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Can a visual art intervention increase quality of life and well-being in care home residents with dementia? An exploratory study

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Can a visual art intervention increase quality of life and well-being in care home residents with dementia? An exploratory study

Katherine Hazel Algar

Thesis submitted to the School of Healthcare Sciences, Bangor University, in fulfilment for the degree of Doctor of Philosophy

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Summary of Thesis

Background: This thesis aims to evaluate whether a visual art programme can increase the quality of life and well-being of care home residents with dementia. This promising area lacks scientific evidence for the positive effects noted anecdotally. Therefore, careful consideration of study design and measures is needed before conclusions regarding efficacy are drawn.

Methods: The research includes a review of observational measures to identify an appropriate measure to evaluate a visual art programme for care home residents with dementia. An adapted version of this tool is evaluated during three conditions: the art intervention, another structured activity, and unstructured time and compared with quality of life and mood questionnaires before and after the intervention. Perspectives of the residents, care staff and artist teams are sought to explore the experience and impact of the intervention. A systematic review and narrative synthesis is conducted to show where the results fit within the wider literature.

Results: Results suggest the Greater Cincinnati Chapter Well-being Observation Tool is an appropriate observational measure and that the adapted version is sensitive to change, shows a relationship with secondary measures, and is suitable to provide a rigorous evaluation of a visual art intervention compared to another structured activity and unstructured time. The participants, care staff, and artist team all speak of the positive impact involvement in a visual art intervention can have on people with dementia. The narrative synthesis demonstrates that evidence for the positive effect visual art interventions have on people with dementia is improving in extent and quality.

Conclusion: The findings from the thesis are discussed, along with practical implications, methodological and theoretical considerations, and limitations of the study. Findings from this thesis make a valuable contribution to the discussion of suitable measures and methodology to evaluate a visual art intervention for people with dementia and offers valuable lessons to inform a future larger scale study.

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"Art on Friday is on, which will make me very happy"

Edna

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Chapter 1: Introduction

Introduction

"The vast majority of... [dementia] research goes towards the expensive and laborious task of finding both cause and cure. The arts will not provide a cure. But the arts programs I have personally facilitated and observed have provided dramatic improvements in quality of life for caregivers and people with dementia. We should certainly continue investing in the search for a cure, but we should also invest in research, design, and implementation that clearly improve life today. Creative expression among people with dementia...offers us the chance to bring hope to the lives of people with dementia and those who care for them" (p.20; Basting, 2006)

In the past decade there has been a steady increase in the popularity of art projects specifically for people with dementia. These projects include involving people with dementia with music (Martin et al., 2004; Sixsmith & Gibson, 2007; Southcott, 2009), poetry (Killick, 1997), drama (Lepp, Ringsberg, Holm, & Sellersjö, 2003), and visual art (Kinney & Rentz, 2005; Rentz, 2002). Those leading the sessions believe in their potential to produce positive effects on the well-being and quality of life of people with dementia. This is illustrated in Basting's words (above), but the scientific evidence for this practice is currently lacking. Methodological issues, which are discussed in Chapter 3, mean that where attempts at scientific study have been made, the evidence obtained is very limited.

In light of this, this thesis aims to explore ways to navigate a passage through the methodological issues to evaluate the potential benefits of art for people with dementia. Potentially suitable assessment approaches and measures are reviewed, in order to select one for further consideration and testing of its appropriateness before using it to evaluate a visual art programme for people with dementia living in a care home. This research also offers a dynamic approach in voicing multiple perspectives of the art programme in order to understand its impact. This includes the residents, care staff and artist team.

Prevalence and impact of dementia

In the UK in 2015, there are an estimated 850,000 people with dementia and this is forecast to increase to 1 million by 2025. In Wales, there are currently 43,477 people living with the condition. Dementia is typically considered a condition that affects older people and prevalence of dementia increases with age. However in the UK 40,000 people

under the age of 65 have early-onset dementia (Alzheimer's Society, 2014). Dementia is costly to society with the total cost now believed to be £26.3 billion in the UK and the average cost per person with dementia is £32,250 per annum (Alzheimer's Society, 2014), which is much higher compared to patients with cancer, stroke and heart disease (Alzheimer's Research Trust, 2010). In 2013, dementia was the leading cause of death among women (12.2%) and third leading cause of death among men (6.2%) in England and Wales (Office for National Statistics, 2014).

A common perception is that dementia is a just a loss of memory. However, dementia is an umbrella term for a number of neurodegenerative diseases that may also affect mood, behaviour, communication skills, and the ability to perform everyday activities. The World Health Organisation (2012) define dementia as

"...a syndrome – usually of a chronic or progressive nature – in which there is deterioration in cognitive function (i.e. the ability to process thought) beyond what might be expected from normal ageing. It affects memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not affected. The impairment in cognitive function is commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation.

Dementia is caused by a variety of diseases and injuries that primarily or secondarily affect the brain, such as Alzheimer's disease or stroke."

There are many different types of dementia but the most common form is Alzheimer's disease which accounts for 62% of all dementias, followed by vascular dementia (17%) and mixed dementia (10%). Three stages of dementia are typically described – mild, moderate, and severe which refer to the progression of the condition. The Clinical Dementia Rating (CDR; Hughes, Berg, Danziger, Coben & Martin, 1982) defines these according to memory, orientation, judgement and problem solving, community affairs, home and hobbies, and personal care. Those with mild dementia have moderate memory loss that interferes with daily life as well as some difficulties in the other categories. Those with moderate dementia have severe memory loss retaining only highly learned material and have much more difficulty in the other categories including disorientation to time and place, and requiring assistance with dressing and hygiene. Those with severe

dementia have extensive memory loss with only small remnants remaining and have little function outside the home or room (Hughes et al., 1982). Just over half of the population of people with late-onset dementia (over the age of 65) have mild dementia (55.4%), 32.1% have moderate dementia, and 12.5% severe (Alzheimer's Society, 2007).

Dementia has received increased policy and media attention in the past five years. All of the nations of the United Kingdom have a dementia strategy (Department of Health, 2009; Department of Health, Social Services and Public Safety, 2011; Scottish Government, 2010; Welsh Assembly Government, 2011) and the Prime Minister supplemented this with a challenge on dementia in 2012 and an update three years later (Department of Health, 2015).

At present there are no disease modifying treatments for dementia. Currently available medication has been associated with benefits to cognitive function in Alzheimer's type dementia. This includes delaying the progression of the condition and improving symptoms such as memory, concentration and the ability to carry out activities of daily living (Qaseem et al., 2008). However there is increasing evidence that non-pharmacological interventions may be equally as effective (Olazarán et al., 2010). In addition, there is now less of a focus on cognitive function and more of an emphasis on improving quality of life and living well with dementia through non-pharmacological interventions including art programmes and reminiscence.

Theories of dementia care

Nearly two decades ago, Kitwood (1997) urged people to see the 'PERSON with dementia' (emphasis as in original), rather than focussing on the disease and introduced the concepts of personhood and person-centred care in dementia care. Moving from the medical model to a biopsychosocial model of dementia care, Kitwood emphasised the importance of maintaining quality of life, dignity and integrity for people with dementia. This significant work changed the culture of dementia care and person-centred care is still something care providers strive for. He defined personhood as "a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being" (p. 8, Kitwood, 1997) and suggested that in order to achieve this, people with dementia have five main psychological needs: comfort, attachment, inclusion, occupation, and identity which in turn contribute to the central need of love.

The term person-centred care was first used by Carl Rogers in the 1960s in terms of psychotherapy but it was not used in dementia care until Kitwood's work (Brooker, 2004). The term is now a 'buzz' word in dementia care but Brooker (2004) argues that it means different things to different people. In an attempt to define person-centred care, Brooker (2004) suggests that there are four elements:

- 1. Valuing people with dementia and those who care for them (V)
- 2. Treating people as individuals (I)
- 3. Looking at the world from the perspective of the person with dementia (P)
- 4. A positive social environment in which the person living with dementia can experience relative well-being (S)

And therefore person-centred care (PCC) = V + I + P + S (p.216).

Therefore, implementing person-centred care requires a care provider to look beyond the dementia and recognise the uniqueness of the person. Creating a positive care environment that promotes these values in day-to-day life which respects residents as individuals can enhance the well-being of the person with dementia.¹ The ground-breaking work of Kitwood has inspired further work that has added to his theory of personhood.

It has been suggested that a successful person-centred care outcome in nursing with older people depends on the relationship between the nurse and the older person and that the term person-centred care disregards this as it concerns only the personhood of the person being cared for and not the carer (McCormack, 2004). Nolan and colleagues proposed that the term 'relationship-centred care' was more appropriate (Nolan, Davies, Brown, Keady & Nolan, 2004). This term was first proposed by an American Task Force established to deliver a new model of healthcare who stated the 'importance of interactions amongst people as the foundation of any therapeutic or healing activity' (Tresolini et al., 1994, p.22). Nolan et al. (2004) took this work further and, after reviewing the literature, developed the 'Senses Framework'.

¹ Brooker & Latham (2015) have recently published an updated 2nd edition book which provides the VIPS Framework of person-centred care to help care providers assess how their care is performing using the 4 elements. Brooker, D. & Latham, I. (2015) *Person-centred dementia care*. 2nd Ed. London: Jessica Kingsley Publishers

Whilst fully acknowledging the concept of personhood, the Senses Framework is based on the subjective perceptions of care experiences for both recipients of care and staff. It is constructed on the belief that relationships between all parties involved in caring should promote a sense of security, belonging, continuity, purpose, achievement and significance. Although originally developed in the context of long term care settings, it has been also been empirically tested in acute hospital settings (Davies, Nolan, Brown & Wilson, 1999). The authors also ran workshops with older people, family carers, multidisciplinary professionals and paid carers from institutional settings and the community to find out how much the senses "resonated with their own experiences and 'spoke' to them in a language that they understood and related to" (p.51, Nolan et al., 2004). Empirical work and further reviewing of extensive literature resulted in Nolan et al. (2004) expanding the summaries of these senses in relation to the older person, staff, and the family carer.

A strength of the Senses Framework is that the senses are applicable and seen as important to all in the relationship. The 'My Home Life Programme' in England and 'My Home Life Cymru Programme' in Wales led by Age UK promote improvements of quality of life in care homes and use the Senses Framework to emphasise the importance of the needs of the care staff as well as the residents (McCormack, Roberts, Meyer, Morgan, & Boscart, 2012).

Although being considered under the title of 'theories of dementia care' in this thesis, it has been suggested that it may be more accurate to consider The Senses Framework as a list of indicators of good care (Dewing, 2004). It was developed following extensive empirical work and participants from their own workshops stated that the framework was a useful reminder for making good care practices more explicit (Nolan et al., 2004). The framework was also used to characterise 'impoverished' and 'enriched' care environments in relation to student nurse placements. However, whether considered as indicators or theory, the sentiment of the following quote encapsulates the importance it brings to improving care for people living with dementia;

"...the Senses Framework captures the important dimensions of interdependent relationships necessary to create and sustain an enriched environment of care in which the needs of all participants are acknowledged and addressed" (p. 9-10; Nolan, Davies, & Brown, 2006).

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This model of care emphasises the person beyond the disease as well as the relationship between the person being cared for and the carer. Although developed with care in mind, it seems that any intervention aiming to improve quality of life and well-being of people with dementia should be underpinned by these core values, and this will be expanded upon in the following sections.

Definition of Well-being

Well-being is a phrase that has moved beyond academia into everyday life. The Oxford English Dictionary defines it as "The state of being comfortable, healthy, or happy" (Oxford University Press, 2015). However, it has been argued that current definitions are actually descriptions of the dimensions of well-being rather than a true definition and that without knowing exactly what the term means there are difficulties in measuring it (Dodge, Daly, Huyton, & Sanders, 2012).

Well-being is a multi-faceted and complex construct that many have attempted to define. Dodge et al. (2012) reviewed the main theoretical perspectives to propose a new definition incorporating aspects of previous attempts. They define well-being as the "balance point between an individual's resource pool and challenges faced" (p.230) and propose a representation of a see-saw where well-being is in the middle with psychological, social, and physical resources on one side and psychological, social, and physical challenges on the other. Therefore, stable well-being is where a person has the resources they need to meet the challenges facing them and when there are more resources than challenges, the seesaw rises and thus well-being is improved. It is therefore also true that well-being decreases when a person faces more challenges than they have resources. The authors state that their definition is simple, applicable to all, reflects an emphasis on positive psychology, and enables easier measurement (Dodge et al., 2012). Further discussion on issues of measurement can be found in Chapter 2.

Lack of meaningful activities in care homes

38.7% of people with dementia live in a care home, either in residential care or a nursing home, but 80% of all residents in care homes have dementia (Alzheimer's Society, 2014; Alzheimer's Society, 2013). Less than half (41%) of relatives of care home residents with dementia surveyed by the Alzheimer's Society replied that their relative was being offered opportunities for activities, although they did not specify the type of activity offered (Alzheimer's Society, 2013). This feeling is echoed by the Older People's

Commissioner for Wales' review of Care Homes (2014), "A Place to Call Home: A review into the Quality of Life and Care of Older People living in Care Homes in Wales", which states that there is a lack of social stimulation within care homes and that residents often do not have choice or control over activities offered.

In a study asking residents, care staff and family carers about meaningful activity for people with dementia in care homes, residents themselves said the barriers to accessing activities were a lack of opportunity and motivation, whereas the staff and family carers identified that staffing levels were to blame for the lack of meaningful activities (Harmer & Orrell, 2008). The residents also said that their mood was affected by the lack of interaction and activity. When asked what activities they found meaningful, rather than identifying a specific activity, residents said activities that met their psychological needs, were enjoyable, and reinforced a sense of identity and belonging were meaningful, echoing the theories of dementia care discussed above (Harmer & Orrell, 2008; Kitwood, 1997; Nolan et al., 2004). Therefore, people with dementia themselves talk of meaningful activity satisfying their needs to be cared for with personhood and relationship-centred care. A lack of meaningful activity can therefore be said to neglect the psychological needs of people with dementia.

Motivation for a visual art intervention in a care home

As already discussed, many care homes are not providing residents with meaningful activities. Care providers are increasingly looking for novel ways to improve health and well-being, and deliver quality services and in doing this have begun to consider innovative approaches such as involvement in the creative arts. In fact, the Baring Foundation report "Creative Homes" states that the arts in care homes are "integral to the definition of excellence in social care" (2011, p.1).

To inform the proposal for the current study, a review of creative therapies such as music, drama, art and dance therapy for people with dementia was undertaken (Salisbury, Windle, & Algar, 2011). Many positive effects were found in the 13 included studies such as the improvement of interaction skills and people coming to terms with and coping better with dementia. Another review carried out by the Mental Health Foundation (MHF, 2011) of the impact on older people of participatory arts such as visual arts, dance, theatre and drama, music and story-telling, found that involvement in participatory art programmes could result in benefits to mental well-being such as increased confidence and self-esteem,

feelings of accomplishment, and new and positive aspects to identity and life roles. They also found evidence for the improvement of cognitive functioning, communication, selfesteem, musical skills, pleasure, enjoyment of life, memory, and creative thinking for people with dementia engaged in participatory art. Impact on the physical well-being of older people, raising awareness in the wider communities and changing attitudes in society were also found.

Visual art and arts in health

For the purposes of this thesis it is important to make two points clear. Firstly, the arts include such a wide variety of activities that it was important to concentrate on only one area – and for the purposes of this thesis visual art was chosen. The author had previously volunteered with visual artists on projects with people with dementia and had already made links with local networks of visual artists.

Secondly, the review by MHF (2011) recognises that terms used to describe art activities are often inappropriately used due to terms such as art therapy and art engagement being used interchangeably. This thesis concerns visual arts engagement, or participatory arts, led by artist facilitators which are associated with Arts in Health approaches to promote general well-being. Arts in Health are defined as "arts-based activities that aim to improve individual and community health and healthcare delivery, and which enhance the healthcare environment by providing artwork or performances" specifically to promote the health and wellbeing of communities and create improved environments within healthcare settings (Arts Council England, 2007). In contrast, art therapy is described as a form of psychotherapy where the art is a tool to communicate emotions or memories (British Association of Art Therapists, 2014).

Therefore, although acknowledging the therapeutic effects of the arts interventions, the thesis talks of an arts in health intervention rather than art therapy as the focus was on providing meaningful activity to improve the quality of life and well-being of care home residents with dementia.

How might a visual art intervention increase quality of life and well-being in people living with dementia?

As the interest in art programmes for people living with dementia increases, so too does the need to consider the mechanisms by which engaging with the arts might increase quality of life and well-being. The psychology of aesthetics and the arts has been defined as:

"...the study of our interactions with artworks; our reactions to paintings, literature, poetry, music, movies and performances; our experience of beauty and ugliness; our preferences and dislikes; and our everyday perceptions of things in our world – of natural and built environments, design objects, consumer products and, of course, people." (p.3; Smith & Tinio, 2014)

It therefore makes sense to begin an enquiry into the impact of a visual art intervention by looking within the literature from the field of aesthetics. Young, Camic, & Tischler (2015) suggest theories of aesthetics to explain the possible cognitive processes affected when engaging with art. In particular, they suggest an information-processing model of aesthetic experiences of visual art (Leder, Belke, Oeberst, and Augustin, 2004; Leder & Nadal, 2014). The model proposes five cognitive processes to explain aesthetic experience: perceptual analysis, implicit memory integration, explicit classification, cognitive mastering and evaluation. There is also constant emotional evaluation throughout the progression of the processes. The stages were originally proposed as occurring in succession but an updated version suggested that the first three stages overlap (Leder & Nadal, 2014).

The interesting aspect of the model which has potential interest in the field of dementia is that the authors propose that aesthetic judgement is independent to aesthetic emotion (Leder & Nadal, 2014). Therefore an emotional response to an artwork can occur whether or not the person fully understands it. Although it has not been applied to people living with dementia, this aspect of the model suggests that someone with a cognitive impairment, such as dementia, which could hinder the understanding of the artwork, would still experience an emotional response which in turn could impact on quality of life and well-being.

The concept of flow, whereby "individuals are fully involved in the present moment" is another theory of interest when trying to explain how a visual art intervention that incorporates an art-making element can impact quality of life and well-being (p.89: Nakamura & Csikszentmihalyi, 2002). 'Flow' is rooted in the study of the creative process. Csikszentmihalyi noticed how an artist carried on single-mindedly, disregarding hunger or tiredness, when a painting was going well, but once finished, lost interest in it. It was the process and not the end result that was so rewarding. He then investigated this further by holding interviews with chess players, dancers, rock climbers and others whose main motivation for doing activity was enjoyment. From these, common factors were found for achieving flow. These include:

- The use of a skill,
- An appropriate level of challenge,
- Clear goals and immediate feedback,
- The activity is worthwhile in itself and the end goal is more of an excuse for the process,
- A sense of total control,
- A focussed concentration,
- The perception of time is distorted (often that time has passed more quickly than usual) (Killick & Craig, 2012).

Nakamura and Csikszentmihalyi (2002) state that flow contributes to quality of life through "*endowing momentary experience with value*" (p.102). The list of common factors could therefore be used to plan an arts intervention to navigate a way for the participants to enter a state of flow and consequently increase quality of life.

Although both the model of aesthetics experience and the concept of flow are clearly related to the arts, it seems that they each explain only one aspect of an intervention – art appreciation or art making respectively. Therefore, each theory could be considered too narrow an explanation if considered alone.

A fuller picture of why an art intervention might increase quality of life and well-being of a person with dementia could be thought of in terms of the theories of dementia care previously discussed. Through attending sessions with an artist a person is given the opportunity to build up a relationship in a social setting which therefore facilitates personhood as defined earlier (Kitwood, 1997). The areas within the Senses Framework also highlight some of the potential pathways to quality of life and well-being in people with dementia involved in an art programme, as shown in Table 1.1.

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Table 1.1

How involvement in an art intervention might facilitate the six senses in the Senses Framework for people with dementia

	How art can relate to sense	
Sense of security	There is no right or wrong so there is less chance of failure	
	increasing opportunities to feel safe	
Sense of continuity	Gives an opportunity for reminiscence and possibly the	
	continuation of activities previously enjoyed, as well as the	
	continuity of the same artist team	
Sense of belonging	Being engaged in a group art session where new	
	relationships can be developed and being made to feel	
	welcome	
Sense of purpose	The opportunity of engaging in a meaningful activity and	
	the opportunity of choice of materials or pictures to view.	
Sense of achievement	The opportunity of making a valued contribution to the	
	session, whether through the creation of own artwork, or	
	through discussions with the artist.	
Sense of significance	Experiences and beliefs can be validated through work	
	being displayed or exhibited.	

Applying this framework in the context of a visual art intervention emphasises the important role of the artist in the intervention and acknowledges importance of the relationship between participants, the artists, and staff. It can provide a guiding framework for the artist to work towards ensuring that sessions create a sense of security, belonging, continuity, purpose, achievement, and significance for the participants, irrespective of whether it is an art appreciation or art marking intervention.

Considering this framework as a possible explanation for how a visual art intervention might increase quality of life and well-being in people living with dementia fully acknowledges that the intervention is not a solitary experience affecting only single processes and that perhaps it is the relationship context with others in the group that facilitate a positive impact. It therefore provides a fuller picture of the pathways that promote an increase to quality of life and well-being. However, it could also be considered too broad a framework which is not specific to art like the theories of aesthetics and flow, as it is a generic framework that could apply to any psychosocial intervention.

This thesis therefore is informed by these ideas and provides further clarification of the mechanisms by which engaging with an art intervention may impact the quality of life and well-being of people living with dementia.

Methodological issues

Although positive effects of art interventions for people with dementia have been found, reviews also found that more information about the art interventions were needed and methods of evaluation needed development and validation (Salisbury et al., 2011). This was further supported by a systematic review of art therapies and dementia (Beard, 2011) which concluded that the existing evidence lacked adequate study design, that measurement tools were either unspecified or missing, that clinical outcomes were emphasised rather than investigating quality of life, and that there was inadequate analysis of the data. Therefore a methodologically sound underpinning for the evaluation of visual arts for care home residents with dementia is needed which this thesis aims to provide.

Motivation for observational measures

As identified in the reviews discussed above (Beard, 2011; Salisbury et al., 2011), previous evaluations of art interventions have been found to use inappropriate measurement tools leading to the question - what type of measure is appropriate for evaluating a visual art intervention in a care home?

There have been many successful evaluations of non-pharmacological interventions for people with dementia including cognitive stimulation, exercise programmes, and behavioural interventions (Olazarán et al., 2010). Out of twenty studies included in a systematic review of the efficacy of non-pharmacological interventions to improve quality of life, most used measures of self-reported quality of life completed by the person with

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dementia, a proxy, or both at various time-points before and after the intervention (Cooper et al., 2012). However possible issues exist in a care home setting where a higher proportion of residents with moderate to severe dementia might struggle with the questions and there may also be difficulties in finding an appropriate person to act on a resident's behalf (to provide a proxy rating). For example, some residents will not have family members that regularly visit and inconsistent staffing means that one staff member might not be able to give a true reflection of a residents' quality of life.

Another issue with using questionnaires before and after an intervention, and especially a creative arts intervention, is that this crucially misses what happens during the session. This might not be important in a physical exercise intervention where you might expect a lasting effect. However, an evaluation of an art viewing intervention in the National Gallery of Australia found that positive effects during the session were not lasting but "you do it for the moment" after observing behaviours from videotapes of the sessions (MacPherson, Bird, Anderson, Davies & Blair, 2009). In other words, if the researchers had relied on pre and post quality of life measures they would have missed the positive impact the intervention had on the participants with dementia during the session.

These findings combined with experience of an evaluation of joint reminiscence groups for people with dementia and carers led to considering other ways of measuring quality of life and well-being to evaluate a visual art intervention. The author of this thesis was a co-facilitator for two of the groups in North Wales in the reminiscence project and each session included an opportunity for creativity. Participants showed improved confidence, enjoyment, and a better relationship with their carer during the sessions but this was not reflected in the results of the measures before and after the intervention (Woods et al., 2012). Had there been behavioural observations during the sessions, the positive results witnessed by the facilitators might have been evidenced. Therefore, in considering how to evaluate a visual art programme for the current study, behavioural observation was chosen as the primary outcome measure.

Aim of the thesis

The aim of the thesis is to overcome some of the difficulties surrounding the existing literature on the effectiveness of visual art interventions to promote well-being and quality of life to people with dementia.

Research questions

The specific research questions addressed in this thesis are as follows:

- 1. What is the most appropriate measurement tool to evaluate a visual art programme for people with dementia?
- 2. Is an adapted observation measure suitable for evaluating a visual art programme for care home residents with dementia compared to another activity and unstructured time?
- 3. What is the experience of a visual art intervention from the perspectives of the residents, care staff, and artist team?
- 4. Where do these results fit with the wider literature and has the evidence base improved?

Structure of the thesis

The thesis consists of chapters based on journal articles which have been published or will be submitted for publication in the future. As some of the chapters report results from the same group of participants and intervention, there is some repetition in methods sections. The thesis includes an introduction chapter, two literature reviews, two empirical studies, two case vignettes, and a discussion chapter.

Chapter 2 is a review of observational measures in the context of recording the well-being of a person with dementia during and outside of a visual arts intervention. The psychometric properties, strengths, and weaknesses of eleven observational tools are reviewed in order to identify the most appropriate for evaluating a visual art intervention for people with dementia. This review supports the Greater Cincinnati Chapter Well-Being Observation Tool as an appropriate measure to evaluate a visual art programme for people with dementia. This review has been published in *Dementia* (Algar, Woods, & Windle, 2014).

Chapter 3 aimed to determine how suitable an adapted observation measure was in evaluating the impact of a visual art programme on quality of life and well-being of care home residents with dementia compared with an alternate structured activity and unstructured time. Findings suggest that the tool was sensitive to change, showed a relationship with secondary measures, and was suitable for providing a rigorous evaluation of a visual art intervention compared with another structured activity and unstructured time. The results from this exploratory study demonstrated an observational measure may quantify the benefits that have been noted anecdotally for many years during visual arts activities.

Chapter 4 presents the qualitative experience of an art intervention for care home residents with dementia from the perspective of the residents, care staff, and artist team. The three groups all spoke of the positive impact involvement in a visual art intervention can have on people with dementia. Enjoyment of the participants was identified in all groups and other benefits identified included improvements in mood, communication / interaction, concentration, independence, confidence, and self-esteem. However, perhaps the most important impact of the intervention found was the change in perception of the abilities of the residents by the care staff and artist team.

Chapter 5 brings together quantitative and qualitative results in two case vignettes to explore the impact of the visual art intervention on the individual.

Chapter 6 is a systematic review and narrative synthesis exploring the effectiveness of visual art interventions. As well as showing where the results from the thesis fit within the wider literature, it also explores whether there have been improvements to the methodological issues present in the field identified in previous literature reviews. Results suggested that evidence for the positive effect of visual art interventions for people living with dementia is improving. However, there is still further work required before anecdotal reports of improvements can be said to have an evidential basis.

Chapter 7 is the discussion chapter with a summary and discussion of findings from all of the chapters. The practical implications of the results are discussed as well as methodological considerations and limitations and possible directions for future research.

Dissemination of findings

The author is aiming to publish all of the findings of this study in peer-reviewed academic journals and also to present the results at national and international conferences. A symposium has been arranged to disseminate the results to the local community.

To date one chapter has been accepted for publication in an academic journal:

Chapter 2:

Algar, K., Woods, B., & Windle, G. (2014) Measuring the quality of life and well-being of people with dementia: A review of observational measures. *Dementia*. Advanced Online Publication. doi: 10.1177/1471301214540163

The following presentations based on the thesis have been made to date:

January 2012, RESEC Conference, Menai Bridge: Paper: Can an arts programme increase quality of life and well-being of care home residents with dementia? An exploratory study.

November 2012, 7th UK Dementia Congress, Brighton: Symposium Paper: Evaluating an arts programme in a care home. Poster: Can an arts programme increase quality of life and well-being of care home residents with dementia? An exploratory study.

January 2013, Dementia with Dignity Conference, Wrexham Social Services: Paper: The creative arts and dementia care.

September 2014, British Society of Gerontology, University of Southampton: Symposium paper: Can a visual arts programme increase quality of life and well-being in care home residents with dementia? Results of an exploratory study.

October 2014, Jornada 20 años 20 acciones: "Programa CCCB Alzheimer", Barcelona: Paper: Can a visual arts programme increase quality of life and well-being in care home residents with dementia? Results of an exploratory study

Another abstract has been accepted:

July 2015, British Society of Gerontology, Newcastle University Symposium paper: "I thought you'd be wasting your time, if I'm honest": A qualitative exploration of the impact of a visual arts programme for care home residents with dementia

Contribution of others to the thesis

As well as contributions from the two supervisors, others have contributed towards some chapters in the thesis. Ms Ana Guerrero aided in data collection for the third wave of intervention presented in Chapter 3. Ms Yolanda Barrado-Martin provided an independent review of the data and themes identified in Chapter 4. Ms Samantha Gregory and Dr Catrin Hedd Jones carried out the initial literature search for the systematic review in Chapter 6. Dr Jones also made independent quality scores for the included studies.

Chapter 2: Measuring the quality of life and well-being of people with dementia: A review of observational measures

Summary

The dynamic nature of psychosocial interventions implies that trying to measure their effects using standardised clinical trials measures may not capture their full effects. Rich and valuable data during the sessions may be missed by using standard quality of life questionnaires. This paper compares observational measures in the context of recording the well-being of a person with dementia during and outside of a visual arts intervention. A literature search was conducted using systematic principles of searching, screening and retrieval to identify peer-reviewed English language evaluations of research projects using observational measures with people with dementia. Psychometric properties, strengths, and weaknesses of eleven observational tools are reviewed in order to identify the most appropriate for evaluating a visual art intervention for people with dementia. This review supports the Greater Cincinnati Chapter Well-Being Observation Tool as an appropriate measure to evaluate a visual art programme for people with dementia. The results of this review will help researchers plan projects to show the full range of effects for people with dementia of taking part in art sessions.

Algar, K., Woods, B., & Windle, G. (2014) Measuring the quality of life and well-being of people with dementia: A review of observational measures. *Dementia*. Advanced Online Publication. doi: 10.1177/1471301214540163

This review was undertaken to inform the decision of which measure to use in the main study. Having decided that behaviour observation would be the primary outcome measure, there was a lack of resources to suggest an appropriate measure at the time of preparing the protocol for ethical approval. It was therefore felt that formalising this process and producing a review would benefit others in similar situations. Therefore, what began as a data-gathering exercise to inform the protocol turned into a review of observational measures; and in turn shifted the focus of the research question of the main empirical study to one about suitable measures.

Introduction

Estimates anticipate a doubling in the number of people with a dementia in the next generation (Alzheimer's Disease International, 2009). As there are no curative treatments as yet for the dementias, it is important to promote well-being and quality of life (QoL) to improve the lives of those living with the condition now. In recognition of this, there has been an increase over the last decade of studies where QoL is viewed as the primary outcome (Ettema, Droes, de Lange, Mellenbergh, & Ribbe, 2005). The World Health Organisation (WHO) defines QoL as

...the product of the interplay between social, health, economic and environmental conditions which affect human and social development. It is a broad-ranging concept, incorporating a person's physical health, psychological state, level of independence, social relationships, personal beliefs, and relationship to salient features in the environment. As people age, their quality of life is largely determined by their ability to access needed resources and maintain autonomy, independence, and social relationships (p.48; WHO, 2004).

This definition highlights that QoL is a multifaceted construct. Non-pharmacological interventions can increase QoL of people with dementia (Olazarán et al., 2010) but measuring such a multi-factorial construct presents many challenges. A number of measures have been developed which measure QoL. Some are generic, meaning that the same measure can be used to measure QoL in people with a variety of different conditions as well as in healthy individuals. For example, the Health Utilities Index (HUI[®]; Feeny, Furlong, Boyle, & Torrance, 1995) which gives a measure of both health status and health related QoL. Other QoL measures are disease-specific and are designed to be relevant to a certain condition. A Dutch review of QoL measures found six dementia specific QoL instruments used in dementia research since 1990 (Ettema et al., 2005). They conclude, however, that the generic QoL measures would only be useful when comparing health related QoL in different populations, and that the dementia specific measures should be preferred when the research concerns people with dementia primarily.

Of these six dementia specific measures, one was observational,(Dementia Care Mapping; DCM; Kitwood & Bredin, 1992), one was through self-report, Dementia Quality of Life instrument (DQoL; Brod, Stewart, Sands, & Walton, 1999), two were through a proxy

report from the caregiver, Alzheimer's Disease Related Quality of Life (ADRQL; Rabins, Kasper, Kleinman, Black & Patrick, 1999) and Quality of Life for Dementia (QOL-D; Terada et al., 2002), and two were from an interview with both the patient and caregiver, Quality of Life in Alzheimer's Disease (QOL-AD; Logsdon, Gibbons, McCurry, & Terri, 1999) and The Cornell-Brown Scale for Quality of Life in Dementia (Ready, Ott, Grace, & Fernandez, 2002). All six measures provide quantitative data.

As previously mentioned, quality of life is an important measure for people with dementia as a cure has yet to be found. It is therefore important to ensure that those with the condition are able to live as good a life as possible, and people living with dementia themselves state that interventions aimed at improving quality of life are more important than improving disease-specific outcomes (Cooper et al., 2012). A more recent systematic review searched for non-pharmacological interventions to improve QoL of people with dementia and found 20 relevant studies (Cooper et al., 2012). All but one used validated QoL measures, including the QoL-AD, ADRQL, and D-QOL, as well as the Quality of Life Assessment, (WHOQOL: World Health Organisation, 1995), health related quality of life for people with dementia - DEMQOL (Banerjee, Smith, Lamping, Foley & Murray, 2004) and the Health Utilities Index Mark 3 (Feeny et al., 2002). All of these measures use self-reported or a proxy report of QoL. Three studies did not use these measures, but instead used observer-rated measures such as DCM and the Quality of Life in Late-Stage Dementia Scale (QUALID; Weiner et al., 2000). Although the QUALID is classified as observer rated by the authors, it seems more appropriately classified as proxy rated QoL as it consists of an interview with an informant about the last 7 days of the person with dementia.

Given the growing number of QoL measures for people with dementia, researchers and clinicians may encounter difficulties in selecting which one might best capture outcomes of interest. To address this, in 2008, a review of outcome measures for psychosocial interventions was undertaken by INTERDEM, Early detection and timely INTERvention for DEMentia; a pan- European research group on early, timely, and quality psychosocial interventions in dementia (Moniz-Cook et al., 2008). They suggest that the QoL-AD is the measure of choice for evaluating QoL in people with dementia, as it is short, has been shown to be sensitive to change in an intervention study, can be used internationally as it has been translated into many different languages, and has been shown to correlate with health utility measures.

Most of these self-report and proxy- report QoL measures already mentioned have been validated, and shown to be sufficiently sensitive to change in order to evaluate interventions (Cooper et al., 2012), however, there are methodological issues worth consideration. Although it is increasingly recognised that people at all stages of dementia can give their own views on what effects their quality of life (Alzheimer's Society, 2010; Harris, 2002; Keady, 1996; Sabat, 2001; Sterin, 2002), using a self-reported measure could limit the group of people able to be evaluated as a number of measures use exclusion criteria according to cognitive or communication abilities. Therefore some self-reported QoL measures are not viable for use beyond a certain severity of dementia. If measuring over several time points, disease progression and changes in cognitive function could result in missing data (Fossey, Lee, & Ballard, 2002). It has also been shown that caregiver's proxy reports underestimate ratings of QoL, especially when the participant is more cognitively impaired, and has a poor affect state (Magaziner, Simonsick, Kashner, & Hebel, 1988).

As an alternative, observation is a way of uniquely representing the experience of the person with dementia within the intervention and quantifying it for statistical analysis. Observation presents opportunities to examine real processes and outcomes of specific research interest (Aspland & Gardner, 2003), regardless of cognitive abilities. This is not to say, however, that people with dementia cannot give an account of their own feelings of quality of life, just that perhaps they might struggle with a formal self-report measure.

Clinical anti-dementia drug trials are often derived from a theoretical framework and have a clear aim of improving cognitive abilities, and thus this has typically been the primary outcome (Moniz-Cook et al., 2008), although changes in functional ability are now increasingly required by regulatory authorities. Psychosocial interventions, however, are more complex and often come from theories from different disciplines and constructs, with several aspects to be measured. The dynamic nature of psychosocial interventions implies that trying to measure their effects using standardised quantitative self-report clinical trials measures and approaches may not capture their full effect. Findings such as 'you do it for the moment' (MacPherson, Bird, Anderson, Davis, & Blair, 2009), an evaluation of the National Gallery of Australia's art viewing programme for people with dementia (PwD), which used systematic observation as one of the methodological approaches, suggest that rich and valuable data during the sessions may be missed by using standard QoL questionnaires, especially with more severe levels of dementia. Fifteen participants with

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dementia attended the gallery access programme from the community and eight from residential care. Observations during the programme showed that while in the gallery, levels of engagement, animation, and confidence increased, and that participants engaged in discussions about the artwork. The authors report that these effects did not last, so perhaps these positive effects would have been missed if the researchers had chosen to use one of the standardised QoL measures already discussed.

There is a growing interest in the use of art, such as the National Gallery of Australia programme, as a psychosocial intervention for people with dementia. Care providers are increasingly looking for novel ways to improve health and well-being, and deliver quality services across the community. In doing this, they have begun to consider innovative approaches such as involvement in the creative arts, as the recent report 'Creative Homes' (Baring Foundation, 2011) suggests.

In a review of creative therapies for people with dementia (including music, art, drama, and dance therapy) 13 studies were identified (Salisbury, Algar, &Windle, 2011). Many positive effects were found from participation, such as the improvement of interaction skills and people coming to terms with and coping better with dementia. However, overall, the studies were of poor quality in that the art interventions needed further clarification and methods of evaluation needed development and validation. This has been further supported by a systematic review of art therapies and dementia (Beard, 2011) which concludes that the existing evidence lacks adequate study design, with measurement tools (if any) unspecified, emphasising clinical outcomes rather than investigating quality of life, and lacks adequate analysis of the data.

Therefore, to add to the evidence base, research examining the creative arts with people with dementia should measure more than clinical outcomes and look at QoL. In addition, rather than rely on self-report of QoL, observational methods could capture the unique effects the arts might have on the person, such as increasing engagement, activity and social interaction. This may provide additional, rich data beyond self-reported outcome measures. Observation therefore offers another way of evaluating psychosocial interventions rather than QoL questionnaires pre and post intervention. It gives an opportunity for evaluation of QoL within the intervention, as well as pre and post if required.

In dementia care research, observational measures have been used for some time to assess the quality of care the person is receiving. However, as demonstrated by MacPherson et al. (2009), systematic observation also has the capacity to be applied in other settings. An earlier review of observational studies (Brooker, 1995) identifies a number of approaches that could potentially be applied in an intervention study. This early review focussed on observing the quality of institutional care and highlights important behaviours to capture, such as engagement, activity and social interaction. It also introduces Dementia Care Mapping (DCM), which at the time was a new approach to capturing a wide range of behavioural categories based on Kitwood's social psychological theory of person-hood in dementia.

Despite this early contribution, researchers, practitioners or clinicians often have limited literature to consult and inform their choice of the most appropriate observational method and measure that could be applied in a psychosocial intervention setting, especially one involving creative activities. This paper aims to address this need for information. It will review observational approaches that could be applied to psychosocial intervention studies involving creative activities. This will update and augment the evidence provided in the early review by Brooker (1995). Specifically it aims to:

1. Identify and compare the strengths, weaknesses and appropriateness of observational measures for recording the well-being of a person with dementia.

2. Develop research and practice implications and recommendations.

Method

A literature search was conducted using systematic principles of searching, screening and retrieval to identify peer-reviewed English language evaluations of intervention studies using observational measures with people with dementia. The academic databases PsycINFO, Web of Science, CINAHL and ASSIA were searched on 7th July 2012 and again on 22nd May 2013. Combinations of the following terms were used as thesaurus terms or keywords: "dementia", "Alzheimer's", "well-being", "quality of life", "intervention", and "observation". Reference lists were scanned for relevant papers. Discussions were also held with experts in observational methods, websites of known researchers / research centres searched, and where necessary, email correspondence with

researchers exchanged. A search of internet search engines was also conducted. Papers were excluded if they were not in the English language, were not relevant, or were not using observational measures in a research capacity for measuring well-being or quality of life (i.e. were about pain assessment).

Results

2,574 papers were identified using the search terms described above. Removing duplicates and screening titles and abstracts left 43 potential papers. Full text was obtained and a further 15 papers rejected as they did not meet the inclusion criteria. This left 28 eligible papers. In total, eleven observational measures were included for appraisal and seventeen supporting papers included.

Table 2.1 gives an overview and summary of the eleven observational measures found in the search. The authors were unable to obtain the original development papers for two of the measures (INTERACT and QUIS), therefore the supporting papers are used for review purposes. Table 2.2 gives a summary of the psychometric properties of each measure in terms of inter-rater reliability, test-retest reliability and validity. The following also discusses other important factors to consider when choosing a measure, such as training requirements, sensitivity to change and practical considerations.

Table 2.1.

Measure	Purpose of the measure	Domains observed	Observation procedure	Key references
AwareCare	To aid identification of behavioural signs of awareness in people with severe dementia	<i>Events that happen</i> : Someone is nearby; Resident is touched; Resident is spoken to; Talking nearby; Loud noise; Object nearby; Food/drink <i>Introduced events</i> : Call by name; Take hand; Introduce one object (picture, lavender pillow, or textured cushion) ; Or introduce a more personal object <i>Response</i> : Eyes flicker; makes eye contact; explores with eyes; smiles; frowns; nods or shakes head; moves head; reaches; grasps or holds; moves towards; moves away; single words; mumbling; shouts or moans	Five separate 30 minute observations made in communal areas while resident is awake, at different times of day. A record is made of each stimulus that happens in the observation session, and all responses, as well as a note about the setting, the residents' behaviour at the beginning of observation, any changes or events that happen during observation and any other behaviours not covered in the matrix	(Clare et al., 2012)
Behaviour Observation	Developed initially to code behaviour from video of people with dementia during an art gallery visit, and later used to evaluate snoezelen room vs garden	Very engaged, Engaged, Neutral, Disturbed/disengaged	Time sampling for 2 minutes of 5 seconds "on" (watching the participant), 5 seconds "off" (coding previous 5 seconds)	(MacPherson et al., 2009)

An Overview of Observational Measures for People with Dementia
Bradford Well- being Profile	To provide a simpler tool than	Can communicate wants, needs & choices; makes contact with other	Each indicator scored as 0 - no sign, 1 -some signs, 2 - significant signs	(Bruce, 2000)
	DCM to indicate the well-being of a care home resident	people; shows warmth or affection; shows pleasure or enjoyment; alertness, responsiveness; uses remaining abilities; expresses self-creativity; is co-operative or helpful; responds appropriately to people/situations; expresses appropriate emotions; relaxed posture or body language; sense of humour; sense of purpose; signs of self-respect		(Bradford Dementia Group, 2008)
Creative- Expressive Abilities Assessment tool (CEAA)	To record 'in-depth' information about the creative abilities of people with dementia.	27 items related to memory, attention, language, psychosocial, reasoning & problem solving, emotion and culture	Each item is assigned a code to indicate the frequency the behaviour is shown during the creative activity: 0=not observed; 1= Never; 2=Rarely; 3= Sometimes; 4= (nearly) Always Up to four participants can be observed at one time and recorded on one score sheet.	(Gottlieb-Tanaka et al., 2008a). (Gottlieb-Tanaka et al. 2008b) <u>http://www.dementia-activities.com/CEAA/product_deme</u> ntia_assessment_tool.html

Dementia Care Mapping (DCM)	To record the quality of care and quality of life for the person with dementia living in a care setting	(DCM 8) Behavioural Category Codes (BCC – Type of behaviour or activity engaged in): Articulation; Borderline; Cool; Doing for self; Expressive; Food; Going back; Intellectual; Joints; Kum and Go; Leisure; Nod Land Of; Objects; Physical; Religion; Sexual expression; Timalation; Unresponded to; Vocational; Withstanding; Excretion; Yourself; Zero option	Observation of five to eight people continuously for six hours in a communal area. After every 5 minute time frame the observer records two codes- BCC and ME for each participant. The mapper also records when Personal Detractions (PD) or Personal Enhancers (PE) occurs.	(Kitwood & Bredin, 1992)
		Mood/Engagement Code (ME – judgement of affect and engagement): +5 Very positive +3 Considerable signs of positive mood +1 Neutral -1 Small signs of negative mood -3 Considerable signs of negative mood -5 Very negative		
Greater Cincinnati Well- being Observation Tool	To measure seven domains of well- being in people with dementia	Indicators developed for each domain of well-being as derived from Lawton's (1991) conceptualisation: Interest; sustained attention; pleasure; negative affect; sadness; self-esteem and normalcy added	Observations for up to three participants recorded every ten minutes – each indicator scored using scale ranging from 0 (never demonstrates) to 4 (always demonstrates)	(Rentz, 2002) (Kinney & Rentz, 2005)
INTERACT	To measure the effects of Snoezelen on people with dementia	22 items relating to mood, speech, relating to other people, relating to the environment, need for prompting, and stimulation level.	An observer watches video of Snoezelen session and scores each item using 5-point Likert scale ranging from 'not at all' to 'nearly all the time'	(Baker & Dowling, 1995)

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Menorah Park Engagement Scale (MPES)	To quantify the varying levels of engagement during activities	Constructive engagement (CE; any verbal or motor behaviour in response to activity); Passive engagement (PE; listening and/or looking behaviour in response to activity); Non-engagement (NE; staring into space, sleeping or motor/verbal behaviour in response to activity not currently participating in); Self-engagement (SE; motor / verbal / listening and/or looking behaviour while activity not on or when choosing not to participate)	Coding length of time in each type of engagement was exhibited during 10 minute observation windows: 0 = never seen; 1= seen up to half of the activity time; 2= seen over half the activity time.	(Judge et al., 2000)
Observed Emotion Rating Scale (OERS)	To measure the affect of a person with dementia by observing facial expression, tone of voice, and body movements	Pleasure; General alertness; anger; anxiety or fear; sadness	After a ten minute observation, the rater chooses one of six possible time interval codes (7=not in view, 1=never, 2= less than 16 seconds, 3=16-59 seconds, 4= 1-5 minutes, 5= more than 5 minutes)	(Lawton et al., 1996) (Lawton et al., 1999)
Positive Response Schedule for Severe Dementia (PRS)	To evaluate an intervention for people with severe dementia	<i>Engagement</i> : deliberate body movement, deliberate head movement, vocalisation, looks at environment, looks at carer, initiates interaction, engagement <i>Emotion</i> : happy, sad, fear	Suggested continuous observations 20 minutes baseline, 20 minute intervention, 20 minute post intervention. Rated at 20 second intervals, with 10 seconds to record. Only the first instance of behaviour in any one time frame is recorded.	(Perrin, 1997)
Quality of Interaction Scale (QUIS)	To assess the number and quality of interactions between people with dementia and staff in a residential setting.	Positive social; positive care; neutral; negative protective; negative restrictive	Series of ten 15 minute observations across the working day, over a period of approximately two weeks.	(Dean et al.,1993)

Table 2.2.

Summary of the psychometric properties of the observational measures

	Inter rater	Test-Retest	Validity		
AwareCare	Inter-rater reliability consistently high (mean > 0.6) for majority of responses	Data was examined but no kappa value reported	<i>Face Validity</i> : Focus groups were held with care staff, family members and care home managers		
	Response to spontaneous stimuli – Cohen's kappa 0.75. Introduced stimuli – complete agreement that given stimulus occurred		<i>Construct validity:</i> Assessed using correlational analysis in terms of the association with dementia severity, cognitive ability and functional behaviour as the theoretical framework of awareness predicts that a greater severity of dementia would mean fewer signs of awareness. Results showed that participants showing more signs of awareness showed less indications of impairment on the other measures. <i>Concurrent validity:</i> Positive correlations between PRS and AwareCare scores indicated that participants giving more		
			positive responses on the PRS also showed more responsiveness on AwareCare		
Behaviour Observation	Kendall's tau-b = 0.72 (p< 0.01)	Not reported	Not reported		
Bradford Well- being Profile	Not reported	Not reported	Not reported		
CEAA	Kappa values ranged from 0.20 to 0.75. For agreement of total score: Cramer's V score = 0.825 Contingency coefficient = 0.975	Not reported	Not reported		
DCM	Fossey et al. (2002) : A minimum kappa value of <0.8 was established Sloane et al. (2007) : An overall agreement for Behavioural Category Codes of 62% with a kappa of 0.54 (p<0.01)	Considerable well- being: r=0.58, p< 0.0001 Activities: r=0.40, p=0.003 Social withdrawal: r=0.33, p=0.007	Concurrent validity: Fossey et al. (2002): Well-ill being score was strongly correlated with QoL derived from Blau scale ($r=0.73$, $p<0.0001$). Sloane et al. (2007): Question the concurrent validity when they found a higher correlation with proxy than direct QoL assessments.		

Greater Cincinnati Chapter Well- being Observation Tool	Kappa coefficient could not be generated for 50% of observations because of perfect agreement or only one discrepancy. Kappa coefficient for the remaining observations	Not reported but discussion of why not attempted.	Not reported
INTERACT	Mean Pearson's $r=0.83$	Not reported	Not reported
MPES	90% agreement over 25 observation windows	Not reported	<i>Face validity</i> : Extensive discussions were held with activities and nursing staff along with long observations of residents to choose the categories.
OERS	Kappa coefficient ranging from 0.76 to 0.89 in all six affect states	Not reported	<i>Concurrent validity:</i> Shown by comparing scores with ratings of QoL by staff and family members.
PRS	Mean of 80% agreement	Not reported	 Face validity: Recognised by how closely the measure is linked to the phenomena being investigated Construct validity: Said to be shown by the theories that the measure is rooted in- engagement theory in 7 items, and theory of non-verbal expression of emotion in 3 items. Concurrent validity: Acknowledged but lack of measures to compare with
QUIS	Observation and coding consistently produce Kappa coefficients of above 0.75	Not reported	<i>Concurrent validity</i> : Ratings of increased quality and quantity of interactions were associated with "improvements in ratings of residents' cognitive impairment, observed depression and functional capacities" (p.824).

Inter-rater reliability

Inter-rater reliability can be defined as the reproducibility of the scores between multiple raters (Kline, 1979). Cohen's kappa is most commonly used to report inter-rater reliability and refers to the proportion of responses that both raters agree (Streiner & Norman, 2003). Altman (1991) suggests the following guidelines by which the value of kappa indicates the strength of agreement (p.404): Poor < 0.20; Fair, 0.21 - 0.40; Moderate, 0.41-0.60; Good,

0.61- 0.80; Very good, 0.81- 1.00. All but one of the identified measures (Bradford Well-Being Profile) report inter-rater reliability statistics. Five of the remaining ten measures (AwareCare, DCM, Greater Cincinnati Chapter Well-Being Observation Tool, OERS, & QUIS) report Cohen's kappa coefficient, ranging from 0.54 to 0.89, which according to Altman, indicates that they all show moderate to very good inter-rater reliability.

As shown in Table 2.2, the highest inter-rater reliability was demonstrated in the OERS which indicated good to very good agreement.

The QUIS and AwareCare are both reported to have a Cohen's kappa of 0.75 or above, showing good inter-rater reliability. In AwareCare, inter-rater reliability was calculated by both researchers observing 12 participants, three from each participating home, at the same time on five occasions (Clare, et al., 2012)

In the Greater Cincinnati Chapter Well-Being Observation Tool, inter-rater reliability was measured by having two trainers observe the same five participants during three Memories in the Making© sessions and three other activities sessions. Despite the fact a kappa coefficient could not be generated for 50% of the observations because of perfect agreement, or only one discrepancy, a good inter-rater reliability was found for the remaining observations (Kinney & Rentz, 2005).

Various inter-rater reliability scores were found for DCM. In a paper establishing the psychometric properties of DCM (Fossey et al., 2002), in Cohort A, a good to very good inter-rater reliability was established between individual raters during pilot mapping sessions. However, in discussing DCM as a research tool, a moderate inter-rater reliability was reported (Sloane et. al 2007). When validating DCM8, Brooker and Surr (2006) report that an inter-rater reliability concordance of 70% was established between the mappers in their study.

Inter-rater reliability is reported in the remaining five measures in a number of ways. The Behaviour Observation in MacPherson et al., (2009) reports acceptable inter-rater reliability as using Kendall's tau-b. The CEAA reports kappa values ranging from poor to moderate inter-rater reliability but also boasts good agreement on total scores using Cramer's V score and contingency coefficient (Gottlieb-Tanaka et al., 2008a). The INTERACT scale reports good inter-rater reliability found when two observers were blinded to the group (control or intervention), and watched the videos twice before scoring (van Weert, van Dulmen, Spreeuwenberg, Ribbe, & Bensing, 2005).

The remaining two measures, the MPES, and the PRS, report inter-rater reliability as a percentage. 90% agreement over 25 observation windows was reported in the MPES (Judge, Camp, & Orsulic-Jeras, 2000), and consistent average inter-rater reliability of 80% was shown in the development of the PRS (Perrin, 1997). However, Hadley, Brown and Smith (1999) achieved inter-rater reliability of at least 99%.

Despite the inconsistency in the way it is reported, all of the measures reporting inter-rater reliability show good agreement.

Test- Retest Reliability

Test-retest reliability can be defined as the reliability of a measure when used or administered on two occasions separated by a short interval of time. The recommended interval of time is dependent on the type of measure, but between two and fourteen days is suggested (Streiner & Norman, 2003).

Test-retest presents challenges when applied to people with dementia, as the behaviour of a person with dementia can vary greatly from hour to hour, day to day. Even if two observations are done at exactly the same time on the same day of the week, a week apart, there are many other factors that could affect behaviour, which presents difficulties in interpreting these statistics. Discussing why they did not attempt to measure test-retest reliability, Kinney and Rentz (2005) note it was due to "the inherent variability in the behaviour of individuals with dementia" (p.222). As such, test-retest reliability is only reported for two of the measures (AwareCare and DCM).

Clare et al., (2012) examined test-retest reliability during the development of the AwareCare tool, comparing two observations. The fifth observation was carried out at the same time of day, a week later than the fourth observation, so that a direct comparison could be made. Data from all 40 of the participants were examined as to the number of times each stimulus was present at each time point, and the number of times that the stimulus elicited the same response in both sessions. They found considerable variability and do not report a Cohen's kappa value. Echoing Kinney and Rentz's (2005) view, the authors comment that the test-retest was affected by the naturally occurring variation across different observations despite being held at the same time of day.

Test-retest reliability is also reported for DCM (Fossey et al., 2002). They measure the test-retest reliability by determining the correlations between the key DCM indices using Spearman's *r*. They report a good level of test-retest agreement for considerable wellbeing, and a more moderate correlation for Activities and Social withdrawal.

Although considered a good indicator of reliability for quantitative measures, test-retest reliability may be less useful in assessing the quality of an observational measure, especially with people with dementia.

Validity

Validity refers to how accurately a measure or test measures what it actually aims to measure (Kline, 1979). There are several types of validity and some are discussed below. The extent to which the measures are validated varies. The Bradford Well-being Profile is not validated.

Face validity is addressed in three of the measures – AwareCare, MPES, and the PRS. This is a measure of whether the test seems to measure what it is intended to. Both AwareCare and MPES address face validity by involving care staff in the development of the measure. In AwareCare, the authors recognise that some of the items with lower kappa values were kept due to the importance placed by staff in the focus groups (Clare et al., 2012).

Construct validity refers to what extent items of a measure represent the construct it claims to measure and relates to other measures in a manner that is consistent with theoretically derived hypotheses (Terwee et al., 2007). It is addressed in two measures – AwareCare and the PRS.

Content validity refers to the extent to which a measure represents all facets of the construct it is designed to cover (Terwee et al., 2007). Although not expressly addressed, content validity is evident in three of the measures (DCM, Greater Cincinnati Chapter Well-Being Observation Tool, & OERS) due to their strong correlation with theoretical constructs. DCM was grounded in Kitwood's theory of personhood and person-centred care and the Greater Cincinnati Chapter Well-Being Observation Tool and person-centred using Lawton's (1991) domains of QoL. Lawton's own measure, OERS is rooted in his (1983) dual-channel hypothesis. This suggests that positive affect is related to engagement in an external event such as a recreational activity, whereas negative affect is related to

internal phenomena such as a memory or thought. In developing the OERS, Lawton was trying to test his hypothesis that affect is a result of antecedent events.

Concurrent validity shows the extent to which scores accurately estimate an individual's current state and can be measured by comparing scores with similar measures. This is addressed in five of the measures – AwareCare, DCM, OERS, PRS, and QUIS.

During the development of the PRS, Perrin suggests that there is no way to establish concurrent validity due to the lack of measures to compare with as the PRS was developed in recognition that the DCM was not sensitive enough to pick up subtle changes shown in people with severe dementia. The PRS was, however, a good measure to compare with AwareCare when it was developed.

Although not stated as concurrent validity, authors suggest that evidence of validity of the QUIS can be shown by comparison with other outcome measures (Dean, Proudfoot, & Lindesay, 1993).

An inspection of the extent to which the measures are validated demonstrates that AwareCare is the only measure to address face, construct and concurrent validity.

Performance of observation measures in previous intervention studies / Sensitivity to change

AwareCare: Although this tool has proved successful in showing changes in behavioural responses by people with severe dementia, it was developed to aid the training of staff to observe responses from residents rather than as a tool for data collection. The authors state it has potential as a research tool, but as yet this has not been tested.

Behaviour Observation: The Behaviour Observation was used when evaluating the effects of taking PwD around the National Gallery of Australia (NGA) to discuss artworks (MacPherson et al., 2009). There were fifteen PwD from the community, and eight from residential care in the group. The group sessions were videoed and week 1 and week 5 rated by two independent observers to show changes over time. The two raters coded participant behaviour separately and then arrived at a consensus of definitions for the range of behaviours indicating affect. The results showed a high engagement from the beginning. In week one, eighty four per cent of the observations fell into the engaged or highly engaged category. There was a significant increase in the number of highly engaged observations among the participants in residential care between week 1 and week 5. It was also used live in real time, as opposed to making observations from a video, to investigate the effectiveness of a Snoezelen room in residential care. Although no significant difference was shown between the Snoezelen room and the other condition (being in the garden), there are many possible reasons given for this, and does not seem to reflect on the sensitivity of the measure (Anderson, Bird, MacPherson, McDonough, & Davis, 2011).

Bradford Well-being Profile: Despite a suggestion that the tool could be used to evaluate the impact of the interventions (Bruce, 2000), it was not found in any peer-reviewed research articles.

CEAA: The user guide suggests that the tool is useful for researchers to answer questions such as effectiveness of one creative activity compared to another in increasing expressive abilities and QoL, the most effective intensity of a programme, and whether a programme is suitable for people with different stages of dementia. However, the searches for this paper found no peer-reviewed journal article using the CEAA.

DCM: Although originally developed as a way of assessing the quality of care, DCM has increasingly become a tool used in research, including for the evaluation of an intervention. In a review of published DCM literature, ten articles were found using DCM to evaluate the impact of different interventions on the person with dementia (Brooker, 2005). Brooker and Duce (2000) use the Well and Ill-Being (WIB) value to compare the well-being of 25 PwD in three different activities - group reminiscence therapy, structured goal-directed group activity, and unstructured time. Researchers used the WIB value as indicators of well-being in each activity. A significant difference was shown between the activities with higher levels of well-being shown in the reminiscence therapy. The authors conclude that DCM was sensitive enough to discriminate between the different activity with this client group' (p.358). Brooker (2005) also concludes her review of DCM in research saying that the measure is suited to smaller studies of within-subjects evaluations of comparisons of group interventions as it has demonstrated the ability to discriminate between various interventions.

The Greater Cincinnati Chapter Well-Being Observation Tool: This tool was developed and piloted to evaluate 'Memories in the Making[©] (MIM), an arts programme for PwD led by an artist facilitator to encourage self-expressions through the visual arts (Rentz, 2002).

Participants exhibited a significantly higher proportion of time in five of the seven wellbeing domains in the art session compared to the other activity. These domains were interest, sustained attention, pleasure, self-esteem, and normalcy. The study showed that the tool was suitable to assess the well-being of PwD, and that it showed differences in well-being within and between the two types of activities in which the participants were observed (Kinney & Rentz, 2005). Another recent study used the Greater Cincinnati Chapter Well-Being Observation Tool to evaluate whether well-being was affected beyond the MIM sessions (Gross, Danilova, Vandehey, & Diekoff, 2013). Seventy-six residents from four long term care facilities took part in a 12 week MIM programme. Interns rated participants within the sessions in weeks one, six and twelve, and staff from the long term care facility rated participants outside of the session "on or about each of the same days as the interns...at times that were convenient to them" (p.8). Despite questioning the psychometric properties of the tool itself, they found that participants showed significant improvements over time within the sessions in the same domains as reported in the previous evaluation by Kinney and Rentz (2005). They did not find any significant changes on any of the domains on ratings made outside of the MIM sessions. However, methodological flaws such as not having the same rater inside and outside of sessions, as well as ratings outside of sessions being made at inconsistent times, could put these results into question.

INTERACT: A study investigating the effect *Snoezelen*, or Multi Sensory Stimulation (MSS), integrated into 24 hour care, had on mood and behaviour of PwD living in a residential setting used video recordings of morning care and analysed them using the INTERACT scale (van Weert, et al., 2005). Results demonstrated that the group receiving the intervention showed

'more happiness and enjoyment, related better to the CNA [Certified Nursing Assistants], were more responsive to speaking, and talked more frequently with normal length sentences than the control group. They were also in a better mood and showed less sadness, bored and inactive behaviour, negativism, and reluctance' (p.30).

MPES: The MPES was developed to evaluate the effects on engagement during Montessori-based activities for people with dementia in adult day care compared with regular activities (Judge et al., 2000). A significant increase of Constructive Engagement was found during Montessori-based activities compared with regular activities. Low numbers of observations in the domains of Self-Engagement and Non-Engagement meant that they were not formally analysed. However it was noted that there were no instances of these two categories at all during the Montessori based activities. The MPES was also used in a similar study comparing Montessori based activities with regular activities (Jarrot, Gozali, & Gigliotti, 2008). Again, participants showed more Constructive Engagement in the Montessori based activities, demonstrating the sensitivity of the measure between different activities.

OERS: The OERS is a well-used observational tool. It is one of the outcome measures used in an evaluation of Time*Slips*, a storytelling programme for PwD (Phillips, Reid-Arndt, & Pak, 2010). The intervention group were observed during the programme and the control group during meal time. Analysis showed that people in the intervention group had significantly higher pleasure than the control group. However, the authors note that four of the categories, anxiety, sadness, anger, and general alertness, were not analysed due to extreme sparseness in distribution as not many people showed these features. This suggests that perhaps the categories are not sensitive enough or too broad.

PRS: Hadley et al. (1999) evaluated individualised interventions for people with severe dementia using the PRS. As the PRS is relatively labour intensive, they undertook two case studies to determine whether the results from the tool could justify using it in a larger scale study. They conclude that the PRS showed more behaviours than DCM. However, they do comment that they found difficulty in differentiating between some of the categories, for example between 'deliberate head movement' and 'looks at environment'.

QUIS: The QUIS was used in an evaluation of two residential units for older people with dementia (Dean, Briggs, & Lindesay, 1993). Observations were made at baseline while the participants were in long-stay dementia wards, and at 3, 6, and 12 months once they had moved to a domus unit. Domus units were developed to replace traditional long-stay institutions for people with dementia and followed the philosophy that it was a home for life, staff and resident needs were equally important, all aspects of dementia were accommodated, and that caring for psychological and emotional needs may be as or more important than physical needs (Dean, Proudfoot, & Lindesay, 1993). An increase of positive interactions was shown from 49.3% on the long stay ward to 99.2% in the domus unit twelve months later. This demonstrates the tool is sensitive enough to show the

changes from poor to good care. However, with such a high level of positive interactions recorded in the domus unit, the tool would no longer be able to show any improvements due to a ceiling effect, with no scope possible for further improvement.

Training requirements

Training requirements vary from measure to measure. For five of the measures (Behaviour Observation, INTERACT, MPES, PRS & QUIS) there is no formal training, but all mention the importance of inter-rater reliability, so it would be assumed that anyone intending to use the measure should practice until they achieve good inter-rater reliability.

A discussion of training is not mentioned in the development of the AwareCare tool, but they do state that the next stage of the project would include training sessions for care staff². The tool is freely available on the internet (<u>http://reach.bangor.ac.uk/AwareCare.pdf</u>) with guidelines on how to use it.

No formal training was found for the Bradford Well-being Profile, but the measure comes with guidelines and instructions of how to use it, and it is suggested that training is given to anyone using it.

The CEAA is copyrighted and can be purchased from a website (<u>http://www.dementia-activities.com/CEAA/product_dementia_assessment_tool.html</u>). The tool comes with a user guide and two training DVDs.

To be able to use the DCM, training from a Bradford Dementia Group approved trainer is essential. The Bradford Dementia Group provide an intensive four day course which ends in a formal exam where a pass mark of over 60% is required to be able to go on to use DCM in practice. They also offer a one-day update for those who don't use the tool regularly and need refreshing. Costs and availability can be found on their website.

The Greater Cincinnati Chapter Well-Being Observation Tool can be requested from the second author, Clarissa Rentz. The authors note that although there are detailed operational definitions for each indicator of well-being that were easily interpreted, quite a lot of training was needed for observers to be able to accurately estimate the extent to which

² This is now published: Clare, L., Whitaker, R., Woods, R.T., Quinn, C., Jelley, H., Hoare, Z., Woods, J., Downs, M., & Wilson, B.A. (2013). AwareCare: a pilot randomized controlled trial of an awareness-based staff training intervention to improve quality of life for residents with severe dementia in long-term care settings. International Psychogeriatrics, 25, 128-139. doi: 10.1017/S1041610212001226

participants showed each indicator. In other words, training was needed in deciding between the different categories on the 5-point Likert scale (Kinney & Rentz, 2005).

In the development of the OERS, a month of training was provided to the observers, including a discussion of emotions and how they manifest and watching a video showing facial expressions. Informal rating sessions then took place with a formal test of inter-rater reliability before study data began. Although the scale is now freely available online (from www.abramsoncenter.org/PRI), by the request of Lawton himself, it is suggested those wishing to use the scale watch a training video developed by the Philadelphia Geriatric Center (Lawton et al., 1999).

Practical Considerations

There are some practical issues worth considering when deciding which observational measure is most suited for an intervention. In particular, the number of people that can be observed in one sitting will determine how long is needed to capture data for every participant, and also how many raters are needed. Not all of the measures report this. Of those that do, DCM reports that between five and eight people can be observed at once; the CEAA suggests up to four participants, and the Greater Cincinnati Chapter Well-Being Observation Tool suggests up to three participants are observed at once. This needs to be considered along with the suggested observation window. For example, DCM is continuous observation for six hours, whereas the MPES and OERS are done in 10 minute observations. Another consideration is whether the observations will be done in vivo or from a video. The Behaviour Observation and INTERACT measures both report that the observations were made from a video. This has the advantage that inter-rater reliability can be more easily determined as it can be assumed that raters are watching exactly the same footage at the exact time. However, relying solely on video footage could lead to data being missed due to technical problems, or even simple things such as someone sitting in front of the camera and blocking the view of other participants. Observing in vivo also has advantages and disadvantages to consider. For example, observing in vivo enables the researcher to move position if their line of vision is blocked. However, issues with maintaining validity and reliability can occur and the observer can impact the behaviour of those being observed.

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Discussion

This review responds to the apparent gap in resources for researchers wishing to choose a suitable measure to record the well-being of people with dementia during a psychosocial intervention. Eleven observational measures were identified. A review of psychometric properties, as well as sensitivity to change, training requirements, and practical considerations has revealed strengths and weaknesses for each measure. Out of all of the measures discussed, the AwareCare tool is the only measure to have reported all aspects of validity and reliability, but has yet to have been used in a peer-reviewed intervention study due to being relatively new.

Two of the measures have been developed to be most suited for use with people with severe dementia. The PRS has been reported to be effective in showing the effects of interventions for people with severe dementia. However, it does seem that a lot of the engagement items depend on the physical abilities of the participant which could affect results. This leads to the AwareCare tool that has already shown to have good inter-rater reliability and validity. Although it was developed to give care staff a tool to aid the identification of behavioural signs of awareness in people with severe dementia, the authors suggest it could be used as a research tool. Although it is measuring awareness, and not engagement, perhaps the responses could be useful in indicating engagement in people with severe dementia, and it may be useful in an intervention setting.

When considering a psychosocial intervention for people with dementia, these two measures would probably be most suited in a one-to-one setting with people with severe dementia, or if in a group setting, it should only have people with severe dementia. If used in a group setting with participants with mixed abilities, a ceiling effect could be shown for some of the more able participants. Although appropriate for people with severe dementia, neither tool seems to cover as many aspects of QoL for evaluating a visual art programme as some of the other measures.

Of the remaining measures, the QUIS is less suited for evaluating a psychosocial intervention. The QUIS has been adapted by David Sheard (2008) and published by the Alzheimer's Society as an evaluation tool to 'capture through observation the lived experience of PwD living or spending time in a care setting' (p.2). The time sampling

method has been changed to every five minutes for a minimum of 2 hours. On top of this, a 'script' is written to record any quotes or notes of experiences that fall outside of the coding. This version of the QUIS seems to give a less labour intensive alternative to DCM.

Although the QUIS has been shown as a good tool for assessing the care people are receiving in a residential setting, and an alternative to DCM, it seems less suited to assessing an intervention. It could be argued that the interactions recorded could be with the facilitator, rather than with care staff, but work to adapt the scale would be needed to make it more suitable for an intervention, and in turn for any creative activities. For example, the definitions of positive care and negative protective items might need to be changed to relate to the intervention rather than the care they are receiving.

DCM was the method of observation most commonly adopted in the papers identified in the searches. It should be noted, however, that caution is needed when reporting reliability and validity scores of DCM, as DCM 8 replaced the 7th version in 2005, and the majority of studies reporting these figures are likely to have used DCM 7. However, Brooker and Surr (2006) compared concurrent validity between DCM 7 and DCM8 and a Pearson correlation coefficient of 0.97 (p<0.0001) was calculated between the individual WIB scores on DCM 7 and 8. They concluded that it can be assumed that the validation of DM8 against other measures of quality of life and quality of care would be similar. They state that this would, however, need to be empirically tested, along with tests of inter-rater reliability, test-retest reliability and internal consistency.

DCM gives a wealth of data and has been shown to be sensitive to changes in QoL within as well as between different activities. It has the advantage that five to eight participants can be observed at a time, compared with other measures where only one participant is observed at a time. However, it is the most time consuming and most expensive measure to train in. A shorter version developed for use in research might make it more suitable in a psychosocial intervention.

The Bradford Well-Being Profile was developed as it was felt that something was needed that did not require such an extensive input of time and resources as the DCM and that could provide an indication of the well-being of care home residents. However, although psychometric testing of the well-being indicators in a previous version did meet validity criteria, the authors advise caution in interpreting them. They state that "the tests of validity conventionally used depend on making mathematical assumptions that may well be unfounded when measuring psychological attributes like well-being" (p.24, Bradford Dementia Group, 2008). They also state that as a psychological attribute, well-being is not something that can be accurately measured meaning issues of inter-rater reliability challenge the validity (Bradford Dementia Group, 2008). For this reason, they removed the scoring system. This means that the newest version of the profile is more of a qualitative tool (Bradford Dementia Group, 2008). The guidelines state that the profile is not suited to be used as an outcome measure for changes in affect during an intervention. Therefore, unless the earlier version was used, this tool is no longer a suitable option for use in a psychosocial intervention.

Behavioural Observation, INTERACT, MPES, and OERS have all been used in evaluations of psychosocial interventions previously, suggesting that they are suitable. The Behavioural Observation was used during an art gallery visit for people with dementia, INTERACT in evaluating Snoezelen, the MPES in evaluating Montessori-based activities, and the OERS for the evaluation of Time*Slips*.

The Behavioural Observation was done from video after the event. This provides an easy way to measure inter-rater reliability as each independent rater can be shown exactly the same clip. However, it is more time consuming to rate after the event and relies on the video. Technical issues could mean a loss of data which may not be detected until after the observational period. However, the same measure was used for live observations to evaluate Snoezelen rooms and no critique was given to suggest that this caused any problems.

It was noted that the categories in the Behaviour Observation were similar to those of the MPES, although they were conceived independently. The MPES has been shown to be sensitive enough to discriminate between activities, and could translate well to a visual arts intervention.

The INTERACT measure also is rated from video. The authors noted that they would change the scoring system of the INTERACT for future studies as a sum score is not given, and they felt that item-by-item analysis could increase the risk of false positive results (van Weert et al., 2005). They propose a scale consisting of 'multi-item subscales measuring the same domains' (p.32). This same critique is also mentioned in another study

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using the INTERACT scale to investigate the physiological and behavioural effects of *Snoezelen* (van Diepen et al., 2002). Despite this, the INTERACT scale seems suitable to be used to evaluate an intervention. Using video recordings means that a more in depth observation can be made. The only reservation one might have is that by analysing the video content after the sessions, it is doubling the time needed. At 22 items, the scale seems too detailed to be able to be used in live observation, if more than one resident is being observed at one time.

As already suggested, the categories in the OERS may not be sensitive enough or are too broad, as four of the six affect states weren't often present. Nevertheless, it is a well-used tool. Another limitation of the scale compared to others is the fact that observations are only made of affect which may be too limiting, a feeling echoed by Fossey et al. (2002) when compared to DCM.

The CEAA was developed with a creative activity in mind and seems simpler to use than some of the other measures. It seems suitable to evaluate the QoL of people with dementia during a psychosocial intervention. However, the measure only gives a broad over-view of the session, rather than time-sampling, for example, so some of the detail might be lost.

The Greater Cincinnati Chapter Well-Being Observation Tool also has the advantage that it was specifically developed for a visual arts programme, but could be used for any psychosocial intervention as shown by it being sensitive to changes within and between different activities.

A recent study critiques the psychometric properties of the Greater Cincinnati Chapter Well-Being Observation Tool (Gross et al., 2013), and perhaps rightly so as it is the first peer-reviewed study to use the tool since development. However, it should be noted that the study itself seems to show some methodological flaws itself. Only one overall rating is made by interns within the MIM session, rather than several ratings made in ten minute observation windows as intended in the development of the tool. It is unclear whether those making the ratings were the same interns who were facilitating the sessions, meaning that they could be preoccupied by running the session rather than observing the participants. Ratings were then made by staff at the long-term residential facility outside of the sessions "on or about each of the same days as the interns…at times that were convenient to them" (p.8, Gross, et al., 2013) implying an inconsistency of time of day that the ratings are made.

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A change in the scoring system of the Greater Cincinnati Chapter Well-Being Observation Tool could combat the limitation mentioned in the discussion of training requirements. As the operational definitions are clear, but the extent to which people display each item is more difficult to rate, a change to time sampling whereby each participant is measured for a minute every 8 minutes could simplify it and make the measure more user-friendly.

This tool has the advantage in that it was specifically developed for a visual art intervention. It also seems to give a detailed picture of how the person with dementia experiences the art sessions.

Each observational tool has its own strengths as has been demonstrated in the above review. Most have been shown to have good inter-rater reliability, be rooted in theory, and are able to show differences in behaviours within and outside of interventions. None are more detailed than DCM, which seems to have set the standard. However, it is also the most labour intensive and most expensive for training. The PRS and AwareCare tools are sensitive when used for people with severe dementia, but might not be so suitable for a group of mixed ability. The QUIS seems more suited for evaluation of care practices, rather than in evaluating an intervention.

The OERS is a well-used measure but the categories seem a little limited for the rich data that are expected in an evaluation of art sessions. Video recording seems a good option as it means that the data can be analysed without the restriction of predetermined categories, although the resulting Behaviour Observation was noted to be very similar to the already existing MPES. However, using video also doubles the time needed as coding is done at a later date rather than being done in the session. It also opens up the possibility to data being lost without realising until after the session.

The CEAA and Greater Cincinnati Chapter Well-being Observation Tool were developed with a visual art session in mind and the Greater Cincinnati Chapter Well-Being Observation Tool has been shown to be sensitive enough to show differences within sessions and between activities. However, whereas the CEAA gives more of an overview of the session, the Greater Cincinnati Chapter Well-Being Observation Tool gives more detail. It is likely to be a good choice for an arts based evaluation.

It would also seem that a combination of observation in real time coupled with a video recording would be the best solution. This way, the video recordings can be a back-up if

any data is missed within a session, and inter-rater reliability can be assessed without the need of a second rater within the session, and without the entire onus being on analysis after the event.

Conclusion

No observational measure will capture all of the rich data demonstrated within a visual art intervention. Brooker (2008) suggests that qualitative interviews and observational measures used together complement each other. Therefore, as well as using observational tools to provide quantitative data, it is also advisable to include qualitative interviews with participants, care staff, and practitioners/those delivering the intervention to gain a detailed understanding through complimentary methodological perspectives.

This review indicates that based on current research to date, the Greater Cincinnati Chapter Well-Being Observation Tool may be the most appropriate measure to evaluate a psychosocial intervention, and in particular, a visual art programme. Videoing the sessions would add to best practice to help achieve the best assessment of well-being of people with dementia in an art session.

Chapter 3: An exploratory study to determine the suitability of an observational tool for evaluating a visual art intervention for care home residents with dementia

Summary

Uncertainty exists as to how best to evaluate art interventions with people with dementia. This study aimed to determine how suitable an adapted observation measure was in evaluating the impact of a visual art programme on quality of life and well-being of care home residents with dementia compared with an alternate structured activity and unstructured time. A visual art intervention was run in two North Wales care homes for people with dementia. Sixteen participants were observed using an adapted version of the Greater Cincinnati Chapter Well-Being Observation Tool during three conditions; the art intervention, another structured activity, and unstructured time. Participants also completed quality of life and mood questionnaires before and after the intervention. The results showed that the tool was sensitive to change, showed a relationship with secondary measures, and was suitable for providing a rigorous evaluation of a visual art intervention compared with another structured activity and unstructured time. Greater observed wellbeing in the art intervention was found especially in comparison with the unstructured time. Observed pleasure increased significantly over time in the arts sessions, but did not change in the alternate or unstructured activity. Improved communication and a trend to improvement in quality of life after attending the art intervention were also found. The results from this exploratory study have demonstrated an observational measure may quantify the benefits that have been noted anecdotally for many years during visual arts activities, but the added value of arts activities over other structured activities remains to be established. The study also suggests that attending a visual art intervention may be associated with an increase in communication and quality of life in care home residents with dementia.

As previously suggested, the focus of this chapter shifted from primarily an evaluation of the impact of a visual art intervention versus two control conditions to testing the suitability of the measure suggested in Chapter 2. This was because during a pilot of the measure, it was felt that adaptations were needed to the scoring. Rather than judging the proportion of time that a participant demonstrated each indicator of well-being over a period of ten minutes, it was made simpler by reporting whether or not the relevant domain of well-being was observed. Although the data collection phase remained the same, additional considerations in the analysis were required to test the relationship with the secondary measures. The positive results in both the observation measure and pre and post quality of life questionnaire were unexpected as the researcher had anticipated the results

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to prove that observing the momentary experience would be the most effective way to evidence the benefits of the intervention.

Introduction

"Arts and culture engagement has been linked directly with better subjective wellbeing" (The All Party Parliamentary Group on Wellbeing Economics, 2014; p.37). The applicability of this generic assertion to the situation of people with dementia is now the focus of much interest. A wealth of research has shown that a range of nonpharmacological interventions can increase well-being and quality of life (QoL) of people with dementia (Olazáran et al., 2010) and engagement with art is increasing in prominence as a psychosocial intervention for people with dementia. Reports such as 'Creative Homes' (Baring Foundation, 2011) suggest that care providers are looking for new ways to improve health and well-being, including innovative approaches such as involvement in the creative arts.

With the increase in interest in creative arts with people with dementia, it is important that definitions are made clear. A review of participatory arts with older people (Mental Health Foundation, 2011) recognises that terms used to describe art activities are often inappropriately used interchangeably. Art therapy is a form of psychotherapy whereby the art is a tool to communicate emotions or memories and can only be practiced by qualified art therapists regulated by professional standards (British Association of Art Therapists, 2014). In contrast, the current study concerns arts engagement, or participatory arts, led by artist facilitators, associated more with Arts in Health approaches. Arts in Health are defined as "arts-based activities that aim to improve individual and community health and healthcare delivery, and which enhance the healthcare environment by providing artwork or performances" and specifically to promote the health and well-being of communities and create improved environments within healthcare settings (Arts Council England, 2007) to improve general well-being, as referred to above.

There are some notable participatory art programmes which are beginning to indicate the potential benefits for people living with dementia and their carers. Some invite participants to make their own art such as the visual art programme developed by the Alzheimer's Association in the USA, Memories in the Making (MIM) (Rentz, 2002; Kinney & Rentz, 2005; Gross, Danilova, Vandehey & Diekoff, 2013). Other art programmes are specifically for viewing art, sometimes based in an art gallery, such as 'Meet me at MoMA' (Mittleman & Epstein, 2009) and an art gallery access pilot programme at the National Gallery of Australia (MacPherson et al. , 2009). Some incorporate both art viewing and art

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participation such as art programmes run in Dulwich Picture Gallery (Eekelaar, Camic, & Springham, 2012) and Nottingham Contemporary (Camic, Tischler & Pearman, 2014). Evaluations of these art programmes are beginning to address the question of whether visual arts can benefit people with dementia with findings such as improvements in cognitive capabilities, interest, sustained attention, pleasure, self-esteem, confidence, mood, and enjoyment (Camic et al., 2014; Eekelaar, et al., 2012; Gross et al., 2013; Kinney & Rentz, 2005; MacPherson et al., 2009, Mittleman & Epstein, 2009). However, this promising area of arts and health is compromised with some methodological challenges which this research aims to address.

Methodological issues

A number of recent reviews of participatory art and art therapies with people with dementia have concluded that the existing evidence lacks adequate study design with unspecified measurement tools, clinical outcomes are emphasised rather than quality of life, and there is a lack of adequate analysis of the data (Mental Health Foundation, 2011; Beard, 2011; Castora-Binkley, Noekler, Prohaska, & Satariano, 2010). These reviews recommended that more funding should be provided for evaluating projects, and that better quality research was needed. A review of findings from systematic reviews of pharmacologic, psychosocial, and cultural art interventions for people with dementia states that these methodological weaknesses mean that many individual studies of art interventions with people with dementia are excluded from systematic reviews (de Medeiros & Basting, 2013). Although they may indicate positive outcomes for people with dementia, they do not provide sufficiently strong evidence for inclusion in reviews informing evidence-based guidelines and commissioning. However, it is worth noting that several useful studies do exist (Camic et al., 2014; Eekelaar et al., 2012; Kinney & Rentz, 2005; MacPherson et al., 2009; Rentz, 2002). Although their designs are either exploratory or evaluations of existing services, they suggest useful methodological approaches for capturing the impact of creative activity on the quality of life and well-being of people with dementia. This study aims to build on this work.

Most clinical trials try to demonstrate a lasting effect of the drug or other intervention by evaluating changes between pre and post intervention measures. However, those undertaking previous research query whether this approach is suitable for art interventions in dementia care. Camic et al. (2014) aimed to examine the impact of a gallery-based art

intervention on carer burden, quality of life of the participant with dementia, and activities of daily living, using validated measures pre and post the intervention. No significant changes were found. However, thematic analysis of semi-structured interviews with the participants with dementia and family carers revealed positive results such as improved quality of life, enhanced cognitive abilities, and feeling more socially included. This discrepancy could suggest that traditional quality of life measures pre and post intervention are not appropriate for capturing the benefits of art interventions with people with dementia.

MacPherson et al. (2009) used observation to obtain data from people with varying levels of impairment. An important aspect of this study was they included people with severe impairment, who are often excluded from dementia research. They found that the benefits for the participants in their gallery viewing programme were only 'in the moment'. They argued that regardless of whether any lasting effects were shown, the increased enjoyment during the participants' time in the intervention meant that the intervention had showed a positive effect. Therefore, observing participants during the intervention itself could be a useful approach to some of the methodological challenges. Researchers could then capture the momentary experience during the sessions themselves, described as "a transformative experience" for people with dementia (de Medeiros & Basting, 2013, p.7).

The review in Chapter 2 concluded that the Greater Cincinnati Chapter Well-Being Observation Tool developed by Kinney & Rentz (2005) was suitable for measuring wellbeing during and outside of a visual art programme (Algar, Woods & Windle, 2014). The tool was developed using Lawton's framework of psychological well-being (Lawton, 1994) to assess engagement and affect. The observer rates the extent to which a person with dementia has shown each of 7 domains during a specified time period (Interest, Sustained attention, Pleasure, Negative affect, Sadness, Self-esteem, and Normalcy) using a 5 point Likert scale (4= Always, 0= Never) (Kinney & Rentz, 2005; Rentz, 2002). Up to 3 participants are observed at the same time in 10 minute observation periods during the session. Therefore, each data point represents a proportion of time that a participant demonstrated each indicator of a domain of well-being.

The tool was used to compare levels of well-being of people with dementia during participation in MIM and in another structured activity. The measure was deemed suitable for showing differences in the seven domains of well-being within and between activities

and they found that participants showed significantly more Interest, Sustained Attention, Pleasure, Self Esteem, and Normalcy in the MIM sessions (Kinney & Rentz, 2005).

The developers of the measure discussed a limitation of the tool in terms of the scoring. The operational definitions and indicators for the domains of well-being were found clear but a difficulty was noted in rating the extent to which each was being demonstrated. Therefore the 5-point scale could be criticised for being subjective. To address these issues the tool was adapted for the current study after a pilot phase during a community visual art programme for people with dementia and their carers. This study aims to adapt and test the suitability of the adapted version of the Greater Cincinnati Chapter Well-Being Observation Tool, and to look at the relationship of the results with results from traditional outcome measures.

Another methodological issue worth noting in regards to the evaluation of visual art interventions is the lack of a control condition in previous studies. Kinney and Rentz (2005) and Gross et al. (2013) use a within subjects design, measuring their participants both in the art session, and either in another activity (Kinney & Rentz, 2005), or outside of the session in the participants' own care facility (Gross et al., 2013). However, Kinney and Rentz reported limitations with their 'other activity' as observations were always made after the Memories in the Making session, meaning that participants could have shown fatigue. The observations outside of the sessions in Gross et al.'s (2013) study were made 'on or around the same day' of the art activity and by different observers which may have influenced the results obtained. Therefore, a study is needed with well-defined control conditions where observations are made in an 'other structured activity' on a different day to the art intervention, and by the same observer.

Aim of present study

The aim of this exploratory study is to respond to the need to re-think evaluation techniques of art interventions with people with dementia by answering the research question:

- Is an adapted observation measure suitable for evaluating a visual art programme for care home residents with dementia compared with another structured activity and unstructured time?

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Methods

Design

The intervention was run in two North Wales care homes for people with dementia, one (Home A) privately owned where the intervention was run twice with different groups of participants and the other (Home B) part of an independent care home chain where the intervention was run once. The homes were chosen as they did not have an existing art programme and the managers and staff were keen to be involved in the project.

A repeated measures (pre and post) approach was adopted to facilitate comparisons and change over time focussing on behavioural observation, but incorporating standardised questionnaires for comparative purposes.

Participants

Inclusion criteria: Diagnosis of dementia according to DSM-IV-TR (including Alzheimer's disease, vascular dementia, mixed Alzheimer's disease and vascular).

Exclusion criteria: Any history of psychosis, or major mental health problem.

Severity level of cognitive impairment was not used as criteria for inclusion/exclusion.

Potential eligible participants were identified with the care home manager. Appropriate care was taken in explaining the research to participants. Wherever possible a family member or other carer was involved. Informed written consent was obtained from participants, or a consultee's opinion was sought if the resident was judged as not having capacity, following guidance of the Mental Capacity Act 2005 (Department of Health, 2005). Participants were advised to feel free not to answer any questions if they chose not to do so and that they would be free to withdraw from the study at any time.

As this was an exploratory study, no power calculations were used to determine the sample size. A target sample size of ten participants for each group was set as this was achievable and deemed sufficient for descriptive statistics to be used.

Ethics

This study was given a favourable ethical opinion by the North Wales Research Ethics Committee- West [Appendix A].

Measures

Demographic information was collected on age, ethnic origin, and marital status from the care home records of each participant.

The Clinical Dementia Rating Scale (CDR; Hughes, Berg, Danziger, Cohen & Martin, 1982) was used to assess the level of the impairment. This is a clinician-rated dementia staging system that tracks the progression of cognitive and functional deterioration throughout the course of Alzheimer's disease on a scale of 0-5, with 0= no dementia, 0.5= questionable dementia, 1=mild dementia, 2=moderate dementia, 3=severe dementia, 4=profound dementia, 5= terminal dementia. The CDR stages are determined on the basis of the presumed order in which specific cognitive and functional abilities are lost during the usual course of Alzheimer's disease (Rush, First, & Blacker, 2008). Good reliability and validity have been demonstrated for this scale.

Primary outcome measure

Greater Cincinnati Chapter Well-Being Observation Tool (Kinney & Rentz, 2005; Rentz, 2002) was used to assess engagement and affect of the participants. For this study, the tool was adapted in answer to limitations noted by the original developers. The adaptations were made by the author of this thesis after piloting the tool during a community visual art programme for people with dementia and their carers. The initial 5 point scoring scale was changed to a simpler coding, with the researcher reporting whether or not the relevant domain of well-being was observed.

This adaptation was felt to be more objective and easier to administer, and less reliant on a subjective judgement of the proportion of time the domain was observed. Another change to the tool was made during the pilot phase. Rather than observing three participants at once, one participant is observed at a time, so that the observer can focus completely on one participant. However, this needed to be balanced with the need to observe a number of participants. Therefore, the decision was made to observe one participant at a time, for one minute each. The researcher then had a minute for scoring whether each indicator of each domain had occurred before moving on to observe the next participant for a minute. Therefore the definition of the first indicator in Sustained Attention (see Table 3.1) was changed to reflect only one minute being observed.

Four participants were observed for an hour meaning that there were eight observations at eight minute intervals for each participant in the hour. Each data point now represented whether or not a participant was demonstrating each indicator of each domain [see Appendix J for score sheet]. A score out of 8 gave the proportion of time observed that the participant showed each indicator. Inter-rater reliability was established by two trained observers rating the same participants in a video of 4 sessions (4 participants in 4 sessions = 16 participants). The Kappa coefficient could not be computed for 70.5% of the pairs (n=176) due to perfect agreement. For the remaining pairs of observations, a moderate Kappa coefficient of 0.551, p< 0.001 was found in the current study.

Although the adaptations were decided independently by the author of the current study, they are supported by suggestions made in a previous study using the original tool which also suggest that one participant should be observed at a time and that ratings should be made at frequent and regular intervals (Gross et al., 2013).

Secondary outcome measures

Quality of Life in Alzheimer's Disease (QoL-AD; Logson, Gibbons, McCurry, & Teri, 1999) was used to measure the self-reported quality of life of participants with dementia. It has 13 items including questions about physical health, energy, mood, and living situation. A higher score indicates a better quality of life. This can be completed either as self-report or by proxy, with moderate correlations reported between these different perspectives (Thorgrimsen et al., 2003). In this study, only the self-report version was used so that there were no issues of handling data from multiple sources and of finding appropriate proxies. A review on outcome measures for psychosocial intervention research in dementia care recommends this as a measure of patient quality of life (Moniz-Cook et al., 2008). The QoL-AD has a good internal consistency, inter-rater reliability, and test-retest reliability, as well as a concurrent validity shown through moderate correlations with other quality of life measures (Thorgrimsen et al., 2003).

Geriatric Depression Scale (Residential) (GDS-12R; Sutcliffe et al., 2000) was used to assess mood of the participants. This is a 12 item easy-to-administer depression scale that is relevant to residential and nursing home populations. This scale shows greater internal validity than longer versions of the GDS.

Holden Communication Scale (Holden & Woods, 1995) was completed to assess communication. This is a scale completed by care home staff or a family member which assesses communication. A range of social behaviour and communication variables are covered. A higher score indicates greater impairment

Table 3.1

The indicators for each of the domains of well-being in the Greater Cincinnati Chapter Well-Being Observation Tool

Domain of well-being	Indicator			
Interest	1.	The participant shows interest in other participants once the activity is		
		underway		
	2.	Without prompting, the participant offers support of a peer's		
		participation in an activity by making eye contact, smiling, looking		
		toward the person, or acknowledging the person verbally, one or all of		
	2	these		
	3.	The participant acknowledges support from peers by eye contact, smile, verbalization extending hand one or all of these		
Sustained attention	1.	While engaged in the activity, the participant has sustained attention for		
		a period of one minute.		
	2.	The participant requires verbal prompting or cueing during the activity		
		to sustain the project or activity.		
	3.	The participant initiates and engages in conversation with peers or		
		facilitator and then returns to activity and refocuses.		
Pleasure	1.	The participant has relaxed body language, smiles, and laughs during the		
	2	activity.		
	Ζ.	The participant verbalizes a sense of pleasure with phrases such as "this		
		reels good", "this is relaxing", or in the verbal expression of		
		unintelligible phrases such as oooh, aah, accompanied with smiles,		
Nagativo affact	1	The portion of eyes, of relaxed facial expression.		
Regative affect	1.	The participant is agitated during the activity.		
	2.	The participant is agriated during the activity.		
	э.	jumpy", "I feel funny today").		
Sadness	1.	The participant is sad during the activity as evidenced by one or all of		
		the specified indicators.		
	2.	The participant verbalizes feeling sad at some point in the activity.		
Self-esteem	1.	The participant nonverbally expresses pride in participating and		
		completing a project by smiling, nodding happily, tearfulness, clapping.		
	2.	The participant verbally expresses satisfaction after completing a		
		successful activity.		
	3.	The participant verbally expresses pride through expressions of		
Normaley	Ĩ.	The participant verbally expresses feeling good shout being in a group		
itor marcy	1.	activity which may be expressed as "I feel normal again" "I don't feel		
		so alone" or other positive statements		
	2	The participant nonverbally expresses social normalcy evidenced by one		
	— ••	or all of the following interest in others sustained attention to task		
		relaxed body language: if there is an affective reaction that reaction		
		does not escalate or perseverate.		
	3.	The participant, when joining or leaving the activity, chats openly with		
		another, shakes hands, pats back, says or nods good-bye.		

The visual art intervention

Following the success of gallery-based interventions such as Meet me at MoMA (Rosenburg, 2009), the National Gallery of Australia (MacPherson et al., 2009), and work in Dulwich Picture Gallery and Nottingham Contemporary (Eekelaar et al., 2012; Camic et al., 2014), with art appreciation a focus as well as art making, a local gallery visit was planned for the start of the intervention. Subsequent sessions were planned to link the art viewing and art making. The artist used images from the gallery as prompts at the beginning of sessions, as well as images of other art work to stimulate conversation and keep an art appreciation element in the sessions. The visual art intervention was led by a local artist who was experienced in running Arts in Health projects. She was supported by two artist volunteers who also had previous experience of working with people with dementia. The artist planned sessions using materials used in her own work. These included watercolours, crayons, inks on textiles, inks, and print blocks. The artist was flexible and all activities were suitable for all participants with differing levels of cognitive and physical impairment.

The intervention was run in two consecutive waves in Home A followed by another wave in Home B. Gallery visits happened in the first and third wave and were led by the artist team supported by a facilitator from the gallery. Art sessions were led in the care home by the same artist team once a week for 8 weeks. Each lasted between one and two hours. Participants were invited by staff to join the art session each week.

The arts intervention and those delivering it adopted the principles of person-centred care (Kitwood, 1997) and the Senses Framework (Nolan et al., 2004) as suggested in Table 1.1. A typical session would begin with a recap of what had been done in the previous week, giving participants a chance to see the work produced. The artist then introduced what they were going to do during the current session and showed images of work to stimulate conversation. She would then do a short demonstration and would ensure that each participant had the materials that they wished to use before they began.

The artist and artist volunteers supported the participants allowing them to work independently. They worked alongside the participants so as to create a welcoming environment rather than making a barrier of 'us and them'. Activities included painting freestyle, using pictures or objects as prompts to create own art work, card making, using print blocks, using inks on textiles which had been prepared using wax to make images and patterns.

At the end of the session, the artist showed participants each other's work, giving a chance to appraise one another, and feel that their work was valued. If participants wished, on completion of the intervention, there was an exhibition and celebration of the work. In Home A this took place in the dining area and in Home B this took place in a local art gallery. Friends and families were invited.

Control conditions

The other structured activity condition was an activity session already running and provided by the home, but led by an external activities worker, on a specific day. In Home A, two different activities were on offer; a physiotherapist led an hour-long chair aerobics session once a week and an activities worker led an hour's session on another day. A typical session would include singing popular songs, as well as playing skittles, carpet bowls, or hoopla. Residents could choose whether they wished to attend either or both activities. In Home B, an activities worker led a 30 minute session in each lounge comprising of chair aerobics exercises to music followed usually by a game of bowls. The sessions were only 30 minutes due to the activities worker needing to do sessions in both lounges. Residents could choose whether or not they wished to participate.

The unstructured time condition was when the resident had free time with no planned activities.

Procedure

Once a participant consented to be involved in the project [Appendix B-F], the researcher extracted background and demographic information from the care home file and an interview was arranged with the participant. Family members were invited to attend if they wished (which was accepted by one family). Here the QoL-AD and GDS-12R were administered. The researcher then completed the CDR and HCS for each participant in consultation with a senior member of care staff.

The Greater Cincinnati Chapter Well-Being Observation Tool was used to observe each participant in all conditions at two time points (T1: Weeks 1 and 2 and T2: Weeks 7 and 8). At each time point, the measure was completed in two observation windows (ob A and ob B). This was in recognition that people with dementia vary day to day, as suggested by

Brooker and Duce (2000). A total of eight observations were possible in the observation window at eight minute intervals. When ob A and ob B were combined, there was a maximum of 16 observations for each indicator, and the number of observations ranged from 0 to 16. All observations were made at the same time of day (early afternoon). In the two weeks of observations during T1 and T2, the researcher visited the care home every day so that observations could be made of all the participants in all of the conditions. When observing, the researcher sat in a position that was unobtrusive to the activity from where they could see all the participants being observed on that occasion. A stopwatch was used to maintain the time-sampling schedule.

Once the intervention had finished and observations had been completed for each participant in all three conditions, a follow-up interview was arranged with the participant where the QoL-AD and GDS were administered. The researcher again completed the HCS in consultation with a senior member of staff.

Data analysis

To prepare the observation data for analysis, the second item in Sustained Attention domain (see Table 3.1) was reverse scored. For each indicator, the overall score was obtained by adding scores for the two observation occasions. This score was then expressed as a percentage of the total number of observations for which the participant was present, and this percentage, allowing comparability across participants, was then used in subsequent analyses. The mean percentage for each of the seven domains was calculated by averaging all of the indicators in the domain. Statistical analysis was undertaken using IBM SPSS Statistics version 20. Observation data were analysed using a 3 x 2 repeated measures ANOVA for each domain of well-being with Condition (art intervention, other structured activity, and unstructured time) and Time (T1 and T2) as factors.

Effect sizes were calculated by first calculating eta squared values using the formula $\eta^2 = SS_{between} / SS_{total}$ and then converting the value into Cohen's d via a spreadsheet from <u>www.stat-help.com</u> using the formula $d=\sqrt{(\eta^2)/(1-\eta^2)} \ge 2$

A paired samples t test or the non-parametric equivalent was conducted to compare the pre and post score from the QoL-AD, GDS-12R, and the HCS.

Effect sizes were calculated by first calculating eta square vales using the formula $\eta^2 = t^2/t^2 + (N-1)$ and then converted into Cohen's d as above.

Cohen's (1988) classification of effect sizes were used as a reference [d=0.2 small, 0.5 (medium) and 0.8 large].

To assess the relationship between the measures, and assess concurrent validity of the GCCWBOT, scatter-graphs with a line of best fit were viewed of scores from relevant domains of the GCCWOBT and scores from the QoL-AD and GDS-12R.

Results

Participant Characteristics

Written consent was obtained for 31 participants; all signed by a personal consultee as the participants were all deemed to lack capacity to consent for themselves [see Appendix I for Mental Capacity Checklist]. 10 participants did not attend any sessions due to turning down the invitation each week (n=6) or not physically being able to attend (n=4). 21 participants attended one or more art sessions, but not all participants chose to or were able to attend every session. The median number of sessions attended by the participants was 6. Five participants attended less than half of the art sessions and could not be included in the analysis as they were not present for observation at both time points. Reasons for attrition were not given beyond declining the invitation each week.

Of the 16 participants included in the analysis, ages ranged between 70 and 95 (mean age 86.1), 5 were male and the remaining 11 were female. All were white British, 4 were married, 1 single and 11 widowed. All but one participant were classified as moderately impaired according to the CDR. One participant was mildly impaired.

Primary outcome measure:

Greater Cincinnati Chapter Well-being Observation Tool

Table 3.2 shows descriptive statistics for each domain for all conditions and time points. One participant did not attend any of the other structured activity sessions therefore 15 participants were included in the analysis for the observation measure (as repeated measures ANOVA only includes participants with complete data sets). The results are presented in Table 3.3. Where sphericity could not be assumed according to Mauchley's test, Greenhouse-Geisser corrected tests are reported.

Only the pleasure domain showed a significant interaction effect of condition x time. Post hoc paired-samples t tests for each condition at each time point indicated that participants

showed a significant increase in pleasure during the art sessions from T1 (M= 19.91, SD= 17.40) to T2 (M=26.42, SD= 17.74); t (15) = -2.09, p=.05.

There was a significant main effect for condition in each domain. A large effect size, according to Cohen's (1988) classification was found in each (Interest: d=1.339, Sustained Attention: d=2.647, Pleasure: d=1.767, Negative Affect: d=1.125, Sadness: d=1.748, Self Esteem: d=1.748, Normalcy: d=1.815). Contrasts revealed that Interest, Sustained Attention and Pleasure were significantly higher in the art intervention and other structured activity than unstructured time and Sadness significantly lower in the art intervention and other structured activity than unstructured time. In the Self Esteem domain, mean scores in the art intervention and other structured activity were also significantly different to unstructured time, but the mean scores increased in the art intervention, and decreased in the other structured activity. The profile plots in Figure 3.1 show a representation of each domain. No significant difference was found between the art intervention and other structured activity in any of these domains.

There was a significant main effect of time in the Normalcy domain, suggesting that the mean scores at T1 were significantly different than at T2. A look at the profile plot (Figure 3.1) shows that this difference was an increase in all 3 conditions between T1 and T2.

Table 3.2

		T1			T2	
Domain	C1	C2	C3	C1	C2	C3
	M (SD)					
Interest	40.86	40.24	27.61	39.45	40.54	32.36
	(14.75)	(28.11)	(20.42)	(16.88)	(20.21)	(17.48)
Sustained	29.85	23.61	15	30.88	26.27	11.52
Attention	(13.26)	(13.99)	(11.97)	(8.63)	(11.72)	(8.10)
Pleasure	20.82	24.51	13.68	28.18	26.73	10.42
	(17.61)	(18.55)	(16.99)	(16.86)	(16.44)	(13.03)
Negative	3.90	4.72	10.02	2.22	4.19	8.33
Affect	(4.79)	(7.11)	(13.55)	(5.25)	(6.76)	(8.98)
Sadness	8.82	10.76	18.33	5.64	12.68	19.17
	(10.98)	(15.58)	(16.78)	(9.08)	(14.92)	(16.53)
Self	3.38	3.64	.56	5.58	2.79	.42
Esteem	(3.09)	(4.60)	(1.66)	(3.51)	(3.51)	(1.17)
Normalcy	27.48	17.64	11.81	29.58	26.73	18.61
	(6.89)	(15.80)	(11.29)	(6.21)	(15.91)	(10.92)

Descriptive statistics for each domain of the Greater Cincinnati Chapter Well-Being Observation Tool in the art intervention (C1), other structured activity (C2) and unstructured time (C3) at each time point
Table 3.3

		Time Main effect			Conditio Main effect	n		Time x Condition Interaction	
Domain	F	Df	Р	F	Df	Р	F	Df	P
Interest	.185 ^a	1,14	.67	6.487 ^a	1.88, 26.37	.006	.621 ^a	1.74, 24.35	.52
Sustained Attention	.001 ^a	1,14	.97	26.04 ^a	1.77, 24.81	.000	1.17 ^a	1.92, 26.88	.32
Pleasure	1.24 ^a	1,14	.28	12.10^{a}	1.82, 25.46	.000	3.31 ^a	1.99, 27.85	.05
Negative affect	1.05 ^a	1.14	.32	4.44	2,28	.02	.135 ^a	1.49, 20.79	.81
Sadness	.006 ^a	1,14	.94	11.14 ^a	1.81, 25.27	.000	.680	2, 28	.52
Self esteem	.397 ^a	1,14	.54	11.26^{a}	1.58, 22.12	.001	2.76	2, 28	.08
Normalcy	11.36 ^a	1,14	.005	12.25 ^a	1.77, 24.71	.000	2.21	1.80, 25.13	.14

ANOVA results^{a, b} for each domain of well-being

^a Greenhouse-Geisser corrected tests are used

^b values are in italics where a significance is found





a. Interest



c. Pleasure

b. Sustained attention



d. Negative affect

45

40

35

30

15

10

0

25 25 20



e. Sadness



g. Normalcy

Figure 3.1 Profile plots for each domain shows mean scores for the art intervention (blue line), other structured activity (red line), and unstructured time (green line) at Time 1 and Time 2.

f. Self esteem

Time 1

Time 2

Secondary outcome measures

QoL-AD

The QoL-AD was completed by 10 participants. A further two data sets had one or two missing items which were replaced by the mean of the remaining items, as allowed by the missing data rules set in the original validation of the measure (Thorgrimsen et al., 2003). There remained 4 sets of missing data: 2 participants were not available for the preintervention interview, and 2 participants did not complete it due to not understanding (i.e. due to the severity of their dementia).

Results from Kolmogorov Smirnov test for normality suggested that normality was a reasonable assumption. Therefore, a paired samples t test was conducted to compare the QoL-AD score pre and post intervention of the 12 data sets. There was a trend to improvement in score pre (M = 34.67, SD = 4.62) and post intervention (M = 36.17, SD = 5.408); t (11) = -2.14, p = .06. A large effect size was found (d=1.281) according to Cohen's (1988) classification.

GDS-12R

5 participants did not complete the GDS-12R. 2 participants were unavailable for the preintervention interview, 2 participants were unable to complete it due to their impairment and 1 participant was too tired to continue and declined to complete it on another day.

Results from Kolmogorov Smirnov test for normality suggested that normality could not be accepted. Therefore, a Wilcoxon Signed-ranks test indicated that there was no significant difference between scores pre (Mdn = 3) and post (Mdn = 3) intervention, Z =.768, p = .44, r = .232 and therefore the null hypothesis could not be rejected. The results therefore indicate that the score on GDS-12R did not improve following attendance at the art sessions.

HCS

As the researcher rated the HCS, the sample size included all 16 participants.

Results from Kolmogorov Smirnov test for normality suggested that normality was a reasonable assumption. Therefore, a paired samples t test was conducted to compare the HCS score pre and post intervention for 16 participants. There was a significant decrease

in score pre (M = 16.06, SD = 6.59) and post intervention (M = 14.88, SD = 6.15); t (15) = 2.45, p =. 03. A large effect size was found (d=1.263) using Cohen's (1988) classification. These results suggest an improvement in communication skills after attending the art intervention.

Relationship between measures

The relationship between QoL-AD post-intervention scores and Time 2 scores from relevant domains (pleasure, negative affect, sadness) in the GCCWBOT in unstructured time were explored. The relationship between GDS-12R post-intervention scores and Time 2 scores from relevant domains (pleasure, negative affect, sadness) in the GCCWBOT were also explored. These scores were chosen as data were most likely to have been collected in the same week, although visual inspection of similar graphs from the art session and other structured time also reflect the results from unstructured time.

Graphical relationships are presented in Figure 3.2 below. The graphs from QoL-AD and the GCCWBOT domains show a positive relationship with pleasure and negative relationship with negative affect and sadness. Therefore as quality of life increases, so does pleasure but negative affect and sadness decrease.

Graphs of the GDS scores and GCCWBOT domains show a slight negative relationship between pleasure and a positive relationship with negative affect and sadness. Therefore, as depression scores increase, so does negative affect and sadness but pleasure decreases.

A further investigation revealed that the Item 3 (Mood) in the QoL-AD post-intervention score was significantly related to the Time 2 mean sadness score on the GCCWBOT in unstructured time, r=.75, p=.002.



Figure 3.2 shows the relationship between QoL-AD and GDS-12R post-intervention scores with Time 2 mean scores of pleasure, negative affect and sadness in unstructured time.

Discussion

This study aimed to test whether an adapted version of the Greater Cincinnati Chapter Well-Being Observation Tool was suitable for evaluating a visual art programme for care home residents with dementia compared to another structured activity and unstructured time. The tool was used successfully in the study, and was clearly able to show differences in resident well-being when participating in activities.

The results of the evaluation also add to the evidence base for the benefits of visual art programmes for people with dementia as a positive trend of some factors of well-being and quality of life were found for participants with dementia involved in an art intervention, compared to another structured activity, and unstructured time. The results are now discussed below in more detail.

Is the adapted observation tool suitable for evaluating a visual art programme for care home residents with dementia?

Sensitivity to change

The results from the repeated measures ANOVA demonstrate the tool is sensitive to change despite a small sample size and provided a rigorous evaluation of the visual art intervention compared to the control conditions. The originality of this study was the inclusion of two control conditions; another structured activity and unstructured time. The first control condition was included so that positive results could not be discounted as the result of the participants being engaged in an activity or being in a group situation. Previous attempts at including a control condition were flawed by the control condition always directly following the art intervention, or inconsistency concerning raters of the tool (Gross et al., 2013; Kinney & Rentz, 2005). It is worth emphasising that the GCCWBOT was relevant in each condition and evaluated well-being of people unable to engage in a structured data collection interviews.

Relationship with other measures

Because of the small sample size, graphical representation was deemed most suitable to investigate the relationship between the GCCWBOT and other measures. Values from Time 2 unstructured time of the GCCWBOT were used to compare with post intervention scores from QoL-AD and GDS-12R as they were collected in the same week. The graphs reveal relationships that would be expected, i.e. a positive relationship between QoL-AD

scores and pleasure, suggesting participants reporting a higher quality of life would show more pleasure; and a negative relationship between QoL-AD and negative affect and sadness, indicating that participants reporting higher levels of quality of life would show fewer indications of negative affect and sadness. Similarly, as expected, a negative relationship was found between the GDS-12R and pleasure domain indicating that more depressed participants would show less pleasure; and a positive relationship with negative affect and sadness meaning that those with higher depression scores would show more negative affect and sadness. Therefore although statistical evidence only exists for QoL-AD item 3 (mood) and GCCWBOT mean sadness scores, concurrent validity has begun to be established.

Practical issues

The tool was used to rate participants in real time. The new scoring system meant there was enough time to observe a participant for a whole minute and then use the next minute to write down scores and any notes before orientating to the next participant. This sometimes meant the researcher needed to move slightly to ensure a full view of the participant. Sessions were also videoed in case of anything needing verifying. It also meant that inter-rater reliability could be tested using a video of the session so raters saw exactly the same session without having two raters in a room that was short of space.

There were also a few obstacles to overcome when using the GCCWBOT in research practice, similar to the 'logistic obstacles' described by Kinney and Rentz (2005) such as participants not attending art and other structured activities when observations were planned, or not staying for the whole observation window. If a participant decided to move from where the observations were taking place, or if they preferred to watch television rather than attend the other structured activity, an observation could not be undertaken. In recognition of this, observations were converted into percentages for analysis to avoid reliance on having a complete observation window. However, the nature of ANOVA analysis meant that only complete data sets could be analysed. Therefore data from one participant who attended all art sessions but none of the other structured activity sessions could not be included in analysis.

Suitability of tool

Results have suggested that the observation measure was sensitive to change in each condition and provided a rigorous evaluation of an art intervention for people with dementia. In addition, it was shown to be an effective way of capturing data from participants more severely impaired who were unable to complete structured conversations for the other data collection tools, and a relationship with QoL-AD and GDS-12R were shown.

Before the adapted GCCWBOT can be deemed completely suitable to evidence the impact of a visual art programme for people with dementia, further work is needed to determine more of the tool's psychometric properties.

Measuring the momentary experience versus lasting effects

Positive results were found using both the adapted GCCWBOT completed during the intervention to capture the momentary experience and the QoL-AD completed before and after the intervention. Therefore rather than showing the suitability of one outcome measure or method of collecting data over another, the results of the study have shown the importance of using a combination of outcome measures to investigate the full impact of an intervention. Pre/post measures evidence lasting effects outside of an intervention whereas observation measures evidence the momentary experience inside the intervention sessions, which was described by MacPherson et al. (2009).

Further adaptations

Adaptations to the tool used in the current study were made to the scoring system in response to issues discussed in the original development paper (Rentz, 2002) and after piloting the tool during community art sessions for people with dementia. Although the measure was found suitable, further adaptations are suggested relating to the items themselves. Despite the mainly clear definitions and indicators, several items would benefit from clarification and some were found missing from the tool. Recommendations are shown in Table 3.4.

A study published after the completion of data collection uses the GCCWBOT (Sauer, Fopma-Loy, Kinney, & Lokon, 2014). Their modified tool incorporates similar changes as recommendations made in this study. Therefore, it is suggested that further work and collaboration is needed to finalise an adapted version of the tool and determine the validity and reliability.

Table 3.4

Recommended adaptations to domains and indicators of the GCCWBOT as a result of this study

Recommended adaptation	Reason for the adaptation	Support and evidence for
		recommendation
Rename Interest domain to	Indicated more of a social interest	Interest found to decrease from T1
reflect social aspect	(interest in other participants).	to T2 in art intervention as
		participants became more
		involved in their own work. The
		pilot work of the original tool
		included 'socialisation' under
		'engagement' and it was
		commented that 'if persons are
		engaged in the art project, they
		would not always be socialising,
		thus "rarely" or "never" would not
		necessarily be a negative outcome
		but a rather positive one' (p.180
		Rentz, 2002).
Add an indicator for 'interest in	Engagement in own work is	Researcher noticed this increased
own work'	missing from the tool. Sustained	over the duration of the
	Attention refers to engagement in	intervention
	the activity but does not assume	
	that it is in the participants own	
	work.	
Add a domain for passive	When a participant sleeps or	The tool is intended for use with
behaviour	stares into space, none of the	people with dementia, who often
	current indicators are relevant	sleep in the day-time, due to
	despite the participant showing	medication, fatigue, health
	behaviour related to well-being.	difficulties or boredom perhaps.
		Throughout the duration of the
		project, the researcher observed
		that participants who fell asleep a
		lot at T1, slept less at T2
Add an indicator for negative	Quotes from participants such as	Incidence of quotes like this
self esteem	'It's not great', 'I'm just colouring	decreased over time when positive
	in' and 'Oh that's no good' were	self-esteem increased.
2	noted down.	

Results of the evaluation

As well as ascertaining whether the observation tool was suitable, the study also added to the evidence base for the benefits of a visual art programme for care home residents with dementia, compared with another structured activity and unstructured time. Sixteen participants attended five or more visual art intervention sessions and were observed using the GCCWBOT during the art session, another structured activity, and unstructured time at two different time points; T1, the first two weeks and T2, the last two weeks of the intervention. Participants were also interviewed before and after the intervention to assess quality of life and mood.

Observed pleasure increased significantly over time in the art intervention but not in the other two conditions. This positive result supports findings from other studies using the GCCWBOT (Gross et al., 2013; Kinney & Rentz, 2005; Rentz, 2002). Also, despite lower numbers of participants completing the QoL-AD, there was an almost significant increase in quality of life before and after attending the art sessions. A significant increase in communication skills was found after participants were rated before and after attending the art intervention using the Holden Communication Scale. The result in this study suggests that this increase in communication skills is carried over beyond the art sessions. Communication was also anecdotally found to be affected during the session by staff members who commented on their surprise at residents who had sat next to each other in the lounge many times without speaking were having meaningful conversations in the art session which supports findings that involvement in art activities can increase verbal fluency during the session (Eekelaar et al., 2012).

A main effect of condition was found in all domains of well-being. However, this generally meant that mean scores from the art intervention and other structured activity were significantly different from unstructured time. Therefore, participants engaging in an activity, whether it was art or the other structured activity, showed significantly greater well-being than when not doing an activity. This supports findings that people with dementia found enjoyment in activities that address their psychological and social needs, and that it is the quality of experience that is important rather than the specific activities that make them meaningful (Harmer & Orrell, 2008; Phinney, Chaudhury, & O'Connor, 2007).

It is worth noting, however, that although a significant difference was not found between the art intervention and other structured activity in any of the domains, mean percentages for Sustained Attention, Pleasure, Self-Esteem, and Normalcy domains were all higher for the art intervention than the other structured activity. Similarly, in the negative domains of Negative Affect and Sadness, mean percentages are lowest in the art intervention than in the other two conditions indicating greater well-being. Therefore positive results indicated a general trend of greater well-being in the art intervention than in the other structured activity and unstructured activity.

Limitations

The exploratory nature of this study gave rise to several limitations. The small sample size limits the statistical power, with a risk of a type II error (missing a difference where one exists). The range of cognitive impairment within the sample meant that the QoL-AD and GDS-12R were not suitable for all participants. Therefore the already small sample size decreased even further. This, however, does strengthen the argument for observation, especially for those more severely impaired.

Another limitation of the study was the potential bias that could arise from the researcher rating the Holden Communication Scale and Greater Cincinnati Chapter Well-Being Observation Tool. A staff member verified the HCS in an attempt to reduce any bias. However, ideally the ratings would have been made entirely by a staff member.

The content and session length of the other structured activity was beyond the control of the researcher as they were activities already provided by the care home and therefore varied across the two homes. However, as an exploratory study to determine the suitability of the measure, they were important to assess the sensitivity to change in various conditions.

Lastly, confounding factors exist due to combining data from all waves so data collected in two different care homes were analysed together. Although efforts were made to reduce this, such as the same artist team leading the intervention, differences existed in the environment and other structured activities on offer at the two care homes.

Implications for practice

The finding of a suitable outcome measure makes a significant contribution to the call for researchers to increase evidence for the benefits of art interventions in a more rigorous way. As a result of the work with the GCCWBOT in this study, the adapted tool incorporating recommendations made in Table 3.4 is now being utilised in a larger scale multi-site project, Dementia and Imagination (<u>http://dementiaandimagination.org.uk/</u>). The author of this thesis provided training to the Dementia and Imagination research team and continues to advise on the data collection using this measure.

The study provides a clear argument and support for the provision of group activities in care homes, including professional artists leading sessions. Therefore, this study strengthens the argument for the provision of specific and ring-fenced funding from commissioners and policy-makers.

Future research

The findings of this exploratory study regarding suitable outcome measures can contribute to a larger-scale main trial to evaluate visual art interventions for people with dementia. A recent methods review for the NIHR School for Social Care Research argues for the increase of chance-based designs (an alternative term for RCT less associated with medical trials where participants are randomly assigned to intervention and control groups) in social care research to provide a more rigorous evidence base (Woods & Russell, 2014). Therefore, a larger scale chance-based study should be considered with control conditions implemented by the research team.

Anecdotal evidence from this project suggested that at least one participant was calmer in the hours following the art sessions. To investigate whether there is a carryover effect of the art intervention, future research should include observations of participants in the hours after the art session, as well as a post-intervention follow-up period of 2 weeks.

Conclusion

The results from this exploratory study have demonstrated an adapted observation measure is sensitive to change and relates to other measures, and is suitable to quantify the benefits that have been noted anecdotally for many years during visual art activities. The added value of arts activities over other structured activities remains to be established.

The study also suggests that attending a visual art intervention may be associated with an increase in communication and quality of life in care home residents with dementia.

Chapter 4: "I thought you'd be wasting your time, if I'm honest": A qualitative exploration of the impact of a visual art programme for care home residents with dementia

Summary

This study aimed to explore the experience and impact of a visual art programme for care home residents with dementia from the perspective of the resident, care staff, and artist team. A visual art intervention was run in two North Wales care homes. Data were collected from 21 intervention participants with dementia through semi-structured interviews which were supplemented by field notes; from eleven members of care staff from the participating care homes through open-ended questionnaires and semi-structured interviews; and from group discussions and reflective diaries from the artist and two artist volunteers running the intervention. The three groups all spoke of the positive impact involvement in a visual art intervention can have on people with dementia. The participants' enjoyment was identified in all groups and other benefits identified included improvements in mood, communication / interaction, concentration, independence, confidence, and self-esteem. However, perhaps the most important impact of the intervention found was the change in perception of the abilities of the residents by the care staff and artist team.

This chapter presents the qualitative findings from the study. This was the researcher's first experience of qualitative data collection within a care home setting and of conducting a thematic analysis. However, it was recognised that this would add an important dimension to the findings and would give the residents, staff, and artist team a chance to discuss their experiences in their own words beyond the constraints of a structured questionnaire. On reflection, the topic guide would have benefitted from more attention as it covered quite abstract topics that participants sometime struggled with. The inexperience of the researcher meant that it was not adapted as the waves progressed. However, the variety of data sources meant that there was supplementary data. Despite these issues, there are important themes identified in the data that complement the results from the previous chapter and support the findings from previous research.

Introduction

As a movement, arts and health have gained more gravitas over the last decade and art interventions are considered to have positive effects on health and well-being (Department of Health, 2007). In fact, attempts at applying monetary terms to quantify and value the impact of cultural activities show that "arts engagement was found to be associated with higher wellbeing... valued at £1084 per person per year, or £90 a month" (Fujiwara, Kudrna, & Dolan, 2014, p.9). The Arts Council, England (2014) found that people were 60 per cent more likely to report good health if they had attended a cultural place or event in the previous month.

Applied to dementia care, arts have been suggested to be aligned to Kitwood's (1997) person-centred care approach by allowing participants to express thoughts and feelings as well as expressing their individuality (Killick & Allan, 1999). The theory calls for the psychological needs of comfort, attachment, inclusion, occupation, and identity of people with dementia to be satisfied to maintain well-being. Developers of an art programme, Opening Minds through Art also argue that their art intervention can meet the psychological needs of people with dementia by creating failure-free structured art sessions (Sauer, Fopma-Loy, Kinney & Lokon, 2014).

Evidence has emerged that involving care home residents with dementia in art programmes can have positive effects on their well-being (Brownell, 2008; Byrne & MacKinlay, 2012; Rentz, 2002; Roe, McCormick, Lucas, Gallagher, Win, & Elkin, 2014; Sauer et al., 2014; Walsh et al., 2011). However, most are small scale studies and few explore the impact of the intervention on the participants, care staff and artist team.

In a review of art interventions, Beard (2011) suggests that studies should include first person accounts from people with dementia. In another review, de Medeiros & Basting (2013) suggest that evaluations of cultural arts interventions should not just consider the participant but also include a larger network such as staff and caregivers, which echoes Brooker (2008) who suggested that qualitative interviews and observational measures used together complement each other.

Aim:

The aim of this paper is to qualitatively explore the experience and impact of a visual art programme for care home residents with dementia from the perspective of the resident, care staff, and artist team.

Methods

Design

The intervention was run in two North Wales care homes for people with dementia, one (Home A) privately owned where the intervention was run twice with different groups of participants and the other (Home B) part of an independent care home chain where the intervention was run once. The homes were chosen as they did not have an existing art programme and the managers and staff expressed interest in being involved in the project.

Participants

Potential eligible resident participants were identified with the care home manager, from residents with a diagnosis of dementia according to DSM-IV-TR (including Alzheimer's disease, vascular dementia, mixed Alzheimer's disease and vascular), excluding any with a history of psychosis, or major mental health problem. Appropriate care was taken in explaining the research to participants. Wherever possible a family member or other carer was involved. Informed written consent was obtained from participants, or a consultee's opinion was sought if the resident was judged as not having capacity, following guidance of the Mental Capacity Act 2005 (Department of Health, 2005). Participants were advised to feel free not to answer any questions if they chose not to do so and that they would be free to withdraw from the study at any time.

Care home staff were recruited through consultation with the manager. Those recommended were approached and the study thoroughly explained. They were given an information sheet [Appendix G] and given sufficient time to decide whether they would like to be involved in the study. Those wishing to take part were asked to sign a consent form [Appendix H]. Care staff were advised to feel free not to answer any questions if they chose not to do so and that they would be free to withdraw from the study at any time and that their employment would not be affected.

It was explained while recruiting the artist team that they would be invited to contribute to the research by participating in group discussions.

Participants from each group were therefore recruited through convenience sampling.

Ethics

This study was given a favourable ethical opinion by the North Wales Research Ethics Committee- West [Appendix A].

The visual art intervention

A local gallery visit was planned for the start of the intervention. Subsequent sessions were planned to link the art viewing and art making. The artist used images from the gallery as prompts at the beginning of sessions, as well as images of other art work to stimulate conversation and keep an art appreciation element in the sessions. The visual art intervention was led by a local artist who was experienced in running Arts in Health projects, supported by two artist volunteers who also had previous experience of working with people with dementia. The artist planned sessions using materials used in her own work. These included watercolours, crayons, inks on textiles, and inks and print blocks. The artist was flexible and all activities were suitable for all participants with differing levels of cognitive and physical impairment.

The intervention was run in two consecutive waves in Home A followed by another wave in Home B. Gallery visits happened in the first and third wave and were led by the artist team supported by a facilitator from the gallery. Art sessions were led in the care home by the same artist team once a week for 8 weeks. Each lasted between one and two hours.

The arts intervention and those delivering it adopted the principles of person-centred care (Kitwood, 1997) and the Senses Framework (Nolan et al., 2004) as suggested in Table 1.1. A typical session would begin with a recap of what had been done in the previous week, giving participants a chance to see the work produced. The artist then introduced what they were going to do during the current session and showed images of work to stimulate conversation. She would then provide a short demonstration and would ensure that each participant had the materials that they wished to use before they began.

The artist and artist volunteers supported the participants allowing them to work independently. They worked alongside the participants so as to create a welcoming environment rather than making a barrier of 'us and them' to promote the development of a relationship that facilitated a sense of security for participants. Activities included painting freestyle, using pictures or objects as prompts to create own art work, card

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making, using print blocks, and using inks on textiles which had been prepared using wax to make images and patterns.

At the end of the session, the artist showed participants each other's work, giving a chance to appraise one another, and feel that their work was valued. If participants wished, on completion of the intervention, there was an exhibition and celebration of the work. In Home A this took place in the dining area and in Home B this took place in a local art gallery. Friends and families were invited.

Data collection

Data were collected by the author as part of a wider study investigating the effects of a visual art intervention on quality of life and well-being of care home residents with dementia. The researcher was therefore present in the care home most afternoons for several weeks before and after the intervention, as well as during the art sessions so residents and staff were familiar with the researcher and aware that they were separate from the artist team. Informal conversations sometimes arose between the researcher and residents outside of data collection.

Data were collected from three groups: resident participants, care staff, and the artist team.

Resident participants: Semi-structured interviews were held with participants individually a week before and a week after the art intervention to explore experiences, likes, and dislikes. These took place in a public but quiet area of the care home. Family members were invited to attend if they wished. Participants were also advised that they could ask a member of care staff to accompany them during the interview if wished.

Interview guides [Appendix K] were developed through consultation with the project advisory team which included an art gallery / museum director, an artist, and an older person's clinical psychologist. A person with dementia and their carer were invited but were unable to attend, so they were invited to comment on notes from the meeting. Interviews were audio-recorded and transcribed by the researcher and a colleague. Before the intervention, the topic guides sought to explore participants' views and opinions about art. After the intervention, similar questions were asked as well as seeking views of the impact of the intervention. The researcher kept field notes during the intervention and endof intervention celebrations. The sessions were also videotaped and observations and quotes taken from these.

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Care staff: A questionnaire including open-ended questions was given to staff to complete independently at the end of the intervention. Staff were also invited to explore their answers further in semi-structured interviews in a quiet area of the care home. The interview guide [Appendix L] was again developed through consultation with the project advisory team and explored their perception of the impact of the intervention. These interviews were audio-recorded and transcribed. Field notes were also made during a training session for staff at the end of the second wave of intervention.

Artist team: The artist team were invited to attend a group discussion after the end of each wave of intervention to discuss the artists' observations from the sessions, their perceived impact and any changes they would make to the intervention. They were conducted as group discussions rather than individual semi-structured interviews for convenience as their time was limited. Two took place in a quiet area of the care home and one in a meeting room at the University. The discussions were audio-recorded and transcribed. The artists were also invited to write a journal after intervention sessions which were typed up.

Data analysis

All semi-structured interviews and group discussions were transcribed either by the researcher or an administrative support staff member, field notes photocopied and typed up, and open-ended questions photocopied and typed up. Transcripts were checked for content, accuracy and for any missing data by the researcher who had conducted the interviews and group discussions.

The researcher (the author) was female and had a Clinical Psychology Master's degree. She had previous experience of evaluating visual art interventions with people living with dementia both in the community and care homes; and therefore brought assumptions based on previous experience of the visual art intervention having a positive impact on participants. The researcher had also undertaken an extensive literature review on the subject prior to data analysis.

The decision was made that data would be analysed using an inductive thematic analysis meaning that the analysis was data-driven and themes were not specified prior to coding. However, once analysis was underway, it was clear that some identified themes were more deductive and linked to the researcher's interest in the area and reading of previous research (for example, the idea of an implicit memory of the intervention was noticed by the researcher during data collection and so primed the subsequent coding). It is therefore more accurate to term the analysis hybrid thematic analysis using both inductive and deductive techniques (Pluye et al., 2011). Themes were identified at a semantic level and interpreted to theorise their significance and broader meanings (Braun & Clarke, 2006).

The process of analysis followed the six stages of thematic analysis suggested by Braun and Clarke (2006). Firstly, the researcher familiarised with the data by reading and rereading transcripts, paying particular attention to those transcribed by the administrative colleague, as well as field notes and observations. During this process, the researcher wrote down initial ideas. Next, the researcher coded the entire data set manually to generate initial codes identifying features in the data of interest [see Appendix M for an example of an annotated transcript]. The researcher then used an Excel spreadsheet to collate data extracts ensuring that enough surrounding data was maintained so that the context of the extracts was not lost. Next, a table of codes was generated to identify potential overarching themes. For the next stage of analysis, a table of themes, subthemes, and data extracts was produced and the themes were reviewed ensuring that the theme fitted with the collated data extracts and that there were no further relevant extracts in the data set. This was an iterative process which resulted in several versions of the table of overarching themes. Once the researcher was satisfied that the themes fitted together and told the story of the data, the themes were then defined, named and quotes chosen for inclusion in the chapter (Braun & Clarke, 2006).

Guidance on the analysis of group data was consulted and decided that it was not required (Kitzinger, 1995). The reason for holding a group discussion with the artist team was practical, therefore, as the focus was not on the interaction of the group, the data from the group discussions with the artist team were analysed in the same way as the rest of the data.

To assure the rigour and trustworthiness of the analysis, data were reviewed by a second independent reviewer (YB-M) who then reviewed the table and themes identified by the researcher. Any inconsistencies were discussed and resolved by re-examination of the transcript.

Results

The results explore the impact of a visual art intervention for care home residents with dementia and are presented from three perspectives: resident participants, care staff, and the artist team.

Participant Characteristics

All 31 resident participants were deemed to lack capacity to consent for themselves, but their involvement was agreed by a personal consultee in each case. 21 participants attended one or more art sessions, but not all participants chose to or were able to attend every session. The median number of sessions attended by the participants was 6. Reasons for not attending any of the session were declining the invitation to attend the session (n=6) and physically not being able to attend (n=4). Results are reported from the 21 participants who attended at least one session.

All of the participants had a diagnosis of mild (n=1) or moderate dementia (n=20) and were aged between 64 and 96.

Data were collected from 11 members of staff (3 managers, 2 senior care staff, 2 activities co-ordinators (one who was appointed as a result of the project) and 4 care assistants) and all three members of the artist team (1 artist and 2 artist volunteers). Demographic information was not collected for staff or artist team but all three artists and all but one staff member were female.

Resident perspective

Three main themes were identified in the resident data: *memory of the intervention, positive experience of the intervention,* and *discussion of art.* The following section presents the findings.

Memory of intervention: Only one resident had an explicit memory of taking part in the intervention when interviewed. She offered insight, spoke about her experience, and wished for more sessions.

Interestingly, some of the other participants who expressed no apparent knowledge of taking part in the intervention showed either an implicit memory or a memory prompted by the intervention when their interviews before and after the intervention were compared. This was identified through a changed preferred artist (whose work was visited during the

intervention) and acknowledgement of attending art classes and a gallery visit that were not mentioned in the first interview.

Table 4.1

Illustrative quotes from the residents demonstrating explicit and implicit memory of the intervention

Explicit

"I do go, on a Friday here. I think that it's a Friday. One day in the week, there's a long table for art.... The time goes too quick" P202, Care Home A, Wave 2

"They'll give you a piece of paper with prints, and I love that." P202, Care Home A, Wave 2

"No but it would be lovely to have an art class every day for instance. If it was only one hour every day it would be wonderful. Otherwise there is nothing." P202, Care Home A, Wave 2

Implicit

"Well Van Gogh rings a bell but I don't think he was very dainty...He was more down to earth and crude I find." P103, Care Home A, Wave 1

"Yes, when I was about fifteen I attended some [art classes]"[which were not mentioned in first interview] P103, Care Home A, Wave 1

[Before intervention]:" No. Couldn't get there [gallery] really." [After intervention]:" Yes. Well I have... I went once really, umm outside." P105, Care Home A, Wave 1

Positive experience of the intervention: The residents found the intervention a positive experience. As discussed previously, only one participant remembered taking part in the intervention so this theme also includes extracts from field notes and observations.

Within this theme, four subthemes were identified. *Enjoyment* and humour were identified in the data. Participants had fun and enjoyed the sessions. They also showed *independence* and choice that can often be lost when a resident is in a care home with staff doing a lot of the tasks they were used to doing themselves. Also, *self-esteem* was evident in quotes from interviews and during the sessions, especially when being complimented on their work. For some, there was an improvement in self-esteem throughout the intervention and residents went from being negative about their own work to accepting compliments.

Lastly, residents experienced a positive *group interaction* during the intervention with residents interacting with each other, some of whom had sat together in the lounge many times without speaking. There was a relaxed atmosphere in the intervention group with residents complimenting each other's work.

Table 4.2

Illustrative quotes from residents demonstrating the positive experience of the intervention in terms of enjoyment, independence, self-esteem, and group interaction

Enjoyment	Independence
"I love going to that table when it is painting day."	he sat down and started working straight away.
P202, Care Home A, Wave 2	Decided on all colours
	Field note (W3 S8), Care Home B, Wave 3
"I've really enjoyed it today!"	All have worked well independently today.
P204, Care Home A, Wave 2	Field note (W1 S5), Care Home A, Wave 1
"I think he [Van Gogh] was copying me!" [said in	Staff helped to put paint onto brush then
jest]	[participant] starts painting; Discussing which
P316, Care Home A, Wave 3	colours she wants to use.
	Field note (W3 S8), Care Home B, Wave 3
Self esteem	Group interaction
"I wouldn't say great" [about own art work]	[Appraising each other's work at end.] "I'm
Field note (W2 S3), Care Home A, Wave 2	delighted to see what she's done"
	P202, Care Home A, Wave 2
Was surprised to be told she had done the work she	Participant to other residents: "Come over here!
liked. "Are they really mine?!"	Come on! It's lovely."
Field note (W1 S6), Care Home A, Wave 1	Field note (W2 S8), Care Home A, Wave 2
"And I've stopped saying to myself 'it's rubbish.	The rest of the participants have a relaxed chat
I'm drawing rubbish, or painting rubbish.' I do	with the artist volunteer and are actively engaged in
what comes out of my head. And it's enjoyable."	the conversation.
P202, Care Home A, Wave 2	Video observation (W1 S3), Care Home A, Wave
	1

Discussion about art: although the data was analysed inductively, this theme relates closely to the interview guide which explored with participants whether they had any previous experience of art making or visiting galleries and their opinions and feelings about art. Only a few of the residents had previous experience of art classes, some spoke of doing some at school and one gentleman had tried doing some art at home. Feelings were mixed about art with some admiring beauty, some who didn't care for it at all, and others who appreciated art but felt that they didn't know enough about it. Again, opinions were mixed regarding preferred styles. Although there was no consensus reached, it was clear that the residents were able to and felt comfortable to express their opinions.

Table 4.3

Illustrative quotes from the residents discussing their previous experience, feelings about, and preferred style or type of art

Previous experience
"[At school] They didn't in those daysthere was none of this lovely art that there is today."
P202, Care Home A, Wave 2
"Just the usual [at] schooldrawing, painting, and needlework" P102, Care Home A, Wave 1
"Only trying myself. I had a go at painting." P107, Care Home A, Wave 1
Feelings about art
"Well, I think it is a beautiful thing. I like to admire it and let other people do the actual work and I'll sit
and admire it." P103, Care Home A, Wave 1
"I've never given it a thought. I'm not artistic." P102, Care Home A, Wave 1
"Well, I appreciate the effort that has gone into it. Yes, I'll accept that but I don't know enough about it to
appreciate it." P104, Care Home A, Wave 1
Preferred style or type of art
"I don't like modern art. Some of it is nice but I don't necessarily go and see modern art"
P102, Care Home A, Wave 1
"[Dislike] Smutty. [Dislike] Crude. I hate it. If you can't keep clean, don't do any."
P103, Care Home A, Wave 1
"Well the country. Landscapes. I like the Welsh landscapes. Well I like um animals. Well I like the
countryside. Yes, and the peace." P110, Care Home A, Wave 1
"I like art in general. But it's got to be good stuff. I don't like rubbish." P317, Care Home B, Wave 3

Care staff and Artist Team Perspectives

Although data were collected and analysed separately, similar themes were identified from the care staff and artist perspectives. In some cases, the two groups offered different perspectives to the same theme. Therefore, they are presented together and compared and contrasted. The four main themes identified from the Care staff and Artist team were: *Impact of the intervention, benefit of gallery visit, benefits of art/artist, and suggestions for future interventions.*

Impact of the intervention: both the care staff and artist team spoke about the impact of the intervention on the resident participants and themselves. The care staff also spoke about the impact on the care home.

Both groups spoke of the impact of the intervention on themselves and were surprised by the impact of the intervention on the residents, as they had under-estimated the abilities of the residents at the start of the intervention. The impact on both the care staff and artist was a change in perception of the intervention and abilities of the residents. The care staff had initially suggested that the researcher was wasting their time by bringing in an artist and were surprised by the results. Once the intervention had begun, the care staff enjoyed being involved in the project, and were eager to find out if they were on the rota for the scheduled art sessions. One care assistant was promoted to activities coordinator and sent on training as a result of the project. The artists were also surprised at how aware some of the less vocal residents were, and how much some of the residents opened up to them.

Table 4.4

Illustrative quotes from the care staff and artist team demonstrating the impact of the intervention on themselves

Care Staff

"I was negative. I didn't think that they would display any interest. That they would just sit there maybe for a couple of minutes and they'd be agitated, edgy and wouldn't want to do it...and I thought that you'd be wasting your time if I'm honest." S351, Care Home B, Wave 3

"I was surprised at their level of ability. And I'm ashamed to say it; I didn't think that they'd do it. No. I didn't think that they would be able to produce beautiful work." S351, Care Home B, Wave 3 "I would recommend it [the art intervention] to any person with dementia or any illness that would aid well-being; It was also very knowledgeable for staff involved." S157, Care Home A, Wave 1 Artist team

"I didn't expect to see such focus and concentration, to be honest, from some of the participants" A02 "They notice so much more than you think they do... they might not understand and remember things that well but they certainly respond to things that you don't expect them to." A01 "They start opening up to you and telling you their life story. And that, that for me was always a big surprise." A01

Both groups spoke about the positive impact of the intervention on the residents with dementia but each group had a different focus for the positive impact. The artist team noticed improvements *over time* in the sessions in skills, confidence, concentration, mood, enjoyment, interaction, and coordination. They also noticed that art could be used as a distraction for participants who were agitated, a way of managing challenging behaviour. The staff, however, spoke of the positive outcomes "*at the time*" such as being relaxed, focused and showing concentration, in an upbeat mood, increased interaction with people they wouldn't normally talk to, enjoyment and self-worth. This was not generally considered to continue after the session. However, one staff member commented on a more lasting effect on residents who were usually agitated.

Table 4.5

Illustrative quotes that demonstrate the different perspectives of the care staff and artist about the positive impact of the intervention on the residents

The staff spoke of the impact the intervention had on the care home. Some spoke of a change in the care home and about ideas for continuing the activities and the breaking down preconceptions of art being elitist. Although one staff member mentions that the art was simple, this is more of a reference to it being more accessible than previously thought rather than a comment on the level of challenge in the activity. Another impact discussed was the legacy of the project, for example having the paintings hanging on the walls of the home.

Table 4.6

Illustrative quotes demonstrating the impact of the intervention on the care home from the perspective of care staff

Care Staff "There's been significant change, especially if you remember when you first came, there wasn't – not that we weren't doing much – we had the outside activities coming in whether it was massage to music or whether it was entertainment, or the staff were doing odd little bits of reminiscence. But I think you class art as in you need to be clever, you need to know what you are doing, and it's not. And during the arts project just even doing something simple, you showing us putting an object on the table." S251, Care Home A, Wave 2

[&]quot;I've even bought paint brushes now from the kitty. New paints. New brushes. So we can start our own little art sessions." S351, Care Home B, Wave 3

[&]quot;One of the things we may be looking at is introducing artists, student artists, that might need to come in from the college to actually to come and volunteer" S251, Care Home A, Wave 2

[&]quot;Once the pictures were hanging up it sparked conversation with carers and residents and made the home look a bit more colourful" S352, Care Home B, Wave 3

Benefit of Gallery visit: A gallery visit took place in two of the three waves of intervention. In the first wave, three participants visited a local community gallery in walking distance to the care home, accompanied by staff and the artist team. The visit had been cancelled three times previously due to bad weather and staffing levels. In the third wave, five residents attended a local contemporary art gallery with staff and the artist team. At each visit, the artist led the session after planning with the gallery staff prior to the event that were also there on the day to support the artist team.

The emphasis of this theme differed between groups as illustrated by the quotes below. The care staff framed the gallery visit in terms of being a nice day out for the residents and 'something normal' which created links with the community, whereas the artist team framed the gallery visit as an opportunity to create a rapport with the residents, enabling them to build a relationship and have a starting point to link throughout the following sessions, which links with their view of the impact of the intervention building over time.

Table 4.7

Illustrative quotes demonstrating the different perspectives of the care staff and artist team around the benefits of the gallery visit.

Care staff
"They enjoyed going out. They enjoyed seeing a totally different place." S351, Care Home B, Wave 3
"It's good for them for links with the community. You know, to feel part of [it]" S158, Care Home A, Wave 1
Artist team
" It was a good opportunity to get to know the participants as well; because I think that helped to build relationships with everybody actually." A01
"I think it kind of underpinned every session in a way, didn't it. Because everything, I mean, it was very much directed and led by them in a way that, you know, everything linked together from the beginning" A01

Both groups discussed practical issues and suitable characteristics of the visit. The care staff felt that it was important that the gallery was closed to the public and that the session was interactive. There was a hint at stigma affecting taking residents out, as they did not want the residents to be made fun of, which could be viewed as the staff being protective of the residents and also linking to the previous theme of underestimating the abilities of the residents. The artist team discussed group size, length of visit, having refreshments and difficulties surrounding cancelling the visit due to weather.

Table 4.8

Illustrative quotes from the care staff and artist team discussing practical issues and suitable characteristics of the gallery visit

Care staff
"[It was important] that it was closed. That nobody would be giggling or not understanding, you know" S351, Care Home B, Wave 3
"I mean if they were just taken around and said 'oh look at that picture or look at that sculpture' or something, then maybe not. But because it was interactive I think they enjoyed it." \$353, Care Home B. Wave 3
Artist
"a few more would have been definitely manageable" A01
"We were there a good 2 hours, weren't we, and they didn't say they wanted to go or anything, did they, so we could have had them there longer even" A01
"It was nice we had a cup of tea there, didn't we, and biscuits." A02

Benefits of art/having an artist: Both groups discussed the benefits of the art intervention compared to other activities offered in the care home setting and the advantages of having an artist to lead it. Staff discussed qualities such as the art intervention being more personal, quieter, and was an opportunity for participants to physically participate in an activity. The artists stated that "*art…is like a language*" which gave residents a way of communicating beyond words and also discussed parts of the brain affected by art.

Table 4.9

Illustrative quotes from the care staff and artist team discussing the benefit of art compared to other activities

Care staff	
"The art was a smaller group and more individualised - there was more person to person atta whereas [external activities worker] is more about getting everybody together as a group." S356, Care Home B, Wave 3	ention,
"I think with the art, it's nice because they can actually get their hands dirty, if you like. You can actually do something." S353, Care Home B, Wave 3	ı know they
Artist team	
"So my feeling was [participant] might not be able to communicate in a way but that colour the way he communicated his ideas. He couldn't verbally do that" A01	mixing was
"I think your brain fires up in a totally different way when you're making creative things I	Different

elements of your brain fire up and it's been proven, hasn't it, in different activities human people do, different areas of the brain fire up." A02 When discussing the benefit of having an artist to lead the sessions, the views were similar in both groups. The care staff valued the attitude and personality of the artists, as well as their knowledge and skills. The artists support this by talking about their expertise, experience and professionalism. They discussed that this made their approach different to how staff would conduct a session and also that they appreciated skills that others might not. Both groups appreciated that another benefit of having an artist lead the session was that they were a different person, in a different capacity to the care staff so residents may respond better. However, a few members of staff thought this might also be a disadvantage, as residents might be intimidated by a new person, which again suggests a protectiveness of the staff towards the residents.

Table 4.10

Illustrative quotes from the care staff and artist discussing the benefit of having an artist leading the sessions

Care staff
"An artist has got very good knowledge of the subject, got the skills and therefore may make the session very interesting and enjoyable" S354, Care Home B, Wave 3
"She was just fabulous wasn't she? She just spoke to them on a wonderful level. She was warm, vibrant. I wanted to pick up a paintbrush and I can't do it. You know she was just fabulous with them. And so were her helpers." S351, Care Home B, Wave 3
"They are an unfamiliar face so they might engage better rather than a carer who they see on a day to day basis" S352, Care Home B, Wave 3
"they could feel quite, um, intimidated if it someone they don't know." S352, Care Home B, Wave 3
Artist team
"It's expertise. The knowledge, the observation. I mean, you know, you can kind of look at somebody and know what kind of materials they need to work with because you wouldn't get somebody without 25 years of knowledge and expertise knowing that." A01
"I just think the staff are going to approach it differently than we would. Staff are looking for an activity which will keep the residents busy for an hour or two. So that's their result isn't it. It's that they've been happily busy But we want to do a different thing really. We want a different result than that," A02
"Because you're not a member of staff and you're not a visitor. But you're there to do something with them for a couple of hours and then you go back to your own life" A01

"I know, and other people aren't picking up how a small change can be a big step for someone really" A02

Suggestions for future interventions: The artist team made a lot of suggestions regarding suitable intervention characteristics over the three waves. They felt that they learnt during the process and suggested that a successful intervention should have elements such as art discussion, which they did through bringing in books to stimulate conversation, they also noted that they should enhance visual and tactile experiences through bringing in objects and changing the environment to make it look like a gallery, and also that they should

break down complex activities while keeping them age appropriate. The staff valued having an exhibition at the end of the intervention, especially when it was held in the art gallery.

Both groups also spoke about practicalities of the sessions such as the length and number of sessions, having refreshments available. Staff suggested that having the sessions in an open plan area meant that people could come and go as they pleased. The artists also spoke about ergonomics and ensuring that participants were comfortable.

Table 4.11

Illustrative quotes from the care staff and artist team discussing suggestions for future

interventions

Care staff
"And it was very nice for them to go and have their art work on display in an art gallery" S351, Care Home B, Wave 3
"The timing was good and I think where you did it was good" S252, Care Home A. Wave 2
"[With open plan] they've got the freedom to come and go then. It is choice whether they stay and participate. They might do it for a little bit but then if they want to go away So I would definitely say open plan" S158, Care Home A, Wave 1
Artist team
"I think the books actually got them rethinking what they thought art could be." A01
"It's not just about the art session it's about giving them an experience of a gallery without being in a gallery, but bring things in. So maybe, you know, big sheets of fabric. We could hang them or drape them on the chair?" A01
"some of those activities could be quite complex, you know. But we broke them down and made them doable really." A01
"and it's age appropriate things too. Rather than pipe cleaners and things" A01
"And maybe not everyone is comfortable working on the table perhaps we need to kind of have something they can rest on their laps to work" A02

Discussion

Summary of findings

This study aimed to explore the impact of a visual art programme for care home residents with dementia from the perspective of the residents, care staff and artists. Themes from the resident perspective included *memory of the intervention, positive experience of the intervention,* and *discussions about art.* Although analysed separately, similar themes were identified in the care staff and artist team perspective: *impact of the intervention, benefit of gallery visit, benefits of art/artist,* and *suggestions for future interventions.*

The three groups all spoke of the positive impact involvement in a visual art intervention can have on people with dementia. Enjoyment of the participants was identified in all groups and other benefits identified included improvements in mood, communication / interaction, concentration, independence, confidence, and self-esteem.

The results support findings from previous research where similar themes are identified. A number of studies reported group interaction and increased verbalisation (Byrne & MacKinlay, 2012; Camic et al., 2012; Eekelaar et al., 2012), enjoyment and improved mood (Eekelaar et al., 2012; MacPherson et al., 2009; Mangione, 2013), and self-esteem and satisfaction with artworks produced (Flatt et al., 2014; Ullan et al., 2013).

The intervention by Camic et al. (2012) was set in an art gallery and results included a discussion about the art gallery setting which was found to empower social inclusion. This supports the staff perspective in the current study. Participants in Camic et al.'s (2012) study compared the gallery with healthcare services and enjoyed not being treated as someone with a memory impairment. This suggests that the difference in care staff and artist perspectives in the current study may reflect the change in environment, both in the care home setting and also through the gallery visit. The care staff may have felt a benefit of being away from their place of work (the care home) and therefore frame their view of the gallery visit as a nice day out for the residents. The artists may have felt more comfortable in the gallery setting; able to create rapport with the residents judgement-free away from the care home environment, with its focus on day-to-day care tasks.

The gallery visit also raises another interesting discussion point. For this project, the gallery was closed to the public when the participants visited. This was favoured by the gallery staff as they felt they could dedicate their time fully to the group and was also the model used at the Museum of Modern Art in New York which has led groups of people with dementia around the closed gallery for several years (Mittelman & Epstein, 2009). Despite the gallery being closed, one staff member in the current project stated that going to a gallery was 'something normal' agreeing with Camic et al.'s (2012) results of visiting the gallery empowering social inclusion. However, another staff member stated that being closed meant that no-one would make fun of residents. This could however be explained by staff being protective of residents and underestimating their abilities which arose in several of the themes, perhaps as a result of a previous bad experience. It could also demonstrate a perceived lack of awareness of dementia in the general public. The Alzheimer's Society (2013) suggests that care homes have an important role in developing dementia-friendly communities and perhaps more visits to the art gallery could facilitate

this. Further research is therefore needed to explore the impact and differences of care home residents visiting open and closed galleries.

Perhaps one of the most important themes identified in the care staff and artist perspectives was the change in perception of the abilities of the residents. Care staff felt that the researcher was wasting their time by bringing in an artist to lead art sessions in the care home. They were being shown art work from participants in previous waves but had difficulty in accepting the abilities of the residents until they experienced the intervention and its impact for themselves. Professional caretakers in previous studies felt that being involved in an art intervention with people with dementia changed the image they had of the participant (Ullan et al., 2012) and raised their assessment of cognitive abilities (Gregory, 2011). MacPherson et al. (2009) discuss excess disability which is also suggested in the current study.

Excess disability is the discrepancy found when a person's functional abilities are lower than warranted by the impairment (Chung, 2004). It has been found especially relevant in dementia care where carers and healthcare professionals underestimate the remaining abilities of the person with dementia, as found in the current study (Malone & Camp, 2007). This excess disability has a direct impact on the day-to-day lives and activities provided to residents if staff underestimate their remaining abilities. Therefore involvement in an art intervention could be said to help staff and family members realise the remaining abilities of residents and that "their artwork is a visual reminder that persons with dementia can still accomplish and learn new things…thus helping others see beyond their limitations to their strengths and beauty" (Johnson & Sullivan-Marx, 2006, p.316).

Implications for Practice

The data presented offer many implications for practice. Each perspective offers evidence for the positive impact a visual art programme run in a care home can have on people living with dementia, the artist, the staff, and care home as a whole. It has also been suggested that art activities are useful distractions for agitated residents, so could be used as an alternative to medication for managing challenging behaviours. Ideas and suggestions for future interventions are described by the artist team and care staff offering practical tips for anyone wishing to run such an intervention, such as creating a stimulating environment through the art from the groups and also the gallery visit is important for any arts practitioners who wish their work to have a positive impact. As only two of the three waves of intervention included a gallery visit, it could have been possible to tease out whether the gallery and art appreciation element, or the art-making element was most important to creating a positive impact. However, this was not intentional and not the focus of the interviews or analysis so was not realised in the current study. This is however an idea that has been attended to in previous studies to which the authors suggest that the integration of art viewing and making are integral to a successful intervention (Eekelaar et al., 2012).

The most important implication for practice is to not underestimate the abilities of care home residents with dementia as this impacts their day-to-day life when not offered opportunities to engage in meaningful activities deemed too complex.

Strengths and Limitations

This study explored the impact of a visual art programme from three perspectives; the residents, care staff and artist teams. This was a strength of the study as it not only gave residents with dementia the opportunity to provide their first- person accounts rather than relying on proxy accounts, it also considered the views of the care staff and the artist team, which have not been compared in existing literature. The results also support previous findings in the existing literature as discussed above.

In an attempt to ensure the quality of reporting the study, the Consolidated Criteria for Reporting Qualitative Research checklist was consulted (COREQ; Tong, Sainsbury, & Craig, 2007). The current study met 27 of 32 criteria. The criteria not met included returning transcripts to participants to check and participants checking the findings.

The role of the researcher was influential at each stage of the study, from formulating the research question, collecting and analysing the data, and the interpretation of the findings. Therefore it is evident that they were unable to remain objective while analysing the data due to the analysis becoming a hybrid of inductive and deductive. Several sources of bias could also exist in the data as the researcher conducted all interviews and group discussions so interviewer and response bias may be present. However, all interviews were recorded so are open to audit and questions were open-ended. The data were also independently reviewed by a second analyst as recommended in the COREQ checklist mentioned above.

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A weakness of the findings is that the majority of participants had no memory of taking part in the sessions by the time of the interview, although field-notes and observations from videos of sessions were used to supplement their views. Therefore in future research, it is suggested that the interviews be conducted on the last day of the intervention, or if this is not possible, that stronger prompts are used such as clips from the video of the art sessions, photos from the intervention, or by showing their own artwork.

Conclusion

This study provides evidence for the positive impact a visual art programme for care home residents with dementia has on the residents, care staff, and artist team. The three groups all spoke of the benefits that involvement in a visual art intervention can have on people with dementia. Enjoyment of the participants was identified in all groups and other benefits identified included improvements in mood, communication / interaction, concentration, independence, confidence, and self-esteem.

However, perhaps the most important impact of the intervention found was the change in perception of the abilities of the residents by the care staff and artist team who underestimated what the residents could achieve. One staff member even stated that "*I thought you were wasting your time, if I'm honest*" when first approached about the project. This clearly exemplifies the excess disability imposed on care home residents and the results of this study have implications for improving the day-to-day life for residents with dementia.

Chapter 5: Case Vignettes

Summary

Two case vignettes are presented combining quantitative and qualitative data as well as observations by the researcher, to demonstrate the personal impact of the visual art programme for two residents from Home A: Mavis and Edna.

During the research process the author spent a lot of time in the care homes interviewing and observing participants during and outside of the art intervention sessions. It became clear that this was a privileged position as they were able to fully appreciate just how much the intervention impacted the lives of the residents. The artists had no knowledge of how the residents were outside of the art sessions, and care staff were often too busy to attend whole sessions and witness the transformation of some of the participants. This chapter attempts to provide a more detailed consideration of the experience of two participants to exemplify the observations of the researcher.

This makes an important contribution to the thesis when considering the importance placed on person-centred care throughout. This chapter focusses on the results of two different participants from Wave 1 and 2. Focussing on the personal impact of the visual art intervention demonstrates the importance of valuing the individual when considering meaningful activities for care home residents with dementia. The impact on individuals can easily be forgotten when focussing on achieving significant quantitative results or high quality qualitative results. While these are essential to improve the evidence base, it is also important to remember the effect on the individual and this chapter aims to remind the reader the reason why the research is so important and how it can have a huge impact on people's lives. Stepping away from the whole picture provided in the results in the two previous chapters will enable the reader to appreciate what increasing quality of life and well-being can mean to the individual.
The aim of this thesis was to answer whether a visual art intervention could increase the quality of life and well-being of care home residents with dementia, as presented in Chapters 3 and 4. This chapter answers this for two individual participants from different waves of the intervention. Focussing on the personal impact of the visual art intervention demonstrates the importance of valuing the individual when considering meaningful activities for care home residents with dementia and is vital for considering person-centred care. The impact on individuals can easily be forgotten when striving for scientific rigour. While this is essential to improve the evidence base, it is also important to remember the effect on the individual and this chapter aims to remind the reader the reason why the research is so important and how it can have a huge impact on people's lives.

This chapter therefore brings together the quantitative and qualitative results, as well as observations and field notes by the researcher in two case vignettes to demonstrate the personal impact of the visual art intervention on the individual. Both names used are pseudonyms. The vignettes were chosen as examples of what a difference the intervention could make to the individual.

Mavis

Mavis was 89 at the first visit and participated in the first wave of intervention. The researcher assessed her as having moderate dementia, as indicated by the CDR. She had been a staff nurse for many years and had a daughter that visited her regularly. Her daughter consented as a personal consultee and although she was keen that her mother had the opportunity to participate, she wasn't sure whether she would take an interest in art.

In the care home, Mavis became distressed a lot and often walked around, aided by her walking frame. She shouted "*Nurse, when can I go home?*" frequently and was often found rattling the door trying to get out. On one occasion when the researcher was present, Mavis went out into the garden and shouted very loudly "*Help! Help! Someone get the police!*" at the top of her voice, she let the alarm off several other times, and tried to smash the door with vases from the dining room tables on another occasion. There was no mention in Mavis' care file that she had been prescribed any medication to calm her distress.

Observations for Mavis, in the unstructured activity in particular, were difficult at times due to her moving from room to room. There were several occasions where the researcher

started an observation but had to discontinue when Mavis went out of view into another room. In contrast to the agitated state described above, when sat down, Mavis often slept. When sat down, and awake, Mavis would take part in activities on offer. She enjoyed listening to the music when the activities worker sang, but was less likely to join in if he was playing games such as skittles. In chair aerobics, Mavis would quietly get on with the tasks, although she often fell asleep.

Mavis attended seven of the eight art sessions (See table 5.1 for more details of the content of the sessions). She seemed keen to join but would doze on and off for periods of 5 minutes or so in the first few weeks, sometimes mid-painting. This was not always captured by the observations as she would wake up and continue painting before the next observation meaning that sustained attention starts high at Time 1. However, the amount of time spent sleeping decreased as the sessions went on which is shown on the Greater Cincinnati Chapter Well-Being Observation Tool by an increase of mean sustained attention (S.A 1) going from 75% at Time 1 to 94% at Time 2. From the beginning, as soon as Mavis had chosen her materials, such as a paintbrush, she worked independently. Her daughter had thought to start with that it would help if she was present, but in fact soon decided that there was no need as Mavis went straight to work on her own. The mean percentage observations of pleasure (P1) started high and increased over time during the art sessions from 68.8% at Time 1 to 87.5% in Time 2, as shown in Figure 5.1.



Figure 5.1 shows the percentage mean in each indicator of the Greater Cincinnati Chapter Well-Being Observation Tool at Time 1 (blue) and Time 2 (purple) in the art intervention for Mavis; I = Interest. S.A= Sustained Attention. P= Pleasure. N.A= Negative Affect. S= Sadness. S.E= Self Esteem. N= Normalcy.

During the art sessions, no agitation was observed in Time 1 or Time 2 which was unexpected by staff and the researcher who had witnessed numerous occasions of distress and agitation during observations outside of the sessions. The manager commented that "Mavis will tend to be the more agitated person so it [art session] helps to calm her down". This was also noticed by her daughter who said "Thank you. It's really fascinating. I've really enjoyed it...Just seeing it. Because she gets so agitated sometimes. But it [the intervention]'s so therapeutic I can just see. She doesn't care if I'm here or not." Staff commented about the reduction in agitation they had noticed during the session and also said that they had noticed that Mavis was calm and settled after the session until 9pm that evening. The intervention was therefore noted to reduce Mavis' agitation beyond the art session.

Table 5.1

Content of Wave 1 intervention sessions and researcher observations of Mavis week by

week.

Week 1: Gallery visit	5 participants had expressed a wish to attend the gallery, however, two participants dropped out on the day (Mavis being one). Once at the gallery with the 3 remaining participants, the artist had picked five artworks from the exhibition to discuss as a group. It was a photographic exhibition with images from across Wales.
Week 2	Following on from discussions around colours and rainbows in one of the artworks in the exhibition, this week the theme was 'playing around with colours' using watercolour paint palettes and watercolour crayons. Reproductions of the artworks from the exhibition and art books were available as inspiration. Mavis listened to the artists' introduction and dozed off. Upon waking, she picked up a paintbrush and started painting with little assistance. She went through cycles of sustained attention followed by dozing off with the paintbrush in her hands for the rest of the session. Mavis was pleased when receiving complimentary comments from other participants at the end of the session. [See figure 5.2]
Week 3	This week the theme was 'fluidity and textures' using inks, paints and crayons with different types of brushes and feathers to create different textures. The artist demonstrated by using a brush and then feathers to create swirls on the paper. One participant commented that it looked like music. Mavis chose to use a medium-sized brush and inks. [See figure 5.2] Her daughter was present at the beginning of the session but decided to leave twenty minutes in. Mavis spent longer periods of engagement before dozing off towards the end of the session. One of the participants spent her time looking through some of the artist's Van Gogh books and discussed his study of the Sunflower.
Week 4	Following the discussion around Van Gogh in the previous session, this week's theme was 'sunflowers'. The artist brought in fresh sunflowers to handle as inspiration as well as having the Van Gogh books available. Mavis started before the artist had finished her introduction and worked independently for the majority of the session. Materials available were watercolour paints and crayons.
Week 5	This session was another opportunity to engage with the sunflowers. Mavis chose to add to her painting from the previous week using some new stronger colours [See Figure 5.2]. She was engaged most of the session, only dozing off twice for short periods of time.
Week 6	This week the artist demonstrated printing using inks and print blocks that she uses in her own work. There were many different colours of inks and watercolour paints and pro-markers to add colour and a range of different themes of print blocks such as nature, fashion, transport. Mavis chose a kingfisher. She slept at times during this session and didn't seem as engaged as previous weeks. However, at the end, she said " <i>Thanks for all your patience</i> " to the artist.
Week 7	Mavis was the first to arrive for the session and spent time one-to-one with the artist before the other participants arrived. She chose the colours she wished to use and continued to work independently painting the kingfisher print she had started the previous week [see Figure 5.2]. She was so focussed on her work that she didn't acknowledge the arrival of the other participants. She remained focussed for the whole session and didn't sleep at all.
Week 8	This week the group were given the opportunity to finish off their artwork. Mavis had 2 of a series of 3 kingfisher prints to complete [see Figure 5.2]. Mavis told a staff member that she " <i>just want[ed] to go to sleep</i> " when she arrived. However, once she started on her art work she became focussed and engaged for the rest of the session. When the artist mentioned it was the end, Mavis asked " <i>when are you coming again</i> ?"

As well as being less agitated and sleeping less during the sessions, the artist commented that "*looking back at all her work, Mavis in particular, her skill level is really, every week it's improved*". This is reflected when looking at the artwork produced each week as she achieves much finer detail as the weeks progress (Figure 5.2).

In her follow-up interview, Mavis had no recollection of the art sessions. But when asked whether she enjoyed making her own art, she said, "*Well, I don't do a lot but yes, what I do.*"

At the celebration event, Mavis's daughter was very pleased with all of her mother's art work, especially those framed. She asked the researcher to send the photos to her so that she could pass them on to other family members. She also offered to come and lead sessions if ever needed.

On the QoL-AD, Mavis's score increased by 8 points from 35 points before the intervention to 43 points afterwards; the highest increase of all participants, indicating a large increase in quality of life between baseline and follow-up. The items with an increase of one point, from 'fair' to 'good' were physical health, and mood; from 'good' to 'excellent' were living situation, family, relationship with daughter, and life as a whole; and Mavis rated her energy 'poor' in the baseline interview and increased it by two points to 'good' in the follow-up. Interestingly, Mavis's GDS-12R increased from 1 at baseline to 4 at the follow-up, indicating that she had entered the range for depression despite this increase in quality of life, and in particular, increase in self-reported mood on the QoL-AD.





Week 3



Week 4 and 5

Week 7



Week 7 and 8

Figure 5.2 shows Mavis' artwork throughout the weeks.

Nobody had been aware of Mavis' interest in art before the intervention. She herself told the researcher "*Oh I was hopeless at school with art...They gave me no encouragement at all*". However, since the intervention, care staff noticed a lasting effect and began to use it as a way to calm her down if she gets agitated.

"Mavis- what we've noticed since she's done this, when she is having a bad day – we will ask her – 'Do you want to come and do some drawing or colouring' and she enjoys it – what's the word I am looking for – it's a diversion, a distraction away from whatever is upsetting her in her mind that day."

Her artwork was put up on her wall in her room and she proudly tells people she did it when asked. If it wasn't for taking part in the research project, Mavis may have never have had the chance to explore her creativity and discover her skill of which she has become so proud. Staff would also not have found out what a positive and calming impact engaging with art sessions had on her. The art intervention made a huge impact to Mavis' day-to-day life. She and staff now have a way of managing her agitation making her life in the care home more pleasant.

Edna

Edna was the least impaired participant. The researcher assessed her as having mild dementia, as indicated by the CDR. She had only been a resident at Home A for a few months before participating in the second wave of intervention. Her daughter regularly brought her grandchildren [Edna's great grandchildren] to visit her in the home and Edna loved giving the children attention. She also had a son who lived nearby and visited regularly.

Edna was actively involved in the consent process with her daughter and discussed the project with the researcher while making her decision. She was happy to participate, although she thought her arthritis might hinder her to actually take part in any art session. She decided, however, that it was worth signing up and coming to have a try. Her daughter, who was present for this discussion, signed as a personal consultee as Edna said she would prefer her daughter to sign.

Due to time constraints, there were no baseline observations for Edna, so the first observations were done at Time 1. At the first art session, Edna did not stay long, and gave lots of reasons for not taking part. It was noted that there was music in the background in the care home which was distracting, and was addressed later in the session. Edna said she was unable to hear as she was 'extremely deaf' and could not see. She also seemed uncomfortable in her seat. After 3 minutes, she got up and left as she was concerned that someone might take her favourite chair in the lounge. She returned a quarter of an hour later and watched for a few minutes before saying to staff "It's too noisy" and leaving.

In the second week, Edna stayed for the whole session. She stated several times that she couldn't do anything due to osteoporosis in her right hand. One of the artist volunteers encouraged her to use her left hand, but she was reluctant. When complimented by a passer-by, she said "*I wouldn't say great, but I'm having a go*".

As the weeks went on [see table 5.2 for detail of the content of the sessions], Edna made sure she brought a cushion so that she was more comfortable. She continued to say things like "*I'm very, very deaf*", but it sometimes seemed that she was selectively deaf, hearing things from the other end of the table sometimes, but insisting she couldn't hear when someone next to her was speaking.

Edna could come across as bossy at times, shouting at other participants "*Oi hello! Don't fall asleep now!*". However, as the weeks went on, it was clear she was fond of the other participants and was trying to help them as she was aware that she was less impaired. In Week 4 she said she was worried she was rude when trying to encourage others. When shown the work of another participant at the end of the session, she said "*I'm delighted to see what she's done*". By the last week, Edna was waiting for the artist when she arrived and worked very well on her own. Edna encouraged other residents to join the art session. In the last week, she shouted to nearby residents "*Come over here! Come on! It's lovely. It takes your mind off. It takes your mind off things. Miserable things*". This quote eloquently describes the transformative effect that Edna felt the intervention had. She was so engrossed in her work that she jumped when her son came to say hello.

At the celebration event, Edna's daughter came with her two young grandchildren. Edna was pleased that they could come and join in with the art session. Her daughter said to her mother and the researcher "*I think you're enjoying [it] aren't you. I think she's enjoying the Friday sessions*". She also questioned whether some of the art work was Edna's as she was surprised at how fine detail she had achieved. Comparing her work from the first few weeks, it can be seen that Edna showed the ability to work in much finer details despite protests regarding her arthritis.

Table 5.2

Content of Wave 2 intervention sessions and researcher observations of Edna week-by-

week

Week 1	There was no gallery visit in this wave as the plans fell through. The session began with discussions of autumnal themes using art books chosen by the artist. They had also brought in autumn leaves, looking at colours and shapes to prompt painting with watercolours. There was music from another part of the home in the background which was distracting. Edna only stayed for a few minutes. She returned later but said it was too noisy and left again.
Week 2	The theme was 'colours and patterns' with books, leaves, and orchids as prompts. Edna was reluctant to try using her left hand (which had been suggested in reply to her osteoporosis in her right hand), but eventually she tried using the watercolour crayons and paints. She stayed for the whole session.
Week 3	The main artist was absent for this session. The artist volunteers brought in sea shells and seaweed to create a sensory experience and inspiration. Not many participants this week. Edna responded well to the handling and painted things that reminded her of the seaside [see Figure 5.3]. After half an hour she got up and left.
Week 4	The artist team introduced print blocks and inks, and adding colour with paints, watercolour crayon, and pro markers. Edna arrived halfway through as she had a visitor. She chose a long brush and watercolours to add to a print that had already been done [see Figure 5.3]. She interacted well with the artist team and complemented other participants' work.
Week 5	Print blocks and inks (Christmas or butterfly theme) with watercolours. There were 2 members of staff and a participant's relative so there was almost a one-to-one artist/staff to participant ratio. Edna arrived 10 minutes into the session and used a print block that staff said was 'Santa' but she was happier calling it red-riding hood [see Figure 5.3]. She stayed for the whole session and was engaged throughout.
Week 6	This week the artist brought more print blocks including more Christmas themed ones for the residents to make cards. Edna attended the whole session and experimented with prints and pro markers. She listened to suggestions from the artist team. She made a card to give to her grandchildren.
Week 7	Finishing cards and embellishing them. Edna arrived late due to having a visitor. When the artist volunteer offered to do a print for her to embellish, she chose to do it herself. She chose to use crayons as she said these were easier for her to use [see Figure 5.3].
Week 8	Painting on textiles in frames. The artist had prepared frames with fabric stretched over them with pre-drawn images in wax. The participants then used inks. Edna was ready and waiting for the session. She found it easier to rest the frame on a facing chair rather than the table. She systematically filled in the shapes rather than any of the surrounding area. She was so engrossed in her work that she jumped when her son came over to say hello.



Week 3

Week 4



Week 5

Week 7





Figure 5.3 shows Edna's artwork throughout the weeks

Edna was the only participant to fully remember taking part in the art sessions. In her follow-up interview, she gave practical feedback about the activities that she enjoyed. For example, she decided the watercolour crayons were easier for her to use.

"Edna: It's harder to work if you decide to use brush and water and paint. It's a bit hard on your [points to wrist] because you've got to go into the water...Whereas, if I decide to do it in crayon, or if it is suitable, then the crayons are ready to just go [motions colouring in]. So that's easier.

Researcher: Ok, so you prefer the crayons?

Edna: It's not that I prefer them, but it is easier. Naturally they're in your hand. If you got water paint, then you've got to dip in the water and do your painting. And because you're shaky, it's too late; you've got paint where it shouldn't go."

She also said that the art sessions were the only activity that she went to and was keen to have more than one session a week. This was reflected in observations; there is only one observation for the other structured activity in which it was clear she was only there as she'd happened to be in the room before the activities worker arrived as she ignored all activity. Due to the incomplete observations for the other structured activity, Edna's data were excluded from the results presented in Chapter 4.

"In fact, it's the only thing I go to unless somebody has a game of these [dominos] with me. There is nothing else to do here, love."

"Ooo yes, I love that [art sessions]. I only wish it was two or three times a week."

Edna spoke of an increase in self-esteem, which was also shown in the observations. The Self-esteem (S.E) 1 indicator on Figure 5.4 is the expression of nonverbal pride, which increased from 0% to 21% over time. Edna also said that attending the art sessions occupied her brain.

"Oh I enjoy it. You enjoy it. And I've stopped saying to myself 'it's rubbish. I'm drawing rubbish, or painting rubbish.' I do what comes out of my head. And it's enjoyable. The time goes too quick."

"Edna: Um yes, it [the intervention]'s made a big difference to my mind. To my, yeah because it passes a good hour once a week"

"Painting or crayoning can take your mind off. And it's colours and I love that. I wish there was a little class every day."



Figure 5.4 shows the percentage mean in each indicator of the Greater Cincinnati Chapter Well-Being Observation Tool at Time 1 (blue) and Time 2 (purple) in the art intervention for Edna; I = Interest. S.A= Sustained Attention. P= Pleasure. N.A= Negative Affect. S= Sadness. S.E= Self-Esteem. N= Normalcy.

Sustained Attention (S.A) 1 on Figure 5.4 shows an increase in sustained attention in Time 2 compared with Time 1 during the art intervention. There is also an increase in pleasure (P1), although very small. In fact, what Edna says in her follow-up interview doesn't match the low pleasure score shown in Figure 5.4. However, perhaps her score of 9 on the GDS-12R could explain this. A cut-off point of 4 or 5 is suggested as an indicator of depression for research purposes, meaning that Edna was in the very depressed range (Sutcliffe et al., 2000). This could also explain her reluctance to do other activities. Despite this, Edna's score on the QoL-AD increased by two points from 30 to 32 points, with her rating her mood as 'fair' at the baseline and 'good' at follow-up. She rated her physical health as 'poor' at the baseline and 'fair' at follow-up; perhaps as a result of realising she could achieve more that she thought.

Edna was aware that she was not as impaired as the other residents and it seemed to be a burden to her.

"Imagine. There's only one lady I've met who knows that she's here for good, like I know. Cos they all think they are going home. And I feel so sorry. I used to try to persuade them not to think that way you see but I've given up."

She also felt a burden to others:

"I would love to still be able to go and look in an art gallery. There weren't such things when I was young. And you can't go when you're older! Who's going to have patience to take you round and [say] 'what do you think of this', 'what do you think of that?"

Without the art intervention, Edna would have had no activity that interested her at the care home, meaning that she wasn't engaging in any meaningful activity in her day-to-day life. The data collected from observations of her may have been excluded from the analysis, but the intervention made a huge impact to her, as she described in her follow-up interview. She was included as a case vignette as a reminder that statistical significance is not the only indicator of a successful intervention. She sums it up perfectly when writing a note to herself to remind her of the following session:

"Art on Friday is on which will make me very happy".

Conclusion

This chapter illustrates the impact of the visual art intervention on the individual and reminds the reader of the importance of not forgetting this amongst the drive to improve the scientific rigour. Whilst improving the evidence base is vital to strengthen the case for providing such programmes (and will be explored further in the following chapter), so too is the impact on the individual.

This chapter demonstrates the importance of person-centred care and also the application of the four elements of person-centred care described in Chapter 1 (VIPS) to providing a meaningful activity such as a visual art intervention. The intervention enabled those around them to value the residents and their skills. Participants were treated as individuals showing their individual style and preference of art and materials. The intervention helped staff to understand the world from the perspective of the residents and identify areas of support required, especially in the case of Mavis who found a new way of reducing her

distress. And lastly, the intervention provided a social environment that supported the psychological needs of the participants such as inclusion, occupation, and identity.

Focussing on the personal impact of the visual art intervention demonstrates the importance of valuing the individual when considering meaningful activities for care home residents with dementia. Lessons can be learnt from taking the time to remember what increasing quality of life and well-being can mean to the individual. The lives of the two participants discussed were transformed by taking part in the art intervention.

Chapter 6: Are visual arts interventions effective in promoting positive outcomes for people living with dementia? A systematic review and narrative synthesis

Summary

Many claims have been made as to the broad range of positive effects that involvement with the arts can have on people living with dementia. However, evidence of any benefits is overshadowed by questions of methodological rigour. Previous reviews have made suggestions for improvements, such as appropriate measures, more details about the intervention and better quality research. In light of this, this systematic review used a narrative synthesis framework to review the effectiveness of visual art interventions for people with dementia and to judge whether the evidence has improved. Sixteen studies were identified that met the full inclusion criteria. The evidence for claims of the effectiveness was found to have improved due to more appropriate measures being chosen. Studies are more concerned with positive outcomes such as well-being and enjoyment rather than clinical outcomes. Studies included more details about the interventions but better quality research designs are still needed. This review found only a few high quality studies.

Overall, the evidence for the positive effect that visual art interventions have on people living with dementia is improving in extent and quality. However, there is still further work required before anecdotal reports of improvements can be said to have an evidential basis.

This review was undertaken after the completion of data collection to inform the introduction to the thesis, as when beginning the project, there had been very little existing research. However, it soon became evident that the field of art interventions for people with dementia had shown such a marked increase since the start of the study that it would not be a true reflection of the limited research available when this project began. It therefore seemed more appropriate to acknowledge this progress in the field by placing the review after the results of the current study and including them in the synthesis. Therefore, the results presented in the two previous results chapters are critically evaluated along with the identified existing research.

For the purposes of this review, Chapter 3 is reported as Algar et al., 2015a and Chapter 4 is reported as Algar et al., 2015b.

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Introduction

Rationale

Many claims have been made as to the broad range of positive effects that involvement with the arts can have on people living with dementia, including those in Chapter 3. However, evidence of any benefits is overshadowed by questions of methodological rigour. Previous reviews of art programmes with older people and people with dementia have all highlighted methodological issues (Beard, 2011; Castora-Binkley, Noekler, Prohaska, & Satariano, 2010; de Medeiros & Basting, 2013; Mental Health Foundation, 2011; Salisbury, Windle, & Algar, 2011).

For example, the Mental Health Foundation (2011) reviewed the impact of participatory arts for older people, including those with dementia. They concluded that the evidence base was inconclusive due to methodological issues and recommended that more funding should be provided for evaluating projects, calling for better quality research which should attempt to show the unique effects of the art activities through inclusion of non-arts based control conditions. Similarly, a review of art participation on health outcomes of older adults (Castora-Binkley et al., 2010) concluded that the then evidence base lacked adequate study designs and sample sizes; measurement tools (if any) were unspecified, clinical outcomes were emphasised rather than quality of life, and data analysis was unsatisfactory.

Beard's (2011) review of art therapies (including music therapy, visual art therapies, drama therapy, and dance/movement therapy), called for studies to include self-reports from people living with dementia, to include those in the early stages of dementia, to include a variety of settings instead of solely being set in a care home, and to measure quality of life and enjoyment, rather than using clinical scales.

de Medeiros and Basting (2013) concluded that a better understanding of the intervention is needed to inform more appropriate designs for future research. They argued that information is needed about what the interventions comprise of, how they are delivered, and who the participants are. In turn this could help answer the question of how art interventions work. Castora-Binkley et al. (2010) also suggested that it would be beneficial for planning a project to know timings and costs associated by clarifying details of the duration of an intervention, how long individual sessions should be, and the frequency. Since these reviews were published there has been a marked increase in the publication of studies of art programmes with people with dementia. The current review focusses only on visual art programmes with people with dementia and aims to explore whether these studies have taken heed of recommendations made in the previous reviews (see Table 6.1), specifically with regards to appropriate outcomes and description of the intervention.

Table 6.1.

Recommendations made in reviews of art interventions with older people and people with dementia.

Review Author (s)	Recommendations
Beard, 2011	 Self-report from PWD People with early stage dementia Variety of settings Measurement of enjoyment Goals of enrichment rather than management of deficits
Castora-Binkley et al., 2010	 Larger and more diverse samples Intervention details – duration, length of sessions, frequency
de Medeiros & Basting, 2013	 Appropriate measures, including qualitative approaches Intervention details – what intervention comprises of, how delivered (how often and by whom), who participants are
МНF, 2011	 Better quality research Intervention details – whether professional artist was involved and their role, setting, sustainability Isolation of unique effect of art through comparison of non-art based activities

A narrative synthesis framework was used to review music therapy literature (McDermott, Crellin, Ridder, & Orrell, 2012). As it is acknowledged in the existing reviews that studies of visual art programmes with people living with dementia are likely to include various study designs of questionable methodological rigour, it was decided that a narrative synthesis would also be the most suitable method to review studies of visual art interventions. This approach 'adopts a textual approach to the process of synthesis to "tell the story" of the findings from the included studies' that goes beyond effectiveness but remains a transparent and systematic process (p.5, Popay et al., 2006). A narrative synthesis framework consists of four elements: 1. Developing a theory of change; 2. Preliminary synthesis; 3. Exploring relationships between studies; 4. Assessing the robustness of the synthesis (p.11, Popay et al., 2006). The review is also guided by the PRISMA statement to ensure quality reporting (Moher, Liberati, Tetzlaff, & Altman, 2009).

Objectives

Reflecting the methodology for narrative synthesis (Popay et al., 2006) and adapted in the work of McDermott et al. (2012) this systematic review and narrative synthesis aims to:

- a. Systematically search and identify primary research studies of visual art interventions with people living with dementia
- b. Develop a theory of change (Narrative synthesis element 1)
- c. Conduct a preliminary synthesis including a critical appraisal of the reported methodological rigour of the studies and detailing the interventions and outcomes reported (Narrative synthesis element 2)
- d. To explore the relationships within and between the studies regarding appropriate outcomes, intervention details, and better quality research (Narrative synthesis element 3)
- e. To assess the robustness of the synthesis (Narrative synthesis element 4)

Methods (Theory of change)

The first element of the narrative synthesis framework is the development of a theory of change to explain how an intervention might work, why, and for whom. This will then inform decisions about the review question and what type of studies to include in the review (Popay et al., 2006).

As few previous researchers have proposed a visual art intervention underpinned by theory it is important to explore further any theories of how and why a visual art intervention may increase quality of life that are suggested in the included studies. This will therefore be a focus when reviewing the intervention details of included studies (and will be explored further in Chapter 7). Previous reviews have acknowledged that more work is needed to inform a theoretical model of how and why visual art interventions might promote positive outcomes for people living with dementia (Castora-Binkley et al., 2010). de Medeiros and Basting (2013) propose that cultural interventions "tap into and develop individual potential and social meaning systems to achieve a transformative experience" (p.7) and Beard (2011) suggests that art interventions are "psychosocial, idiosyncratic and experiential" so should not be considered in biomedical terms (p.647). Lastly, Castora-Binkley and colleagues propose theories of mastery and social engagement provided by Cohen and colleagues (2006) and a theory of 'flow' from Csikszentmihalyi (1990).

For the purposes of this review it is important to make clear definitions to inform the review question and inclusion criteria. The current review concerns visual arts engagement, or participatory arts, led by artist facilitators that are associated with Arts in Health approaches to promote general well-being. Therefore although acknowledging the therapeutic effects of the arts interventions, the review will not include studies of Art Therapy, which is a form of psychotherapy where the art is a tool to communicate emotions or memories (British Association of Art Therapists, 2014).

Definition of visual art intervention for this review

Theory:

- Use of visual art to promote a participant's health and well-being
- Therapeutic effects of art, not art therapy

Practice/operational definition:

- Conducted by an artist, artist practitioner, gallery/museum staff, not an art therapist
- No restriction on setting

Evidence:

- Qualitative: Observations, focus groups, interviews
- Quantitative: RCTs, quasi experimental studies, observational studies

Eligibility criteria

Inclusion criteria:

• Primary research conducted with people with dementia

- Interventions that relate to art, creativity, community, museums, galleries, hobbies and learning.
- Published in English
- Published in peer reviewed journals
- Visual art; Participatory art; community art

Exclusion criteria:

- Research of no relevance to Alzheimer's disease/dementia
- Pharmacological intervention studies
- Research adopting only neurological measures such as MRI or EEG
- Art therapy as defined above
- Papers reporting exclusively from the perspective of interventionist/ those delivering the group

Information sources

Studies were identified by searching databases, scanning reference lists of articles and consultation with experts in the field. Limits were applied for language and only English language studies were considered. The search was applied to ASSIA, Medline, SAGE, CINAHL, Psych Info, PsycARTICLES, Web of Knowledge, JSTOR, and Sociological abstracts. The last search was run in November 2013. A limited update literature search was performed from November 2013 to September 2014.

Search strategy

The following terms were used to search databases: dementia, dementia care, creativity, creative, art, quality of life, elder, visual art, art, artist, artist health disability, community, meaningful activity, enjoyable, well-being, self-esteem, group activity, hobbies, older adults

Study selection

Titles and abstracts were screened and eligibility was assessed independently by SG and CHJ. Disagreements by reviewers were resolved by consensus. KA checked the full papers of included studies to ensure agreement.

Data collection

Data was extracted independently by CHJ and KA for each included study using the Cochrane Collaboration Data Collection Form which was retrieved from the Cochrane Collaboration website. This form was then used by KA to develop an Excel spreadsheet to allow comparison between studies.

Data Items

Information was extracted from each included study on: 1. Characteristics of participants (including age, gender, stage and severity of dementia) 2. Aim of the study 3. Intervention description (including setting, who leads it, and timings) 4. Control conditions 5. Type of outcome measure 6. Analysis 7. Results

Risk of bias in individual studies

The Mixed Methods Appraisal Tool (MMAT; Pluye et al., 2011) was used to appraise the quality of reporting in the studies included in the review, following data extraction. It was chosen as the tool can be used to appraise and compare the reported methodological rigour of qualitative, quantitative and mixed methods studies, and the appropriateness of what is being measured and how. A tutorial is available to aid in application of the criteria. The MMAT consists of sections for qualitative and quantitative studies, (either randomised controlled trials, non-randomised, or descriptive studies), and a mixed methods component which is completed in addition to the qualitative and relevant quantitative section. The tool appraises the reported methodological quality by representing the number of criteria met, divided by the number of criteria possible for that study (i.e. If a qualitative study, only 4 criteria are possible compared to a mixed methods study where 11 criteria are possible), including whether an appropriate measure was used. The MMAT has been found easy to use with inter-rater reliability ranging from moderate to perfect agreement on first ratings which increased to 76% perfect agreement after discussion and reference to the tutorial (Pace et al., 2012). To minimise bias, two reviewers (CHJ and KA) evaluated the studies independently. Where any discrepancies existed, they were discussed and agreed upon.

Summary measures

In recognition of the recommendation in Beard's (2011) review, the outcome of primary interest was quality of life and enjoyment.

Synthesis of results

Preliminary synthesis

A preliminary synthesis was undertaken using tabulation to provide details of the characteristics of each study, grouping and clustering studies to aid the process of description and analysis, and translating primary themes from qualitative data to explore similarities and differences between studies (Popay et al, 2006).

Exploring relationships within and between studies

To explore the relationship between the characteristics of individual studies and their reported findings and between the findings of different studies, a process of considering variability in outcomes, study populations, interventions, and settings was undertaken. This was done by analysing moderator variables and subgroup analyses (Popay et al., 2006).

Results (Preliminary synthesis)

Study selection

Figure 6.1 provides a flowchart of the review process. A total of 16 studies were identified for inclusion in the review. The search of databases provided a total of 5017 citations. After adjusting for duplicates 4983 remained. Of these, 4968 were discarded because after reviewing the titles, abstracts, or full text, these papers did not meet the criteria.

Characteristics of included studies (Groups and clusters)

A summary of each included study is provided in Table 6.2, and Table 6.3 presents details of the interventions provided in each study.

Participants

The included studies involved 325 people living with dementia, 73 carers, and 3 artists. The level of impairment of those living with dementia ranged from mild to very severe. Where reported, ages ranged from 58 to 97 for the participants living with dementia.

Intervention

The sixteen included studies related to thirteen visual art programmes for people living with dementia. Two studies concerned art viewing and appreciation (MacPherson et al.,

2009; Mangione, 2013) seven art making (Brownell, 2008; Byrne & MacKinlay, 2012; Gross et al., 2013; Kinney & Rentz, 2005; Rentz, 2002; Sauer et al., 2014; Walsh et al., 2011), and seven art viewing/appreciation and art making (Algar et al, 2015a; Algar et al., 2015b; Camic et al., 2013; Eekelaar et al., 2012; Flatt et al., 2014; Roe et al., 2014; Ullan et al., 2013).

Six were based in an art gallery setting (Camic et al., 2013; Eekelaar, et al., 2012; Flatt et al., 2014; MacPherson et al., 2009; Mangione, 2013; Roe et al., 2014), three in a day centre (Kinney & Rentz, 2005; Rentz, 2002; Ullan et al., 2013), and the remaining seven in a long term care facility (Algar et al., 2015a; Algar et al., 2015b; Brownell, 2008; Byrne & MacKinlay, 2012; Gross et al., 2013; Sauer et al, 2014; Walsh et al., 2011).

The art interventions were led by gallery or museum educators in all six gallery-based studies (Camic et al., 2013; Eekelaar, et al., 2012; Flatt et al., 2014; MacPherson et al., 2009; Mangione, 2013; Roe et al., 2014), artist facilitators / educators led the intervention in five other studies (Algar et al., 2015a; Algar et al., 2015b; Kinney & Rentz, 2005; Rentz, 2002;Ullan et al., 2013), students/interns led the activity in three studies (Brownell, 2008; Gross et al., 2013; Sauer et al., 2014), an 'interventionist' in one (Walsh et al., 2011), and chaplains or pastoral carers in another (Byrne & MacKinlay, 2012).

Art activities were based on themes that followed the work discussed beforehand or based on items shown in the group. The length and frequency of programme ranged from oneoff sessions to 20 weekly sessions and number of participants involved ranged from oneto-one sessions to group tours.



Figure 6.1. Flowchart of the review process

Table 6.2Table of study characteristics

Author (publication year)	Study Design	Number of participants (PWD ; Carers)	Level of impairment	Type of intervention	Control	Measure	Key findings
Algar, Woods, & Windle (2015 a)	Repeated measures pre/post	16	Mild to moderate	Art appreciation and art making	Another structured activity and Unstructured time	QoL-AD, GDS- 12R, GCCWBOT, HCS	Observed pleasure increased significantly over time in the art but not in control conditions. Improved communication skills and a trend to an improvement in quality of life found after attending the art intervention. Mean percentages for sustained attention, pleasure, self-esteem and normalcy were higher in the art intervention than the other conditions indicating greater observed well-being in the art.
Algar, Woods, & Windle (2015b)	Qualitative	21;11; (3 artists)	Mild to Moderate	Art appreciation and art making	-	Semi structured interviews with residents, care staff and artist team; field notes and observations from videos of sessions	Themes identified were: Residents- memory of the intervention; positive experience of the intervention; and discussions about art. Care staff and artist team – impact of the intervention; benefit of gallery visit; benefits of art/artist; suggestions for future interventions.
Brownell (2008)	Quasi experimental design with a control and intervention group	36;7 [Inconsistency as states 36 on p.7 and 40 on p.8]	Moderate to severe	Art making	Simple drawing activity	AARS, LOE, ABMI	At Time 3, those in control condition showed significantly more anxiety/fear and significantly more verbal agitation. No significant differences were found in level of engagement between the two conditions.

Byrne & MacKinlay (2012)	Qualitative	11; N/A [Inconsistency -states 15 in abstract, but 11 in text]	NR but comorbidity of depression	Art making	-	Audio recorded sessions, journal of non-verbal behaviours, facilitator journals	Themes identified: Communication style of the facilitator; Relationship/connectedness; Identity; Group atmosphere/environment; Engagement in group activities; and Meaning in life
Camic, Tischler, & Pearman (2013)	Mixed methods pre- post	12;12	Mild to moderate	Art viewing and art making	-	DEMQOL, ZBI, BADLS, Semi structured interviews	No significant differences found between the 2 galleries so data was combined. No significant differences between pre and post intervention were found using the combined data for carer burden, activities of daily living, quality of life.
							Themes identified were: Social impact -social aspect of the group, caring relationships; Cognitive capacities - engagement, new learning, memory ; Art gallery setting - empowering social inclusion, feeling valuable, comparison to healthcare services, engaging with the artwork, and intervention structure.
Eekelaar, Camic, & Springham (2012)	Mixed methods. Pre- post with 4 weeks follow-up	6;6	Mild to moderate	Art viewing and art making	-	Episodic memory, verbal fluency, thematic analysis	Improvement of episodic memory in PWD which was maintained at follow- up a month later. Verbal fluency improved during gallery sessions.
							Themes found: 1. Social activity - isolation, structure 2. Becoming old selves - recalling memories, improvement in mood, increased verbalisation 3. Shared experience - learning together, making art together

Flatt et al. (2014)	Cross sectional qualitative study	10;10	Mild (Early stage)	Art viewing and art making	-	Satisfaction survey, Focus group	Art making rated significantly higher than group interaction and guided art discussion, group interaction rated higher by the PWD than family caregivers, and past experience of visiting a museum or art making associated with overall programme satisfaction. Correlation found between overall satisfaction and feelings of belonging and morale. Three themes found concerning enjoyable aspects of programme (cognitive stimulation, social connections, and self-esteem) and two concerning practical aspects for improving future programmes (activity-related concern and logistical issues).
Gross, Danilova, Vandehey & Diekhoff (2013)	2 x 3 within subjects repeated measures design	76; N/A	Moderate to severe	Art making	Care staff rated outside of session	Greater Cincinnati Chapter Well-Being Observation Tool	Significant change in all domains of 'well-being' from beginning to middle of programme. No difference found outside of sessions.
Kinney & Rentz (2005)	Within subjects quasi experimental	12; N/A	Mild to very severe	Art making	Traditional day centre activity	Greater Cincinnati Chapter Well-Being Observation Tool	Significant difference found between ratings in MiM and other activity. Higher levels of interest, sustained attention, pleasure, self-esteem and normalcy found.
MacPherson, Bird, Anderson, Davis & Blair (2009)	Mixed methods	15 [Inconsistency - says 23 in abstract and 15 in text]	Moderate to severe	Art viewing	ā	Behaviour observations, focus groups	Levels of engagement, animation, and confidence increased, and participants engaged in discussions about the artwork. Main outcome from the study was the enjoyment of the participants.

Mangione (2013)	Qualitative	5;12	NR	Art viewing	-	Open ended and semi structured interviews	Educators felt 'Art-means-everything' whereas participants felt 'art-means- aesthetics'. Art educators focussed on effects art can have on normalising and providing access, participants simply took pleasure in the art and enjoyed acquiring new knowledge.
Rentz (2002)	One off observation	41; N/A	NR	Art making	-	Early version of Greater Cincinnati Chapter Well-Being Observation Tool	Participants always or some of the time had sustained attention. Had a pleasant sensory experience, experienced pleasure and verbalised feeling good about themselves
Roe et al. (2014)	Feasibility study: independent qualitative evaluation	17;11	NR- "diagnostic labels were seen as irrelevant"	Art viewing and art making		Non-participant observation and field notes; semi- structured group interview (Spradley's framework & Triangulation)	Impact of programme split into: act and actors; space and time; goals, events, objects and activities; and feelings. Benefits, impact on well-being and the feasibility of the programme also discussed. Concluded arts-for-health programme is feasible and creative arts, cultural appreciation and social engagement promote well-being, quality of life and social inclusion.
Sauer, Fopma-Loy, Kinney, & Lokon (2014)	Quantitative descriptive with a control	38; N/A	Moderate to severe	Art making	Traditional art activities	Modified GCCWBOT	More engagement than social interest or pleasure during intervention sessions. Mean intensity score for all domains of well-being significantly higher during intervention than control

Ullan et al. (2013)	Exploratory qualitative study	21; N/A	Mild to moderate	Art viewing - and art making	Participant observation, assessment by facilitators, focus groups with PWD, focus group, focus group with professional carers	Positive results included commitment to the activity, an interest in learning new things, satisfaction during the creative process and with the results from the participants. Dementia does not stop participation in programme and that "facilitating access to art and artistic education to people with dementia can contribute to enforcing their rights and to improving the care systems provided for them" (p.20).
Walsh et al. (2011)	Qualitative hermeneutic phenomenolo gical content analysis	4;4	Severe	Art making -	Field notes and observations (researcher) participant observations (INT) videotapes	Two clusters of themes emerged: Trusting/thirsting/following and Choosing/connecting/reminiscing

Table 6.3

Details of the intervention provided in each study

Author	Intervention name (if specified)	Participants	Type of intervention	Duration in weeks	Length of each session	Frequency	Setting	Led by	More details provided?
Algar et al., a & b		Care home residents with mild to moderate dementia	Art appreciation and art making	9	Between 1- 2 hours	Weekly	Care Home	Artist and 2 artist volunteers	Yes – describes materials used, a typical session, activities, style adopted by artist
Brownell	Intergeneratio nal art program	Residents with moderate to severe dementia	Art making	20	45 minute	Weekly	Long term care facility	Students enrolled in senior art class at local high school	Very brief – mentions materials and how activities were planned
Byrne & MacKinlay	-	Residents with dementia and co-morbidity of depression	Art making	18	1 hour	Weekly	Residential Aged Care Facility	Chaplains or pastoral carers	No detail – just mentions that it was designed by an art therapist
Camic et al.	A multi- session art- gallery-based intervention	People with (mild to moderate) dementia and carer dyads	Art viewing and art making	8	2 hours	Weekly	Gallery	Gallery educator	Yes – describes sessions in gallery and materials used in art making
Eekelaar et al.	-	People with mild to moderate dementia and family carers	Art viewing and art making	3	90 minute	Weekly	Gallery	Art educator	Yes –briefly describes themes and sessions

Flatt et al.	Art museum engagement activity	People with mild dementia and family caregivers	Art viewing and art making	1 off	3 hours	1 off (x4)	Gallery	Museum's education curators or staff	Yes – describes sessions in gallery, providing example questions and materials used in art making
Gross et al.	Memories in the making	Residents with moderate to severe dementia	Art making	12	1 hour	Weekly	Long term care facility	Junior, senior, undergraduate university interns	Yes – describes philosophy of programme, materials used, and style adopted by artist
Kinney & Rentz	Memories in the Making	People with mild to very severe dementia	Art making	NR	Offered at the Adult Day Centre	Weekly	Adult Day Centre	Artist Facilitator	Yes- describes philosophy of programme
MacPherson et al.	An art gallery access programme	7 PWD from the community and 8 PWD from residential care	Art viewing	6	45-60 minutes	Weekly	Gallery	Gallery educators	Yes – briefly describes session and attempts at promoting consistency
Mangione	-	People with dementia and their family and professional caregivers	Art viewing	1 off	Between one hour and 90 minutes	Over 2 summers	Gallery	Museum educators	Yes – describes themes, provides example questions, and style of educators
Rentz	Memories in the Making	People with dementia	Art making	NR [Until 41 participant s had been observed	One hour	Weekly	Adult Day Centre	Skilled artist facilitator	Yes – describes philosophy of programme and mentions materials

Roe et al.	Coffee, cake and culture	8 PWD from supported living and 9 PWD from care home and care staff and relatives	Art viewing and art making	6 months	2 hours	Once a month	Gallery	Gallery / museum staff	Yes- brief description but provides a programme
Sauer et al.	Opening Minds through Art (OMA)	Residents living with moderate to severe dementia	Art making	12	One hour	Weekly	Long term care facility	Trained student interns	Yes – describes philosophy of programme, style adopted by trained student volunteers, materials and techniques used.
Ullan et al.	Artistic educational programme	Users of State Day Centre (People with mild to moderate dementia)	Art viewing and art making	Unclear – Cycles of 5 workshops in one or two sessions	60-90 minutes	frequency	State day centre	Artistic educators	Yes – very detailed description of sessions and provides tables of criteria, the cyanotype process, and a breakdown of all artworks visited in each workshop.
Walsh et al.	Creative Bonding Intervention	Residents with severe dementia	Art making	3	30 minutes	Weekly	Care home	Interventionists	Yes – provides philosophy of programme, materials and activity of each session, and style adopted by Interventionist

Comparisons

A third of the studies (5) included a control condition (Algar et al., 2015a; Brownell, 2008; Kinney & Rentz, 2005; Gross et al., 2013; Sauer et al., 2014). These were all within subject designs where the participants, or a subset of participants, were their own controls. The control conditions included participants being provided with other activities such as chair aerobics, drawing, traditional arts and crafts, and current events, and/or being rated in free time outside of activity sessions.

Outcomes

Of the 10 studies including quantitative measures, outcomes varied with no universal outcome although the primary outcome of interest, well-being/quality of life, was the most common. The outcomes measured can be categorised into five areas:

- Well-being / QoL (Algar et al., 2015a; Camic et al., 2013; Gross et al., 2013; Kinney & Rentz, 2005; Rentz, 2002; Sauer et al., 2014).
- Social (Algar et al., 2015a; Brownell, 2008; Camic et al., 2013; Flatt et al., 2014).
- Behavioural (Brownell, 2008; MacPherson et al., 2009).
- Mood (Algar et al., 2015a; Brownell, 2008).
- Cognitive (Eekelaar et al., 2012).

Qualitative themes can be categorised under the following five overarching themes:

- Social (Algar et al.,2015b; Byrne & MacKinlay, 2012; Camic et al, 2013; Eekelaar et al., 2012; Flatt et al., 2014; MacPherson et al., 2009; Ullan et al., 2013; Walsh et al., 2011).
- Cognitive (Algar et al., 2015b; Camic et al., 2013; Eekelaar et al., 2012; MacPherson et al., 2009; Ullan et al., 2013).
- (Self) Identity (Byrne & MacKinlay, 2012; Eekelaar et al., 2012; Flatt et al., 2014; MacPherson et al., 2009; Mangione, 2013).
- Engagement / pleasure (Algar et al., 2015b; Byrne & MacKinlay, 2012; Camic et al., 2013; Eekelaar et al., 2012; MacPherson et al., 2009, Mangione, 2013; Roe et al., 2014; Ullan et al., 2013).

Practical advice / logistics (Algar et al.,2015 b; Byrne & MacKinlay, 2012; Camic et al., 2013; Flatt et al., 2014; MacPherson et al., 2009; Roe et al., 2014; Ullan et al., 2013).

Study design

Five studies were of a quantitative design (Algar et al.,2015a, Gross et al., 2013;Kinney & Rentz, 2005; Rentz, 2002; Sauer et al., 2014), six qualitative (Algar et al., 2015b, Byrne & MacKinlay, 2012; Mangione, 2013; Roe et al., 2014; Ullan et al., 2013; Walsh et al., 2011), and five took a mixed methods approach (Brownell, 2008; Camic et al., 2013; Eekelaar et al., 2012; Flatt et al., 2014; MacPherson et al., 2009). The majority of studies (11) were published after 2011, post-dating all but one of the previous reviews, demonstrating the increase in interest in the area.

Table 6.4

Quality assessment for each study using the MMAT (Pluye et al., 2011) shown in order of quality rating

Author	Year	Qualitative Component (0-4)	Quantitative Component (0-4)	Mixed Methods Component (0-3)	Total Score % Score / relevant criteria x 100
Algar et al.	2015b	3	N/A	N/A	75
Eekelaar et	2012	2	4	2	72.72
al.					
Flatt et al.	2014	3	3	2	72.72
MacPherson	2009	2	3	3	72.72
et al.					
Camic et al.	2013	2	2	2	54.55
Algar et al.	2015a	N/A	2	N/A	50
Mangione	2013	2	N/A	N/A	50
Roe et al.	2014	2	N/A	N/A	50
Ullan et al.	2013	2	N/A	N/A	50
Walsh et al.	2011	2	N/A	N/A	50
Brownell	2008	0	3	0	27.27
Kinney &	2005	N/A	1	N/A	25
Rentz					
Sauer et al.	2014	N/A	1	N/A	25
Byrne &	2012	0	N/A	N/A	0
MacKinlay					
Gross et al.	2013	N/A	0	N/A	0
Rentz	2002	N/A	0	N/A	0

Risk of bias within studies

Table 6.4 shows the quality assessment scores for each of the included studies. The decision was made to include quasi experimental and non-randomised studies without control conditions due to the limited number of methodologically rigorous studies.

Of the five quantitative and five mixed methods studies, all were assessed using the quantitative descriptive studies criteria (Algar et al., 2015a; Brownell et al., 2008; Camic et al., 2013; Eekelaar et al., 2012; Flatt et al., 2014; Gross et al., 2013; Kinney & Rentz, 2005; MacPherson et al., 2009; Rentz, 2002; Sauer et al., 2014). All but two (Gross et al., 2013; Rentz, 2002) used appropriate measures with clearly defined variables that are accurately
measured, measurements justified and appropriate for answering the research question, and measurements reflecting what they are supposed to measure.

Rentz (2002) describes the development of a tool so validity was an issue and Gross et al. (2013) chose an appropriate measure but applied it inappropriately. The interns delivering the intervention made one-off ratings using the Greater Cincinnati Chapter Well-being Observation Tool rather than in observation windows over the whole session and the comparative ratings were made by the care staff at inconsistent times. Five of the studies included a sample representative of the population under study (Algar et al., 2015a; Brownell et al., 2008; Camic et al., 2013; Eekelaar et al., 2012; Flatt et al., 2014; MacPherson et al., 2009), explained inclusion and exclusion criteria and why eligible individuals chose not to participate. Only three studies (Eekelaar et al., 2012; Flatt et al., 2014; MacPherson et al., 2009) had a sampling strategy relevant to the research question with a relevant source, a standard procedure for sampling, and the sample size justified. Three studies had an acceptable response rate of 60% or above (Brownell, 2008; Eekelaar et al., 2012; Flatt et al., 2012; Flatt et al., 2014).

Therefore, the most common issues affecting the reported methodological rigour of the quantitative studies rest with the sampling strategy and response rate. This could be due to the majority of studies being an evaluation of a programme already in place, using purposive or convenience sampling without an experimental framework. None of the studies use a power calculation to justify the sample size and all report results from small sample sizes, with the exception of Gross et al. (2013).

Eleven studies included a qualitative component (Algar et al., 2015b; Brownell et al., 2008; Byrne & MacKinlay, 2012; Camic et al., 2013; Eekelaar et al., 2012; Flatt et al., 2014; MacPherson et al., 2009; Mangione, 2013; Roe et al., 2014; Ullan et al., 2013; Walsh et al., 2011). Six had relevant sources of qualitative data to address the research question with a clear selection of participants and appropriate to collect relevant and rich data and explained why potential participants chose not to participate (Algar et al., 2015b; Byrne & MacKinlay,2012; Eekelaar et al., 2012; Flatt et al., 2014; MacPherson et al., 2015b; Byrne & MacKinlay,2012; Eekelaar et al., 2012; Flatt et al., 2014; MacPherson et al., 2009; Ullan et al., 2013). Eight of the studies had a relevant process for analysing the data with a clear method of collecting the data, the form of data clear, and the data analysis addressing the research question (Algar et al., 2015b; Camic et al., 2013; Eekelaar et al., 2012; Flatt et al., 2013; Eekelaar et al., 2015b; Camic et al., 2013; Eekelaar et al., 2012; Flatt et al., 2013; Eekelaar et al., 2015b; Camic et al., 2013; Eekelaar et al., 2012; Flatt et al., 2013; Eekelaar et al., 2015b; Camic et al., 2013; Eekelaar et al., 2012; Flatt et al., 2014; MacPherson, et al., 2009; Mangione, 2013; Roe et al., 2014;

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Walsh et al., 2011). Five of the studies give appropriate consideration to how the findings relate to the context, and in particular the setting in which the data were collected (Camic et al.,2013; Flatt et al.,2014; Mangione, 2013; Roe et al., 2014; Ullan et al., 2013). Only two studies consider how the findings relate to the researcher's influence (Algar et al., 2015b; Walsh et al., 2011).

The strongest component of the qualitative studies was the reporting of the analysis process. However, only two studies reported any consideration of the researchers' influence which is important to consider when a researcher is developing the research question, and undertaking both the data collection and analysis.

Of the five mixed methods studies, all but one (Brownell, 2008) explain the rationale for integrating qualitative and quantitative methods. Brownell (2008) does not acknowledge that it is a mixed methods study as a focus group is only mentioned in the results section. For the same reason, Brownell is the only study where the mixed methods approach is not relevant to the research question. Only MacPherson (2009) gives appropriate consideration to the limitations associated to the integration of quantitative and qualitative data.

Discussion (Exploring the relationships within and between the studies)

Relationship between characteristics of individual studies and reported findings:

Characteristics of the studies according to setting:

Gallery (n=6) Five of the studies aimed to measure quality of life, enjoyment, and wellbeing (Camic et al., 2012; Flatt et al.,2014; MacPherson et al.,2009; Mangione, 2013; Roe et al., 2014). Eekelaar (2012) measured episodic memory and verbal fluency but also explored the impact of the intervention on participants in qualitative interviews. Two studies were of art viewing interventions (MacPherson et al., 2009; Mangione, 2013) and the interventions in the remaining four studies were art viewing and art making (Camic et al., 2012; Eekelaar et al., 2013; Flatt et al., 2014; Roe et al., 2014). The study population in half of the gallery-based interventions were people with mild to moderate dementia. All of the studies in a gallery setting had the highest quality ratings (72.72 – 50%).

Day Centre (n=3) Two of the studies aimed to measure participants' sense of well-being during an art making intervention (Kinney& Rentz, 2005; Rentz, 2002), but had poor

quality ratings (25%, 0%). Ullan et al. (2013) aimed to find out participants' experience in an art viewing and art making intervention and had a quality rating of 50%. The study population were people with mild to very severe dementia.

Care Home (n=7) Three of the studies aimed to measure well-being during an art making intervention (Rentz, 2002; Sauer et al., 2014; Walsh et al., 2011), and two during an art appreciation and art making intervention (Algar et al., 2015a; Algar et al., 2015b). Brownell (2008) aimed to measure emotion, level of engagement, and agitation and Byrne & MacKinlay (2012) aimed to measure spirituality during an art making intervention. Where reported, the study population were people with moderate to severe dementia. Quality ratings ranged from 75 to 25 per cent.

Focus of the investigations and study effects:

This section of the review discusses the studies according to the recommendations made in the previous reviews and 'identifies factors that might explain differences in direction and size of effect across the studies and how and why the interventions might have or not had an effect' (p.14, Popay et al., 2006).

Appropriate measures / Measurement of well-being, enjoyment and quality of life.

Recommendations regarding measures from the previous reviews include the use of first person accounts from the participants with dementia, an emphasis on quality of life and enjoyment rather than scales traditionally used in clinical trials, and choosing appropriate measures, including qualitative approaches (Beard, 2011; de Medeiros & Basting, 2013).

Over 70% of the studies (n=11) used well-being, enjoyment or quality of life as their main outcome to assess the impact of visual art programmes on people living with dementia. Five of these used the Greater Cincinnati Chapter Well-being Observation Tool in various stages of development. Rentz (2002) developed the tool during a pilot study as facilitators noted anecdotally that participants were showing signs of increased pleasure during Memories in the Making. The tool was developed using Lawton's framework of psychological well-being (Lawton, 1994) to assess engagement and affect in two domains of psychological well-being, affect state, and self-esteem using 12 declarative statements (Rentz, 2002). Positive results were found suggesting that participants had sustained attention, a pleasant experience, and verbalised feeling good about themselves. However, the author states that the study was designed to develop an appropriate measure, and not as a research project.

Following suggestions made by Rentz (2002), the tool was developed further and used in a study that included a control condition. In this version, the observer rates the extent to which a person with dementia has shown each of 7 domains during a specified time period (Interest, Sustained attention, Pleasure, Negative affect, Sadness, Self-esteem, and Normalcy) using a 5 point Likert scale (4= Always, 0= Never) (Rentz, 2002; Kinney & Rentz, 2005). Up to 3 participants are observed in 10 minute observation periods during the session. Therefore, each data point represents a proportion of time that a participant demonstrated each indicator of a domain of well-being.

The tool was used to compare levels of well-being of people with dementia during participation in Memories in the Making and in another structured activity. The measure was deemed suitable for showing differences in the seven domains of well-being within and between activities and they found that participants showed significantly more Interest, Sustained Attention, Pleasure, Self Esteem, and Normalcy in the art sessions (Kinney & Rentz, 2005). However, the authors reported limitations with their 'other activity' as observations were always made after the Memories in the Making session, meaning that participants could have shown fatigue. They also indicated limitations with the tool such as observers needing a lot of training in the scoring system and the fact that they had to dichotomise the results which changed them from a proportion to whether or not the indicator was present.

Gross et al. (2013) also used the same version of the Greater Cincinnati Chapter Well-Being Observation Tool to evaluate Memories in the Making, using a larger sample size and also aimed to investigate whether a carry-over effect was present outside of the session. Results indicated a significant change in interest, sustained attention, pleasure, self-esteem, and normalcy from the beginning to the middle of the art programme which supported the previous findings. No difference was found outside of the sessions. However, limitations such as the observations outside of the sessions being made at inconsistent times 'on or around the same day' of the art activity and by different observers, and the possibility of bias from interns leading the art sessions also completing the ratings, puts their results into question and as a result, the MMAT scores indicated a

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lack of methodological rigour. It is worth noting that the main issue was not the choice of measure, but the application of it.

A further adapted version of the tool was used in a study which aimed to compare levels of well-being and ill-being during person-centred and traditional arts activities for people with dementia (Sauer et al., 2014). They modified the domains to include well-being domains of Social Interest, Engagement, and Pleasure, and ill-being domains of Disengagement, Negative Affect, Sadness, and Confusion, and changed the scoring to rating the frequency and intensity of the indicator. They found participants showed more engagement than social interest or pleasure during the intervention sessions and that mean intensity scores for all of the domains of well-being were significantly higher during the intervention than in the control condition. The authors were unable to obtain demographic information and therefore the results are not readily generalizable.

Algar et al. (2015a) aimed to test the appropriateness of an adapted version of the Greater Cincinnati Chapter Well-being Observation Tool to evaluate the impact of a visual art programme compared with another structured activity and unstructured time. Modifications were made to the scoring system to avoid the subjective judgement of the proportion of time observed in a domain. Observers now rated whether or not an indicator was present. Positive results included a significant increase in pleasure over time and greater observed well-being in the art sessions compared to the two control conditions. The tool was deemed feasible but further modifications were suggested. Limitations noted included a small sample size and confounding factors arising from combining data from different care homes.

Observations during the sessions allow for rating of 'in the moment' rather than relying on lasting effects commonly anticipated through pre and post measures.

This is further supported by MacPherson et al. (2009) who aimed to evaluate the impact of an art gallery access programme for people with dementia at the National Gallery of Australia. The programme's effectiveness was analysed by observing videotapes of sessions and the level of engagement was determined using time-sampling methods; focus groups also took place with carers, participants and museum guides. Observations during the programme showed that while in the gallery, levels of engagement, animation, and confidence increased, and that participants engaged in discussions about the artwork. The main outcome from the study was the enjoyment of the participants. Whether benefits of

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this programme can be shown long-term is not known although the enjoyment during the session was seen as sufficient justification "you do it for the moment".

Camic et al. (2013) aimed to evaluate the impact of an art viewing and making intervention at two different styles of gallery on carer burden, quality of life, and activities of daily living for the people with dementia using standardised questionnaires and interviews pre and post intervention. Carer burden was measured using the Zarit Burden Interview (ZBI), quality of life of the person living with dementia using the DEMQOL-4, activities of daily living using the BADLS, and a semi structured interview held 2-3 weeks after the intervention ended explored participation in the programme. No significant differences were found between the traditional and contemporary gallery so the data was combined. No significant differences between pre and post intervention were found using the combined data for carer burden, activities of daily living, quality of life. However, thematic analysis of the interviews revealed positive results regarding social impact, improved cognitive capabilities and the empowering art gallery setting. The results from this study demonstrate that the measures used do not map onto the dimensions of change identified quantitatively and adds support to the argument made by de Medeiros & Basting (2013) regarding the choice of appropriate measures.

Well-being, quality of life, and enjoyment also emerged as themes from five further studies whereby enjoyable aspects of the programme were discussed as including cognitive stimulation, social connections, and self-esteem (Flatt et al., 2014), participants took pleasure in the art and enjoyed acquiring new knowledge (Mangione, 2013), an arts-forhealth programme was found to promote well-being, quality of life, and social inclusion (Roe et al., 2014), people living with late stage dementia showed evidence of well-being during an art making intervention (Walsh et al., 2011), and enjoyment of the participants was identified by the residents, care staff, and artists (Algar et al., 2015b).

Eight of the studies included self-report from the participants with dementia in the form of self-report quality of life questionnaires such as QoL-AD and DEMQOL (Algar et al., 2015a; Camic et al., 2013), a satisfaction survey (Flatt et al., 2014), focus group (Flatt et al., 2014; MacPherson et al., 2009) and semi-structured interviews (Algar et al., 2015b; Camic et al., 2013; Eekelaar et al., 2012; Mangione, 2013; Ullan et al., 2013).

Following a discussion of measures used in the included studies in the current review, it has been shown that more appropriate measures, including self-report from the

participants, are being used to evidence the benefits of visual art programmes for people with dementia.

Intervention details

As Table 6.3 shows, the basic level of information provided about the interventions is in line with the recommendations by Castora-Binkley et al. (2010) and de Medeiros & Basting (2013). The most common information not reported was the level of impairment of the participants with dementia, which was intentional in the case of Roe et al. (2014) who stated that 'diagnostic labels were seen as irrelevant' (p.14). However, where reported, the study population of the intervention studies ranged from people with mild to very severe dementia, which again is in line with the recommendation to include people in early stages of dementia (Beard, 2011).

Despite improvements in the details provided about the interventions, few are replicable. This is a common limitation in non-pharmacological interventions which has led to the development of a Template for Intervention Description and Replication (TIDieR; Hoffmann et al., 2014), a 12 item checklist of information to include when describing an intervention. It is suggested that this template is used in future research with visual art interventions for people living with dementia

Where some studies provide limited information, others give very detailed descriptions of the intervention. By exploring further than the basic information and discussing strengths and weaknesses and the authors' views and suggestions, it is possible to start to unravel how and why a visual art intervention might have a positive effect on people with dementia.

Contrary to findings in Beard (2011)'s review, the interventions from the included studies were not all set in a care home. Six of the studies were set in an art gallery or museum and include a discussion about the suitability of the setting. Camic et al. (2013) suggest that the gallery setting is "stimulating and empowering" (p.6) which can encourage social inclusion; something also suggested by Roe et al. who suggest that attending an intervention in the gallery gave a chance for the participants to be in the 'real world'. Eekelaar et al. (2012) go further and describes the gallery taking on a therapeutic role as the artwork helped participants process difficult personal experiences. On a similar theme, Flatt et al. (2014) describe the gallery as a protected space where the environment is "less

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about the illness" (p.9) which is also echoed in MacPherson et al. (2009) who describe their intervention as 'going beyond many activities available for people with dementia' and being more mainstream. This is again emphasised in Mangione's (2013) study where a museum educator states the programme is:

"Just sort of... normalizing dementia ... You know, to have people out in a dignified setting where they experience their intellect and their memory and their emotions. I think that's just a great thing. I think that's just part of being human and I think that's something that can be dangerously left by the wayside when people are experiencing dementia" (p.36)

Another discussion that appears in several of the studies is how a visual art intervention can help retain strengths and abilities and even exceed those that precede dementia. Rentz (2002) suggests that the artwork produced by the participants can be a reminder of the retained abilities of the individual to both family and the public and MacPherson (2009) reports participants' feeling that taking part in art discussion showed they could still do things and felt intelligent. Ullan et al. (2013) states that dementia is not an obstacle to participation in an art intervention, and in fact the participants are interested in learning new things which is a theme that also appears in two other studies (Camic et al., 2013; Flatt et al., 2014).

Eekelaar et al. (2012) suggest that the integration of art viewing and art making were integral to the intervention. However findings from their thematic analysis suggested that other components such as social contact were just as important. This is supported by the finding by Flatt et al. (2014) that although the component rated the highest overall (by both the participants with dementia and caregivers) was art making over group interaction and art discussion, participants with dementia rated group interaction as more important than the care givers. Kinney and Rentz (2005) wonder whether a sense of belonging during the intervention is a reason for pleasure and engagement in the visual art intervention, which is supported by another finding by Flatt et al. (2014) of a correlation between overall satisfaction and a sense of belonging. Brownell (2008) also suggests involving students to lead the intervention can provide links with community through increased interaction between those in long term care and the local community.

Several of the studies provide practical and logistical advice which would be helpful in determining how and why a visual art intervention might have positive outcomes for

people with dementia. Brownell suggests that activities should be appropriate for the functional level of participants which is echoed by findings that the activities should be customised to disease stage (Flatt et al.), should 'favour the use of participants' cognitive capabilities' (p.3, Ullan et al., 2013), and be age appropriate (Algar et al., 2015b). Camic et al. (2013) suggests not relying on the recall of memories. Byrne & MacKinlay (2012) suggest that the communication style of the facilitator can affect the success of the intervention, so-much-so that they dedicate the whole results section to that one theme and Algar et al. (2015b) also discuss the benefits of having an artist leading the sessions rather than care staff. In a similar vein, four studies discuss the importance of having trained staff with experience of working with people with dementia to lead the sessions (Flatt et al., 2014; Roe et al., 2014; Sauer et al., 2014; Ullan et al., 2013).

Other suggestions include having small groups of participants (Flatt et al., 2014; MacPherson et al., 2009), ensuring availability of transportation and parking for gallery interventions (Flatt et al., 2014, MacPherson et al., 2009), pre-planning the content of the session (Roe et al., 2014; Ullan et al., 2013; Walsh et al., 2011), and developing standalone sessions so that participants aren't disadvantaged if they did not attend the previous session (Roe et al., 2014). This however contrasts with Brownell's (2008) study that found as residents became familiar with the art programme, more chose to participate.

In addition to the theories referred to in the theory of change, several of the interventions have a theoretical basis which could be used to further explain why a visual art intervention could promote positive outcomes on people with dementia. Camic et al. (2013) drew from three different theoretical perspectives in developing their intervention. The first was the constructivist museum model (Hooper Greenhill, 1997) which explains a 'triangle of knowledge' where knowledge is constructed through an interaction between the visitor, gallery educator, and the artwork and does not rely on 'facts and figures'. The second was social flexibility, where there is no hierarchy so control of where the discussion goes is shared. The third perspective was two psychological growth phases influencing creativity and ageing proposed by Cohen (2009): the liberation phase and the summing-up phase.

Sauer et al. (2013) state that Opening Minds through Art is grounded on strength-based psychology (Ranch, 2003) and Kitwood's (1997) philosophy of person-centred care. By creating failure-free structured sessions, they suggest that the psychological needs for

attachment, comfort, inclusion, identity, and occupation of the participants are met. Algar et al. (2015 a & b) also state that the intervention and those delivering it adopted the principles of person-centred care and Byrne and MacKinlay (2012) mention personhood as a way of encouraging spirituality.

The Creative Bonding Intervention (CBI) discussed by Walsh et al. (2011) uses a theory of self-transcendence proposed by Reed (2008) which suggests that art activities might have a positive effect on self-transcendence and well-being. The theory also incorporates "freedom to choose" proposed by Frankl (1984) which guided the interventionists to ensure participants were given opportunities to make choices throughout CBI sessions.

Better quality research

This is an area needing more attention. As shown in Table 6.4, the reported methodological quality of the studies was only above 50% in five of the studies included. Three studies didn't meet any of the criteria and would usually be excluded. However, the decision was made to include them due to the limited evidence available. The standard of control conditions was also lacking. The MHF review (2011) calls for non-art based activities to be used as a control condition which only occurs in three studies with varying success.

The gold standard in clinical trials is a double-blind randomised control trial (RCT) where neither the patient receiving a treatment, nor the doctor administering it, knows whether it is the drug under investigation or a placebo. This approach is not possible when applied to an art intervention as it is difficult to conceal that someone is involved in art activities. In their review of systematic reviews of pharmacologic, psychosocial and cultural arts interventions de Medeiros & Basting (2013) discuss how measures and study designs used traditionally in clinical trials are not suitable for art interventions, and that researchers need to rethink how to demonstrate these positive outcomes. They suggest that psychosocial interventions, and specifically art interventions, can achieve a "transformative experience" for participants that are not expected in a pharmacological intervention (p.7).

However, this view neglects to acknowledge the many successful examples of high quality RCTs of psychosocial interventions in dementia care; for example, the multicentre pragmatic randomised trial of joint reminiscence groups for people with dementia and their carers, REMCARE (Woods, et al., 2012). A recent methods review for the NIHR School

for Social Care Research argues for the increase of chance-based designs (an alternative term for RCT less associated with medical trials) in social care research to provide a more rigorous evidence base (Woods & Russell, 2014). Although a double-blind RCT might not be possible in psychosocial interventions, other forms of RCT, or chance-based designs, exist that might be more appropriate. Therefore perhaps the methodological issues do not lie in the study design but in the chosen outcome measures.

The reminiscence project mentioned above used validated questionnaires pre and post intervention (Woods et al., 2012). No difference in quality of life, mood or relationship between person with dementia and carer was found between those attending and not attending reminiscence groups. However, group facilitators reported changes in participants. Perhaps the trial would have reported different results if different outcome measures were used that captured the impact of the intervention during the sessions.

As already discussed, there seems to have been a shift to more appropriate measures, but the study design now needs more consideration. A large number of the studies were an evaluation of an existing intervention. More research with experimental designs is needed so that the positive outcomes that are now accepted are given more credence.

Another way of improving the methodological integrity of future research would be to publish an intervention protocol before-hand perhaps using the TIDieR checklist mentioned previously (Hoffman et al., 2014).

Limitations (assessment of the robustness of the synthesis)

This is the first narrative synthesis of visual art interventions with people living with dementia. It was conducted and reported using the PRISMA statement (Moher et al., 2009) and 'Guidance on the conduct of narrative synthesis in systematic reviews' (Popay et al., 2006) to ensure transparency of the review. Therefore, there were defined inclusion and exclusion criteria, a systematic search strategy, data extraction and quality appraisal using pre-defined criteria, and a synthesis of results guided by Popay et al. (2006). However, several limitations exist.

Reflecting critically on the synthesis process

The methodological weaknesses already described in previous reviews (Beard, 2011; Castora-Binkley et al., 2010; de Medeiros & Basting, 2013; MHF, 2011) meant that the

evidence used was of poor quality, and validity, and therefore lacked generalisability. There was also a potential bias due to two of the included studies being written by the author of the current review. However, the studies underwent the same process of independent quality appraisal as the other studies to reduce the risk of bias.

Discrepancies and uncertainties were identified in several of the studies with inconsistent numbers of participants reported in different sections of the paper (Brownell, 2008; Byrne& MacKinlay, 2012; MacPherson et al., 2009).

Conclusion

This review aimed to establish where the results of the evaluation reported in Chapter 3 fit within the wider literature, and whether there have been improvements to the methodological issues identified in previous reviews (Beard, 2011; Castora-Binkley et al., 2010; de Medeiros & Basting, 2013; MHF, 2011; Salisbury et al., 2011).

By including the quantitative study from Chapter 3 and the qualitative study in Chapter 4 in the narrative synthesis, they were judged according to the same criteria as the other studies. Results of the evaluation are in line with those reported in other studies included in the review and the reported methodological rigour was average. The inclusion of two control conditions in the quantitative paper and the perspectives of the artist team in the qualitative paper set them apart from most and suggests that this is something to be replicated in the future.

Since previous reviews were published, the evidence for claims of the effectiveness of visual art programmes at promoting positive outcomes for people with dementia has improved due to more appropriate measures being chosen. Studies are more concerned with positive outcomes such as well-being and enjoyment rather than clinical outcomes.

The majority of the 16 included studies provided details about the visual art interventions but a checklist such as the TIDieR (Hoffman et al, 2014) should be considered in an attempt to provide uniform information to ensure that the intervention is replicable.

The studies made suggestions of how a visual art intervention can increase quality of life and well-being of a person with dementia. These included visual art interventions enabling the person to retain strengths and abilities, giving the opportunity of social contact, and achieving a sense of belonging. Some studies suggested further theories to strengthen a future theory of change.

Better quality research designs are still needed. This review found only a few high quality studies. Future studies should consider chance based designs to improve their rigour.

Overall, the evidence for the positive effect that visual art interventions have on people living with dementia is improving. However, there is still further work required before anecdotal reports of improvements can be said to have an evidential basis. **Chapter 7: Discussion**

This thesis aimed to answer whether a visual art programme could increase the quality of life and well-being of care home residents with dementia. This promising area lacked the scientific evidence for the positive effects noted anecdotally. Therefore, careful consideration of study design and measures was needed. A review of observational measures (Chapter 2) highlighted an appropriate measure that could be used in an empirical study of the effects of visual arts. The following empirical study of the thesis (Chapter 3) built on these findings and tested whether an adapted version of the Greater Cincinnati Chapter Well-being Observation Tool was suitable to evaluate a visual art programme for care home residents with dementia compared to another structured activity and unstructured time. The following chapter (Chapter 4) presented qualitative results of the impact of the visual art programme from the perspective of the residents, care staff, and artists. Chapter 5 brought together qualitative and quantitative results in two case vignettes to look at the effect on the individual. Finally, following increasing interest in the area, a systematic review and narrative synthesis was conducted to show where the results from the thesis fit within the wider literature and whether there had been improvements to the methodological issues present in the field (Chapter 6).

Summary of findings and how they fit within the existing literature

Measuring the quality of life and well-being of people with dementia: A review of observational measures

This review aimed to compare observational measures in the context of recording the wellbeing of people with dementia during and outside of a visual art intervention. A literature search was conducted using systematic principles of searching, screening and retrieval to identify peer-reviewed English language evaluations of research projects using observational measures with people with dementia. Psychometric properties, strengths, and weaknesses of eleven observational tools were reviewed in order to identify the most appropriate for evaluating a visual art intervention for people with dementia. This review found the Greater Cincinnati Chapter Well-Being Observation Tool to be an appropriate measure to evaluate a visual art programme for people with dementia. The results of the review can be used to help researchers plan projects to show the full range of effects for people with dementia of taking part in art sessions, and led to its inclusion as primary outcome measure in Chapter 3.

An exploratory study to determine if an observational tool is suitable for evaluating a visual art intervention for care home residents with dementia

This study aimed to test whether an adapted version of the Greater Cincinnati Chapter Well-Being Observation Tool is suitable for evaluating a visual art intervention for care home residents with dementia compared with another structured activity and unstructured time. A visual art intervention was run in two North Wales care homes. Sixteen participants were observed using an adapted version of the Greater Cincinnati Chapter Well-Being Observation Tool during three conditions; the art intervention, another structured activity, and unstructured time. Participants also completed quality of life and mood questionnaires before and after the intervention. The tool was found to be sensitive to change in all three conditions and showed a relationship with the secondary measures suggesting that the measure is suitable to rigorously evaluate a visual art programme for people with dementia compared with another structured activity and unstructured time. Further adaptations were recommended for future use of the tool that were supported by similar modifications being made independently by another research team (Sauer et al., 2014).

Greater observed well-being in the art intervention was found especially in relation to the unstructured time. Observed pleasure increased significantly over time in the arts sessions, but did not change in the alternate or unstructured activity. This positive result in the art intervention supports the findings of other studies using the original GCCWBOT (Gross et al., 2013; Kinney & Rentz, 2005; Rentz, 2002). Improved communication and a trend to improvement in quality of life after attending the art intervention were also found, in contrast with Camic et al.'s (2013) report of no (significant) difference in the quality of life of participants engaging in a gallery-based intervention.

The results from this exploratory study have demonstrated an observational measure may quantify the benefits that have been noted anecdotally for many years during visual arts activities, but the added value of arts activities over other structured activities remains to be established statistically. The study also suggests that attending a visual art intervention may be associated with an increase in communication and quality of life in care home residents with dementia.

The qualitative impact of a visual art programme for care home residents with dementia from the perspective of the residents, care staff, and artists

The aim of this study was to explore the experience and impact of a visual art programme for care home residents with dementia from the perspective of the residents, care staff, and artists. A visual art intervention was run in two North Wales care homes. Data were collected from 21 intervention participants through semi-structured interviews which were supplemented by field notes; from eleven care staff through open-ended questionnaires and semi-structured interviews; and from group discussions and reflective diaries from the artist and two artist volunteers running the intervention.

Themes identified from the care home residents included: *memory of the intervention* – explicit, implicit or prompted, *positive experience of the intervention*- enjoyment, independence and choice, self-esteem, and group interaction, and *discussions about art*-previous experience, feelings and opinions of art. Themes identified from the care staff were: *impact of the intervention*- on the residents, care staff, and care home, *benefit of the gallery visit*- impact on the residents, suitable characteristics, *benefits of art/artist*- benefits of artist, benefits of art vs other activities, and *suggestions for future interventions*- suitable intervention- on the residents, on artist team, *gallery visit*- impact of the intervention, practical issues, *benefits of art/artist*- benefits of artist, 'art...is like a language', and *suggestions for future interventions*- suitable intervention characteristics of *art/artist*- benefits of artist, 'art...is like a language', and *suggestions for future interventions*- suitable intervention.

The three groups all spoke of the benefits that involvement in a visual art intervention can have on people with dementia. The participants' enjoyment was identified in all groups and other benefits identified included improvements in mood, communication / interaction, concentration, independence, confidence, and self-esteem.

The results support findings from previous research where similar themes are identified. A number of studies reported group interaction and increased verbalisation (Byrne & MacKinlay, 2012; Camic et al., 2012; Eekelaar et al., 2012), enjoyment and improved mood (Eekelaar et al., 2012; MacPherson et al., 2009; Mangione, 2013), and self-esteem and satisfaction with artworks produced (Flatt et al., 2014; Ullan et al., 2013). The artists'

theme 'art...is like a language' also support the quantitative results of improved communication in the Holden Communication Scale over time presented in Chapter 3.

Perhaps the most important impact of the intervention found was the change in perception of the abilities of the residents by the care staff and artist team. Staff initially felt it was a waste of time to have an artist to lead an intervention in the care home as they did not believe they had the abilities to participate, and were surprised when they did. This supports previous research where professional care takers felt that being involved in an art intervention with people living with dementia changed the image they had of the participant (Ullan et al., 2012), and raised their assessment of cognitive abilities (Gregory, 2011). MacPherson et al. (2009) suggest this underestimation of skills is 'excess disability' bestowed on the residents by the care staff, which is supported in the current study. This excess disability has a direct impact on the day-to-day lives and activities provided to residents if staff underestimate their remaining abilities. Therefore, involvement in the art intervention could be said to help staff and family members realise the remaining abilities of residents.

Are visual arts interventions effective in promoting positive outcomes for people living with dementia? A systematic review and narrative synthesis

Many claims have been made as to the broad range of positive effects that involvement with the arts can have on people living with dementia, including those in Chapter 3. However, evidence of any benefits is overshadowed by questions of methodological rigour. Previous reviews of art interventions for people with dementia made suggestions for improvements, such as using appropriate measures, providing more details about the intervention, and better quality research (Beard, 2011; Castora-Binkley et al, 2010; de Medeiros & Basting, 2013; Mental Health Foundation, 2011). In light of this, this systematic review used a narrative synthesis framework to review the effectiveness of visual art interventions for people with dementia and to judge whether the evidence has improved. It also aimed to show where the results from Chapters 3 and 4 fit within the wider literature. This was the first narrative synthesis of visual art interventions with people living with dementia.

Sixteen studies were identified that met the full inclusion criteria. The evidence for claims of the effectiveness was found to have improved due to more appropriate measures being

chosen. Studies are more concerned with positive outcomes such as well-being and enjoyment rather than clinical outcomes. The results found in Chapters 3 and 4 were in line with results found in other included studies.

The studies included more details about the interventions than indicated previously but better quality research designs are still needed. This review found only a few high quality studies.

Overall, the evidence for the positive effect that visual art interventions have on people living with dementia is improving in extent and quality. However, there is still further work required before anecdotal reports of improvements can be said to have an evidential basis.

Discussion of findings

Methodological considerations

Findings from this thesis contribute to the discussion of suitable measures and methodology to evaluate a visual art intervention for people with dementia. In Chapter 1, initial thoughts surrounding the topic were presented and introduced the idea of using observation measures during the intervention to investigate any benefits to participants, rather than using standardised questionnaires before and after the intervention, as used traditionally in intervention trials (e.g. REMCARE, Woods et al., 2012). Findings from the systematic review in Chapter 2 suggested that the Greater Cincinnati Chapter Well-Being Observation Tool might be suitable but identified some improvements to the tool. Therefore in Chapter 3, an adapted version of the measure was used to evaluate a visual art intervention for care home residents compared with another structured activity and unstructured time. Quality of life and mood questionnaires were also administered before and after the intervention. Results showed that the tool was sensitive to change in all three conditions, practical to use, and showed a positive relationship to the other measures.

The results didn't show that one measure was more appropriate than the other as anticipated. Positive results were found in both the GCCWBOT and the QoL-AD. The qualitative results supported the decision to use the GCCWBOT at two time points as although care staff spoke about an impact of the intervention on the residents "at the time" the artists noticed an improvement over time. Therefore, rather than favouring one measure or method of collecting data over the other, the results suggest that both measures

are valid, and that using both gives a more complete picture of what effect a visual art intervention can have on a person with dementia, both in the momentary experience and over time. Including a qualitative element also adds further depth to the results and is important to include (Brooker, 2008). Edna's case vignette in Chapter 5 supports a mixed methods approach as although she attended the art intervention and spoke eloquently about her experience, her quantitative data could not be included due to her not attending any of the other structured activity sessions.

The review in Chapter 6 highlighted that better quality research designs are still needed to provide a solid evidence base for visual arts interventions for people with dementia, and that chance-based designs should be considered, as suggested by Woods & Russell (2014). The work in this thesis was exploratory and covers aspects of development and feasibility/piloting in the Medical Research Council (MRC) Framework for the evaluation of complex interventions, which makes a valuable contribution to inform a larger trial (MRC, 2008). Woods & Russell (2014) provide an overview of the framework in their methods review in an effort to encourage more chance based designs in social care research.

The contribution of this thesis to the development stage of the evaluation of complex interventions (MRC, 2008) include identifying and systematically reviewing the evidence base so far and a discussion of the emerging theories of why a visual art might make a difference, which can be used to develop a theory underlying the approach (Chapter 6; and will also be discussed in the following section).

The thesis also contributes to the feasibility/piloting stage where consideration of appropriate outcome measures (Chapter 2) led to an adapted version of an observation tool being tested (Chapter 3) and modifications suggested. In doing this, the intervention was also tried out three times giving the opportunity for learning each time and to consider the practical implementation of a visual art intervention run in a care home. The artist team leading the intervention and care staff from the homes where the intervention was run were consulted each time and asked to consider how practical the intervention was (Chapter 4). This work has also offered the opportunity to consider possible barriers to recruitment. In the current study, however, the recruitment of participants through consulting the manager was found acceptable but issues prevailed in ensuring all that consented attended the art sessions, as demonstrated by 10 participants never attending any session. The data

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collected can also be used in power calculations to estimate appropriate sample sizes for a larger trial.

Therefore, important lessons have been learnt in terms of appropriate outcome measures which can be built upon in a larger trial. In the current study, the control conditions were activities already provided by the care homes so weren't entirely compatible with the arts intervention and could be classed as treatment as usual. Issues such as session length, content, and format were beyond the control of the researcher. However, it was important to include this control condition so that the observation tool was tested outside of the art intervention during another activity. With more resources, a main trial would include control conditions introduced by the research team which are more like the art intervention in terms of format and session length.

Theoretical considerations in existing literature

Some theories were suggested as a theory of change in the narrative synthesis (Chapter 6) which can now be expanded upon using additional theories suggested in the included studies. de Medeiros and Basting (2013) proposed that cultural interventions "tap into and develop individual potential and social meaning systems to achieve a transformative experience" (p.7) and Beard (2011) suggested that art interventions are "psychosocial, idiosyncratic and experiential" so should not be considered in biomedical terms (p.647). Lastly, Castora-Binkley and colleagues proposed theories of mastery and social engagement provided by Cohen and colleagues (2006) and a theory of 'flow' from Csikszentmihalyi (1990).

It was suggested that other theories proposed in the included studies could strengthen the theory of change. Camic et al. (2013) drew from three different theoretical perspectives in developing their intervention – the constructivist museum model (Hooper Greenhill, 1997) social flexibility, and two psychological growth phases influencing creativity and ageing proposed by Cohen (2009): the liberation phase and the summing-up phase.

Sauer et al. (2013) state that Opening Minds through Art is grounded on strength-based psychology (Ronch, 2003) and Kitwood's (1997) philosophy of person-centred care. Byrne and MacKinlay (2012) also mention personhood as a way of encouraging spirituality. The intervention discussed by Walsh et al. (2011) was underpinned by the theory of selftranscendence proposed by Reed (2008) which suggests that art activities might have a positive effect on self-transcendence and well-being. The theory also incorporates "freedom to choose" proposed by Frankl (1984) which guided the interventionists to ensure participants were given opportunities to make choices throughout the sessions.

However, the majority of the studies reviewed in Chapter 6 were not guided by theory. A re-examination of some of the theories of aesthetics, flow, and dementia care previously discussed in Chapter 1 in relation to the results from this thesis may further answer the question of how and why an increase of quality of life and well-being is observed in people with dementia when involved in an art programme.

Contribution of thesis in relation to previous work

The results in Chapter 3 support an evaluation of Memories in the Making compared with another activity which showed a significant increase in interest, sustained attention, pleasure, self-esteem, and normalcy (Kinney & Rentz, 2005). The authors make some suggestions as to why this might be, but comment that whether this was the case or not was beyond the scope of their study.

The first suggestion is one of brain reserve. They question whether involvement in an art programme was tapping into reserves that are unaffected by dementia. This is an argument favoured by Zeisel (2009) who writes that "Art touches and engages the brain in a more profound way than other activities...arts link together separate brain locations in which memories and skills lie" (p.81).

Brain reserve is also discussed and observed in the Creativity and Ageing Study in America (Cohen, 2009). The study was to examine the effects of participatory arts on the general health, mental health, and social activities of older people. The idea is that when challenged and stimulated by activities, new neurons develop in the brain, adding to the brain reserve.

Cohen also goes on to suggest that being involved in art for older people is like "chocolate to the brain" (p.77, 2005) in the way that the brain "metaphorically savours" the activity. The brain is said to be less lateralised in older people and art encourages greater engagement of the left/right hemispheres which is suggested to explain sustained involvement and engagement in the art activities. Findings from Chapter 3 suggest that

engagement was possible for a group of residents with quite marked cognitive impairment, and that this type of art activity may tap into abilities that remain well into the progression of the condition, in some cases after the ability to complete a questionnaire like the QoL-AD, supporting this theory.

Another suggestion by Kinney and Rentz (2005) relates to the Dementia Quality of Life instrument (D-QOL; Brod, Stewart & Sands, 1999). When developing the D-OOL, the researchers included a sub-scale on aesthetics. The D-QOL is administered by an interviewer and has 29 statements across five scales; self-esteem, positive affect/humour, negative affect, feelings of belonging, and sense of aesthetics. They defined the latter as "the experience of appreciation and pleasure obtained from sensory awareness on either a verbal or nonverbal level" (p.29). Within this scale they included the pleasure derived from viewing or creating artwork. It was included after consultation with three focus groups; one with caregivers, one with healthcare providers and one with people with dementia. The aim of the focus groups was to "develop a comprehensive, dementiaspecific definition of QoL that would include domains truly meaningful to mildly to moderately demented persons" (p.26). Although not one of the traditional domains of quality of life, it was commented on by both the healthcare professionals and the group of people with dementia as something that gave a lot of pleasure to someone with dementia even in the late stages of dementia. Therefore, people with dementia themselves support the idea that involvement with the arts can increase quality of life, as has been demonstrated in previous studies (Camic et al., 2012; Gross et al., 2013; Kinney & Rentz, 2005; MacPherson et al., 2009; Roe et al., 2014) as well as the current study.

An information-processing model of aesthetics was introduced in Chapter 1 as a model that could potentially be used to explain how a visual art intervention could increase the quality of life and well-being of people living with dementia. It was suggested that the interesting aspect of the model was that aesthetic judgement is independent from aesthetic emotion which meant that an emotional response to an artwork could occur whether or not the person fully understands it (Leder & Nadal, 2014). This had not been applied to people living with dementia before. This idea could be supported by the fact that there was a significant increase in observed pleasure and a decrease in sadness in the art sessions, compared with the discussion about art where one participant stated that "*I don't know enough about it to appreciate it*". However, the intervention in the current study did not contain as much of a focus on art appreciation as others discussed in Chapter 6 (e.g. Camic

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et al., 2013; Eekelaar et al., 2012) so it would be hard to attribute an increase in quality of life and well-being in the current study to this model.

Another concept discussed in Chapter 1 was the concept of flow, whereby "individuals are fully involved in the present moment" (p.89: Nakamura & Csikszentmihalyi, 2002). It could be argued that flow was demonstrated in this study which supports a previous review of art interventions for people with dementia (Castora-Binkley et al., 2010). Anyone who has witnessed people with dementia involved in an art programme will most probably have witnessed this flow in action, even if they are unaware of the concept. Involved in art, people with dementia have shown an ability to concentrate for much longer lengths of time than in everyday life, which was commented on by staff in Chapter 4. Also, in contrast to evaluations of Memories in the Making (Gross et al., 2013; Kinney & Rentz, 2005), the current study found a decrease in the GCCWBOT domain of interest over time during the art intervention. It was noted that as the participants became more involved in their work. their interest in others around them decreased. Further support for flow in the current study was provided by Edna's quote in Chapter 5 that "The time goes too quick" demonstrating a distortion of time which is in the list of common factors of flow. Therefore, findings from this study support the applicability of the concept of flow but perhaps there are additional factors in play.

Kitwood's (1997) influential work on person-centred care, which was discussed in Chapter 1, asked people to see the person with dementia rather than focusing on the disease itself. Kitwood emphasised the importance of maintaining quality of life, dignity, and integrity for people with dementia. The definition of person-centredness (already referred to in Chapter 1) could explain how engaging in an arts programme could increase the quality of life and well-being of a person with dementia. Through attending sessions with an artist, a person is given the opportunity to build up a relationship in a social setting; something that has been observed by several researchers and reflected in the subtheme of group interaction in the residents' perspective in Chapter 4 (Schmitt & Frolich, 2007; Basting, 2006; Johnson et al., 1992).

As discussed in Chapter 1, the Senses Framework (Nolan et al., 2004) is based on the subjective perceptions of care experiences for both care recipient and staff. It is constructed on the belief that relationships between all parties involved in caring should promote a sense of security, belonging, continuity, purpose, achievement, and significance.

The areas within the Senses Framework highlight some of the potential pathways to quality of life and well-being in people with dementia involved in an art programme as suggested in Table 1.1.

Results from the thesis, and existing literature, provide further evidence to expand the ideas from Table 1.1 and will be explored further in relation to each of the six senses. In Week 6, Mavis thanked the artist team for being so patient (Table 5.1) displaying a sense of security within the environment to acknowledge that she had not felt up to her best during the session. The artists had created an environment where there was no right or wrong so less chance of failure (Harlan, 1993).

A sense of continuity was created by the same artist team providing the sessions each week. Also, engaging in an arts programme has been shown to encourage self-expression, reminiscence and socialisation (Eekelaar et al., 2012; Johnson et al., 1992; Stewart, 2004) which can facilitate a sense of continuity for the person with dementia.

A sense of belonging has been recognised to be important for quality of life for people living with dementia by several different researchers (Brod et al., 1999; Kinney & Rentz, 2005; Kitwood, 1997). Kinney and Rentz (2005) stated that being engaged in a group art session gave a sense of belonging which was supported by findings in the current study that participants showed higher levels of Normalcy (non-verbal signs of being in a group) in the art intervention. However, one could question whether this sense of belonging is something specific to an art intervention, or just being in a group setting. This was the motivation for including another structured activity as a control condition so that any changes could not just be attributed to being in a group setting. An examination of Figure 3.1 shows that Normalcy was higher in the art intervention than in the other structured activity, indicating that participants demonstrated a greater sense of belonging in the art group.

A sense of purpose was built up through the opportunity of engaging in a meaningful activity and in the opportunity of choice. Previous researchers have observed that art sessions provide the opportunity for personal control through the choice of art materials or pictures to view which was supported by the residents' perspective in Chapter 4 (Harlan, 1993; Hannemann, 1996). Being offered choices can become important to a person in care who often has things done for them rather than being given a choice. The intervention also

gave residents the opportunity to demonstrate their remaining abilities which changed the perception of the care staff who in turn will be able to offer more meaningful activities.

A sense of achievement was promoted by the opportunity of making a valued contribution to the session, whether through the creation of own artwork, or through discussions with the artist. Results from the GCCWBOT indicated an increase in self-esteem over the course of the art intervention which was supported by the qualitative results in Chapter 4. Quotes such as "Are they really mine?!" demonstrated this sense of achievement the participants felt, which is also supported by existing literature (Camic et al., 2013; Flatt et al., 2014; Gross et al, 2013; Kinney & Rentz, 2005;).

Lastly, a sense of significance was developed through experiences and beliefs being validated through work being displayed or exhibited, which was identified by the staff perspective in Chapter 4, and Mavis (Chapter 5) being so proud of her work on the wall of her bedroom.

Having discussed several theories, it is clear that several theories can contribute, at least in part, to our understanding of why an art intervention may increase quality of life and wellbeing in people with dementia living in a care home. There are influences from the psychology of aesthetics and art, the psychological concept of flow, and psychological theories of dementia care such as Kitwood's person-centred care. However, the results from the thesis support the Senses Framework most strongly in that it acknowledges the importance of the interaction between the participants, artists and staff to create an enriched environment. It is also clear that a sense of belonging is an important theme present in much of the research discussed above and it appeared to be higher in the art intervention compared to the other structured activity. It is therefore crucial that a future art intervention should aim to create a sense of belonging.

Implications for policy, research, and practice

There is little value in doing research in dementia care that cannot be translated into practice to benefit the lives of people living with dementia. Research is key for improving dementia care and support through informing policies, which in turn will change care practices to improve the quality of life and well-being for people living with dementia.

This study has provided a valuable contribution to the field with evidence of suitable and appropriate outcome measures and suggested a methodology which can be implemented in

a larger scale study to establish solid evidence for the benefits of a visual art intervention for people with dementia. The adapted version of the Greater Cincinnati Chapter Well-Being Observation Tool is now being used in a much larger, multi-site project which will also provide useful data to confirm the psychometric properties of the measure.

The study has also offered further evidence for the benefits that a visual art intervention in a care home can have on the residents, care staff and the artist team. The results from Chapter 3 did not provide statistical evidence for the added value of arts activities over the other structured activities but does support the argument for provision of meaningful activities as the domains of Interest, Sustained Attention, and Pleasure on the GCCWBOT were significantly higher in the art intervention and other structured activity than unstructured time, and Sadness significantly lower in the art intervention and other structured activity than unstructured time. However, visual inspection of the profile plots in Figure 3.1 show that the art intervention was higher in the positive domains of well-being and lower in the negative domains than the other structured activity. This was supported by the care staff and artist team's perspectives who discuss benefits of the art intervention over the other structured activities suggesting there was something intrinsic about the art. The artist team believed that 'art...is like a language', a view supported by Junker (2010) who also spoke of art being a way to communicate.

The results from this thesis can therefore inform policy regarding the benefit of providing meaningful activities, including a visual art intervention for care home residents with dementia. The findings have shown the benefits to residents, as well as acknowledging the importance of the interaction between the participants, artists, and staff to create an enriched environment. This suggests that psychosocial interventions developed for care homes should not only focus on improving the well-being of residents but also acknowledge the importance of staff involvement. The study also shows that a visual art intervention can enable the staff to realise that the residents can achieve more than previously thought, and in turn remind them of the person behind the dementia.

Both the care staff and artist team spoke about the benefits of an artist coming in to lead the intervention over a member of the care staff leading it. However, findings reported in Chapter 6 suggest for this benefit to be realised the artist must be trained to work with people with dementia. This is supported by an observation made by the author of this thesis when the artist missed a session and the artist volunteers led the session [Table 5.2]. The artist volunteers had worked with people with dementia briefly before, but they didn't have the wealth of experience of the artist and participants lost interest during the session.

Chapter 4 offered many implications for practice for artists wishing to lead a successful art intervention for care home residents with dementia. Sessions should include art discussion, the environment should be enhanced with visual and tactile experience, and complex activities should be broken down but kept age appropriate. It was also suggested that holding the session in an open plan area meant that residents could come and go as they pleased. Discussions of possible theoretical underpinnings suggest that the participants should be made to feel a sense of belonging. The results also support a visit to an art gallery. Even though not all participants attended, it was found that this visit underpinned the rest of the sessions.

Another very important implication for practice is the finding that care staff underestimated the abilities of the residents. This has a direct impact on the day-to-day life of a resident and should be fed into dementia awareness training.

Strengths and Limitations

Strengths

This study had several strengths, including the study design and novel approaches in synthesising and presenting the results. The study has provided evidence of suitable and appropriate outcome measures and suggested a methodology which can be implemented in a larger scale study. The inclusion of two control conditions set it apart from previous research in the area and enabled any results found in the visual art to be distinguished from participants being in a group setting. Another strength of the quantitative results was that significant and near significant results were found despite small sample sizes.

The qualitative chapter is the only paper within existing literature to offer the perspective of the resident, care staff, and artist when exploring the experience and impact of a visual art intervention. It was also shown possible to collect data from the sometimes challenging environment of a care home. Despite only one participant remembering taking part, enough data was collected from field notes and video observations to supplement their views.

Chapter 6 is the first narrative synthesis of visual art interventions for people with dementia and is therefore a novel approach of synthesising existing literature in the field. This also gave the opportunity to critically evaluate Chapters 3 and 4 to demonstrate where they fit within the wider literature. The reported methodological rigour of Chapter 3 was found to be average, mainly due to issues with a small sample size. The qualitative paper (Chapter 4) was, however, the highest-rated of all sixteen included studies.

The results from the study have replicated findings from many previous studies, but as already discussed, in a more methodologically rigorous manner. In contrast to previous attempts of evidencing the benefits of visual art interventions for people with dementia through questionnaires before and after the intervention, this study found a significant increase in communication and a near significant increase in quality of life. The study results were able to demonstrate that collecting data both during an intervention and before and after gives the researcher a more complete picture of what effect a visual art intervention can have on a person with dementia, both in the momentary experience and over time.

Limitations

The study was intended to be a stepped design with the intervention being delivered in 3 successive occasions (waves), with assessments being undertaken before and after each intervention. It was planned that the data be discrete within each wave, so no comparisons were planned between waves and a different group of participants was used for each wave. However, due to such a small number of participants in each wave they were analysed together. Even analysed together, the sample size was small which limits the statistical power, with a risk of a type II error. The methodological rigour of the study reported in Chapter 3 was scored at 50 % using the MMAT in Chapter 6. The main issues were related to the small sample size.

Missing data affected the already small sample size. In some cases, participants were unable to complete the structured interviews for the QoL-AD and GDS-12R due to the severity of their cognitive impairment. Other reasons for incomplete questionnaires were participants being too tired or agitated or not available for one of the time points. Therefore, in the current study there were 4 cases of missing data for the QoL-AD and 5 for the GDS-12R. In cases where there are only one or two missing items, according to the missing data rules (Thorgrimsen et al., 2003), the score could be imputed as a mean of the remaining items. This was the case for two of the participants in the current study.

Although the observation tool was deemed a suitable outcome measure to evaluate a visual art intervention for care home residents with dementia, there were still limitations found associated with observation. Practical issues existed such as participants not attending sessions that were planned as an observation and participants leaving before the end of the observation window. As the mood of participants varied day-to-day, it was important to observe them twice in each condition at each time point so that an average could be taken. However, this wasn't always possible due the reasons already stated such as participants not attending the session.

The time-sampling technique that was used in the adapted version of the tool solved the issue of subjectivity in rating the proportion of time a person was showing an indicator, however, it brought with it issues of its own. By observing a participant for a minute every eight minutes, information was lost about the participant in those eight minutes, so the overall picture was lost. This was particularly apparent in the case of Mavis who would doze off regularly but be awake again by the time of the next observation window. Therefore, although the researcher could notice that the incidences of her dozing off decreased; this wasn't necessarily reflected in the snapshots provided by the GCCWBOT scores.

Lastly, the care home environment also created research challenges. Residents who hadn't signed up for the study often joined in with the sessions. Although this shows the appeal of the intervention even to those who had declined the opportunity originally, it meant that some were caught on videos of the session without giving consent. Arranging the gallery visit was also a challenge in the care home environment. A lot of planning was needed to ensure that extra staff were added to the rota and that travel arrangements were made. The visit was cancelled several times in the first wave and it was clear that there was reluctance from staff. However, it was noted by the artist team that the staff accompanying the residents to the gallery were quite emotional at the positive impact it had on the residents. Only one of the residents interviewed remembered taking part in the art intervention, therefore it is suggested that they are interviewed following a session so that they are still in the moment, or if this is not possible that more prompts are used such as videos and photos from sessions and their own art work.

Directions for future research

This exploratory study has determined the adapted version of the Greater Cincinnati Chapter Well-Being Observation Tool as a suitable measure to evaluate a visual art intervention for people with dementia. Further research is needed to determine the psychometric properties of this adapted version. Following this, a larger scale trial is needed to establish high quality evidence for the benefits of visual art interventions for people with dementia, including mixed methods approaches to provide the whole picture.

Conclusion

Interest in the effects of visual art programmes with people with dementia has increased dramatically over the last decade and there are calls to establish a solid evidence base so that the area gets the same recognition as other psychosocial interventions in improving the well-being of people with dementia. This thesis answers important questions arising regarding suitable measures and methodology. A visual art intervention for care home residents with dementia was shown to increase some factors of well-being and quality of life and the perspectives of the residents, care staff, and artist provided. The results were shown to be consistent with existing research. Suggestions are made to improve the methodological rigour of evaluations.

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Appendix

Appendix A: Ethical Approval Letter

Part of the research infrastructure for Wales funded by the National Institute for Social Care and Health Research, Welsh Government. Yn rhan o seilwaith ymchwil Cymru a ariannir gan y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd, Llywodraeth Cymru



Pwyllgor Moeseg Ymchwil Gogledd Cymru - Y Orllewin North Wales Research Ethics Committee – West

> Betsi Cadwaladr University Health Board Ysbyty Gwynedd Clinical Academic Office Bangor, Gwynedd LL57 2PW

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Miss Katherine Algar Dementia Services Development Centre, Bangor University 45 College Road, Bangor, Gwynedd LL57 2AS

21 March 2012

Dear Miss Algar,

Study title:

REC reference:

Can an arts programme increase quality of life and well-being of care home residents with dementia? An exploratory study 12/WA/0080

The Research Ethics Committee reviewed the above application at the meeting held on 15 March 2012. Thank you for attending to discuss the study.

Ethical opinion

Ethical issues raised by the Committee in private discussion, together with responses given by you when invited into the meeting

Social or scientific value; scientific design and conduct of the study

The Committee recognised this as an important study into patient quality of life and wellbeing outcomes, and generate evidence for any beneficial effects of arts programmes for people with dementia, with a potential impact on the delivery of care services. The Committee raised a query regarding uptake of the sessions by a group of residents or individually. You clarified that the visual arts programme is artist led to a group. A clarification was requested on whether the analysis of covariance (ANCOVA) is to be performed on the Greater Cincinnati Well-Being Observational Tool only? If so then this will include only 8 of the 9 possible combinations of the 3 conditions (intervention, other structured, unstructured) and 3 times (baseline, T1, T2) as there is no baseline and intervention combination. If this is the case then care needs to be taken in setting up the 2 factor ANCOVA as the full factorial structure of 3 time points in each of the 3 conditions is not available.

The Committee concluded that the research design is suitable for answering the research question, but recommended that the you seek guidance in reworking the statistical analysis plan. This is not a condition of the favourable ethical opinion. No further ethical issues were raised.



Cynhelir Cydweithrediad Gwyddor lechyd Academaidd y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac lechyd gan Fwrdd Addysgu lechyd Powys

The National Institute for Social Care and Health Research Academic Health Science Collaboration is hosted by Powys Teaching Health Board



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Fair participant selection

The Committee noted that it is not clear what criteria are used for participants' selection: the protocol and application form state that potential participants will be "identified with the care home manager" (Protocol, page 8); a qualitative study would try and get a variety of residents; a quantitative study would randomly select residents. You clarified that the participants the care home mangers can identify who is interested in taking part in the arts programme and staff will be given information sheet and given the opportunity to participate. The Committee queried whether there would be residents who can express an interest but not be chosen to take part. You clarified that the study will be carried out in 3 waves, so it is hoped that all residents who wanted to take part would be able to do so; The Committee was satisfied that the selection of potential participants has taken into

account their clinical care; the application gives a clear description of the arrangements made with the clinical team regarding the recruitment of participants;

Compliance with the Mental Capacity Act (England and Wales), 2005

The Committee considered the following issues:

i) Relevance of the research to impairing condition

The Committee agreed that the research is connected with an impairing condition (dementia) affecting persons lacking capacity, and with the treatment of the condition.

ii) Justification for including adults lacking capacity to meet the research objectives The Committee agreed that the research could not be carried out as effectively if it was confined to participants able to give consent.

iii) Balance between benefit and risk, burden and intrusion

After discussion the Committee agreed that the risk to participants is negligible, the research will not significantly interfere with their freedom of action or privacy, and it will not be unduly invasive or restrictive.

The Committee noted that while the research may not benefit participants directly (or provide limited benefit) it is intended to provide knowledge of the causes, treatment or care of the condition affecting participants lacking capacity (dementia), without imposing a disproportionate burden.

iv) Arrangements for appointing consultees

The Committee considered the arrangements set out in the application and the supporting documentation for appointing Consultees under section 32 of the Mental Capacity Act to advise on whether participants lacking capacity should take part and on what their wishes and feelings would be likely to be if they had capacity. After discussion the Committee agreed that reasonable arrangements were in place for identifying Personal Consultees and for appointing Nominated Consultees independent of the project where no person can be identified to act as a Personal Consultee.

v) Information for Consultees

The Committee reviewed the information to be provided to Consultess about the proposed research and their role and responsibilities as a Consultee. The Committee was satisfied that the information was adequate to enable Consultees to give informed advice about the participants of persons lacking capacity.

vi) Additional safeguards

The Committee was content that nothing will be done in the course of the research to which participants lacking capacity appear to object or which would be contrary to any known advance decision or statement they have made. If participants indicate in any way that they wish to be withdrawn from the project, they will be withdrawn without delay. The Committee was satisfied that reasonable arrangements would be in place to comply with the additional safeguards set out in section 33 of the Mental Capacity Act

vii) Other ethical issues

As the project involves adults lacking capacity the Committee is satisfied that the team have the competencies required and an understanding of the relevant aspects of the MCA and code of Practice, including the core principles of the Act, the assessment of capacity and the safeguards relating to research. A query wad raised regarding the person conducting the assessment of capacity. You clarified that you will be conducting the assessment of capacity based on the checklist of items recommended by the Code of Practice; in cases where uncertainty would arise you will be liaising with the Academic supervisor, Professor Robert Woods, who has extensive experience in dementia research.

Informed Consent process: Adequacy and completeness of Participant Information The Committee noted that written informed consent is taken as part of a process, and discussed whether participants and Consultees have adequate time to consider the information, and opportunity to ask questions before being asked to consider consenting to take part. The information is clear to what the participant consents and there is no inducement or coercion.

The Committee agreed that generally the procedures described in the protocol have been addressed in the Information Sheet, but felt that the Participant Information Sheet is too long and complex for the residents, particularly if it was felt necessary to use the large type and pictures in the part one of the document. You clarified that different levels of understanding are required, the large print Participant Information Sheet is given to asses initial interest, and should the participants express an interest to participate a more comprehensive Participant Information Sheet is given, explaining in detail the requirements of the study in order to ensure that participates give fully informed consent. This Participant Information Sheet is not only given to potential participants to read, but is explained in detail by the researcher.

<u>Suitability of the applicant and facilities, community considerations; Site Specific Assessment</u> The Committee discussed the suitability of the applicant and concluded that you are excellently qualified and adequately supervised to carry out this research.

The Committee concluded that local facilities and arrangements are suitable, and community issues have been considered.

It was noted that the applicants have submitted a non-NHS SSI application form, requesting a Site-Specific Assessment. The Committee discussed the requirement for Site-Specific Assessment for the non-NHS sites involved (Richmond House care home) and concluded that the study can be considered SSA exempt as it involves no clinical interventions and all study procedures at these sites will be undertaken by your team. The REC was satisfied that the risk to participants is likely to be negligible and the study procedures will not significantly interfere with participant's freedom of action or privacy or be unduly invasive or restrictive. No further ethical issues were raised

<u>General comments/ missing information/ typographical errors/ application errors</u> The Committee noted that the protocol suggests that more than one care home will be approached. However the application form suggests only one care home is involved in the study. You clarified that initially only one care home (Richmond house) would be approached.

The Chairman thanked you and Dr. Windle for attending to speak to this submission and gave you an opportunity to ask questions. You did not raise any issues.

The Committee considered your responses.

On the basis of the information provided, the Committee was satisfied with the following aspects of the research:

- Social or scientific value; scientific design and conduct of the study
- Independent review
- Fair participant selection
- Favourable risk benefit ratio; anticipated benefits/ risks for research participants
- <u>Care and protection of research participants; respect for participants' welfare & dignity;</u>
 data protection & participant's confidentiality
- Informed Consent process
- Compliance with the Mental Capacity Act (England and Wales 2005)
- Adequacy and completeness of Participant Information
- Suitability of the Applicant and Supporting Staff

The members of the Committee present gave a **favourable ethical opinion** of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Mental Capacity Act 2005

I confirm that the committee has approved this research project for the purposes of the Mental Capacity Act 2005. The committee is satisfied that the requirements of section 31 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

A decision of Site Specific Assessment exemption has been recorded for Richmond House care home (non-NHS research site) as it involves no clinical interventions and all study procedures at these sites will be undertaken by the Chief Investigator's team.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
REC application (submission 96043/299205/1/340)		05 March 2012
Non NHS SSI application form (submission 96043/299171/7/777/144601/237230)		01 March 2012
Protocol	2	27 February 2012
Participant Information Sheet:	4	27 February 2012
Participant Information Sheet: Leaflet	3	27 February 2012
Participant Information Sheet: Personal Consultee	4	27 February 2012
Participant Information Sheet: Nominated Consultee	4	27 February 2012
Participant Information Sheet: Staff	3	21 February 2012
GP/Consultant Information Sheets	3	21 February 2012
Participant Consent Form	4	27 February 2012
Participant Consent Form: Personal Consultee Declaration Form	4	27 February 2012
Participant Consent Form: Nominated Consultee Declaration Form	4	27 February 2012
Participant Consent Form: Staff	3	21 February 2012
Interview Schedules/Topic Guides: Participant	3	21 February 2012
Interview Schedules/Topic Guides: Staff and Artist	3	21 February 2012
Other: Assessing Capacity Checklist	3	21 February 2012
Questionnaire: Clinical Dementia Rating Scale		
Questionnaire: Quality of Life in Alzheimer's Disease		
Questionnaire: Geriatric Depression Scale (residential)		
Questionnaire: Holden Communication Scale		
Questionnaire: Approaches to Dementia Questionnaire		
Questionnaire: Zeisel Stigma Scale		
Questionnaire: Greater Cincinnati Well-Being Observational Tool		
Investigator CV (Miss Katherine Algar)		29 February 2012
Other: Academic Supervisor CV (Prof R Woods)		28 February 2012
Other: Academic Supervisor CV (Dr G Windle)		29 February 2012
Evidence of insurance or indemnity	UMAL	01 August 2011

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

No conflicts of interest were declared in relation to this application.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

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After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- · Adding new sites and investigators
- · Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

12/WA/0080 Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely

Rossela Roberts

Pi

Mr David Owen Chairman

Email: rossela.roberts@wales.nhs.uk

Enclosures:

List of names and professions of members who were present at the meeting and those who submitted written comments

"After ethical review – guidance for researchers"

Copy to: Sponsor: Prof Robert Woods, IMSCaR, Bangor University

North Wales Research Ethics Committee - West

Attendance at Committee meeting on 15 March 2012

Committee Members

Name	Profession	Capacity	Present
Dr. Karen Addy	Clinical Psychologist	Expert	Yes
Dr. Swapna Alexander	Consultant Physician	Expert	Yes
Mrs. Kathryn Chester	Research Nurse	Expert	Yes
Dr. Christine Clark	Consultant Obstetrician & Gynaecologist	Expert	Yes
Mr. Derek James Crawford	Consultant Surgeon (Vice-Chairman)	Expert	Yes
Mrs. Gwen Dale-Jones	PA (retired)	Lay +	Yes
Mr. Hywel Lloyd Davies	Solicitor (Alternate Vice-Chairman)	Lay +	No
Mr. Ron Evans	Retired Teacher	Lay +	Yes
Mr. Henry Alan Owen Hughes	Pharmacy Professional Services Lead	Expert	No
Ms. Gillian Jones	Student	Lay +	No
Dr. Mark Lord	Consultant Pathologist	Expert	No
Mr. David Owen	Retired Chief Constable (Chairman)	Lay +	Yes
Mr. Paramasivam Sathyamoorthy	Consultant Orthopaedic Surgeon	Expert	Yes
Dr. Thanthullu Vasu	Consultant Anaesthetist	Expert	Yes
Mr. Christopher John Whitaker	Statistician	Expert	Yes
Dr. Philip Wayman White	General Practitioner	Expert	Yes

Deputy Members

Name	Profession	Capacity	Present
Mrs. Rebecca Burns	Research Nurse (deputy to Mrs. Chester)	Expert	No
Dr. Michael Cronin	Consultant Paediatrician (deputy to Dr. Clark)	Expert	No
Mrs. Mair Rhiannon Martin	Pharmacist (deputy to Mr. Hughes)	Expert	Yes

In attendance

Name Position (or reason for attending)		
Dr. Rossela Roberts	Committee Coordinator	
Miss Angela Filippi	Assistant Coordinator	

Appendix B: Participant Information Leaflet (given on first contact)

Do you enjoy art: If so, we think you will find this an enjoyable experience!



Can you help?

We are looking for people who live in a care home to take part in art sessions provided by us and be part of a research project

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Version 3, 27/02/2012



There is a lot of anecdotal evidence that being involved in a visual art programme can increase the quality of life and well-being of people with memory problems. However, there isn't much research evidence of this, so this project aims to add to the evidence and develop a visual art programme for people with dementia living in a care home.





If you decide to take part we will:

- . Come and meet you and ask you some questions for about an hour.
- Ask you to attend weekly art sessions led by an artist, run in your care home.
- Observe you while you go about your day, during the art session, and during another activity in your care home.
- Come and meet you again to ask you the same questions as before

It is up to you if you want to take part. If you do decide to take part, you can withdraw at any time.



The project is being led by Kat, a PhD student. She is happy to answer any questions you have.

Please ask your manager at Richmond House if you are interested in finding out more information about the project.

Appendix C: Participant Information Sheet (given when asked for more information)

Developing and Evaluating a Visual Arts Programme in a Care Home

PARTICIPANT INFORMATION SHEET

Invitation to participate in a research study

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this information sheet.

What is the purpose of the study?

There is a lot of anecdotal evidence that being involved in a visual arts programme can increase the quality of life and well-being of people with memory problems. However, there isn't much research evidence of this, so this project aims to add to the evidence and develop a visual art programme for people with dementia living in a care home.

Why have I been invited?

You have been invited to take part because you have difficulties with memory and are living in a care home. The project is going to be done in three stages and we are looking for 10 people who have memory problems for each stage.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care that you receive.

What do I have to do?

This study is preliminary research. We hope to establish the benefits of taking part in a visual art programme. If you do decide to take part, your participation in the study will last for about 5 months.

Following discussion of any questions you have with the researcher, and signing the consent form, you will be asked to:

1.) Allow the researcher to look at your care home / medical notes to give us an understanding of your health.

- 2.) Meet with a researcher for about an hour to complete some questionnaires covering your quality of life and mood. We will also ask you some questions about your views and perceptions of art. We will record the interview using a digital audio recording device so that we can talk with you without having to write everything down. The time stated to complete the interview is an estimate; you may take as many breaks as you want or feel necessary. You can complete the process over two sessions on the same day or at a later date if you prefer.
- 3.) Allow a researcher to observe you for an hour while going about your day, on several separate occasions. These observations will only happen when you are in a public place such as the lounge. The researcher will not come into your bedroom or any other private places. The researcher will stay out of your way, and make sure no disruption to your day occurs. This will be videoed to aid the researcher's observation. For us to be able to show whether the art sessions have a benefit, we need to be able to compare it with how you are during a normal day.
- 4.) Attend art sessions run in your care home by an artist. The artist will be accompanied by a volunteer to assist him/her. They will be chosen by the research team and care home staff together, and will have experience of working with people in a care home. They will have had an enhanced Criminal Records Bureau check run by the research team before they start. Whilst you are at the art session, the researcher will be observing you on several separate occasions. Again, every effort will be made to cause no disruption to your activity. The sessions will be videoed to aid the researcher's observation. Things that you say may be used in the final report but it will not be linked to your name.
- 5.) Allow a researcher to observe you for an hour on several separate occasions while you do a usual activity run in the care home, such as music, or during chair aerobics. The researcher will stay out of your way and make sure no disruption to yourself occurs. The sessions will be videoed to aid the researcher's observation. This is so that we can compare observations from the art sessions and this activity to show whether there is something special about art that has benefits.
- 6.) A week after the art sessions end, you will be asked to meet with a researcher for about an hour to complete the same questionnaires covering your quality of life and mood as before. We will also ask you some questions about your views and perceptions of art, and what you liked/disliked about the art sessions. Again, the interview will be recorded using a digital audio recording device.

All interviews will be recorded using a digital audio recorder, and all observation sessions will be videoed to help the researcher analyse the data. We may also use pictures of artwork and/or sections of the videos in presentations when disseminating the results but your real name will never be given.

What are the possible disadvantages and risks of taking part?

Some of the questions in the questionnaires ask about your mood in detail. If you do find any questions upsetting or distressing, you do not have to answer them, and the researcher will be on hand to give any support needed.

While taking part in the art sessions, there will always be a member of care home staff available if you require any assistance.

What are the possible benefits to taking part?

If you decide to take part, you will be attending weekly sessions with an artist and previous research has reported that many people enjoy the experience greatly. The aim is that the information we get from this study may help us to offer better treatment to people with memory problems in the future.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. All data is stored without any identifying details under secure conditions. The only people who will have access to view identifiable data is the researcher and supervisor. Confidentiality would only ever be broken if there was a concern that you might be at risk of harm.

Involvement of the General Practitioner/ Family doctor (GP)

We will ask your permission to send your GP a letter explaining that you have agreed to take part in the study.

What will happen if I don't want to carry on with the study?

You will be free to withdraw from the study at any time, without giving a reason. Withdrawing from the study will not affect the standard of care you receive. You will have the option of any data collected up to that point of withdrawal not to be used in the study.

What if there is a problem?

If you are harmed by taking part in this study, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you have grounds for a legal action, but you may have to pay for your legal costs.

Regardless of this, if you wish to make a complaint about any aspect of the way you have been approached or treated during the course of this study, the normal University complaints procedures should be available to you. If you are unhappy or dissatisfied about any aspect of your participation, we would ask you to tell us about this in the first instance, so that we can try to resolve any concerns and find a solution.

Katherine Algar, Dementia Services Development Centre, Wales Bangor University, 45 College Road, Bangor, Gwynedd. LL57 2AS Tel: 01248 382226 Email: <u>k.algar@bangor.ac.uk</u>

If you remain unhappy and wish to complain formally, you can do this by contacting Professor Bob Woods, Head of the Institute of Medical and Social Care Research, Bangor University.

Professor Bob Woods, Director, Dementia Services Development Centre, Wales Bangor University, 45 College Road, Bangor, Gwynedd. LL57 2AS Tel: 01248 383719 Email: <u>b.woods@bangor.ac.uk</u>

What will happen to the results of the research project?

The results of the research project will be published in relevant academic journals. The researcher also intends to hold a meeting for local care home managers, families and people with memory problems to share the results. No participants will be identified in any publication arising from the study without their written consent. We will make arrangements for participants to be informed of the findings of the study where desired.

Who is organising and funding the research?

The research is funded by the National Institute for Social Care and Health Research (NISCHR), Welsh Government, as part of a PhD sponsorship and is under the direction of the Dementia Services Development Centre at Bangor University. This funding covers the running costs of the research project which is being led by Katherine Algar (PhD student) and supervised by Professor Bob Woods and Dr. Gill Windle.

Who has reviewed this study?

All research in the NHS is looked at by an independent group of people called a Research Ethics Committee to protect your safety, rights, well-being, and dignity.

This study has been reviewed and given favourable opinion by the North Wales Research Ethics Committee - West.

Who can I contact for further information?

For more information about this research, please contact:

Katherine Algar, Dementia Services Development Centre, Wales Bangor University, 45 College Road, Bangor, Gwynedd. LL57 2AS Tel: 01248 382226 Email: <u>k.algar@bangor.ac.uk</u>

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Appendix D: Participant Consent Form

Developing and Evaluating a Visual Art Programme in a Care Home

PARTICIPANT CONSENT FORM

- I confirm that I have read and understand the information sheet (Version 4, 27/02/2012) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
- 2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason, without my medical care or legal rights being affected.
- 3. I understand that sections of any of my medical notes may be looked at by researchers involved in the research where it is relevant to my taking part in this research. I give my permission for researchers to have access to my records.
- 4. I give permission for my GP to be informed of my participation in the study.
- 5. I understand that all information given by me or about me will be treated as confidential by the researcher unless there is risk of harm.
- 6. I agree to pictures of my artwork to be shown in presentations by the researcher when disseminating the results.
- 7. I have been made aware that all observational sessions will be videoed for analysis purposes, and the interviews audio recorded. I know that there may be a possibility of things I say being included in the report but it will not be linked to my name.
- 8. I agree to take part in the above study.

Name of Participant	Date Signature	
Researcher	Date	Signature







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Appendix E: Personal Consultee Information sheet

Developing and Evaluating a Visual Arts Programme for People with Dementia

PERSONAL CONSULTEE INFORMATION SHEET

Introduction

We feel your relative/friend is unable to decide for him/herself whether to participate in this research.

To help decide if he/she should join the study, we would like to ask your opinion whether or not they would want to be involved. We would ask you to consider what you know of their wishes and feelings, and to consider their interests. Please let us know of any advance decisions they may have made about participating in research. These should take precedence.

If you decide your relative/friend would have no objection to taking part we will ask you to read and sign the personal consultee declaration on the last page of this information sheet. We will then give you a copy to keep. We will keep you fully informed during the study so you can let us know if you have any concerns or you think your relative/friend should be withdrawn.

If you decide that your relative/friend would not wish to take part it will not affect the standard of care they receive in any way.

If you are unsure about taking the role of consultee you may seek independent advice.

We will understand if you do not want to take on this responsibility.

Before you give advice, it is important that you understand what the research will involve for your relative/friend and why it is being done. Please take time to read the following information and discuss it with others if you wish. Ask us if there is anything that is not clear or if you require further information about this study. Take your time in deciding whether or not this person would wish to take part.

Thank you for reading this information sheet.

What is the purpose of the study?

There is a lot of anecdotal evidence that being involved in a visual arts programme can increase the quality of life and well-being of people with memory problems. However, there isn't much research evidence of this, so this project aims to add to the evidence and develop a visual arts programme for people with dementia living in a care home.

Why has my relative/friend been invited?

Your relative/friend has been invited to take part because he/she has difficulties with memory and is living in a care home. The project is going to be done in three stages and we are looking for 10 people who have memory problems for each stage.

Does my relative/friend have to take part?

Your relative/friend does not have to take part. It is up to you to advise whether or not your relative/friend should be included. If you do decide that your relative/friend would wish to participate, you will be given this information sheet to keep and be asked to sign a consent form. You are still free to change your advice at any time without giving a reason. A decision to withdraw your relative/friend at any time, or advice that he/she should not to take part, will not affect the standard of care that he/she receives.

What will my relative/friend have to do?

This study is preliminary research. We hope to establish the benefits of taking part in a visual art programme. If you advise for your relative to take part, his/her participation in the study will last for about 5 months.

Following discussion of any questions with the researcher your relative / friend will

- 1.) Allow the researcher to look at his/her care home / medical notes to give us an understanding of their health.
- 2.) Meet with a researcher for about an hour to complete some questionnaires covering his/her quality of life and mood. We will also ask him/her some questions about views and perceptions of art. We will record the interview using a digital audio recording device so that we can talk with your relative/friend without having to write everything down. The time stated to complete the interview is an estimate; your relative/friend may take as many breaks as he/she want or feel necessary. Your relative/friend can complete the process over two sessions on the same day or at a later date if preferred.
- 3.) Allow a researcher to observe him/her for an hour on several separate occasions while going about his/her day. These observations will only happen when he/she are in a public place such as the lounge. The researcher will not go into his/her bedroom or any other private places. The researcher will stay out of his/her way, and make sure no disruption to the day occurs. This will be videoed to aid the researcher's observation. For us to be able to show whether the art sessions have a benefit, we need to be able to compare it with how your relative/ friend is during a normal day.
- 4.) Attend art sessions run in their care home by an artist. The artist will be accompanied by a volunteer to assist him/her. They will be chosen by the

research team and care home staff together, and will have experience working with people in a care home. They will have had an enhanced Criminal Records Bureau check run by the research team before they start. Whilst your relative / friend are in the art session, the researcher will be observing him/her on several separate occasions. Again, every effort will be made to cause no disruption to the activity. The sessions will be videoed to aid the researcher's observation. Things that this person say may be used in the final report but it will not be linked to his/her name.

- 5.) Allow a researcher to observe him/her for an hour on several separate occasions while he/she do a usual activity run in the care home, such as music, or during chair aerobics. The researcher will stay out of his/her way and make sure no disruption to the activity occurs. The session will be videoed to aid with the researcher's observation. This is so that we can compare observations from the art sessions and this activity to show whether there is something special about art that has benefits.
- 6.) A week after the art sessions end, your relative / friend will be asked to meet with a researcher for about an hour to complete the same questionnaires covering his/her quality of life and mood. We will also ask him / her some questions about views and perceptions of art, and what he/she liked/disliked about the art sessions. Again, the interview will be recorded using a digital audio recording device.

All interviews will be recorded using a digital audio recorder, and all observation sessions will be videoed to aid the researcher analyse the data. We may also use pictures of artwork and/or sections of the videos in presentations when disseminating the results but the real name of your relative / friend will never be given.

What are the possible disadvantages and risks of taking part?

Some of the questions in the questionnaires ask about your relative / friend's mood in detail. If your relative/friend does find any questions upsetting or distressing, he/she does not have to answer them, and the researcher will be on hand to give any support needed.

While taking part in the art sessions, there will always be a member of care home staff available if your relative / friend requires assistance.

What are the possible benefits to taking part?

If you advise your relative/friend take part, he/she will be attending weekly sessions with an artist and previous research has reported that many people enjoy the experience greatly. The aim is that the information we get from this study may help us to offer better treatment to people with memory problems in the future.

Will my relative/friend's taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about him/her will be handled in confidence. All data is stored without any identifying details under secure conditions. The only people who will have access to view identifiable data is the researcher and supervisor. Confidentiality would only ever be broken if there was a concern that your relative/friend might be at risk of harm.

Involvement of the General Practitioner/ Family doctor (GP)

We will ask your permission to send your relative/friend's GP a letter explaining that he/she is taking part in the study.

What will happen if my relative/friend doesn't want to carry on with the study?

He/she will be free to withdraw from the study at any time, without giving a reason. Withdrawing from the study will not affect the standard of care he/she receives. You and your relative/friend will have the option of any data collected up to that point of withdrawal not to be used in the study.

What if there is a problem?

If your relative/friend is harmed by taking part in this study, there are no special compensation arrangements. If he/she is harmed due to someone's negligence, then you have grounds for a legal action, but you may have to pay for your relative/friend's legal costs.

Regardless of this, if you wish to make a complaint about any aspect of the way your relative/friend has been approached or treated during the course of this study, the normal University complaints procedures should be available to you. If you are unhappy or dissatisfied about any aspect of your relative/friend's participation, we would ask you to tell us about this in the first instance, so that we can try to resolve any concerns and find a solution.

Katherine Algar, Dementia Services Development Centre, Wales Bangor University, 45 College Road, Bangor, Gwynedd. LL57 2DG Tel: 01248 382226 Email: <u>k.algar@bangor.ac.uk</u>

If you remain unhappy and wish to complain formally, you can do this by contacting Professor Bob Woods, Head of the Institute of Medical and Social Care Research, Bangor University.

Professor Bob Woods, Director, Dementia Services Development Centre, Wales Bangor University, 45 College Road, Bangor, Gwynedd. LL57 2DG Tel: 01248 383719 Email: <u>b.woods@bangor.ac.uk</u>

What will happen to the results of the research project?

The results of the research project will be published in relevant academic journals. The researcher also intends to hold a meeting for local care home managers, families and people with memory problems to share the results. No participants will be identified in any publication arising from the study without their written consent. We will make arrangements for participants to be informed of the findings of the study where desired.

Who is organising and funding the research?

The research is funded by the National Institute for Social Care and Health Research (NISCHR), Welsh Government, as part of a PhD sponsorship and is under the direction of the Dementia Services Development Centre at Bangor University. This funding covers the running costs of the research project which is being led by Katherine Algar (PhD student) and supervised by Professor Bob Woods and Dr. Gill Windle.

Who has reviewed this study?

All research in the NHS is looked at by an independent group of people called a Research Ethics Committee to protect your safety, rights, well-being, and dignity. This study has been reviewed and given favourable opinion by the North Wales Research Ethics Committee- West.

Who can I contact for further information?

For more information about this research, please contact:

Katherine Algar, Dementia Services Development Centre, Wales Bangor University, 45 College Road, Bangor, Gwynedd. LL57 2AS Tel: 01248 382226 Email: <u>k.algar@bangor.ac.uk</u>

If you have any complaints about this study, please contact:

Professor Bob Woods, Director, Dementia Services Development Centre, Wales Bangor University, 45 College Road, Bangor, Gwynedd. LL57 2AS
Tel: 01248 383719 Email: <u>b.woods@bangor.ac.uk</u>

Appendix F: Personal Consultee Declaration form

Developing and Evaluating a Visual Art Programme in a Care Home

PERSONAL CONSULTEE DECLARATION FORM

- 1. I have been consulted about 's participation in this research project. I have read and understand the information sheet (Version 4. 27/02/2012). I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
- 2. In my opinion he/she would have no objection to taking part in the above study
- 3. I understand that I can request he/she is withdrawn from the study at any time, without giving reason, without his/her medical care or legal rights being affected.
- 4. I understand that relevant sections of his/her medical notes may be looked at by researchers involved in the research where it is relevant to his/her taking part in this research. I agree to researchers having access to his/her records.
- 5. I agree to his/her GP being informed of their participation in the study.
- 6. I agree to pictures of my relative/friend's artwork to be shown in presentations by the researcher when disseminating the results.
- 7. I have been made aware that all observational sessions will be videoed for analysis purposes, and the interviews audio recorded. I know that there may be a possibility of quotes from my relative/friend being included in the report but there will be no link to their name. Date

Name of Consultee

		AD
Relationship	to	participant:

Researcher	Date	Signature		















Signature

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Appendix G: Staff Information Sheet

Developing and Evaluating a Visual Art Programme in a Care Home

STAFF INFORMATION SHEET

Invitation to participate in a research study

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this information sheet.

What is the purpose of the study?

There is a lot of anecdotal evidence that being involved in a visual arts programme can increase the quality of life and well-being of people with memory problems. However, there isn't much research evidence of this, so this project aims to add to the evidence and develop a visual arts programme for people with dementia living in a care home. At the same time, we are also evaluating whether involvement in the research project alters the attitudes care home staff have towards dementia.

Why have I been invited?

You have been invited to take part because you are a member of staff at the care home that is participating in this research project. We are intending to recruit as many staff as possible looking after residents with memory problems, who have agreed to take part in the study.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect your job or work at your care homes.

What do I have to do?

The researcher will ask you to complete a number of questionnaires on 2 occasions over a 5 month period. The questionnaires should take no longer than 20 minutes to complete, and are about your attitudes to dementia care. You may also be asked to take part in an interview to find out you views of the art programme. This will be audio recorded so that the researcher can talk to you without having to write everything down. Quotes that you make may be included in

the final report but will not be linked to your name. Taking part in the study does not involve any changes to your work.

What are the possible disadvantages and risks of taking part?

We do not anticipate any disadvantages or risks arising from participation.

What are the possible benefits to taking part?

There are no immediate benefits from taking part in this study, but the results of this research are intended to contribute towards better care for people who experience memory difficulties in the future.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. All data is stored without any identifying details under secure conditions. The only people who will have access to view identifiable data is the researcher and supervisor.

What will happen if I don't want to carry on with the study?

You will be free to withdraw from the study at any time, without giving a reason. Withdrawing from the study will not affect your present or future job as a member of staff at a care home. You will have the option of any data collected up to that point of withdrawal not to be used in the study.

What if there is a problem?

In the unlikely event that you are harmed by taking part in this study, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you have grounds for a legal action, but you may have to pay for your legal costs.

Regardless of this, if you wish to make a complaint about any aspect of the way you have been approached or treated during the course of this study, the normal University complaints procedures should be available to you. If you are unhappy or dissatisfied about any aspect of your participation, we would ask you to tell us about this in the first instance, so that we can try to resolve any concerns and find a solution.

Katherine Algar, Dementia Services Development Centre, Wales Bangor University, 45 College Road, Bangor, Gwynedd. LL57 2AS Tel: 01248 382226 Email: k.algar@bangor.ac.uk If you remain unhappy and wish to complain formally, you can do this by contacting Professor Bob Woods, Head of the Institute of Medical and Social Care Research, Bangor University.

Professor Bob Woods, Director, Dementia Services Development Centre, Wales Bangor University, 45 College Road, Bangor, Gwynedd. LL57 2AS Tel: 01248 383719 Email: <u>b.woods@bangor.ac.uk</u>

What will happen to the results of the research project?

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Who is organising and funding the research?

The research is funded by the National Institute for Social Care and Health Research (NISCHR), Welsh Government, as part of a PhD sponsorship and is under the direction of the Dementia Services Development Centre at Bangor University. This funding covers the running costs of the research project which is being led by Katherine Algar (PhD student) and supervised by Professor Bob Woods and Dr. Gill Windle.

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Who can I contact for further information?

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Appendix H: Staff Consent Form

Developing and Evaluating a Visual Art Programme in a Care Home

STAFF CONSENT FORM

- 1. I confirm that I have read and understand the information sheet (Version 3, 21/02/2012) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
- 2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason, without my employment or legal rights being affected.
- 3. I understand that all information given by me or about me will be treated as confidential by the researcher.
- 4. I have been made aware that I may be asked to take part in an interview which will be audio recorded. I know that there may be a possibility of things I say being included in the report but it will not be linked to my name.
- 5. I agree to take part in the above study.

Name of Participant	Date	Signature
	•••••	
Researcher	Date	Signature









1.	_	-	
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Appendix I: Mental Capacity Checklist

Developing and Evaluating a Visual Art Programme in a Care Home

Checklist: Assessing Capacity

Participant ID: _____

Participant can:

• Understand the information relevant to the decision.

<u>AND</u>

• Retain the information.

<u>AND</u>

• Use or weigh the information to arrive at a choice.

<u>AND</u>

Communicate the decision

**failure on any part indicates a lack of capacity

NOTE:









Appendix J: Score Sheet for Adapted Greater Cincinnati Chapter Well-Being Observation Tool.

Greater Cincinnati Chapter Well-Being Observation Tool Scoring Sheet (P1) Participant ID: _____

Phase / Condition:

Date: _____

									Total	
	(Minute) (start time)	0-1	8	16	24	32	40	48	56	1
	Interest in others									
terest	Without prompts offers support of a peer									
5	Acknowledges support from peer									
Attention	While engaged sustains attention									
	Requires verbal prompting or cueing									
	Initiates or engages in conversation									
ure	Relaxed body language, smiles, and laughs									
Pleas	Verbalizes sense of pleasure									
ct	Anger									
ve Affe	Physical signs of agitation									
Negati	Verbalizes feeling anxious									
SSS	Behavioral signs of sadness									
Sadne	Verbalizes feeling sad									
	1	1	1	1	1	1	1	1	1	1
em	Non-verbal expression of pride									
elf Este	Verbal expression of satisfaction									
Se	Inferred prideful reminiscence									
×	Verbal expression of normalcy									
ormalcy	Non-verbal expression of social normalcy									
Ž	When joining or leaving; interacts with others									

Qualitative Observations (indicate time):

Greater Cincinnati Chapter Well-Being Observation Tool (P2) Participant ID: Participant ID: ______ Phase / Condition: ______

Date:

			(2		10					Total
	(Minute) (start time)	2	10	18	26	34	42	50	58	19
	Interest in others									
Interest	Without prompts offers support of a peer									
	peer									
E	While engaged sustains attention									
tention	Requires verbal prompting or cueing									
Ire At	Initiates or engages in conversation									
Pleasure	Relaxed body language, smiles, and laughs									
	Verbalizes sense of pleasure									
e Affect	Anger									
	Physical signs of agitation									
Negativ	Verbalizes feeling anxious									
SS	Behavioral signs of sadness									
Sadne	Verbalizes feeling sad									
	1	1	1	1	1	1	1	1	1	1
em	Non-verbal expression of pride									
Self Estee	Verbal expression of satisfaction									
	Inferred prideful reminiscence						1			
	Verbal expression of normalcy									
ormalc)	Non-verbal expression of social normalcy									
N	When joining or leaving; interacts with others									

Qualitative Observations (indicate time):

Greater Cincinnati Chapter Well-Being Observation Tool (P3) Participant ID: _____ Phase / Condition: _____

Date:

									Total	
	(Minute) (start time)	4	12	20	28	36	44	52	60	
	Interest in others									
Interest	Without prompts offers support of a peer									
	Acknowledges support from peer									
Attention	While engaged sustains attention									
	Requires verbal prompting or cueing									
	Initiates or engages in conversation									
sure	Relaxed body language, smiles, and laughs									
Pleas	Verbalizes sense of pleasure		c							
t	Anger									
ve Affe	Physical signs of agitation									
Negat	Verbalizes feeling anxious									
sss	Behavioral signs of sadness									
Sadne	Verbalizes feeling sad									
	1	1	1	1	1	1	1	1	1	1
em	Non-verbal expression of pride									
lf Este	Verbal expression of satisfaction									
Se	Inferred prideful reminiscence									
~	Verbal expression of normalcy									
ormalc	Non-verbal expression of social normalcy									
ž	When joining or leaving; interacts with others									

Qualitative Observations (indicate time):

Greater Cincinnati Chapter Well-Being Observation Tool (P4) Participant ID: Participant ID: ______ Phase / Condition: ______

Date: _____

ġ.

									Total	
	(Minute) (start time)	6	14	22	30	38	46	54	62	
	Interest in others									
Iterest	Without prompts offers support of a peer									
-	Acknowledges support from peer									
Attention	While engaged sustains attention									
	Requires verbal prompting or cueing									
	Initiates or engages in conversation									
sure	Relaxed body language, smiles, and laughs									
Pleas	Verbalizes sense of pleasure									
t	Anger									
ve Affec	Physical signs of agitation									
Negat	Verbalizes feeling anxious									
SSS	Behavioral signs of sadness									
Sadne	Verbalizes feeling sad									
	1	1	1	1	1	1	1	1	1	1
em	Non-verbal expression of pride									
lf Este	Verbal expression of satisfaction									
Se	Inferred prideful reminiscence									
~	Verbal expression of normalcy									
ormalc	Non-verbal expression of social normalcy									
ž	When joining or leaving; interacts with others									

Qualitative Observations (indicate time):

Appendix K: Participant Topic Guide

Developing and Evaluating a Visual Art Programme in a Care Home

Qualitative Interview Topic Guide

Participant version

Before intervention:

Explore any previous experiences with art. How do they feel about art?

What does art mean to them?

Perceptions of art?

After intervention:

What does art mean to them?

Perceptions of art?

Enjoyed the art sessions?

What did they like / dislike?

Were there any difficulties experienced during the art sessions?

How did taking part in the art sessions make them feel?

Any perceived consequences of the art sessions?

Appendix L: Staff Topic Guide

Developing and Evaluating a Visual Art Programme in a Care Home Qualitative Interview Topic Guide

Staff version

Perceptions of arts programme?

Were anticipated outcomes met?

Were there any unexpected outcomes?

What would you change about the art programme?

Were there any implementation issues that arose?

How acceptable was the art programme for a care home setting?

Did they notice any effects on the residents? What would they say the impact of the intervention was?

What was it about the intervention that worked / didn't work?

Appendix M: Example of an Annotated Transcript

S352 Follow-up Interview

R So I'm just trying to get a few perspectives about the project. Obviously you saw me doing all my observations and stuff. Um and now I'm trying to get the whole picture. So I've spoken to some of the staff, and the artist team, and I'm hoping to talk to [participant]'s wife as well, just to get an overall picture.

Um so when you first heard about the project and that we were coming in for the art sessions, what were your first impressions or expectations?

- S352 Um I thought it was a good idea but I worried for our residents because they are quite far gone, well some of them are. Whether they'd struggle a little bit. But I thought it was a good idea. Because it's relaxing isn't it, drawing, and colouring and painting. [*First impressions doubting ability of residents, art is relaxing*]
- R And I mean I'm not sure whether you were around much when they were happening, but did this change as we went along? Your expectations.
- S352 Um. Well, I think, I think the outcome is really nice. So it became more positive I suppose. [*Changed Expectations*]
- R And did you notice any changes in any of the participants either during or after the art sessions?
- S352 Um, no. [No impact on residents]
- R Or hear of anything?
- S352 Um no I don't think I did, no. [No impact on residents]
- R Has anything surprised you?
- S352 Well [participant] and his drawing surprised me a lot. Um how well he did. Because I was told he did most of it himself so [*Surprise in ability of resident*]
- R Yeah he did, he was amazing.
- S352 Yeah so that was it really. Something new to find out. It's good [Unexpected outcome of intervention learning new skills of residents]
- R So you weren't aware of this?
- S352 No I didn't know he could draw at all, no. [Unexpected outcome]
- R Is this something you think you might try and continue, doing some art activities?
- S352 Yeah. If err, yeah. [Continuation of activities]

- R Again, you didn't come on the gallery visit but did you hear any feedback from anyone?
- S352 That it was good; that the residents enjoyed it. [Impact of gallery visit participants' enjoyment]
- R Do you think you might do another visit or? Do you think it something that you might do? Well I know obviously there are bus issues and things.
- S352 What me personally, or with the residents?
- R With the residents
- S352 Yeah if we could. [Continuation of activity] I don't see why not. If they enjoyed themselves, then yeah. [Impact of gallery visit participants' enjoyment]
- R From a staff perspective, is there anything you'd change about the art sessions?
- S352 It's hard to say, because I haven't really seen much. Um so I'm sure really, to be honest.
- R Whether there was anyone moaning that we were in the way?
- S352 No I don't remember that. It was mainly the men chatting you up! [laughs] Well I don't remember anyone saying anything bad. The residents didn't complain. *[Set up of intervention]*
- R Um can you think of any advantages or disadvantages of having an artist coming in, rather than having one of you leading a session?
- S352 Well the advantages, I think, would be they may listen a bit more. Because sometimes when they see our uniform they kind of have that automatic reaction of 'they are going to wash me. I don't want to be washed' or, you know, so they don't always want to listen to you. And it would be nice I think to have a different person in. They see us all the time. [Advantages of artist different person]

Um, trying to think of disadvantages. I suppose depending on who the residents are, they could feel quite um intimidated if it someone they don't know. If it is a male, I think the females can get a bit [Disadvantage of artist – residents intimidated]

- R Um have you noticed any impact of having the art work on the wall?
- S352 It has cheered the place up, definitely. I think I've seen a few of the residents look at them and that. And it starts conversation as well which is quite good. [Impact on home pictures on walls]
- R Oh that's great. Have you heard anyone making any comments?
- S352 Just the staff really. The staff, the staff saying. The staff like it. [Impact on staff]

- R We're trying to get some little plaques for the names on. I suppose you didn't really see many of the art sessions, did you?
- S352 No I didn't
- R I was going to see whether you could see any benefits of the art sessions compared with, like when [activities worker] comes in. Do you think there is a difference in the activities or do you think?
- S352 I think sometimes the activities that Pauline can play can be a little degrading. It depends on the resident though. Because some of them like, some of them like dancing to music it all depends. But I think it all depends on the resident as some of the residents like singing and playing bowls whereas others I think would prefer to sit down and do a bit of art. It's quieter as well. You haven't got music playing. And it's more of a personal thing really.

I think it is good to have both really. [Art versus other activity]

R Yeah. Oh yeah, I felt it was quite important to be observing in both because if we get some positive results in the art...people could say well that's just because they are being engaged for an hour. So that's why I tried to make sure I was there when [activities worker] was there to see whether there was a difference.

But yeah, some of the residents really come alive with her don't they.

- S352 Yeah, it's nice. Nice to see.
- R Um so as a whole, do you think there has been an impact on any of the residents, or on the home as a whole?
- S352 Um I don't think. I haven't noticed much change with the residents. [No impact on residents] Um I just think that the pictures have cheered the place up really. It's made it look more homely. But I haven't noticed anything major. [Impact on home]
- R Ok, I think that is it really. As I say, I just wanted to get the overall picture.
- S352 Well I think it is a good thing. [Opinion of the intervention]
- R That's great. Well thank you very much.