The use of creative activities in dementia in residential aged care facilities in Australia: A cross-sectional descriptive study

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Dementia, creativity, art therapy, engagement, quality of life, residential aged care facilities, engagement, well-being, Behavioural and Psychological Symptoms of Dementia

Abstract

Background: There is increasing interest in non-pharmacological interventions in dementia care to improve quality of life. Although one of the care strategies for people with dementia in residential aged care facilities (RACFs) is to implement creative recreational activities, the implication and the understanding of creative activities in the life of people with dementia is fractured. While studies show that creative activities have the potential to improve quality of life for people with dementia through positive effects on sociability, mental acuity, self-esteem, memory, emotional expression and reductions in Behavioural and Psychological Symptoms of Dementia (BPSD), the occurrence and the characteristics of these activities in the residential care environment is unknown.

Aim: This descriptive study used a mixture of quantitative and qualitative methods and had two main aims: 1) examine the incidence and the characteristics of creative activities currently provided in RACFs in Australia; and 2) explore the quality of these activities, such as the opportunities offered for emotional and self-expression and engagement through creativity, and to what extent these activities are used to alleviate BPSD.

Method: First, an Australian national survey was undertaken. The 13-item survey was designed in the form of multiple choice and open-ended questions and sent online to all RACFs (n = 1675) that had a valid email address. Second, to gain a deeper understanding of the topic, in-depth interviews with activity coordinators (n=15) were conducted.

Result: This study found that 249 facilities (15.3%) responded to the survey over a one month period. Most facilities (242, 97%) reported that they offer one, two or more of the following activities: music (95%); visual art (83%); dance (47%) and drama activities (9%). The data also revealed that most of the facilities conduct activities in both group and individualised conditions (148, 63%) and that the bigger facilities are more likely to have visual art activity than smaller facilities (χ^2 = 10.443, df=3, p=0.015). Open-ended survey questions revealed some

benefits of implementing creative activities: facilitation of self-expression; managing BPSD; and providing opportunities for social interaction. Further, respondents indicated that creativity is a journey and implementation of creative activities depends on the abilities of the residents.

Thematic analysis was used to analyse the detailed interviews. Five major themes and a number of sub-themes emerged that describe the activity coordinators' understanding of creative activities in dementia care. These themes were labelled as follows; Diversity of creativity; Considering dementia; Values of creativity; Person centred activity care; and Routine assessment for evaluation.

These findings suggested that, while every activity coordinator valued creative activities, there were two lines of understanding of the significance of creative activities in dementia care. One line of understanding, articulated by the majority of activity coordinators, was that creative activities work as sensory or cognitive stimulation and can be an aid for reminiscence and provide meaningful engagement. Another line of understanding of creative activities was presented by the minority of activity coordinators, those with art backgrounds or experience, who, in addition to the previous values, clearly articulated that creative activities can be a means of self-expression. Similarly to the survey results, it was also articulated that many activity coordinators find that dementia itself can be a barrier to the implementation of these activities. Only a few activity coordinators stated that creative activities should be used to overcome these barriers.

Typically activity coordinators did not use creative activities for managing BPSD; they had other strategies such as one-to-one activity, redirection and alternative therapies such as massage to involve people with dementia in activities and improve apathy and withdrawn behaviour.

Conclusion: The evidence gained from this study indicated some understanding of the use of creative art activities by activity coordinators in RACFs. However, it also revealed that the understandings of these practices were not consistent and the deeper understanding of the implication of creative activities is only apparent

to those activity coordinators with art backgrounds or training. To gain more understanding of the implementation of creative activities a more robust study including observations of people with dementia engaged in activities with activities therapists will be necessary, to understand, verify and further explore the themes found from this study.

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Statement of original authorship

“The work contained in this thesis has not been previously submitted to meet requirements for an award at this or any other higher education institution. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made.”

QUT Verified Signature

Signature

Date 18/02/2015

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Preface

The story of Doc- Narrative from an art therapist

Doc, as she insisted on being called, was 94 when she needed skilled nursing care. A former physician, she had moderate to severe dementia and enjoyed talking to people. Her speech pattern mimicked that of an intellectual conversation, but the content was lower than high school level. When she saw a peer creating an interesting pattern on paper, she would say, "My those are interesting test results." Doc often resisted getting involved with art materials. In group sessions, she would watch others, preferring not to participate herself. One day, I asked her to write me a prescription. She immediately picked up a piece of chalk and scribbled something before signing her name clearly. She asked me why I needed the prescription, and I responded that I had hay fever. In a later session, Doc began rubbing chalk on black paper and then blending. She explained that red mixed with yellow made orange and said she remembered that from grade school. On her own initiative, she began writing the names of the colours with the appropriate colour chalk and then wrote across the black paper, "Advise onset of green." It is one of my favourite pieces; it was a real triumph for Doc to be able to express something of herself on paper using colours. In other sessions, I traced her hands and asked her to fill them in. She enjoyed this exercise as it probably reminded her of her role as a physician. She talked about using her hands to care for sick people. Eventually, Doc allowed herself to engage with watercolours, tempera paint, and clay. Although not a social person, Doc seemed to enjoy sitting around the table, getting involved with various colours and media and looking at what her peers were creating. She became a regular participant in the art therapy group (Stewart, 2004, p. 153).

Chapter 1: Background

Introduction

The story of Doc illustrates a situation where a person whose cognitive state was compromised by dementia had an opportunity for self-expression through a creative medium. The story highlights that, if given an opportunity, creativity can enhance the person's quality of life and provide a means of communication, especially if the activity awakens past life events in the case of living with dementia. The story also reflects that it is often difficult to engage people with dementia in activities in everyday situations in a residential care environment. Implementing person-centred care principles can be a way to generate meaningful engagement. Focusing on the improvement of the quality of life and implementing holistic approaches in dementia care has become an essential part of dementia research. This study was undertaken to explore the perspective and the characteristics of the creative activities presently offered for people with dementia in aged care facilities around Australia.

Statement of the problem

Finding ways to improve the quality of life of people living with dementia is a key concept of contemporary dementia research. One of the care strategies for people with dementia in residential aged care facilities is to implement recreational activities to promote several quality of life dimensions such as pleasure, improved function and social engagement (Schreiner, Yamamoto, & Shiotani, 2005). Participating in these activities on an everyday basis is one of the most common forms of occupation and can be utilized as part of a non-pharmacological treatment strategy to alleviate BPSD, as well as satisfy the basic human need for meaningful involvement in activities (Kolanowski, Litaker, & Buettner, 2005). The Creative Ageing theory suggests that creativity in leisure activities can improve a number of functions in older age through sense of control, social engagement and brain plasticity and is recommended for dementia care (Cohen, 2006). Additionally, participation in artistic activities can provide people with

dementia with ways of being meaningfully engaged and communicating (Killick & Allan, 2000). Examination of the use of creative activities in the dementia literature mostly focuses on the cure effect of art therapy; less attention has been given to the evaluation of the process of creativity itself and its psychosocial benefits. While studies show (Swann, 2012; Beard, 2011; Hannemann, 2006) that various creative activities can benefit people with dementia in different ways, the incidence and implementation of these activities is unknown in the literature. This study was designed to address this gap in the literature via two main aims: 1) examine the incidence and the characteristics of creative activities specifically focused on visual art activities provided at present in residential aged care facilities in Australia; and 2) explore the quality of these activities, such as the opportunities offered for emotional and self-expression and engagement through creativity, and to what extent these activities are used to alleviate behaviour symptoms of people living with dementia. The design of these activities and their importance in the life of people with dementia in relation to engagement and participation were examined.

This chapter will provide a description of dementia, the background of the study and the theoretical framework that supports and informs the research project. It will also provide an overview of this thesis in general.

Description of dementia

Dementia is a collective term that encompasses many different diseases characterised by impairment of brain functions. According to the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (2013), the main criteria for diagnosis of dementia are memory impairment and cognitive disturbances in at least one other area of functioning, impairments severe enough to interfere with social or occupational functioning and impairments that worsen over time.

Diagnosis of dementia

While there is no definitive list of diagnostic tests to diagnose a person with dementia there are general recommendations for the diagnostic process. According to Alzheimer's Australia (2008) and Cantley (2008) the diagnostic process should start with a careful medical history and physical examination, which will determine the next necessary test. Additionally, neurological examination and psychiatric consultation as indicated, laboratory haematology studies to exclude underlying metabolic or other medical illnesses, mental status assessment, cognitive tests and a CT scan and/or MRI of the brain are recommended as basic diagnostic processes for dementia.

Type of dementias

According to the Department of Health and Ageing (DOHA) (2006), by outlining the patterns of behaviour and neuropsychological deficits, different types of dementia have been identified, including Alzheimer's disease (AD), Vascular dementia (VAD), Fronto-temporal dementia (FTD), Dementia with Lewy bodies (BDL), Parkinson's disease dementia and Huntington's disease. Depending on the presentation, in many individual cases there are mixtures of two or more types of dementia. The most common form of dementia is AD which accounts for around 50% of cases in Australia, and is associated with atrophy of the brain due to nerve cell loss. Abnormal brain tissue changes occur in the form of tangles and plaque. VAD is the second most common dementia accounting for around 20% of cases. The manifestation of VAD occurs through a reduced blood flow to the brain, usually through stroke. Dementia with Lewy bodies is similar to AD but progresses much more rapidly and is associated with abnormal brain cells and occurs in around 15% of all dementia. Fronto-temporal dementia is associated with tangled bundles of proteins in brain nerve cells as well as rounded ones. It accounts for about 5% of all dementia cases and can occur as young as age 30-40. Parkinson's disease accounts for around 3% to 4% of all dementia cases. This progressive disease of the central nervous system results from the loss of the

neurotransmitter dopamine in the brain. Huntington's disease is a hereditary disorder of the nervous system which affects 1 in 10000 people (DOHA, 2006).

The clinical manifestation of dementias

While dementia affects people in different ways the cardinal symptom is memory loss of some type. The severity of symptoms will vary depending on type of dementia and the stage of the condition. According to DOHA (2012), generally the progression of dementia is divided into three phases. In early stage dementia the symptoms may progress more slowly and it is possible that it can be mistaken as being part of the ageing process. Some of the early signs include frequent memory loss, impaired judgement and physical condition, disorientation to time and space, apathy and withdrawal, learning and concentrating difficulties, loss of sleeping patterns and changes in personality (Australian Institute of Health and Welfare (AIHW, 2012). In the moderate stage of dementia the symptoms already experienced in the early stage become more apparent. Symptoms may include difficulty with activities of daily living such as eating and bathing, mood swings, anxiety, suspiciousness, agitation, increased forgetfulness, wandering and getting lost and difficulty recognising family and friends. In the advanced stage of dementia the person may need 24 hour supervision and care because they may lose the ability to respond to people and their environment and may not be able to perform basic tasks without assistance (DOHA, 2012).

The prognosis of dementia

According to the DOHA (2012) dementia affected around 250,000 Australians in 2009 with this estimated to increase to 591,000 by 2030. Given the projected increase of the ageing population and the increase of this disease, dementia places a tremendous burden, not only on the people affected by it, but also on society and has already been established as one of the major challenges of this century. According to the AIHW report in 2012, the total estimated direct expenditure which was directly attributed to dementia related services was 2.0 billion dollars

in 2009-2010. Based on that report the Commonwealth has now identified dementia as one of its nine national health priorities (AIHW, 2012).

Behavioural and Psychological Symptoms of Dementia

While dementia itself imposes difficulties in both treatment and the caring process, there is general agreement that the behavioural and psychological disturbances that often accompany dementia and are defined as are some of the most difficult and distressing parts of the process of caring for people with dementia, their families and their caregivers (Verkaik, Van Weert, & Francke, 2005; Ballard et al., 2001). Additionally, behavioural symptoms are the leading cause of healthcare expenditure in this area and therefore finding an effective control not only plays an important role for the caring staff but for the wider community (Lenze, 2011).

The most common BPSD

According to Cohen-Mansfield (2004) the most common behavioural symptoms of dementia include physical aggression, physically non aggressive behaviours such as wandering, depression and apathy. Additionally, people with dementia often show symptoms of agitation in the form of constant repetition of sentences and verbal aggression such as screaming. Because these behavioural symptoms are associated with many poor health outcomes, such as decline in physical functioning, social isolation and increased risk of abuse, the appropriate management of BPSD is an essential priority in the treatment of dementia itself (Kolanowski, Fick, & Buettner, 2009).

Treatment of dementia and underlying BPSD

Kolanowski et al. (2009) states that while biomedical research has advanced the understanding of the genetic and biological bases of dementia disorders, unfortunately the treatments for dementia and its related behavioural symptoms have not translated into a cure, which leaves numerous challenges to the treatment

and the care of people with dementia. There are two main recommended therapies for dementia at present, pharmacological and non-pharmacological.

Pharmacological therapy

The pharmacological drug therapies are grouped into anti-dementia drugs, which treat the cognitive symptoms of dementia, and drug therapy for the associated neuropsychiatric symptoms or BPSD. While studies showed promising results for the use of anti-dementia medications, due to the different types and different stages of the disease, the administration of anti-dementia medication still has limited ability to treat dementia. According to Alzheimer's Australia (2014) Cholinergic treatment, the use of acetylcholinesterases are beneficial for people who have mild Alzheimer's disease, while memantine treatment works better in the moderate to severe stage of Alzheimer's disease. Regarding the treatment of other types of dementia, the use of acetylcholinesterases and memantine therapy is ineffective and still remains controversial in the literature (Alzheimer's Australia, 2014). Currently a variety of atypical and typical antipsychotics as well as anticonvulsants and cholinesterase drugs are the most regularly used medications for the treatment of BPSD. While the use of these medications is a common practice, there is limited evidence in the literature to support those practices, due to the commonly reported adverse side effects and the hazardous outcome of drug-drug interaction (Seitz, Gill et al., 2013).

Non-pharmacological treatment

There are a number of reasons reported in the literature which support the advantages of non-pharmacological interventions in dementia. According to Cohen-Mansfield (2004), non-pharmacological intervention aims to address the reasons for the psychosocial behaviour, it has no adverse side effects and has no limitation to cover the real needs and communication of the already compromised person.

Studies of non-pharmacological interventions usually address a wide range of behaviour concerns and can be grouped into sensory therapies, social contact, behaviour therapy, structured activities, environmental interventions, medical/nursing interventions and combinations of therapies. Although these studies mostly reported positive outcomes, the clinical significance of results was limited (Cohen-Mansfield, 2004).

The importance of recreational activities

In Australia it is a common practice that people with dementia are accommodated in residential aged care facilities, and in 2008-9 over 53% of residents in residential aged care facilities had a diagnosis of dementia (AIHW, 2012). The utility of recreational activities plays a vital role in the implementation of non-pharmacological interventions in dementia care to target psychosocial needs and for the management of BPSD in RACFs. The value of recreational activities in RACFs is based on the essential human need for activity (Csikszentmihalyi, 1993). It is increasingly recognised by the Australian government that activities need to be dementia specific and based on the Person-Centred Care (P-CC) approaches (AIHW, 2012). According to the Aged Care Act (1997), recreational activities are designated as part of the personal care services, which need to be provided and suitable for all residents. In the United States authors Cohen-Mansfield, Thein, Dakheel-Ali and Marx (2010) and Kolanowski, Buettner, Litaker and Yu (2006) identified that RACFs are required to provide activities for their residents and one of the indicators of the quality of the facilities is whether residents are engaging in meaningful activities. Engaging in meaningful activities is not only an indication of the quality of care, but can largely contribute to the quality of life of people with dementia, at both an individual and social level (Harmer & Orell, 2008).

Conceptual framework of the thesis

There are theoretical models in the ageing and the dementia literature that reflect the importance of quality of life of people with dementia. Three major theoretical

models identified in gerontology research guided this study; the Creative Ageing theory, the Person-Centred Care model, and the Need-Driven Dementia-Compromised Behaviour Model. The genesis of these theories and their importance to this thesis will be presented in the next part of this chapter.

The Creative Ageing theory

The model of Creative Ageing emerged at the beginning of the 21st century as a part of the major conceptual changes of ageing and focuses on the potentials of ageing. The leading proponent of this theory is Gene Cohen who emphasises that creativity can promote health in any stage in life including older age. According to Cohen (2006) this theory is based on the underlying mechanism of sense of control, the influence of the mind on the body, social engagement and the brain plasticity mechanism.

The mechanism of sense of control as described in research findings (Rodin, 1986) which declare that older people had positive health outcomes by experiencing a sense of mastery and an increased level of comfort and empowerment by exploring new challenges. The relationship between being creative and well-being as explained by Cohen (2006) is that arts can provide the opportunity to experience a new sense of control, therefore being creative promotes well-being (Cohen, 2006).

Creative art can also influence the mind on the body mechanism which is based on the studies in psychoneuroimmunology. According to Kiecolt- Glaser (2002) positive feelings associated with the sense of control can trigger responses in the brain that signal to the immune system to produce beneficial immune cells.

The general health benefits of social engagement on ageing, ranging from cardiovascular to immunological to endocrinological, have been demonstrated by a number of studies in the past (Glass, de Leon, Marottoli & Berkman, 1999; Avlund, Damsgaard & Holstein, 1998). According to Cohen (2006) the social engagement mechanism is included in the Creative Ageing theory because

participating in artistic activities provides a number of opportunities for social engagement for the ageing population.

The last underlying mechanism of the Creative Ageing theory is based on recent advances in the understanding of the brain's ability. Studies from neurosciences showed that when the ageing brain is challenged by activities and new experiences, it is able to form new connections by forming new synapses; this refers to the plasticity mechanism (Kramer, Bherer, Colcombe, Dong & Greenough, 2004). The nature of creativity has the potential to sustain and provide new challenging experiences (Cohen, 2006).

Cohen and colleagues conducted a national study in the United States in 2001 to explore the association between creativity and ageing. This controlled study of Creativity and Ageing found that being involved in professionally conducted creative programs in the community over a one year period in older age resulted in a number of health benefits. The intervention group showed statistically significant better health, less doctor visits, medication use, falls, and had less depression and loneliness. Overall, this study found that being creative in older age can improve quality of life measurements (Cohen et al., 2006).

While the main focus of creative ageing is to use the benefits and the influence of art to enhance quality of life in old age the study of Creativity and Ageing only focused and tested on general ageing population. Although Cohen (2006) stated that creativity should be extended to populations with compromised cognition such as people with dementia, because for those with compromised cognition there are shortages of quality of life experiences, the Creative Ageing theory has not been tested on people with dementia.

Person-Centred Care model

Another theoretical model that guided this study is the P-CC model in dementia, which was developed by Professor Tom Kitwood in the 1990s. According to Kitwood (1997), as opposed to the old culture of care in dementia, which is based

on the biomedical task orientated model, P-CC in dementia is a holistic approach which values humanity and autonomy of individuals. It was founded on the ethic that all human beings are of absolute value and worthy of respect, no matter their disability, and on a conviction that people with dementia can live fulfilling lives. The essence of P-CC in dementia is to maintain personhood in the face of the failing of mental powers. The attention to personhood includes recognition of the centrality of relationship, the uniqueness of the person and of the carer (Kitwood, 1997). According to Kitwood and Bredin (1992) this standpoint is based on the observation that the presentation of dementia cannot simply be reduced to the effects of neuropathologic damage, but is instead a combination of factors such as personality, biography, physical health, neurologic impairment and social psychology. The philosophy of P-CC in dementia is focused on the psychosocial needs; the establishment and maintenance of a positive environment for persons with dementia. In this situation personhood of individuals may be enhanced by strengthening the person's positive feelings, nurturing their abilities and helping the healing of a psychic wound (Kitwood & Bredin, 1992).

Person-Centred Care emphasises the importance of individual and sociological personhood (Kitwood, 1997). At a practical level, addressing individual personhood includes providing individuals with sensory and cognitive stimulation, encouraging meaningful human connection and purposeful occupation, rather than managing deficits. To fulfil social personhood the care needs to focus on the individual as part of the community. This can be achieved by providing an environment where social relationships can flourish, and building on the maintenance of personhood at the individual level may reduce socially needs driven behaviours (NDBs) and allow full participation as a contributing member of a community (Thornton, 2010).

According to Edvardsson and Innes (2010), despite the widespread practical use of this theory in the United Kingdom and Australia, person centred practices have not been measured by researchers and the empirical literature is lacking a validated tool which could contribute to measurable evidence of such practices. Despite this the tenets of P-CC have been integrated broadly into RACFs in

Australia, with high variability in the extent to which individual facilities integrate P-CC into everyday practice.

The Need-driven Dementia-compromised Behaviour model

The Need-driven Dementia-compromised Behaviour (NDB) model was first conceptualised by Algase and colleagues in 1996 and more recently has been studied by Kolanowski and colleagues in 2005 and in 2011. According to Penrod et al. (2007) the NDB model placed the person centred model at a new level of care because it not only accepts the person's present abilities, it also facilitates the understanding of who the person with dementia was as an individual and the abilities that person has lost, while giving close attention to P-CC. Kolanowski et al. (2005) claimed that the NDB model has contributed to changing the negative view of behavioural symptoms, and made it understood that the cause of certain behaviours, such as agitation and passivity in dementia, is due to unmet needs. Kolanowski et al. (2005) believed that while long-lasting lack of stimulation can be harmful to people in RACFs , especially those who live with dementia, because it magnifies BPSD, in contrast, meaningful engagement in activities can have positive effects on people with dementia, such as a marked increase in happiness, elevated interest and alertness and a decrease in boredom. According to Kolanowski et al. (2005), before intervening with people with dementia, identification of their past and present interests and systematic evaluation of the personality changes is required. To address the necessity of improved engagement NDB derived recreational activities were designed and tested by Kolanowski, Litaker, Buettner, Moeller and Costa (2011). The study found that activities designed according to a personal style of interest resulted in greater engagement than general activities. The finding of this research suggests that engagement in recreational activities can be positively influenced when factors such as personal interest are considered, in other words, personhood accounted.

Of the chosen frameworks for this study the NDB model is the only one which has been empirically tested. While the study by Kolanowski et al. (2011) found that designing recreational activities upon personal interest can contribute to the

improvement of quality of life measurements by reducing poor mood, agitation, anxiety and passivity with people with dementia the activities in the study were general recreational activities as opposed to activities which can be considered 'creative'.

The integration of the chosen concepts

In this section the summary of the chosen concepts and the possible integration of them will be described. The connection between these theories is presented in Figure 1.1

The person centred model of care informs dementia practices in that if personhood is acknowledged and nurtured at an individual and social level it can enhance well-being and maximise the best quality of care for people with dementia. It highlights the importance of individualised sensory and cognitive stimulation and of providing a meaningful occupation which also contributes to being a valuable member of the community. To nourish personhood in dementia care also contributes to the reduction of BPSD.

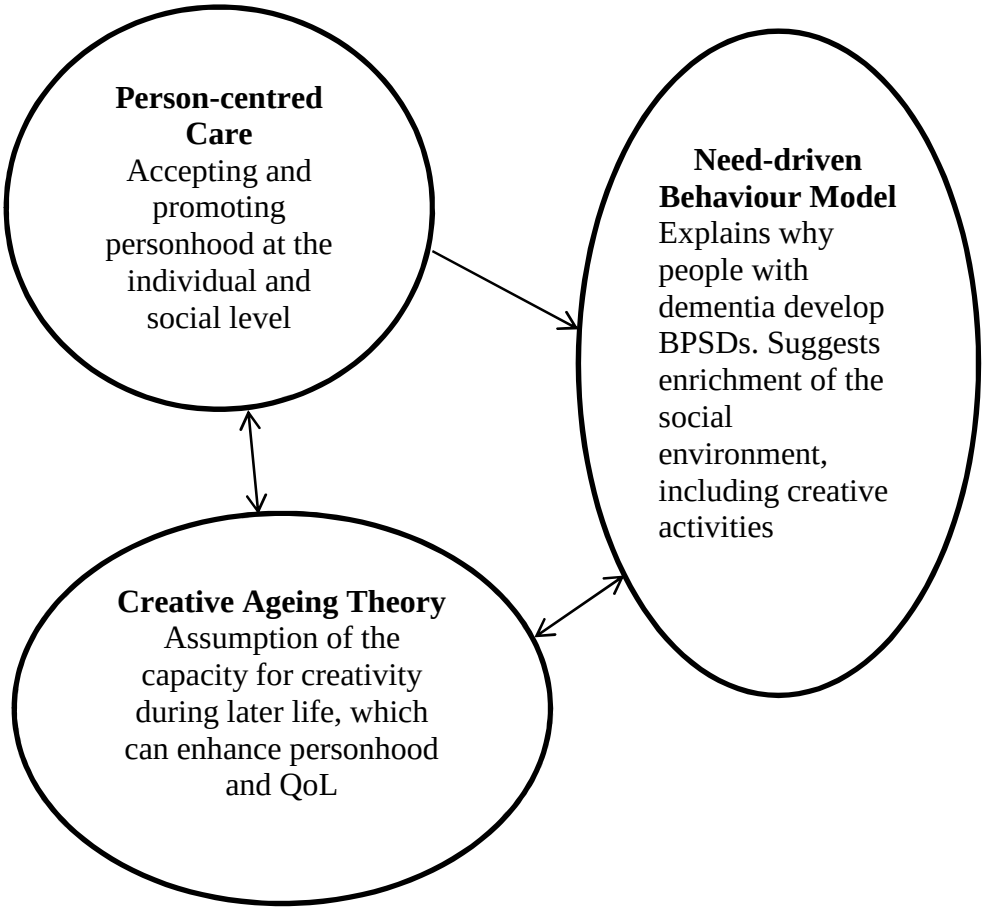
The NDB model, however, articulates that personhood is a dynamic concept and it is important to understand the background and the proximal factors of the person with dementia to implement beneficial interventions. Additionally, disregarding personhood in dementia care can be associated with behavioural symptoms. The NDB model suggests that implementing NDB driven recreational activities can reduce BPSD and positively influence cognition and quality of life for people with dementia. While the person centred care model articulates the elements for providing quality of care, the NDB model conceptualises the possible barriers and clarifies the method, such as NDB driven activities to improve quality of care and the quality of life of people with dementia.

The Creative Ageing theory, however, proposes possibilities and offers directions for how personhood can be understood and flourishes. Cohen stated that being creative not only enhances general well-being but also assists meaningful

occupation and therefore improves social engagement. In relation to cognitive stimulation creative ageing may improve cognitive reserve through brain plasticity (Cohen, 2006). Additionally, creativity can be a vehicle to enhance quality of life experiences for people with dementia, which they often lack opportunities for, due to the nature of the disease (Cohen, 2006).

While the P-CC and the NDB model emphasise the quality of care approaches in dementia care, the Creative Ageing theory offers interventions to improve cognition, general well-being and social health. This study will explore the importance and the possible integration of these theories based on the available literature.

Figure 1.1. The correlation of the concepts



The chosen concepts and implications in this research

The study that is the subject of this thesis applied these theories in the following manner. First of all, the main focus of the literature review was to search the available literature for the presence and the use of creative activities in dementia care to picture the current evidence on the topic. During the literature review special consideration was given to note if any of the P-CC approaches and the NDB model were considered as a conceptual framework or influenced the design and the outcome of the studies.

Secondly, Creative Ageing guided the central focus of the formation of the research questions which aimed to explore the presence and the use of creative activities in residential aged care facilities in dementia care in Australia. Questions were also aided by the P-CC approaches as it was formulated to enquire about the specific needs and the NDB model as one research question enquired about engagement and participation.

Thirdly, the data collection of this study was also influenced by the chosen theoretical models in the way that the questions of the survey and the interview guide questions were also influenced by the theories. For example; as creative activities are one type of recreational activity and are therefore essential elements of the caring process of people with dementia. The person centred approach in the context of this research was a guide to explore the characteristics of these activities. The person centred focus takes into account the whole person, in the mirror of promoting pleasure and quality of life and a way to connect to people with dementia. The NDB model guided the exploration of whether the design and the implementation of creative activities has been influenced by personal interest or these activities used for managing NDBs.

Finally, the report of the outcome of this study constantly reflected on the chosen theories while discussed the important findings of this project.

Significance of the research

Information about the use of creative activities is essential to the provision of dementia care and treatment. This study is relevant to understanding the current use of these activities from the carers' perspective. Additionally, it reveals details of the context, engagement, participation and evaluation of these activities. Implementation of the creative activities has not been researched from this perspective; previous studies mostly evaluated experimental trial art therapy programs. This research may provide a new insight on this topic and provide knowledge for further improvement of creative activities for people with dementia in residential aged care facilities.

Method and outline of this thesis

Chapter 1 has provided background information and context to the research. In Chapter 2, the literature review will further expand upon the vital components of the implementation of creative activities in dementia care and identify the gaps in the literature. Chapter 3 will detail the methods used in this study. The fourth chapter will present the results of the first phase of this study. Chapter 5 begins by presenting a short description of each participant. The chapter then describes the findings of a thematic analysis of the activity coordinators' understanding about creative activities in dementia care in the RACF where they are employed. Chapter 6 discusses the research results within the context of contemporary dementia literature. This chapter also includes the limitations of the study, the recommendations for practice, education and further research.

Chapter 2: Literature review

Introduction

This chapter presents a review of the literature on the implementation of the various creative activities in the treatment and care of dementia. First, it will describe the aims and methods of the review. Second, it will present the significant studies and concepts that are found in the literature on the relevant topic.

The aims of this review

The aims of this literature review are to examine the scientific literature in the context of the application of creative art in dementia care and treatment, to shape an understanding of the current knowledge of the topic. The literature review for this study was guided by the chosen theoretical framework and the following questions were addressed for the review: What is creativity? What are the most commonly implemented creative art forms in the dementia literature? What is the focus of the empirical base on using creative activities with people with dementia? How are these studies designed and evaluated? What findings are reported? What do these studies tell about the prospect of creative activities for helping people with dementia that live in the residential care facility environment?

Method

The following steps were taken to reveal the significant literature in the context of creative activities and dementia. First, a search of the major databases (CINAHL, MEDLINE, ProQuest, ScienceDirect, Cochrane, Psychlit, Blackwell Synergy, and Art Full Text) was undertaken to retrieve English language publications using key words such as dementia creativity, creative art, treatment and care to glean a broad understanding of the key issues that scholars and researchers present in the literature. The broad search identified that creative art in the context of dementia literature is separately explored in the form of music, visual art, drama and dance

or movement therapy. To achieve the aim of the review, an additional search needed to be conducted separately on the different creative art media. The second search was conducted on the same data bases with the following terms used : 'dementia', 'Alzheimer's disease', 'art therapy', 'creativity', 'making art', 'BPSD', 'behaviour', 'depression', 'apathy', 'health', 'wellbeing',' physiological', 'psychological' and/or 'spiritual' 'effects', 'recreational activity', 'person-centred', 'design', 'engagement', 'participation' and 'caregiver' in various combinations. Finally, these terms were applied to both the Australian Digital Theses database and the international Proquest Dissertation and Thesis database. All reference lists of all relevant articles obtained were checked and additional potential relevant research articles retrieved. For inclusion, research papers needed to be written from 2000 to the present.

Results of the search

In the dementia literature creative activities were mostly discussed as part of a non-pharmacological, psychosocial treatment strategy. This literature review revealed that there were four main creative art forms that were identified as the most important (Beard, 2011) and researched in the context of dementia: visual arts, drama, music, and dance activities. Among the creative art interventions, music therapy was the most commonly researched topic and had the largest indication of its effectiveness. This was followed by visual art, dance and drama activities. This review also revealed that creative art is interchangeably used as therapy and activity in the dementia literature. Although some authors suggested that creative art should fall into the "activity" category in the context of dementia (Killick & Allan, 1999), in this review "activity" and "therapy" will be used according to the definition of the study under review. Table 2.1 shows the number of studies by topic, that were reviewed, further details of these studies can be found in Appendix A.

Table 2.1: Research studies analysed

Studies by topic	Number of studies
Music therapy	8
Visual art therapy	7
Dance studies	5
Drama studies	1
Total	21

The next part of this chapter will begin with the definition of creativity and its significance in dementia, then the examination of the use of various creative activities in the context of alleviating BPSD will be described. This section then moves to examining the quality value of creative activities in the life of people with dementia.

Definition and the importance of creativity in dementia care

According to Davies (2007) the concept of creativity and its application through various artistic activities has been identified as a powerful catalyst for personal growth and emotional and spiritual adjustment in a range of life domains. Grounded on the act of making and doing, creativity underpins the conception of meaningful products and ideas through the convergence of cognitive and emotional processes, which in its optimal state, strengthens the human spirit and facilitates the natural healing process in the human psyche (Davies, 2007).

Scholars articulated that being creative, whether artistic or not, in leisure activity time at old age is a vital contribution for physical and mental health and it is closely associated with successful ageing processes (Cohen, 2006; Fisher & Specht, 1999). Creativity is defined by Cohen (2000) as *'our innate capacity for growth. It is the energy that allows us to think a different thought, express*

ourselves in a novel way. It enables us to view life as an opportunity for exploration, discovery, and an expanding sense of self... and it knows no age.' (Cohen, 2000 p. 47). Cohen believed that the importance of creativity is that it prospers on limitation, which forces the brain to meet a challenge and develop a different solution and come out of rigidity. This new model of the ageing brain provides an understanding of the importance of creativity for the ageing population.

Studies evaluating BPSD

Finding a way to alleviate BPSD in dementia care is a significant aim in the dementia literature. According to O'Connor, Ames, Gardner and King (2009) the effectiveness of creative and sensory therapies for BPSD is due to the benefits of engagement and connectedness, it can be a relief from over-stimulation and boredom. Exploring the effectiveness of various creative art forms in the reduction of BPSD is a common practice, especially in the music literature.

Music studies on BPSD

Of the defined creative interventions in the literature, music had the most understanding as an intervention and its effects for people with dementia. According to Aldridge (1996) and Sacks (2007) it is apparent that many musical abilities such as musical perception, sensibility, emotion and memory may remain responsive when other forms of memory no longer evoke reactions. Aldridge (1996) stated that it is hard to find an explanation for this phenomenon, but it is possibly because language development is musical and it is acquired prior to lexical functions. Based on this understanding, music interventions are widely studied in the dementia literature.

There were different dimensions to music interventions in the literature, such as active and passive participation, patient and therapist selected music, individual or group therapy. Several studies including randomised control trials (RCT) have been conducted on the association of music therapy and dementia and these

studies mostly focused on the effect of music on BPSD in general and/or specifically chosen aspects such as depression, apathy, anxiety or agitation.

Studies focused on general BPSD

There were three studies presented in this review that aimed to explore the effect of music therapy on general BPSD (Raglio et al., 2010; Raglio et al., 2008; Svandottir & Snaedal, 2006). In the two randomised control trial studies (RCT) by Raglio et al. (2010, 2008) the effects of group relaxation music therapy on different BPSD were examined, compared to educational and entertainment activities for people with severe dementia. Implementing repetitive relaxation music therapy, when the patient listens to music, is one of the most cost effective interventions and it is commonly used in treatment of psychological symptoms (Guetin et al., 2009). Raglio et al. (2008) found that the most relevant improvement with the intervention group was on delusion, agitation, anxiety, apathy, irritability, aberrant motor activity, and night time behavioural disturbances.

In a later RCT study, Raglio et al. (2010) employed identical experiments and outcome measurements for people with severe dementia, with a different schedule of music therapy administration. The result of this study also showed that music therapy can improve BPSD in patients with severe dementia, , when group music therapy was administrated in three cycles of 12 minute sessions three times a week with each cycle of treatment period followed by one month of break period, and the whole experiment lasting six months. These well designed studies by Raglio et al. (2010, 2008) provide strong evidence that group music therapy programs are effective treatments for reducing behavioural disturbances in dementia.

In contrast to passive music therapy discussed by Raglio et al. (2010, 2008), the effect of active participation in familiar music, played live on guitar was the focus of the study by Svandottir and Snaedal (2006). The therapeutic practice of using familiar music therapy in dementia is based on the understanding that stimulation

of musical memories, which can be stored for a long time in the case of dementia; familiar music may provide a sense of safety which can reduce anxiety (Vink, Bruinsma, & Scholten, 2003). In this RCT n=38 patients with moderate to severe Alzheimer's disease were allocated into experiment and control group. The experiment group, with 3-4 participants in one group, received 30 minutes of active participation with familiar music three times a week for six weeks. The control group received normal care. Assessments of BPSD were carried out with BEHAVE-AD instrument at baseline, during the intervention periods and at 4 weeks follow-up. While there were no changes found on the total scores, there were three significant improvements on the subscales of activity disturbances ($p=0.02$), aggressiveness, and anxiety ($p< 0.01$). While this study, similar to Raglio et al. (2010, 2008), also contributed to the knowledge that music therapy can reduce BPSD, its design including the blinding of assessors and employing the same person to carry out the therapy, and the use of live music, giving opportunity for interaction of the participants, added methodological strength to the study.

Music studies on depression, agitation and anxiety

There were three studies reviewed in the context of music therapy that examined the effect of music on specific BPSD such as depression (Ashida, 2000), anxiety and depression and presented agitation (Guetin et al., 2009) and only agitation by Ledger and Baker (2006).

Using reminiscence with people with dementia is a common practice to provoke memory, singing songs from the past can reinforce safety and reduce depression (Vink et al., 2011). In a before and after intervention quantitative study by Ashida (2000) n=20 people, with four people in each group, were enrolled with different types of dementia. The intervention design of this study was carefully considered, first, it actively involved the participants in live music performance (playing drums together), which was followed by songs based on reminiscence topics which the participants were familiar with, such as home, hobbies and travels sung by the therapist, accompanied by guitar music. The data collection of this study

included two weeks of observations which focused on measuring depressive symptoms, using the Cornell Depression Scale (CDS) and videotaped sessions for general participation and engagement observation. The findings of this study showed that reminiscence focused live music therapy resulted in significant improvements on depression after the third week period ($p<0.05$). While the main outcome of this study focused on the music therapy effect on depression, this study also found a high active participation which can reflects a high quality engagement level.

Similarly to Ashida (2000), based on the reminiscence therapy, individualized music therapy was implemented by Guetin and colleagues (2009) to explore the effect of individualised music therapy on people with Alzheimer's type of dementia who were additionally diagnosed with anxiety and depression and presented agitation. The individualised music referred to the music being chosen by the participants; however, instead of live music in this study, passive listening was implemented. The results of this study also showed significant improvement in the music therapy group on both the Depression and Apathy Scale from week 4 until week 16 ($p< 0.01$) and this improvement was maintained after the cessation of the therapy at week 24. While this study by Guetin et al. (2009) also confirmed that music can have positive effects on depression, agitation and anxiety even after the cessation of the therapy, it also demonstrated that passive music listening is mostly associated with the calming effect of music and does not allow reflection on engagement as such active music therapy (Ashida, 2000).

In contrast to Guetin et al. (2009), Ledger and Baker (2006) did not report a significant effect of music intervention on agitation. The design of the study by Ledger and Baker (2006) included an individualized group music program which was carefully chosen to respect individual preferences and encouraged active participation for people with mild to severe dementia. The long term effect of this program was compared to normal care over a one year period. While the finding of this non randomized experimental study reported improved scores on the Cohen-Mansfield Agitation Inventory (CMAI) scale for a short period of time for both groups, it also showed that the CMAI scores similarly fluctuated from one

data collection point to the other time in both groups, which resulted in no significant differences between the intervention and control groups in the range, frequency and severity of agitated behaviours over time.

Reducing BPSD with visual art

According to Malchiodi (2007) visual art therapy includes drawing, painting, sculpture and the use of colours, and has emotional expression as a central purpose, as opposed to craft activities. Art therapists assert that creative art activities are ideal for individuals with dementia because they require a procedure (like brushing a surface with paint) without heavy strains on explicit retrieval while priming participants for success by emphasising procedural skills (Seifert & Baker, 1998). Despite its simplicity, exploring visual art for the reduction of BPSD is less common than using music.

The most cited randomised control trial investigating the effect of visual art therapy for people with dementia was conducted by Rusted, Sheppard and Waller (2006). The aim of this study was to evaluate the immediate and long -term effects of art therapy for people with dementia in a community setting as well as in RACFs. Although the overall description of the method of this study is well detailed, the report of the activities was not comprehensive, only general information was given; the art therapy group used a variety of art materials and for the control group a selection of recreational activities was designed. This study incorporated several outcome measurements of BPSD and cognition and psychosocial outcomes. Interestingly, Rusted et al. (2006) found that the art therapy group showed slow and stable improvements over time on mental acuity, sociability, calmness and physical involvement with all p value of ($p<0.05$); however, the depression and anxiety scores indicated that the art activity group became more depressed and anxious than the activity group. This finding implies that creating an environment that facilitates emotional expression may create a negative psychological reaction, which could be positively influenced if the activity were more individualised and more personhood need centred as suggested by the P-CC model (Kitwood, 1997).

There was another study found within the visual art literature that explored the effect of visual art in reducing BPSD. Implementing an individualised visual art therapy program for a patient with severe dementia with BPSD where the patient had limited response to a range of pharmacological and non-pharmacological treatment was the aim of the study by Peisah, Lawrence and Reustens (2011). The subject of this study was an 82 year old female RACF resident with severe dementia, with prominent frontal deficits and expressive dysphasia, with the Mini-Mental State Examination (MMSE) score of 0. The manifestation of BPSD included aggression, intrusive behaviour and "purposeless" activities. Peisah et al. (2011) described that after assessment, which identified the strengths and the deficits of the patient, an individually designed art therapy program was implemented. The strengths of the patient included ability to recognise colour and shapes and identify the location of objects in space. The patient also showed high sensitivity when colouring in shapes and in the use of paint and pencils, despite a lack of any artistic history except enjoying colouring in activities with her children and grandchildren in the past. The designed program was considerately chosen to support her visuospatial function and patternmaking; she was given cut felt materials in different colours and shapes to place on stencils and pre-drawn lines. The program required no special environment other than it being free from interruption. It was held in RACF one to two days per week over five or six sessions for a minimum of one hour to a maximum of two by an art therapist or a nurse. The result of this case report was only based on observation. Peisah et al. (2011) reported that during art making the patient was focused and calm, engaging, using body language and eye contact with a positive emotional state. The additional finding of this case study was that the staff of the RACF responded positively to the individualised art program, because it helped them to understand the patient's preferences and abilities, which assisted in the settling processes. While the result of this study only provided an indication of the benefit of art therapy in dementia, and that capacity for creativity can continue even in those with severe dementia, it also indicated that visual art therapy might be a useful activity in dementia and it is a viable consideration for further well designed studies. Although this case report was only a descriptive study, the considerate

assessment and art material choices were its strength and an example for further study design. Considerate choices in designing activities is aligned with a number of authors who emphasised the NBD model (Kolanowski et al., 2011; Hill, Kolanowski, & Kurum, 2010) which highlights that individualised assessment for program design could be a key point of an effective therapeutic program for people with dementia.

Dance therapy for BPSD

According to Guzman-Garcia, Hughes, James and Rochester (2012) dance therapies are suitable psychosocial interventions for people with dementia because they incorporate music, reminiscence and physical movements. However, one study was found, which examined and showed the benefit of dance therapy on agitation amongst people with dementia in residential aged care settings.

A study by Duignan, Hedley and Milverton (2009) implemented specific dance, namely Wu Tao dancing, to evaluate its effect on agitation. This uncontrolled pilot study included six people with dementia who also presented agitation symptoms measured with CMAI (average score 66.38). The participants in this study attended 60 minute, one day per week dance sessions for four weeks. The design of the intervention also included staff participation in the dance sessions, based on the evidence from another study which found that dance activity can allow time for celebration and can smooth boundaries between carers and those cared for; this is particularly important in dementia care, where carers can experience high levels of stress due to the nature of the disease (Coaten, 2001). Data collection for this study included pre- and post- CMAI, questionnaires from participants and from participating staff, and observation for nonverbal expression during the activities. The results from post CMAI showed decreased average scores (60.67) which indicated reduced agitation after the dance therapy. Results from the questionnaires showed 100% satisfaction, both from residents and staff, and interaction with staff from residents who are usually disagreeable and hard to involve in activities.

In contrast to Duignan et al. (2009) a study by Hokkanen et al. (2008) found no behaviour changes with various levels of dementia after participating in nine dance sessions. However, it reported minor improved cognitive functions, such as planning ability and visuospatial function.

Cognitive stimulation

Studies which examined the possibility that creative activities can positively stimulate cognition with people with dementia were also found in the literature. According to the Creative Ageing theory, cognitive stimulation through creative art may improve cognitive reserve through brain plasticity (Cohen, 2006). There were two studies retrieved for this literature review, both in the visual art literature; that specifically explored the effect of visual art on cognition. However, there are other studies which indicated that cognition could be positively influenced; by dance activity; Hokkanen et al. (2008), and Ridder, Wigram and Ottesen (2009) used music to improve verbal stimulation.

Visual art and cognition

A case study by Kaufman (2008) assessed the effects of Montessori painting on an 89 year old female care home resident diagnosed with dementia. While Kaufman (2008) described the purposeful choice of this particular resident who had previous interest in art, the study did not describe the state of her dementia. The design of the intervention was a series of twice-weekly 50 minute sessions consisting of ten minutes pre-test, 30 minutes painting an unfinished craft project such as a wooden box and ten minutes of post-test. The result of this study indicated improvement in memory status after the intervention by 75% of the time completing the memory card faster than the pre-test period. While this study showed a positive result it also raised a number of questions. For example, could other types of activity than art create the same effect? How much of the effect is due to the one to one attention given to the subject? A multiple participant controlled study would facilitate finding an answer to the question; does visual art therapy has an actual positive effect on memory status in dementia.

Eekelaar, Camin and Springham (2012) in their study also found that visual art based interventions had a positive influence on cognition for people with dementia, specially focused on episodic memory and verbal fluency. The intervention contained two parts; art viewing and art making. Art viewing consisted of 30 minutes of group discussion about specific paintings, distinguished by themes, over the three-week intervention period with an art educator. Art making, led by an art therapist in the gallery included art materials, reproduction of paintings and art books, with the participants engaging with the materials as they wished. Participants (n=6) had a diagnosis of mild to moderate dementia. Data collection for this study included pre-intervention interviews, which incorporated visiting participants in their home and presenting them with quality reproductions of paintings. While Eekelaar et al. (2012) found that episodic memory increased during the interventions and post-intervention; however, the findings for verbal fluency were ambiguous. The thematic analysis resulted in four main themes with two sub-themes each. The social activity theme included the isolation sub-theme, which expressed reduced sense of isolation, and the sub-theme structure which expressed the appreciation of the activity, they feel important. The becoming their old selves theme included the sub-theme of recalling memories and improvement in mood. Finally, the theme shared experience included the sub-theme of learning together and making art together. The qualitative finding of this study suggests that people with mild to moderate stage of dementia can appreciate doing art activities in a public place like Art Galleries, it reduces their feeling of being isolated and improves their mood.

Studies on well-being

According to Beard (2011) studies which purely evaluate the experience, or focus on the process of the participation in creative activities can play just as important a role in the context of dementia as the therapeutic studies which predominantly focus on cause and cure. Firstly, because information on psychological well-being such as self-esteem, pleasure, self-worth, empowerment, meaningful engagement and enjoyment is also an essential part of measuring general well-being and they

are a strong indication of quality of life (Cohen, 2006). Secondly, creative art might play a major role in the expression of the impaired cognition (Hannemann, 2006). In the next part of this review studies will be presented that examined the experiences of creative art activities in the context of general well-being, engagement and self-expression.

Visual art and well being

Studies in this literature review, which explored the experiences of people with dementia participating in various creative activities, found that visual art can enhance general well-being and improve enjoyment. Ullan et al. (2011) conducted an exploratory qualitative study to examine contributions of an artistic educational program for people with dementia. The aim of the study was to evaluate whether people with mild and moderate dementia could participate in the artistic activity and what this program could add to their experience. The program was designed, organised and carried out in two stages. The first part included watching an audiovisual material of diverse familiar artists' works of art which the participant could view and comment on. The second part of each session included performing a personal work with a cyanotype. After selection criteria 21 people with various types of dementia, selected from day centre care with MMSE scoring from 12-17, participated in the study. The data collection incorporated participant observation, which included field notes by the authors, video recording the sessions, post-session questionnaires about each participant's engagement filled out by the artistic educator, and one focus group was carried out with the participants and one with professional caretakers. The data from the focus groups showed three outstanding positive aspects of the program: enjoyment, learning and better self-image. The participant observation largely revealed satisfaction during the creative process. While this qualitative study finding indicated that mild and moderate dementia was not a barrier to participation in contemporary art educational programs that have a positive therapeutic effect on the participants (Ullan et al., 2011), the intervention activity seemed to be complicated and costly, which may interfere with its application in everyday practices.

Kinney and Rentz (2005) in a comparative quantitative study aimed to evaluate the effect of participation in a visual art activity and observe the well-being of individuals while they participated in Memories in Making Art program; as opposed to different traditional day care structured activities. The overall goal of this visual art activity was to encourage self-expression and communication through art while enjoying a sensory experience. Twelve (n=12) participants were recruited for the study from Adult Day Care (ADC) centres. On each observation day, three participants were observed using an observation tool specially designed for the study: The Greater Cincinnati Chapter Well-Being Observation Tool is a 19 item tool developed to assess via direct observation of seven domains of well-being among individuals with dementia in both in art and the traditional activities (Kinney & Rentz, 2005). The seven domains included: interest, sustained attention, pleasure, negative affect, sadness, self-esteem and normalcy. This tool is structured such that the data was collected in 10 minute intervals with the rating from 0-4 on the seven domains. The results of this study showed that participants demonstrated significantly more interest ($p= 0.010$), sustained attention ($p=0.000$), pleasure ($p=0.009$) and self-esteem ($p=0.028$) and normalcy ($p=0.014$) during the art program however, there was no statistical difference between observed negative affect and sadness. Interestingly this finding has similarities with those found by Rusted et al. (2006) where depression and anxiety were increased in the art activity group. While in this study sadness and negative affect were not statistically higher, it was still present, which suggested that art activities might have no effect or negative effect on mood for people with dementia. This finding also implied that careful consideration is needed when creating an environment that facilitates emotional expression for people with dementia, because it may create a negative psychological reaction, which needs to be acknowledged, or could be positively influenced if the activity were more individualised as the NDB model suggested (Kolanowski et al., 2011).

Dance studies and well-being and social aspects

In addition to general well-being, most studies which explored the experience of participation by people with dementia found better communication and therefore, improved socialisation, especially in the context of dance therapy. The aim of a qualitative study by Guzman-Garcia, Mukaetova-Ladinska and James (2013) was to explore the effect of Latin ballroom dance on the experience of people with dementia. Thirteen (n=13) home care residents with different types of dementia were recruited to the study. The intervention included 35 minute dance classes twice a week over a six week period. The severity of dementia was indicated by the mean score of MMSE (11.71). The data for this qualitative study was collected with semi-structured interviews from seven residents who were able to provide interviews, and nine care staff. According to the interviews the results revealed that the participants enjoyed the dance activity and it positively affected their mood, mental stimulation, socialisation and communication, as well as having positive effects on their behaviour. The staff interviews also revealed positive results on physical health and reminiscence of the residents.

The effects on general well-being, social interaction, mood and quality of life of people with dementia were the main focus of a pilot study by Hamill, Smith and Rohricht (2011). In this pilot study a total number of eighteen people (n=18), eleven (n=11) with moderate to severe dementia and seven (n=7) carers took part in circle dancing. According to Hamill et al. (2011), the choice of the circle dance symbolised community and connectivity, which is an important aspect in the life of people with dementia, who are often isolated in their community. The therapy sessions lasted 45 minutes, once a week, for 10 weeks. The authors reported improved general well-being based on both patients' and carers' evaluation measures. Qualitative findings emerged from descriptive data and revealed that circle dancing had a positive effect on the mood, concentration and communication of the participating residents. Although the considerate design of the intervention, such as the choice of the dance, and the inclusion of the participant's evaluation can be claimed as the strength of this study, there were several limitations, such as no description of the data analysis method.

Music and well-being

Vleuten, Visser and Meeuwesen (2012) measured quality of life variables to evaluate music therapy for people with dementia. The description of this intervention stated that selected people with various levels of dementia (n=45) from RACFs were to listen to live music for 45 minutes. The evaluation of live music's effect on the quality of life of people with dementia was based on four dimensions: 1) participation, which focused on human contact, 2) care relationship and communication, 3) mental well-being focused on positive and negative emotions and 4) communication, physical well-being and residential conditions. The observation scale used in this study was developed by the researchers; it included 17 items with using three-point scales and was completed by caregivers and family members after the performance. The dataset for people with mild dementia and the dataset for people with severe dementia were analysed with one sample t-test. The results of this study revealed that live music performance was associated with improved human contact, care relationships and emotion especially for people with mild dementia. While this study has some limitations, in that the description of the intervention was inadequate, and the observation scale used in the study was not a validated instrument, it included information relevant to this thesis, such us that music participation can lead to improved quality of life measurements.

The importance of engagement

The concept of engagement

Due to the nature of dementia, participation in activities can be altered from that of those who do not have dementia; therefore the concept of engagement is one of the cornerstones in dementia research about activity participation. It is argued that in dementia care one of the key issues in evaluating the efficacy of any recreational activity is understanding the factors which can effect residents' engagement. Orsulic-Jeras, Judge and Camp (as cited in Cohen-Mansfield et al., 2010, p. 471) defined engagement 'as motor or verbal behaviours in response to

activity'. While the importance of engagement is underlined by numerous researchers, the findings from studies of RACF residents regarding their engagement have shown that they mostly spend their time without occupation (Cohen-Mansfield et al., 2010; Kolanowski et al., 2006). In a cohort design study, Bates-Jensen et al. (2004) examined 15 RACFs and found that most of the 451 residents they observed spent at least 17 hours a day in bed. Another observational study also found that residents living with dementia in RACF spent only 10% of their time in recreational activities (Chung, 2004), and even less when there was severe cognitive or functional impairment. Inactivity and low levels of engagement can contribute to loss of physical function, social isolation and poor quality of life (Kolanowski et al., 2006).

The importance of the quality of engagement for people with dementia is articulated by a number of authors in the literature. Kovach and Magliocco (1998) stated that the quality of engagement depends on whether the action is active or passive. Active involvement means that an individual is physically or verbally engaging in an activity, whereas a passively involved individual can pay attention to the activity or to others participating in it or might comment on it without being directly engaged. Because active involvement is related to physical and psychological well-being and effects the quality of life the aim is to promote active engagement for people with dementia (Hill et al., 2010).

There were two studies in the literature that specifically evaluated engagement in participating in a visual art based activity by MacPherson, Bird, Anderson, Davis and Blair (2009) and Ridder et al. (2009) that looked at music activity and engagement.

Visual art activity and engagement

Only one research study found in the creative literature evaluated the effect of visual art based activity and engagement of people with dementia. MacPherson et al. (2009) studied the effect of an intervention based Art Gallery Access Program for people with dementia which aimed to provide an intellectually stimulating

environment in which people with dementia could actively engage with other people and with artworks. Fifteen (n=15) people, with seven still living at home with mild to moderate dementia, and eight from two residential care facilities with moderate to severe dementia gave consent to participate in the study. The program included educator facilitated discussions on artworks (preselected by the facilitators) each week for 6 weeks duration. The program effectiveness was evaluated by filming each session and films were coded using time-sampling methods focusing on patient behaviour. Additionally, focus group sessions were conducted with participants, carers and educators. While the data analysis showed that home care residents were very engaged and engagement significantly increased from time 1 to time 2, ($p=0.03$) the overall engagement was high for all participants and only a small proportion of observations were neutral or negative. The focus group interviews were held 2-3 weeks after the intervention, which in this study was not very considerate design because memory testing was not the aim. According to MacPherson et al. (2009), this compromised the findings as those residential participants had a poor memory to recall the program. The participants who could recall the event reported benefits such as memory stimulation, increased confidence and the sense of achievement. The other important finding of this study was that when carers were present participants seemed to lose confidence. While there were no long term effects reported on cognitive, behavioural or social improvement for this project, the result of the intervention highlighted that, under circumstances which promote independence, people with moderate to severe dementia can achieve more than is typically observed in their daily interactions.

Music and engagement

A study by Ridder et al. (2009) contributed to the knowledge of how engagement in musical activity can influence other emotional responses of people with dementia. This mixed method case study examined the effects of music therapy, mainly focused on quality of life of the participants, as part of the evaluation of their individualised design music program. Two participants with severe fronto

temporal lobal dementia were selected to undertake 16 music sessions over four weeks. The design of the music therapy took into consideration the cognitive deficits in communication of people with dementia. The music in this experiment was carefully selected to make the participants comfortable, at ease, to allow them to concentrate and interact with the therapist. The therapeutic objective was to meet the psychosocial needs and the person centred culture of the care of the participants. Qualitative data were collected from relatives about the life story of the participants before intervention. The therapy sessions were video recorded and analysed for observation of engagement of the participant in behaviour such as joining in singing, or making eye contact, as well as the verbal comments of the participant. The video analysis revealed that one participant showed active musical engagement and enjoyment, and the effects of verbal stimulation were evident from the analysis. While the music therapy had only positive effects on that participant, the other participant exhibited less musical engagement, and only showed emotional responses when certain songs were played which referred to singing lullabies. According to the authors, this result might be due to the individual differences related to that particular participant being frustrated at being isolated and remote (Ridder et al., 2009).

Self-expression

Although some editorial literature indicates the importance of the expressive role of creative art in dementia, the empirical literature has very limited investigation to date on this topic. According to Hannemann (2006), creative art activities can play a vital role in the care of people with dementia, especially those who have lost the power of choice and decisions, or are emotionally vulnerable and isolated, because creative activities might improve these compromised states through a new way of communication and might provide new understanding of individuals.

Drama and self-expression

Although studies of drama therapy found positive psychological health benefits such as general increased well-being and the facilitation to express inner worlds in

the general senior population (McKee et al., 2005; Snow, D'Amico, & Tanguay, 2003) drama therapy studies are less common than music, visual art or dance studies in the dementia literature. In relation to drama therapy the most commonly mentioned form in the dementia literature is the life stories-reminiscence therapy and it has not been evaluated rigorously by a formal research project. According to Gregory (2011) reminiscence takes many forms and one of the popular forms is when residents tell stories about their life events.

In a qualitative study, Gregory (2011) evaluated a poetry based reminiscence program in three different RACFs and one community centre. The program included three components conducted by a poet and delivered over four weeks. The first session incorporated a talking session with the resident in the presence of carers and families about whatever topic they wished, while the poet took notes from the words of the residents and composed poems. In the second session the poems, which were viewed as co-authored pieces, were read back to the residents and families and carers. The third session was a workshop for carers, addressing issues such as listening, non-verbal communication, boredom, anxiety and isolation amongst clients. The aim of this study not only included evaluating the role of poetry for people with dementia, it also included the evaluation of the impact of poetry on caring practices for people with dementia. Data for this study were collected from six caring staff in the form of in depth semi-structured interviews. Data analysis was guided by phenomenological methodology. Six main themes and several sub-themes emerged from the data. The first theme *exploring and preserving memories* summarized the thoughts that the value of reminiscence for people with dementia in the carer's eyes is not surprising, however, putting it into a new context such as to create poetry, brought new life into it, and made it more alive and emotive. The data suggested that the carers viewed the poems as three-dimensional creations which went beyond finding out basic information from the participants. The second theme was identified as *communicating with service users*. This theme expressed that this project enabled effective communication to residents who otherwise had problems with comprehensible communication and taught the carers to think of using different

approaches in their care for people with dementia. The third theme was revealed as *co-authorship of poems,* which articulated that the participating residents had pride and satisfaction in taking part in the creation of the poems, it gave them a voice. The theme of *humanising dementia sufferers* reflected that creativity can place the care of people with dementia into a more humanistic level, in a way that embodies people with dementia personhood. The last two themes, *the broader care context* and *continuity,* reflected on the caring method, such as how the intervention applied to the role as a carer and the questioning of the long term benefits of the intervention. This study by Gregory, (2011) indicates that using a creative art form can benefit people with dementia by improving self-expression and communication, and can inspire new caring methods, and it may also allow carers of people with dementia to understand residents better through their expression.

The meaning of a creative activity in everyday life

According to Brooker and Duce (2000), presently there are more types of activity available for people with dementia than at any other time before. Despite scholars articulating the importance of the use of creative art in everyday practices in the care of people with dementia (Swann, 2012; Beard, 2011; Hannemann, 2006), there was only one study in the literature which evaluated an already existing dance program in a RACF and explored the activity coordinators' opinion of the program (Palo-Bengtsson & Ekman, 2000).

Palo-Bengtsson and Ekman (2000) explored the meaning of social dance events in the life of people with dementia, organised by the caregivers and described by the caregivers. Different regular social dance events were videotaped and evaluated by the caregivers during unstructured interviews. The data was collected from seven caregivers and analysed using qualitative phenomenology. There were five consistent themes that emerged from the data, where the caregivers talk about how they planned and implemented the events, how they felt about persons with dementia and themselves. The first theme summarized the *prerequisites for dance events* which expressed the preparation and planning of the events, caregivers'

experiences, co-operations between themselves and the residents, knowledge about the residents such as life histories, and planning technical matters. The second theme revealed the importance of *creating and preparing different kinds of activities related to the dance events*. The caregivers reported the meaning of joining the dance activity to other activities such as baking, dressing up, playing dance music, so that dance becomes more appealing to people with dementia. The third theme highlighted the *emotional arousal* of social dance. This theme included the positive effects of togetherness, communication, joy and happiness and physical well-being of the social dance sessions. The fourth theme was the *caregivers' situational understanding,* which emphasised that as a caregiver it is important to understand that when people with dementia experience a circumstance which is not an everyday practice it can effect their security and self-assurance, therefore for a caregiver to lead by example using humour and joy can help to provide a positive experience. Additionally, this situation can be made smoother by having adequate training and using creativity. The last theme that emerged from this data was *dance events and contextual consequences* and appeared from the understanding that different kinds of dancing are suitable for different individuals, which also reflects the severity of the disease. For some people, being allowed to sit and watch without pressure was an important factor for enjoyment of this activity.

The above study not only contributed to the knowledge of the use of a creative activity in the life of people with dementia in everyday practises, it also revealed important facets such as effects on well-being, considerate choices of the design and implementation of creative intervention, in this case dancing in the life of people with dementia.

Summary of the literature review

This literature review revealed that there are a number of differences across the creative art media in the dementia literature with regard to the interest and availability, the designs and the chosen methodologies. It became clear that the most researched medium was music followed by visual art, dance and the least

explored topic was drama therapy. While various strengths were identified, such as considered choices of the intervention, double blinded RCT, there was a lot of weakness across the literature. Studies in this review had inadequate elucidation of the intervention or the design and it seemed that, due to numerous differences within the measurement tools used, there is a lack of conformity on specific measurement tools in the creative art and dementia.

This review also made known that empirical data about the use of creative activities in dementia care is fairly limited. Due to the fragmented nature of this literature it was difficult to make synthesis across the studies. It is difficult to make any conclusions about the effect of these activities in relation to people who live in RACFs because the available data came from different background environments, such as day care centres and community settings.

Despite the differences this review revealed, there are some initial indications of the positive effects of creativity in the treatment and care of dementia. This literature review showed that creative activities may have a vital role in the life of people with dementia, either in a therapeutic way, such as managing BPSD or improving cognition, or as an opportunity for self-expression and new ways of communication. However, currently there is limited information in the literature about the context of the leisure time activities in general and there is no information in regard to the use of creative activities specifically in the life of people with dementia who live in an institutionalised environment. There was only one study in the literature which evaluated an already existing dance program in a RACF and explored the activity coordinators' opinion of the program (Palo-Bengtsson & Ekman, 2000).

Rationale and purposes of the study

In a search for an understanding of the purpose and the role of creative activities in the life of people with dementia, further research is required to determine the availability, the context and the characteristics of creative activities. It is believed that no such study has been conducted in Australia or anywhere else to date.

The focus of this study explored the use of creative art in the life of people with dementia who live in RACFs. Residential aged care facilities accommodate a large number of residents with a dementia diagnosis. The proportion of residents in RACFs diagnosed with dementia was estimated to be 53%, in 2009-2010 according to the AIHW (2012). While the enquiry was about creative activities in general, it had a special focus on visual art. There are two reasons for this; the first is that the literature search revealed that there is limited research available on this art form; all of the studies found in the search are presented in this review, the second is that the researcher has a personal interest in this topic.

The first purpose of the study was to determine the proportions and explore the characteristics of creative art and visual art activities provided for residents of RACF in Australia. To accomplish the first purpose of the study the following research questions were formulated.

1. What is the scope and nature of creative art activities currently offered to RACFs residents with dementia?

2. What is the proportion of creative art activities that are visual art activities in RACFs in Australia?

3. What are the characteristics of the RACFs which are implementing art activities?

The second purpose of this study was to establish knowledge about the design and the importance of creative activities, focusing specifically on visual art in the life of people with dementia, in relation to engagement, and participation in creative activities currently offered in RACFs in Australia. To accomplish the second purpose of the study the following research questions were formulated.

4. To what extent are creative activities designed for people with dementia and their specific needs?

5. How important are these activities in the life of people with dementia in relation to engagement and participation?

6. How are these activities evaluated and implemented in RACFs for people with dementia?

The next chapter will describe the methods chosen to address the purpose of this study.

Chapter 3: Methodology

Introduction

The previous chapter concluded that the use of various creative arts activities in dementia care has a vital contribution to make to the psychological and psychosocial health of people with dementia. While research studies show positive outcomes in relation to the implementation of these activities, the use of creative activities in everyday practice in the life of people with dementia in residential aged care facilities has rarely been considered for research. This study used descriptive methods of a mix of quantitative and qualitative approaches, to evaluate the use and the characteristics of creative activities in dementia care in RACFs in Australia. This study also sought to assess the potential for this information to assist in further developing and implementing such activities in the future care of people with dementia. A national survey and in-depth interviews with activity coordinators produced the data drawn on for analysis. This chapter will outline the process in detail and address the various key components of the research approaches.

Outline of this chapter

The first part of this chapter will provide a description of the first phase of the study including the survey questionnaire developed from the literature review and of the sampling procedures. Data collection, analysis and ethical considerations will then be discussed. The second part of this chapter will explain and justify the use of the qualitative approach to explore the characteristics of the creative art activities currently offered in RACFs in Australia from the perspective of the care staff. Then the second part of this chapter will provide a description of the interview guide developed from the literature review, the sampling procedures and the selection of the participants. The data collection, analysis and the ethical considerations for the second phase of the study will also be presented in this chapter.

Study design

In conducting this research, a non-experimental descriptive design was employed. This study included two parts; first, an exploratory survey design utilised mostly quantitative methodology, which allowed the collection of basic information at a large scale, national level about the use of the creative activities. Second, qualitative interviews were undertaken, which allowed the collection of refined details about the characteristics of the implementation of these activities in RACFs.

Phase 1 of the study

The exploratory survey approach

Due to the absence of any information about the use of creative activities in dementia care in Australia, a cross-sectional national survey was designed and conducted to gather basic information about the topic. The survey was delivered online and self-administered. Self-administered questionnaires are an efficient way of obtaining a large volume of information (Polit & Hungler, 2004).

The questionnaire

Knowledge about the use of creative art activities in residential care facilities is limited. Most available studies evaluated trial programs specifically designed for the research project and the understanding of the use of creative activities is fragmented in the literature (Vleuten et al., 2012; Beard, 2011; Hill et al., 2010; Ridder et al., 2009; Hannemann, 2006). A 13 item questionnaire (Appendix B) was therefore designed specifically for this study with QUT Key Survey software (version 8.2) to gather information about the use of creative activities in residential aged care facilities. The questionnaire was designed so that respondents who did not answer Q6, (this question enquired about the types of creative activities) proceeded to Q10 (which enquired about the opinion of the benefit of the creative activities), as the questions in between were not applicable.

Most questions were fixed response items providing categorical data. The survey also included three open-ended questions. One, Q11, asked about the possibility of implementing creative activities. Another two questions, Q10 and Q12, gathered opinions regarding the application of creative activities in the everyday life of people with dementia in residential aged care facilities.

Socio-demographic data

Socio-demographic data were collected from participants in relation to location, occupation, qualifications of the activity coordinators of the facility, and type, size, and number of residents with dementia in the facility.

Data about creative activities

Based on the literature review, questions about the four main creative activities, namely, visual art, music, dance and drama were formulated in the survey. Additionally, a question about the role of the residents with dementia, in relation to being in individualized or group activity session was also included. The literature review also identified that there is very little known about the opinions of care staff in relation to creative activities in dementia care. Due to the lack of information in this area, it was necessary to include two open-ended questions, to allow the expression of respondents' opinions in relation to the implementation of creative activities in dementia care. Open-ended questions are the most suitable form of data collection when the researcher wants to capture the respondents' own words in a narrative way (Polit & Hungler, 2004). The open ended questions were formulated to create knowledge, from the care staff member's point of view, about the benefits of and barriers to the implementation of creative activities for people with dementia.

The last question of the survey was formulated with the intention to provide an opportunity for participants to express an interest in further involvement in the second part of the study.

Reliability and validity

To improve the reliability and validity of the questionnaire several procedures were performed. A quality audit check was undertaken, followed by a pilot test and review by experts.

Quality audit check

According to Polit and Hungler (2004) quality audit check is an essential part of the development of a structured self-report instrument. The importance of the quality audit check is to maximize the quality of the questionnaire and consequently the quality of the research and to minimize bias. During the development of a questionnaire the draft should be discussed critically with people who are knowledgeable in the area in relation to content as well as technical problems (Polit & Hungler, 2004).

To improve the quality of the questionnaire of this research the following steps were carried out; 1) the draft of the questionnaire was presented to the two supervisors who are experts from the field to ensure content validity; 2) suggestions received from the experts included clarification of wording and the extension of the items which were incorporated into the final questionnaire; 3) technical and layout changes were made to improve organisation and readability.

Pilot testing

Prior to the initial launch of the survey, a pilot launch was undertaken to three different persons to uncover technical and interpretation difficulties of the questionnaire and enhance content validity of the tool, before the actual data collection in the study. The test launch of the survey received positive feedback; therefore no further changes were required.

Research protocol

Target population

The target population was all RACFs in Australia. The sampling frame used was the publicly available list of all Australian RACFs from the Department of Health and Ageing (DOHA) website. This list represented the whole population; however, email addresses were only available for a subset of the list; 1675 RACFs out of 2752 population.

The inclusion criteria for the survey included residential aged care facilities that

- were included on the DOHA website list
- operating within Australia

Procedure

First an email invitation (see Appendix C) was sent simultaneously to all RACFs with email addresses, explaining the purpose of the study, the focus of the questions and the obligations of taking part in the research project. The email invitation also included two links: one to proceed to the survey and complete it; and another link provided a preference to not participate and to be removed from the list and avoid further inconvenience such as a reminder email. The email invitation was addressed to the Manager or Director of Nursing, and it specifically asked that it would be preferable for the survey to be filled out by the activity coordinator.

Facilities that responded with a preference not to participate (n=36) at all were removed from the contact list at the time of their expression of no participation. Completion of the survey required approximately 5-10 minutes, with respondents given the choice of completion online or by telephone. There were four responders who expressed the preference to complete the survey via telephone. The researcher attempted to contact them several times, but unfortunately they

were not available, so the telephone survey could not be completed. Data for the first part of the study were collected from 29th of July to 29th of August 2013.

Ethical considerations

There were no anticipated physical, psychological, social or legal risks associated with participation in the survey. Participants were first informed about the study in general through the invitation email, and then an informed consent form was incorporated into the electronic survey design.

The consent form (see Appendix F) stated that if the participants submitted the completed survey it was accepted as giving consent to participate. It explained that participation was entirely voluntary and participants were advised that they could withdraw at any time without penalty. Participants were assured that all identifiable data would be removed after data collection and that anonymity would be maintained in relation to the publication or dissemination of any results of the study.

Ethics approval for the first part of the study was sought and granted by the Queensland University of Technology Human Research Ethics Committee (number 1300000356).

Data security

All completed surveys were stored electronically on the secure QUT server within the survey software. This software was password protected and was accessible only to the researcher and to the supervisors with direct involvement.

Data management and analyses

After data collection all survey data was transported to an Excel file and imported into the Statistical Package for Social Sciences (SPSS) version 21 for analysis. All data were checked for consistency and out of range values. Data from

participants choosing “other” responses were coded into existing categories where possible.

Statistical procedures

Quantitative data were analysed using descriptive statistics in the form of frequencies and percentages for categorical variables, means and standard deviations for continuous variables to detail the characteristics of the participating respondents. Additionally, Chi-square tests were used to test relationships between different categorical variables. Continuous variables were divided into categories before running these tests.

Qualitative interpretation of the open ended questions

Data from two open-ended questions were transcribed and analysed by a systematic approach to descriptive qualitative analysis to reveal key patterns underlying perception about the benefits and the barriers to implementing creative activities in the life of people with dementia.

Preparation and data analysis

All open-ended questions were first transcribed by the researcher. After transcription the questions were initially read separately in a superficial manner to gain a broad perspective on the responses. At this point it became clear that the answers for Q12 (question about the barriers to implementation of creative activities) and Q7 were very short and repetitive, therefore the answers were grouped and categories created and quantified.

Compiled responses for Q10 were then subjected to careful reading, whereby words and phrases that captured the concepts related to what the respondents were saying were highlighted. Different concepts were highlighted with various colours. Highlighted phrases with shared meanings were then grouped into concepts through a dynamic process of constant comparison. Through this

process natural variation across respondents was discovered, and five main concepts were created to provide an organised description of the respondents' opinions.

Phase 2 of the study

Taking a qualitative approach

The second phase of this study was designed to gain in-depth information about the nature and the content of creative activities used in residential care facilities for the care of people with dementia. To achieve this aim an exploratory, descriptive qualitative design was used in the second part of the study. Taking a qualitative approach means that the phenomena under investigation can be explored in a deep and holistic style, through the collection of rich narrative material (Olsen, Dysvik & Hansen, 2009). Qualitative methods provide an insight into how people make sense of their knowledge that cannot be easily provided by other methods. To create truly exploratory descriptive findings from this study, the most suitable approach was to ask participants about their thoughts and experiences. Qualitative data collection tools such as interviews legitimated the participants to describe their own knowledge and express their thoughts in regards to their care practices.

Justification of the research design

The rationale for taking a descriptive qualitative approach in this phase of study was based on the fact that no scientific study has been conducted previously on the topic of using creative activities in RACFs in everyday practices. Therefore, this study project was designed to explore and describe the quality of these activities from the carers' perspectives. In nursing research descriptive qualitative design is a frequently used approach, especially when unknown phenomena are under investigation, because it can originate knowledge and results in meanings and solid findings (Vaismoradi, Turunen & Bondas, 2013).

Sandelowski (2000) articulated that a descriptive qualitative method is the most appropriate choice for research design when the aim of the project is straight description of the phenomena. Although a descriptive qualitative method, unlike other qualitative methodologies, has no pre-existing theoretical or philosophical commitment, most qualitative descriptive studies tend to draw from the philosophy of naturalistic enquiry (Sandelowski, 2000). The essence of the naturalistic enquiry is to study the phenomena in its natural state, as it occurs, and with 'no a priori commitment to any theoretical view' (Sandelowski, 2000, p 337). However, while there is no theoretical commitment in descriptive qualitative research, no study should be free from any theoretical or conceptual influence. According to Sandelowski (2010) the methodological value of descriptive studies lies on the hues and tones from the other qualitative approaches. Accordingly, this descriptive qualitative study has grounded theory overtones, as some techniques such as coding the data and constant comparison were applied, which are mostly associated with grounded theory, without attempting to produce any theory.

The second phase of the study, from forming the research questions through sampling, data collection and analysis to the interpretation of the data employed descriptive qualitative methods, as the main aim of this study was to obtain and interpret straight unadorned data.

Methods

Participants

Identifying the sample population for the second part of the study in this project was based on self-selection and purposeful sampling. Purposeful sampling is the most common form of sampling technique in qualitative descriptive design (Collingridge & Gantt, 2008).

The last question of the survey questionnaire asked the respondents to indicate their interest in further involvement in the study. Forty seven respondents, being a mixture of activity coordinators and managers, indicated a desire for further

involvement in the study. Participants for the interviews were selected from this list.

Recruitment and data collection procedures

Identify the sample size

Generally, in qualitative research there is no definite recommendation for minimum and maximum sample size. However, there are references across the literature which support that the sample size of a qualitative project has to be adequate to the research design and needs to be influenced by practical consideration (Cleary, Horsfall & Hayter, 2014; Robinson, 2014). One of the practical recommendations in the literature by Robinson (2014) is that qualitative studies at the initial stage should have a predetermined minimum and maximum sample size, which can be flexibly changed during the data collection process. At the initial stage of the second phase of the study (including within the ethical clearance application) the proposed sample size of this study was between 15 and 20. The decision to use these numbers was partly based on the adequacy to the research design, as a minimum of 15 in-depth interviews will provide an appropriate amount of data to describe the phenomena under study, as the method was descriptive and no theory was developed. Additionally, practical consideration such as the timeframe and the nature of Masters Research also influenced the choice of the sample size of this study. However, during the data collection and the recruitment period the final sample size was open to flexibility until the data analysis process was finalised. The recruitment period, the data collection and the final sample size of this study occurred in the following manner.

Recruitment for the interviews was an ongoing process. To establish broad knowledge of the topic, the participant recruitment was done with special consideration for the inclusion of participants from different states, which provided an opportunity to collect heterogeneous data. According to Robinson (2014), heterogeneous sample groups in qualitative studies help to provide

evidence that the findings are not exclusive to one particular group or place and the findings can be applied to another context. To collect information from the various parts of the country the researcher selected ten contacts from different regions who were initially contacted by telephone. Those who were still interested in participation confirmed an interview appointment with the researcher, and were sent an informed consent form and information sheet via email. Seven activity coordinators were recruited and returned the informed consent forms after the initial contact. After the initial seven interviews were conducted, recruitment continued in the same manner until the number of interviews reached fifteen. When the 15th interview was completed, the data collection paused and all of the interviews were transcribed. The transcribed interviews were shared with the supervisors, and upon general agreement that the data contained no new information, data collection stopped.

Interviews

Each participant was interviewed once within six weeks of recruitment. Qualitative interviewing is the most common approach used to gather information on an experience or events (Minichello, Madison, Hays & Parmenter, 2004; Holloway & Wheeler, 2002). In this study a semi-structured approach to interviewing was undertaken. Although the questions were predetermined, the sequence and the number of questions asked varied according to the respondents' ideas. This allowed the participants and the researcher the freedom to diverge if necessary, pursuing an idea in more detail (Olsen et al., 2009; Endacott, 2005).

The interview guide

An interview guide with a number of semi-structured questions was developed to ensure the collection of similar types of data from all participants, covering all of the topics relevant to the aims and objectives of the study (Holloway & Wheeler, 2002). The topics and themes for the interview guide (see Appendix D) were derived from the published literature, specifically focusing on the quality and the content of the creative activities in dementia care in residential care facilities. The

interview guide enquired about what opportunities were offered for emotional and self-expression and engagement through creativity and to what extent these activities were used to alleviate behaviour symptoms of people with dementia. The design of these activities and their importance in the life of people with dementia in relation to engagement and participation were also included.

Data collection sites

Interviews with respondents outside of Brisbane and the Sunshine Coast were conducted via telephone and electronically recorded using software from a designated computer at the Dementia Collaborative Research Centre: Carers and Consumers, QUT. While the best practice recommendation is to conduct qualitative interviews in person (Minichello et al., 2004), it was not feasible to travel to different states., However, local facilities - two in Brisbane and one on the Sunshine Coast - were visited personally for the purposes of the interviews. The personally conducted interviews were recorded with a digital voice recorder. The length of the interviews varied from 20 minutes to 45 minutes.

Data analysis

Data from the interviews were transcribed by the researcher. As suggested by academics, undertaking this activity oneself allows the researcher to become very familiar with and immersed in the data (Liamputtong, 2009; Braun & Clarke, 2006; Endacott, 2005; Holloway & Wheeler, 2002). During this process any material identifying the participant was removed and a pseudonym assigned.

The thematic analysis approach

Thematic analysis was used to analyse the data sets. Thematic analysis, a common type of analysis in descriptive qualitative research, aims to discover and report the patterns within the data (Liamputtong, 2009). Although qualitative data analysis is usually determined by the methodology used, common to all approaches is the identification and clustering of concepts. These concepts are then further grouped

to form sub-themes or themes. The researcher also searched for links or associations between themes (Liamputtong, 2009; Endacott, 2005; Holloway & Wheeler, 2002). The patterns that were formed provide the description of the phenomena under study.

The following analytical steps were undertaken to develop the themes for this project.

Step 1: Transcription of all the interview data.

Step 2: After the interviews were transcribed, a hard copy was created and the researcher set about re-familiarising with what the interviewers said. Then the transcripts were read through and notes were taken on the pages.

Step 3: Upon completion a clean hard copy was made of the interview transcripts and this time the examination concentrated on each line of data. This process is commonly referred to as 'line by line coding' but is also known as open coding or substantive coding (Dey, 2004). First, the transcript was marked with coloured highlighter pen and a code was made in the margin. As the reading continued, words and phrases considered important were underlined. For example, "*we spend a lot of <u>one to one time with them</u>, one staff one dementia resident and <u>we look at their history</u>, what they used to like before they came in here, then if they were a sewer, we will then get magazines, and if they are capable we will get big needles and we just encourage them just to sew, bring back their memories and that <u>encourages them to reminisce</u>*". After underlining, comments were made in the margins, always asking the question, "*What is happening here*?". During this process a single word or phrases were given that captured the concepts related to what the interviews were saying. At this point it was attempted to give a 'name' to what the researcher was 'seeing' using the participant's own words but also trying to use one word to describe what was happening in the data. Staying focused on the minute detail of the transcripts helped to prevent the researcher from imposing their own framework or ideas on the data (Holloway & Wheeler, 2002).

Step 4: After every interview was coded in this way the data was read again, this time attempting to group like concepts. This was a dynamic process whereby searching for similarities and differences within the data began (Boeije, 2009). This technique is known as constant comparison (Dey, 2004). A Word document was used to start to cluster like or similar pieces of data together with their associated concepts. For example "*recognized their needs*", "*hold their interest*" "*get to know them*" "*implement activities according to their interest*" were all placed together. In this manner tentative themes started to form.

This process continued over and over again. Always asking the following questions; "*What are the interviewees really saying*?" "*What do I understand about this data*?" It was noticeable that the names the clusters were initially given changed over the analysis process, as the researcher became increasingly able to articulate what was 'happening' in the data. In this way a cluster or group of concepts became a theme or subtheme.

Step 5: During the coding process special attention was paid to not only discovering commonalities across the data but seeking natural variation (Polit & Hungler, 2004). For example, one of the interview participants was a qualified artist, who consequently had a different focus on the implementation of creative art in residential aged care facilities. During the analysis process, special attention was given to the natural variation that often occurs during qualitative data analysis; that some data does not fit into a theme and therefore some important information can be lost. As suggested by Silverman (2000), the exploration for alternative themes was attempted, but this was not necessary, as in the final process, when the researcher who analysed the data was able to 'see' how all the themes fitted together.

The analysis process was also aided by the fact that semi-structured questions were used in the interview process. For example "Tell me about the creative activities that are available in your facility?" The data thus 'fell out' in a specific way. For example, the list of activities reflected the meaning of the creative activities, how "creative activities" were interpreted by the different activity

coordinators, and how they reflected on this question according to their qualification.

Step 6: The last step of the data analysis included reading the data again and comparing the developed themes and subthemes. It also included searching for links or relationships between the themes. In this way some themes condensed and eventually developed into five main themes, four of which had sub-themes, which described the activity coordinators' knowledge about the use of creative activities in residential aged care facilities in Australia.

Trustworthiness

Trustworthiness in qualitative research refers to methodological soundness and adequacy (Holloway & Wheeler, 2002). In this research, trustworthiness was ensured in the following ways: 1) By exploring the subjective meanings of the participant's knowledge through the data collection; and 2) through conducting the interviews.

A validity check was used to determine the trustworthiness of the data. The transcribed data and the developing themes were shared with the supervisors during research meetings and this was done in the following manner. First, the themes which were developed and the original sources where the themes came from were presented to the supervisors for discussion and compared to their opinions. Second, with the consideration of the supervisors suggestions the developing themes were revised and shaped into the final version.

Data security

Consent Forms and other hard copy data were stored in a locked cabinet at the Dementia Collaborative Research Centre: Carers and Consumers, QUT as per the Queensland State Archives Universities Sector Retention and Disposal Schedule.

Ethical consideration

Separate ethics approval was sought and granted by the Queensland University of Technology Human Research Ethics Committee for the second part of the study through a variation to the original approval (number 1300000356). The information sheet and consent form are presented in Appendix E. Similarly to the first part of the study, there were no anticipated physical, psychological, social or legal risks associated with participation in the study. Participants were assigned a pseudonym and assured of anonymity in publications and dissemination of the study results. All participants were volunteers who could withdraw at any time.

Conclusion

This chapter has presented the research design and the methodology of both phases of this study. Discussion of the target population, sample and sampling methods were included and details of the questionnaire used and the content validity of these has been discussed. The data security, data management and ethical considerations have also been discussed. Finally, the description of the qualitative approach and the techniques associated with constant comparison in the process of analysis, moving from induction to deduction and back again; constantly comparing concepts, emerging themes and hypothesising about the interlinking relationships were presented. In the following Chapter 4 the findings of the self-administered questionnaire will be presented.

Chapter 4: Results from the First Phase

Introduction

The results of Phase 1 of this study are presented in this chapter and are divided into two sections. The first section will detail the descriptive statistics to demonstrate the characteristics of the sample and the incidence of creative activities in RACFs in Australia. The second section will detail the findings of the open-ended question which described the opinions of the respondents about the benefits of and the barriers to creative activities in the care of people with dementia in RACFs in Australia.

Sample

Characteristics of the sample

A total number of 1675 residential aged care facilities had valid contact email addresses on the DOHA list (out of 2752, 61%). Chi-square goodness-of-fit tests were used to indicate whether there were statistical differences between the sample that had email addresses and the total population in relation to geographical and organisational type and the size of the facilities. The Chi-square goodness-of-fit test revealed that there were no statistically significant differences between the email sample and the total population on geographic type (major city, inner regional, outer regional, remote, very remote) or on organisational type (Private, Charitable, Religious, or Community/Government, Not for profit/not specified). However, there was a significant difference for facility size, such that the sample with email addresses had more of the smaller facilities and fewer of the larger ones than expected given the total population.

Of the facilities sent an email, 249 (15.3%) returned the survey over a one month period. After the launch of the survey 54 automated replies were returned with the messages of out of office, or the director no longer working at that facility. During the one month period one reminder email was sent out to those that did not

respond after the launch (n=1514). Overall, 639 facilities clicked through the survey and 38 were still in progress on the day the survey closed. Table 4.1 outlines the demographic characteristics of the responding participants.

Table 4:1 Demographic Characteristics of Participants

Characteristic	Total N=249 n	%
Location of the facilities		
NSW, ACT	78	31
VIC	71	29
QLD	44	18
WA	24	10
SA	18	7
TAS	6	2
Geographical Location of the facilities		
Major cities of Australia	149	62
Inner regional Australia	64	27
Outer regional Australia	26	11
Remote Australia	1	0.4
Type of organization		
Private/for profit	78	31
Charitable	50	20
Not for profit/not specified	43	17
Government/Community	41	16
Religious	36	14
Size of facilities (number of beds)		
1-46	53	21
50-74	72	30
75-99	46	18
100+	71	28
Occupations of the survey responders (activity coordinators)		
Lifestyle coordinators	69	28
Diversional therapist	44	18
Recreational officer	26	10
Occupational therapist	17	7
Occupations of the survey responders (others)		
Director of nursing	45	18
Managers	43	17
Registered nurse	2	0.8
Physiotherapist	1	0.4
Administrator	1	0.4
Care leader	1	0.4
Activity coordinators qualification		

Certificate III	12	5
Certificate IV	102	41
Diploma	11	6
Bachelor degree	27	11
Master degree	3	1
Others	37	15

The location of the responding facilities

The information on the location of the responding facilities was based on the postcodes they provided The most responses were received from New South Wales and Australian Capital Territory, n=78 (31%). The second most responses were received from Victoria n=71 (29%) followed by QLD n=44 (18%). The rest of the responses came from Western Australia n=24 (10%), South Australia n=18 (7%) and n=6 (2%) facilities responded from Tasmania. There were no responses received from the Northern Territory.

The geographical location, which indicated whether the responding facilities were from major cities, n=149 (62%), inner regional, n=64 (27%), outer regional, n=26 (11%) and remote, n=1 (0.4%) or from very remote n=0 Australia was also analysed based on the postcodes they provided.

The occupation of the responding person

While the survey was sent to the available email addresses and were possibly received by the administrator or the director of nursing, the email invitation specifically asked that it would be preferable if the survey could be filled out by the activity coordinator. The reason for that was to collect the information from the person who provided the activity itself. A total number of 156 (63%) out of 249 respondents were from various occupation groups classified as activity coordinator: lifestyle coordinator (n=69), diversional therapist (n=44), recreational officers (n=26), occupational therapist (n=17). The rest of the responses, 93 out

of 249, consisted of (n=45) director of nursing, (n=43) managers, two registered nurses, one physiotherapist, one administrator and one care leader.

Qualifications of the activity coordinators

This survey also enquired about the activity coordinators' qualifications. The results revealed that in residential aged care facilities, the qualifications of activity coordinators, those who had the main role of the implementation of creative activities, had great variation. The most numerous qualification was Certificate IV (n=102, 41%), followed by Bachelor degree (n=27, 11%), Certificate III (n=27, 5%), Diploma (n= 11, 6%) while Master's degree (n=3, 1%) was the least numerous qualification.

Type of organisation

In Australia residential aged care facilities are funded by the Commonwealth but operated by different bodies, such as Government/community support, private for profit, charitable and religious organisations (McIntosh & Phillips, 2003). In this research, data about the type of organisation were collected to draw a picture of the responding facilities and provide categorical data for further data analysis. The result revealed that 31% of the surveys were completed by private/for profit organisations, followed by charitable organisations with 20%, 17 % were not for profit/not specified organisations, 16% were government/ community and 15% were religious organisation funded facilities.

The size of the facilities

Data were collected about the size of the facilities and this was drawn from the number of beds in the facility. The minimum sized facility was designed for 6 beds and the maximum size was 300 beds. The mean bed numbers of the responding facilities was 83.6 (SD= 48.3).

Creative activities

To the question of the implementation of creative activities 242 (97%) facilities reported that they offer one, two or more of the following activities. The most indicated activity was music, 237 facilities (95%) offer music activity, and the next most common activity was the visual art activities with 210 responders (84%) implementing visual art activities. Nearly half of the responding facilities 117 (46%) offered a dance program and 23 (9%) specified drama. In the other category, activities such as pottery, photography, and visiting art gallery were included. Seven facilities (3%) answered that they do not have any creative activities because of staff and funding problems, and one facility did not accommodate people with dementia.

Group versus individualised activity

The data of this survey showed that creative activities are mostly conducted in both group and individual conditions. Out of 230 responding facilities n=148 (63%) indicated that they provide both group and individualised activities for people with dementia. The reason was that the nature of the activity determines the situation, for example dancing and music, or drama activities are mainly designed for groups. The other common explanation was that residents participate both individually and in small groups because they are encouraged to participate according to their ability and according to individual physical, intellectual, social and emotional needs. Seventy nine (n=79) facilities offered only group activities and three (n=3) responders answered that only individual activities were available due to the nature of dementia, which often requires one to one attention. Table 4.2 shows the characteristics of creative activities.

Table 4.2 Characteristics of the creative activities

Characteristic	N	Total N=249 %
Type of activity		
Music	237	95
Visual art	210	84
Dance	117	46
Drama	23	9
No activity	7	3
Group v. individual activity		
Group	79	34
Individual	3	1
Both	148	63

Relationship between types and size of facilities and visual art activity

The results of the Chi-square test shown in table 4.3 revealed that no significant relationship existed between the type of organisation (Private, Religious, Charitable, Government, Not for profit/not specified) and whether or not the facility had any visual art activity ($\chi^2 = 0.759$, df=4, p= 0.944). The test results of Chi-square test also did not show significant difference between the types of geographical areas (Major and Inner cities, Outer regional and Remote) and whether or not the facility had any visual art activity ($\chi^2 = 1.440$, df=2, p=0.487). However, in testing the relationship between the size of the facilities and the use of visual art activity the result showed statistical significance. The test revealed that bigger facilities are more likely to have visual art activity than smaller facilities ($\chi^2 = 10.443$, df=3, p=0.015). The results are presented in table 4.3.

Table 4.3: Relationship between type and size of facilities and visual art

Independent variable	Visual art activity: No		Yes		Total	
Type of organisation	n	%	N	%	n	%
Private	13	17	65	83	78	100
Religious	6	17	30	83	36	100
Charitable	9	18	41	82	50	100
Government	5	12	36	88	41	100
Not for profit/not specified	6	14	37	86	43	100
Total	39	16	209	84	248	100
Number of beds						
1-49	10	19	43	81	53	100
50-74	17	24	55	76	72	100
75-99	2	4	44	96	46	100
100+	7	10	64	90	71	100
Total	36	15	206	85	242	100
Geographical areas						
Major Cities	20	13	129	87	149	100
Inner Cities	9	14	55	86	64	100
Outer Regional/Remote	6	22	21	78	27	100
Total	35	15	205	85	240	100

Results of open ended questions

Benefits of creative activities

Question 10 was an open ended question and enquired about the benefit of creative activities in the life of people with dementia. Two hundred and forty six (n=246) facilities responded to this question. This data also revealed that 24

responses were only short one word "*yes*" answers. The majority of responders were two short sentence answers. All answers included positive attitudes which in general expressed the opinion that creative art activities were beneficial for people with dementia. Descriptive analysis was used to interpret answers from responding participants and revealed five common concepts. The concepts are shown in table 4.4.

Table 4. 4: Main concepts from Q10

Express themselves
Beneficial to managing BPSD
Social interaction
Creativity is a journey
Depends on abilities

Express themselves

The most frequently articulated response was that creative activities are excellent tools for expression of self. Individuals who work with people with dementia found that creative activities offered an opportunity for expression when verbal communication is impaired *"It allows them … when they have trouble doing this with words"*. Self-expression was also connected to improved tactile and sensory engagement. Many respondents mentioned that these activities helped "*to explore their abilities*" because creativity was able to "*increase fine motor skills and sensory stimulation*". For some, creative activities facilitated self-expression through improved *"cognitive abilities"*.

There was a general consistency through the data that creative activities generated pleasure: "*joy"* and "*smile"*. Additionally, it contributed to quality of life of people with dementia because it enhanced "*self-worth"*.

It was also a common pattern that creative activities, especially music, although some mentioned that visual art helped *"reminiscence"*. Reminiscence was revealed in the circumstances that certain creative activities stimulated memory and assisted in self-expression. This could contribute to the staff better understanding the person with dementia.

Beneficial to managing BPSD

This theme was revealed from the data with small variation. Responding individuals described that creative activities were often observed to have a positive impact on BPSD as these activities had a "*calming and relaxation effect*". Some responses described the positive influence on specific behavioural symptoms such as; "*depression with people with dementia*", the influence on "*centre residents who can be restless and wander*".

Social interaction

The theme of 'Social interaction' was another frequent area within the responses. This theme was elicited from the answers which expressed that creative activities could also be a tool for improving social interaction with family and staff in the life of people with dementia: *"form of therapy can be a way of engaging with their family, friends and staff"*. Some answers articulated the importance of these activities as the only means of social interaction, otherwise *"they don't have any other interactions with other residents"*. Importantly, responses placed significance on creative activities that not only benefitted residents directly but also gave an opportunity for staff to understand residents with dementia through their creative expression.

Creativity is a journey

The fourth theme was extracted from the answers which expressed that creativity could be described as a process like a journey. Many responding individuals indicated that creative activities were suitable to engage residents with dementia because there was no right or wrong way to do it; the process itself was the

benefit. It could be a journey which was purely about "*the person to feel whole and heard throughout the process of creating art"* and "*no expectations of their work",* which allowed them to enjoy the process itself.

Depends on abilities

The last theme emerged from the consideration of engagement and the limited abilities of people with dementia. While all of the responses articulated positive influences of creative activities, parallel to those benefits, concerns were also expressed. Some respondents articulated the problem that people with dementia have different cognitive impairment levels, which can be a barrier to engagement in activities. *"Depending on the level of dementia it is very hard to engage active meaningful participation … Dexterity and object identification can be problems." "Occasionally a person is not able to cope with any stimulus."* Some responses linked the problem to group activity situations, where it was very hard to help people according to their different level of abilities: *"Depending on individual residents, if they can't, then maybe a one to one option will be more beneficial. If they have advanced dementia."* because the cognitive decline was more advanced a specially designed activity would be more beneficial for them.

Barriers to the implementation

The last open ended question enquired about the barriers to implementation of creative activities in RACFs for people with dementia. Four main concerns were raised by the responding individuals. The most frequently mentioned difficulty was the "*staff*" (n=83, 37%) as in not enough staff to implement the activities, and also that the staff lacked the understanding of dementia to implement meaningful activities. Another frequently identified problem was the lack of funding (n=57, 25%). The residents' abilities were raised again as considerable barriers to the implementation of creative activities 38 responders (17%) indicated this issue as a barrier. The least indicated barrier was lack of time and space (n=23, 10%). There were also 23 responders who answered that there are no barriers to the implementation of these activities.

Conclusion

This chapter has presented the major findings of the first phase of the study. The demographic profile of the sample has been described. The basic characteristics of creative activities such as proportion and structure are also presented. The results of the open-ended question has been detailed and described. The next phase of the study will portray the details of the knowledge of the selected activity coordinators in Chapter 5.

Chapter 5: Results from the Second Phase

Introduction

This chapter presents the findings of a thematic analysis of interviews with fifteen activity coordinators to explore their understanding of the creative activities in dementia care in the RACF where they were employed. The chapter begins with a short description of the participants' roles and education. The five major themes and their relevant sub-themes are then described. These were labelled: Diversity of creativity; Considering dementia; Values of creativity; Person centred activity care; Routine assessment for evaluation. The summary of the themes and sub-themes of the data appear in Table 5.1.

Table 5.1: Themes and Sub-themes

Major Themes	**Sub-themes**
Diversity of creativity	·'Creative' activities for entertainment · Overcoming barriers to creativity
Considering dementia	· Specific scheme · Optimising participation
Values of creativity	· Creative expression through reminiscence · Creativity facilitates engagement · Catalyse positive and negative affect
Person centred activity care	· Respecting individual needs · Flexibility of the coordinator
Routine assessments for evaluation	

The participants and their workplace

As the survey results showed, the activity coordinators in aged care facilities had a variety of job titles and different levels of qualifications. This pattern is further elaborated on through the data from the fifteen interview participants, which revealed that all of the interview participants had more than one qualification and role. Facilities ranged in size from small, (less than 50 beds), medium, (less than 100 beds), large, (between 100-200 beds) to very large, (more than 200 beds). All names used below are pseudonyms to protect the privacy of the activity coordinators.

'Peta' was a recreational coordinator in medium size residential aged care facility in rural Victoria, which had a separate unit to accommodate people with dementia. She had worked in aged care and with people with dementia for 20 years in various roles. Her primary qualification was a Bachelor's degree in visual art, and she also held a postgraduate diploma in community cultural development. Her current role was to organize and run the activities; she was working with seven paid staff members and a number of volunteers.

'Janette' was a severe behaviours, dementia and therapy manager in a very large size facility in rural Queensland. Her workplace also provided a separate unit for people with dementia. She had a Bachelor's degree in nursing and her speciality and main experience was psychiatric nursing. Her current role included managing different therapy teams throughout the facility, including diversional, physiotherapy team and any roles that come under therapy. The facility she was working for also worked with a number of volunteers, including qualified music and art therapists, to provide activities for people with dementia.

'Fran' was a lifestyle coordinator in a medium size Brisbane facility. Her qualifications included a Bachelor degree in psychology and a Technical and Further Education (TAFE) certificate in Lifestyle and Leisure Coordination. She explained that in her facility every staff member works together in the care of

people with dementia, including activity times, but without the help of volunteers the work would be very difficult.

‘Jean’ was a lifestyle coordinator from a medium size Brisbane residential aged care facility which accommodates 120 people and has a separate unit for people with dementia. She had been working with people with dementia for seven years, had a TAFE Diploma in Lifestyle and Leisure Coordination and an Associate Diploma in aged care. At her facility she and another four paid staff members were designing the activities for the residents and implementing them with the help of volunteers.

‘Cecily’ was a diversional therapist in a large size facility in Brisbane. She had a TAFE Diploma in Diversional Therapy and was also a qualified Assistant in Nursing. Her role included designing and implementing the activities for the residents. She was working with two other staff members in that role and with a large number of volunteers.

‘Bea’ was a recreational activity officer in a very small size rural New South Wales facility. She was originally trained as a high school teacher but she had a TAFE Certificate in Aged Care and Health and Leisure. She also had training in special methods designed for working with people with dementia, such as the Steiner Method. She was working by herself in her role as a paid staff member with the help of volunteers.

‘Tom’ was a facility manager in a medium size inner city Melbourne facility. His qualifications included Bachelor of Nursing and he had extensive (20 years) experience as a facility manager. In the facility he was managing 23 staff were employed, and everybody was expected to be an active member of the implementation of the activities, including himself. He described himself as a leader of implementing creative activities which are often outside of the usual practices. The facility had regular activities run by the diversional therapy team and volunteers including professional artists.

‘Penny’ was a lifestyle coordinator in a medium size facility in rural Victoria. She had a TAFE Certificate and Diploma in Lifestyle and Leisure Coordination. Her role included designing and implementing activities for the residents. She was working together with two other colleagues and a number of volunteers.

‘Leila’ was working as a diversional therapist at the time of the interview in a medium size facility in rural New South Wales which had a separate wing for people with dementia. She had a university degree in diversional therapy and health science. She had extensive experience working with people with dementia and was formerly an assistant in nursing. She was working together with three other activity staff and volunteers.

‘Ann’ was working as a diversional therapist in a small size facility in Melbourne where people with dementia were accommodated together with residents without dementia. She had certificate training in TAFE in Leisure and Health. She was working together with other paid staff members and volunteers in her facility and she described that she mainly worked as a therapist and her role did not include organization.

‘Kate’ was a diversional therapist in a medium size facility in rural Queensland. The facility she was working for had a separate dementia wing, she was working with volunteers and she was the only paid activity staff member for the whole facility. Her training included a diploma in diversional therapy and 10 years’ experience working with people with dementia.

‘Nelson’ was working as a coordinator for the diversional therapy program in a large size aged care facility in Brisbane. His qualifications included a Graduate Diploma in Fine Art and Business Management. He also had a university degree in Nursing. He had wide experience implementing art in aged care and with people with disability. His role at the facility included the creation of innovations for the existing activity program. He was working with five diversional therapy staff and volunteers.

‘Ella’ was employed as a lifestyle and leisure coordinator in a medium size aged care facility in Hobart where the people with dementia were accommodated together with the other residents. She had a Fine Art Degree and a Diploma in Diversional Therapy. She was working in the facility 15 years and shared the activity implementation with other lifestyle coordinators and volunteers.

‘Mary’ was a diversional therapist from a medium size facility in rural Victoria. At her work place there is a memory unit for people with dementia. She had a degree in nursing, allied health and a diploma in diversional therapy. At the time of the interview she had been involved in aged care for 35 years and had experience in alternative therapy. She worked by herself as a paid staff member designing and implementing activities for people with dementia in the memory unit with the help of volunteers.

‘Danni’ was a recreational officer in a large size rural New South Wales facility. Her training included a TAFE Certificate in Assistance in Nursing. Her role included coordinating and implementing the activities with six other paid staff and with the help of volunteers.

Activity coordinators' knowledge about creative activities in RACFs

Diversity of creativity

This major theme was elicited from the data that described the information about the creative activities. It was revealed from the data at a very early stage and throughout the whole of the data that creativity and creative activity have diverse meanings for different activity coordinators. This situation resulted in two distinct sub-themes.

‘Creative’ activities for entertainment

There was a commonly repeated pattern in the data that a majority of participants comfortably listed many different kinds of activities while they talked about

creative activities. For eleven activity coordinators, while they mentioned *"art"*, according to their description creative activities also included *"bingo, card games, board games, watching movies"*. Some descriptions included *"cooking, bus trips, and special lunches"*. All participants except two mentioned "*craft"* which most commonly included *"knitting and sewing"* as part of creative activity. Interestingly, these activities, which can be categorized as activities that are for entertainment or occupation, were mostly mentioned by activity coordinators who did not have experience or qualifications in art.

A lot of music activities that were mentioned in the interviews and available in aged care facilities for people with dementia follow a common pattern such as a "*volunteer comes in and plays music for the residents*". According to the description of the activity coordinators, the composition of these activities places the residents in the role of a passive listener in various live concerts or music from CD players, which makes this activity more of an entertainment than a creative activity.

There was another form of music activity which appeared in the data to be a very popular activity in dementia care; the sing along sessions. The majority of activity coordinators believed that singing songs from the past, which "*brings back memories"*, is an essential contribution of dementia activity focused care because it helps "*reminiscence"*, and therefore enhances the quality of life of people with dementia.

Overcoming barriers to creativity

During the interview every participating activity coordinator listed one or more art activities that they implemented for their residents with dementia. The two most mentioned creative activities were some forms of visual art such as "*painting"* or "*drawing"* and "*music"* activity. However, when it came to the detailed explanations it was revealed that there were characteristic differences in the implementation of creative activities. First, in those places where the care is involved residents with higher needs , creative activities were more structured; as

Danni explained; "*the artist draws the pictures…, they won't able to do that, they are high care residents"*. Fran described that "*the staff guide the resident to … grip the brush … with dementia, unfortunately they do not have function to visualize"*. Others gave their voice to the concern that if these activities are not structured it is "*very overwhelming"* for people with dementia. As Ann said, or as Peta described, the need for structure is essential, because residents with dementia often do not know what to do with the material itself. Ann expressed her concern that people with dementia often *"try to eat the paint"*. Penny also explained that "*we actually have an outline of something, because a blank page is very threatening"*.

Despite the structured nature of creative activities, art products created by the residents often ended up as part of the decorations in the facility or displayed for the wider community, as expressed by many activity coordinators or "*sometimes we have exhibitions in town"* (Peta).

Although, there were some concerns about the implementation of creative activities in the life of people with dementia, there were some creative activities where the possibility of true creation was expressed by activity coordinators. These options were mainly rooted in choosing the right approach and the suitable activity for people with dementia. Nelson's description perhaps best captures the sentiment of all participants: *"I made the activity easy for them … breaking it down into very tiny modules … for example, ceramics worked quite well, one women had very advanced dementia and she was able to write, making the mark on the pot"*. Bea also expressed that choosing the right creative activity for people with dementia is the key for being creative. She articulated that she leads *"my people very little and very small instructions each time … and we create a story with mono-printing … anyone with any ability"* can participate in this activity. Tom enthusiastically explained that he lets the residents choose colours and paint the facility walls and their rooms with the help of volunteers to fulfil the residents' wishes and creativity, and he experienced this as a "*very achievable activity*" for people with dementia. For some "*creative expression where people can do*

drawing, painting, colouring in, or just interaction with any centring materials" (Ella) was satisfactory to being creative.

Two activity coordinators mentioned that they modified their music activities to be a bit more creative, where people with dementia could actively participate in a music session. Cecily said that their sessions with musical instruments, which include "*the residents pick up an instrument of their choice and play along with the flow of the music"*. Nelson explained that in the facility where he was working, people with dementia who had musical skills were "*encouraged to perform alongside of other performers"* in a concert situation.

Only Nelson and Tom described the importance and the possibility of dancing activity for people with dementia. Tom adapted the limitations of some of the physical disabilities of people with dementia and he introduced *"wheelchair ballet"* to his residents. Nelson saw the opportunity to employ a dance therapist and "*turned the exercise classes into dance classes"*.

Considering dementia

This theme emerged from various parts of the data regarding the activity coordinators' opinions about how creative activities could contribute to engagement and expression in the life of people with dementia. There was a unanimous statement that activities need to be specifically designed for people with dementia. There were two dimensions to this theme.

Specific scheme

The data revealed that implementing a special method is a commonly preferred practice in dementia care. For example, the Montessori method was originally developed for the education of children and only recently adapted to the care for people with dementia. The principle of this method is based on the importance of the "*stimulation of social, emotional, cultural, physical and cognitive functions"* of individuals, as Fran explained. The facilities which were using this method

were designing all of their activities, including the creative activities, to try to address the stimulation of these aspects of life (Fran, Jean, Ella, Janette).

Optimising participation

It was an interesting discovery in the data that implementing modern technology as part of the creativity program is not foreign in present day dementia care. For some, using iPads and digital photography for different creative activities is an exciting innovation which works exceptionally well with people with dementia. Leila stated that using the iPad for people with dementia to design pictures not only "*adds to the imagination"*, and contributes to the sensory stimulation, but reduces the limits of the dexterity and tactile function of dementia *"it is easy to use, just pushing the screen"*. Nelson used an iPad to create "*digital story telling"* sessions and "*composing music"* sessions with people with dementia for similar reasons to Leila. Taking pictures by people with dementia with the digital camera was favourably described by Peta. She also highlighted that modern technology can contribute to the success of creativity for people with dementia in ways that reduce physical limitations, to *"grab a digital camera and point and shoot it does not require dexterity"*. Taking photographs as part of a creative activity program was also mentioned by Bea.

Considering physical abilities as part of optimising participation also arose in the context of immobility of people with dementia. It was mentioned by a number of activity coordinators as an important consideration in the implementation of a creative project with the assistance of the community. The involvement of the community was seen as beneficial because it serves two functions. One is to apply freshness into the program and the other is to enhance the social connection of the RACFs with the community. For example Bea explained that when she invited a community member to present a travel story with wonderful pictures, it contributed to a sensory experience as well as the connecting with the community: *"invite members of the community to be part of us , it makes good going"*. Nelson stated that "*school children coming in making digital stories with seniors, it was amplifying the community connectiveness"*. Similarly, Mary talked about local

school children being invited to create a "*life story"* with residents. The importance of bringing community to people with dementia was also identified by Penny, who added a bit more detail of the consideration of the involvement of men in creative activities, for "*men's group creative things we have Bunning's come out"*.

The data revealed that the timing and the choice of the surroundings of the activities were also important in dementia care and considering environmental influences was part of optimising participation strategies. Leila and Peta mentioned the "*Sundowners Program"* which offers a quieter creative time for people with dementia in the afternoon in a smaller group or in a one on one situation. Nelson also said that afternoon programs often included smaller group situations and activities which were more relaxing and still included people with advanced dementia "*in the afternoon, we used puppetry, inclusive with advanced dementia"*. For others, considering other environmental issues such as "*room temperature and lighting"* (Penny and Mary), or as Cecily commented on, considering physical comfort like "*do they need to be toileted before activity"*, were particularly important in dementia care.

Values of creativity

This theme was formed around opinions about how creative activities contribute to the quality of life of people with dementia. Despite the different understandings of creativity it became clear from the data that all activity coordinators articulated that creative activities have an important place in the life of people with dementia. This was presented in a number of different ways. For some the most important value was associated with improved cognition as Leila said "*giving the chance to still dream, and think"* or add to the experience "*to live in the moment* "(Danni). For others, creative activities were seen to assist the experience which can be closely associated with "*self-worth"... achievable outcome"* (Ella) and the "*sense of achievement"* as Ann articulated. The value of "*enjoyment"* and the enhancing effects of positive feelings are the most significant value of creative activities in the life of people with dementia (Janette, Kate and Bea).

While participation in creative activities gives meaning to life that *"is worth living"*(Tom) the key value of the creative activities lies in the *process itself"* (Peta) and the possibility *"to build meaningful engagement"* through creativity, as Nelson pointed out in his interview. According to the activity coordinators these values are mostly appreciated through activities which provide social engagement, but most of all it was the music activities which offered the most value to people with dementia.

This major theme resulted in three distinct sub-themes which reflected the activity coordinators' understanding of the possibilities of creativity communicated in the data.

Creative expression through reminiscence

For many activity coordinators the main expressive effect of creativity for people with dementia was connected to reminiscence. This was described in two ways: First that the residents use creativity as a tool for self-expression; second is when the residents have been given, and been stimulated by, art materials which help them to remember the past. Cecily articulated that art can express what happened in the past *"sometimes bring it out in paintings"* and gave an example of one of her residents who was always painting a boat, which made her understand that he had been a fisherman. Similarly, Peta found that "*appropriate activities, really helps finding out what they did in the past"* because it can aid communication. She told a story about a gentleman who had severe dementia. He had been a truck driver and when he was a new arrival to the facility he preferred to be isolated and just draw trucks and landscapes. Nelson also stated that one of the residents, who had very limited communication, was able to communicate through an artistic medium when she wrote the word 'volcano' on a mountain shaped pot as an expression of her origin in South America. Nelson stated that this creative activity was able to *"draw out what she did remember"*. In these situations the residents are using the activity to express a memory they are conscious of.

There were more examples given in the data for other situations when people with dementia were given an opportunity and materials to help them to remember the past and, through that, provide joy. One of the activities that were mentioned was the music and sing along session. According to Danni *"a big sing along session ... the residents just love it because it brings back memories and they all know the words still"*. Poetry sessions, activities with old post cards or activities which incorporate photos from the past were also mentioned as a suitable activity to "*spark the memory"* and enhance happiness. Seeing the residents expressing joy is a source of satisfaction for the facilitators (Ann, Bea, Danni).

It was also commonly articulated by the activity coordinators that creative activities need to be designed around specific foci. It almost seemed that this is an essential intervention in dementia care, to set a goal, so that residents have a special purpose to work towards, which helps to acknowledge the achievement of creativity. The way to achieve this was also connected to reminiscence. The most important thing is "*pinpointing their interest"* as Jean articulated, which can be connected to a special event which they can remember from the past. Special occasions such as "*Christmas, Easter or St' Patrick*'s *Day"* were mentioned, when residents make art for the environment, objects as part of the facility decoration (Ann, Jean, Penny, Peta, Ella). Other themes, like seasons and birthdays were also highlighted in the interviews, as Fran described that the importance of these days lies in that "*specific celebrations ... give them something to think about"*.

Creativity facilitates engagement

This sub-theme was elicited from the data that described how the expression of the creative activities can be associated with engagement itself. This was expressed in different forms of engagement. Kate explained that if the activity is interesting enough *"they can get really interested"*. Cecily stated that the value of creative activities is that they "*encourage conversation",* or *"verbal expression"* as Peta described. Bea highlighted that the creative activities, especially singing and music sessions, can contribute to the *"stimulation of social skills"*. The

importance of social engagement is also mentioned by Tom who wove the line further with his example that when the residents create a wonderful product it encourages the families to be part of their relative's life.

Catalyse positive and negative affect

Another sub-theme of the overarching theme of 'Creativity catalyses expression' was how some activity coordinators evaluated the different effect of creative activities. While almost only positive effects were reported, such as "*self-determination, empowerment"* (by Nelson), and as Tom explained, because they are given an opportunity to be a part of a creation they *"take ownership"* of, there were some negative outcomes mentioned by a few interviewees. Ella found that creative activities "*can trigger negative emotions"* for "*whatever reasons*", with people with dementia it is hard to tell. For Bea, alongside the smile "*can even be a tear, the tear or two"*, but she found that while tears can be an outcome of negative expression, which is also a right of people with dementia, it is a good indicator that activity "*went down the right way*", because the activity has stimulated expression, which is preferable to an absence of expression.

Person centred activity care

This theme arose from the understanding of the activity coordinators' attitude regarding the design of the activities. There were two dimensions to this theme.

Respecting individual needs

This sub-theme formed from the commonly expressed knowledge by the activity coordinators that people with dementia had different stages of the disease and according to their needs activities needed to be modified. The majority of the interviewees said that people with dementia often need "*one on one intervention"* during activities time to be able to actively participate, especially higher care residents. However, for some, being together with other people can also be stimulative and can be a way to encourage active participation *"we can separate them, but often being in a group or community activity is more engaging"* (Bea).

Cecily also emphasized that "*encouraging them to come into the group instead of just being isolated"* was more productive.

Although the data strongly suggested that activity coordinators tried many different ways to encourage participation by people with dementia, there was an unanimous statement about the respect for the resident's choices. Every interviewer stated that if, after a lot of encouragement was given and the residents still choose not to participate, they would leave them and respect their choices. *"It's purely their choice, if they want to, but we offer different things"* (Cecily).

Respecting individual needs was also a central consideration of any design of creative activities, including the resident themself and their interest. The activity coordinators pointed out that taking a life history assessment when the resident arrives at the facility was one of the routine practices, and this practice essentially guides the design of the creative activities. Leila mentioned at the beginning of the interview that the main focus of her activities was *"they're client centred, individual tailored"*. Jean said that the history assessment has two main parts and one of them enquires about *"past interest"*. The importance of the client's past history and the definition of *"person centred care"* were used by Mary and Janette as well.

While the past interests were very much taken into account for the activity designs there was another interesting pattern that emerged in the data. Some activity coordinators mentioned that alongside of the past interests the present interests or choices are also considered. *"It's based on any articulated needs, we have request forms"* as Peta stated. Others, Kate and Bea, said that *"we ask them"* because the *"communication"* is the key for planning the activities together with the residents. It showed in the data that taking account of past and present interests in the implementation of creative activities was a major contribution to the quality of life of people with dementia.

Flexibility of the coordinator

People with dementia often need to be helped with BPSD, which can be a barrier to successful participation in any activities, including creative activities. There were a number of redirections mentioned that activity coordinators used to help people with dementia to become part of an activity. Some expressed this in more general terms, "*finding something that is specifically for them and holds their interest"* as Cecily said, or "*it is all about knowing the residents*" as Jean articulated. Others were a bit more specific, as Ann said, we "*might put music on in the background",* provide "*relaxation massage* "(Leila) or "*taking them for a walk* "(Danni).

The flexibility of the coordinators was also reflected with regard to the design of the activities, which suggested some experimentation. Ella articulated that *"we just try a range of things, what works we keep on with, what does not work we let go"*. Cecily also underlined that a *"lot of it is also trial and error "*. For some, in addition to the knowledge from the residents and their own experience, the plan of these activities is coming from organizations such as Diversional Therapy Australia or from other colleagues.

Routine assessments for evaluation

This theme is derived from the activity coordinator's description of the participation and the evaluation practices of the creative activities. The data revealed that there were many similarities about the assessment and evaluation practices in use.

It seemed, from the data, that the assessment of the residents' participation was part of routine practice. While the features of these assessments are fairly standardised it was revealed that different facilities used different tools and methods. Using an activity participation sheet was commonly mentioned with various names such as "*tick and flick sheet, activity log, KITME and NAMAD"*. According to the facility coordinators these assessments not only assisted them to document the resident's participation, they also followed their progress and the

outcome of the activity. Ella and Kate similarly described that these assessments can also include the report of engagement "*whether they're passive or whether they've been fully engaged"*. In some places the assessment incorporated the individual's preferences; Kate said that she recorded *"did they enjoy it, what was wrong, why did they not like it"*.

While the data revealed many similarities in the assessment practices some variation occurs in the data. Bea stated that she is not doing formal assessment on paper; she only does observation and reports verbally to the clinical team. Another variation which occurred related to before and after activity assessment: Nelson expressed his dissatisfaction with the routine assessment practice, which does not reflect the individual's outcome. He suggested that it needs to be emphasised more; *"perhaps somebody's mood when they come in to the activity and their mood when they leave"*.

The data also showed that the purpose of these assessments is to provide a base for evaluation which is regularly put into service "*three monthly or monthly"* as commonly mentioned by everybody. It also became clear from the interviews that in most of the facilities these evaluation meetings involved the clinical teams and the facility managers and these meetings facilitate the improvement of the quality of activities. Additionally, it highlighted that family involvement in evaluation is welcomed in facilities, which meant that any family suggestion was welcomed and considered in the implementation of the activities and families are encouraged to be actively involved in the care of their family member.

Conclusion

This chapter began with the introduction of the participants and the descriptions of their workplace. The second part of this chapter presented the activity coordinators' understanding of the creative activities in dementia care through themes and sub-themes, supported by their words. The following major and sub-themes emerged from the data: the major theme of Diversity of creativity with the sub-themes of 'Creative' activities for entertainment and Overcoming barriers to

creativity, the major theme of Considering dementia with the sub-themes of Specific scheme and Optimising participation, major theme of Values of creativity with the sub-themes of Creative expression through reminiscence, Creativity facilitates engagement and Catalyse positive and negative affect, the major theme of Person centred activity care with the sub-themes of Respecting individual needs and Flexibility of the coordinator and the last major theme of Routine assessments for evaluation. The aim of this chapter was to provide an insight into the use of creative art activities in dementia care in RACFs from the carers' perspective. Chapter 6 will present the discussion of the findings from the first and the second phase of this study in light of the current and relevant literature.

Chapter 6: Discussion

Introduction

This study used descriptive methodology with a mix of quantitative and qualitative approaches to evaluate the use and the characteristics of creative activities in dementia care in RACFs in Australia. It contained two phases; phase one was designed to gather basic information about the topic using a self-administered survey, the second phase of this study used in-depth interviews with activity coordinators to gain detailed information about the characteristics and the content of creative activities used in residential care facilities for the care of people with dementia. In this chapter the major findings from both phases are discussed with reference to the relevant empirical and theoretical literature. Finally, the chapter concludes by presenting the limitations of the study and the recommendations for clinical practice, education and further research.

The aims of the study

Creative activities have been researched and identified in the literature as important in the context of dementia care for reducing BPSD, improving cognition and general well-being and some indication as a tool for self-expression (Gregory, 2011; Ullan et al., 2011; Raglio et al., 2010). However, the provision of leisure-time activities in Australia in general and creative activities specifically, as part of the care of people with dementia who live in an institutionalised environment has not been the focus of inquiry prior to this research project. Therefore, the overall purpose of this study was to first determine the proportions and seek general understanding of the implementation of creative art activities: and secondly, to explore the characteristics of creative art activities and seek an understanding of how activity coordinators interpreted their knowledge about creative activities for people with dementia in RACFs in Australia. To obtain the data for the first phase a self-administered survey was designed and conducted online within Australian RACFs. To obtain data for the second phase of the study

in-depth interviews were conducted via telephone and in person with activity coordinators employed in RACFs in Australia.

This study was guided by three conceptual frameworks; the P-CC model, the NDB model and the Creative Ageing theory. The next part of this chapter will discuss the major findings and their association with the chosen conceptual frameworks.

The main findings of this study

The meaning of creative activities

The results of the national survey indicated that implementing creative activities is a common practice in RACFs in Australia; the most implemented creative activity was music (95%), followed by visual art (83%), dance activity was offered by nearly half of the responding facilities (47%) and drama activities were the least implemented activities. Interestingly, this result is consistent with the literature, in the order of the most researched creative activities in dementia care (Guzman-Garcia et al., 2012; Vleuten et al., 2012; Hamill et al., 2011; Kinney & Rentz, 2005). Until the in-depth interviews had been completed this survey finding only indicated that creative activities were present in the care of people with dementia in RACFs, which did not allow an understanding of the characteristics of these activities. However, the detailed interviews revealed that the meaning of creative activities varied between activity coordinators. This finding was suggested in the following way; that when the activity coordinators were asked about the creative activities, many listed, alongside of the creative activities, all kinds of activities such as bus trips, bingo, watching movies, activities which could be more accurately categorised as social and entertainment activities.

It was also common that craft activities such as knitting, sewing, and working with paper such as cutting paper shapes to be used for matching colours, were mentioned amongst the creative activities. While craft and creative art are often interchangeably used the difference between art and craft is clearly articulated in

the literature. Khol (2014) stated that art is creative and offers self-expression, craft is repetitive and imitative, and while creative processes are undertaken the process is valued over the finished products, as opposed to working on a craft project, where the finished product is the goal. Furthermore, other authors such as Hahnemann (2006) and Bathcelor (2009) stated that the main value of creative activity processes is that it opens an emotional outlet, which in the case of dementia, when many cognitive functions are compromised, allows emotional expression, a key element for understanding the resident.

The data from this thesis showed that only a few activity coordinators distinguished between creative and other activities. This perception reflects two understandings of the topic: one is that according to most of the activity coordinators any type of activity could be listed under creative activities, which suggests that to involve and engage people with dementia in any kind of activities is the primary focus. While these results showed that for most activity coordinators creative activities were not the main focus of the recreational activity program, these coordinators were achieving the primary goal of occupying and engaging people with dementia in meaningful activities, as highlighted by scholars (Cohen-Mansfield et al., 2010; Kolanowski et al., 2006; Tilly & Reed, 2006). This perception was completely aligned with the P-CC model and some practical use of the NDB model, as well as the social and general wellbeing effect of creative activities; however, it did not place particular, additional importance on the creative activities in the life of people with dementia.

In contrast, the second perception was that creative activities have an important and significant therapeutic role qualitatively distinct from other recreational activity programs. Although this view was only articulated by the minority of activity coordinators it added an important meaning to this research data. According to these coordinators, creative activities can be a catalyst for self-expression, which can facilitate the understanding of the person with dementia who might not be able to express themself in other ways due to the cognitive decline. These perceptions fully articulate the possibility of all three conceptual models in the practical level. Interestingly, it became very clear in the data that

this understanding of the use of creative activities was only articulated by activity coordinators who had education in art or an artistic background.

While the majority of activity coordinators did not distinguish or place a special importance on creative activities in the care of people with dementia, they were able to articulate the values of creative activities in their practices. This understanding of the data influenced this research into an interesting direction.

The next part of this chapter will discuss the differences and overlapping similarities of these perceptions. It will start with the exploration of the general values of creative activities which was an overarching understanding that was articulated by the activity coordinators.

Valuing creative activities

While this study found that the understanding of creative activities by activity coordinators in RACFs in Australia had differences, the data showed that all activity coordinators stated the possibility that creative activity provided enjoyment and meaningful values. This understanding was highlighted by data from both the survey and the in-depth interviews. This finding is parallel with most of the research findings which evaluated the effect of various creative activities on well-being in people with dementia (Guzman-Garcia et al., 2012; Vleuten et al., 2012; Hamill et al., 2011).

While the data showed that the activity coordinators regarded creative activities as a beneficial occupation for people with dementia, because it can accelerate positive feelings, the meaning of the values also varied in the data. The values of creative activities were expressed in different levels and these levels will be presented in the next paragraphs.

The different levels of creativity

Creative activities are sensory stimulations

The descriptive data from the survey revealed that creative activities were valued as an opportunity to facilitate self-expression for people with dementia. The meaning of self-expression was made known through better communication, exploring abilities through sensory stimulation and/or enhanced cognitive abilities. This result articulated that the benefits of creative activity are made possible by sensory stimulation or cognitive stimulation. The importance of sensory stimulation in dementia care is highlighted by the theoretical literature and explains the benefits of the right balance of stimulation that enables the person with dementia to understand and interpret the input they receive (Cook, 2011). While using multiple sensory stimulation is mentioned as a popular practice and as part of the holistic P-CC approaches in dementia care, formal guidelines and scientific evidence to support these practices are very scarce in the literature (Bauer, Rayner, Koch, & Chenco, 2012). The understanding and the categorisation of certain types of creative activities such as music and dance are presented as a sensory therapy in the literature. Bauer et al. (2012) found that music is the most implemented sensory therapy and dance therapy is also listed within the multiple sensory therapies implemented in RACFs in Victoria.

The results of the in-depth interviews also reflected that the majority of activity coordinators regarded creative activities as a sensory stimulation. This is made known from the description of creative expression, which mostly included examples of when creative activities were used as stimulations. The most popular activity that was dedicated to the best self-expression was music, especially singing sessions. Many activity coordinators stated that music, especially singing, helps the residents to remember words and express themselves. While the benefits of music therapy have been shown in the literature in many dimensions; reducing BPSD and enhancing wellbeing (Vleuten, et al., 2012), there is limited evidence of the beneficial effects of singing in dementia care. Bannan and Montgomery–Smiths (2008) found that group singing enhances general well-being and quality

of life for people with dementia; however, the stimulation of the recalling effect and language is only mentioned by Brotons and Koger (2000), and by Ridder et al. (2009) who also detailed how an individualised music program improved verbal expression of the residents.

The other activity that was mentioned which is useful as sensory stimulation was poetry. Some activity coordinators articulated that reading poetry, especially poems from the past that the people with dementia could connect to, often encouraged verbal expression and conversations. The finding of improved verbal expression by drama and poetry aligns with reports by an art therapist based on experiences of working with people with dementia (Hannemann, 2006) and is also consistent with some empirical studies that indicated that creative activities enable self-expression by poetry for people with dementia (Gregory, 2011).

There was another practice mentioned by some activity coordinators as useful; narrative creation activities, and a common sensory stimulation is creating the life story of the residents. This activity was mentioned as an especially practical activity because it involves the person with dementia at a personal level, which can contribute to sensory stimulation in different ways such as visual (e.g. viewing photographs) or verbal (e.g. talking about life stories). Creating life stories with people with dementia in RACFs is a well known practice (Moos & Bjorn, 2006). According to Moos and Bjorn (2006), creating a biography of the resident often helped to raise self-esteem and self-integration through the preservation of self, and therefore improved the quality of life of people with dementia. Furthermore, creating life stories is not only an expression of respect for the person's personhood, it can also contribute to decreasing the distance between the carer and the person with dementia, so that the carer could have a better understanding of the person with dementia. This practice is associated with the P-CC model, which appoints the humanistic emphasis on seeing the person with dementia as a person capable of having experiences (Kitwood, 1997).

While these findings reflected that creative activities can improve well-being and can facilitate self-expression as sensory therapies it showed overlapping

associations with one of the main understandings and practices of dementia care, that these activities were linked to reminiscence.

The importance of reminiscence

While the data showed that there were differences in the understanding of creativity, there was a common articulation of the significance of reminiscence in relation to creative activities. From the survey answers it arose that one of the perceived benefits of creative activities was that they facilitated reminiscence. This statement was clarified by the in-depth interviews, that creative activities were considered useful because they could be an aid for reminiscence. One of the defined examples of an opportunity to use reminiscence articulated in the interviews was that the creative activities were designed around specific themes. These themes included special events such as birthdays or the celebration of Christmas and Easter. These occasions could not only prompt memories but also help to connect with the present. According to Subramanian and Woods (2012), memories can be explored in many creative ways to connect to the past events which can bring new awareness to the present and can serve as a source of positive experience, either by encouraging self-esteem or by generating enjoyment and pleasure.

According to Killick (2000), creative activities are valuable media to serve reminiscence. The focus on reminiscence in implementing creative therapies is mentioned in many studies; Svandottir & Snaedal (2006) and Ashida (2000) found that music stimulated memories, and Gregory (2011) used poetry to aid reminiscence. According to Gregory (2011) reminiscence can take many forms and the purpose of reminiscence is to prompt memory. The idea of the significance of reminiscence is also apparent in the P-CC model by Kitwood (1997), who articulated that reminiscence is more than just revisiting the past, it can be a metaphor, a storyline which can help a person with dementia express themselves and restore personhood and dignity. This storyline can enable carers to understand the uniqueness of the person with dementia and it can also help to eliminate the barriers between carers and the person they are looking after.

Visiting the past may also contribute to a better understanding of that person's needs, which was highlighted by Kolanowski et al. (2005) as a central foundation of the NDB model.

The scientific explanation as to why reminiscence related activities are successful for people with dementia is based on the cognitive psychological distinction of memory functions. According to Machado et al. (2009), one form of memory, the explicit memory, is accountable for conscious and direct recall or recognition of recently processed information, while the other form of memory, called implicit memory, is able to reflect the unconscious effects of previous experiences on subsequent tasks without conscious recollection. Today, there is plentiful evidence in the literature that memory impairment in dementia, especially in Alzheimer's disease, is related to explicit memory while the implicit memory can be relatively intact or less severely impaired (Kessels, Feijen, & Postma, 2005). This scientific understanding makes it evident that past events and experiences can be stimulated in the person with dementia and that reminiscence can contribute to the quality of life of people with dementia.

The connection between reminiscence and creative activities in this study suggested that the creative concepts can facilitate P-CC while understanding and respecting the person's past as Kolanowski et al. (2011) pointed out in the NDB model.

Meaningful engagement

One of the vital considerations in dementia care, the concept of engagement, was also highlighted by the in-depth interviews. They revealed that the activity coordinators regarded certain creative activities as a tool that they were able to use to engage patients with dementia; this was articulated in two different dimensions, at a personal level and at a social level. It was articulated that occupation at an individual level with colours, shapes and music could encourage engagement at times for people with dementia. This reflects the findings of MacPherson et al. (2009), who found that, in an artwork based stimulating environment, people with

moderate to severe dementia were able to maintain engagement. The importance of meaningful engagement in activities is highlighted in the literature in general (Cohen-Mansfield et al., 2010; Kolanowski et al., 2006) and it is also articulated that creative activities can be a meaningful way to engage people with dementia (Killick & Allan, 2000).

The data from this study also suggested that creative activities can stimulate engagement at a social level. This was mentioned in the context of being in a group activity which encouraged social interaction, the most effective activity for this was singing and music activities. This finding is consistent with studies which also observed similar effects of participating in a group music activity (Vleuten et al., 2012). The importance of social activities in general is highlighted in the dementia literature as a central goal in the implementation of quality of care. According to Tilly and Reed (2006), to enhance social engagement for people with dementia is one of the critical elements of quality of care. The main goal of the social activities should be to maintain functional abilities through the sense of community, choices and fun for people with dementia.

Interestingly, there was another dimension of social engagement drawn out from the data; that creative activities were able to stimulate social engagement in a way that family members could be involved and appreciate a product made by their relatives. This level of social engagement is crucially highlighted in the literature, according to Tilly and Reed (2006), activities should be designed that can be done with the resident, not “to” or “for”, but together.

Many activity coordinators also expressed the possibility of meaningful engagement in creative activities for people with dementia; they suggested that to make the resident interested in these activities, especially the visual art activities, they need to be attached to special themes and the activities all work around the themes, such as special celebrations like Christmas and Easter. Working around the themes had already arisen in the context of reminiscence, however, it is a fine example of the way to engage people with dementia in activities. Palo-Bengtsson and Ekman (2000) found similar understandings in their study, they suggested that

to make an activity, specifically a dance activity, appeal to the resident it was important to set a specific focus, and all other activity can work around that focus.

While the Creative Ageing theory was originally developed for the general ageing population, this study showed that creative activities can provide meaningful occupation for people with dementia. It also revealed that the concepts of engagement are an important consideration for the activity coordinators and those creative activities can contribute to engagement and participation at a personal and social level in the life of people with dementia in RACFs. This finding also mirrors one of the main benefits proposed by the Creative Aging model; that creative activities assist social inclusion (Cohen, 2006).

Summary of the different values of creative activities

This section of the discussion presented the various values that activity coordinators attached to creative activities. It has been revealed that creative activities are beneficial because they work as sensory therapy, they can aid reminiscence and can facilitate meaningful engagement. While this level of values is consistent with the fundamental concepts of P-CC and NDB model and highlighted the importance of the Creative Ageing theory, there was an additional understanding that arose in this study. It had been articulated by some activity coordinators that creative activities can be implemented as a tool for self-expression, which is a slightly different application of the practice. This understanding was mainly articulated by the activity coordinators who had experience and education in art.

Self-expression through creativity

The survey from the first phase of the study did not provide an opportunity for detailed explanation about the meaning of self-expression, however, the in-depth interviews made it evident that some activity coordinators regarded creativity as a tool to open the inner self, feelings and emotions of people with dementia. This understanding placed the use of creative activities at another level in this study. It

was mentioned during one interview that when a male resident was given art material he began painting objects that were important for him in the past, another example described a situation where a lady with severe dementia whose verbal communication was entirely compromised was able to express childhood memories with crayons. While only two studies were found and categorised in the empirical literature that indicated such benefits (Gregory, 2011; Palo-Bengtsson & Ekman 2000) there are a number of case studies that indicated such experiences (Fomazzari, 2005; Stewart, 2004). The story of Doc, presented at the beginning of this thesis, provided an example of the situation where people with dementia who have no artistic background are able to express themselves through an artistic medium by visiting the past (Stewart, 2004).

According to Fomazzari (2005) and Hannermann (2006), the possibility of visiting the past through creative art, which can facilitate self-expression, might be one of the reasons why creative activities are becoming popular in the therapy of dementia. Fomazzari (2005) believed that to adapt such alternatives for people with dementia could provide the opening up of windows and it might also enhance cognitive reserves, as Cohen proposed in the Creative Ageing theory (Cohen, 2006).

It was also mentioned by the activity coordinators in the interviews that creativity is a possible way to encourage self-expression, that the significance of such activities is not the end product, but the creative process itself. Although such understanding of these creative effects is difficult to compare to the existing literature and is challenged by the lack of investigation, there are some descriptions that can be found, for example, an artist who had early stage dementia described that it does not matter what the person wanted to say, what matters is that he or she enjoyed the process of painting (Fomazzari, 2005).

This understanding and practice of creative activities reflected the possibility and value of the creative concepts in the level which was associated with artistic education of the activity coordinators. Activity coordinators who allowed people with dementia to use creative media understood that creativity can overcome

barriers caused by dementia. The importance of this practice also highlighted a fundamental mechanism which is stated in the Creative Ageing theory; that the experience of a new sense of control can contribute to an increased level of comfort and empowerment, which consequently can improve quality of life (Cohen, 2006). In contrast to this understanding many activity coordinators articulated that there are many barriers to the implementation of creative activities.

Interestingly, the matter of different understanding of the implementation of creative activities was indicated by the survey results. Activity coordinators and managers indicated that staff understanding was one barrier to the implementation of creative activities.

Overcoming barriers

According to the NDB model, respecting past interests must be compatible with regard to the present cognitive and physical functioning of the individual, as an essential contribution to providing quality activity time for people with dementia (Kolanowski et al., 2005). The result of this study showed that while there was much interest and some understanding about creative activities in RACFs there were many concerns about the implementation of these activities because of the compromised cognitive and physical states of the residents. These concerns were articulated both from the survey and from the in-depth interviews. Most of these expressions showed that the activity coordinators were uncomfortable with implementing certain activities, mostly visual art, due to physical disabilities. Expressing the difficulties of implementation also suggested that these activities were not worth implementing as creative activities, because of a need for too much structure, which takes away the creative side of the activity and leaves it at an occupational level. While the concept of unstructured activity time was associated with creativity the boundaries of structured and unstructured creativity is not clearly defined in the literature (Gero, Jiang & Williams, 2013). According to Gero et al. (2013), creativity can be both structured and unstructured; data from

this study suggested that most creative activities in RACFs are structured, especially for people with dementia.

Although most of the activity coordinators were comfortable with the idea that structured activity time cannot be creative, some coordinators were able to describe the ways they altered those activities so that they became manageable for people with that particular degree of dementia. While this understanding is aligned with the recommendation of the NDB model (Kolanowski et al., 2005) and studies where such consideration has been taken into account with the implementation of the activity (Peisah et al., 2011), it was not clear from the interviews that these practices were actually derived from evidence based research.

Interestingly, activity coordinators who were able to give an example of a method of overcoming barriers mentioned a specific emerging innovation, which they incorporated into the implementation of their creative art activities. According to them, using modern technology such as an iPad was an excellent way to overcome cognitive and physical disabilities, while creativity could still be fostered. This practice is consistent with the increasing interest in implementing modern technology into dementia care in general, and especially in implementing creative activities. Mihailidis et al. (2010), in their study presented a development program which was designed by art therapists, using computer technology to overcome the physical and cognitive difficulties of dementia in the implementation of creative activities. It also aimed to reduce the staffing and the financial barriers to such activities by providing art activities which people with dementia could engage with autonomously and independently without requiring additional staff to implement an art program, eventually reducing costs (Mihailidis et al., 2010).

According to Thornton (2012), the increasing aged population and the demand for modern aged care facilities is likely to increase the gap between the cost and the available funding, which is already imbalanced. Finding resources for “extras”, such as to implement creative activities is already a concern. The concern of employing extra staff and the cost of service was clearly articulated as the two

main barriers to the implementation of these activities by the survey respondents. Therefore, implementing technological innovation in the provision of creative activities may help to overcome the physical and cognitive barriers and contribute to cost effective care delivery, without having to compromise the quality of services.

Managing BPSD

Although the national survey showed that many respondents regarded creative activities as a beneficial intervention for behaviour management the in-depth interviews did not reveal any specific examples of such practices. While the majority of studies in the empirical literature reported positive effects of the various creative activities on different BPSD, such as music therapy effects on depression (Ashida, 2000), agitation and anxiety (Guetin et al., 2009), and on general BPSD (Raglio et al., 2010, 2008), the in-depth interviews did not highlight such use of the creative activities. The results of the interviews mostly demonstrated that the activity coordinators did not consider using creative activities for behaviour management itself, and the use of creative activities as part of behaviour management by other staff members of the facilities also was not evident from the interviews. The in-depth interviews mostly revealed that for the activity coordinators, finding ways to encourage people with dementia to participate in the activities was more important. Music activities were an exception; it was frequently mentioned by many activity coordinators as a suitable calming therapy. The findings of this research showed that the activity coordinators had ways other than creative activities to manage BPSD such as one on one activity, respecting individual choices, massage therapy or redirections. The practice of respecting individualized needs was derived from the fundamentals of the P-CC approach, which was articulated by Kitwood (1992) and reflects the quality of care for people with dementia. The understanding of these needs by caring staff in the everyday life of people with dementia within institutions was demonstrated by studies outside of the creative context (Wilson, Swarbrick, Pilling, & Keady, 2013).

In the context of respecting individual needs, it also became clear that this included respecting individual choices, which often includes refusal to participate in activities. It has been articulated in the literature that P-CC, while focused on socially involving people with dementia as far as possible, also respects solitude (Tilly & Reed, 2006). The result of this study, in the context of creative activities, also drew out that the activity coordinators, while respecting individual needs, could be flexible, to encourage residents to participate in the activities. In this framework the need for redirection was raised and many examples were given of how to do that, such as going for a walk or relaxation massage. Redirection practice is an accepted behaviour management strategy in dementia care (Irvine, Ary, & Buorgeois, 2003), which although it does not have a specific connection with creative activities, can usually be applied in any context. In this study it arose in the context of creative activities.

Overall, the findings of this study showed that the special needs of people with dementia are considered in many ways in the context of the implementation of creative activities. The interviews revealed that for some activity coordinators, mostly coordinators with artistic background, dementia as a disease itself is not considered a barrier to the implementation of creative activities and they could find creative ways to implement these activities. Interestingly, the result of the survey and the interviews with regard to managing BPSD through creative activities showed different views. Based on the literature and the survey results it was anticipated that creative activities can play an important role in managing BPSD, however, the activity coordinators in this study did not express such practices. The data revealed other ways to encourage participation and dealing with BPSD such as redirection, one on one activity time and alternative therapies like massage.

Person centred designs

The connection between all three theoretical models was most noticeable in this study when the activity coordinators talked about the design of the creative activities. Person centred care practice was emphasized in the framework of

designing the activities. From the interviews it became clear that taking into account the individual's past was one of the main considerations of the design of the activities. This is consistent with some of the studies cited earlier where the intervention was based upon the individual's past interests. Ashida (2000) designed the music activity by playing songs which were related to the residents' hobbies and home life. Peisah et al. (2011) designed an art activity which was based on the past interest of the resident, such as colouring in with grandchildren. These studies mainly evaluated the effect of these activities on BPSD and they provided an example of the considered design which takes into account the resident's abilities and past interests. The practice of designing activities with the consideration of the past interests of the person with dementia is also aligned with the recommendation of the NDB model which underlines that in aiming for meaningful engagement, the past interest of the person should be considered (Kolanowski et al., 2005). Furthermore, the interviews also revealed that not only past interest is a consideration in the design of the activities, but many RACFs included the present requests of the residents. This practice is also mentioned in the NDB model, as a reflection of person centred care, where the present changes are included (Kolanowski et al., 2005).

In relation to the design of the activities the data also revealed that in every facility the role of the relatives of the resident in suggesting and giving direction to which activities were preferable for the resident was welcomed and plays an important part. In addition to the family member taking part in the design of the activities, being part of the implementation of the activities was also commonly reported by the activity coordinators. According to the activity coordinators, while the design of the activities was strongly based on the personal interest and preference of the residents and exclusively done by a trained activity coordinator the implementation of these activities was more flexible and most of the time involved volunteers.

The result of the person centred design was also reflected in that creative activities are designed with the consideration of the special needs of people with dementia.

The P-CC and the use of the NDB model were articulated in the context of the design of creative activities for people with dementia.

Regulative evaluation processes

While this study revealed many differences in the understanding and the implementation of creative activities in RACFs in Australia there was one finding of this study which was unanimous across all respondents. The process of evaluating the activities followed the same pattern across all RACFs studied. These included filling out regular observation sheets, which appeared to have various names, and regular meetings with the clinical teams. Although these practices suggested that creative activities were monitored and determined as a significant part of recreational activities, this data did not allow further understanding, such as the reasons for, and the regulation of the evaluation processes of these activities. In contrast, there was one activity coordinator who acknowledged the essential meaninglessness of the "tick and flick" approach and suggested that perhaps looking deeper into whether creative activities contribute to quality of life would be more useful to the evaluation of these practices. According to Masso, Westera, Quinsey, Morris and Pearse (2011) the main target of the evaluation practices in RACFs is to promote evidence based practices. Due to the fragmented understanding of creative activities from the literature and the limited understanding of creative activities practice in RACFs, to compare evaluation practices to evidence based practices at this point was not practical.

The limitations and the strengths of the study

There were several limitations to this study. These are concerned with the response rate of the survey, the self-selection of the participants and the data collection method for the second phase of the study.

Response rate

The results of the response rate reported in chapter four revealed that out of 1675 facilities 249 facilities answered and returned the survey, a response rate of 15.3%. According to Livingston and Wislar (2012) 60% is traditionally accepted as a good response rate in biomedical research. However, these rates are also known to be lower for e-mail or web surveys (Scott et al., 2011). The low response rate of this survey can be associated with several factors; it is known from the literature that while electronic surveys have many advantages, such as cost and time saving, in general they produce a lower response rate than other types of survey such as postal or telephone surveys (Scott et al., 2011). There are several reasons suggested for this in the context of health research, including: a possible lack of familiarity with the internet, inconsistent reliability of internet access, particularly in remote areas, specifically in RACFs a low usage of computers and internet in the everyday tasks of their jobs, a lack of trust in regard to sending confidential information and because health care professionals often receive surveys about many aspects of their roles, this may lead to them only completing questionnaires which are absolutely necessary (McPeake, Bateson, & O' Neill, 2014).

Although the survey response rate of this study was low (15.3%) when compared with expected response rates quoted by Livingston & Wislar (2012) (60%), in the framework of this study it can be regarded as a good response rate because it indicated that many RACFs take an interest in providing creative art activities in their facilities in Australia. In balance of these limitations the diversity of the sample provided strength to the study, as indicated below.

Demographic characteristics

The location of the responders provided a national sample. The results of the location of the facilities showed that facilities from every state and territory responded except the Northern Territory.

The email invitation for the survey specifically asked that it would be preferable if the survey could be filled out by the activity coordinator. The reason for this was to obtain knowledge directly from the people responsible for the delivery of the activities. The data showed that the answers for the survey were, in the majority, answered by the activity coordinators (63%), which helped to confirm that the data came from the person who was most actively involved in the implementation of the activities.

Type of organisation

In addition to the diversity of the location, this study also showed diversity of organisation type. The results of this survey reflected the range of RACF provider types in Australia, in that 78 responding facilities were private/for profit, 50 were charitable, 43 were not for profit, 41 were government/community and 36 were from the religious sector. Interestingly this distribution is similar to the ownership ratio of RACFs in Australia identified by DOHA in 2010 which showed that RACFs in Australia are owned and regulated by 59% of not for profit, 35% private/for profit and 6% of Government organisation (Thornton, 2012).

Self-selection of the participants

According to Yin (2000), self-selection sampling of internet based surveys has its advantages and disadvantages. An advantage of self-selected sampling can be associated with gaining more insightful data of the phenomena because the responders are more likely to be interested in the topic, however, self-selected samples are mostly associated with bias in the resulting data in the literature (Randall, 2008; Yin, 2000). Randall (2008) stated that, self-selection bias is a common problem of surveys, especially of online surveys where the responders have the choice to participate or not. In self-selected sampling there is a degree of propensity for participating in the survey which is associated with interest in the topic of the research and can result in participants who chose to respond to the survey not representing the entire target population.

In the first phase of this study, while self-selection sampling can be regarded as a strength in the sense that the gathered information were insightful, because only representatives of RACFs which had a creative program or strong interest in implementing a creative program completed the survey it also added to the limitation that the data will have bias in favour of a creative program.

Another limitation of this study can be associated with the self-selection of the participants for the second phase of the study. This limitation can add to the bias because only those activity coordinators who were sufficiently interested in this topic and implementing some form of creative activities were likely to indicate their interest in participation in the second phase of the study.

Conducting the majority of the interviews (n=12) via telephone can limit the advantages of establishing rapport with the interview participants. While the best practice recommendation is to conduct qualitative interviews in person (Minichello et al., 2004), in the circumstances of this study it was not feasible to travel and collect the data personally.

Recommendations

Implications for practice

This study provided a basic understanding that creative activities are present in the life of people with dementia in RACFs in Australia. It revealed that the implementation of creative activities is fairly unregulated and the understanding of these practices depends on the activity coordinators' experiences and qualifications.

Today, when finding ways to improve the quality of life of people with dementia is crucial, RACFs may refine the implementation of these activities so that creative art activities can provide more opportunities for self-expression and more effective therapeutic outcomes. It might be a reasonable consideration to find ways to employ artists in the design and implementation of these activities. In

Australia art councils have opportunities to support artists to implement programs in different settings including health related areas; such opportunities could enhance the programs of RACFs and would enable the activity coordinators to expand their practices.

Implications for future research

The evidence gained from this research indicated some understanding of the use of creative art activities by the activity coordinators. It revealed that creative activity practices have some application to the chosen theories such as the implementation of P-CC and taking account of the past and present abilities of the people with dementia as highlighted in the NDB model. However, it also revealed that the understanding of these practices is rather unregulated and the deeper understanding of the implication of creative activities is only apparent to some activity coordinators. To gain more understanding of the implementation of creative activities a more robust study with an observational component will be necessary to understand the meaning of the indicated values of this study. It would be necessary to explore further the characteristics of engagement, such as length, intensity, passive or active engagement. To reduce the fragmented understanding of the different creative activities and their implications for dementia care, it would be more feasible to concentrate on one creative medium for a whole research project, including the effect on BPSD. It would also be reasonable to observe the evaluation and the outcomes of the evaluation practices.

For an intervention study it would be interesting to implement an art based activity series led by an art expert. The intervention series could provide a comparison with regular art activities to specially focus on outcome measurements of engagement, and outcomes which are proposed in the Creative Ageing theory, such as general well-being, medication use, social interaction and effects on cognition.

Conclusion

The understanding of the use of creative activities in RACFs in the life of people with dementia is inconsistent and limited in the literature. In response to the substantial interest from the clinical and research perspectives this research was designed and conducted to gain more understanding of the use of creative activities in dementia care in RACFs in Australia.

The conceptual frameworks for this study were chosen from the ageing and the dementia literatures and based upon the reflection of the importance of quality of life of people with dementia; namely the Creative Ageing theory, the Person-Centred Care model, and the Need-Driven Dementia-Compromised Behaviour Model. These conceptual works were used to build this research, including the research design, data collection methods and tools and the interpretation of the data.

This study used descriptive methods incorporating a mix of quantitative and qualitative approaches, to evaluate the use and the characteristics of creative activities in dementia care in RACFs in Australia. First, a national survey was conducted to reveal some understanding of the use of creative activities in RACFs around Australia. Second, to gain deeper understanding of the topic in-depth interviews with activity coordinators were conducted to produce the data for this research project.

The first phase of the study revealed that there were many (n=249) facilities that were interested in providing information about their practices of creative activities. The survey also revealed that most of the responding facilities (97%) were providing creative activities. The proportion of visual art activities within creative activities showed that visual art activities were the second most implemented activities (83%) in RACFs for people with dementia. The first phase of this study also revealed some characteristics of these activities including some benefits, such as self-expression, managing BPSD, providing opportunities for social interaction and creativity. Further, respondents indicated that creativity

is a journey and the implementation of creative activities depends on the abilities of the residents.

The detailed interviews revealed that most of the activity coordinators regarded creative activities as sensory therapies, activities which can facilitate meaningful engagement and have a key function in reminiscence. It also revealed that understanding creativity has different levels of degree among activity coordinators. Many activity coordinators found that dementia itself could be a barrier to the implementation of these activities and only a few activity coordinators articulated that the function of creative activities should be used to overcome these barriers. This understanding was expressed by activity coordinators who had education and experience in art. The possibility of using creative activities as a tool for self-expression was only articulated by those activity coordinators.

Interestingly, the limitation of understanding of the different values of creative activities by the activity coordinators was also articulated by the survey respondents. One of the barriers to implementation was the limited understanding of the staff.

The result of this study also revealed that activity coordinators did not use creative activities for managing BPSD, they had other ways, such as one to one activity, redirection and alternative therapies such as massage, to involve people with dementia in activities and overcome apathy and withdrawn behaviour. This result reflected that creative activities were designed to meet the specific needs of people with dementia and activity coordinators placed importance on engaging them in these activities.

This study also revealed that the evaluation practices regarding the implementation of activities were schematic and did not provide opportunities to evaluate the quality of such activities.

In conclusion, while this study has limitations regarding the low response rate and limited sampling methods, it provided insightful information about the current use of creative activities in RACFs in Australia. This research project revealed that creativity is not fully understood by activity coordinators unless they have an artistic background, however, respecting the person hood and BPSD in the lives of people with dementia was wholly addressed around the activities.

In this chapter the main findings of this study were discussed and analysed relative to the relevant empirical and the theoretical literature. The aim of this chapter was to frame and highlight the most momentous themes of the study. The content of this chapter also emphasised some characteristics of the currently used creative activities in participating RACFs which were previously unknown in the literature and provided some knowledge for further research development.

References

Ashida, S. (2000). The effect of reminiscence music therapy sessions on changes in depressive symptoms in elderly persons with dementia. *Journal of Music Therapy, 37,* 170-182.

Aged Care Act. (1997). Retrieved from http://www.comlaw.gov.au/Details/C2014C00260

Aldridge, D. (1996). *Music therapy research and practice in medicine: from out of the silence.* London: Jessica Kinglsey Publisher.

Alzheimer's Australia. (2014). *Drug treatments & Dementia*. Retrieved from http://www.fightdementia.org.au/understanding-dementia/drug-treatments-and-dementia.aspx

Alzheimer's Australia. (2008). Tests used in diagnosing dementia. *Update Sheet* ,(8),1-4.Retrieved from http://www.fightdementia.org.au/common/files/NAT/20080600_Nat_NP_16AustDemRes.pdf

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington DC: Author.

Australian Institute of Health and Welfare (AIHW). (2012). *Dementia.* Retrieved from http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=10737422943

Avlund, K., Damsgaard, M. T., & Holstein, E. E. (1998). Social relations and mortality: An eleven year follow-up study of 70-year-old men and women in Denmark. *Social Science & Medicine, 47,* 635-643.

Ballard, C. G., Margallo-Lana, M., Fossey, J., Reichelt, K., Myint, P., Potkins, D., & O'Brien, J. (2001). A 1-year follow-up study of behavioural and psychological symptoms in dementia among people in care environments. *Journal of Clinical Psychiatry*, *62*(8), 631-636.

Bannan, N., & Montgomery–Smiths, C. (2008). Singing for the brain: reflections on the human capacity for music arising from a pilot study of group singing with Alzheimer's patients. *The journal of the Royal Society for the promotion of Health, 128,* 73-78.

Batchelor, V. (2009). Creativity. In H. Birx (Ed.), *Encyclopedia of time: Science, philosophy, theology, & culture.* (pp. 238-244). Thousand Oaks, CA: SAGE Publications, doi: http://dx.doi.org/10.4135/9781412963961.n44

Bates-Jensen, B. M., Alessi, C. A., Cadogan, M., Levy-Stroms, L., Jorge, J.,Yoshii, J.,…Schelle, J. F. (2004). The Minimum Data Set bedfast quality indicator: Differences among nursing homes. *Nursing research, 53,* 260-272.

Bauer, M., Rayner, J., Koch, S., & Chenco, C. (2012). The use of multi-sensory interventions to manage dementia-related behaviours in the residential aged care setting: a survey of one Australian state. *Journal of Clinical Nursing, 21,* 3061-3069. doi: 10.1111/j.1365-2702.2012.04306.x

Beard, R. L. (2011). Art therapies and dementia care: A systematic review. *Dementia, 11,* 633-656.

Boeije, H. R. (2009). *Analysis in Qualitative Research.* London: Sage.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3,* 77-101.

Brooker, D., & Duce, L. (2000). Wellbeing and activity in dementia: a comparison of group reminiscence therapy, structured goal-directed group activity and unstructured time. *Aging & Mental Health, 4,* 354-358. doi: 10.1080/13607860020010510

Brotons, M., & Koger, S. M. (2000). The impact of music therapy on language functioning in dementia. *Journal of Music Therapy, 37,* 183-195.

Cantley, C. (Ed.). (2008). *A handbook of dementia care*. Berkshire, UK: Open University Press.

Chung, J. C. C. (2004). Activity participation and well-being of people with dementia in long-term care settings. *OTJR: Occupation, Participation and Health, 24,* 22-31.

Cleary, M., Horsfall, J., & Hayter, M. (2014). Data collection and sampling in qualitative research: does size matter*? Journal of Advanced Nursing, 3,* 473-475.

Coaten, R. (2001). Exploring reminiscence through dance and movement. *Journal of Dementia Care, 9,* 19-22.

Cohen, G. D. (2006). Research on creativity and aging: The positive impact of the arts on health and illness. *The American Society on Aging, 30,* 7-15.

Cohen, G. D., Perlstein, S., Chapline, J., Kelly, J., Firth, K. M., & Simmens, S. (2006). The impact of professionally conducted cultural programs on the physical health, mental health and social functioning of older adults. *The Gerontologist, 46,* 726-734.

Cohen, G. D. (2000). *The creative age: Awakening human potential in the second half of life*. New York: Avon Books

Cohen-Mansfield, J. (2004). Nonpharmacologic interventions for inappropriate behaviours in dementia: Review, summary and critique. *Focus, The Journal of Lifelong Learning in Psychiatry, II,* 288-308.

Cohen- Mansfield, J., Thein, K., Dakheel-Ali, M., & Marx, M. S. (2010). Engaging nursing home residents with dementia in activities: The effects of modelling, presentation order, time of day, and setting characteristics. *Aging & Mental Health, 14,* 471-480.doi: 10.1080/13607860903586102

Collingride, D., S., & Gantt, E. E. (2008). The quality of qualitative research. *American Journal of Medical Quality, 23,* 389-395.

Cook, G. (2011). Dementia care: sensory environments. *Nursing & Residential Care, 13,* 240-243.

Csikszentmihalyi, M. (1993). Activity and happiness: Towards a science of occupation. *Journal of occupational Science, Australia, 1,* 38-42.

Davies, L. (Eds.). (2007). *The Art and Soul of Midwifery*. Philadelphia: Churchill

Department of Health and Ageing (DOHA). (2012). *About dementia. Stages of dementia*. Retrieved from http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-dementia-stages.htm

Department of Health and Ageing (DOHA). (2006). *Dementia- a national health priority: Dementia research mapping project: Final report.* Canberra: Commonwealth Department of Health and Ageing. Retrieved from http://www.aro.gov.au/documents/Dementia%20RMP%20Report%20final.pdf

Dey, I. (2004). Grounded Theory. In C. Seale., G. Gobo., J. F. Gubrium, & D. Silverman (Eds.), *Qualitative Research Practice* (pp. 80-93). London: Sage.

Duignan, D., Hedley, L., & Milverton, R. (2009). Exploring dance as a therapy for symptoms and social interaction in a dementia care unit. *Nursing Times, 105,* 19-22.

Edvardsson, D., & Innes, A. (2010). Measuring person-centered care: A critical comparative review of published tools. *The Gerontologist, 50,* 836-846. doi: 10.1093/geront/gnq047

Eekelaar, C., Camin M., P., & Springham, N. (2012). Art Dalleries, episodic memory and verbal fluency in dementia: An exploratory study. *Psychology Psychology of Aesthetics, Creativity, and the Arts,* doi:10.1037/a0027499

Endacott, R. (2005). Clinical research 4: qualitative data collection and analysis. *Intensive and Critical Care Nursing, 21,* 123-127.

Fisher, B. J., & Specht, D. K. (1999). Successful aging and creativity in later life. *Journal of Aging Studies, 13,* 547-472.

Fomazzari, L. R. (2005). Preserved painting creativity in an artist with Alzheimer's disease. *European Journal of Neurology, 12,* 419-424.

Gero, J.S, Jiang, H., & Williams, C. (2013). Design cognition differences when using unstructured, partially structured and structured concept generation creativity techniques, *International Journal of Design Creativity and Innovation, 4,* 196-214.doi:10.1080/21650349.2013.801760

Glass, T. A., de Leon, C. M., Marottoli, R. A., & Berkman, L.F. (1999). Population based study of social and productive activities as predictors of survival among elderly Americans. *British Medical Journal, 319,* 478-483.

Guetin, S., Portet, F., Picot, M. C., Pommie, C., Messaoudi, M., Djabelkir, M.,… Touchon, J. (2009). Effect of music therapy on anxiety and depression in patients with Alzheimer's type dementia: Randomized, controlled study. *Dementia and Geriatric Cognitive Disorders, 28,* 36-46.

Guzman-Garcia, A., Hughes, J. C., James, I. A., & Rochester, I. (2012). Dancing as a psychosocial intervention in care homes: a systematic review of the literature. *Geriatric Psychiatry, 28,* 914-924. doi: 10.1177/1471301211429753

Guzman-Garcia, A., Mukaetova-Ladinska, E., & James, I. (2013). Introducing a Latin ballroom dance class to people with dementia living in care homes, benefits and concerns: a pilot study. *Dementia, 12*, 523-535.

Gregory, H., (2011). Using poetry to improve the quality of life and care for people with dementia: a qualitative analysis of the Try to Remember programme. *Arts & Health, 3,* 160-172. doi: 10.1080/17533015.2011.584885

Hamill, M., Smith, L., & Rohricht, F. (2011). Dancing down memory lane: circle dancing as a psychotherapeutic intervention in dementia-a pilot study. *Dementia, 11,* 709-724. doi: 10. 1177/1471301211420509

Hannemann, B. T. (2006). Creativity with dementia patients. *Gerontology, 52*, 59-65.

Harmer, B. J., & Orell, M. (2008). What is meaningful activity for people with dementia living in care homes? A comparison of the views of older people with dementia, staff and family carers. *Aging & Mental Health, 12,548*-558. doi: 10.1080/13607860802343019.

Hill, N. L., Kolanowski, A. M., & Kurum, E. (2010). Agreeableness and activity engagement in nursing home residents with dementia. *Journal of Gerontological Nursing, 36*(9), 45-52.

Hokkanen, L., Rantala, L., Remes, A., Harkonen, B., Viramo, P., & Winblad, I. (2008). Dance and movement therapeutic methods in management of dementia: a randomized controlled study. *Journal of the American Geriatric Society, 56,* 771-772.

Holloway, I., & Wheeler, S. (2002). *Qualitative Research in Nursing* (2nd ed.). Oxford: Blackwell Science.

Irvine, A. B., Ary, D. V., & Buorgeois, M. S. (2003). An interactive multimedia program to train professional caregivers, *Journal of Applied Gerontology, 22,* 269-288.

Kaufman, E. (2008). Effects of Montessori painting on an older adult with dementia. *UWL-L Journal of Undergraduate Research XI,* 1-4.

Kessels, R. P. C., Feijen, J., & Postma, A. (2005). Implicit and explicit memory for spatial information in Alzheimer's disease. *Dementia and geriatric cognitive Disorders, 20,* 184-191. doi: 10.1159/000087233

Kiecolt-Glaser, J. K., McGuire, L., Robles, T. F., & Glaser, R. (2002). Emotions, morbidity, and mortality: new perspectives from psychoneuroimmunology. *Annual Review of Psychology, 53,* 83-107.

Killick, J. (2000). Storytelling and dementia. *Elderly Care, 12,* 8-10.

Killick, J., & Allan, K. (2000). Undiminished possibility: the arts in dementia care. *Journal of Dementia Care, 7,* 22-24.

Killick, J., & Allan, K. (1999). The arts in dementia care: tapping a rich recourse. *Journal of Dementia Care, 7,* 35-38.

Kinney, J., M., & Rentz, C., A. (2005). Observed well-being among individuals with dementia: Memories in the Making, an art program, versus other structured activity. *American Journal of Alzheimer's Disease and other* dementias, 20,220-227. doi: 10.1177/153331750502000406

Kitwood, T., & Brendin, K. (1992). Towards a theory of dementia care: Personhood and well-being. *Ageing and Society*, 12, 269-287.

Kitwood, T. (1997). *Dementia reconsidered: The person comes first.* Bristol: Open University Press.

Kohl, M. F. (2014). *Art vs. Crafts.* Children's Art. Retrieved from http://www.barnesandnoble.com/u/MaryAnn-Kohl-Arts-Crafts/379002813

Kolanowski, A. M., Buettner, L., Litaker, M., & Yu, F. (2006). Factors that relate to activity engagement in nursing home residents. *American Journal of Alzheimer's Disease and other Dementias, 21,* 15-22. doi: 10.1177/153331750602100109

Kolanowski, A. M., Fick, D. M., & Buettner, L. (2009). Recreational activities to reduce behavioural symptoms in dementia. *Geriatric Aging, 12*(1), 37-42.

Kolanowski, A. M., Litaker, M., Buettner, L. Moeller, J., & Costa, P. T. (2011). A randomized clinical trial of theory-based activities for the behavioural symptoms of dementia in nursing home residents. *Journal of the American Geriatric Society. 59,* 1032-1041. doi: 10.1111/j.1532-5415.2011.03449.x.

Kolanowski, A. M., Litaker, M., & Buettner, L. (2005). Efficacy of theory-based activities for behavioural symptoms of dementia. *Nursing Research, 54*(4), 219-222.

Kovach, C. R., & Magliocco, J. S. (1998). Late-stage dementia and participation in therapeutic activities. *Applied Nursing Research, 11,* 167-173.

Kramer, A. F., Bherer, L., Colcombe, S. J., Dong, W., & Greenough, W.T. (2004). Environmental influences on cognitive and brain plasticity during aging. *The Journal of Gerontology, Series A, Biological Sciences and Medical Sciences, 59,* 940-957.

Ledger, A. J., & Baker, F. A. (2006). An investigation of long-term effects of group music therapy on agitation levels of people with Alzheimer's disease. *Aging & Mental Health, 11,* 330-338.

Lenze, E. J. (2011). Treating depression in older adults with dementia. *Journal of American Geriatrics Society, 59,* 754-755.

Liamputtong, P. (2009). Qualitative data analysis: conceptual and practical considerations. *Health Promotion Journal of Australia, 20*(2), 133-139.

Livingston, E. H., & Wislar, J. S. (2012). Minimum response rates for surgery research. *Archives of Surgery, 147,* 110. doi: 10.1001/archsurg.2011.2169

Machado, S., Cunha, M., Minc, D., Rortella, C. E., Velasques, B., Basile, L. F,… Ribeiro, P. (2009). Alzheimer's disease and implicit memory. *Arquivos de Neuro-Psiquiatria, 67,* 334-342

MacPherson, S., Bird, M., Anderson, K., Davis T., & Blair, A. (2009). An Art Gallery Access Programme for people with dementia: 'You do it for the moment'. *Aging & Mental Health, 13*, 744-752.

Malchiodi, C. A. (2007). *The Art Therapy Sourcebook*. New York: McGraw-Hill.

Masso, M., Westera, A., Quinsey, K., Morris, D., & Pearse, J. (2011). Encouraging best practice in residential aged care program: Final evaluation report. Centre for Health Service Development, University of Wollongong. Retrieved from http://ahsri.uow.edu.au/content/groups/public/@web/@chsd/documents/doc/uow108882.pdf

McIntosh, G., & Phillips, J. (2003). Caring for the elderly-an overview of aged care support and services in Australia. Retrieved from http://www.aph.gov.au/About_Parliament/Parliamentary_Departments/Parliamentary_Library/Publications_Archive/archive/agedcare

McKee, K. J., Wilson, F., Chung, M. C., Hinchliff, S., Goudie, F., Elford, H., & Mitchell, C. (2005). Reminiscence, regrets and activity in older people in residential care: associations with psychological health. British *Journal of Clinical Psychology, 44*, 543-561.

McPeake, J., Bateson, M., & O' Neill, A. (2014). Electronic surveys: how to maximise success. *Nurse Researcher, 21*, 24-26.

Mihailidis, A., Eng, P., Blunsden, S., Boger, J., Richards, B., Zutis, K.,… Hoey, J. (2010). Towards the development of a technology for art therapy and dementia: definition of needs and design constraints. *The Arts in Psychotherapy, 37* 239-300. doi:10.1016/j.aip.2010.05.004

Minichello, V., Madison, J., Hays, T., & Parmenter, G. (2004). Doing qualitative in- depth interviews. In V. Minichello., G. Sullivan., K. Greenwood, & R. Axford (Eds.), *Handbook of Research Methods for Nursing and Health Science* (2nd ed.). (pp. 410-446). Sydney: Prentice Hall Health.

Minichello, V., Sullivan, G., Greenwood, K., & Axford, R. (Eds.). (2004). *Handbook of Research Methods for Nursing and Health Science* (2nd ed.). Sydney: Prentice Hall Health.

Moos, I., & Bjorn, A. (2006). Use of the life story in the institutional care of people with dementia: a review of intervention studies. *Ageing and Society, 26,* 431-454. doi: 10.1017/S0144686X06004806

O'Connor, D. W., Ames, D., Gardner, B., & King, M. (2009). Psychosocial treatments of psychological symptoms in dementia: a systematic review of reports meeting quality standards. *International Psychogeriatrics, 21,* 241-251.

Olsen, K. D., Dysvik, E., & Hansen, B. S. (2009). The meaning of family members' presence during intensive care stay: A qualitative study. *Intensive and Critical Care Nursing, 25,*190-198.

Palo-Bengtsson, L., & Ekman, S. L. (2000). Dance events as a caregiver intervention for people with dementia. *Nursing Inquiry, 7,* 156-165.

Peisah, C., Lawrence G., & Reustens, S. (2011). Creative solutions for severe dementia with BPSD: a case of art therapy used in an inpatient and residential care setting. *International Psychogeriatrics*, 23, 1011-1013. doi:10.1017/S1041610211000457

Penrod, J., Yu, F., Kolanowski, A. M., Fick, D. M., Loeb, S. J., & Hupcey, J. E. (2007). Reframing person-centred nursing care for person with dementia. *Research and Theory for Nursing Practice: An International Journal, 21,* 57-72.

Polit, D. F., & Hungler, B. P. (2004). *Nursing research: Principles and methods* (7th ed.). Philadelphia, PA: Lippincott Williams & Wilkins.

Raglio, A., Bellelli, G., Traficante, D., Gianotti, M., Ubezio, M. C., Gentile, S.,… Trabucchi, M. (2010). Efficacy of music therapy in the treatment based on the cycles of sessions: A randomized control trial. *Aging and Mental Health, 14,* 900-904.

Raglio, A., Bellelli, G., Traficante, D., Gianotti, M., Ubezio, M. C., Villani, D., & Trabucchi, M. (2008). Efficacy of music therapy in the treatment of behavioural and psychiatric symptoms of dementia. *Alzheimer Disease & Association Disorders, 22,* 158- 162.

Randall, O. (2008). Self-selection bias. *Encyclopaedia of Research Methods,* doi: http://dx.doi.org/10.4135/9781412963947

Ridder, H. M., Wigram, T., & Ottesen, A. M. (2009). A pilot study on the effects of music therapy on frontotemporal dementia-developing a research protocol. *Nordic Journal of Music Therapy, 18,* 103-132. doi: 10.1080/08098130903062371

Robinson, O. C. (2014). Sampling in interview-based qualitative research: a theoretical and practical guide. *Qualitative Research in Psychology, 11,* 25-41.doi: 10.1080/14780887.2013.801543

Rodin, J. (1986). Aging and Health: Effects of the sense of control. *Science, 233,* 1271-1276.

Rusted, J., Sheppard, L., & Waller, D. (2006). A multiple-centre randomized control group trial on the use of art therapy for older people with dementia. *Group Analysis*, *39,* 517-536. doi: 10.1177/0533316406071447.

Sacks, O. (2007). *Musicophilia. Tales of music and the brain*. New York: Alfred A. Knopf Publisher.

Sandelowski, M. (2010). What's in a name? Qualitative description revisited. *Research in Nursing & Health, 33,* 77-84. doi: 10.1002/nur.20362

Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing & Health*, *23,* 334-340.

Schreiner, A. S., Yamamoto, E., & Shiotani, H. (2005). Positive affect among nursing home residents with Alzheimer's dementia: The effect of recreational activity. *Aging & Mental Health, 9,* 129-134.

Scott, A., Jeon, S. H., Joyce, C. M., Humphreys, J. S., Kalb, G., Witt, J., & Leahy, A. (2011). A randomized trial and economic evaluation of the effect of response mode on response rate, response bias, and item non-response in a survey of doctors. *BMC Medical Research Methodology, 11, 1*-12.

Seale, C., Gobo, G., Gubrium, F., J. & Silverman, D. (Eds.). (2004). *Qualitative Research Practice.* London: Sage.

Seifert, L. S., & Baker, M. K. (1998). Procedural skills and art production among individuals with Alzheimer's-type dementia. *Clinical Gerontologist, 20,* 3-14.

Seitz, D. P., Gill, S. S., Herrmann, N., Brisbin, S., Rapopart., Rines, J.,… Conn, D. K. (2013). Pharmacological treatments for neuropsychiatric symptoms of dementia in long-term care: a systematic review. *International Psychogeriatrics, 25,* 185-203.

Silverman, D. (2000). Doing Qualitative Research: A practical handbook. London: Sage.

Snow, S., D'Amico, M., & Tanguay, D. (2003). Therapeutic theatre and well-being. *The Arts in Psychotherapy, 30,* 73-82.

Stewart, E. G. (2004). Art therapy and neuroscience blend: working with patients who have dementia. *Art Therapy: Journal of the American Art Therapy Association, 21,* 148-155.

Subramanian, P., & Woods, B. (2012). The impact of individual reminiscence therapy for people with dementia: systematic review. *Expert Reviews Neurotherapy, 12,* 545-555.

Svansdottir, H. B., & Snaedal, J. (2006). Music therapy in moderate and severe dementia of Alzheirmer's type: a case –control study. *International Psychogeriatrics, 18,* 613-621.

Swann, J. I. (2012). From pottery to plays: arts activities in the home. *Nursing & Residential Care, 14,* 195-198.

Thornton, G. (2012). Service costs in modern residential aged care facilities. Australian Cost of Residential Aged Care research, Retrieved from http://www.grantthornton.com.au/files/cost_of_care_research_120201.pdf

Thornton, L. (2010). Person-centred dementia care: An essential component of ethical nursing care. *Canadian Nursing Home, 22,* 10-14.

Tilly, J., & Reed, P. (2006). Dementia care practice recommendations for assisted living residences and nursing homes-phases 1and pgases2. Alzheimer's Association, Retrieved from http://alz.org/national/documents/dementiacarelitreview.pdf

Ullan, M. A., Belver, H. M, Badia, M., Moreno, C., Garrido, E., Gomez-Isla, G., … Tejedor, L. (2011). Contributions of an artistic educational program for

older people with early dementia: An exploratory study. *Dementia*, *12*, 1-22.doi: 10.1177/1471301211430650

Vaismoradi, M., Turunen, H., & Bondas, T. (2013). Content analysis and thematic analysis: implications for conducting a qualitative descriptive study. *Nursing and Health Sciences, 15,* 398-405.

Verkaik, R., Van Weert, J., & Francke, A. (2005). The effects of psychosocial methods on depressed, aggressive and apathetic behaviours of people with dementia: a systematic review. *International Journal of Geriatric Psychiatry, 20,* 301-14.

Vink, A. C., Bruinsma, M. S., & Scholten, R. J. P. M. (2003). Music therapy for people with dementia. *Cochrane Database of Systematic Reviews, 3,* 1-47. doi: 10.1002/14651858.CD00347.pub2.

Vleuten, M., Visser, A., & Meeuwesen, L. (2012). The contribution of intimate live music performances to the quality of life for persons with dementia. *Patient Education and Counselling,* 89, 484-488.

Wilson, B., Swarbrick, C., Pilling, M., & Keady, J. (2013). The senses in practice: enhancing the quality of care for residents with dementia in care homes. *Journal of Advanced Nursing*, 69, 77-90. doi: 10.1111/j.1365-2648.2012.05992.x

Yin, Z. (2000). Using internet for survey research: A case study. *The American Society for Information Science*, 51, 57-68. doi: 10.1002/(SICI)1097-4571(2000)51:1<57::AID-ASI9>3.0.CO;2-W

Appendix A

Details of studies under review

Study	Design and sample	Interventions	Measurements	Relevant Findings
		Studies on BPSD		
Peisah, Lawrence, & Reustens (2011)	Descriptive Case study 82 years old female with MMSE score 0	Individually designed art project using felt material to place on stencils and pre-drawn lines for alleviating behavioural and psychological symptoms of dementia	Observations	The result of this study showed that during art making the patient was focused and calm, engaging using body language and eye contact and positive emotional state. The additional finding of this case study was that the staff of the nursing home responded positively to the individualized art program, because it helps them to understand the patient's preferences and abilities,

				which assisted in the settling processes.
Raglio et al. (2010)	RCT n=30 experiment group n=30 control group MMSE mean score 8	Experimental group listened to music therapy 3 cycles of 12 sessions with a month break for 6 months	Barthel Index Neuropsychiatry Inventory (NPI)	Significant difference between groups on the reduction on NPI global scores F=4.84, p<0.5 And improved single scores on anxiety, agitation and apathy , p<0.001 for the experiment group
Duignan, Hedley, & Milverton (2009)	Uncontrolled pilot study n=6 low care residents	Wu Tao dance 60 minutes x 1 day per week for 4 weeks	CMAI	Reduced agitation for 4 resident and the average reduction on CMAI was 6.16 in pre and post scores
Guetin et al. (2009)	RCT n=15 experimental group MMSE mean score 19.8 n=15 control group, MMSE mean score: 20.7 Alzheimer type of dementia	Repetitive music via headphone chosen by the resident for 1 day a week 24 weeks	Hamilton Scale, Geriatric Depression Scale	Significant improvement in experimental group in anxiety (p<0.0.1) and depression (p<0.01) from week 4 until week 16
Hokkanen, Rantala, Remes, Harkonen, Viramo &	RCT n=19 experimental group	Dance therapy for 30-45 minutes x 1 day a week, for 9	Clock Drawing Test (CDT) Nurses Observation Scale for	No significant differences in scores between experimental

Winblad (2008)	MMSE mean score 19.8 n=10 control group Alzheimer and Vascular dementia	weeks	Geriatric Patients (NOSGER) Boston Diagnostic Aphasia Test	and control group after 9 weeks CDT (p=0.44) NOSGER (p=0.01)
Raglio et al. (2008)	RCT n=30 experimental group MMSE mean score 11.1 n=29 control group MMSE mean score 10.7	Experimental group listened to music therapy 30 music session for 16 weeks	Barthel Index Neuropsychiatry Inventory (NPI)	NPI scores significantly decreased in the experimental group at week 8, 16 and 20 (F=5.06, p=0.002)
Ledger & Baker (2006)	Non-randomized experimental design n=26 experimental group n=19 control group	Experimental group listened to music once a week for 42 weeks	CMAI	Both group showed short term reduction on agitation (F= 2.61, p<0.05) there were no differences between the group in the range, frequency and severity of agitated behaviours (F=1.61, p=0.432)
Rusted, Sheppard & Waller (2006)	RCT and Qualitative design n=45 experimental group n=6 control group	Intervention group Visual art Control group Recreational activities	Mini Mental State Exam, Cornell Scale for Depression in Dementia, Multi Observational Scale for the	Within session, the art therapy group showed slow and stable increased scores over time on mental acuity, sociability,

			Elderly, Rivermead Behavioural Memory Test, Test of Everyday attention, Benton Fluency Test, Within session measurements: Bond-Lader Mood Scale, Skill Builders, Clifton assessment, Procedures for Elderly, Rating Scale for Aggressive Behaviour in the Elderly	calmness and physical involvement with all p value ($p<0.05$) and outside session measurement showed that the art therapy group had a higher mean score on CSDD than the activity group, with the increase in CSDD scores at 40 weeks relative to baseline and the 20 week assessment than the activity group ($p<0.05$). On the MOSES there were no effects found except on anxious and depressed mood which also was increased in the art therapy group ($p<0.05$) which mirrored the CSDD scores.
Svandottir & Snaedal (2006)	RCT n=38 with moderate to severe dementia	Participation in 3X 30 minutes group interactive singing for live music for 6 weeks	BEHAVE-AD	No changes in total scores, however, improvement on subscales 'activity disturbance'($p=0.02$) and

				aggressiveness and anxiety ($p<0.01$) for therapy group
Ashida (2000)	Before and After Experimental design n=20	Participating in 1 week daily reminiscence based live music program	Cornell Scale for Depression (CSD)	Improve scores on CSD after the therapy ($p<0.05$)
Studies on cognitive stimulation				
Eekelaar, Camin & Springham (2012)	Mixed exploratory design n=6 participants with mild to moderate dementia	Participation in An Art Gallery programme viewing and making art	Pre- and post- intervention semi- structured interviews and during intervention observational data	Increased episodic memory during the interventions and post-intervention, the findings for verbal fluency were ambiguous. Qualitative themes: *social activity theme* ;sub-themes-isolation and-structure, *becoming their old selves* ;sub-themes- recalling memories and-improvement in mood, *shared experience*; sub-themes- learning together and-making art together

Kaufman (2008)	Case study 89 years old female with dementia	Montessori painting	Observational pre and post-test included 72 cards of Memory Game	Improvement in memory status after the intervention by 75% of the time completing the memory card faster than the pre-test period.
Studies on well being				
Guzman-Garcia, Mukaetova-Ladinska & James (2013)	Uncontrolled qualitative pilot study n=13 8 participants moderate to severe AD, 2 FTD , 2 VAD, 1mixed, mean score of MMSE (11.71)	Latin Ballroom dance for 35 minutes x 2day per week for 6weeks	Semi -structured interviews	Residents' interviews revealed that they enjoyed the activity. The interviews from the staff showed that the dance activity positively effected the residents mood, socialization, communication and behaviours.
Vleuten, Visser & Meeuwesen (2012)	Quasi-experimental design n=45 mild to moderate dementia	Participating in one live music performance	Observational scale	Improved human contact and communication ($p<0.0001$), care relation($p< 0.006$)
Hamill, Smith & Rohricht (2011)	Mixed method study n=18 moderate to severe	Participating in 45 minutes x 1 per week circle dance	Mini-Mental State Examination, Quality of Life	Improvement in all scores from pre measurements

	dementia	sessions	Scale in Alzheimer's Disease, The General Health Questionnaire, Observation	included general well-being, mood, concentration and communication
Ullan et al. (2011)	Exploratory qualitative study n=21 people with various type of dementia	Participation in an audiovisual programme watching art works followed by discussions and participating making Cyanotype	Focus group interviews Observations included field notes, video recording and short questionnaire	The result of focus groups showed three outstanding positive aspects of the programme; enjoyment, learning and better self-image. The participant observation largely revealed satisfaction during the creative process
Kinney & Rentz (2005)	Comparative quantitative study n=12 participants with various dementia	Participation in the Memories in Making Art programme and other traditional day care activities	Greater Cincinnati Chapter Well-Being Observation Tool	Participants demonstrated significantly more interest p (0.010), sustained attention, pleasure and self-esteem and normalcy during the art programme however, there was no statistical difference between observed negative affect and sadness.

Studies on engagement				
MacPherson, Bird, Anderson, Davis & Blair (2009)	Mixed methods 15 participants with 7 still living at home with mild to moderate dementia and 8 from residential care moderate to severe dementia	Participation in public Art gallery programme viewing art works and discussions	Observational data and focus group interviews	Home care residents were very engaged and significantly increased from time 1 to time 2 $t(7)=2.70$, $p=0.03$ the overall engagement was high for all participants and only a small proportion of observations were neutral or negative. Additionally, short term effects included increased memory, confidence and sense of achievement.
Ridder, Wigram & Ottesen (2009)	Mixed method before and after study 2 participants	Individualized music therapy session for 4 weeks (total 16 sessions)	ADRQL, CMAI, NPI, and video analysis	Participant 1: improved ADRQL and CMAI scores, musical engagement and increased confidence Participant 2: limited musical engagement and ADRQL

				scores worsened possibly to isolation, positive attitude to familiar song
Study on self-expression				
Gregory (2011)	Qualitative design n=6 care staff	Evaluating a poetry based reminiscence program	In-depth semi-structured interviews	Data analysis used phenomenological method and revealed 6 themes; exploring and preserving memories; communicating with services users; co-authorship of poems; humanising dementia sufferers; the broader care context and continuity
Study on a creative activity from everyday practice				
Palo-Bengtsson & Ekman (2000)	Qualitative design n=7 care givers	Regular dance activity in the residential care setting	In-depth unstructured interviews	Data analysis used phenomenological method and revealed 5 themes; prerequisites for dance events; creating and preparing different kinds of activities

				related to the dance events; emotional arousal; caregivers' situational understanding; dance events and contextual consequences

Appendix B

Visual art activities in residential aged care facilities in Australia-

1. What is your postcode?

.....

2. What is your role in your organization? Please choose.

Director of Nursing

Manager

Level 2 Registered Nurse

Administrator

Occupational Therapist

Other

.....

3. How would you describe your organization? Please choose.

For-profit/private

Religious

Charitable

Government/Community

Other

.....

4. How many beds do you have in your facility?

.....

5. Do you accommodate people with dementia? If yes, how many?

Yes

No

How many?

.....

6. Do you provide any creative art activities in your facility for people with dementia? If yes, please choose. If

none apply, leave blank and press Next.

Visual art (including painting, drawing)

Dance

Drama

Music

Other (please specify)

.....

.....

7. If you chose any of the activities above, can you please describe the resident's role in that activity? For example, do they participate as an individual or in a group?

.....

.....

.....

8. What is the position of the facilitating person of these the activities, and what qualifications does this person have?

.....

.....

.....

9. How often are these activities provided?

Daily

Weekly

Monthly

Other

Comments

.....

.....

10. Do you think creative art activities are beneficial for people with dementia? Please describe.

.....

.....

Have you ever considered implementing creative art including visual art activities in your facility?

.....

.....

12. Please discuss any barriers you see to your facility implementing creative art activities.

.....

.....

13. Only for Brisbane metropolitan RACF who have visual art as part of their recreational program. Would you be interested to participate in an observation study in your facility? If yes, please provide your contact details below. You will be contacted by the researcher with more details. (This information will not be associated with your survey answers.)

Name
.....
Organization
.....
Phone
.....
Email
.....

Appendix C

Email invitation

To: The Manager/ Director of Care

My name is Ilona Pappne Demecs. I am a Master's research student from Queensland University of Technology. I am conducting a study of creative art and visual art activities in residential aged care facilities in Australia (RACFs). You are invited to participate in this project because you are a representative of your RACFs. This survey would best be answered by the Activities Director (or someone else familiar with activities available for residents) at your facility. The survey can be done online, however, it can also be done by telephone if preferred, please indicate your preference by return email. If you do not wish to participate in this research at all, no response is required to this email or the reminder notice that will follow.

The survey site is active now and we invite you to participate in this important project. Simply follow the link below and you will be directed to the online survey which should take only 5-10 minutes to complete.

Insert Link Here

The survey will remain active until 29/08/ 2013. Further information about the study is included below on the participant information sheet and if you have any questions please do not hesitate to contact the research team.

Ilona Pappne Demecs/ Student

QUT School of Nursing

Phone 07-54845049
Email i.pappnedemecs@student.qut.edu.au

Elizabeth Beattie/ Professor
QUT
Queensland Dementia Training Study Centre

Phone 07-31383389
Email elizabeth.beattie@qut.edu.au

What is the study about?

The purpose of this project is to determine the proportion of residential aged care facilities (RACFs) in Australia that currently use creative art activities and to describe the characteristics of these activities. Non identifiable data of this project will be used to future study development to improve dementia care.

How long will the survey take to complete?

The survey will take approximately 5-10 minutes to complete.

Do I have to complete the survey?

No, participation is entirely voluntary.

What information will be asked to provide?

1. Provide demographic detail of your organization that you work for

2. Provide characteristics information of your organization that you work for

3. Identify creative activities currently being implemented in your facility

4. Describe the characteristics of these activities

5. Identify barriers to implementing creative activities

Will my responses be used to identify me or the organization I work for?

The names of individual persons are not required in any of the responses. The e- mail address of those responding to the initial survey will be collected so

that any reminder e-mails can be sent only to those who have not yet responded. The identity of those responding to the internet survey also will be required to select participants for the follow up telephone survey, however all identifying data will be removed before the final report and deleted to provide anonymity.

Does the study have ethical approval?

Yes, the project has received ethical approval from the Queensland University of Technology Human Research Ethics Committee (Approval no.: 1300000356).

What is the benefit to my organisation and the people we care for?

This project will not benefit the participating facilities directly. However, it may benefit people with dementia in the future because the outcome of this project will be used to improve the provision of creative activities in dementia care.

Kind regards,

Ilona Pappne Demecs/ Student
School of Nursing
Queensland University of Technology
Victoria Park Rd
Kelvin Grove QLD 4059

Appendix D

Interview Guide

1. What is your role in your facility?

2. Tell me about the creative activities, and any other staff involved in providing them, that are available in your facility?

3. To what extent do these activities offer opportunities for emotional expression and creativity for people with dementia?

4. Are any activities specifically designed for people with dementia? If yes go to question 5, if no, go to question 7.

5. How is this done?

6. In what ways are people with dementia, who may be depressed, withdrawn or apathetic, engaging in these activities?

7. Do you implement these activities as part of the routine activity program or are they tailored to meet specific needs, for example; behaviour management?

8. How is participation determined?

9. How do you evaluate the engagement of people with dementia in these activities?

10. How do you provide feedback on engagement to families and the clinical team?

11. How do you decide on which activities to implement for your residents and for people with dementia?

12. In your experience, which activities are the most engaging for people with dementia?

13. How do you think participating in creative activities can contribute to quality of life of people with dementia?

14. Tell me about your training and experience working with people with dementia?

Appendix E

Queensland University of Technology
Brisbane Australia

PARTICIPANT INFORMATION FOR QUT RESEARCH PROJECT

– Interview –

Visual art activities in residential aged care facilities in Australia

QUT Ethics Approval Number 1300000356

RESEARCH TEAM

Principal Researcher: Ilona Pappne Demecs-Master's student
Associate Researcher: Professor Elizabeth Beattie, Dr Elaine Fielding, and Dr Maria O' Reilly
School of Nursing-Faculty of Health-Queensland University of Technology (QUT)

DESCRIPTION

This study is being undertaken by the Principal researcher as part of the requirements for a Master's degree.

The purpose of this project is to gather additional information about the recreational creative activities implemented in residential aged care facilities for people with dementia in Australia. This interview is an extension of the online survey previously completed by you or another representative person of your facility designated by you as part of this research. The knowledge derived from this interview will help to refine details of these creative activities such as the design, engagement and involvement of people with dementia in these activities.

You are invited to participate in this project because you or another representative person of your facility designated by you completed the initial survey on this topic and indicated an interest in further involvement in this project.

PARTICIPATION

Your participation will involve an audio recorded interview at or from your workplace that will take no longer than 40 minutes of your time. The interview will focus on how you decide, implement and evaluate these activities for people with dementia in your workplace. Questions will include: Are any activities specifically designed for people with dementia? How do you evaluate the engagement of people with dementia in these activities?

The interview is planned to be audio recorded for data analysis purposes if you consent. If you decline to be audio recorded please note that the interview may take longer than 40 minutes because notes have to be taken.

Your participation in this project is entirely voluntary. If you do agree to participate you do not have to answer any question(s) you are uncomfortable answering and you can withdraw from the project at any time without comment or penalty, before data analysis commences. This is approximately a month after the interview. After this time you will not be able to withdraw and the interview you give will be used as data for this project. Any identifiable information already obtained from you will be destroyed.

Your decision to participate or not participate will in no way impact upon your current or future relationship with QUT or with your employer.

EXPECTED BENEFITS

It is expected that this project will not directly benefit you. However, it may benefit residential aged care facilities and residents who are suffering from dementia in the future, because the outcomes of this project will be used to improve dementia care.

RISKS

There are minimal risks associated with your participation in this project and primarily relate to giving up not more than 40 minutes of your time, or longer if you wish not to be audio recorded. The risk will be minimized by fully informing you in advance of the likely time required of you. If you do feel uncomfortable during the interview process, please inform the Researcher conducting the interview, so that she can discuss your concerns. You may also stop the interview at any time during the interview process if you wish and continue the interview at another time.

PRIVACY AND CONFIDENTIALITY

In respect to any information obtained during the course of the project all comments and responses will be treated confidentially unless required by law. Interviews used in the project will be coded with a number related to your contact details for data analysis purposes; however after data analysis all identification will be removed.

The interviews for this project will be audio recorded and if you wish to verify your comments after the interview is completed you will be given an opportunity to do so. The audio material will only be accessible by the research team for data analysis purposes. After data analysis is completed audio materials will be destroyed.

Any data collected as part of this project will be stored securely as per QUT's Management of research data policy.
Please note that non-identifiable data collected in this project may be used as comparative data in future projects.

CONSENT TO PARTICIPATE

We would like to ask you to sign a written consent form (enclosed) to confirm your agreement to participate.

QUESTIONS / FURTHER INFORMATION ABOUT THE PROJECT

If have any questions or require further information please contact one of the research team members below.

Ilona Pappne Demecs
07-54845049
i.pappnedemecs@student.qut.edu.au

Professor Elizabeth Beattie
07-3138 3389
elizabeth@beattie.qut.edu.au

CONCERNS / COMPLAINTS REGARDING THE CONDUCT OF THE PROJECT

QUT is committed to research integrity and the ethical conduct of research projects. However, if you do have any concerns or complaints about the ethical conduct of the project you may contact the QUT Research Ethics Unit on [+61 7] 3138 5123 or email ethicscontact@qut.edu.au. The QUT Research Ethics Unit is not connected with the research project and can facilitate a resolution to your concern in an impartial manner.

Thank you for helping with this research project. Please keep this sheet for your information.

Queensland University of Technology Brisbane Australia	**CONSENT FORM FOR QUT RESEARCH PROJECT** **– Interview –**

Visual art activities in residential aged care facilities in Australia

QUT Ethics Approval Number 1300000356

RESEARCH TEAM CONTACTS

Ilona Pappne Demecs
07-54845049
i.pappnedemecs@student.qut.edu.au

Professor Elizabeth Beattie
07-3138 3389
elizabeth.beattie@qut.edu.au

STATEMENT OF CONSENT

By signing below, you are indicating that you:

- Have read and understood the information document regarding this project.
- Have had any questions answered to your satisfaction.
- Understand that if you have any additional questions you can contact the research team.
- Understand that you are free to withdraw at any time, without comment or penalty.
- Understand that you can contact the Research Ethics Unit on [+61 7] 3138 5123 or email ethicscontact@qut.edu.au if you have concerns about the ethical conduct of the project.
- Understand that non-identifiable data collected in this project may be used as comparative data in future projects.
- Agree to participate in the project.

Please tick the relevant box below:

- Provide permission for interviews to be audio-recorded.

☐Yes ☐No

- Please indicate if you wish to be provided with feedback in the form of a project summary.

☐Yes ☐No

Name .....

Signature .....

Date .....

Please return this sheet to the investigator.

Appendix F

Queensland University of Technology Brisbane Australia	**PARTICIPANT INFORMATION FOR QUT RESEARCH PROJECT** **– Questionnaire –**
Australia	Visual art activities in residential aged care facilities in **QUT Ethics Approval Number 1300000356**

RESEARCH TEAM

Principal Researcher: Ilona Pappne Demecs, Masters student, QUT
Associate Researcher: Elizabeth Beattie, Professor, QUT, Dr Elaine Fielding, Research Fellow, QUT

DESCRIPTION

This project is being undertaken as part of a Masters study for Ilona Pappne Demecs.
The purpose of this project is to determine the proportion of residential aged care facilities (RACFs) in Australia that currently use creative art activities and to describe the characteristics of these activities.
You are invited to participate in this project because you are a representative of your RACF.

PARTICIPATION

Participation will involve completing a 13 item questionnaire with multiple choice and open ended questions that will take approximately 5-10 minutes of your time. For example, questions will include: Do you accommodate people with dementia? If yes, how many? Do you provide any creative art activities in your facility for people with dementia? If yes, please clarify.
Your participation in this project is entirely voluntary. If you agree to participate you do not have to complete any question(s) you are uncomfortable answering. Your decision to participate or not participate will in no way impact upon your current or future relationship with QUT or with any associated external organisation. If you do agree to participate you can withdraw from the project at any time without comment or penalty. Any identifiable information already obtained from you will be destroyed. However, as the questionnaire is confidential once it has been submitted it will not be possible to withdraw.

EXPECTED BENEFITS

It is expected that this project will not directly benefit you. However, it may benefit the people in your facility who are suffering from dementia, because the outcome of this project will be used to improve dementia care.

RISKS

There are minimal risks associated with your participation in this project. It may be for example that you are inconvenienced by giving up 5-10 minutes of your time.

PRIVACY AND CONFIDENTIALITY

All comments and responses will be treated confidentially unless required by law. The names of individual persons are not required in any of the responses. The e- mail address of those responding to the initial survey will be collected so that any reminder e-mails can be sent only to those who have not yet responded. The identity of those responding to the internet survey also will be required to select participants for the follow up telephone survey, however all identifying data will be removed before the final report and deleted to provide anonymity.
Any data collected as part of this project will be stored securely as per QUT's Management of research data policy.
Please note that non-identifiable data collected in this project may be used as comparative data in future projects.

CONSENT TO PARTICIPATE

Submitting the completed online questionnaire is accepted as an indication of your consent to participate in this project.

QUESTIONS / FURTHER INFORMATION ABOUT THE PROJECT

If you have any questions or require further information please contact one of the research team members below.

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Phone 07-54845049
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Queensland Dementia Training Study Centre
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CONCERNS / COMPLAINTS REGARDING THE CONDUCT OF THE PROJECT

QUT is committed to research integrity and the ethical conduct of research projects. However, if you do have any concerns or complaints about the ethical conduct of the project you may contact the QUT Research Ethics Unit on [+61 7] 3138 5123 or email ethicscontact@qut.edu.au. The QUT Research Ethics Unit is not connected with the research project and can facilitate a resolution to your concern in an impartial manner.

Thank you for helping with this research project. Please keep this sheet for your information.