an example of not connecting with the person:

“Facilitator: Don’t have to have a name for it. Did you enjoy doing it?
Peter: No.
Facilitator: You didn’t enjoy it?
Peter: No.
Facilitator: What was missing today? A paintbrush?
Peter: Yes.
Facilitator: That was what was missing today wasn’t it?
Peter: No, my thoughts. My thoughts were missing.
Facilitator: Your thoughts were missing?
Peter: Yes.
Facilitator: So you didn’t engage as much today?
Peter: No.
Facilitator: You were elsewhere where you?
Peter: That’s right.
Facilitator: Far away?
Peter: Yes.
Facilitator: Did it trigger any memories for you *?
Peter: Yes.
Facilitator: Good memories?
Peter: No.
Facilitator: So was there anything *? Peter: No. No.”

By week 17 of the group, an entry from the RA journal shows the distance that Peter had come, from being aggressive and using sexually offensive remarks at the first weeks of the sessions, to now: “Peter informs Facilitator that he has found her voice to be the nicest part of the session and that he considers her voice to be, ‘soothing.’”

d) Affirmation of work and person
Note that transcripts mostly focus on the tasks of the art work, not the participants and their needs. When the participants were the focus of conversation, it was a fairly generic response, for example:
One participant stated she was ‘not feeling well’ and the following exchange occurred:

“Facilitator: Nice cake. Wonderful. And Lucille? If I was to ask you what was the best thing about being here today, what do you think would say? Would you think of an answer?
Lucille: I’m not very well today.
Facilitator: You’re not well today.
Lucille: No, no. Not really.
Facilitator: So it was an effort for you to get here but you still came, didn’t you?
Lucille: Yes. I suppose so.
Facilitator: You did. And do you think, after being here, that you’re glad you came?
Lucille: Everything else, I’m glad I’m came, just not well.”

The facilitator responds to the person, but does not explore what the issue is. Participants were frequently asked if they enjoyed themselves, part of this was possibly due to the cards being filled in at each session where they were asked to identify their feelings according to a set of facial expressions on the cards. The facilitator repeatedly asked “did you enjoy it?”, so much so that participants may get the idea that they have to satisfy the facilitator by saying ‘yes’. If the facilitator is connecting with the participant, s/he would not need to ask this question. Evidence would be shown by the participants engaging more in the sessions and spontaneously saying that they enjoyed the group.
An example of missing out on a participant comment, in regard to her brother, is below with researcher comment in italics:

“Facilitator: Do you think that men have bigger ears than ladies?
Ruth: No, I don’t think so.
Facilitator: How will we use the men’s ears? You think they would be better to use.
Ruth: I’d love to do it with my brother.
Facilitator: With your brother, like grab him by the ear?
Ruth: Yeah.
Facilitator: Like your mum and dad did when he was young. Did they used to do that?
Ruth: No, they didn’t do it.
Facilitator: They didn’t do it.
Ruth: Kids did it.
Facilitator: Kids did it. Grab you by the ear. Anyone else been grabbed by the ear?
Ruth: Yeah. He was very gentle. He was a very gentle boy. (This would have been a good place to follow up: Who was gentle? What made the participant think of that, how did it connect with, for instance memories and / or meaning for that person?)
Facilitator: Oh look, they worked well. They worked well. Now everybody you’ve been hard at work. I want you to have a look at your work and see what you’ve got in front of you and have a look at everybody else’s as well and what they’ve been doing and what they’ve all accomplished there. You’ve accomplished a lot today. So what do you think about yours?
Peter: I think it is stupid.
Facilitator: Do you?
Peter: Yes.
Facilitator: In what way? What do you think would make it better?
Peter: I think maybe you know to do something specific.”

Rather than following up on the comments made by Ruth, the facilitator moved on with the session and shifted focus to another participant. The opportunity to take the conversation to a deeper level was not taken, and Ruth’s comments were not explored further.

e) Recalling and anticipation
Participants were observed to make comments regarding prior and future sessions, such as when Constance spoke to the RA at the end of the session and told him she would “say a prayer before bed and ask God to bring them (the art group) all back together soon.” Anticipating and recalling sessions does show that participants remember and look forward to sessions. But often, the reminding was done by the facilitator.

f) Sharing stories
There was a lot of reminiscence, but the nature of it is mostly confined to memories of events, not meaning; only in some instances did it get to the level of meaning. Perhaps, all the activity of the art work does not particularly assist in sharing deeply.

g) Facilitator being complimented
There were numbers of instances where the participants complimented the facilitator.

5.2.1.2. Relationship/connectedness
In previous research (Hughes, Louw and Sabat 2006; MacKinlay 2006), it has been shown that relationship remains important for people with dementia. The need for connection with others remains, as it does for all people. Connections can be verbal
or non-verbal, and in some cases, that need for relationship or connecting was made by the facilitator reaching out physically to the participants, as in this instance, from the data, Olive did not appear to be addressed at all during the session, although the journal indicated that the facilitator held her hand, so that touch was used to support her. While Constance, another participant states that the session has been great and laughs.

One participant, Ruth, enjoying the group, said: “It’s lovely. It’s just lovely. To have your father and mother sitting here, well, that’s in my brain. And they’re all talking about it, the girls and that.”

The conversation continued as follows:

“**Facilitator:** Yes. Good. Yes, that’s good, though. Yeah. So it’s bringing back some special memories for you, isn’t it, Ruth?
**Ruth:** Yes. Well, I think they’re lovely, lovely.
**Constance:** And they all join in, maybe.”

The participants in this interchange were connecting back to earlier experiences of life, and expressing the important of family, perhaps as they enjoyed this activity in the art work. There is a sense in which these two participants are talking about something that isn’t ‘real’ but they know that and they hold that in their conversation. It is a shifting of reality to include a broader parchment on which to engage.

Participants’ responses to the group work, related to another aspect of being, that includes communication – learning:

“**Facilitator:** Thank you, Peter. What was the best thing about being here today?
**Peter:** Learning.
**Facilitator:** Learning.
**Peter:** Learning.
**Facilitator:** Learning: that’s a good word. The best thing about being here today for Peter was learning. What a good word. What was the best thing about being here for you today?
**Constance:** Just watching everybody and listening. It was really lovely.”

It is often thought that learning does not happen with older people, and therefore would be most unlikely for people with dementia.

5.2.1.3. Identity

a) Identity

Identity of the participants was expressed in a variety of ways. One of which was the expression/representation of self in the art they were creating. In one week’s journal the RA recorded the following: Facilitator asks Constance what she sees when she looks at her work. Constance replies: “I see me.”

The facilitator often affirmed the participants and respected their dignity. The affirmation of identity was expressed in a variety of ways. Facilitator comments were noted of a participant having their hair done, or complimenting them on the clothes they were wearing.
b) Trust and feeling safe
Most of this theme was found in the comments of the facilitator, as she affirmed the nature of the group sessions as being a place and time where the participants could feel safe and building an atmosphere of trust. The participants agreed with the facilitator in these comments. On the other hand, a couple of participants, when asked, stated that they felt anxious and apprehensive about the program at first.

c) Choice/autonomy
Choice was offered in all areas of the art program, and this was a way of giving participants a sense of control over their environment. Choice operated in a range of situations, from Peter being told he did not have to come to the sessions, but was welcome if he wanted to come back. This was in response to Peter’s early aggression prior to the session. He later came to the session (and subsequent sessions), by his choice. Other areas of choice were in the art medium, types of materials and colours used.

d) Sharing life stories
This may be an important connection with meaning making for participants, however, as it was used in this program, it was more about the particular memory, and the fact that they remembered it rather than connecting with meaning in the memories. Most memories elicited during the sessions were about facts and events, as in the previous example of the bucket and spade at the beach.

5.2.1.4. Group atmosphere/environment
Overall the participants were mostly engaged in the group process; some were, at times, distracted. Frequent comments from the RA journals about participants were: alert, engaged, happy, laughing, and at another time, tiredness of a particular participant. Two participants commented on how nice it is to have the door closed and “retreat from the world,” and “the rest of [the facility].” Comments on room temperature were made on a number of occasions.

a) Stillness, quietness
At times the room is very busy with people talking over each other and many activities going on at the same time, at other times there is stillness and quietness, which is commented on and appreciated by a number of the participants.

b) Creating sacred and safe space
There were many examples of facilitators describing the group meeting place as a safe and sacred space. The participants were often asked if they felt that it was a safe place to be, and if they felt it to be a sacred space.

c) Non-participant presence
On a number of occasions, there are other people in the room that cause interruptions to the sessions; for instance, staff collecting blood samples, a physiotherapist, other unknown staff who come and go, sometimes speaking to facilitators and group
members. Sometimes other residents come in and are politely escorted out of the room. A daughter of one of the participants came and observed the group.

d) Lethargy and feeling unwell
Some participants became tired and one reported feeling very lethargic and lacking in the energy needed to participate. One of the requirements for participation was having sufficient energy for the group sessions. For the most part, participants did have sufficient energy to complete the sessions. Energy loss is part of the ageing process, associated with frailty (MacKinlay 2006); it can also be associated with increasing levels of cognitive impairment, or with other illness or chronic conditions that many of the participants lived with. It is perhaps surprising that the attendance levels were so consistently high across the group sessions.

e) Physical limitations and mobility problems
This was particularly noticeable with two participants, who could only ‘do things’ with considerable physical support, due to severe arthritis and other mobility problems. Their needs were supported in this program, but in other settings, other than research based, this may cause overstretching of staff and these people may not be offered these kinds of programs.

f) Facility – program logistics
There is a lot of organization that needs to be done for effective group functioning. The following description from the RA journal, regarding the set up for the first week of the first group, illustrates the difficulties of this process and the need to plan ahead.

“Just prior to the scheduled start of the session, the facilitator…struggled to have materials ready and the room appropriately set up. This was not the fault of [the facilitator]. [The facilitator] was informed that the room and materials would have ready [sic] by 11 am and set up by the two Facilitator Assistants. Furthermore, [the facilitator] was informed that all participants would have been gathered in the room, waiting for the session to begin at 11 am. The difficulty extended to not having enough tables to accommodate the number of participants and the scheduled activity. [The facilitator] was informed that all details regarding the set up of the room would have been prepared prior commencement of the first session. Furthermore, there was only one Facilitator’s Assistant…present. [The facilitator] was informed on the morning of the first session that the second [facilitator’s assistant] was on annual leave. Gradually, participants were escorted to the room designated to the project, some by [facility] personnel and others by [the facilitator]. An additional member of the…Lifestyle Team (the team designated to act as [assistant facilitators]) appeared and remained until the session commenced. Due to the unforeseen difficulties, the session did not commence 11:17 am.”

Some participants who were more physically and/or verbally challenged required more support and assistance in the group sessions, which, in turn, meant requiring extra support staff. In designing groups for future use, it will be important to keep
the group sizes to a manageable level. Perhaps three to four people who have considerable communication and/or physical difficulties would be a more desirable maximum number for a group.

Reading, seeing and hearing problems also need to be considered and accounted for within the group settings. Staff need to have a high level of awareness of issues such as a participant not having his/her glasses or if s/he seems to have trouble hearing.

g) **Conflicting times**
It was difficult to find suitable times in the facility for the regular session times. In many aged care facilities more emphasis seems to be given to bus trips and other outings for residents. The real benefits of such trips are largely unknown, and it must be asked whether indeed these are meaningful activities for the residents, or whether they are merely a way of being seen to ‘do something’ for these people.

Interruptions and missing sessions included such things as going on trips, physiotherapist appointments, and doctors arriving during the group times. It seems that in many cases the wishes of the participants are not taken into account. In each case in this study, where it is documented that a person either could not attend, or was taken out of the session, it was taken as a normal happening, the resident was not once asked if it was alright to leave the session. This of course, as well as disregarding the dignity of the resident, clearly demonstrates that this program is regarded as being of little value, despite comments to the contrary.

5.2.1.5.  **Engagement in group activities**

a) **Connecting in the group**
In the interchange below, the facilitator asked participants about their feelings of connection within the group. It is hard to see how much connection is going on in this communication, as the questions are not asked to elicit more than yes/no answers. How do the participants really respond to the connections that they experience in this small group? It is hard to tell.

“**Facilitator:** I was really meaning to with that one - is that each of us has placed our own canvases on here but we’re joining them and connecting it, just like each one of us is connected in each way. When we come in to this room, is that something that you had a sense of, of being connected? What do you think?

**Peter:** Yes.

**Facilitator:** Yes, Peter. Do you, Ruth? Do you feel like you’re connected, Ruth, to this group that when you come in here that it’s a place where you feel connected to the other people here with the things we do?

**Ruth:** This is true.

**Facilitator:** It’s true? And Constance? What about Constance? You’re doing well there, Constance. Do you also have a sense of connection with this group?

**Constance:** No, not quite.

**Facilitator:** Not quite? We’re working on it, aren’t we?

**Constance:** Yes.

**Facilitator:** And Lucille, when you come in here, can you see how this is all coming together, sort of being connected together?
AF 4: How’s that look?
Facilitator: Do you feel a sense of connection when you come in here?"

Lucille’s response is not clearly audible on the recording, but the RA reported that her response was that she was concerned about making a mistake.

b) Non-participation
Participants did not respond when some themes were introduced; it was not obvious why this occurred, but perhaps a clue to non-responses could be seen in the way questions were asked, for instance, what does that remind you of – for a painting, it may not elicit a response, when in fact it was an abstract painting. It may have been more fruitful to ask for their feelings when they looked at the painting, or their responses to it.

c) Self-direction, independence
There were differences in the participants’ level of independence, some needing a great deal of guidance and support, while others, one group in particular, were working more independently.

d) Creativity
The following two excerpts are taken from the RA journal of one of the art groups in week 17 and show participants confident in their creative work.

“AF 3 comments to Peter on how he has a “good understanding of design.”
Peter agrees with AF 3’s comment by nodding his head.
Constance begins using her fingers to paint. Constance comments on how her painting is “very nice and interesting.”
Martha comments to Facilitator on how she has enjoyed painting and that “it is very nice.”

“Constance informs Facilitator that after having painted, she no longer feels ‘like a silly woman.’
Facilitator and Constance have a long conversation. Constance appears to concentrate as she recalls raising her children.
Peter continues to paint by using a paper towel to smear green paint across his canvas.
Facilitator compliments Peter on his creativity. Peter laughs and tells Facilitator that he didn’t plan it. Peter continues to work on his canvas as he speaks with Facilitator.
Lucille watches Peter and comments to AF 3 that Peter’s painting is ‘very nice.’”

In the following instance of conversation, the participant identifies commonsense and perhaps, innate abilities that have allowed her to do the art work. She speaks of ‘nous’ behind the creative activity and she says ‘we’ did it. Then she reaches out to include one of the other participants too.
“Facilitator: Now what would you say have been some of the special moments today of if you think about what you’ve been doing and what you’ve created in front of you, what have been the special moments or the special things about today?
Ruth: We used our nous and we did this.
Facilitator: Yes I think that’s a good point, Ruth, yes.
Ruth: Nous doesn’t sound right I suppose.
Facilitator: No nous doesn’t and we all know what nous is. That’s terrific and you do need to use your nous don’t you to do it, to be so creative in your thinking and what am I going to do, it’s amazing isn’t it?
Ruth: Yeah. It is. *.

e) Interpreting, discussing art work
Various comments from participants show their engagement with the process and their imagination, for instance:

“AF 3 asks Walter about his painting. Walter comments on how the trees were burnt by a fire and that the painting ‘hatched’ from his imagination.”

“Constance independently works and dabs paint with a sponge on her page. Constance informs AF 2 that she has created ‘different systems’ on her page.”

“Walter informs AF 5 that he ‘was brought back to the desert’ by doing the tile activity.”

The following two excerpts from transcripts also reflect the participants’ engagement and imagination:

“Facilitator: What did you have in mind when you did that? Were you thinking along those lines or were you thinking something just the artistic look of it?
Peter: No. I just thought to make it look like nothing that you could call it, is probably something. Just call it nothing.
Facilitator: Call it nothing?
Peter: Yes.”

“Facilitator: … see this here, this shape what does that remind you of, when you look at that? Does it remind anybody of anything in particular that big shape?
What does it look like?
Myra: The sun.”

5.2.1.6. Meaning in life
There was little in the sessions that could be coded as meaning in life. Yet, perhaps in an art program it is hard to evaluate. It seems that the connections and joy that the participants expressed, often in relation to being directly asked: ‘Did you enjoy today’s session’ were the best indication of the meaningfulness of the program. This, we suspect, is a very indirect measure of meaning. The quantitative measures of morale and depression measure this best. The following excerpt from the transcripts
was one example selected from the sessions that seemed to touch into the spiritual nature of being and ageing.

“Facilitator: There you go – well that’s a good place to be isn’t it? And Constance, how do you feel about being here today?
Constance: I feel really happy about it.
Facilitator: Do you?
Constance: Yes I love it.
Facilitator: It’s good isn’t it. Okay. Well I think I wanted to just ask a couple of questions about you – you know what we created here is very special and we’re going to do some more of this, but I wanted to talk about dreams for yourself and the future generations.
Constance: Oh that would be nice.
Facilitator: If you look at this and you see the way that it’s all connected, what do you think about what are the sorts of things that you would like to pass on to the next generation? What is it about you or your life or words of wisdom that you would like to pass on to the next generation?
Constance: What I thought *but I didn’t have a chance to pass it on.
Facilitator: What you thought was…
Constance: My brother came home and…
Facilitator: Yes.
Constance: And it was like, * more or less and he was ‘oh’ and I couldn’t stop him.
Facilitator: Okay.
Constance: But it didn’t matter.
Facilitator: It didn’t matter?
Constance: No, he came back, he likes that sort of thing.
Facilitator: He likes it. What sort of things do you think you would like to pass on to the next generation? Has anybody got any ideas?
Lucille: Oh dear.
AF 5: What would you like to pass on…
Facilitator: If you were to pass on to the next – what things? Do you dream?
Do you have dreams?
AF 5: Do you wish that [your daughter] would visit more do you?
Constance: [Singing]
Facilitator: That’s good. There will be love and laughter and dreams ever after. That was a very appropriate song for you to sing Constance.
AF 5: You don’t want to be forgotten.
Facilitator: Love and laughter, is that a good thing to pass on?
Constance: Yeah it’s just a steady thing that’s gone on in my life and I’ve always used it because *.
Facilitator: Yes.
Constance: That’s how I like that so that * about my brother and his sweetheart and here we are.”
a) Satisfaction – enjoyment
In a sense, this program enabled participants to respond to meaning, through connections with art. When something is enjoyable, then it is perceived to have meaning. There are many expressions of satisfaction and enjoyment during the sessions, even though a high proportion of these are responses to questions asked by the facilitator. The follow comments express the feelings of participants as they engaged in the art work.

“Facilitator: Ruth, now if I was to ask you how you’re feeling now?
Ruth: I’m feeling, wait I’m, I’m feeling like a bag of happy beans.
Facilitator: Are you?
Ruth: Happy beans.”

In the next session, Ruth describes her work as ‘excellent’, and in a still later session: “who would imagine that I could do this?” There seemed to be a growing sense of enjoyment as the weeks passed. Participants also complement and enjoy the art work of others in the group, making for connections between them. According to the RA journal: “Ruth comments upon how she did not expect to enjoy painting but has come to enjoy painting as a result of her experiences in the sessions.”

A clear example of the value of the group is provided at the end of the session for one of the groups in week 6, recorded in the RA journal: “As the research assistant assists cleaning paint from the table surface near Constance, Constance informs him that she will say a prayer before bed and ask God to bring them (the art group) all back together soon.”

A further RA journal entry was: “without prompt, Constance informs Facilitator that she crept into the room late one night and fell asleep on the sofa. When she awoke, Constance described how much better she had felt and how lovely it was to be in the room surrounded by the art.” These responses indicate that, even though the participants did not speak much during the sessions, the art work was having a very positive emotional effect on them.

When one session was being drawn to a close, the following exchange occurred:

Facilitator: Alright everybody what are the special moments about today? Let’s gather in our special moments and think about what's been good about today that you enjoy the most?
Ruth: Well I’d say that I’ve enjoyed every minute of your day here, it’s wonderful * because it comes back to you.
Facilitator: It comes back to you. It’s nice.
Ruth: You know what I mean by that?
Facilitator: Yes I do know that. I've had that feeling myself, so I actually understand what you mean. Yeah that’s good, Ruth.

5.2.2. Music program-Participation
Music has been a fundamental activity of humans for most of time. Storr, quoted in Sacks (2008) stressed the primary function of music in all societies as both collective and communal. It has been suggested that these functions of music have been in
decline in recent times, noting that these days we have a ‘special class of composers and performers, and that others tend to become passive listeners’ (Sacks 2008, p.266). Here Sacks writes of the communal function, where it is seen today as binding people together:

“The binding is accomplished by rhythm – not only heard but internalised, identically, in all who are present. Rhythm turns listeners into participants, makes listening active and motoric, and synchronises the brains and minds (and since emotion is always intertwined with music, the hearts) of all who participate” (Sacks 2008, p.266).

Sacks (2008), writing out of his vast knowledge and experience as a neurologist working with people with dementia, notes that music “of the right kind can serve to orient and anchor a patient when almost nothing else can” (p.266).

This program had two conditions; one was named music participation, and the other, music listening (see program description). This program was very different from the art program, pastoral care program, and prayer and meditation program in that there was little dialogue during the sessions and it was therefore difficult to qualitatively analyse the effectiveness of the program from this respect. However, in this case it is really necessary to rely upon the quantitative data to measure the outcomes of the program. Recent work in choir work at Hammond Care has shown the benefits in using choirs to reduce depression levels among people with dementia (Robertson-Gillam 2008). The data in this program did not show clear benefits of the programs, although there were positive comments from a number of participants. In a follow-up debriefing of the music programs at the facility, program staff, including the site coordinator, expressed their opinion that although the quantitative testing did not indicate significant reduction in depression, there were perceived benefits, including lifting of spirit and depression.

The main themes of the music participation program were: identity, meaning in life, responding to meaning, music, relationships, transcendence, engagement with music, and group atmosphere.

5.2.2.1. Identity

Most of the theme actually focused on the individual choices of participants regarding instruments and songs that they would or would not sing. Participants were empowered by being able to make these choices. There were few other indicators of identity within the program. Some participants responded more positively to music than did others.

5.2.2.2. Meaning in life

a) Reminiscence

The sub-theme of reminiscence had 279 references in the qualitative data. This was obviously an important theme; however, conversation that did occur stayed very much on a ‘doing’ level and did not go deeper. As in the following excerpt from the RA Journal:

“When the song finishes, Music Facilitator 1 asks June if she had to wave anyone goodbye during the war. June replies that she said goodbye to a cousin.”
“Emma tells Music Facilitator 1 about going to Turkey a long time ago and finding a red rose.”

“June comments how these songs bring up lots of memories. They make her feel mellow and very sad. She says that her husband was too young to go to war. Emma tells about another song her father knew from WWI.”

5.2.2.3. **Responding to meaning**

**a) Recalling and anticipating**

A number of the examples in this sub-theme are of looking forward to the next session or forgetting about the sessions. Some memories are of tunes that link to earlier life.

**b) Satisfaction – enjoyment**

There are 474 references to this theme in the program. This makes it the most commonly occurring theme in the program, however, most of the comments are based on activity in the program, rather than using person centred care to connect with the participants. Most of these relate to connecting with the music or the song, some with playing the various instruments provided.

5.2.2.4. **Music**

**a) Singing**

As to be expected, as this was designed as a music program, and there were many songs in the program, this theme follows the episodes of singing in the weekly sessions. Some of the comments show the encouragement needed by participants to actually sing. Others find it difficult to follow along from the song sheets; some speak the words from the song sheets rather than sing. Some participants needed a lot of encouragement to join in.

Excerpts from the RA Journal:

“Emma opens her eyes and starts reading the words out loud. PR goes up behind her and starts singing. Emma then starts singing too.”

“Emma sings, but not always in time with the voice on the CD.”

“Florence sings a little bit, but very quietly.”

“Emma sings the whole song. Everyone joins in for the chorus.”

“Emma and Jane both sing.”

“Everyone sings.
Emma: singing, tapping foot and ringing bell occasionally”

“Facilitator 1: tambourine, singing
Jane: singing

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Emma: singing
Florence: noding head & tapping foot, singing a little bit towards end”

“Jane: singing
Emma: on wrong page. Goes to right one and starts to sing.”

b) Engaging without singing
In the following excerpts from the RA Journals, it can be seen that participants are engaging, even when not singing.

“Jane also starts reading the words out loud, not in time with the music.”

“‘Ooh, that’s a lot of words!’ says Facilitator 2, referring to the page in the lyric booklet with all the words to the poem printed out. She tells Emma and Jane to just listen. They both start to whisper the words out loud.”

It seems that participants want to at least read along with the words, if they feel they can’t sing. They want to engage. Even when not singing, the participants seem to follow the words of songs, as in these excerpts from the RA Journal:

“Evelyn is still playing the triangle and tapping her foot. She is following along with the words, but is not singing.”

“Evelyn shaking tambourine & looking at words”

“Evelyn looking at words”

“Timothy looking at words”

“Evelyn appears to follow all the words, but does not sing. Her arm dangles down at her side, toward the floor, holding and playing the castanet.”

Some participants, though, were not engaged with the music.

c) Program materials
One of the issues that needs to be addressed in this program in order to allow residents the opportunity to participate is the font size of the songs. The font size needs to be large enough for participants to read easily.

d) Preparation for sessions
It is important to prepare well for group sessions, which means that program staff should ensure participants are ready with glasses and hearing aids.

“I [Music Research Assistant (RA) 1] ask Florence if she is on the correct page. She then tells Facilitator 1 that she hasn’t got her glasses. Facilitator 1 fetches them from her seat in her walker. Florence puts them on and says: ‘Now what do
you want me to do?’ I say: ‘Sing.’ Florence then proceeds to read out loud all the lyrics from the song. When she gets to the end she says: ‘Isn’t that nice?’”

5.2.2.5. Relationships

a) Family
Many of the songs remind the participants of family and times gone by

b) Anxiety
There were only 5 references recorded, and these were mainly related to the singing program.

“Jane says: ‘Oh dear oh dear oh dear.’ She comments that she is out of breath. I tell her singing is good for her lungs. Facilitator 1 tells her the same thing. Florence: looking worried
Session ended and Facilitator 1 invited them all to stay for Happy Hour. Jane very worried that no-one knew where she was.”

“Gladys has a worried look on her face and then starts trying to turn her page over again.”

“Genevieve: anxious short breaths
Facilitator 3: It’s OK, do you want me to sit right next to you? I’ll sit right next to you. Are you OK?
Genevieve: mumbling
Facilitator 3: It’s alright”

c) Loneliness
There was only one reference in this sub-theme, and that was of a resident who wandered into the group, but was not one of the group participants (see below). As loneliness stood out as an important factor in the PGC scores then, the dialogue in this program was not picking up on it.

“Resident: ‘Pity we can’t have a few more. Music makes for good companionship. Don’t get that much here. Find it very lonely.’
Discussion followed between Facilitator 1 & the resident re her sitting place for meals and her difficulties with some other residents. Facilitator 1 was going to try & move her place so she could be with others with may give her more companionship.”

d) Touch
Touch was used frequently as affirmation and support, mostly by facilitators to participants, and sometimes between participants.

“Facilitator 2 sees that Emma is leaning over in her chair. She places a cushion at her side and props her up. She gives her a quick massage on her shoulders. Emma says: ‘Oh, that’s nice.’”
“Facilitator 2 goes to help Florence again as she has lost her place. Florence says to Facilitator 2: ‘I think they’ll have to pay you for getting up all the time.’ Facilitator 2 kisses her on the forehead. They hold hands and sing the song.”

“Facilitator 2 goes and stands behind Florence and puts her hand on her shoulder. She points to the words on Florence’s lyric sheet and Florence begins to sing.”

“Facilitator 2 then points to the words for Jane and puts her hand on her shoulder too.”

“Francine has been unable to keep her eyes open since being wheeled into the room. RA 2 rings the bell in front of Francine in an attempt to wake her, but it has no effect. RA 2 then rubs her on her back and asks if it feels good. Francine nods her head ‘yes’ but doesn’t open her eyes.”

5.2.2.6. Transcendence

A number of examples of transcendence were recorded, over a range of sub-themes.

a) Transforming negative to positive

Engagement with music can be an important linking into the emotional and spiritual dimensions (Sacks 2008). In this study, the importance of staff to believe in the project is highlighted. The extract below demonstrates one of the positive sides of the program. However, there were numbers of instances where residents were not ready in time for the groups, and staff did not seem to follow up and encourage participants to attend.

“I da: Well, that was quite pleasant.
RA 2: Oh, good Ida. I’m glad you came along because you didn’t want to at first did you?
Ida: No. I haven’t been very well but I think it’s done me good.
RA 2: Yeah, I think it’s picked you up.
Ida: Yeah. I think you’re right.
RA 2: I think music is good for you.
Ida: Well I’m sure it always has been for me….Beautiful.
RA 2: Well that’s good. Well we see you all…
Ida: It speaks all languages doesn’t it?
RA 2: Mmm, it does.
Ida: That’s what I love about it.
RA 2: Yeah, music is lovely. Do you like it too Esther?
Esther: Yes, love it.
RA 2: Well that’s good. See you all next week again.
Ida: Yeah, God willing….Well I didn’t think I’d see this weekend a few days ago I was so ill. I was really sick.
RA 2: Oh, you’re better now.”
b) Memory loss
Memory loss was, on occasion, acknowledged by participants.

“**Timothy:** By gee, they are old songs. My memory is not so hot.
**Facilitator 3:** I heard you singing Timothy. Did you enjoy that?
**Evelyn:** I can’t see very well
**Facilitator 3:** Makes you cheer up.
**Genevieve:** Yes, I think so.
**Facilitator 3:** Do you feel better, more relaxed Genevieve?
**Genevieve:** Yes
**Facilitator 3:** Do you feel better Timothy?
**Timothy:** Used to know all the songs
**Facilitator 3:** You remember parts of it.”

“**Jane:** What have we got here? Oh, Show Me the Way to Go Home, yes, I’ll need that. (*laughs*)”

“**Jane:** Mmm. *Show me the Way to go Home.* Yeah, .......... obviously. (*laughing*)”

c) Self doubt – lack of self-confidence
A number of the participants in the program were very lacking in self-confidence particularly in their ability to sing. This is interesting, as when their generation were young, group singing was much more frequently done, for instance, sing-a-long around the piano, and other community activities. There was one particular participant who often voiced her self-doubt, while her ability to sing was often affirmed by program staff.

“**Jane** says: ‘I’m not much of a singer.’ Facilitator 2 tells her that she is an excellent singer and that she remembers all the old songs.”

“**Jane** grimaces, as if in pain. (Before the session began, she had complained of a terrible pain in her left rib cage.) I [RA 1] ask her if she is in pain. She replies: ‘A little bit. I’m not a singer by any means.’”

“After the first verse, Jane tells me she has a croaky voice.”

“**Jane** tells Facilitator 1 that all the songs are lovely, but she can’t sing. Facilitator 1 tells her that’s OK,”

“**Jane** says: ‘Sorry, I’m not a singer.’
**Jane** tells Facilitator 1 that she has a shocking voice. Facilitator 1 asks her how she feels when she sings.”

“**Jane** says: ‘Very good, very nice! If you who can sing it, too!’ She laughs. ‘I can’t, you can!’ I [RA 2] say: ‘Oh you can, Jane!’”
“Jane says: ‘Excuse me singing, ‘cause I’ve got a shocking voice!’”

“Jane says: ‘They’re good old songs, aren’t they? Not that I can sing.’”

“Just before the song begins, Jane comments that her singing will be very soft because she hasn’t got a good voice. Facilitator 1 replies that they will all help each other.”

“Facilitator 1: Jane, number 4.
Jane: Sorry, I didn’t realise. This is more my style, not that I’m a singer by any means.
RA 3: That’s OK.”

“Jane says: ‘Mm, they’re nice old songs, aren’t they? Not that I’m a good singer, by any means!’ Facilitator 1 tells her it is just nice to hear her sing, even if it is a sad song.”

“Jane says: ‘What’s next, “South of the Border”. You’d think I was a singer the way I’m going on!’”

“Jane: (singing Rose of Tralee). Nice old songs aren’t they.
Nell: They are
Jane: I don’t have a good voice, I sing a lot but I’m not in time.
Facilitator 1: But it’s lovely, I don’t ......find it hard to sing but I just play an instrument
Jane: But I’m not, you know, I just sing it, I can’t sing
Facilitator 1: But it’s lovely, it warms my heart listening to all of you sing.
Jane: Well, all to be together it’s good, you know, you enjoy it don’t you.”

“Jane: Sorry, my voice is... (she coughs)”

“Facilitator 2: Mm, I didn’t, I didn’t, I’ve never heard that one before to tell you the truth.
Jane: I’m not much of a singer but, you know.
Facilitator 2: Oh, you’re an excellent singer. You remember all the songs.

“Jane: Oh, my voice is awful. (She coughs.)”

“Jane: I’m spoiling it for everyone else.”

There were still others who doubted their ability to sing, but who were encouraged to sing, as in the example that follows. The participants in these groups gave consent to participate, but it is wondered, if they had also been given choice in the type of group they wished to engage in, would this have made a difference? For instance, might some of these people have been better suited to an art group, or to pastoral care? All of these groups have the potential for facilitating deeper connections, both emotionally and spiritually.
“Facilitator 3: You like to sing, don’t you Genevieve?
Genevieve: Yes.
Evelyn: I like to sing, but I can’t.
Facilitator 3: Everyone can sing, darling. It doesn’t….Singing is about enjoying yourself. Everyone should sing. Do you want to turn your page over, sweetheart? We’ll have another one, another one you know.”

Note the terms of ‘darling’ & ‘sweetheart’. These terms are patronising, disrespectful and lack the possibility of really connecting with the person. The name that the person would like to be called should be used, noting that some older people have never been called by their first name, but perhaps their second name, and in aged care settings, this may be disregarded and the person becomes someone else. Mary Jane may have always been called Jane, but now finds herself being called Mary, and she feels uncomfortable but unable to do anything about it – she is vulnerable. Further, she might feel uncomfortable being on first name terms with the carers and prefer ‘Mrs’ or ‘Miss’.

d) Confusion and disorientation
A large number of entries appear in this sub-theme stating that certain participants are confused regarding the correct page of the lyrics while they are singing. Other comments are seen about being confused as to what day and time the group is on, often a sign, even for with people with dementia, that means this program is not something they particularly want to do.

e) Wisdom and ageing
There was only one entry/occurrence relating to wisdom. In a group setting that encouraged person centred care this comment may have elicited a continuing and fruitful conversation.

“Facilitator 1: It is a romantic picture. Young love.
Nell: Doesn’t have to be young. Love doesn’t die as you get older, you learn more.
Facilitator 1: I didn’t mean that.”

f) Behaviour change during the course of program
The only entry related to this sub-theme was as follows, from the RA Journal:

“An occupational therapist (OT) who works at this hostel has heard all the music and [has] come in to watch. ‘Fabulous!’ she says. ‘Isn’t that wonderful?’ She comments quietly to Facilitator 3 that Grace has become very animated.”

g) Growing older
Growing older is, obviously, inevitable. This process can be acknowledged or denied. Acceptance of the ageing process can be a growth point for these people. In the extracts below, age and learning are linked, and the satisfaction of remembering is seen in the second extract.
“Facilitator 4: You knew that one.
Gladys: I think the older you get, the more you learn.
RA 1: (Laughing)
Facilitator 4: (Laughing) I’m sure you do.”

“(CD states that the song was published in 1935)
Ida: I’m old, I can remember all this. (Laughs).
Betty: Speaks quietly to herself.
RA 2: Brings back memories. (To Ida).”

h) Illness/not feeling well
Many of the participants in this program were ageing veterans and this is illustrated in the following exchange recorded in the RA Journal:

“Bill: Groans and excuses himself from the room as his leg pain (quite common since the war) is giving him grief.
RA 2: Expresses her sorrow to Bill about him being in pain.
Esther: Asks why Bill is leaving.
RA 2: Explains to Esther that Bill has bad legs.”

5.2.2.7. Engagement with music

a) Responding to music
This sub-theme could have been a means of tapping into feelings and emotions related to music; instead, it remained on the surface, “do you remember?” Then, let’s pass on the next song. Even the suggestion of the special gown could be followed up, to take the conversation deeper.

“Facilitator 1: Do you remember buying a special gown or a dress for the ball?
Jane: Not really I didn’t, not a lot you know. But...I can go back to different things that happened, you know. What do you want now, darl? Oh, yes. Oh, “Fascination”. Oh, I like that.
It does happen that way too, doesn’t it? (This is in reference to the comment on the CD about being fascinated with something or someone.)
Facilitator 1: Mm.
- Wrist/hand bells.
Jane: Sorry, darl.
- Singing
- Clapping
- Playing instruments
(The song ends.)
Jane: Mm. (She laughs)
RA 1: Do you like that one, Jane?
Jane: It’s a nice one that, mm.”
b) Responding to song lyrics
In this sub-theme, participants responded to the words of the songs. Some of these trigger memories.

c) Desire to leave group
A number of participants wanting to leave session early, to go to the “Happy Hour”
Timing of group sessions is important so that they do not overlap with other activities that participants want to take part in.

“Lewis: * (Wants to leave to get his beer when he sees Facilitator 5 leaving to get a drink of water).
Facilitator 5: No, stay there, Lewis.
RA 2: A couple more songs. Not long to go.
Lewis: Oh.

Lewis: I’ve gotta go.
RA 2: When we’ve finished, when we’ve finished you go.
Facilitator 5: Yes, be patient Lewis.
RA 2: Be patient Facilitator 5 said.
Facilitator 5: You’ve got 2 hours till your happy hour.
RA 2: We’re saving the best for last. (To Lewis).
Esther: What does he want *
Facilitator 5: He’s been asking for it since 11 o’clock. (Laughs).
Lewis: * how long until four.
RA 2: An hour and a half away.
Facilitator 5: Just wait, Lewis. Lewis, that clock is wrong. Be patient. You’re not going to get it for 2 hours.”

d) Emotional response to music
It is evident that on a number of occasions, participants emotionally responded to the music. In person centred care, these are opportunities to engage with the person, what does this mean for them? It shows that those facilitating small groups with music do not necessarily have the skill mix to work effectively with person centred care.

“Grace becomes very emotional and starts to cry.”

“Gladys begins to look a bit upset and then really starts to cry.”

“When the song finishes, Gladys says that she must apologise for crying. RA 1 tells her it is amazing how music has the power to trigger emotions and memories.”

“Nell: Reminds me, they love all these guys, well they wouldn’t say guys, they love all these chaps, (Jane laughing) Why are they crying at these songs? That’s what I wondered with grandmother and my sisters, and cousins and aunts. It
would all be cry, cry cry but they would say what a wonderful night, it was, we had such a happy night but they would be crying, weep, wet everybody’s hanky.  

Jane: They like that  
Nell: It was good clearance for the body”

“Facilitator 1: Well remember you have tears we cry when we’re sad and tears we cry when we’re happy  
Jane: That’s right  
Nell: But then pack up your troubles and get on with it. You don’t wallow in it, that’s what I was taught.”

Gladys is finding it difficult to deal with her emotions at this stage. There are two extracts provided, one from the very first week of the program and one in week nine, and the difference can be seen.

“Program author: Yeah.  
Gladys: It’s too close.  
Program author: Is it? It is close. Yeah...memories, it brings back memories.  
Francine: Close...  
Gladys: I’m sorry.  
RA 1: I think they can be quite therapeutic though sometimes, Gladys.  
Gladys: Ay?  
RA 1: It can be quite therapeutic, to get it out.  
Gladys: You think so?  
RA 1: Yeah.  
Francine: Yes, I do.  
RA 1: It’s better than keeping it in there.  
Gladys: (inaudible comment)  
RA 1: Yeah. No, get it out.  
Facilitator 6: It’s all right.  
Program author: You’ll feel better afterwards. You will, if you...  
Gladys: I think so.  
Program author: I think you will, yeah. I wouldn’t worry too much about it. Music does that to a lot of people, actually.  
Gladys: So say, say if you don’t want me back.  
Program author: Oh, we’d love to have you back. (She laughs.)  
RA 1: You must come back.  
Program author: No please do, yeah.  
RA 1: You must! Come back!  
Program author: You sang so well too. You’re a good singer.  
Gladys: Yes, I just feel such a fool.  
Facilitator 6: No! We all cry. It’s good, sometimes.  
Program author: Oh, don’t worry. Yeah.  
Francine: No, don’t.  
Gladys: Well, thank you for putting up with me.”
Note, at week 9, it is a pity that she had not had assistance to help her through the emotions – simply acknowledging the feelings is good, but working with the person and their feelings is even more helpful. Training in person centred care would be of great advantage:

“Gladys: started to cry.”

“RA 3: You got a little bit upset at the last song. Does that remind you of something, that song, the last song?
Gladys: Yes
RA 3: Yes, sometimes songs do that, don’t they, but that’s OK, no one’s worried. That’s OK. I might open this door and we’ll let some fresh air in.”
Gladys: I feel a fool.
RA 3: Oh, no, don’t be silly. That’s what songs do, they make you feel emotional don’t they?
Sylvia: Absolutely, specially old ones like....
RA 3: They get into....they bring back lots of memories don’t they? That’s OK Gladys. It’s good that you have feelings; you don’t want to have no feelings.
Gladys: I’ll have to have someone to help me.”

e) Responding to instruments
A variety of instruments were used, including maraca, buttons in a jar, castanets, different coloured bells, egg shaker, tambourine, triangle, drum sticks, clacker

“Francine: “I’ll have that one, it’s much more lively.” Comment in response to CD which said to select an instrument. Francine chose the castanets.”

“Gladys asks if there is a group of people out in the dining room. She then says that she will book me up with a red one and a golden one. (She would like to buy a red bell and a golden egg shaker.)”

“Matthew bangs the tambourine and is surprise, calling out “Oh!”.
Betty laughs as she says, “Throwing eggs at me now”.”

“Bill asks, “What’s that?” as he can’t make out the tune.
RA 2 answers that it is the flute?
Lewis confirms that it is the flute.”

“RA 2 shows Matthew how to use drumsticks. He picks them up and says it’s like riding a horse.”

“Matthew picks up castanet. RA 2 gives him his lolly and asks/checks if to eat. He and RA 2 laugh.”

f) Relating music to film and singer
Some of the participants become quite emotional and cry during the music that they connect with, remembering the film or the singer, and the circumstances of the song.
g) Non-participation
Some participants just sat and listened quietly, some did not appear to be interested.

h) Learning
This program enabled learning to take place, including learning new words to songs.

“Harriet comments that she had never known all the words to this song before.”

“Facilitator 6 says: ‘I’ve never heard that song before, but...!’ I [RA 1] express my surprise and then Facilitator 6 goes on to say that she doesn’t know most of these songs. ‘Maybe you ladies can teach me?’ Francine replies: ‘Yes, I think that’s a good idea.’”

“Facilitator 3: Well that’s what I find interesting, how many of these were written in the 1800s and 20s
RA 1: I always thought they wrote that song.
Facilitator 3: So did I! (laughs) I thought, ‘Oh, I didn’t know that’.
Evelyn: I think they’re lovely.
Facilitator 3: Aren’t they. I’m finding this fascinating, like the history of the songs. Same with ‘Somewhere my Love’ I thought that was written for Casablanca….Sorry, not ‘Somewhere my Love’, sorry, ‘As time goes by’. I thought it was written for Casablanca but it was written years before.”

“Facilitator 4: You knew that one.
Gladys: I think the older you get, the more you learn.
RA 1: (Laughing)
Facilitator 4: (Laughing) I’m sure you do.”

“Program author comments that Betty knows this one and asks her if she ever played the piano.
Betty answers “No, but I could always sing”. She goes on to explain that she was in the conservatorium of music and that out of a choir of thirty people, she was the only person who could sing in tune. Betty also talks with the program author about how in those days, girls were not important and that the boys got all the opportunities like music lessons and everything else. They laugh about how times have changed and Betty says that it is all around the other way now as the women are the bosses and the program author jokes that the poor men just have to struggle along now.”

“Everyone sings, even though there are no words to follow.”

i) Death and dying
This theme had only 7 references and related mainly to death of other people, either family members or other residents.
5.2.2.8.  Group atmosphere

The importance of an atmosphere suitable for the group is important. Temperature, being uninterrupted during the sessions, people being able to see and hear, and having comfortable seating are all important. But a vitally important component of the group atmosphere is the atmosphere set by the facilitator. The attitudes and work of the facilitator, we have found make an enormous difference to the responses of the participants. One of the meeting rooms was described:

“This room has natural lighting. It is sunny and breezy outside, with barely a cloud in the sky. A top of about 20 degrees is expected. A workman is outside using a whipper-snipper. Participants are having tea and coffee and playing around with the various instruments. They are seated around a rectangular table.”

The mood of participants greatly varied across sessions, as in the following examples from the RA Journals:

“Mood of Participants: Everyone was happy to participate in the music therapy session.”

“Comment: Ida declines and Matthew also (she said maybe next week?) Esther doesn’t want to either (she didn’t want to do it today, maybe next week). Lewis arrives a little late as he was asleep. We help him to sit and pull chair in. The program author arrives, she hands out more instruments. The program author came along again today to show [the facilitator] how to run the session given she was away the 1st week that the program author came. Therefore we had a few extra instruments from the program author”

“Mood of Participants: Bill: should be coming late. Was difficult to get Lewis to come as he was waiting for his 4pm medication (drink).”

“Mood of Participants: Thelma’s brother died today, she is ok, just a bit concerned about where she will live. Bill was sleepy so he was waking up.”

“Mood of Participants: Bill – said earlier that he wanted to get out of music therapy15 – he doesn’t think it is therapy and didn’t realise what he was getting into”

15 There seems to be some confusion about the use of the term ‘therapy’ here. This program was not actually therapy, but a music program or music group. An important distinction is made between the two different programs. Therapy assumes a therapy, conducted by a masters qualified specialist practitioner. These programs were designed to be facilitated by people who had specific training in the program but not highly skilled in music therapy.
It is important to be careful in practice to name activities and programs appropriately, so that it may be clearly understood what the function of the particular program is. These programs were not therapies.

5.2.3. Music program—Listening

The main themes of the listening program were very similar to those of the music participation program. However, one main area of difference was the sub-theme of program logistics.

a) Program logistics

In some cases, participants still had words to songs, but the facilitator was absent or out of the room.

The room for the session should be prepared before participants arrive, but this did not always happen, as in the following examples:

“Facilitator 7 says we should set room up the old way so she can get around room better.”

“RA 2 says we can do it now. We rearrange the chairs during intro. Edith cries looking at Facilitator 7 as she watches Facilitator 7 move around room. Nancy doesn’t understand why she has to move.”

There were more problems with getting people to the groups on time, and it seems, less commitment to the function of the group, for example:

“Norman wanted to come along for the music session, however he had a sleep after lunch and therefore needed help to be lifted out of bed as he is in a wheelchair after being in a car accident. He had pressed his call button and was waiting for a staff member to come and help lift him out of bed. Unfortunately the staff member only came at the end of the session, so he missed out today.”

“RA 2: Quietly tells Facilitator 7 that it is a shame about Norman as he looks forward to the music session but he is currently still waiting for a staff member to help him get out of bed. Facilitator 7: Goes to check to see if the person outside the room was there to help Norman get out of bed but it was the cleaner.”

There was some confusion about the layout of the CD used for the music listening program and staff discussed that at length. The value of the introductions/stories on the CD were questioned, as mentioned in the following excerpt from the RA Journal:
“Note: Facilitator 7 commented at end of session that she is not sure they really listen to story intros. I agreed but said sometimes they do comment about something said good e.g. today of that.”

5.2.3.1. Discussion

In comparison with the art program, where all the participants were frequently asked if they were enjoying the program, the participants in the music programs are very infrequently asked if they are enjoying their involvement in the music.

It seems that there was some slippage between the plans for the two programs; the listening program was to be simply, listening, while the participation program aimed to engage the participants in the music. There were no significant differences between the two conditions, and we wonder if they might have been too similar in nature. Apart from the music listening group mean GDS score lessening slightly at test time 3, neither program showed significant or even trends in changes of depression level or morale across the sessions. This was disappointing.

5.2.4. Pastoral Care

The main themes identified in the pastoral care program were communication style of facilitator, relationships, meaning, response to meaning, transcendence and hope/fear. Meaning is also seen indirectly in each of these themes.

5.2.4.1. Preparing for the group sessions

There were many factors to take into account to prepare for effective group sessions, these included, knowing something about each participant’s spiritual profile or history, liaising with facility staff and convincing them that this was a worthwhile project, and addressing issues of noise and environmental disturbances within the facility.

The following extracts from facilitator journals illustrate these points:

“I started very simply today. I was pleased I had done the Spiritual Assessments – this was very helpful in already knowing something of the spirituality of each of the participants. It also meant that I knew that not all the five participants found strength in their religious faith, though each one stated she was a member of the “Church of England”. This brings up issues of intrinsic and extrinsic religiosity. Some had emphatically replied “no” to the question – “has your religious faith helped you cope?” I was aware of the degree of cognitive loss of two of the participants in today’s group and didn’t want them to feel at all threatened.” (Pastoral Care Facilitator 1, Group A, Week 1)

“On the way back Elsie said she was glad it was a small group, that she didn’t like being in a large group of women, all talking.” (Facilitator 1, Group A, Week 1)

“When I took Elsie back to the house where she is temporarily living (due to a problem with a male resident), the diversional therapist said that Elsie is
unsettled each time she returns from the group, and that other staff have mentioned this as well. I doubt that the group upsets her, but perhaps the walk to and from the library and perhaps some further confusion and disorientation in returning to her usual area for the session. Today there was also some stress as staff attempted to distract the man in question as we walked [through] the building. On leaving Elsie she said “thank you for taking me”. The diversional therapist had forgotten each week that she was going to the group and had her colouring pictures each time I arrived.” *(Facilitator 1, Group A, Week 3)*

“Today’s time…began with every obstacle presenting itself! We arrived in the library to discover workmen were smashing the concrete verandas immediately outside the building! I found the manager and enquired about the possibility of using a different room. She showed me a small kitchenette, which, while being just down from the library, was a lot quieter. Our next challenge was the fire alarm, and the closing of all the fire doors! Eventually we gathered in the kitchenette, only to have the workmen start up again. By this stage it seemed we might need to cancel this session, as no-one could hear. However the noise level dropped and we were able to begin. We still had several interruptions, with people coming into the room to collect things.” *(Facilitator 1, Group A, Week 6)*

5.2.4.2. Communication style of facilitator- across all groups

The differences between groups shown in the quantitative results made it important to carefully examine the communication processes within the groups. Analysis showed this to be a crucial component that affected quality and quantity of participant communication. Different ways of communicating with people with dementia can either facilitate their communication, or restrict their ability to communicate (Kitwood 1997). An important aspect of this study is the use of mixed methods to enable detailed study of the methods used within the different treatment conditions and compare with the quantitative data. This was particularly relevant in the pastoral care group, where more talking was found, and it was possible to carefully analyse the themes drawn from the transcripts of audio recordings and journals.

In the rich sources of data available to the researchers, it was clear that groups where the participants were engaged in the group process as equals in the process produced more deep communication than groups where ready-made stories and readings were made for the participants. Where a story was effective in eliciting discussion of the participants, such as the archetypal story the Prodigal Son, it could be seen from the transcripts, that the participants were gently engaged in the story.

Engagement seemed to be a key factor in facilitating communication and a sense of control for the participants. In the groups where the process was more facilitator led, and the group members were more passive they remained so, and contributed less to the discussion and conversation.

**a) Questioning techniques**

Due to the marked differences in the amount of participant dialogue in the different groups of the pastoral care program, we decided to examine the way that questions were asked; for example, the speed of question delivery, the space left before
paraphrasing, space between questions, and the space between sentences. We examined the art program too, but not the music program, as there was little dialogue within the music program.

As we suspected where there was much facilitator dialogue and little participant response, a pattern could be seen as follows:

The facilitator for the art program gives very little time for response to questions - usually less than a full second, and she repeats/rephrases the question, or even moves onto a new question, until someone begins to speak. This facilitator also speaks quite quickly. And, with the number of staff present in the sessions, the other staff also chime in (maybe not asking questions, but making sure participants can hear/see/understand).

Pastoral care facilitator 1 gives space for participants to answer—on one occasion where no one responded, she'd waited 6 seconds after asking the question (what do you think of the poem), and then she said, 'mm, I like it', but she even said 'mm' fairly quietly and slowly, still giving them the space to answer in that time. She also, in contrast to the others, leaves a small space (1-2 seconds) between sentences. There was no occasion where she did not pause after asking a question.

Facilitator 2 gives some time for participants to answer--participants responded within 4 seconds in all the parts of audio recording listened to. This facilitator also allows time for participants to continue their thoughts after they have responded (usually, not always, waiting approximately 3 seconds after someone responds before beginning to speak).

Facilitator 3 does give space to answer questions (usually participants begin to respond within 3-5 seconds), also allowing time for them to finish their thoughts, if they pause in the middle of speaking, but facilitator 3 does speak fairly quickly.

Facilitator 4 gives space for participants to answer--up to 6-7 seconds, but on occasion the assistant facilitator seems to respond to facilitator 4’s questions after 3-4 seconds (answering the question for herself, or prompting someone else); once someone begins to speak, the chaplain facilitator gives them space to answer (in one case, the participant spoke, trailed off, then there was a space of 6 seconds of silence, and then she finished her thought).

Facilitator 5, who was a replacement facilitator for two weeks when facilitator 1 was unable to be present, gave participants little time to answer after asking a question, immediately rephrasing it or asking a follow-up question (within a second).

These findings are important to incorporate into training and planning work with people who have dementia. These differences certainly seem to account for the marked differences found in the transcripts of sessions in each of the facilities, taking into account that the cognitive and morale measures are quite similar, except for group A where the depression levels were higher and morale initially lower than other group, but where the communication of participants is enhanced. The facilitator of that group was the one who gave the greatest space.

b) Affirmation by facilitator

Qualitative analysis of the data showed that attitudes and communication style were important predictors of how participants would respond within the group sessions.
The first example from the transcripts demonstrates affirmation of the group process by facilitator.

“**Facilitator 1:** Isn’t that good. Here we all are again. I think it’s lovely, I think we’re all getting to know each other a little bit better each week. I feel like I’m getting to know you all a bit better and I really enjoyed last week. It was a lovely get together

**Elsie:** Yes it was

**Facilitator 1:** Wasn’t it

**Elsie:** It was nice

**Facilitator 1:** Yes it was

**Elsie:** It gives you a chance to chat differently with people Otherwise you could go for 5 years and say the same things I s’pose.

**Facilitator 1:** Yeah that’s right Elsie.

**Elsie:** And you like people anyway

**Facilitator 1:** Yeah, yeah I agree. It gives you a chance to talk about other things, you know that are important to us. Doesn’t it?”

The following interchange shows how important it is to choose words carefully to enhance understanding of participants:

“**Facilitator 2:** Today we’re going to find out what gives us strength in our daily challenges and about if you know anybody who’s had a life-changing challenge; I have an example here I’ll talk to you about that. So what gives you strength for today? What motivates you to get you out of bed?

**Rebecca:** You do.

**Laura:** Well, if I didn’t get out of bed, I’d end up with a headache for lying in bed.

**Rebecca:** Aren’t I awful?

**Facilitator 2:** No, darling, no. What motivates you, gives you strength?

**Cora:** Sharing, I think. It’s not a very easy thing to do, sharing; that’s what I like.

**Facilitator 2:** That gives you the strength. What gives you strength, Pauline?

**Pauline:** What did I think?

**Facilitator 2:** What gives you strength to get up in the morning?

**Pauline:** Well, we just do get up every morning, I think; it’s just a habit and you don’t think anything about it.

**Facilitator 2:** It’s like a ritual; I’ve got to get out of bed and get –

**Pauline:** And you want to go to the bathroom, you get up. You do it every day, it’s just as you say, it’s a ritual, you don’t think about it, do you? It’s just something you do. And if you don’t feel well, you don’t get up and then there’s something really wrong if you don’t get up, I think.

**Facilitator 2:** True, because it’s good to get up and come and sit here and –

**Pauline:** You get tired of bed.”

c) **Group facilitation techniques**

Note that the participants in the quotation above had focused on the words of the facilitator, “What gives you strength to get up in the morning?” Perhaps if the
facilitator had used the words, “What is most important in your life?” or, “What gives you strength for each day?” or even more simply, “What gives you strength?” the participants may have been more able to respond, at a deeper level.

Communication that links into emotional and spiritual, that is, meaning, seem to elicit more fruitful responses from people who have dementia (Hughes, Louw & Sabat 2006; MacKinlay & Trevitt 2006). Use of words such as ‘darling’ and ‘dear’ are not respectful of people. Each person should be called by the name that they prefer to have used, thus helping to affirm their dignity.

A good way to enter into the group process is by a guided relaxation time at the beginning of the session.

The following interchange demonstrates that it is possible not to go deeply in meeting with these groups. The participants in each of the sessions had very similar cognitive status, but the outcomes from the group sessions were quite different.

“Pastoral Care Assistant Facilitator (AF) 1: Arthur do you have a favourite season?
Arthur: Autumn.
Sara: Arthur likes autumn, that’s when all the leaves fall, Arthur.
AF 1: Sweep them up.
Facilitator 3: I suppose have you being a person whose had to get up and sweep the leaves, as Sara was saying, have you been a raker and a cleaner-up-er-er?
Arthur: Yes.
Facilitator 3: So you’ve done that over your lifetime too?
Arthur: Yes.
Facilitator 3: I suppose most of us have had to do some cleaning up in autumn, but it’s still a beautiful time of the year.
Edward: Yes.
Sara: Have you had your cup of tea?
Facilitator 3: You’ve missed it Sara. [laughs] You’ll have to wait now.
Facilitator 3: Stand by the door AF 1. [laughs] We could get you a drink if you like, are you desperate?
Sara: AF 1 would love to get me one. A coffee please, one and a bit sugars.
AF 1: One and a bit sugar, yep.
Sara: Not too strong.
AF 1: Okay.
Sara: Thank you AF 1.
Facilitator 3: Thank you. So with the autumn, one of our other groups was talking about autumn, just like Arthur mentioned, and was saying what they liked about autumn was it reminded them of the autumn of their life, that there are some things as you get older, you can appreciate more because you’ve had life experiences, and maybe some things as a youngster, you just overlook them and you don’t realise how important they are, some of the simple things, and then experience them as a mature person, you start to enjoy more.
Edward: Yeah, that’s it. Mature is the right word.
Sara: Mature is the right word, yeah. It takes a long time to get there, but never mind.
Facilitator 3: So would you describe yourself as mature now?
Sara: Oh yes, very much so.
Facilitator 3: What about the rest of you, Amanda’s smiling.
Sara: She’s mature too.
Facilitator 3: Sara was saying she’s mature now.
Amanda: Oh.
Facilitator 3: And so is Amanda. What do you think Amanda, are you mature?
Amanda: Oh, I suppose so. I’m old enough to be.”

I. **Ways of using the weekly themes for the groups**
The program to be used by all pastoral care groups contained broad topics and activities which allowed for some variance among the groups in how the theme could be explored, but the program was not always adhered to. In Group D, Week 7, the theme was not adhered to; the facilitator used their own way of doing, providing mostly very simple concrete examples, with no attempt to go deeper. Again, in Week 16 of that group, the theme was not explored in the way intended by the program author; the theme was hope and expectation, as the RA journal reports, the session broached the theme in the following manner: “Other topics also discussed centered around buying lottery and raffle tickets, lucky numbers as related to the topic.” The facilitator did not use the prompts for the theme, but instituted their own, so as to make them easier for these people to understand, or words to that effect! The communications were condescending and paternalistic.
In the facilitator journal for week 5 of Group D, the facilitator remarks that participants can’t handle abstract concepts; however, it has been found that people with dementia can certainly understand emotional and spiritual concepts (Hughes, Louw & Sabat 2006; MacKinlay 2006). So perhaps the distinction is between cognitive abilities/understanding and emotional and spiritual understanding. Communication skills are important:

“Theme of Joy and Happiness was explored. Visuals of happy children's faces quickly aroused interest. It will be important in future sessions to provide visuals reflecting a variety of situations, gender and age groups, to have a wider appeal and promote broader conversations and recall. Extending the theme to encompass joy through struggle and difficult times, may be too abstract or inappropriate for some participants. It took a long process to actually draw out the simple recall of happy times. There was not time to explore the extended theme.
Some simple jokes and riddles were used to promote interest in the theme. They were politely received and only understood by some. Responses to the visuals were enthusiastic. The discussions of happy times in the past and present were less enthusiastic and less animated experiences compared to the effect obtained through use of visuals.” *(Facilitator 3, Group D, Week 5)*

Examples of riddles from the transcript:
Facilitator 3: This fellow’s been to the doctor and he says ‘Doctor, doctor, I keep thinking I’m a goat and the doctor says ‘how long have you had this feeling’ and he says ‘since I was a kid’
(Edward and Carol laugh)
Edward: Oh right
Facilitator 3: That was a bit better was it? Ok, what about this one? Why did the little girl tip toe past the medicine cabinet? Why did the little girl tip toe past the medicine cabinet?
Carol: Cause he was told not to touch it
Facilitator 3: That’s a good idea. Well, she didn’t want to wake the sleeping, the sleeping, something that was kept in the cupboard, in the medicine cabinet?”

These riddles are of entertainment value, not spiritual; perhaps there might be a place for their use in some settings, but hardly in pastoral care. The theme of joy and happiness can be handled by people with moderate to advanced dementia, provided the facilitators believe that it can, and if the facilitators respond appropriately. Jokes and riddles are probably infantilizing these people (Kitwood 1997)
The remark: “They were politely received and only understood by some” demonstrates a lack of knowledge of the nature of dementia by the facilitator. There may have been a number of reasons for the seemingly low response of participants to these riddles, including that they were deemed to be inappropriate; it is not possible to categorically state on the basis of this interaction whether the participants did or did not understand the riddles, and a further question comes to mind – does it matter? How does the facilitator know who understood what? Is this a test?

II. The theme for week 8: Images of God
The following is an extract from the facilitator journal. It is noted that the concept was ‘too abstract’ however this same concept has been used many times with people with at least moderate dementia, and there have been meaningful responses. Perhaps it is the way that the question is asked, and the time allowed for responses. The following is quoted from the journal:

“The Theme, "Image of God" was challenging. As the question "What is your image of God?" was posed, there was a "deathly" silence.” One contribution offered was that you "can't define God.” Perhaps this may suggest that this theme is too abstract for some who may never have contemplated matters involving God. The question may have been a Theological concept never contemplated before. Perhaps it is now too difficult at their level of dementia to actually discuss.” (Facilitator 3, Group E, Week 8)

“The Eggheads were well received by all except Anna, who showed little interest. Anna had shown limited interest back in the previous session of this theme. However, it would appear that Anna continued a previous conversation relating to last week's session. The pictures on the wall relating to the 23rd Psalm reminded Anna of her birth state Tasmania. She spoke of this to RA 2 in Week 7. Her conversation at first had appeared to relate to the current theme. It may have been that her focus simply moved on to an area of her own interest.
Katherine offered the group her special insight concerning "love" in its many dimensions. It could not be conceived that Katherine could have expressed this in any other program or in fact, been prompted to make this comment in any other context.” (Facilitator 3, Group E, Week 8)

In Group D, the theme ‘Image of God’ is mentioned, but the facilitator fails to stay with the topic and returns to surface topics, as follows:

“Facilitator 3: He might. So images of God. Anyone else would like to give us a thought about how you see God, or a picture of God?
Sara: I don’t know, I think of Him as never gets old, and a young man to me.
Edward: He’s with you all the time.
Facilitator 3: It’s something to think about isn’t it. Is it something we think about very often?
Amanda: What.
Facilitator 3: About God, do we think about God very often?
Amanda: No.
Facilitator 3: So today is a good opportunity to think about Him, isn’t it?
Amanda: Yes.
Facilitator 3: I’m going to open up my box.
Sara: Your eggs.
Facilitator 3: Eggs, yes. And in fact, it’s a little home for the Egg-heads. Now are you ready to meet the Egg-heads?
Sara: Yes.”

III. Themes: response to meaning
Sub theme gratitude and blessings: In this sub-theme, there were many things about relationship expressed as things for which to be grateful.

In the following interchange, note that the facilitator introduces the word ‘precious’ as the start of this interchange, which occurred in the first week for Group A. This is a word filled with meaning; note that facilitator 1 uses it to draw the person into deeper and further conversation.

“Facilitator 1: What are some of the good things in your life Elsie?
Elsie: Everything, can’t think about anything bad, so far anyway.”

The facilitator then draws this out further:

“Facilitator 1: We are talking about some of the good things in our lives, precious things. Does anybody have anything to share about blessings or anything precious in their lives?
Elsie: I have 5 children and they are all precious.
Facilitator 1: Fred is the oldest one isn’t he? That’s lovely Elsie. What about you Ethel? What is precious in your life?
Ethel: I think everything is precious.
Pastoral Care Research Assistant (RA) 1: We have lot to be thankful for don’t we Ethel? I don’t know about you, but I think sometimes we take life for granted. We really do.

Facilitator 1: What about you Gail, what is precious in your life?

Gail: I’m very fond of animals

Facilitator 1: Any in particular?

Gail: No, dogs

Facilitator 1: Do you have any dogs around here?

Gail: I have 2 or 3 dogs of my own, but others that come around as well.”

In contrast to the notes for this session in Group A on gratitude and blessings, which are broad and help focus on things that are important for group members, Group D, after the introductions, began the program with the facilitator shaping the answers by the specific use of props, including a focus on pictures of Australia. Types of questions used were all at a surface level, eliciting little interaction. The following interaction is indicative of the approach used, with participants often answering in one or two words:

“Facilitator 3: A beautiful beach yeah, yes (inaudible)

Facilitator 3: Ah, Arthur. What about you? When you look at some of these pictures, what memories come back for you? Have you got memories that come back when you look at some of these pictures?

Arthur: Not so far. I mean I’ve been to these couple of places, but, ah no, they’re just, ah, photos to me.”

The poem by Dorothea McKellar would have been known by anyone of this generation, who went to primary school in Australia. The facilitator does not use that knowledge, even when the participants make it clear that they do know the poem. One of the activities was to write ‘something that I am grateful for’ on a cut out leaf that will go on a tree: by way of introduction the facilitator says:

“Facilitator 3: Ah yes, yes that’s right. It was a very cheap way to have games, wasn’t it? Just with the autumn leaves, yeah, yes. So you’ve all had to come up with some lovely ideas too about things you’re thankful for so we’re just going to jot down one thing for each of you and we’ve got, um, a piece of paper, and AF 1’s going to come around and there’s just a tag on them and we’re going to hang them on a tree. Now, we’ll bring round, AF 1 will help you if you want some help with writing or he’ll just write it for you, but AF 1’s got a list of things if you might of forgotten about what you made a comment about things you’re thankful for. I know for Amanda you were very grateful for [your daughter] to be able to take you out to Mentone, which is nice isn’t it?”

“AF 1: Will I put down Mentone beach? Is that something you enjoy?

Amanda: Yes, Mentone, yeah
Facilitator 3: Well I’m going to start to make it a gratitude tree and I’ll put Sara on too, there you go. So Sara’s got Christian friends, I’ve got Autumn leaves. How we going? Anyone else…
Faye: I would like a pencil
Facilitator 3: Oh you’d like a pencil. You’re right Faye, there you go. Carol, there you go, you want to write something down? That you’re grateful for?
Carol: Oh, practically everything
Facilitator 3: You can write that down, practically everything. Would you like me to write that down for you?
Carol: Yep, yes
Facilitator 3: Practically everything, I like that. Practically everything, that just about practically covers it all, doesn’t it?
Carol: Yes, I can go now (Carol laughs)
Facilitator 3: (Facilitator 3 laughs) Thanks Carol, I needed that. There we go, practically everything (inaudible)
Facilitator 3: Arthur, we’ll keep thinking for you? What about your breakfast?
Arthur: No
Facilitator 3: No, we can’t include your breakfast? What about your lunch to come?
Arthur: No
Facilitator 3: No (Facilitator 3 laughs) that’s fine, we’ll leave that. Ok, what about my beautiful blue eyes?
Arthur: Yeah, yea they’re nice
Facilitator 3: They’re nice? Ok, if you can’t think of anything else we’ll include my blue eyes later.
Arthur: Yes, well I like Autumn
Facilitator 3: You like Autumn? Yes, yeah. And how does that make you feel when you’re in Autumn?
Arthur: Well, locked in this damn place I can’t feel it
Facilitator 3: Yeah, we don’t get out enough sometimes do we?
Arthur: No, no
Facilitator 3: It is difficult. Ok, well thanks for that it’s given us a good thought. Ok, well I just thought that we’d better put Faye’s, Faye would you like an extra sheet of paper (Facilitator 3 laughs)
Faye: No thanks (Faye laughs)
Facilitator 3: Wonderful
Faye: Why you asking?
Facilitator 3: Well, that’s terrific. Can I have a look at some of those?
Faye: Sure
Facilitator 3: Ok. Family, friends, education, music, country, picnics, would you like to read the rest of them?
Faye: Good food, comparatively peaceful country and health
Facilitator 3: And health?
Faye: Yeah”
It is noted that the distress of Arthur was ignored. There was no comment that his concerns were taken up at another time.

The following is an effective introduction to the start of the first week of group sessions. The facilitator draws the participants into the group interaction, engaging them in the session. Facilitator 4 is the facility chaplain. Soon the participants are initiating the conversation.

Group B, Week 01, Start of session

“Facilitator 4: The conversation will be recorded and we will also have a conversation around a particular theme or an idea and that idea will change each week. And so we have some things here today to explore what our theme is. And the idea is that I kick off the conversation but you each should feel free to contribute your stories and leap in when you like. You should feel free just to converse as are over a cup of tea.

So what might be the theme here. Have a look at the table. What are some of the things we have got here?

Adeline: A parrot feather?
Facilitator 4: Yes
Beatrice: It’s a parrot’s feather!
AF 2: I found it on the ground
Beatrice: What a find!
AF 2: Beautiful colours in it. Feels gorgeous.
(Passing it around)
Adeline: It is a parrot’s feather, one of the little rosellas.
Facilitator 4: A rosella or something like that.
Facilitator 4: We’ve also got another feather as well.
Mary: What’s that feather out of?
Facilitator 4: Where do you think that’s from, Mary?
AF 2: Mary knows. Come on, think Mary, think.
Facilitator 4: Well, what would you guess?
Mary: Ostrich?
Facilitator 4: Yeah it could be, got to be from a large bird.
Mary: From a large bird.
Facilitator 4: This is the flight feather though.
Mary: A pelican.
Facilitator 4: Out where you’re from. You see them flying all around Tantawangalo.
Mary: Do you?
Facilitator 4: Mm, big eagles.
Facilitator 4: Probably wedge tail eagle, something like that.
Adeline: And did you pick that up somehow?
Facilitator 4: I’ll tell you who gave me this. Mrs. Smith gave me this. Their farm is called NN. They must be able to look out from their farm and see the wedgies. You can feel it wanting to take off if you move that fairly quickly...
Adeline: Oh yeah.
All: Oh, ah, nice, lovely.
(passing it around)
Adeline: I’ve got one like that in my room.

...

Facilitator 4: If you put all of those images together. What is the theme we are trying to create for today? What might be the idea for a theme?
Adeline: The church?
Facilitator 4: Church is part of it perhaps
Adeline: mm
Adeline: The group?
Beatrice: * (unclear, joke about attending church)
(laughter)
Facilitator 4: It’s more a theme of creation really, today. Look at the beauty of the things we see in nature. The birds, you’ve seen the feathers, a beautiful statue.
Carrie: An anchor maybe
Facilitator 4: There is an anchor there too, Carrie.
Mary: I like the anchor too.”

Note how the facilitator listens and picks up on important words, phrases:

“Facilitator 4: And Carrie. You are a Tasmanian lass. Did you grow up in the city there or in the country area.
Carrie: The country area.
Facilitator 4: On the land? Farming people?
Carrie: No, no. just workers. We were seven children. Four girls and three boys.
We had a very happy life. Because we never ever had fights or arguments. All played together. Never had any problems like that. …
Beatrice: I have a granddaughter there.
AF 2: You two have a big connection. Beatrice goes to Tasmania occasionally and so does Carrie. You should go together!
(laughter)
Facilitator 4: There’s such rich agricultural land around there. I have done a lot of work around Scottsdale years ago. Where all the little farms are growing carrots and peas and corn. Very rich black soil. And they used to get a lot of rainfall.
Carrie: Oh yes.
Facilitator 4: As you were reading this poem here, what was coming out of it for you?
Carrie: Well all about the country. My home country. The part at the end there. I will never forget my home country. I liked it there. Family. And all about life and country and all that sort of thing you know. Quite nice. I liked it. But then I came over here of course but that was because my two sons married local girls.
Facilitator 4: Do you pass that love of country and family on to them?
Carrie: Yes, I think so. They would enjoy living there and that sort of thing. I liked it there but when I came here I liked it too! I wouldn’t go back because this
is home. They look after you so well here and it’s a beautiful place. Everybody is so nice and helpful and friendly.

Adeline: I can agree to that

Facilitator 4: This is one thing I find in this poem here. When she talks about the land and she says the terror of it but also the beauty of it and she talks about the animals and the stock and the like but there is no mention of people

All: No

Facilitator 4: …in this story at all

Mary: Yeah

Facilitator 4: Carrie, that is an essential ingredient in your life but it is not represented here in this poem. For you land and people go very closely together. One of the reasons you love being here is because you love the people here. The community. Is that correct to say?

Carrie: Yes. I think it is wonderful to be able to live here.

Beatrice: I had a nice unit down the bottom. And I was hoisted out of there up to here.

(laughter)

Facilitator 4: Hoisted? That’s a strong word. Sounds like it was not according to your will?

Beatrice: That’s right! I spent a lot of money on furniture in it. Heaven’s knows where that is gone. Maybe in a garage. A mighty big garage! And I paid a lot of money for my bed. That had drawers underneath. And I loved that bed but I wasn’t allowed to bring it. And quite a few things disappeared.

AF 2: But in the end that all those material things don’t really matter?

Beatrice: Yes, but I still miss some of it.”

In the following, the facilitator affirms the participants, and asks clarification from them, they obviously feel comfortable in exploring concepts in her presence:

“Cora: Can I ask a question?

Facilitator 2: Of course you can.

Cora: Does anyone here know what a dolichos bush is?

Pauline: What a what?

Facilitator 2: A dolichos bush, no I'm sorry, I'm a bit ignorant.

Pauline: A dolichos?

Facilitator 2: What is it, Cora?

Cora: A dolichos bush was a little creeping of the pea family that sort of crept over old dead stumps and crept over *

Facilitator 2: Like a ground cover?

Cora: … and made a little sort of dreamy fairy cubby house. If I had problems or I had pleasures I rushed off to my dolichos bush.

Facilitator 2: That was your quiet place?

Cora: It was a quiet place but…

Facilitator 2: Did you do that when you were little, when things didn't go quite *

Cora: Oh, very little… I would have been in the three to fours.

Facilitator 2: That's wonderful.
Cora: I've got emotional bags now and I've got too many goods, the dolichos isn’t big enough. So girls, if you see my crouching down near a chair, you'll know I'm at the dolichos bush.

Facilitator 2: The dolichos bush, that's wonderful. Yes, I mean, we can all have quiet times and go somewhere when it's quiet, can't we. Just the peacefulness of it.

Cora: You've got time to lick your wounds too. Getting a bit mixed up with the dolichos.”

d) Enjoyment and pleasure in groups

There were numerous questions asking participants whether they were enjoying themselves, and mostly they responded in the affirmative. Some other interactions actually explored where enjoyment was found. There are many instances in the transcripts where participants have spontaneously broken into laughter, especially when they were talking together, rather than with jokes that were provided by facilitators.

“Carrie: It is, look it has changed my life, I tell you… (laughs) I’m quite happy and, you know, comfortable now.

Facilitator 4: Is it that sense of community, is that.. is that what the difference is?

Carrie: I’m sure it is. Having other people around and helping and... after you’ve been left on your own, your husband’s gone and you sort of feel like you’ve…I feel like I’ve come to life again, sort of thing, you know.

Facilitator 4: Yes. New lease of life.

Carrie: Yes, yes. Because it’s not much fun being on your own,

Facilitator 4: Mm

Carrie: …you know, after being married with a family and everything, it just…it feels as if everything’s passed you by but then with a place like we’ve got here, it’s just absolutely wonderful I think, I wouldn’t change it for anything. (laughs)

So my life’s settled there, I’m all right there. (laughs)

Facilitator 4: Okay.

Carrie: As long as I can.

Carrie: Yes, for a while I did, after my husband passed away. And when I came here, it was a new change of life altogether, everything was changed. You had company, you had someone to talk to. You was never lonely. That’s something that I … I always used to be lonely, but now…not nowadays. You can just turn around and talk to somebody, you know…

Facilitator 4: Yes

Carrie: …get help from somebody or whatever…

AF 4: And there is always someone knocking on the door, isn’t there. (laughter)

Carrie: Oh yes, is there ever. (laughter) You don’t have to open your door. It’s wonderful, I’m really lucky. I was really lucky to get here. Because when I came to see this place they said there is a room here straight away, you can move in there straight away if you can, if you want to. But I had promised to go up to…away on a holiday and I told the lady there in charge. She said well, we’ll
just see what you think when you get back, and when I came back the room was still there, it was still there after four weeks!

Facilitator 4: Wow, yes.
Carrie: So I thought I was very, very lucky, for sure.
Facilitator 4: Yes. Mm.
Carrie: Because I know a lot of people have been trying to get in here, you know, a lot of people. And a lady in the post office in Bega said to me one day, ‘how did you get into that place, she said my mum’s been trying for ages and she can’t get in there!’”

e) Effective communication – facilitator led

The facilitator of this group affirmed and guided discussion:

“The Facilitator 1: How should we finish off today? We’ve got our little leaves? Did anyone like to add a leaf to the tree? Anybody wants to, anything else that anybody feels grateful for, any other blessing that you’d like to write on a leaf and put on the tree?

Alice: I don’t know, there are so many blessings.
Facilitator 1: Yes.

Alice: Our lives, the very fact that we are here, alive and well, it’s the greatest thing of all.
Facilitator 1: Can I write that on a leaf and put it on a tree?

Alice: Yes.
Facilitator 1: Thank you Alice. Exactly as you said it, the very fact that we are here and alive and well is the greatest blessing, is that right?

Alice: The Lord must have been blessing us all the way along our lives.
Facilitator 1: And you know another blessing that the Lord’s given us today, the whipper snipper moved.

Alice: Oh yes. Yes. I didn’t register when that stopped.
Facilitator 1: No, I didn’t either, I just realised now.

Alice: I was involved with what we’re doing, it’s great.
Facilitator 1: That’s a good sign, isn’t it?

Alice: Yes.
Facilitator 1: That’s lovely. The very fact that we’re here and alive today is the greatest blessing.

Alice: Blessed getting together, for stopping the lawn mower, or whatever it was.
Facilitator 1: Yes. I’m going to put that one down.

Alice: Yes, good to know that we’re so involved with what we’re doing that we hadn’t noticed.”

f) Cutting off conversation of participant

A number of instances occurred where facilitators cut off the participants before they had a chance to complete sentences, for example, in the following exchange:

“The Facilitator 3: So we’re very pleased with that. Now this morning I just want to welcome everyone, and we’ve got Sonia come to be a part of our group this
morning, some of you know Sonia, some of you don’t, but welcome Sonia. So we’ve got Carol, Amanda, RA 2, Arthur, AF 1, and Edward. That’s very good.

Carol: Sounds all right. I’m not going to give you *

Facilitator 3: Sounds all right to me. As long as I didn’t miss out on anybody. Last week we had a talk about the seasons; we thought about the seasons of the year, and we thought about the seasons of life. And for some of us we had some very strong preferences about some of the seasons, the seasons that we enjoy – what seasons do you enjoy most of all, out of summer, winter, autumn and spring?

Carol: Spring. I like spring, because it comes up after.

Facilitator 3: It comes up after the cold winter.

Carol: Yeah.

Facilitator 3: It’s lovely isn’t it. Anyone else got a favourite season?

Edward: I wouldn’t mind summer.

Facilitator 3: A special reason for that?

Edward: No, it’s just you have more sport in summer.

Facilitator 3: Sporting people, yes.

AF 1: I like autumn, the winds are a bit steadier than summer.

Amanda: I hate the heat, but I love the beach.

Facilitator 3: Hate the heat but love the beach.”

These participants already had difficulty in communicating and being cut off would make it hard for them to retain their thought processes and to come back to a topic once they had been interrupted.

5.2.4.3. Relationships

Relationship or connection with others is vitally important for humans, whether they have dementia or not. Relationship was an important theme in this project. Relationship may have a spiritual dimension as well, either with deep connections with other human beings or with God.

a) Being alone and loneliness

Loneliness was unchanged by the group sessions, over the duration, according to the PGC tests. Loneliness is certainly challenging and has been remarked on by many older people both with and without dementia, in many settings, including the community and in residential aged care. Might this be addressed through intentional spiritual connection and development of friendships among the participants? However, it is important to also be aware of the potential for abuse of friendship, but at the same time we may err too far on the other side to deny the possibility of friendship to lonely older adults, especially those who live with dementia.

Being alone is not always a negative experience as seen in the following exchange:

“Facilitator 3: What about the rest of you? The rest of you sort of had that experience where you just like to be by yourself sometimes?

Edward: Yes. Quite often.
**Facilitator 3:** Yeah. What about you, Arthur? I think you like being by yourself every so often.

**Arthur:** Yes, I do. Yes.”

Being alone is a common experience of later life, yet little remarked on in these sessions.

Below, expressions of loneliness:

“Alice: Really enjoyed our get-together.

**Facilitator 1:** Yes, it’s good to get together, it’s very important.

**Alice:** Yes.

**Facilitator 1:** I think, you know, people can get lonely in places like this, and it’s nice to get together and have a chat about the important things.

**Alice:** Individual rooms like this, it gets very much alone.

**Facilitator 1:** Yes.

**Alice:** Getting together in the dining room is alright, but you mightn’t have got someone sitting at your table who can talk.

**Facilitator 1:** That’s right, they can be very quiet places, too, can’t they?

**Alice:** Yes, that’s right.

**Facilitator 1:** Yeah.”

This facility had only single rooms, and while this has been a standard sought by the wider community, it does make it difficult for these people to make new friends. It is therefore important to establish opportunities for people with dementia to be able to develop new friendships through programs, such as the pastoral care and art programs. Many of the activities in aged care facilities do not assist residents to get to know others nor to develop friendships.

“Alice: I'm glad you went up and spoke to him. That's good. I'm sure he’s lonely and meeting me, he just needed something like that.

**Facilitator 1:** Yeah. Yes. You're probably right, Elsie. Yeah.

**Alice:** Well most of those people are very lonely.

**Facilitator 1:** Yeah? Yeah. Yeah.

**Alice:** I think the men might notice it more than the women. The women have their little occupations as they go, as they grow older and don't have the housework to do and that sort of thing, like their knitting and crocheting and sewing. And some of them even turn to painting and that. But the men seem to miss out and they get very lonely.

**Facilitator 1:** That's sad, isn't it?”

“**Facilitator 4:** What is it about having company that can help us? What do you find, Carrie?

**Carrie:** Oh, it has made a world of difference to my life, I think.

**Facilitator 4:** Yes, how is that?

**Carrie:** Oh well, you feel very sad and lonely if you’re just on your own…

**Facilitator 4:** Mm
Carrie: …all the time but you can play with other kids and if you can help the parents or whatever, I think it makes a big difference.

Facilitator 4: Mm.

Carrie: If you’re just being on your own it is not very happy life, you know, if you can have company, and you can do things and help other people and I think it makes a world of difference.

Facilitator 4: Yes.

Carrie: If you’re being on your own all the time, that’s not much fun. *(laughs)* Yeah.”

On the other hand, as this same group discussed in the twelfth week of sessions, company can be found in residential aged care:

“Carrie: Yes, for a while I did, after my husband passed away. And when I came here, it was a new change of life altogether, everything was changed. You had company, you had someone to talk to. You was never lonely. That’s something that I … I always used to be lonely, but now…not nowadays. You can just turn around and talk to somebody, you know…

Facilitator 4: Yes

Carrie: …get help from somebody or whatever…

AF 4: And there is always someone knocking on the door, isn’t there.

*(laughter)*

Loneliness was seen among the participants and was one measure of the PGC morale scale that did not change over the duration of the studies. There were many entries for this theme. The following quotes are entries from facilitator journals:

“She appears lonely and has expressed this. She also talked again about Jesus being abandoned by his friends in the garden and even feeling abandoned by His Father. I suspect this echoes her own feelings of loneliness and aloneness. She talked about Jesus going in to the hills alone to pray, seeing this as an expression of his loneliness.” *(Facilitator 1, Group A, Week 4)*

“Today she spoke a lot about her sadness in not seeing her son more often, in spite of the fact he lives nearby.” *(Facilitator 1, Group A, Week 16)*

“Towards the end of the session another resident came from her room, stating that she wanted to join us because she was lonely in her room. On chatting with her afterwards and explaining the project to her, she stated she wants to keep coming to the group, so we will follow this up.” *(Facilitator 1, Group C, Week 3)*

The benefits of the group are expressed in the following extract from a transcript:

“Facilitator 4: How do you cope, Adeline, when you are feeling down?

Adeline: Oh, it is hard.

Facilitator 4: It is hard? Because you’re feeling fairly down at the moment, aren’t you?”
Adeline: Yeah.
Facilitator 4: And yet what is wonderful today is that you have come to join us in this group.
Adeline: Yeah.
Facilitator 4: Do you feel any support from a group like this?
Adeline: Yeah.
Facilitator 4: How do you think this group might be able to help you? Help you to cope. What is it about coming along to a group like this?
Adeline: It takes away what worries me.
Facilitator 4: Yes, yeah.
AF 4: What is it that worries you?
Adeline: Mm?
AF 4: Do you know what it is that worries you?
Adeline: I don’t know.
AF 4: You don’t know?
Adeline: No.
AF 4: It’s nice to listen to someone else’s worries as well?
Adeline: Yeah.
Facilitator 4: Perhaps in a group there’s not the same sense of loneliness?
Adeline: No.
Facilitator 4: Because I think certainly one of the traps in living in a community is you can chuck yourself away in a room, can’t you. And choose to remain isolated. So, it is wonderful that you have come along today.
Adeline: Yeah.
Facilitator 4: And maybe you can see this as a tool to be able to cope in difficult times.
Adeline: Yeah.
Carrie: Share your troubles.”

b) Relationship with God
For Christians, this is an important theme that was recorded in all groups. Contact with family is sometimes important in supporting people in their faith journey:

“Her daughter appeared before we began the session – I have had previous contact with her and she is very anxious about her mother. Following the session I again met her and she explained that her mother had drifted away from her religion (Catholic) and that it is wonderful she is now at peace in being in contact with it again.” (Facilitator 1, Group C, Week 2)

“Facilitator 4: God, who we can’t see. How can we think of God having his hands on our lives? Well, I think Adeline in her story just answered it. If we can’t see God, how is God’s hands touching our lives, do you think?
Alice: You feel his presence, don’t you?
Facilitator 4: Yes, he is there. But there is more direct things. More directly, when AF 2 encourages you to join in. Well, these are God’s hands in your life. Encouraging, lifting you and supporting you. You can think of God acting in your life through the love of friends.
Beatrice: That’s true.
All: Yes.”

In group C, the facilitator had done in-depth interviews with each of the participants prior to the groups beginning and had valuable background to their spiritual and religious practices.

“Facilitator 1: Any ideas, Adam?
Adam: God? I don’t think about it really.
Facilitator 1: I remember you saying, ephemeral was the word that you used.
Adam: Ephemeral, yes.
Facilitator 1: That’s a good word, isn’t it?
Adam: I think so.
Facilitator 1: Mystery. One of the images of course that Jesus gave us about what God is like is a shepherd, that’s Psalm 23.
Pauline: The Lord is my shepherd.
Laura: ‘The shepherd watched his flock by night’, isn’t that a song?
Facilitator 1: That’s right, a Christmas carol.
Laura: The shepherd watched his flock by night. I forget all the words; you know the first lot, and you forget the other.
Facilitator 1: ‘The angel of the Lord appeared in glory, shone around’ This might be a different translation from the one you’re used to – ‘the Lord is my shepherd, I shall not want, he makes me lie down in green pastures’.
Laura: ‘The Lord is my shepherd I shall not want, he makes me lie down in green pastures (speaking with Facilitator 1) That’s it. Right through to me there.
Pauline: ‘… still waters, he restores my soul’.
Facilitator 1: … even though I walk through the darkest valley, I fear no evil, you are with me…’
Laura: ‘…the kingdom, the power and the glory, for ever and ever, Amen’.
Pauline: I used to do it at school over and over and over. (laughs)
Facilitator 1: ‘Your rod and your staff, they comfort me’. To music too, I think they sang it at the Queen’s coronation. (singing song) That’s a very familiar one, isn’t it?
Laura: Yes.
Facilitator 1: Yes, it sure is. Do you think your ideas about what God is like have changed over the years? For some people it might mean that they no longer believe in God, or maybe for some people their faith has grown stronger? Do you think your ideas about what God is like have changed?
Pauline: Probably I think.
Laura: I don’t know. It could.
Facilitator 1: Any ideas how?
Pauline: I think I’ve changed considerably since I grew up. Let’s face it, you think about things, when you’re a child, you just take what people tell you as being correct, don’t you. When you grow up you think for yourself, or you should anyway.
Facilitator 1: Yes, that’s right you start questioning things. Good point. What about you Rebecca, do you think your ideas about what God is like have changed?
Rebecca: Still the same. When you’re praying every day.
Pauline: I think as you grow up you don’t give it too much thought. I don’t think so, no. When you’re a child you do, but I don’t think when you’re grown up you give it a great deal of thought as to what God is like. It’s just that things happen and things don’t happen, I don’t know really who makes them happen though.
Facilitator 1: What about you Harriet, do you think your ideas about God change as you grow up and get older?
Harriet: Yes, I do. When you’re a child you think like a child, but when you grow up, your thoughts are more mature.
Pauline: When you grow up you have to think for yourself, don’t you.
Harriet: And I think I think more about it, and I think there must be some aftermath, it can’t be a nothing, it must be a something, and all will be revealed, I suppose, I think it probably will. Your thoughts change as you grow older because you mature, naturally you think differently, you’re more mature.”

c) Touch

Touch is recognised as important in establishing connections between people; in cases where communication is difficult, touch becomes even more important.

From the RA Journal for group D:

“Arthur comments on the evolution of the human species regarding the gesture of embrace and the need to touch and connect with another. In part Arthur’s comment was prompted by Facilitator 3’s reference to the image regarding the Prodigal Son.”

The sensation of touch is appreciated by participants in this example:

“Winifred holds the scarf up to her face to feel the texture of the silk before she passes it onto Jeanette. As the scarf is passed around the group, Facilitator 3 informs the participants of the scarf’s history.”

d) Giving and receiving

In the theme of being grateful, some spoke of giving, others of receiving:

“Well I gave [my daughter] – she’s got a lot and then I bought all new down there, and then the lady who put the Gardenias in for me, she’s in hospital, she’s had a hysterectomy, so she won’t be back another four weeks, I bought her a little crown with bells on and green and gold and some lovely smelling soap and a little – you know the cardboard boxes you can buy with little, you know what I mean? Wrapping and you put *
Facilitator 1: Yes, in a little gift bag.
Pearl: Well somebody gave me one so I put them in there.
Facilitator 1: Nice.
Pearl: And then the lady that gave me this outfit, I gave her another one.”

e) Forgiveness
The theme of forgiveness is an important one and especially for older people. A large number of instances were found in the pastoral care program’s responses. There were marked differences between group responses to the themes in the program. In some groups, there was deep discussion of issues around forgiveness, while in other groups, there was very little response at all. It is noted that the groups had very similar starting points in cognitive levels (see Table 7). It is also noted that, although the group numbers were too small to measure statistical significance, depression levels rose in the groups that did not discuss forgiveness and fell in the group that discussed this concept more deeply:

“Interesting discussions developed in regard to family frictions, following on from the Gospel reading, especially on the part of Pauline. She also spoke about the difficulties in forgetting and forgiving.” (Facilitator 1, Group C, Week 9)

In contrast, in another group the following comment was made in the facilitator journal:

“Both groups were happy to respond to the theme of Peace with their own comments. The comments and stories relating to forgiveness were listened to but comments were not forthcoming. This has happened on previous occasions. No personal comments were made relating to forgiveness.” (Facilitator 3, Group E, Week 15)

We suspect that the type of communication used within the group can be very influential in supporting or blocking communication of these deeper topics and issues. There has to be a real and perceived atmosphere of trust and respect, and the dignity of the people present affirmed. As well, the facilitator needs to have an expectation that the people will be able to participate, or the conversation may well remain on more surface content. In the area of forgiveness, this can only be discussed when the person feels accepted and affirmed.

In contrast, within another group the following extract from the transcript is opening up the topic of forgiveness:

“Alice: I heard the footballers talking the other day and I think they were people who, you know, who control the game as it goes on. And somebody apparently had upset somebody in the past – 1946 – and he was still carrying that with him – and he was just waiting for the opportunity to get even.
Facilitator 1: Yeah?
Alice: What a miserable life would that be?!
Facilitator 1: Oh that’s for sure! Yeah, yeah. That’s right. It’s a funny thing these days too isn’t it? That’s, sometimes you see people who have had some crime committed against them which must be terrible, but they seem to think that
once the person goes to court and is put in jail or whatever, everything’s going to be ok. But they haven’t solved it in their own hearts sometimes. Mmm – it’s a bit of that ‘eye for an eye, tooth for a tooth’ kind of thinking I think. Yeah.

Alice: Yes carrying things with you like that – you’re not going to get peace out of that sort of thing.

Facilitator 1: No. that’s right. Yeah, yeah. So that’s why I was reading the story of the prodigal son before. You know it’s just such a beautiful example of how um, of the father in the story being like God and welcoming the son back, welcoming us back with open arms.

Alice: That right.

Facilitator 1: Yeah - no matter what we’ve done. Even if we’ve spent all our inheritance and gone away and end up feeding the pigs. That would have been the worst thing, wouldn’t it? For the Jewish people – to be feeding there, feeding the pigs.

(sounds of agreement)

Alice: And the thing that the father did before the son even got to the house before any of the servants saw him in such an utterable misery as he was. The father brought the best robe and put a ring on his finger and shoes on his feet and made him look presentable before he even got to the house, so that the general run of people wouldn’t know what a wretched situation he’d come to.

Facilitator 1: Yeah –that’s beautiful. I hadn’t thought of it like that, Alice.

Alice: Yes – the father thought about all that before he got him to the house.

Facilitator 1: Now that’s beautiful – what a lovely insight.”

“Alice: That’s like with Jesus. He says – I’ll remember your sins no more. They’re at the depths of the sea.”

In the following extract from the transcripts for week 3 of Group B, the facilitator gently leads the group through the implications of the story of the Prodigal Son. It is clear that his expectations of the group are that they will be able to follow him and interact with him. These group members have very similar levels of cognitive impairment as the other groups in the study, yet, they are able to interact effectively within the group.

“Facilitator 4: But the father has resolved it. Amelia, what has the father done there?

Amelia: Forgiveness.

Adeline, Carrie: Yeah. Of course.

Facilitator 4: Was it forgiveness over time or was it immediate. What was happening there?

(quiet)

Facilitator 4: I’ll read it again.

(reads the last passage again)

Facilitator 4: What’s happening there, Carrie?

Carrie: He has forgiven his son and apparently the son is a changed man. He has found God I would say.

Facilitator 4: He is welcomed back by his father.
Carrie: He is welcomed back. I don’t know about the mother.
Facilitator 4: No, it seems a bit silly just to talk about fathers and sons here when you are all ladies.
(laughter)
Facilitator 4: But it could work equally well with a mother and daughter. A sense of immediate welcome, and immediate forgiveness and an abundance of forgiveness.
Carrie: Of course, of course.
Facilitator 4: And from that comes a sense of peace and celebration and the child he is instantly welcomed back…
Carrie: Yes
Facilitator 4: …and the father is not worried about what has caused the rift, he is just overjoyed to have him back.
Carrie: He is forgiven.
Facilitator 4: When you hear a story like that, what does that make you feel?
Carrie: (mumbling) Feel happy and you pray to God for help. And that would make you really well, a really different person, wouldn’t you. Feel wonderful.
AF 2: The love for your children is so strong, isn’t it. You will forgive them anything.
Carrie: Yes
Facilitator 4: The father’s anxiety there seems to be overcome the second he sees the child. All this anxiety seems to melt away.
Carrie: Seems to melt away.
Facilitator 4: He acquires a sense of peace just to see him.
Carrie: Just to see him would be enough.”

How can these people with dementia be assisted to come to a level of wholeness and forgiveness, to come to a place of peace in their lives? The following example from one of the transcripts shows this in action. It is noted that by this point, the group had been meeting weekly for 14 weeks, so their trust within the group would have had the chance to grow, or not, depending very much on the quality of group interactions over the weeks:

“AF 2: Hey, I have a nice little quotation here on forgiveness. “Forgiving is not something you do for someone else. It is not even something you do because you should, according to the standards of religious belief or human decency. Forgiving is something that you do for yourself. It is one way of becoming the person you were created to be--and fulfilling God's dream of you is the only way to true wholeness and happiness. You need to forgive so you can move forward with life. An unforgiven injury binds you to a time and place that someone else has chosen; it holds you trapped in a past moment and in an old feeling”
Adeline: That’s true.
AF 2: That’s true isn’t it.
(All nodding.)
AF 2: Can you relate to that one? Amelia, can you relate to any of that?
Amelia: Some of it
AF 2: Some of it?
Amelia: Yeah
AF 2: Have you got something in the past you needed to forgive and when you finally did you can look back and think, well I needed to do that now I can move on.
Adeline: Yes
AF 2: Yeah?
Adeline: Yes.”

f) Pain and anger in relationship – un-forgiveness
Issues of un-forgiveness can prevent spiritual growth in the later years (MacKinlay 2006). Being hurt may be hard to forgive, but the issue remains until it can somehow be let go.

“Adeline: I have problems with my daughter and my son. They do not communicate very well *. That upsets me. And I tried to talk to her on the phone yesterday. But she lets it ring out because she knows my number and that upsets me * . My son’s got four children and always goes crook on me because I’m always crying. And a son is a son until he takes a wife.”

“Facilitator 4: ….some changes that have brought great sorrow to your lives. Think…you don’t have to share the experiences necessarily if you like, but can you think of how you coped in those times? In those times of sorrow, of despair or tragedy.
Beatrice: I cried a lot.
Facilitator 4: So crying?
Beatrice: Yes.
Facilitator 4: Was that something that was helpful, Beatrice?
Beatrice: I don’t know, it just comes.
Facilitator 4: Does it, yes.
Beatrice: You feel sad and…you just…actually it broke my heart…and I vowed I would never have another man. …
Facilitator 4: Mm. Mm
Beatrice: I’ve had a couple of choices…but no, thank you.”

g) Connecting with family - story
This is an important sub-theme with many entries. Story is an important component of how we find our identity and being within a family. Story is central to our individual identity; it is a changing and developing story with ourselves as the authors, and yet, in many ways, with the listeners as co-authors. Stories need to be told and listened to. The story is, for each of us, a work in progress (Kenyon 2003). In many respects, it is interesting that the transcripts often contained fairly short and superficial particles of stories, yet in two of the groups (groups A and B), the stories emerged much more readily. It is a way of expressing meanings and in line with this, many of the items relating to family are in the context of story:

“Facilitator 4: What are some of the things you are proud of in them?
Carrie: Well, their work especially. They’ve done very well with their work. Excellent.
Facilitator 4: What do you mean, done well?
Carrie: Done very well in their choice of work and they’ve done well with it. They are able to do it. Excellent, I think. I’m real proud of them, every one of them. They’ve got on well. I’ve got no problem at all.
Facilitator 4: That must give you a great sense of hope.
Carrie: Yes, one is an electrician, one is an electrician worker. They don’t drink and they don’t smoke. It’s good, I’m pleased about that part. Both, the two elder ones have done very well with their work and yeah... One is an electrician and he is the manager of two shops.... I’m very proud of him and he is my youngest one and he comes to see me, and he gives me a kiss every time, and that doesn’t happy very often.

(laughter)
Carrie: Always does it, never misses it. I’m very proud of him. When my husband was very sick and in bed he used to come after work in the evening and pick [him] out of the bed where he was and he’d pick him up as a little baby and then put him to bed then go back home. I was proud of him because not many men would have done that. It was a wonderful thing. It was one way of showing his love for his father.
Facilitator 4: Yes. It’s lovely to hear that sound of joy and pride in your voice as you share those stories.

Beatrice: I was sorry I didn’t have any boys. There are no boys in the family. My grandmother had two boys and they died and she had four girls. And then her eldest daughters died. But my grandmother she never liked me and she liked my sister, but then again she knew my sister when she was little and I came eight years later and there were other kids that came up in between. We went somewhere, I forget where it was but there was a brick wall and it had holes in it. If you put your hand through you’d get a present. I’ve put mine in and got a present and she snatched it from me and said you’ve got a father. I didn’t think it mattered whether you had a father or not. Mum said, let it go. And I said, it’s not right. I could not understand that part of the family. They were always jealous of Mum and Mum had the least education of all of them. And one worked with machines, something similar to computers. Auntie was taught that, one was taught the piano, one was taught singing. And Mum was taught nothing. Because Mum had a husband they thought she had everything, but she didn’t. She had a happier life than they did.

Adeline: Some people choose to be like that.

Beatrice: Yeah!

Adeline: * dad worked for the Shire Council, he cut sleepers for a long time and cut wood for other people and our treat was a bag of lollies Friday night. And he used to camp away a lot. He built Frogs Hollow Bridge, he built the Brogo bridge. He was always doing something, and all of a sudden then he got very sick and he was bleeding internally and it was the aorta. And I was called by the hospital and they said come on Adeline, he is asking for you. And he had * it was stopping the blood from running down. He died a terrible death. He was 81, and mum was 92. She died in a nursing home. But dad died a terrible death.
Facilitator 4: That’s hard,
Adeline: Yeah. And we went up to Canberra. And they took him in an air ambulance. And the Chinese doctor was so wonderful. He said I hate to say it but he will never get over it. He was a wonderful dad.
Facilitator 4: Are there things in life that you deliberately try and copy from your dad’s qualities?
Adeline: Yes. Honesty, gratefulness, peace.
Facilitator 4: Inner peace?
Adeline: That came on to me. I was having nervous breakdown after nervous breakdown and now they’ve got me on the right drug. My father was a very nervous man. I just, they set me up on *, I couldn’t hold a cup of tea, they ran me through something. I said, it’s the lithium, take me off it. And they did, and I’ve never looked back. I haven’t been back in two years.”

Elsie spoke of the isolation of her family when they migrated to Australia and the need to be resilient in hard times: “…talked about what keeps people going in difficult times. Elsie continues to believe you just have to keep going, and to state that she hasn’t had many difficult times in her life. Her hopes were about “family together”, the closeness of her family. When we talked about what keeps people going in the tough times Ethel mentioned that her parents came to Australia not having any connections here.” (Facilitator 1, Group A, Week 10)

In all groups, the participants spoke of many different family members, spouses, children, grand children and great grandchildren; they spoke of extended family and events that connected them across the years. They spoke of newborn babies and of their own parents. For many, the relationship with their now deceased parents was a continuing one, as described by de Vries (2001). They also spoke of special family times of Easter and Christmas, when families gathered, and of weddings and funerals.

h) Joy of babies and children
Most of the comments in this large sub-theme affirmed the joy of seeing babies and small children.

“What is it about looking after babies that you enjoy?”
Rhoda: Oh with babies?
Facilitator 4: Mm.
Rhoda: I think they’re all beautiful.
Facilitator 4: Yes.
Adeline: Yeah.
Rhoda: It doesn’t matter what they look like or anything, they’re beautiful.
Facilitator 4: Mmm. Yeah.
AF 2: They are so innocent.
Rhoda: *…that I have come across.
AF 2: They’re so innocent aren’t they. They’re so pure and innocent?
Rhoda: Ehh?
**AF 2:** There’s nothing wrong with them. They’re perfect…they’re innocent aren’t they.

**Rhoda:** And if someone asked me would I...could I look after their baby when I was, you know...before I came here...and I’d look after their baby while they were out or..yeah…”

**i) Friends**

There were many entries in this sub-theme. The theme took in a wide variety of situations, long lasting friendships, joy of friends, of betrayal by friends. The importance of friends now, in their later life, was also spoken of.

**j) Animals and pets**

This sub-theme was mostly about various dogs and cats, most of the stories came from groups D and E.

5.2.4.4. **Meaning in life**

Deepest life meaning is what makes life worth living, and touches into the spiritual domain. In this program of pastoral care, meaning is seen in the main themes of response to meaning, relationship (which is almost synonymous with meaning for people with dementia (Hughes, Louw & Sabat 2006; MacKinlay 2006)) and in the struggles towards transcendence, and finally in the theme of hope and fear. Faith and life story were strong sub-themes, such as in the extract below on faith.

“The thing we learned at Sunday school is God is love and we are his little children. God is love and we should be like him.

**Facilitator 1:** And Alice, wasn’t that lovely to grow up with that, knowing that all through your life?

**Alice:** Yes, that’s the beginning of my recollection of everything we heard about God. That he was the Father and Jesus was the one who was to come and bring salvation.

**Facilitator 1:** That’s so lovely.

**Alice:** We had to wait for that.

**Facilitator 1:** That’s a blessing, isn’t it?

**Alice:** We are now in the waiting time, almost at the end of waiting time.

**Facilitator 1:** Waiting patiently

**Alice:** Yes. When you see things happening that have been prophesied in the Bible, you go through Matthew 4, and all the things that Jesus warned them about. When the disciples said to him, when shall these things be? What’s sign of coming? When is it going to happen, and he explained it all to them, but they were still pretty thick in the skull, and they didn’t accept all that he said, because, again he used parable, and he mixed up his first coming and the destruction of Jerusalem, he combined them into his second coming, when he would come for the salvation of those who were faithful, that believe in him.

**Facilitator 1:** That’s right, and that was a blessing, Alice, to grow up with that understanding of God as love, isn’t it?

**Alice:** Oh yes.

**Facilitator 1:** Yeah, I think I was saying about that picture…sorry Alice.
Alice: Yes, it was always an amazement to me, being brought up with the idea that God is love and Jesus was His son, and all the stories of his healing, and the help that he gave them when he did come. Then the scribes and the Pharisees came and said, well show us a sign, and we will believe you, and all the hundreds of signs that he gave them day after day after day, and they still came and asked him for a sign. And he just turned away from them and said, well if you're so dumb you can’t see these signs, I’m not going to tell you any more.

Facilitator 1: Yeah, I suppose it’s like that for us now, isn’t it, we’ve got signs around us of God’s love.

Alice: So many, I mean, when you think of the earthquakes and the tsunami, and all the things that are happening in our day at our own time.

Facilitator 1: Yes. And all the beautiful things around us, like we talked last week about nature, didn’t we, and we talked about that poem, My Country, by Dorothea McKellar, and all the things that she loved in Australia, you know that one, I love a sun burnt country.

Alice: That’s right.

Facilitator 1: Yeah, a land of sweeping plains. So many signs around us that God is with us.

Alice: Yes, we know it’s going to be destroyed in the end, but God still hasn’t withdrawn all the signs and beauty that He’s given us.

Facilitator 1: That’s beautiful.

Alice: Even though the human beings are making such a mess of everything, he still maintains enough beauty to keep the ones that do believe, sort of, realising that He’s still the same God, the God of love, but this idea of, that God is there with a big stick, and all that sort of thing, is, you know, a time for judgement, forget about the judgement and attend to what He tells us, I think it’d be the answer to most of our problems.

Facilitator 1: You’re a wise woman, Alice.

Alice: It all comes out of the Book, it’s all there for us to see. Trouble is, so many people don’t read it.”

In the sub-theme of life story/reminiscence, there were many rich examples that tied to the identity of the person. In fact this was such a large sub-theme that there were 745 references in the qualitative data related to story.

5.2.4.5. Response to meaning

The way we respond to life is influenced by where we see meaning, if despair lies at the centre of our being, then we will respond to all of life from that attitude, on the other hand, if joy and hope lie at our centre, then we will respond to life through that (MacKinlay 2006).

a) Gratitude and blessings

This sub theme contained a number of different aspects of gratitude, including being grateful for being able to live in Australia (a participant who had migrated to Australia), grateful for a beautiful day, for family and friends, for living in peace and ‘practically everything’. Others mentioned having good health as a source of gratitude. Some expressed the opinion that we may take things too much for granted.
“AF 2: Do you remember the first one we did, we wrote on our leaves? And I’ll just remind you of what you wrote. “I am grateful for the wonderful country we live in.” and “I am grateful for everyone and love being here.”

Adeline: That was me.

AF 2: Actually, I think that was Carrie. That was Carrie. Isn’t it lovely?

Adeline: Mm.

AF 2: “I am grateful for sharing time and holidays by the coast”.

RA 3: Mary.

AF 2: Mary, yeah. Do you remember saying that, Mary?

(Mary nods)

AF 2: “I am grateful for my family and the love we share”. Was that you Amelia?

Amelia: Hm?

AF 2: “I am grateful for my family and the love we share”.

Amelia: I don’t know.

AF 2: Do you remember? It is a lovely, isn’t it.

Adeline: I didn’t get one of those.

AF 2: You did. I remember you doing it. “I am grateful to be alive and I love where I am”. That was you.

Beatrice: Was that me?

AF 2: That was you. (Beatrice and AF 2 laugh) And I don’t think Rhoda was here that day. So we’ve got some more and we’ll write some more before we end off today. But let me just start with this.

Adeline: What was mine?

AF 2: You weren’t here that first day either, Adeline.

Adeline: All right.

AF 2: So well get some more and we’ll hang them on our tree. Right, to start off with, listen to this one and see what jumps out at you.”

People are not always able to respond with gratitude, as in the following extract:

“Sara: Starting each morning with an attitude of gratitude. I’m afraid I haven’t felt like that. No matter what the circumstances can splash joy over the rest of your day. How I rejoice in the Lord how he has blessed me.

Facilitator 3: So your morning didn’t quite start off with an attitude of gratitude is that right?

Sara: No, I thought what’s God blessing me with, these horrible things.

Facilitator 3: Yes. So we’ll see how the rest of the morning goes.

AF 3: I think we’re sort of getting back to the beginning.

Facilitator 3: It’s gorgeous isn’t it.”

b) Image of God

What is God like? There was discussion within groups about the character of God. The discussion mostly led by facilitators, with little input from participants, but again, the responses varied between groups. The following is an example of how one group worked with this concept:
“Facilitator 4: We were playing with the playdoh and trying to make images of God.
Adeline: Yeah
Facilitator 4: Thinking about images of God in our own life. And this week are going to be taking up the next step, and thinking about aspects of God character, if you like.”

c) Use of rituals
Rituals, both religious and secular are important marking points and pointers to meaning in life. Rituals around Christian liturgical seasons were discussed:

“Facilitator 1: Yeah. Is that, I think the whole thing about Advent, is about, it means coming. So that's about coming and the coming of Jesus at Christmas and about expectation and about hope and looking forward.
Alice: Yes. The coming of Jesus and when he returns.”

“Harriet: Why do we always light candles?
Facilitator 1: I think it helps create a bit of an atmosphere.
Harriet: Spirit of Life?
Facilitator 1: Yes. Like you were saying before about peaceful atmosphere, it’s important to have a peaceful atmosphere around us and I think just little symbols like that help create that.
Harriet: Yes, perhaps they do. They – I mean it’s very prominent in churches isn’t it?
Facilitator 1: Yes.
Harriet: It wouldn’t be a church if it didn’t have candles alight in it. I think that’s one of the great attractions. I suppose it’s the Spirit of Light. Without it the church is dark isn’t it?”

d) Attending church
A number of participants spoke of attending Sunday school, and some spoke of attending church when they were younger.

e) Recalling - anticipating
Staff seemed to be surprised that some group members remembered the group of which they were a part. There were a number of reports of participants looking forward to coming.
The Facilitator for Group D reports on an interesting incident that affirms a growing view that people with dementia are more likely to remember meaningful incidents:

“About 4.20 pm, Faye approached Facilitator 1 in Hostel Community area. She said seeing me reminded her of the seedlings this morning. She continued across room and looked at the seedlings lined up near the window. This surprised me, as I often find that Faye has forgotten recent details and looks rather vague. Faye did not offer comments about the conversations or theme rather remembered the enjoyable, practical experience of planting. She said was anticipating beautiful
flowers. This could be seen as a link with a previous theme of hope and expectation. Rather than discussing the theme, she was experiencing it first-hand.” (Facilitator 3, Group D, Week 14)

f) Interests and the arts
Other interests that were spoken of in the groups included knitting, art, music and football.

5.2.4.6. Transcendence
Transcendence is a spiritual task and process of ageing (MacKinlay 2006). There are a number of factors that may influence the development of transcendence, including increasing frailty and disability, decreasing energy levels and living with chronic illnesses. A number of these issues were discussed within the groups. Transcendence is a way of growing spiritually, of moving beyond the difficulties of ageing, and a real part of this is the way people respond to loss and disability, their attitudes may lead to denial and becoming stuck, or may lead to continuing growth in spirituality.

a) Hard things and strength remembered
Most of the hard things remembered related to war, especially WWI and bushfires, floods and other similar crisis situations. One example of hard experiences being remembered from Group A, see below.

Memories of hard things:
“Facilitator 1: That would’ve been hard work.
Alice: Yes, but my brother he was mentally afflicted somehow or other, he wasn’t at the war, he only worked in Australia, but eventually he got a TPI, and yet those who had been to the war and been wounded, and sent home as wounded soldiers, couldn’t get a pension.
Facilitator 1: I think the fact that your generation, I’m not that far behind you, but your generation had been through tough times, like 2 world wars and the Great Depression, it’s made you very strong people. Very wise people and resilient people, on the whole. I think a lot of strength can come out of the hard times, too, can’t it?
Alice: That’s the difficult part, I think, to go through war and then come back to a peaceful position, you know, in the homeland.
Facilitator 1: Yes, and adjust again to an ordinary kind of life.
Alice: And readjust. They had to readjust. They had to wipe out all those memories and all those horrors that they’d been through, lived through, and then to come home and settle down and be a peaceful man again. What a terrible transition it must have been.
Facilitator 1: Yes, and some of them just couldn’t do that, could they?
Alice: They couldn’t, some of them.
Facilitator 1: No, and some of them just couldn’t talk about it, could they?
Alice: No, some of them never talked about it. A day like we just had, Armistice Day, the 11th, and they get half-full, and then they loosen their tongues and talk, but apart from that, it’s totally non-speakable sort of thing.”
“**Facilitator 1:** Can you think of any times like that Laura, when you’ve gone through some pretty tough times and then afterwards you think; something good comes out of it?

**Laura:** Yes, I did.

**Cora:** * live on, all those years back.

**Facilitator 1:** All those experiences. What about happy people you have known, if I ask you about happy people you have known, can you think of any people that come to mind straight away?

**Pauline:** Oh yes I think I do, friends I think are very happy people. Not a lot of them, but one or two I think who are very happy, who are very lucky to be happy, aren’t they.

**Laura:** It’s very good down here though, because when you’re going down, someone will go past you and say ‘good afternoon, how are you?’ a gentleman, don’t even know who they are, we just say ‘hello’.”

**b) Humour**

The best humour came spontaneously from the group members, as in the following example:

“**Facilitator 1:** Well welcome. Are we right RA 4? Are we right? Goodness gracious. It’s lovely to be here again. It’s lovely to be with you again. I really enjoyed getting together last week.

**Laura:** That’s how you’re getting older quicker.

**Facilitator 1:** Is that what it means?

*(laughter)*

**Facilitator 1:** We had a lovely chat last week about – well the first week we talked about things we’re grateful for and last week we talked about images of God, how we see God, and we talked about Jeremiah the prophet, talking about going down to the potter’s house and seeing the potter making the clay, vases and things and we thought, well, that’s a bit what God’s like. Like the potter at the wheel, making something. When it doesn’t quite work out He can reshape it and make it again and make it even more beautiful and that’s just what we’re like in God’s hands. Things aren’t working so well in our lives, God can reshape them, make them even better.

*(laughter)*

**Facilitator 1:** It’s a nice image isn’t it?

**Rebecca:** Oh yes.

**Laura:** Yes.

**Facilitator 1:** Today I thought we would gain a bit of that.

**Pauline:** Am I supposed to be here or not?

**Facilitator 1:** Yes, I’ve missed you, that’s lovely.

**Pauline:** Someone said something about a meeting or something.

**Facilitator 1:** Oh good on you. It’s lovely you’re here. It’s even more cosy now. I didn’t go and get you because you were lying on your bed, and I thought you weren’t well. It’s good you’re here.

**Laura:** I’ve been sitting here talking to myself and I get good answers back.

**Facilitator 1:** We only just started. We were thinking…
(exchanges re seating arrangements between Laura and Pauline)

Laura: Well this is the best fun I’ve had here since I’ve been here. Every morning – because my room is just over there – and I look out there and I talk to myself.

Facilitator 1: Do you?
Laura: I get good answers back.
Pauline: Strange don’t we all.
Laura: And then I go crook about my husband not being there because he passed away.
Rebecca: Oh gosh.
Laura: He lived over there, or we lived over there, and I see a photo of him and I say, “Malcolm, if you were here today I could clobber you.” Malcolm’s been gone nearly a year and a half now.
Facilitator 1: You would miss him Laura.
Laura: Goes quick doesn’t it?”

Memory loss and insight
Memory loss was treated differently by participants and by staff, some admitting to it readily, others denying.

“It would appear that their names are a crutch she holds on to with her memory failing. When I asked her about children she couldn’t remember if she had any. I suggested we would look at the photos in her room afterwards and she appeared happy with this, after saying “this is terrible” – not being able to remember.” (Facilitator 1, Group C, Week 1)

“Pauline appears to hide her loss of memory with brusqueness.” (Facilitator 1, Group C, Week 5)

“Cora also asked why some people’s memories cause them to repeat themselves, when Harriet repeated the story of her mother combing the hair of the four girls as children.” (Facilitator 1, Group C, Week 6)

d) Health
This was a minor sub-theme in respect to number of references. Only some chronic illnesses that participants live with were mentioned, but not discussed at length in the groups.

e) Distress, anger and despair
There is a need to be sensitive to resident needs and wishes. It is very important to ensure that potential participants understand and can accept what is happening about them. People with dementia who are agitated may become more distressed by perceiving to be pushed into any activity or group. This is challenging as their very participation in a group may have the potential to reduce their agitation.

“We believed that the negativity, particularly of Abigail and John, would be upsetting for the latter group.” (Facilitator 1, Group C, Week 1)
“I was also intrigued that in spite of their negativity towards religion and belief in God, they live in a Catholic facility and apparently occasionally attend services. I am wondering if this is their choice or is due to over-enthusiasm on the part of pastoral carers!” (Facilitator 1, Group C, Week 1)

“Our previous encounters with Abigail and John had been difficult, with John walking out during testing. The previous week we had tried to start the groups, but none of the residents was available [sic]. Abigail and John had walked off, after an initial conversation, when they saw the pastoral carer, believing the group to be connected to “church”. In this session John frequently encouraged his wife to leave with him and finally walked out with her.” (Facilitator 1, Group C, Week 1)

Arthur has strong pre-existing issues that relate to his initial placement in an ACF.

“Arthur was withdrawn and sat hunched on his chair, he gave the impression that he did not want to be there.” (Facilitator 3, Group D, Week 2)

“Arthur had a difficult start to the day. He was in denial of his need of showering. Negative words were exchanged. Unit staff asked AF 3, an assisting facilitator and new chaplain to encourage Arthur to shower. Her intervention was greeted negatively. This was discussed with facilitator.” (Facilitator 3, Group D, Week 3)

“Arthur took the opportunity to express his continuing dissatisfaction of living in an ACF. Rather than fill out individual sheets concerning mood identification, it was done as a group effort today. Arthur’s comment was noted by other residents. A short silence followed. Other residents were given the opportunity to express their thoughts. Residents continue to give a consistent comment. Edward talked at length of working with the Staff and accepting their assistance. The others also recognize they require support but did not express their thoughts in such negative terms.” (Facilitator 3, Group D, Week 17)

These issues were also conveyed in the conversations in the sessions, as in these two excerpts, from weeks 1 and 17, respectively.

“Facilitator 3: They’re nice? Ok, if you can’t think of anything else we’ll include my blue eyes later
Arthur: Yes, well I like Autumn
Facilitator 3: You like Autumn? Yes, yeah. And how does that make you feel when you’re in Autumn?
Arthur: Well, locked in this damn place I can’t feel it
Facilitator 3: Yeah, we don’t get out enough sometimes do we?
Arthur: No, no.”
“Facilitator 3: Getting there, okay. What about you, Arthur, how are you feeling at the moment? You're sitting with the sun shining on you.
Arthur: I hate this bloody place. I hate it.
Facilitator 3: It's really difficult, isn't it? Yes. Do you find, or have you found, that just having some programs and some different things, does that sort of help you a bit?
Arthur: My own entertainment helps me.”

f) Letting go of responsibilities
This is part of the concept of transcendence, of moving from human doing to human being and becoming, as the interchange below illustrates.

“Mary: You’re lucky you don’t have to do that now.”

“Facilitator 4: Oh, is that right, yes. Mm. And yet, this must have been…even this move to… a comfortable and lazy life as you say. It must a big wrench to leave the family home and move to the hostel here. How did you cope with that big change in your life, moving from your farm to your little unit here? How did you cope?
Mary: Oh, quite easy.
Facilitator 4: What made it easy.
Mary: Eh?
Facilitator 4: What made it easy.
Mary: I don’t know. It was altogether different. So it was.
Facilitator 4: What were some of the differences?
Mary: Mm?
Facilitator 4: What were some of the differences? Between your life at the farm and here. What were some the big differences that you noticed immediately?
Mary: Don’t know.
Facilitator 4: No.
Mary: Too many * to tell you. (laughs)
Facilitator 4: Okay.
RA 3: You don’t have to cook here.
Mary: No, I don’t have to cook (laughs)
Facilitator 4: Yes.
RA 3: Do the laundry.
Mary: That’s right. Oh, I didn’t mind it.
Facilitator 4: No.
AF 4: You don’t have to pick up after the kids anymore?
Mary: Eh?”

g) Confusion and disorientation
There were many comments about confusion and disorientation of participants, being unaware of place, time, and being unable to recognise objects.
h) Talking about growing older
The experience of ageing is spoken of, for some older people this is a time of trial associated with disability, for others, the process of transcendence assists them to move to another place of experience, and finding hope, even in the midst of living with chronic illness.

“Facilitator 1: Even if we walk through the darkest valley, God is with us. Rod and staff to comfort me, we’re never alone.

Alice: While we walk with His word, there’s no reason to be doubting anything.

Facilitator 1: That’s right, yeah. Yeah. What do you think some of the harder things are, might be, as you get older? What are some of the tough things?

Alice: Parting families. When you think of all the families, not now so much, not many children in families, but when you think of families of 8 and 9, and then they all grow up, go away, live in different countries, and all I want them to do is come back for Christmas, and they’re all so far spread apart, they can’t get back.

Facilitator 1: Yeah.

Alice: And then the old feeling with Christmas is gone.”

i) Vulnerability / self-sufficiency
There is often a struggle in adjusting to the losses and changes that occur naturally in later life, loss of energy, mobility, and cognitive function. These changes may become catalysts for spiritual growth in the form of transcendence (MacKinlay 2006).

“Alice again spoke about the hurt she experienced in one of the staff telling her to “be independent”. She had mentioned this at the time of the Spiritual Assessment. She is well aware she has had to be independent all her life, following the death of her husband when her son was still very small. She states she wouldn’t have asked for help if she hadn’t really needed it. It is interesting that she has such a strong spirit and this has hurt her so deeply. It would have been difficult for her to ask for help – she recalls proudly the jobs she used to do to help the other residents in her early years at [the facility].” (Facilitator 1, Group A, Week 4)

“Elsie then spoke about her experience of a carer coming in to her room to shower her and choose her clothes. A conversation followed about the pain in losing independence and how important it is for them to keep doing the things they can manage.” (Facilitator 1, Group A, Week 4)

“One lovely contribution to the session was in Harriet telling the story of giving up her licence – at 94! She decided she had an unblemished driving licence and didn’t want to spoil it. Also she said she had money to leave to her children, but she wanted to leave something even more important, that when her son is old he will remember what she did and follow her example in letting go. We talked about the significance of the licence – that it’s not just giving up a card, but a good deal of independence. Pauline also identified strongly with this – she also chose the time to give up her licence. I affirmed their wisdom in making this
decision for themselves. A conversation also arose about money – how good it is to have enough to do the things you want to do. Harriet stated that she had been “selfish” in not sharing hers as much as she should have with those in need.”

(Facilitator 1, Group C, Week 3)

“Facilitator 4: What about you Amelia? What are some of the things that have taken peace away?
Amelia: Being silly.
(laughter)
Amelia: Since I’ve had a stroke, things are different, you know. To get things.
AF 2: And you’ve always been someone who is very organised and in control of everything in your life.”

j) Growing older and changing
Further developments in the process of physical ageing and the possibilities of changing, and growing spiritually, even then, are seen in the exchange below.

“Facilitator 4: What about as you got older in life. Some of you would have experienced wonderful times and some miserable times as some of you have shared with me. Where did you see God? Did your image of God change as you got older?
Beatrice: No
Facilitator 4: It stayed the same for you, Beatrice.
Beatrice: I don’t go to church. I like to say my own prayers at night.
Facilitator 4: So, you have a very personal relationship with God then. God is someone who you can speak to and he is there for you.
Beatrice: Yes
Facilitator 4: All right. Lovely image. Okay. That’s also a good image.”

“Facilitator 4: Is that one of your concerns as you get older, well your children are establishing well now, but their children are the ones who are coming up now. Do you think about how they are getting on in the world?
Adeline: It will be very hard for them, because it is a different era.
Facilitator 4: Do you have a sense of peace about that, Adeline?
Adeline: No, it makes me very anxious. My oldest grandchild will be 12 in March. She has already matured and she is very bright and she knows she is good. She went to the Town Hall playing the recorder, no not the Town Hall, to the Sydney Opera House. And she is very with it.
Facilitator 4: But that doesn’t sound like anxiety to me, you talk with some joy and pride and hope.
Adeline: Also I’m very proud of her.
Facilitator 4: Good, so a sense of pride. Good.”

In this conversation, group members are connecting the growing of spring bulbs with new personal growth, in the broader sense of being.
“Facilitator 3: I think that’s right, so we have a variety, when we think of like spring for instance when Sara was saying she likes the, yeah the new what was it again? 
Sara: The new growth
Facilitator 3: The new growth
Sara: And the flowers that come out
Facilitator 3: And the flowers
Faye: Regeneration, isn’t it?
Edward: Yes. It's just incredibly stupid of us. We should have *.”

k) Joy
The joy of taking a dog for a walk, the joy of grandchildren were some of the joys that participants experienced or had experienced. Being with family and with friends was a joy. Memories of early life and deprivations brought the realisation that joy may not come from material things.

l) Anxiety
Anxiety about the future was expressed by some, anxiety about activities of daily living was another. However, this sub-theme had little content.

5.2.4.7. Hope / fear
Holding hope is life-giving. On the other hand, fear can block emotional and spiritual growth. There are a number of factors involved in the concept of hope.

a) Trust
The following is an example of trust and sharing with others.

“Facilitator 4: What are the sort of things you think maybe in your prayer life, or as you experience life, how is God interacting with you? Is God helping you change to be a different person? Is God helping you to grow? Is God helping you in difficult times to cope? What is God doing in your life?
Adeline: He is there for me all the time. If I don’t go to church. I think it’s bad. Like this afternoon I won’t be able to go because my head is just spinning around.
Facilitator 4: Other people want to share on that? Times when they have seen God very present in their lives. Or helping you coping with a situation or helping you adapt to a situation. You’re nodding, Amelia?
Amelia: We’ve always been brought up to follow God. My husband wasn’t. I’ve been to various sorts of churches. We moved around. We went to the *
Facilitator 4: There are slight differences, isn’t there?
Amelia: That’s right.”

b) Peace
It initially appears that participants cannot respond to the word ‘peace’ however, a rephrasing of the questions elicits insightful comments from participants, as in this excerpt from the RA Journal for Group D:
“Facilitator 3 asks AF 1 about the monument that was erected in Japan in honour of the girl which refers to, Peace.
Facilitator 3 asks the participants to share their memories of peace.
Participants appear to have difficulty in responding. Again there is silence in the room.
Facilitator 3 asks if there are things that take away a sense of peace or a “sense of rest.”
Faye responds by stating, “levels of cruelty and cold blooded intention.”
Facilitator 3 refers to having her sense of peace removed after reading a newspaper article regarding animal cruelty.
Facilitator 3 reframes her earlier question to the group: “perhaps a better question is what gives you a sense of peace?”
Sara responds by stating, “hoping for a better life after this.”
Faye refers to a community and reading the Bible.
Facilitator 3 prompts a response from Amanda. Amanda states, “flowers.”
Facilitator 3 refers to Amanda’s painting skills and Amanda responds by describing her enjoyment of painting.
Facilitator 3 refers to Sara’s husband who painted and asks Sara how she feels when she admires her husband’s paintings. Sara comments on how she enjoys looking at the paintings and how they remind her of her husband.”

c) Passing on to future generations
Part of the tasks of ageing involves what we hand on to the coming generation, what have we learnt that will be of value to them. This has been termed the final life career (Heinz 1994). Another is letting go of things that are no longer possible.

“Carrie: We must always hope for the future.
Facilitator 4: Yes. Hope has a lot to do with the future.
Carrie: You have that to look forward to. Hope for the future. Everyone’s future.
AF 2: And the next generation to enjoy.
Carrie: Of course, Everyone’s future.
Beatrice: I’ve got four great grandchildren, and I’ve got two in Tasmania. (pause) I’ve got some other grandchildren that I can’t take to, isn’t it awful?
Facilitator 4: They live their own lives. What is your hope in that situation?
Beatrice: I hope that when they grow up that *…”

d) Hope and expectation
The following is an example of a session that engages with hope for the participants:

“Facilitator 4: What is hope and what gives you hope in life? That is what we are going to think about today.
AF 2: I just loved that.
Facilitator 4: Look at that.
AF 2: Isn’t that beautiful.
(4 photos are passed around: Martin Luther King, Barack Obama, Ghandi, Black adult hand and white baby hand)
Facilitator 4: These are some photographs that AF 2 put together. Do you recognise this fellow?
Beatrice: mm?
Mary: I’ve seen him around.
AF 2: No, this young man, a young version of this in a way…And I just love this man. This morning I was looking at it and…ahh..I’ll just bring him with me.
(All looking at photographs)
Beatrice: What a difference! (looking at photo of two hands)
AF 2: And this is our new suite.
Facilitator 4: Yes I was admiring that as I came in.
Beatrice: Do you know the story about this fellow?
Facilitator 4: Yes I do.
Beatrice: I have two.
Facilitator 4: Tell us your stories.
Beatrice: My mum used to go to belong to * and meetings, to do with religion. Because her mother, my grandmother, always refers to the Bible and somehow or other his name turned up about how a good fellow he was and somebody chuck him.
Facilitator 4: Yes that’s right.
Beatrice: I think what a wicked thing to do, and because he was *. He educated him a bit. And the same with this fellow here, he is a good fellow too. Just because they’re black that doesn’t mean to say they’re not decent people and I have respect for that fellow.
Facilitator 4: Yes. Both of those men? Which one were you telling the story about?
Beatrice: Arthur Luther King.
Facilitator 4: Yes, Martin Luther King.
Beatrice: And the president of the States.
AF 2: Well done, Beatrice!
Facilitator 4: Yes, that’s Barack Obama. Well done. Because I can recognise faces without always being able to put a name on them.
Beatrice: That’s right, that’s true.
Facilitator 4: Does that happen to you, Beatrice?
Beatrice: Yes, but I happen to know those two!
(laughter)
Facilitator 4: And Amelia you have been enjoying that photograph here.
Amelia: It takes a lot of working out, doesn’t it?
Facilitator 4: What do you see in that photograph? What do you see there?
Amelia: Yes. It is a man’s hand and a baby’s hand, isn’t it?
Facilitator 4: Yes, isn’t it.”

“Facilitator 4: What is it in your life that has given you hope, Rhoda?
Rhoda: I’m just very happy here. And all the friends and ladies are very nice and if you need something you can speak to them, things like that. I find everyone is really nice and no one sort of puts you back.
Facilitator 4: Sometimes hope is a very strong… something within us which sustains us when times are very dark. Where is God in this? This will address
your question, Beatrice, about where we find hope, where God is in hope. Martin Luther King had a number of death threats against him.

**Beatrice:** Yeah.

**Facilitator 4:** And probably his most famous speech “The promised land” speech, the very night before he was murdered. And he speaks in that speech about his own death.”

The concept of seasons of life is introduced to the group:

**“Facilitator 4:** What are the seasons people have seen in their own lives?

**Adeline:** It has turned back to winter, hasn’t it.

**Facilitator 4:** It has outside, but in your lives? Imagine you had the word season instead of time. What have been the seasons in your lives?

**Adeline:** A season to pluck up.

**Facilitator 4:** What does that mean?

**Adeline:** Well, I get up in the morning. AF 2 teaches me exercises and I do exercises before I go in the shower. She is a lovely girl, she is my best friend.

**AF 2:** Thank you. Same here.

**Adeline:** Then I go in the shower, wash my hair and then get on with my life. I go to breakfast.

**Facilitator 4:** It sounds as if you have a pattern in a day. You seem to find that helpful.

**Adeline:** Yeah.

**Facilitator 4:** How is that helpful?

**Adeline:** It is not because you want to do these things, you have to, it’s a must, you’ve got to, no matter how much you might be hurting you can also….you’re also thinking, well if I’m hurt I can’t go on, but I’m not hurting anymore, because I asked Jesus to help me and he has.”

e) Death, dying and grief

Many of the older people in residential aged care have lost all or most of those nearest to them, and they are facing their own ageing and dying. It would be natural to speak of death and dying, but for the widespread denial of death in western societies. Those who work with older people can either facilitate speaking of death, when it is appropriate, or show by their actions and speech, that death should not be spoken of. There were differences in the way the death of a group member was handled, depending on the group facilitator. Therefore, in some groups death was spoken of openly, while in other groups, it was hardly mentioned at all. A number of participants in these groups simply and naturally raised topics of death and dying, for loved ones, and even for pets, for instance:

The following interchange is about dying and dying well, Group A, Week 11:

“**Facilitator 1:** That’s a lovely memory, thanks Pearl, about you were going home to England. That’s lovely. It’s lovely you got back a second time as well.

**Pearl:** We decided to do that. When he left he said we’ll be back again and we did, we went back. That really…we nearly lost him twice because he had a big motorbike accident when he was married the first time but he was only a few
weeks old and I was six or seven. He had all brain damage but they weren’t going to let us immigrate to Australia because of that but we had to go and get a big medical and they gave him special tablets. He used to take fits and they’d rush him to the hospital then one night through the night the priest came and said it was touch and go they took him then. He just died in the chair. * All his clothes. Jumpers, pants and jacket. So I flew across the road to my girlfriend’s place, she was Italian and she was a nurse in Venice. So she came over and she said Pearl, he’s either dead or dying. And that just happened then. On his birthday he played all his tapes and open razor shaved. That was marvellous wasn’t it? Facilitator 1: Yes, peaceful way to go isn’t it?”

And in Group B, a conversation on the inevitability of death and feelings surrounding that:

“Facilitator 4: It is a lovely reading, lots of people know this reading, what are your thoughts? Do you agree with it?
Adeline: Yeah, we are all going to die but who knows when. I’m here today but I could be gone tomorrow, but I don’t dwell on that
Facilitator 4: And Mary you are nodding as well, in agreement?
Mary: Yeah.
Facilitator 4: What is this reading say to you?
Mary: It is true. A time to keep silent and a time to speak. A time for love and a time for hate, a time for war and a time for peace. That’s lovely
Facilitator 4: But do all of these things have a time, do they have a season?
Adeline: Yeah.
Facilitator 4: But if we say there shouldn’t be time to weep or mourn but there should always be time to laugh or to dance? Or do you think that there needs to be a season for bad things in life?
Mary: Oh no.
Facilitator 4: What do you think? You are shaking your head vigorously, Mary?
Mary: Yeah.
AF 2: But if you don’t have the bad, how do you know the good?
Adeline: That’s right.”

Following the death of one of the participants in Group C, the facilitator began the session:

“Facilitator 2: Thank you for coming everybody. Just sad that God’s called Harriet home. She was a wonderful lady; she was 96, and she enjoyed coming here. She was looking forward to coming today because it was on faith, and I spoke about faith in one of them, and she was going to share her faith with us, but...never mind. Today we’re going to find out what gives us strength in our daily challenges and about if you know anybody who’s had a life-changing challenge; I have an example here I’ll talk to you about that. So what gives you strength for today? What motivates you to get you out of bed?”
We may wonder how the participants in the group felt after this brief acknowledgement of the death of one of their group. Space certainly was not given for group members to express their feelings nor to attempt to deal with this within the group setting.

In contrast, this is an example of a group member from Group B dying during the week before. When the group met next, the facilitator speaks of the death and enables the remaining group participants to come enter into the grieving process. The program planned for the day is put aside to focus on the immediate needs of the group participants at this time. This is affirming them as people of worth and enabling them to enter into this process of grieving. Nearly the whole session is devoted to grief and loss.

“Facilitator 4: We’ll look at that, but before we do that I think it would be lovely if we just spent some time thinking of Carrie, who died suddenly late last week, and I understand her…was her funeral yesterday?

AF 4: Mm.

Facilitator 4: Yesterday?

(AF 4 nodding her head.)

Amelia: Which one is Carrie?

Facilitator 4: Carrie, who came and sat next to Rhoda each week. Carrie Jones.

Facilitator 4: Here we are.

Amelia: She didn’t die?

Facilitator 4: Mm.

Amelia: Yes, I wondered where she was!


Amelia: She didn’t. She looked so fit and..

Facilitator 4: Mm.

AF 4: She looked fitter than I did.

Amelia: Mm?

AF 4: She looked fitter than I do.

Adeline: Can I have a look, Facilitator 4. * the funeral * around *

Facilitator 4: Yes, absolutely.

Adeline: Yeah. …”

“Facilitator 4: …and maybe we could just think of memories of Carrie, and you might want to share some of those memories.

Adeline: Yeah

Facilitator 4: All right. Let’s take a moment in prayer. Heavenly father, we thank you for the gift of life, we thank you that you have made us in your image, and we thank you for Carrie’s life. We pray for her family in this time of grief and sudden adjustments. We pray for her friends, so that they too adjust to Carrie’s passing, and we ask your blessing and comfort to be upon them in this time of grief. And we thank you for Carrie’s energy and the expressions she gave to the great love she had for her family, for the pride she had in seeing her children and grandchildren growing up, and the joyful memories she had of growing up in Tasmania, and her contribution to this group. We praise you Lord
and thank you for her memory, we pray to you in confidence that in Jesus Christ Carrie has come through death into your nearer presence, and we look forward to that day Lord when you shall return and when death will be no more and we will be reunited with our brothers and sisters in Christ and every tear will be wiped away. We pray Lord in gratitude for your loving arms that are wrapped around Carrie at this time. In Jesus name we pray. Amen.

Adeline: Amen”

“Adeline: Yeah.
Amelia: I didn’t know!
Facilitator 4: No, you found out this morning, didn’t you?
Amelia: She sat at the next table.
Facilitator 4: She sat at the next table to you here at lunch did she, Amelia?
Amelia: Yeah.
Facilitator 4: How long did you know her, Amelia?
Amelia: Since she’d been here I’ve been talking to her. Not very close.
Facilitator 4: No.
Mary: Had she been sick?
Facilitator 4: No. No, I don’t think so.
Mary: She was?
Facilitator 4: I doubt that she had been sick. No, it was quite sudden, Mary.
Mary: Must have been her heart.
Facilitator 4: I think it was a stroke.
Adeline: Yeah, it was.
Facilitator 4: Mm. Yes, that can take us suddenly.
Amelia: Yeah, that’s right.
Facilitator 4: Mm. Very suddenly.
Adeline: But at least now…at least now, she’s in peace.
Facilitator 4: Mm.
Adeline: She could’ve come back a vegetable.
Facilitator 4: Right. Mm.
Adeline: And you know, I cried my eyes out last night.
Facilitator 4: Mm.
Adeline: I…I miss her so much. Because she used to talk to me when I was upset. She said Adeline, Adeline don’t cry, you know, be strong.
Facilitator 4: Mm.
Adeline: But I’m getting stronger each day. And I pray for her every night when I go to bed.
Facilitator 4: Yeah.
Adeline: Yeah. My brother no doubt would have gone to the funeral.
Facilitator 4: Oh okay.
Adeline: Because he knew…ah…[her family].
Facilitator 4: Oh okay, right, oh that’s good, so you were represented then.
Adeline: Yeah, yeah.
Facilitator 4: Oh very good. Mm. And Mary do you have any things you wanted to say about Carrie’s death, or memories of Carrie that you wanted to share?
Mary: Oh, I’m shocked!
Facilitator 4: Yes, yes.
Amelia: And I am. I am...just...everyday I met her here at lunch. And I didn’t know, nobody ever told me.
Mary: Oh, you never know, do you.
Facilitator 4: No, you never know.
Mary: It’s a good thing.
Facilitator 4: You think it is a good thing we don’t know.
Mary: Ah yeah, yeah. Poor old Carrie, we used to have a laugh together.
Facilitator 4: Did you? *laughs* Yeah. Can you remember any episodes, what?”

A lengthy conversation continued for some time as participants expressed their grief and guided by the facilitator remembered the person who had just died and reflecting on their own forthcoming deaths.

5.2.5. **Prayer and Meditation**

Why prayer and meditation? Prayer is widely acknowledged to be used by older people, and numerous studies provide evidence of this (Koenig et al 2001) and people with dementia can still pray (MacKinlay 2006). This program also addressed issues of connecting through the creative use of ritual and symbol that is known to be of value for people with dementia (Hide 2002).

**Themes**

At no point in the group sessions were participants asked where they found meaning in life. The focus of the themes of the program were mostly on struggle and difficulties of growing older, and fitted with many of the experiences of these older people who have dementia. It would be good also to have a focus on meaning. Perhaps a valuable way of doing this would be to bring together elements of the pastoral care program with the prayer and meditation program.

Main themes identified during the group sessions of prayer and meditation were transcendence, relationships / connectedness, meaning in life, response and connection to meaning, and the final main theme was hope versus fear.

5.2.5.1. **Transcendence**

Sub themes for transcendence are listed in Table 12 below. Transcendence is recognised as one of the spiritual tasks in the process of ageing, MacKinlay’s model (2006). It is strongly linked to perceived and real vulnerability of the older person. Ego transcendence was described as part of the ageing process as long ago as the 1960s by Peck (1968). The theme identified (MacKinlay 2001) that gives rise to this task is the continuum of self-sufficiency versus vulnerability. This theme was an important one in this program of prayer and meditation. The majority of the themes found in the six week program (repeated over 18 weeks) addressed questions of transcendence and vulnerability.
Table 12: Sub-themes for transcendence from the data

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**a) Coping**

Coping was the most commonly occurring sub-theme. Pargament (1997) has conducted numbers of studies into the subject of religious coping and its importance among older adults. Depending on coping strategies used, coping may lead to transcendence. The most mentioned coping methods for the participants were in the field of religious coping and were prayer, and faith. The following two excerpts from the data show the participants sharing their coping methods with the group. The first one was using prayer as a means of coping:

**Facilitator 1:** … Peg, what helps you?
**Peg:** Well, I used to go away and have a quiet time of prayer because I think the Lord's the only one that can help me.”

In this second excerpt, the group is seen to continue to explore these concepts of coping:

**Facilitator 1:** Do you find times when you feel powerless? Everything's beyond you?
**Peg:** I sure do.
**Facilitator 1:** You do? What sort of things happen? What sort of things, can you remember, that happen like that? Does it feel like it these days? Do you feel powerless?
**Peg:** Yeah. It's when I'm on my own very much.
**Facilitator 1:** When you're on your own?
**Peg:** And it just seems to be against me.
**Facilitator 1:** Yeah. Is it day to day do you feel that nowadays?
**Leonore:** Sometimes.
**Facilitator 1:** Sometimes you do, Peg?
**Peg:** Yes. The road is not always easy is it?

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16 The participants had to be selected as people willing to take part in a prayer and meditation group, so this is, at one level, not surprising (it is noted that in spite of this, one participant reported not finding the group ‘what she had thought’).
Leonore: No, it's not always, no. Thank goodness, God helps us. We don't need to always worry. There were some times * really don't know what happened by so. Then you can sit down in private or talk with God on what you want and what you want to change.”

On the other hand, Beverly responded to this question about coping by saying: “Just sitting and thinking”. Positive coping may lead to transcension and a sense of peace and well-being.

b) Struggle & change

A second theme was struggle and change. Struggle is seen in many older people (Erikson et al 1986) and the struggle may lead to behavioural change including transcendence; on the other hand, it may lead to despair. In an earlier study MacKinlay (2001) found that often people who had experienced greater adversity in their lives had grown more spiritually, than those who had experienced little adversity. People of this age cohort experienced war, and the memories are still there. It seems that in later life, things that have previously never been spoken of become likely topics of conversation. Coleman (1999) found this in his work with Eastern Europeans who had suffered trauma in WWII. Topics of trauma earlier in life may be especially likely among people with dementia, as cognitive function declines. In this program, the topic of war was raised by the participants:

“Facilitator 2: Wendy, can you think of a time when things were pretty hard, pretty dark?
Wendy: The Second World War.
Facilitator 2: Can you tell us a bit about that?
Wendy: Well, they killed *
Facilitator 2: And was it hard for your family? What happened with your family?
Wendy: *
AF 1: Were you okay? Were you okay during the wartime?
Wendy: Yes.
AF 1: Was it hard?
Wendy: Oh, no, I was very little, but my father *
AF 1: Was your father at war?
Wendy: Yes.”

One of the participants, from Hungary, remembered hard times during the war, times of struggle.

“Leonore: I think that is * children, * children, come in my brain, does what God done for you, and that I always remember, airplane come through the bomb in Germany, I always think, * this happen to me, I can go on, it’s funny is a idea I got it, and thank goodness it doesn’t happen and lots of people dying because of it, I was….still alive.”
This same participant was also able to speak of change and the challenges of life that may lead to the need to change.

“This 

Leonore: … You think again something maybe very small change, *, isn’t it? Is not very easy.

Facilitator 2: No, it’s not very easy. But making a small change is really…

Leonore: Yeah, making small change helping thinking.

Facilitator 2: Yes.

Leonore: It’s not very easy.

Facilitator 2: But if you make one small change today, and one small change tomorrow, and one small change the next day… it’s huge isn’t it?

Leonore: We can’t do it. Sorry, I can’t say, we can’t do it because we are, takes too much time, think about, that do it, I done it this way, and should do it other way, what should I do? Which way’s the best? It’s not very easy.

Facilitator 2: No, it’s not very easy. But when you do decide, and you decide I’m gonna change this little bit, make a little step, how does that feel?

Leonore: Yeah, we can, I make a little step, you do this way, better step, you never know, can help.”

Further sub-themes related to transcendence

Further sub-themes related to transcendence, but with little content included: memory loss and remembering, learning and change, acceptance and gratitude, growth/change, perceptions of age, motivation/perseverance, resilience and reassurance, independence/loss, physical limitations and disabilities (including hearing problems, verbal challenges, and sight and reading problems), surrender, and jealousy and regret.

5.2.5.2. Relationships / connectedness

This theme has been found to be important in all groups and programs. Participants acknowledged their own need for friendship, for example: Wendy: “I think it's wonderful when we're here all together as women”. Further, Eileen responded: “Yes, it's good to be here among friends and to never be on your own again because there's always someone near”. The members of this women only group were appreciating each other’s company. The sharing of story arose naturally in this setting:

“Facilitator 1: Any others have a story to tell, to share, when you felt like this, that you were being carried and you didn’t know how it was going?

Leonore: Yes. When I come to Germany, I come from Hungary, from Budapest, everything was strange, and even the language, I feel a little bit lost, but the people were very nice to me.

Facilitator 1: Who carried you?

Leonore: I start - unbelievable, I was in Budapest and some old lady come to me and said, “I watch you couple of days, I like to take you to Germany. Do you want to come with me?” “So I can’t speak German.” “You learn it.” And I went and was very happy. Was wonderful church, wonderful ladies, and my shoulders were always somebody come to you, talk to you, learn your German,
because it was some ... and it was a wonderful time. I’m very, very proud of the ...
... it was a wonderful time. I learned German and learned everything and make
me belong.”

The need for connection with others does not diminish in the presence of dementia.
In previous studies, of spiritual reminiscence work with people who have dementia,
MacKinlay & Trevitt (2006) the need for connection or relationship was seen as
being almost synonymous with relationship.
The sub-themes for relationship / connectedness are listed below:

a) Family
Family was important and frequently talked about in the group process.

b) Interactions between participants
Participants seemed to naturally respond to each other in the groups, speaking and
sharing, supporting each other, both verbally and non-verbally.

c) Friends
Two of the participants spoke of the friendship and companionship in the group of
women in the sessions. This theme, mentioned above, is expanded here:

“**Facilitator 1:** When Beverly said what?
**Wendy:** I think it's wonderful when we're here all together as women.
**Facilitator 1:** Yeah, and we can pray together.
**Wendy:** Yeah.
**Facilitator 1:** And for you, Eileen?
**Eileen:** Yes, it's good to be here among friends and to never be on your own
again because there's always someone near.”

However, it is noted that Eileen withdrew from the group after week seven. Many of
the participants in residential aged care facilities have lost all their friends and family
through death or sometimes through being in an aged care facility at a considerable
distance from their loved ones. As they are already vulnerable and may have
difficulty with communications, opportunities for making new friends in small group
sessions such as these could be important means of finding new connections for
these people, thus guarding against loneliness.

d) Further sub-themes
Relationship was also evident in the sub-themes of: support from others, caring for
others/nurturing, grief, forgiveness, animals/pets, being alone, and touch. This
program did not seem to draw forth much on the topic of forgiveness, which has
been found to be an important topic in some other settings.

5.2.5.3.  Meaning in life
Although meaning in life was not a main topic in this program, meaning in life can
be seen in the theme of relationship and connectedness, even though it was not
specifically addressed. This is not surprising as meaning is so central to human identity. There were two important sub-themes, faith and reminiscence and two other sub-themes, with little content, although important in other programs, identity and choice.

**a) Faith**

Participants were asked what, in times of difficulty, helped them and kept them going. Eileen replied: “Quite a few times but just every now and again it happens. And I just sort of feel that my faith keeps me going.”

“**Facilitator 2:** Thank you. And Peg, have you ever had a black time when things were a bit hard for you, a bit black? Can you remember any time like that in your life?

**Peg:** I thought it was a bit hard *

**Facilitator 2:** What happened?

**Peg:** Because when I was working and someone would come, I would want to go to church because I was always going to church, what you want to go there for? Tell me the reason why. * Feel silly. But when the time goes, we’ll find out who’s being silly, won’t we?

**Facilitator 2:** We will.

**Peg:** We will. We might have to wait awhile longer yet, but we’ll find out before long.

**Facilitator 2:** Mmmmm. Well, it looks as if some people have had some difficult times, some dark times, and some of you haven’t, which is even better, probably, I’d say. Um, but sometimes when we’re in the middle of a dark time, or looking back on our lives, we realise that things didn’t stay dark forever. They weren’t black forever, they kind of improved. Um, and usually it’s our faith in God, as Peg just mentioned. Um, that encourages us to keep going, like the little man in the prayer. He just kept going until he got out the gate and then went towards the horizon. He just kept right along that path, and just had enough courage and enough…

**Peg:** That’s lovely, that’s how you get there. Yeah.

**Facilitator 2:** It is how you get there, isn’t it?

**Peg:** That’s true.

**Facilitator 2:** Yeah, just put your head down, or up, and you just keep going along that path.

**Peg:** Yeah.

**Facilitator 2:** So, can you, can anyone remember a time when it was your faith in God that really encouraged you to keep going and, maybe you felt a bit stronger because you did believe in God and you knew God was there with you, maybe you even sensed God was there with you, but you believed in God, so can anyone think of a time like that?

**Beverly:** I think sometimes, we all go, sometime in our lives have needed that help.

**Facilitator 2:** Right. And have you felt that help yourself?

**Beverly:** *

**Facilitator 2:** Can you think of a time when you really needed some help and
God was there for you?

**Beverly:** Yes, I guess I did, it’s all God for me now because I’m in the old, old age now, yes, no, I think it’s necessary for some people, it helps them very much, nice to know that that help is there.”

“**Facilitator 2:** Can anyone think of a particular time when somebody helped you, you needed some help?

**Leonore:** Yes, yes, yes, yes.

**Facilitator 2:** Mmmmm.

**Leonore:** I was at home, Hungary, and I want to go back to Germany. I was * And, I was not sure should I ask the man or the woman, and I thought, the man is made better, stronger and need of help, she go and help the people, and I tell the man, I like to meet somebody, tell me which way is the best to starting to leave, and, oh yes, a couple of nice men here, and *, I don’t want to tell her name, but she want to know which way should go, which way to go out, and she don’t know which way the best. And the man say, there is a girl, she go down on knee and pray to God, there is only one thing that can help her, and I done it, and I really, nobody talk to me, but in my head, tell me do that and that, and I went home and I tell my father about this, what should I say, I don’t want to bother you, wherever you go, I am not so much *, and I talk to the lady, and the lady was very nice to me, * since that, and ask yourself, it has come from you really *, * a man, somebody tell, I will tell her, she must pray properly. A gentleman come and tell me, and it’s wonderful.

**Facilitator 2:** Wonderful. So, you asked for help, and you asked some men for help, and they were able to help you…

**Leonore:** Yes, yes.

**Facilitator 2:** And later on you asked a woman for help…

**Leonore:** Yeah.

**Facilitator 2:** And she was able to help…

**Leonore:** She informed me of this way and that way, and it was very magnificent.

**Facilitator 2:** And you were praying to God …

**Leonore:** Yes, yes.

**Facilitator 2:** At that time, for help…

**Leonore:** Yes, yes. When I stand, because my father said, my darling, you’ve got to go pray.

**Facilitator 2:** Yes.

**Leonore:** And I think you mental, mental illness, mentally you don’t think about this, did I help you, you thinking this way or that way. It was very nice.

**Facilitator 2:** So your father encouraged you to pray?

**Leonore:** Yes, my father.

**Facilitator 2:** Yes.

**Leonore:** If you want something, you should take that, yes pray, you go and use your brain.

**Facilitator 2:** Thank you Leonore.”

Eileen also expressed how her faith sustained her:
“Facilitator 1: And Eileen? Times for you?
Eileen: Quite a few times but just every now and again it happens. And I just sort of feel that my faith keeps me going.”

Leonore explained her sense of God in her life:

“Facilitator 2: So, how do you feel when you read that God carries us sometimes? He’s right there for us.
Leonore: I think so, feel it, and we know that He’s right. Because I was frightened to think about and frightened to do, let us think about, and thinking, yes, ask your God, not 100% clear sometimes. Sometimes very hard. Sometimes when you feel it, and God is there to help you.
Facilitator 2: So you sense, somehow, God’s presence with you.
Leonore: Yeah.”

Peg echoed the words of Leonore: “That’s right. I always say with the Lord’s help, that He’s on my side.” Peg also said that she prayed “a lot” in difficult times. Eileen also shared her experience of prayer, seen in the following passage:

“Facilitator 1: Do others find that story familiar for you? In what ways?
Eileen: Well I feel better when I’ve prayed. I prayed a lot last night about my son and I felt better and I was just sort of, was passing on to God what I would like to do myself that I don’t feel I can. I can't afford to, but him, but I was just trying to get God to help him and that felt better.”

Participants talked about the importance of trust and it was seen as a part of their faith.

b) Sharing life-story Reminiscence

Most reminiscence focused on memories of family, of war and for Leonore, of leaving her home country to live in another country and needing to learn to speak German.

War and tragedy formed another theme in reminiscence. For example, one participant had a boyfriend who went to war, two others had fathers in the war. Wendy often talked of her father and sang:

“Facilitator 2: Oh, can you tell me a bit about that?
Wendy: My father had been a master mariner. He was…It’s a long way to Tipperary, it’s a long way to go. It’s a long way to Tipperary, to the sweetest girls I know. Good-bye Piccadilly, farewell Leicester Square. It’s a long, long way to Tipperary, but my face, my face, my feet are there.”

Wendy often sang this song, interrupting her sentences as she sang. It has been said that often those who have fought in war do not talk about it. The women in this small group were touched by war, and Leonore had experienced war firsthand. They did share stories of war at times during the sessions. Some of the themes raised by these
participants within the group could provide important material to work with on a one-to-one basis with the participant in pastoral care, for example Wendy and her story of her father interwoven with the song: “It’s a long way to Tipperary”

c) Identity

Identity lies at the core of what it means to be human. The individual’s perception of who they are as a person is critical to human identity. It has been argued by some that identity and hence, personhood is lost in dementia (Singer 1993) while others argue identity is retained in at least in some form by Post (2000), and Hughes, Louw & Sabat (2006). There was little seen that was related to this theme in comparison with the amount of material found in the pastoral care groups. It may be that elements of the two programs could be combined to more effectively engage with people with dementia.

d) Choice

There was little in this program that related to participants actively making choices, although they were offered choices by the facilitators.

5.2.5.4. Response – connection to meaning

a) Engagement with group sessions

All participants joined in prayer and in responses including the reading of poetry in the group sessions. Some sang with the music. At points during the sessions there was laughter. Following the session in week five, the RA journal noted: “Following session, Beverly speaks with Facilitator 1 for a few minutes about how this session has given her a lot to think about; she does not go into much detail, but repeatedly states that she has a lot to think about.”

At the end of sessions the group passed ‘the peace’:

“Facilitator 1: Peace be with you Wendy. Peace be with you AF 1. Peace be with you Peg. Peace be with you Beverly.
Beverly: And I’d like to return that to you. I like the thinking.
Facilitator 1: Okay.
Beverly: Thank you.
Facilitator 1: You’ve got a lot of thinking to do.
Beverly: At the moment, yes.”

The facilitator thanked the group members and brought the session to a close; some participants responded, as in this excerpt from week 7:

“Facilitator 2: Okay, well, thank you very much again for coming.
Leonore: Thank you very much.
Beverly: Sometimes it’s very nice to discuss it with people of something about *
Facilitator 2: Mm..
Beverly: Sometimes you just close up.
Facilitator 2: That’s right. I’ve always found people’s stories really interesting.
Beverly: Yeah.

Facilitator 2: You’ve had such a different life from my life, and, yeah. As for being in the Second World War, would have been very scared.”

It seemed that these people with dementia were finding the sessions to be valuable.

- **Desire to withdraw**

Two participants withdrew from the sessions:

“AF 1 reports to RA 2 that Eileen said program was too long and repetitive and that Beverly said she didn’t know it would be prayer and thought it would be something different; AF 1 also said that staff had noticed a change in Eileen’s level of depression while she was attending the sessions, and that there is also a change in Leonore.” [That is, a staff perceived lowering of depression.]

It was noted in a previous session that Eileen stated that she wished to withdraw:

“1148 Eileen tells RA 1 that “I won’t be back” for more sessions.” Staff spoke with Eileen and it seemed that she no longer wished to attend the sessions.

- **Non-participation**

The only mention of this was Beverly dropping off to sleep during a session.

- **Satisfaction-enjoyment**

Closure at the end of the sessions was important, as these sessions had been running weekly for 18 weeks. The facilitator brought the group to a close with the following interchange:

“Facilitator 2: Thank you. So, next week I’m going to miss you because I’m not going to be here.

Peg: We’re going to miss you, then.

Facilitator 2: Oh, thank you. I’ve really, really enjoyed being here for these weeks. Really, really enjoyed it.

Leonore: Mm.

Facilitator 2: So thank you for who you are, for, for coming along and your faithful presence; that you’re faithful to God and you’re faithful to this group, and you’ve been really wonderful, tremendous group.

Leonore: And we enjoy it very much. Every time when I come here, I go, always, is alive is just, how can change, how can go other side, no wonder sometimes, matter if wrong steps, oh why don’t you do that, really was so close to us, and we can change it which way want to.

Facilitator 2: Yes. Yes.”

- **Thinking and reflecting**

These people with dementia spoke of thinking and reflecting about their experiences in the group, as in these excerpts from week 5:
“Facilitator 1: What is it that helps us endure to get through things when they seem so awful, and you seem to have no energy left? What is it that helps you? Anything in particular? Beverly? Peg?

Beverly: * help a lot.

Facilitator 1: Sorry, what?

Beverly: Just sitting and thinking.

Facilitator 1: Sitting and thinking...

Beverly: Mmm.

Facilitator 1: Helps?

Beverly: Sorting myself out.

Facilitator 1: So you sense there’s some way through.

Beverly: Mmm.

Facilitator 1: Somehow there’s going to be an answer.

Beverly: That’s right.”

“Beverly: Thinking.

Facilitator 1: Yes, go on. I’d like to hear what you’re saying.

Beverly: Yeah. Just doing a lot of thinking.

Facilitator 1: A lot of thinking.”

b) Ritual

Ritual was used in these sessions of prayer and meditation. Ritual is important for humans, whether religious or not (Geertz 1975; Greeley 1982). Rituals help people to connect with meaning. It is therefore obvious that rituals only work if they carry the meaning, if people are able to see and connect with the meaning of the ritual. In this program, ritual and symbol were used in each of the sessions, music, singing, written prayers, poems, religious symbols including rosaries and crosses, candles, plants and seeds, shells, stones and rocks, photos, wool, and more. Even the simple ritual of passing the peace which was engaged in at the end of the sessions:

“Facilitator 1: Peace be with you.

Peg: Peace be with you.

Facilitator 1: Peace be with you. Peace be with you.

RA 1: And also with you.

Facilitator 1: Peace be with you.

Eileen: And also with you.”

This is simple, but to these participants, this was a familiar greeting regularly used in religious services, or even in greeting outside of a service. It is a means of connecting; it is a part of Christian ritual and may not be meaningful to others who do not have a religious background, and yet, it may be quite effective, even in non-religious settings. The participants always responded to these words of peace.

c) Prayer

Prayer was often mentioned spontaneously during the sessions and it can be seen
from these excerpts from the sessions that participants used prayer often as intercession; asking for things for others, and for strength for themselves in difficult situations. It is also noted that these people, who were able to do little by way of social interaction anymore due to their frailty and dementia, were still able to engage in prayer, themselves, and not necessarily in services of worship.

Leonore spoke of being helped by others and being encouraged by her father to pray (see page 128 for a fuller version of the excerpt):

Leonore: Yes, yes. When I stand, because my father said, my darling, you've got to go pray.
Facilitator 2: Yes.
Leonore: And I think you mental, mental illness, mentally you don't think about this, did I help you, you thinking this way or that way. It was very nice.
Facilitator 2: So your father encouraged you to pray?
Leonore: Yes, my father.”

“Facilitator 1: Or you stay what you are. Peg, what helps you?
Peg: Well, I used to go away and have a quiet time of prayer because I think the Lord's the only one that can help me.
Facilitator 1: Okay. And Wendy, what helps you?
Wendy: Just friends.
Facilitator 1: Friends. And Eileen?
Eileen: Much the same as Peg.”

“Facilitator 1: So the powerlessness feeling is supported by having friends?
Eileen: There's always somebody to talk to around me. You can pray at any time. I was praying like mad last night.
Facilitator 1: Were you?
Eileen: Yes, for one of my sons who’s having a bit of trouble.
Facilitator 1: You're very concerned about him?
Eileen: Yeah, his marriage.
Facilitator 1: And you feel powerless, what can you do?
Eileen: Well I can't do anything and I mustn't do anything because I've just got to pray that God will help him and tell him what to do.”

The facilitator raised the question of whether the participants thought God listened to them when they prayed, both these participants clearly affirmed this was the experience for them:

“Facilitator 2: And do you think God listens to you? Does God listen to you when you pray?
Peg: Oh, yes.
Leonore: I think you can feel it yourself. You can inside your brain, not your brain, you can relax yes, I come through, I come through.”
d) Responses to symbols & music

There were a variety of symbols available for the participants, including religious symbols, pictures, shells rocks and so forth. Participants responded to these:

Week 1: “AF 1 takes a wooden cross for Wendy
Leonore reaches and takes a cross.”

Week 5: “Facilitator 1 hands Leonore a rosary; Nora holds out hand for Facilitator 1 to pass something to her (from table). AF 1 hands Wendy cross and Peg stone; Facilitator 1 hands Beverly small stone
Wendy sitting with hand still up while listening to music (arm at 90 degree angle); Leonore moving rosary beads in her hand”

Week 16: “Wendy takes shell from Facilitator 2’s hand.”

Week 18: “Facilitator 1 shows the group [picture] of Mary cradling the baby Jesus; Leonore takes the picture from Facilitator 1”

e) Recognising/not recognising text- song- poems

It was seen that participants responded better to songs that they were familiar with; they often joined in singing these.

5.2.5.5. Hope vs fear

Participants expressed both hope and fear in their life experiences. These expressions of fear or anxiety present possible times of pastoral support and intervention. Eileen remembered one time when she was afraid:

“Facilitator 2: Eileen, can you think of a time when you were a bit scared?
Eileen: Only before, before I went up for my brain tumour removal, I was a bit scared.
Facilitator 2: Oh gosh.
Eileen: But other than that, no.
Facilitator 2: So, how did you feel then, Eileen?
Eileen: Scared.
Facilitator 2: Yes. Scared.
Eileen: You don’t know what they’re going to find.
Facilitator 2: No.
Eileen: Or anything like that.”

“Facilitator 2: So, Eileen, how did you get yourself out of the worry about that operation?
Eileen: I didn’t have much time to worry. Because I was going in, I said to them, I want to go to Sydney for it, and they said you wouldn’t get there.
Facilitator 2: Oh.
Eileen: So they just took me in and away I went.
Facilitator 2: So, very quick.
Eileen: Yeah.
Leonore: You had operation?
Eileen: Yes, on my brain tumour.
Leonore: Anyways, very good, wonderful.
Eileen: Yeah, I was in hospital 5 months.
Leonore: No, no.
Facilitator 2: So, when you look back Eileen, was the fact that you didn’t have much time to worry about it, was that good in a way?
Eileen: Oh yes, yeah. Very good.
Leonore: Anyways, people always nice, they help you.”

Fear and anxiety of the unknown was expressed in the following interchange:

“Facilitator 1: Can you recall, I don’t know whether you have times right now that you feel fearful, do you? I sometimes have times when I feel fearful even now, do you?
Leonore: Yes, sometimes, yes.
Facilitator 1: Sometimes? Yeah. What might you encounter these days that makes you feel fearful?
Leonore: I think so with the life.
Facilitator 1: The life. How is it going to be?
Leonore: Yes. What is yet …
Facilitator 1: What is yet to happen.
Leonore: How was, how yet, what will be.”

a) Sources of hope

Group members readily discussed their sources of hope; main sources were prayer and friends, and examples have been given in previously mentioned excerpts from Nora, Leonore, Peg and Eileen.

Beverly spoke of her sources of hope that included God and family:

“Facilitator 2: Can you think of a time when you really needed some help and God was there for you?
Beverly: Yes, I guess I did, it’s all God for me now because I’m in the old, old age now, yes, no, I think it’s necessary for some people, it helps them very much, nice to know that that help is there.
Facilitator 2: Okay.
Beverly: Sometimes you can’t speak to your own parent…
Facilitator 2: That’s right.
Beverly: …but you can speak to somebody else, and, * goes to waste. That’s just my opinion.
Facilitator 2: And, Beverly, who would the somebody else be that you might talk to?
Beverly: I don’t know.
Facilitator 2: Would that be your minister, perhaps, or a friend?
Beverly: No, *, that’s a long time ago, it stays with you, it does stay with you. You know, deep down if you’re in real trouble, you can *, it builds up all over again.”

b) Death and dying

The topic of death, dying and grief emerged during the sessions of prayer and meditation, and participants spoke of it naturally:

“Facilitator 1: And, Nora, did you, you were going to say something before I think. Sometime, when you felt that God was there with you or that God was giving you encouragement and hope.
Nora: Yes. Uh, really, it was just when my parents died. * I needed help
Facilitator 1: And you felt God was there?
Nora: Mm.”

“Facilitator 1: Nora, can you think of a time when things were, seemed kind of blocking your path, like a great big monster stone, like, you know, you’d been going along the, just doing things in the ordinary way, and then something cropped up, and stopped you, kind of, keeping on going.
Nora: I can’t think of anything…
Facilitator 1: A death of someone, or anything, no?
Nora: Oh, I guess, the death of both my parents.
Facilitator 1: Oh!
Nora: Not together.
Facilitator 1: No.
Nora: Separately.
Facilitator 1: Right. And how was that for you? How did you feel then?
Nora: Mm, very saddening. They were older.
Facilitator 1: Mmhmm.
Nora: It was, they were out of their pains…
Facilitator 1: Right. So you were glad for them. Not too glad for yourself by the sound of it.
Nora: No.”

“Facilitator 1: Peg, can you think of a time when you knew that God was there, that presence of light was there? Giving you faith and encouraging you.
Peg: Yes, I think that’s when I was, my boyfriend at the time, was overseas, *, and I used to pray very hard that he’d come back home, my pray was answered, he come home *, and I felt *. * used to say the good die young.”

5.2.5.6. Logistics within the facility

In week nine of program, two group members had been taken on a bus trip at the time of the group session. It is assumed that this was an indication of the lack of importance given to the research project by some staff. Contact was made by the principal researcher with the facility manager and group attendance numbers restored.
There was a tendency for the activity officer (AF 1) in the group to become part of the group. It is important that facilitators and any other staff who attend the sessions realise that the group sessions are for the benefit of participants, rather than staff. It may be awkward for group facilitators to deal with this within the group session. It would probably be more appropriate for the facilitator to deal with this quietly with the activity officer apart from the group. A number of distractions can occur in group sessions that may make it hard for participants to concentrate on the session, for instance, mobile phone belonging to an assistant ringing in the group session.

6. Discussion:

6.1. Benefits and challenges of working across disciplines

6.1.1. Benefits of working across disciplines

This project involved working closely across disciplines at all stages, from planning, to implementation and evaluation. Such partnerships can bring a richness to spiritual and pastoral care. Multiple perspectives of reality and differing professional insights challenge people from various disciplines to see situations and experiences in new ways. This may lead to innovations in practice as new lenses are used to see resident needs in complementary ways.

6.1.2. Challenges of working across disciplines

The shape of pastoral and spiritual care is still not well understood by all practitioners in all disciplines. Assumptions are sometimes made, understandably, on the basis of socialisation into one’s original discipline of study, thus the lens through which practitioners see a clinical situation is coloured by the possibilities they envisage.

For instance, if the person with dementia is seen principally through the lens of cognitive measurement, then this defines the potential of this person to engage with others and may limit the potential for well-being in that person. This is especially so in situations such as dementia, where the people are compromised by cognitive difficulties, yet, given a supportive environment (MacKinlay 2006; MacKinlay & Trevitt 2006), these people may achieve more than was thought possible. These changes, it seems, are not so much through an increase in cognitive status, but in affirmation of the person and their remaining abilities.

The term ‘re-mentia’ used by various authors, including Kitwood (1997) and Swinton (2008), describes ways in which people with dementia may seem to regain some of their abilities to function effectively even when they have a diagnosis of dementia.

Facilitators in the music and art programs, and in some pastoral care groups often focused on the activity, rather than the person, missing opportunities to engage in genuine person centred care. On the other hand there were some excellent examples in some pastoral care groups of effective communication and of spiritual and emotional support in some pastoral care groups. It is emphasised that the level of communication of participants in this study was not dependent upon the participants’ cognitive levels.
6.2. Critiques (including limitations)

The limitations of the methodology have been discussed in a previous section of this report (point 4.8).

7. Conclusions and recommendations:

The aim of this project was to find ways of connecting with the spiritual dimension, especially for people with dementia. This is based on the model MacKinlay (2006) explored of ways of mediating spirituality. The model named four modes of connecting with the spiritual: relationship, the arts, the environment and religion. Art and music were chosen in response to critique of the method of spiritual reminiscence, that it focused too much on words, and some practitioners thought would not connect with many of these participants. However, this project appears to show that it may be more difficult to use art and music for connecting deeply than to use spiritual reminiscence unless facilitators have adequate training and a high level of self-awareness.

The following remarks are prefaced by the acknowledgement that statistical findings from this program see the participants’ levels of depression diminishing over the period of the 18 week study, when all group results are analysed together. This is an important finding. However, when each program was analysed separately, the depression levels rose in art. It is acknowledged that the numbers tested in the art groups were too small to allow statistical significance. It is noted that the treatments continued weekly for 18 weeks and the participants were followed for a further three months, making the whole program 30 weeks in duration, a long time to follow through with people with moderate dementia. However, in view of previous findings in spiritual reminiscence with people with dementia, it is suggested that this program appeared to be conducted more within the focus of an activity, which is valid within its own right, rather than as a program that would use art or music as a way of connecting into the spiritual and life meaning with these people.

7.1.1. Communication style of facilitator

This emerged as a critical variable over all the programs within this study. Use of the quantitative measures to detect differences between groups allowed study of the rich qualitative data to be analysed to tease out the differences in the group processes used in each group. This was possible since all groups except group A in pastoral care had very similar measures across all scales on entry into the program. (Group A had lower cognitive scores and higher levels of depression than the other groups). Analysis of the transcripts, journals of RAs and facilitators allowed pictures to emerge of the processes in action in the groups. There were very similar responses from group members within each group, but marked differences between groups. We were particularly able to test this across the five small groups in different facilities in the pastoral care program.

In some groups, the participants spoke very little and most responses were to direct questions to the group, which called for yes/no answers. In other groups, the questions were deeper and open ended; in response to these questions, the group members responded more readily and more fully.
Another factor that we examined was the rate of speech and space allowed after each question, before rephrasing or asking another question. We found that facilitators who spoke more slowly and paused after each sentence had improved responses from participants. We also found that some facilitators moved very quickly to ask another question, after only 2-3 seconds. Facilitators who waited longer, from 5-6 seconds (a time that may be uncomfortable for some people), elicited much better responses. In some instances, the facilitator even waited at the end of the participant’s response, and given the extra time, the person enlarged on their answer. The differences are clearly seen in the transcripts. It does take time for people with dementia to respond to questions. Facilitators therefore need to be trained to be able to be comfortable in communicating in these ways with people who have dementia.

7.1.2. **Person centred care: What needs to happen for that to take place?**

There is a vital need for person centred care. This term has been in use for a couple of decades, yet its use in practice does not seem to be well established. Person centred care recognises the dignity and value of each human being. The essence of the person with dementia remains; even though their cognitive abilities become increasingly compromised. That does not mean that they are less of a person, but, perhaps, that we, who do not have compromised cognitive abilities, need an attitude shift to see people in wider terms than simply as a cognitive object. Each person is a wonderful combination of body mind and spirit, not simply a biological organism of separate parts. Recent work from neurobiology sees the wholeness of the person. Where communication difficulties arise, the person is still there and it is the attitudes and beliefs of others, so called cognitively competent people, that can do much to affirm and value these people with dementia, or to relegate them to objects to be cared for.

What was seen in this study, in some of the best aged care facilities, is probably indicative of the level of practice in aged care generally. It would be fair to say, that if it is hard for some pastoral carers to practice person centred care, then it is hard for many who work in aged care to practice these skills. All workers in aged care need to have person centred care at the centre of their practice. These skills, used across the sector would revolutionise aged care. We have seen how well people with moderate and advanced dementia responded to the use of these skills in this study; we have also seen the lack of use of these skills that made enormous differences to the participants’ abilities to communicate. Adequate training in these skills is essential to lift standards of care and thus morale right across the aged care sector.

7.1.3. **Conclusions and recommendations for art program**

7.1.3.1. **Art as a way into the spiritual**

In this project, it seems that it was often difficult for the facilitators to use the art as a means of connecting deeply with the participants. Often the program theme was subsumed in the ‘doing’ of the art work. Facilitators seemed to become focused on producing outcomes and showing that the participants were able to ‘do things’.
Perhaps, in working with very vulnerable people as these were, it is natural that the facilitators would want to see the participants achieving good outcomes. There were times when the remarks initiated by participants were lost, as the focus kept returning to the ‘doing’. As a result, participants were not seen to be able to initiate their own comments and often responded with very few words following complex questions from facilitators. It was also noted that some facilitator assistants were too ready to ‘do for’ the participants, rather than leave them to do their own work. These vulnerable people find it hard to react against these behaviours.

7.1.3.2. Recommendations

As a result of this study and the findings from the art group, the following recommendations are made in regard to the art program that has been developed as a result of this project:

1. Need to distinguish between an activity and a meaningful activity for these people with dementia. Often ‘sharing of story’ in the context of this art group was only remembering facts, and while enjoyable, to some extent, this does not offer the participants the opportunity to connect with meaning through the experience of sharing story.

2. Skills of facilitators need to be built, so that they are more readily able to engage in person centred care and thus facilitate more effective communication with people who have dementia.

3. Time tabling in aged care facilities needs to take account of resident wishes, to ensure both that residents may engage in meaningful activities and that appointments do not impinge on these.

4. The art program designer and researchers will apply findings from the project to re-design the program.

5. Training programs will be designed to develop the required skills that may be needed across disciplines, art therapists to learn person centred skills, and pastoral carers to learn skills to engage.

6. That program will be published for dissemination in ageing and aged care. Distribution of the program should be linked to engagement with the training program, emphasising the importance of developing the skill levels required to offer the group successfully.

7.1.4. Conclusions and recommendations for music programs

7.1.4.1. Music as a way into the spiritual

As with the art program, the music program emerged as an activity, not as a way into the spiritual. The differences between the music listening and music participation were small. It is noted that the depression levels rose across the time of the music participation groups. What could be the reasons for this? The focus of the music program is firmly on music and the providing opportunities to sing. It was hard to find examples of spiritual linkages. There was very little dialogue with a concentration on singing and making music. This in itself may have had an effect on participants. In line with Murphy’s (2006) assertion that memory does not truly capture all of what is required to secure personal identity (pp.137-138), these memories that people are tapping into in these groups are enjoyable, for
the most part, but not all there is. It is not simply the fact that an event is remembered, but what is the meaning of that event? People with dementia who are able to find meaning may be more engaged with life and have a better quality of life. Perhaps it may be just as important for people with dementia to experience music, that does not have to be a song with words, but music that may open their spiritual being and provide a sense of joy in the everyday living out of their disease. Not all people with dementia would respond to the same kind of music, just as people who don’t have dementia respond to different kinds of music. A spiritual assessment, of the kind used in this study, may elicit important information about the interests of the person. Training of facilitators in both music but more particularly in person centred care, may make a greater difference.

7.1.4.2. Recommendations
Taking these findings into account, the following recommendations are made for the music programs:

1. Music is a way into the spiritual and meaningful in life. For people with dementia, engagement with music must be meaningful for the person.
2. Selection of participants for music based programs should be based on pre-assessment of their spirituality to find whether music is one way they like to engage the spiritual dimension.
3. The skill sets of the facilitators needs to be extended to include skills in person centred care.
4. The programs need to be redesigned based on the findings of this program.
5. Training will be needed if these programs are to be of benefit.

7.1.5. Conclusions and recommendations for pastoral care program

7.1.5.1. Conclusions
Some of the findings from the pastoral care programs can be applied to all the treatment groups, others are more appropriate to the pastoral care modality. Communication is a vitally important aspect of pastoral care, whether it is delivered on a one-on-one basis, or as in this study, in small group settings. The strong benefits of small groups for pastoral care are, first, in the facilitating of making new friends. Second, there are often feelings of commonality among the group members, for example, in a previous study (MacKinlay and Trevitt 2006), the small group of people with dementia, all widowed women, discovered that the concerns of one woman, having been absent when her husband died, were shared with others in the group, thus bonding between them over this experience was enhanced. As well, on a very practical level, it is possible to bring pastoral care to more people at once, and spiritual and emotional growth can be enhanced, for more people.
Grief was another important topic discussed in some groups and not in others. In some groups, if the topic was raised, for instance, where a participant had died in the week preceding the session it might be briefly mentioned and then the facilitator would move on, without acknowledging the loss. In other groups, particularly in group B, grief work was actively engaged in within the group sessions. This had the
effect of acknowledging death and dying as a normal part of life and gave the participants the opportunity to grieve for the loss of friends through death. Not to acknowledge death and dying is to support the denial of death; dying and death is close to these people.

Story is central to our individual identity; it is a changing and developing story with ourselves as the authors, and yet, in many ways, with the listeners as co-authors. Stories need to be told and listened to. The story is, for each of us, a work in progress (Kenyon 2003). In many respects, it is interesting that the transcripts often contained fairly short and superficial particles of stories, yet in two of the groups (groups A and B), the stories emerged much more readily. The communication style of the facilitator made a crucial difference in the amount of participation by the group members.

Expectations of the facilitators was also important in the types of experiences they were willing to offer to participants. Therefore, where the facilitators had low expectations of the participants, the opportunities for meaningful engagement in the study sessions were more limited.

7.1.5.2. **Recommendations**

The following recommendations are made for the pastoral care program, based on the findings of this study:

1. Facilitator expectations of the person with dementia have a large influence on their ability to communicate. Labelling of people according to their cognitive abilities seems to impact on facilitator mode of communication (Pygmalion effect).
2. Communication should aim to connect with the *person* who has dementia (not their cognitive ability).
3. Participants with dementia find it easier to respond to emotional and spiritual concepts, therefore it is recommended that communication skills should focus on these rather than on cognitive concepts.
4. Intentional development of programs that facilitate communications and connections between residents in aged care facilities to combat loneliness. These programs need to be more than entertainment or activities, but rather programs that assist people to develop new friendships.

7.1.6. **Conclusions and recommendations for prayer and meditation program**

7.1.6.1. **Conclusions**

The main themes identified in this program of prayer and meditation had some common areas with the other programs, but some differences. Prayer and personal faith as means of religious coping were clearly evident. Relationship and connectedness was an important theme, as was response to meaning through ritual and symbol; these latter themes were more readily seen in this program than in the other programs of this project. The theme of meaning in life was more implicit than in some other programs, mostly seen in relationship. Hope and fear received more attention in this group process than in other programs.
This program of prayer and meditation for people with dementia was valuable for these people, who engaged in prayer with the facilitator. The prayer program would be valuable for any who wish to engage in this activity, keeping in mind that its roots are Christian. However, its topics are broad and could be used with other faith groups as well. The use of spiritual assessment to assist in finding the best programs for particular people would be of value. The six week program, by its nature, could be extended or used with other programs evaluated in this project. One of the participants remarked that the program was repetitive, and this had been deliberately done as part of the research design.

7.1.6.2. **Recommendations**

The following recommendations are made for the prayer and meditation program:

1. Spiritual assessment is recommended prior to suggesting this program to any potential participants.
2. It is recommended that the program be redesigned without repetition.
3. The sessions could be further developed to enlarge the experience for the participants and gather the richness of all the programs together.
4. This program to be refined based on findings of this study.
5. Consider ways of including this program within a larger publication that will contain, pastoral care, prayer and meditation, art and music.
6. The program to be prepared for publication.
7. Develop training programs in the use of this program.

7.1.7. **The study as a whole**

The **most important theme** that emerged as being accountable for group differences in communication was that of facilitator style. This was irrespective of cognitive level of the participants. We believe this to be an important finding of this study. It cuts right to the core of what it means to be human and what it means to have dementia and still be human. Simply basic person centred care would assist greatly, and it is possible to establish communications at deep levels with people who have dementia, despite their cognitive levels. Person centred care needs to be extended to take account of the spiritual and emotional. Communication is about emotions and spirituality as well as cognitive processes.

Some reasons for the focus on doing rather than connecting with the participants could be:

- Lack of preparation in skills of person centred care
- Lack of self awareness and confidence as a facilitator (relating to training needs)
- Lack of knowledge of the ageing process, and therefore what to expect as possible ways of being in later life
- Lack of knowledge of dementia and the characteristics of the person who has dementia and therefore, what may be possible for them in communication and understanding
7.1.8. **Overall recommendations**

Based on the findings of this study, the following recommendations are made for the field of aged care:

1. Activities in aged care for people with dementia can lower levels of depression in dementia.
   - **Recommendation:** People with dementia are able and should be given the opportunity to participate in activities of their choice in residential aged care.

2. Clear distinctions need to be made between entertainment and quality programs giving benefit and meaning to the lives of people with dementia. Too often an activity is ‘done’ because it has always been done, or it is something to distract the residents from the daily existence in the facility. Sometimes, it may be just as important for older people simply to sit quietly and contemplate.
   - **Recommendation:** Staff in aged care develop a new philosophy of seeking to find what is important in the lives of older people that acknowledges the wholeness and individuality of the person and their needs for connection with others.

3. Staff working with people who have dementia and with older adults need to learn about the ageing process and about the characteristics of people who have dementia. Too often staff work with myths and assumed knowledge about ageing and dementia and do not have the opportunity to learn new ways of seeing the possibilities of ageing and dementia, based on recent scholarship and research.
   - **Recommendation:** Staff acquire knowledge of relevant research of ageing, aged care and dementia for improving practice in caring for these people.

4. Assessment of meaning in life, values and beliefs are important areas of inquiry to establish appropriate quality care for people with dementia.
   - **Recommendation:** People with dementia should be assessed to establish where they find meaning, and their values and interests, before assigning them to particular groups. They need to have choice.

5. Groups for people with dementia need to be small. Previous research has shown clearly (MacKinlay and Trevitt 2006) that, depending on communication difficulties, the groups may even need to be as small as 3 people. With not so marked communication difficulties, it is possible to work effectively with up to 6 people in one group, but no more. In larger groups, the people with dementia are lost and find it difficult to focus on competing stimuli. Staff levels would need to reflect this change. The changes to depression levels may offset the extra costs of group facilitators.
   - **Recommendation:** Small group work with people with dementia be available in all aged care facilities.

   **Recommendation:** Staff trained to facilitate small group work.

6. Staff reported positive changes in behaviour among some group participants that lasted during the intervening week. There may be other benefits, including economic benefits and raised staff morale from group
participation relating to staff time in care when groups are being run in a facility.

Recommendation: Further study to be undertaken to investigate economic benefits and staff morale related to the conduct of such programs.

7. Meaningful activities will make an even greater difference in both depression levels and in morale of the participants. It is not simply being in a group that makes a difference.

Recommendation: Meaningful activities to be designed for people with dementia.

8. Working with people who have dementia may be challenging. Yet using principles of person centred care can make an enormous difference to the quality of life for people with dementia and also for those who care for them.

Recommendation: Training programs to be designed and implemented widely to effectively train workers in aged care to provide person centred care.

9. Death and dying are facts of being older and must be a real part of the agenda when caring for people who have dementia and for older people. How death and dying are dealt with will have enormous effects on these elderly people as they face their own dying.

Recommendation: Training programs contain relevant content and training in working effectively with people who are dying and those who live with them.

10. The culture of aged care needs change. Many of those who work in this industry, in low paid positions, have a sense of their own inability to make change. A focus on a medical model of care is too narrow a focus in an area where people desperately need to be recognised as human beings first, and have appropriate care of their medical conditions second. That is not to say that good care of medical conditions is not needed, but that the focus has to be on the person first. These requirements are already in the Aged Care Standards for Australia (Pringle 2010), but are often not fully addressed. This will start to change the climate of the whole industry.

Recommendation: Effective training in person centred care be implemented throughout the aged care industry.

11. Spiritual well-being is a basic requirement for resilience and hope among older residents of aged care. This is a relatively new component of care. It is a new paradigm that can well be developed across disciplines. Training in this area goes even further than person centred care.

Recommendation: Education and training programs be developed to take account of the latest research in spiritual care.

12. Recruiting for this study found that there are few people with the appropriate qualifications available now.

Recommendation: Urgent attention be given to preparing practitioners to work in art, music and pastoral care with older people and especially for equipping them to work effectively with people who have dementia.

13. If there is a shortage of suitably qualified people in the major Australian cities then remote and rural areas of Australia are even more deprived of
people who can provide this care.  

**Recommendation:** Special training programs be developed and made available to people working with people who have dementia in rural and remote areas.

8. References


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