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ART GALLERY–BASED INTERVENTIONS IN DEMENTIA CARE

Section A: What is the evidence that arts–based activities for people with dementia may have significant cognitive, social, and psychological benefits for this population?

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Section B: An art gallery–based intervention to enhance episodic memory and verbal fluency in dementia: An exploratory study

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Summary of the portfolio

Section A: This review considers whether arts-based activities for people with a dementia (PWD) have significant cognitive, social, and psychological benefits for this population. There is a variety of theoretical perspectives on dementia that encompass the biological, psychological, and social effects of the disease on the wellbeing of PWD. Visual arts may be an appropriate way of addressing some of the challenges that PWD face by providing a means of ameliorating some of their cognitive, social, and psychological difficulties. Literature from the field of arts-based activities with PWD suggests that there is no apparent theoretical conceptualisation in the area, as most studies have attempted to evaluate various art programmes with no clear rationale for expected findings; rather, they have taken a more exploratory stance. However, they indicate that arts-based activities can have social and psychological benefits by increasing confidence, enthusiasm, enjoyment, social contact, mood, quality of life, and ratings of depression. The review concludes with a rationale for why it is important to expand the current evidence base on arts-based activities for PWD.

Section B: This exploratory study involved six PWD and six family carers attending an arts-based intervention at a major London art gallery for three sessions over three weeks, in which they engaged in structured art-viewing and art-making. Using audio recordings, the study sought to explore possible changes in cognition of PWD during the intervention, namely episodic memory and verbal fluency. Using a mixed methods design, data were collected at five points and analysed using content and thematic analyses. The findings suggested that episodic memory and verbal fluency appeared to improve during the art gallery-based

intervention. This was substantiated by family carers who also reported that PWD showed increased mood, confidence and social interaction, and that they valued the shared experience and learning opportunity. Whether these changes can be attributed to the intervention is a matter for further research beyond this exploratory study. The study has implications for further research and clinical implications regarding facilitating the establishment of more arts-based community interventions for dementia care.

Section C: A critical appraisal of the research is presented. Research skills that have been learned and developed over the course of the process are discussed, such as increased awareness of the benefits of working within a wider research community. There is consideration of the need to communicate clearly and sensitively with other professionals from differing backgrounds and organisations, as well as the importance of building on a coherent evidence base when designing a research project. Better organisation relating to recruitment and investigation into recording during the art-viewing sessions at the gallery are identified as aspects that would be done differently, as well as consideration of using a case study approach. Clinical consequences of the research are discussed, such as utilising a community psychology approach and involving art and creativity in therapeutic sessions. Finally, further research in the area is considered, such as by expanding the study and using robust neuropsychological measures to detect cognitive change.

Table of Contents

	Page number
Section A	
Abstract	10
Introduction	11
Perspectives on dementia	11
Biomedical perspective	12
Psychological perspectives	12
Sociological perspectives	13
Holistic model of dementia	14
Arts and health	15
Viewing art and art-making	17
Functions of visual art	17
Aesthetic processing	18
Reviewing the evidence on art-based activities and dementia	21
Wellbeing	21
Social, psychological, and cognitive functioning	24
Mood, quality of life, self-esteem, and social support	25
Psychological health	26
Summary and rationale for research	27

Summary of arts-based activities and dementia	27
Rationale for further research	28
References	30
Section B	
Abstract	36
The present study	39
Method	42
Participants	42
Design	42
Procedure	44
Measures and materials	45
MMSE scores	45
Interview schedule	45
Gallery materials	46
Ethical considerations	46
Validity and reliability	47
Validity of the design	47
Reliability of coding system	47
Results	51
Content analysis	51

Episodic memory	52
Verbal fluency	52
Responses to paintings	53
Response to gallery group	54
Soliciting information	55
Thematic analysis	56
Theme 1: Social activity	57
Theme 2: Becoming their old self	58
Theme 3: Shared experience	60
Discussion	63
Engagement in visual arts	64
Social interaction	65
Shared experience between participants	66
Learning opportunity	67
Limitations	67
Research and clinical implications	69
Conclusion	70
References	72
Section C	
Critical appraisal	80

References	87
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Tables and Figures

Table 1: Overall frequency of code occurrence measured in PWD	56
Table 2: Higher order themes and subthemes	62
Figure 1: Thomas Gainsborough. Mrs Moody with her sons Samuel and Thomas	48
Figure 2: Adam Pynacker. Landscape with sportsmen and game	49
Figure 3: Charles Le Brun. Horatius Cocles defending the bridge	50

Appendices

A: Search terms	89
B: Excluded articles	90
C: Ethics and R&D approval	92
D: Information sheets and consent forms	93
E: MMSE	105
F: Interview schedule	106
G: List of paintings	108
H: Initial codebook	109
I: Inter-rater reliability	115
J: Sample coded transcripts	117
K: Finalised codebook	118

L: Individual frequency data	123
M: Conference information	126
N: Proposal for future study	127
O: End of study information to ethics	128
P: Summary of study's findings for dissemination	129
Q: Research diary	130

SECTION A

What is the evidence that arts-based activities for people with a dementia (PWD) may have significant cognitive, social, and psychological benefits for this population?

Abstract

This review considers the literature on the cognitive, social, and psychological aspects of arts-based interventions on people with a dementia (PWD). It explores different perspectives of dementia and suggests that visual art may provide a means of ameliorating some of the cognitive, social, and psychological difficulties PWD face. It considers the current arts and health arena in the UK, and follows this with an appraisal of the literature on the functions of visual art and theories of how aesthetic stimuli are processed by its creators and viewers. The review then critiques current research on arts-based activities for PWD in the context of their biological, psychological, and social effects. The review concludes with a rationale for why it is important to expand the current evidence base on arts-based activities for PWD.

Introduction

There are currently 750,000 people with a dementia (PWD) in the UK. This is expected to rise to over a million by 2025 (Alzheimer's Society, 2011). The increase in the ageing population has led to a growing awareness of the need to improve the social and psychological wellbeing of PWD and their carers. There is a variety of theoretical perspectives on dementia that encompass the biological, psychological, and social effects of the disease on the wellbeing of this population. Visual arts may be an appropriate means of addressing some of the challenges that PWD face. The extensive literature on the function of art and aesthetic processing suggests that visual art may elicit cognitive and affective responses in the viewer (e.g. Kreitler & Kreitler, 1984; Leder, Belke, Oeberst, & Augustin, 2004; Rose, 1996), increase neuron activity in the brain (e.g. Zeki, 1999), and strengthen social cohesion (e.g. Coe, 2003; Aiken & Coe, 2004). This review will consider theoretical perspectives of dementia before examining the arts and health profile in the UK. It will then appraise the literature on the visual arts in terms of its functions and process on viewers and creators before presenting a critique of the existing research on the biological, psychological, and social effects of arts-based activities for PWD. The review will conclude with a rationale for why it is important to expand the current evidence base on arts-based activities for PWD.

Perspectives on dementia

The term dementia refers to an assortment of symptoms that include cognitive difficulties (e.g. difficulties with language, visuospatial function, executive function, and memory problems) combined with an overall decline in daily living skills (Knapp & Prince, 2007). Common dementia illnesses include Alzheimer's disease, predominantly a cortical dementia (Miller & Morris, 1993), and vascular dementia, caused by problems with the blood

supply to the brain. However, dementia is commonly not just regarded as a neurobiological disease but is also considered within a psychological and social context.

Biomedical perspective

Dementia is associated with a wide variety of changes in the brain that contribute to cell death and impaired functioning of remaining cells. Some dementias are degenerative (e.g. Alzheimer's disease and dementia with Lewy bodies), others are related to problems with blood supply to the brain (e.g. vascular dementia), some are related to trauma (e.g. cerebral anoxia or following head injury), or transmissible (e.g. AIDS dementia or Creutzfeldt-Jacob disease) (McKeith & Fairbairn, 2001).

The biomedical model maintains that the disease is independent of psychological or social factors and can solely be understood in terms of biological processes (Engel, 1977). The model also promotes the medicalisation of dementia through expert control from medical professionals and absence of consideration for the individual's or carer's perspective (Bond, 2001). Estes and Binney (1989) considered that the biomedical model promotes negative attitudes towards ageing by normalising medical intervention for older people and reinforcing the view that ageing inevitably leads to deterioration and disease.

Psychological perspectives

The neuropsychological perspective of dementia maintains that a better understanding of PWD can be attained if the nature of their cognitive difficulties can be clarified (Maciejewski, 2001). For example, there is some understanding that generalised atrophy, cell loss, structural changes in the brain that result from abnormalities in protein metabolism, and neurochemical changes are key aspects of Alzheimer's disease (Morris, 2004). These neurobiological changes directly affect neuropsychological functioning. In Alzheimer's disease, a typical cognitive profile during the early stages includes impairment of recent

memory, poor learning and retention of information over time, some language deficits, such as inability to recall names of objects, and some visuospatial skills impairment (Pasquier, 1999). By investigating these specific impairments, PWD can be better understood and supported.

These cognitive impairments may result in a psychological reaction, such as perceived loss of abilities, memories of people and places, continuous identity, and sense of security (e.g. Coleman & Mills, 2001). Indeed, there is a high prevalence of anxiety and depression in PWD (e.g. Burns, Byrne, & Maurer, 2002; Wands, Merskey, Hachinski, Fisman, Fox, & Boniferno, 1990), although the relationship between depression and dementia is not clear. Korczyn and Halperin (2009) reviewed the inconclusive empirical evidence and suggested that depression may be a risk factor for dementia and vice versa, owing to similar changes linked to both conditions in neurotransmitter levels, vascular brain disease, and changes in the hippocampus. Similarly, insight into a decline in cognitive abilities could lead to a depressive episode, or cognitive decline could be indicative of a pre-existing depression.

Kitwood (1997) theorised about key psychological needs of PWD at any stage of the condition, comprising specific bonds or attachments to others, inclusion within a group, occupation, identity (knowledge of who one is both in cognition and affect), and comfort. If these needs are met, an individual may be able to move from fear, grief, and anger as a response to dementia, into a more positive state.

Sociological perspectives

Social models emphasise the systemic relationship between PWD and carers, and the influence of wider societal attitudes towards dementia and ageing. Bond (2001) posited a sociological model of dementia incorporating earlier social models of illness and disability, which emphasised the importance of PWDs' and carers' personal responses to dementia. The

meaning that is attached to the disease will be heavily influenced by their political, social, and material environment and their life history.

Western society's attitudes to ageing are often negative (e.g. Clare, 2008; McConatha, Schnell, Volkwein, Riley, & Leach, 2003) and therefore minimise the opportunities for PWD to present themselves in society (Sabat, 2001) and lead to disempowerment and invalidation, which Kitwood (1997) termed "malignant social psychology" (p.46). The concept of excess disability demonstrates a negative and potentially damaging consequence of living in a malignant social environment. Excess disability is defined as the "gap between actual function and judged potential function" (Brody, Kleban, Lawton, & Silverman, 1971, p.125). Commonly, individuals are considered more impaired than they actually are, or their intact abilities overlooked. Literature has identified tendencies to engage PWD in activities inappropriate to their level of functioning (e.g. Buettner & Fitzsimmons, 2003) and marked discrepancies between residential and day centre staff in reported abilities of PWD, suggesting that staff have failed to recognise strengths and have overemphasised deficits (Sabat, 1994).

Holistic model of dementia

Kitwood (1997) developed an influential conceptual framework of dementia, based on clinical work and empirical research, emphasising the biopsychosocial aspects of the condition by suggesting a more complex interplay between neurological impairment, psychological factors of the individual, and the social context in which the individual is situated. This framework stated that PWD experience psychological responses to their cognitive difficulties and similarly, psychological experience may affect brain structure owing to brain plasticity, which is to some degree retained even in dementia. In an adverse social environment promoting excess disability, PWD may experience accelerated decline. A

positive, benign social environment may be able to slow down deterioration or PWD may even regain lost skills for a limited period. Therefore, maintaining each individual's "personhood" (Kitwood, 1997; p.8) by acknowledging their unique biological, psychological, and social circumstances is paramount when understanding and treating dementia.

Kitwood's (1997) holistic conceptualisation of dementia contributed to a growing awareness of person-centred care in the treatment of dementia and became one of the key principles underpinning the Department of Health's (DoH) National Service Framework (NSF) for Older People (DoH, 2001). The more recent Living Well with Dementia: A National Dementia Strategy (DoH, 2009) continues to prioritise person-centred services and attempts to address some of Kitwood's dimensions by outlining, among its main objectives, awareness of inappropriate use of antipsychotic medications, knowledge and understanding from the general public, strategies for community engagement, therapeutic and meaningful activity in care homes (such as creative arts), and access to personalised social activity. Clare (2008) proposed a holistic approach to treatment of dementia that encompasses all three levels of Kitwood's biopsychosocial framework; drug treatments and physical care at the biological level, therapeutic and supportive psychological interventions to aid adaption to and coping with dementia, and education and support of carers. Attempts should also be made to change societal attitudes and support PWD who are stigmatised.

Arts and health

In recent years, the arts have been developing a prominent profile in the health arena in the UK. The Arts Council England defines arts and health 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" (Arts Council England, 2007,

p.5). Camic (2008) suggested that the arts and health field includes developing community arts and health promotion interventions, using artworks in healthcare settings to improve their visual appearance, and being involved in research that examines the impact of art participation on biopsychosocial factors.

In a review carried out by the DoH Arts and Health Working Group, it was recommended that arts and health are integral to health and healthcare provision, and that arts and health initiatives across the country are yielding measurable benefits to health and wellbeing consistent with key government initiatives (DoH, 2007). However, the document acknowledged that the research in this area is in its infancy, as much of it involves smaller, qualitative studies that do not always hold as much gravitas in the NHS as larger quantitative research projects, which has implications for their funding.

Nevertheless, there is a growing body of research suggesting that the arts have positive effects on health and wellbeing. Fisher and Specht (1999) found that the creative arts provided older people with a sense of purpose, motivation, competence, and growth, which contribute to successful ageing. A report on social inclusion and arts found that there were significant improvements in empowerment, social inclusion, and mental health for people with a range of mental health problems engaged in community arts (APU/UCLAN Research Team, 2006). In a review of the arts and medical literature, it was concluded that arts programmes yielded beneficial outcomes such as more positive psychological and physiological clinical outcomes, improved doctor–patient relationships, and higher staff job satisfaction (Staricoff, 2004).

There is increasing interest in providing more arts-based interventions to enhance psychological wellbeing (Camic, 2008; Clift et al., 2009). For example, dancing has been found to successfully promote emotional wellbeing (Cook & Ledger, 2004), as has choral

singing (Von Lob, Camic, & Clift, 2010). A positive correlation between creative writing and factors that are associated with wellbeing has also been identified (Jensen & Blair, 1997). A systematic review undertaken by Clift et al. (2008) examined the empirical evidence that singing has a beneficial effect on wellbeing and health but the authors found it difficult to reach any comprehensive conclusions owing to the sparse and highly variable nature of the studies. A pilot study involving an art-viewing and art-making intervention in a major London art gallery identified beneficial outcomes for people with mental health problems and their carers, by providing a valuable forum for communicating difficult feelings, and creating a shared experience through the collective viewing and creating of art (Shaer et al., 2008). Viewing art and art-making are examples of creative arts-based activities and this review will now focus on the theoretical perspectives on visual art.

Viewing art and art-making

This review will briefly outline some perspectives on the function of visual art, followed by some key models put forward that endeavour to explicate the processes involved in viewing aesthetic stimuli.

Functions of visual art

The evolutionary perspective concerns itself with the proposition that the arts serve an adaptive function for survival and reproduction. Art-viewing and art-making may well have provided our ancestors with an adaptive function and this concept is supported by observations that art is evidenced across all cultures in all known societies past and present. Young children often display artistic behaviour, such as making marks on paper at a very early age. Art is largely pleasurable, as are other adaptive functions, and much physical,

psychological, and practical effort goes into art-making, such as time, acquisition of materials, and thought (Dissanayake, 2008).

Theories from an evolutionary perspective include the proposition that art enhances cognition and making better adaptive decisions, such as healthy judgements about mate selection (Volland & Grammer, 2003). Furthermore, visual art may promote sexual selection, such as through visually depicting desirable physical traits or enhancing sexual attractiveness through body art, as observed in a wide variety of cultures (Boyd, 2005).

Leder and Belke (2006) referred to ideas prevalent in the eighteenth century about gaining truth through aesthetic experiences, which have contributed to the proposition that art somehow provides the perceiver with positive and rewarding knowledge or experiences. Aiken and Coe (2004) suggested that this rewarding experience could be a social one (e.g. bringing together parent and child through viewing art).

Social cohesion may be strengthened by the process of art. Coe (2003) put forward the “ancestress hypothesis” (p.3), in which visual art was created in order to generate a sense of identity for kin throughout subsequent generations, and was initially conveyed from mothers to their offspring. Dissanayake (2008) supported the social utility of art and proposed that the function of art was to make the ordinary into something extraordinary (for example, visual embellishments on everyday objects such as hand tools and cave walls). In her anthropological studies of contemporary and ancient societies, she suggested that the process of making the ordinary special may serve adaptive purposes such as coping with uncertainty and adverse life events, unifying group members, demonstrating emotional investment in objects, events, or rites of passage, and making sense of uncertainty and the unknown.

Aesthetic processing

Jacobsen (2006) proposed a strongly multifaceted framework for the understanding of aesthetic processing that incorporated seven perspectives: the person (e.g. individual personality), situation (e.g. the individual's schemata), diachronia (relating to changes over time such as cultural or biological evolution), ipsichronia (the vantage point focusing on comparisons at a given time, such as comparisons between cultures), mind (e.g. psychological processes including cognition and emotion), body (e.g. neurological processes), and content (of the stimulus, such as a painting). This review will briefly outline some psychological and neurological factors involved in viewing and creating art.

In an attempt to understand the function of producing and viewing visual images, explanations using cognitive and affective processes have been considered. Berlyne (1974) suggested that psychophysical factors (such as colour and intensity), ecological factors (such as semantic meaning of the stimulus), and collative factors (such as complexity, novelty, or ambiguity) contributed to arousal and excitement when viewing stimuli. Kreitler and Kreitler (1984) found that the longer a stimulus is perceived, the more meaning it acquires. Therefore, the cognitions and previous experiences of the perceiver are fundamental to aesthetic appreciation.

A psychoanalytic stance on the affective response to art is offered by Rose (1996), who theorised that affect can be induced from an interaction between object and viewer. The dynamic of tension and release through creating a piece of artwork is reciprocated in the viewer and translated as an affective response. As well as the tension and release that is transmitted through the artwork, tension and therefore affect can be further heightened by the use of certain incongruous shapes; therefore the artist's knowledge of the craft of creative arts can also elicit affect in a viewer.

A comprehensive model put forward by Leder et al. (2004) outlines key processes within the perceiver during an aesthetic experience, which focuses on cognitive and affective procedures. An early process is perceptual analysis of the stimulus (e.g. colour). Implicit information integration refers to identifying familiar variables within the stimulus, while explicit analysis depends on the perceiver's knowledge of art. This is followed by cognitive mastering and evaluation, where the perceiver attempts to understand and interpret the stimulus. The result is translated into cognitive and affective output (more specifically referred to in the model as aesthetic judgement and aesthetic experience/pleasure).

Neuroaesthetics is a broadly used term that refers to the neurobiological responses to aesthetic experiences. Brain imaging experiments have managed to identify areas of the brain that are activated when viewing art. For example, Kawabata and Zeki (2004) identified increased activity in the orbito-frontal cortex when viewing subjectively determined beautiful images, and increased activation in the motor cortex when viewing both beautiful and ugly images. As the orbito-frontal cortex has also been found to be responsive to rewarding stimuli, the authors concluded that there is a change in the brain's reward system when something is judged aesthetically beautiful. Other investigations into neuroaesthetics include studies with neurologically impaired participants, indicating that art reflects basic neurocognitive mechanisms (e.g. Mendez, 2004), and investigations into neuron activity, for example Zeki's (1999) findings that neuron activity in localised areas of the brain increases when viewing art.

Neuroaesthetics, however, has also been criticised for being reductionist and for being divorced from the artwork's cultural context and the perceiver's individual history (Tallis, 2008). Therefore, Jacobsen (2010) advised that findings in the neuroaesthetics field must be considered in conjunction with Jacobsen's (2006) psychology of aesthetics model outlined

above, that incorporates the context in which the visual art is embedded, and the multifaceted characteristics of the viewer.

Reviewing the evidence on art-based activities and dementia

Studies for review in this section were included if they contained empirical data, focused on visual art as an arts-based activity, and used PWD (see Appendix A for search terms). Studies were excluded if the intervention proposed was identified as art therapy, which is defined as “a form of psychotherapy that uses art media as its primary mode of communication” (British Association of Art Therapists, 2011), rather than an arts-based activity without a psychotherapeutic component (see Appendix B for excluded articles). Four studies were identified through the database searches and a further paper (Rosenberg, 2009) was found through a manual search.

None of the five studies were completed in the UK; three were carried out in the US, one in Australia, and one in Italy. All of the studies used quantitative methods and some included a qualitative component. They all focused on aspects of psychological and social functioning of PWD attending an art-based activity. Two studies aimed to evaluate the effect of an art programme for PWD on wellbeing (Rentz, 2002; Kinney & Rentz, 2005); MacPherson, Bird, Anderson, Davis, and Blair (2009) sought to gauge any changes in social, psychological, and cognitive functioning; Rosenberg (2009) specifically evaluated mood, quality of life, self-esteem, and social support; and Musella, Carloni, de Marino, di Bartolo, Gaeta, di Maggio, and Fasanaro (2009) focused on psychological health. Qualitative data was also gathered from PWD and their carers in four out of five of these papers.

Wellbeing

Rentz (2002) evaluated an art programme called Memories in the Making for people in the early to middle stages of dementia. Sessions were offered weekly across six sites: four day centres, a residential home, and an assisted living site. The sessions were led by skilled artists who encouraged the participants to express themselves by creating colourful images using a variety of art materials. The author devised an observational tool that attempted to measure two domains of Lawton's (1991) conceptualisation of wellbeing: affect state and self-esteem. Staff members across the sites observed and evaluated one participant for one hour-long session and rated the participant on indicators for the two domains, completing observations on 41 different participants.

Salient findings by Rentz (2002) were that 83 per cent of participants sustained attention and engagement in the art activity for a period of 30–45 minutes and 66 per cent of participants socialised with one another upon entering the art session. Observed nonverbal behaviours suggested that 80 per cent of participants had relaxed body language all of the time, and 78 per cent nonverbally expressed pride all of the time. It was concluded that these high ratings suggested that the programme enhanced affect and self-esteem in participants. Qualitative responses recorded suggested that participants valued the experience, with one participant stating that “in here I feel like a person again” (p.178).

Rentz's (2002) study had a number of methodological problems, although it is important to consider that this was a pilot evaluation. While the observational tool provided some quantitative data, the ratings were subjective, particularly ratings of nonverbal expression. There was little consideration of the validity and reliability of the measure, apart from using multiple raters. The tool arguably lacked content validity owing to unclear operational definitions of the ratings. It is difficult to determine meaningful outcome from the programme because the data produced cannot be compared with the wellbeing of the

participants engaged in other activities or the participants' general demeanour. Furthermore, demographic data such as age, ethnicity, gender, diagnosis, and disease progression were not recorded. Therefore, the findings lack generalisability.

With the above methodological issues in mind, Kinney and Rentz (2005) conducted another study using the Memories in the Making programme that aimed to be more methodologically rigorous and endeavoured to compare data from the programme with data from other structured activities. The observational tool was expanded to incorporate all of Lawton's (1991) domains of wellbeing (interest, sustained attention, pleasure, negative affect, sadness, and self-esteem) and a seventh domain, normalcy. Operational definitions were more clearly defined and revised through a scrupulous pilot. Twelve individuals from two day centres and with various dementia diagnoses participated in the study. Observations at ten-minute intervals were carried out during the programme and a structured activity that followed (such as word games) and participants were rated according to the indicators of the wellbeing domains. The authors reported significantly higher levels of interest, sustained attention, pleasure, self-esteem, and normalcy during the Memories in the Making programme compared with the other activity.

The observational tool demonstrated more robust psychometric properties, such as inter-rater reliability evaluated using the Kappa coefficient of concordance. A limitation of the study, however, was the timing of the art programme in relation to the other activity, the former of which always preceded the latter. Therefore, lower ratings on the positive aspects of wellbeing during this activity may be related to participant fatigue. However, the highly significant findings prompt investigation into what aspects of the art programme were eliciting such a positive response. The authors discussed whether the creative element

prompted changes in how the brain was processing the environment or whether the sense of group cohesion along with one-to-one facilitator support was an influential aspect.

Social, psychological, and cognitive functioning

MacPherson et al. (2009) developed a six-week programme at the National Gallery of Australia that invited people with a diagnosis of dementia (ranging from mild to severe) and their carers to attend the gallery to view and discuss artworks. Seven participants from the community and eight from residential care took part. Sessions were videoed and observed using time-sampling methods to identify a range of behaviours as indicators of affect.

Results found that the residential participants' engagement significantly increased during the course of the programme but this was not the case for the community participants, where elevated engaged ratings were consistently high through the programme. It is worth noting that the residential participants were significantly more impaired cognitively than the community participants. Focus groups following the programme yielded qualitative data that indicated that participants felt that the programme had sparked new interests in art, facilitated the discovery of residual abilities, and increased social contact and enjoyment. Carers described how participants expressed enjoyment and enthusiasm, although they consistently reported no long-lasting changes. The art educators reported memory stimulation for participants within the group (e.g. recognising other participants or paintings), and higher confidence and enthusiasm in the gallery compared with when they visited participants in a different context.

MacPherson et al.'s (2009) study demonstrated a compelling mixed methods design that aimed to encapsulate the effects of an art programme on PWD and their carers. Results indicated positive social, psychological, and possibly cognitive effects on PWD attending a gallery programme, although these did not appear to be long lasting. The study did, however,

raise a similar issue to that of Kinney & Rentz (2005) in regard to identifying specifically what aspect of the programme is beneficial. Furthermore, it is difficult to conclude whether or not the art programme enhanced affect and engagement, because no baseline or post-intervention measures were taken. The observational method that has been employed by MacPherson et al. (2009), Kinney & Rentz (2005), and Rentz (2002) also has shortcomings because potentially rich data was broken down into quantifiable categories for the purpose of statistical analysis. Therefore, a rating of being “very engaged” could mean active participation by an individual but seems an inappropriate rating to give for a usually aphasic individual expressing themselves vocally.

Mood, quality of life, self-esteem, and social support

Rosenberg (2009) reported the evaluation of a project at the Museum of Modern Art (MoMA) in New York entitled Meet Me at MoMA for people in the early stages of Alzheimer’s disease and their carers. The evaluation involved 37 PWD and their carers attending the museum and viewing up to five pieces of artwork over a one-and-a-half hour session, facilitated by a trained educator. Small group discussions were encouraged. Self-rating scales were filled out by participants and their carers, including self-esteem, mood, quality of life, and social support scales, before and after the session. The session was observed by two raters, specifically looking at responses to the artwork and to the educator.

Following analysis, the data suggested that PWD and their carers expressed a significantly more positive mood following the session compared with before the session. There was an observable, positive change in self-esteem before and after the session for PWD. However, the author acknowledged the difficulties that participants with cognitive problems faced with filling out the large number of complex questionnaires. The participants spent a significant amount of time observing the art and the educator, although they needed

prompting to share thoughts with the group. Positive reactions such as smiling were commonly observed and negative emotions such as agitation were rarely expressed. Participants valued learning new things, sharing a new experience with loved ones, being in an accepting environment, and engaging in social interaction with others.

This study is groundbreaking in that the findings were statistically significant, and the results suggest that a gallery project such as Meet Me at MoMA can improve the quality of life of PWD and their carers. The evaluation used pre and post measures, which other studies have yet to do. Therefore, it is with more confidence that it can be hypothesised that art-viewing, for PWD and their carers, helps to improve psychological and social factors.

Psychological health

Musella et al. (2009) carried out an art project aiming to understand the effectiveness of an art project on the psychological health of PWD. The project was facilitated by art experts in which ten participants with Alzheimer's disease attended three sessions on their own where they were presented with paintings and encouraged to identify physical and emotional aspects within them, followed by two sessions in a group at a museum with the other participants. The latter two sessions involved observing paintings collectively and sharing thoughts about them. Each participant filled out a mood scale measuring their tension, depression, aggressiveness, vigour, fatigue, and confusion before and after the intervention.

The results are not exhaustively reported in Musella et al.'s (2009) paper, making the conclusions potentially less convincing as there is a lack of quantifiable data to support them. However, it appears that the intervention yielded improvements in mood for participants and that attention and communication gradually improved for nine of the ten participants. The authors stated that anxiety ratings significantly decreased after the intervention. However,

closer inspection of the results tables indicated that four participants reported higher levels of anxiety, two remained the same, and four participants' ratings decreased, thus rendering this conclusion questionable. The raised anxiety levels may be explained by the authors' assertion that the visual arts release trapped emotion, thereby encouraging expression of feelings, positive or negative. This is an interesting hypothesis that could be supported by some of the aesthetics literature related to affect (e.g. Leder et al., 2004; Rose, 1996).

Summary and rationale for research

Summary of arts-based activities and dementia

The review of the literature pertaining to arts-based activities and dementia highlights how few studies have been undertaken in this area. The importance that is ascribed to the arts throughout history and the evolutionary significance of visual art for humans indicate that visual arts and their impact on social, psychological, and cognitive factors should not be ignored. However, the evidence base suggests that there is no apparent theoretical conceptualisation in the area, as most studies have attempted to evaluate various art programmes with no clear rationale for expected findings; rather, they have taken a more exploratory stance. All of the studies identified were relatively small scale. Most of them used a variety of measures, which makes comparisons difficult. Furthermore, it is impossible to make generalised conclusions owing to confounding variables that, largely, have not yet been addressed in this field; for example, type of dementia diagnosis, level of cognitive impairment, previous interest in art, and educational attainment earlier in life.

All of the studies, despite their limitations, indicated some social and psychological improvements in wellbeing (Rentz, 2002; Kinney & Rentz, 2005); confidence, enthusiasm, enjoyment, social contact (MacPherson et al., 2009); mood, quality of life, self-esteem

(Rosenberg, 2009); and ratings of depression (Musella et al., 2009). Cognitive improvements were less rigorously evaluated; however, it was observed that there were improvements in engagement and attention (Kinney & Rentz, 2005; Rosenberg, 2009, Musella et al., 2009), and residual abilities observed by carers (MacPherson et al., 2009). The aesthetics literature is congruent with these findings as it suggests that visual art may stimulate cognitive and affective responses in the viewer (e.g. Kreitler & Kreitler, 1984; Leder et al., 2004; Rose, 1996), increase neuron activity in the brain (e.g. Zeki, 1999), and strengthen social cohesion (e.g. Coe, 2003; Aiken & Coe, 2004).

The small existing evidence base provides a good foundation upon which to justify the development of arts-based activities for PWD. The use of mixed method designs and validated measures make Rosenberg's (2009) and MacPherson et al.'s (2009) findings stand out as providing some compelling preliminary evidence that PWD can experience social, psychological, and cognitive improvements. Interestingly, these two studies were exclusively conducted in well-known art galleries, which provides further impetus for the development of community arts projects advocated by both the Arts Council and the DoH's objectives for dementia care (Arts Council England, 2007; DoH, 2009). The context for this type of intervention may play a role in reinforcing a benign social environment, free of stigmatisation, which may then have positive effects on psychological and cognitive functioning (Kitwood, 1997).

Rationale for further research

Further research could attempt to isolate which components of the projects relate to which beneficial outcomes, in order to develop a theoretical understanding of the effects of art-based activities on PWD and improve and expand upon existing arts projects. There is also a need for the development of validated and robust measures that can be directly utilised

with a population for whom concentration, attention, and memory are problematic. Indeed, the cognitive effects of art-based activities have only been briefly remarked upon in the current literature; therefore, further investigation either by using comprehensive neuropsychological tools or by employing a greater focus on cognition may provide more elucidation on the cognitive changes that have been observed.

There is a deficiency of research studies that address confounding variables, such as past educational attainment, diagnosis of dementia, and past interest in art, which would provide more clarification as to whom such an arts project may readily benefit. Furthermore, given the significance of art across all known societies and cultures, cross-cultural evaluation may yield more insight into the social benefits of these types of programmes.

With an expected increase in dementia worldwide, it is progressively more important to gain knowledge about methods by which to ameliorate the biological, psychological, and social difficulties experienced by this population.

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SECTION B

An art gallery-based intervention to enhance episodic memory and verbal fluency in dementia: An exploratory study

Abstract

Dementia refers to a variety of diseases that are characterised by cognitive difficulties and an overall decline in daily living skills. Arts and health interventions may be particularly valuable ways of improving the lives of people with a dementia (PWD) and their family carers. This exploratory study involved six people with mild to moderate dementia and six family carers attending an arts-based intervention at a major London art gallery for three sessions over three weeks, in which they engaged in art-viewing and art-making. Using audio recordings to record PWDs' responses, rather than standardised measures, which are often problematic with this population, the study sought to explore possible changes in cognition of PWD during the intervention, namely episodic memory and verbal fluency. Using a mixed methods design, data were collected at five points and analysed using content and thematic analyses. The findings suggested that episodic memory and verbal fluency appeared to improve during the art gallery-based intervention. This was substantiated by family carers who also reported that PWD showed increased mood, confidence and social interaction, and that they valued the shared experience and learning opportunity. Whether these changes can be attributed to the intervention is a matter for further research beyond this exploratory study. Future research is proposed to further understand the implications of these preliminary findings.

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The term dementia describes a variety of diseases characterised by cognitive difficulties (e.g. memory problems and difficulties with language, visuospatial function, and executive function) as well as an overall decline in daily living skills (Knapp & Prince, 2007). As well as cognitive decline, people with a dementia (PWD) can also experience changes in behaviour (e.g. Fairburn & Hope, 1988; Burns, Jaccoby, & Levy, 1990), and mood (e.g. Teri & Wagner, 1992; Boland, 2000; Ownby, Crocco, Acevedo, John, & Loewenstein, 2006).

There are 750,000 PWD in the UK and as the ageing population increases, this is expected to rise to over a million by 2025 (Alzheimer's Society, 2011). Therefore, there is a growing need to address the wellbeing of this population and those who care for them. The Department of Health (DoH, 2009) recently made recommendations for dementia care in the UK that included a raised awareness of knowledge and understanding from the general public about dementia, strategies for community engagement, and access to therapeutic, meaningful, and social activity.

Arts and health projects may be a particularly valuable way of addressing the needs of PWD. The Arts Council England defines arts and health 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” (Arts Council England, 2007, p.5).

Although research in this area is only recently emerging, there is some indication that arts-based activities in the community can provide positive clinical outcomes (both physically and psychologically), improvement in mental health, and a sense of social inclusion and empowerment (Staricoff, 2004; APU/UCLAN Research Team, 2006; Clift et al., 2009). Fisher and Specht (1999) discovered that older people who contributed to an art exhibition

found creative activity fostered a sense of purpose, competence, and motivation, which then facilitated successful ageing. Other examples of arts activities with beneficial effects on wellbeing and stress reduction include group singing (Von Lob, Camic, & Clift, 2010), dance (Cook & Ledger, 2004), and creative writing (Jensen & Blair, 1997).

The Arts Council England (2007) emphasised the value of joint working between the NHS and community organisations and there is evidence to show that arts projects can promote a sense of community and challenge stigma (e.g. Howells & Zelnik, 2009). Shaer et al. (2008) developed an art-viewing and art-making experience in a major London gallery for people with mental health problems and their carers. Beneficial outcomes included a sense of inclusion, a shared experience through collective art activities, and improved communication as the gallery space offered a unique forum for communicating difficult feelings. The therapeutic value of the art gallery setting was also found in a recent study that used an art gallery intervention to help people with psychosis make sense of their experiences (Roberts, Camic & Springham, 2011).

Research into art-viewing and art-making activities for PWD is sparse, although there are a handful of recent studies that investigated the effects of this type of arts-based programme for PWD. Although all have employed small samples, there is compelling evidence emerging that suggests that PWD who engage in arts-based activities show improvements in social and psychological wellbeing (Rentz, 2002; Kinney & Rentz, 2005), increased confidence, enthusiasm, enjoyment, and social contact (MacPherson, Bird, Anderson, Davis, & Blair, 2009), and decreased ratings of depression (Musella, Carloni, de Marino, di Bartolo, Gaeta, di Maggio, & Fasanaro, 2009).

Rosenberg (2009) reported on a study on the Meet Me at MoMA programme at New York's Museum of Modern Art, in which people in the early stages of Alzheimer's disease

and their carers attended the museum and viewed up to five pieces of artwork, facilitated by an educator. The PWD and their carers reported improved mood following the session compared with before the session and there were positive changes in PWDs' self-esteem. Furthermore, the participants valued the social interaction and education about the paintings.

A surprising observation that emerged from much of the literature cited above is the apparent cognitive stimulation experienced by PWD who engage in arts-based programmes. None of the studies purposely examined changes in cognitive abilities during or after these activities; however, there has been anecdotal evidence to suggest some cognitive changes. In MacPherson et al.'s (2009) study, art educators reported that PWDs' memories appeared to be stimulated during an art-viewing session in an art gallery as they seemed to have more recognition of other participants or paintings compared with when they visited the PWD in a different setting. During arts-based activities, there were also reports of increased sustained attention, engagement, and communication (Kinney & Renz, 2005; Musella et al., 2009; Rosenberg, 2009). However, these effects appeared not to be maintained long term.

Although the observations of stimulated memory, attention, and language abilities are far from conclusive evidence that arts-based programmes can lead to cognitive improvements in PWD, this warrants further exploration. Therefore, the current study was a pilot study to explore how the cognitive features of episodic memory and verbal fluency might be affected during a gallery-based intervention for PWD and their carers.

The present study

This pilot study explored a novel way to gather PWDs' episodic memory and verbal fluency, through audio recordings, during a gallery-based intervention in a major London art gallery. An exploratory stance was undertaken to investigate the association between visual

arts-based interventions within the context of a public art gallery and cognitive stimulation. The study did not aim to determine a causal link between the art gallery intervention and PWDs' cognitive functioning.

The gallery-based intervention comprised two elements: art-viewing and art-making, which builds on the structure of gallery-based interventions in previous studies (Shaer et al., 2008; Roberts et al., 2011). Art-viewing consisted of a 30-minute tour of specific paintings in the gallery with discussions facilitated by an art educator. Art-making was led in a studio within the gallery by an art therapist, in which art materials, reproductions of paintings from the gallery, and art books were presented. Participants spent an hour engaging with the materials in any ways they wished.

The type of memory being investigated was episodic memory, which is defined as “conscious or declarative retrieval of specific events located in time and place and/or retrieval of the contexts of experienced events” (Hoyer & Verhaeghen, 2006, p.214). Episodic memory impairment is usually one of the earliest features of Alzheimer’s disease, which increases as the disease progresses (Morris, 2008). Therefore, units of text were coded as a memory if they related to retrieval of a specific event, person, or object from the person’s lifetime.

Language impairment is also often a distinct early indication of Alzheimer’s disease and can encompass a broad range of deficits, one of which is verbal fluency. The fluency of spontaneous speech may be impaired, known as a disfluency. A verbal disfluency is characterised by false starts, revisions, prolongations, repetitions, hesitations, and/or filled pauses. The rate of disfluencies in speech considered normal among adults is 3% of the words uttered (Ellis & Rittman, 2009). This distinction has been utilised in previous studies (e.g. De Nil, Sasisekaran, Van Lieshout, & Sandor, 2005; Blomgren, Robb, & Chen, 1998).

Therefore, disfluencies were measured by calculating whether over 3% of a text unit possessed the characteristics of a disfluency.

Naming problems in dementia are often characteristic in the early stages and affect verbal fluency (White Williams, Mack, & Henderson, 1989). Loss of language function has been studied in PWD and often features the loss of semantic skills (e.g. Garrard, Patterson, Watson, & Hodges, 1998; Forbes, Shanks, & Venneri, 2004). The current study attempted to measure the semantic aspect of verbal fluency in the PWD by considering Troyer, Moscovitch, & Winocur's (1997) research, in which semantic verbal fluency is measured in part by the ability to cluster (produce related words within a semantic subcategory). Therefore, text units were coded as semantic clustering if the PWD used semantically related words one after another (e.g. "cat and dog").

Given the lack of research into art gallery-based interventions and cognitive function in PWD, this was a pilot study that explored the following aspects relating to an art gallery-based intervention:

1. PWD retrieval of episodic memory;
2. PWD levels of verbal fluency;
3. Family carer observations of the PWDs' response to the art gallery-based intervention.

Method

Participants

After receiving NHS ethics and NHS Research and Development (R&D) approval (Appendix C), PWD were recruited from a community mental health team for older adults. The study was explained to staff in a team meeting and further details were provided in referrer information sheets (Appendix D). Participants were included if they were aged 50 or over and in the early to mid stages of a dementia, as signified by a Mini Mental State Examination (MMSE; Appendix E) score between 10 and 24 (within the mild to moderate impairment range) (Folstein, Folstein, & McHugh, 1975). Participants also had to have a consenting carer accompany them to the gallery sessions, and be able to participate in pre and post interviews. Potential participants with severe mental health problems were excluded from the study, as were those with significant attentional or communication difficulties, which would make engagement difficult.

Six PWD and their family carers¹ met the study criteria. Three PWD were male and three female; three family carers were male and three female. Five of the six PWD were accompanied by their spouse as their carer; one was accompanied by her son as her carer. The mean age of PWD was 78.67 (range of 68–91) and 70.22 (range of 66–96) for carers. MMSE scores ranged from 18–24 (within the mild and moderate ranges), with a mean score of 21.67. All PWD had been diagnosed with a dementia within the past five years and were currently being supported by an NHS community mental health team for older adults.

Design

¹ Participants have been anonymised.

In this exploratory study, participants were audio-recorded in a pre-post mixed methods design, as a new way to investigate episodic memory and verbal fluency in PWD. Content analysis was used to analyse PWDs' episodic memory recall and verbal fluency within the gallery setting and during the pre and post interviews. This method was chosen because of its qualitative and quantitative capabilities as "the best content-analytic studies use both qualitative and quantitative operations on text. Thus content analysis methods combine what are usually thought to be antithetical modes of analysis" (Weber, 1990, p.10). Krippendorff (2004) maintained that both quantitative and qualitative approaches in content analysis is highly valuable as some quantification of qualitative data can be helpful in understanding the data in the context of a research question.

Neuendorf (2002) described individual messaging as a viable analytic source in which content analysis can identify a particular pathology within the individual (e.g. Rosenberg & Tucker, 1979). As all PWD were diagnosed with dementia, the study sought to specifically explore changes in episodic memory and verbal fluency. Therefore, content analysis of each individual's speech was deemed an appropriate methodology to capture these particular features.

The data from each PWD/family carer dyad at the gallery sessions and the pre and post interviews were transcribed and systematically analysed using quantitative content analysis (Krippendorff, 2004; Weber, 1990), which has been successfully utilised in previous studies (e.g. Reichert, Baron, & Fawcett, 1993; Samarel et al., 1998).

In addition, thematic analysis was applied to comments from the family carers at the post interviews in order to more fully explore both their and PWDs' experiences of the gallery intervention and to gain their perspective on any episodic memory or verbal fluency changes in the PWD. This qualitative approach was employed to add richness to the

exploration into the intervention. Thematic analysis enables patterns (themes) within data to be identified and analysed and tends not to be too closely associated with any pre-existing theoretical framework (Braun & Clarke, 2006). Therefore, the thematic analysis used in this study followed a realist epistemological perspective that explored carers' experiences of the intervention and understanding of PWDs' experiences of the gallery group.

Procedure

Suitable potential participants were identified at a local older adults community mental health team, and received an information sheet explaining the aim and nature of the research (Appendix D). They were then visited at home by the researcher and given a further opportunity to clarify details. Informed consent was gained and consideration given to capacity to give continued informed consent by clarifying the family carer's role of personal consultee during the study. The researcher used subjective judgement on whether the PWD were able to make an informed decision about participation at that particular time.

After consent was obtained, the researcher visited the PWD/family carer dyad at home in order to gauge episodic memory and verbal fluency before the art gallery sessions. The researcher conducted the pre interview, when the participants were presented with reproductions of paintings from the gallery and asked to offer their reflections about them; this interview was audio-recorded for analysis.

The PWD and family carers then attended three 90-minute gallery sessions over three weeks. Each session possessed a distinct theme: portraits (Figure 1), landscapes (Figure 2), and narrative paintings (Figure 3). The first 30 minutes were spent as a group in the gallery viewing artwork with an art educator, who introduced three paintings corresponding to the week's theme and facilitated a group discussion about the paintings. The group spent the final

hour in an art-making session, conducted in an art studio within the gallery building, with an art therapist, the art educator, and the researcher. The art educator was knowledgeable about the gallery's collections. The art therapist worked in the NHS at an older adults mental health service. Participants were presented with art materials, reproductions of the paintings viewed in the gallery, and art books. They were encouraged to engage in art-making in any way they wished, and had a chance to look at more artwork reproductions. The researcher encouraged free conversation among the dyads during this session and audio-recorded this for analysis.

A month later, the dyads were interviewed again. They were shown more reproductions of paintings for discussion and asked for feedback about the group. This interview was also audio-recorded.

Measures and materials

MMSE scores

The MMSE was devised by Folstein et al. (1975) and is widely used for detection of cognitive impairment by assessing orientation, attention, immediate and short-term recall, language, and the ability to follow simple verbal and written instructions. The MMSE is regarded as useful in assessing the overall clinical picture of an individual's cognitive state, although it cannot identify specific diagnoses without further investigations (Anthony, LeResche, Niaz, von Korff, & Folstein, 1982).

Interview schedule

A semi-structured interview outline (Appendix F) using open-ended questions was designed to elicit verbal responses from the PWD and family carers at the pre and post interviews and during gallery sessions. Analysis of free speech provides richer and less

obtrusive data than a lengthy questionnaire (e.g. Gottschalk, Stein, & Shapiro, 1997), which has been found particularly problematic in research with PWD (e.g. Rosenberg, 2009). Krippendorff (2004) advocated using open-ended interviews and focus group data for analysis in order to subsequently adapt and develop theory from the data. As the research focused on an art gallery-based intervention, questions about the gallery's artwork were used to elicit verbal responses.

Gallery materials

During the pre and post interviews, participants were shown reproductions of paintings from the gallery. All paintings were from the 17th and 18th century (see Figures 1, 2, and 3 for examples, and Appendix G), the era in which the gallery specialises. Materials at the art-making session included paper, paints, charcoals, pastels, and pencils, reproductions of paintings, and art books.

Ethical considerations

A local NHS research ethics committee (REC) and R&D department (Appendix C) approved the study. A crucial ethical issue, given the degeneration of cognitive abilities inherent in dementia, concerned using appropriate methods to obtain informed consent from participants and assessing their continued capacity to give this consent. Therefore, the family carer was asked to act as a personal consultee to advise whether the person was able to continue in the study or should be withdrawn. This follows guidelines relating to the Mental Capacity Act on ethical guidance on working with people whose capacity to consent may change over the course of a research project (Department of Constitutional Affairs, 2007). Furthermore, confidentiality of data during all stages of the study was protected and measures

put in place in the event that any participants might experience distress; for example further advice and support could be offered.

Validity and reliability

Validity of the design

Although this was an exploratory study that did not aim to draw generalised conclusions, external validity was considered by ensuring that coding was examined by both supervisors. Content validity was considered by ensuring that code definitions reflected the full domain of the concept being measured (Carmines & Zeller, 1979). Therefore, past research into episodic memory and verbal fluency impairments in dementia was examined in order to clearly define their constructs and translate these into meaningful criteria for coding.

Reliability of coding system

Inter-rater reliability was addressed by testing the reliability of the author's coding. Following a training session with the researcher on application of the coding system, an independent rater analysed three sections of transcript using the researcher's code book (Appendix H). Random samples of transcript from the pre interview, during the sessions, and the post interview were identified that made up 20% of the data, in line with suggestions in the literature that anything over 10% is an appropriate subsample size (e.g. Wimmer & Dominick, 1997; Kurasaki, 2000, Potter & Levine-Donnerstein, 1999). Inter-rater agreement between the independent rater's and researcher's coding was assessed using Cohen's kappa coefficient and found to be $\kappa = 0.91$ (Appendix I), indicating a high level of agreement that is beyond the outstanding level of concordance of 0.80 (as recommended by Landis and Koch, 1977).



Figure 1: Thomas Gainsborough (c. 1779–85). Mrs Moody with her sons Samuel and Thomas.

Reproduced with permission from the Dulwich Picture Gallery, London.



Figure 2: Adam Pynacker (c. 1665). Landscape with sportsmen and game.

Reproduced with permission from the Dulwich Picture Gallery, London.



Figure 3: Charles Le Brun (c. 1642–43). Horatius Cocles defending the bridge.

Reproduced with permission from Dulwich Picture Gallery, London.

Results

The results are organised by methods of data analysis. Implications are considered in the discussion section.

Content analysis

Data were recorded at the pre interview, the art-making component of the gallery sessions, and at the post interview. All the PWD provided data at the pre interview. Two dyads attended all three gallery sessions, two dyads attended two sessions, and two dyads attended only one session. Reasons for missing gallery sessions were being unwell and going on holiday. Ill health prevented two PWD from participating in the post interview. However, feedback from their family carers was obtained.

The data were divided into text units, which were then organised into categories (see Appendix H for the codebook with examples of the text units and Appendix J for sample coded transcripts). The approach to coding was based on two techniques recommended by Neuendorf (2002). One uses theory and past research consistent with the research questions (e.g. identifying text units relating to episodic memory and verbal fluency). The other promotes an emergent process in order to identify key variables, which may also relate to the research questions and provide a greater understanding of the art gallery experience for PWD. Therefore, recurrent variables that appeared common to most participants and related to the experience of the paintings or the art gallery sessions were also coded. Table 1 shows the overall frequency of each code's occurrence at pre interview, during the art-making component of the gallery sessions, and at post interview.

According to Shaw & Mitchell-Olds (1993), owing to its imbalance, the data from the content analysis would challenge the assumptions of a statistical procedure such as an

analysis of variance (ANOVA). For example, there are missing data from two post interviews and some gallery sessions; the length of recordings of data varied greatly from case to case because of the individuals' verbal abilities; and there may be extraneous variables affecting the observations because the data were not collected under strict experimental conditions. Furthermore, the sample size of six is generally considered too low to produce interpretable results from an ANOVA (e.g. Fleiss, 1986). Therefore, it was decided that it would be more meaningful to examine the descriptive data from the content analysis.

Episodic memory

The codes representing episodic memory were collapsed into one code, memory, as it was decided that this would provide a clearer depiction of the overall content of speech pertaining to episodic memory for PWD. The initial codes of lifetime memory, memory of previous session, personal descriptive information, and sharing factual knowledge were amalgamated into this single code (Appendix K). The frequency of references to episodic memory increased from 7.03% at the pre interviews to 25.90% during the gallery sessions. The improved recollection of memory was maintained at the post interview, with the frequency of episodic memory content at 26.47%.

The individual frequency of memory codes (Appendix L) generally follows the pattern of increased episodic memory during the gallery sessions compared with the pre and post interviews (PWD A, C, and F). PWD B's data suggested that episodic memory increased even at post interview (from 22.22% at the gallery sessions to 25.00% at the post interview). Two PWD demonstrated higher levels of memory at the pre interview compared with the gallery sessions (both PWD D and E scored 5.00% and 5.88% respectively at the pre interviews and 0% during the gallery sessions), but both only came to one gallery session.

Verbal fluency

The codes depicting verbal fluency suggest an increase in fluency during the gallery sessions as compared with the pre interviews. Semantic clustering increased from 0% to 5.76%. This effect did not appear to be maintained, as the frequency dropped to 2.94% at the post interviews.

The frequency of disfluencies suggests a slight decrease in disfluent speech during the gallery sessions (7.91%) compared with the pre interviews (9.38%). Disfluencies appeared to rise greatly at the post interviews (20.59%).

The individual data reflect the overall frequency pattern of semantic clustering but demonstrate some disfluencies anomalies, with disfluencies actually increasing rather than decreasing from pre interview to gallery sessions and then post interview. PWD F showed an increase in disfluencies from the pre interview to gallery sessions (5.88% to 15.38%) and two PWD (C and D) also showed slight increases in disfluencies from the pre interview to the gallery sessions: 4.00% to 4.55% and 5.00% to 11.11% respectively, with this frequency rising dramatically at the post interviews (4.55% to 22.58% (PWD C), and 11.11% to 30.00% (PWD D)).

Responses to paintings

The interviews and gallery sessions focused on art-viewing and art-making. Therefore, responses to paintings viewed were also coded. There were high levels of factual observations of painting (e.g. “there is no white colour in that one”) and opinion of painting (e.g. “that picture there, it looks really, just modern in a way”) (32.00% and 28.91% respectively) at the pre interviews. These dropped considerably during the gallery sessions (11.51% and 8.63% respectively). Both frequencies rose at the post interviews (13.97% for factual observations and 19.85% for opinions).

Emotional reaction to painting (e.g. “but I mostly love this landscape...for some reason. I don’t know why!”), a response to Figure 2) appeared at similar frequencies at the pre interview and during the gallery sessions (8.59% and 9.35% respectively) but dropped at the post interviews (4.41%).

The individual data show a similar pattern of factual observations of the paintings in some participants. However, PWD B and C showed a continued decrease of factual observations at the post interview (from 22.22% to 8.33% (PWD B), and from 15.15% to 9.68% (PWD C)). All participants followed the frequency pattern of opinions of paintings decreasing from pre interview to the gallery sessions before increasing at post interview, apart from PWD E, who displayed no opinions in all three contexts.

Individually, the frequency of emotional reaction to paintings varied. PWD A and B both displayed a decreasing trend. The highest emotional responses were at pre interviews (19.23% (PWD A) and 17.39% (PWD B)), decreasing to 0% and 11.11% respectively during gallery sessions, and to 0% and 8.33% respectively at post interviews. PWD C and F showed an increase of emotional response during the gallery sessions compared with the pre and post interviews. PWD F’s response rose from 0% to 7.69% from pre interview to during the sessions (with missing data for the post interview). PWD C’s response rose from 4.00% at pre interview to 15.15% during gallery sessions, then fell to 9.68% at post interview. PWD D showed no emotional response at pre and post interviews but displayed a frequency of 11.11% during gallery sessions. PWD E showed no emotional response throughout.

Response to gallery group

Whether PWD reacted emotionally to the gallery group, either during the group or at the post interview, was explored. For example, PWD C enthused: “thank you very much, I really enjoy it here”. 6.47% of speech during the gallery sessions concerned the PWDs’

experience in the group, falling slightly to 4.41% at the post interviews. This pattern was observed in the individual data for all except PWD C, whose positive emotional reaction to the group increased from 7.58% to 12.90% by post interview. Some PWD expressed a desire to continue with art-related activities; 2.16% of speech displayed this during the gallery sessions, and 2.94% at the post interviews.

Soliciting information

Soliciting information covers seeking knowledge and requesting guidance. There were similar frequencies of seeking knowledge (e.g. “And when was it painted?”) at the pre interview and during the gallery sessions (13.28% and 14.39% respectively). This dropped at the post interview to 4.41%.

Text units were coded as requesting guidance if PWD directly questioned the facilitators of the group about what to do or say (e.g. “I don’t know...have I got it the right way up?”). There were higher levels of requesting guidance during the gallery sessions (7.91%) compared with the pre and post interviews (0.78% and 0%). This, however, was from only one PWD (E).

Data from individual participants demonstrate an inconsistent pattern regarding seeking knowledge. Some (PWD C, D, and F) displayed higher rates of seeking knowledge during the gallery sessions than at the pre or post interviews. However, PWD A showed no knowledge seeking at the pre interview or during the sessions but did at the post interview. PWD B’s seeking knowledge increased over the course of the study, whereas PWD E showed high levels of seeking knowledge in the pre interview only.

Table 1

Overall frequency of code occurrence measured in PWD at the pre interview, during the art gallery sessions, and at the post interview

Code	Pre interview	Art gallery sessions	Post interview
Memory	7.03%	25.90%	26.47%
Semantic clustering	0%	5.76%	2.94%
Disfluencies	9.38%	7.91%	20.59%
Factual observation of painting	32.00%	11.51%	13.97%
Opinion of painting	28.91%	8.63%	19.85%
Emotional reaction to painting	8.59%	9.35%	4.41%
Emotional reaction to group	N/A	6.47%	4.41%
Art activities after group	N/A	2.16%	2.94%
Seeking knowledge	13.28%	14.39%	4.41%
Requesting guidance	0.78%	7.91%	0%

Thematic analysis

Seven key themes emerged from the family carers' qualitative data, and these were subsumed within three higher-order themes: social activity, becoming their old self, and shared experience. The first higher-order theme relates to the importance of the social setting of the group. The second refers to observable changes in the PWD, and the third describes the experience of collaborative working between carers and PWD. Table 2 lists the seven themes

subsumed under the higher-order themes. Each theme is briefly described below, with verbatim examples from the carers' accounts.

Theme 1: Social activity

This higher-order theme encompassed two themes relating to the social aspect of the group.

- 1) Isolation. Family carers described the group reducing their sense of isolation and the process of caring for someone with dementia as a lonely experience:

“And also I think you don't feel you're the only person who's got memory problems or whatever. That's the thing, that's always such a nice thing with groups. That you feel, you don't feel you're the only person in a certain situation like it. It's just knowing other people experience things as well as you.” (Carer A)

Many family carers appreciated that the group enabled PWD to feel less alone by meeting other sufferers, and feel supported by other carers. A strong feeling emerged that participation offered increased contact with the outside world. There was a sense of returning to normality and activities enjoyed prior to the onset of the dementia:

“We...made a bit of a day of it. Came to the gallery, went for a cup of tea in the cafe afterwards, you know, saw a bit of the world outside our four walls. Really lovely actually.” (Carer F)

- 2) Structure. Family carers expressed the importance of the group providing a structure to their lives. Many were disappointed that the group was not continuing beyond the three weeks:

“But what was important was it was something we could do together and there was a consistency and it went on. And it’s a great loss, you know, now that that doesn’t, it isn’t going on, because we’ve come to rely on it [...] Because you lose, you lose the pattern to your week [...] I think this [the group] was extremely productive. It gave us something to look forward to at the same time each week.” (Carer B)

Not only was meeting other people reassuring and supportive, the regularity of the group provided family carers and PWD with a sense of purpose and some organisation to an unstructured routine and perhaps an isolated life.

Theme 2: Becoming their old self

This higher-order theme included three themes signifying carers’ observations of PWDs’ demeanour during the group, which implied that PWD were more like the way they were before their dementia diagnosis.

- 1) Recalling memories. Some family carers observed an increase in reminiscence among PWD during the group. This could either be remembering past life events, or retrieving information from short-term memory. Family carers considered that the group in some way stimulated this cognitive ability, such as Carer F, who refers below to the painting in Figure 2:

“She was looking at the paintings in the gallery and, erm, a couple of times she turned to me and commented that something reminded her of something. She...err, said that one of the dogs in that hunting one we saw looked like one of her dogs she had growing up...I think...I was thinking that maybe it’s the paintings that jog her memory or something.” (Carer F)

- 2) Improvement in mood. Family carers reported positive changes in mood in the PWD during or following the group:

“Since he start going, er, to that place [the gallery] to meet the other people, I feel like it is a little bit change his self because otherwise he was always shutting door and just moaning because he hasn’t got nothing to do. Now...when he was getting home he little bit more relaxed. This make so much difference to him now.” (Carer C)

[Comment directed at PWD A] “I think you were more confident in the group, especially as it went on. You’re quite shy around other people. There was something relaxing and easy about it [the group].” (Carer A)

- 3) Increased verbalisation. Many family carers reported that some changes involved increased verbalisation from PWD during the group:

“He was more interested in things. Erm, probably because he loves art anyway so being at the gallery was a real treat. He was really enthralled by some of the paintings and was much more talkative about them...during the group and in the car on the way home.” (Carer B)

“I did notice she was more involved in the gallery, she kept pulling me to one side, pointing things out in the other paintings. That felt different, often when we go out she is more tentative...quieter.” (Carer F)

Theme 3: Shared experience.

This high-order theme included themes around the value of sharing an activity, whether learning or art-making.

- 1) Learning together. Family carers emphasised the unique opportunity to engage together in an educational endeavour:

“We like to do things that we can share. It’s hard when you are responsible for someone with memory problems, you become, erm, a carer, and your relationship changes. With the group, we were doing it together. [...] It was nice, like learning something from scratch together.” (Carer B)

- 2) Art-making together. Some family carers suggested that art promoted a unique and valuable mode of interaction and understanding between the pair:

“I was surprised at how small you did the drawings. I was trying to read a bit into that. And I thought, ‘why didn’t he fill the whole page?’. And then [name of PWD]’s a bit...you’re a bit sort of a shy sort of person, aren’t you? [...] I thought perhaps he doesn’t want to do a big ‘here I am, this is what I’ve done’. He wanted to do some little things and think ‘well I wonder what they’ll think about this’.” (Carer A)

One family carer reflected on whether the visual stimulation of art enabled the PWD to remain engaged as he had observed that his mother found it difficult to remember verbal instructions or follow an activity at home:

“...we had the drawing that she was doing, again it’s something that again she might forget the instructions, which was, you know, you’re drawing the nearest person sitting opposite you, kind of thing. She’s still, if she’s making lines and she’s kind of looking down at it and she’s...in a way like probably she can see what she’s doing in a way. So even though she’s forgotten the instructions or why she’s there at all, or who I am, or who you are, there’s still something that’s kind of accessible to her.” (Carer E)

Table 2. Higher order themes and subthemes

Social activity

Theme 1: Isolation

Theme 2: Structure

Becoming their old self

Theme 1: Recalling memories

Theme 2: Improvement in mood

Theme 3: Increased verbalisation

Shared experience

Theme 1: Learning together

Theme 2: Art-making together

Discussion

The content analysis findings suggested that the PWDs' episodic memory increased at the gallery sessions and that this appeared to be maintained at the post interviews. The findings for verbal fluency are more ambiguous, the data suggesting that verbal disfluencies decreased only slightly at the gallery sessions; however, semantic verbal fluency appeared to increase. Therefore, overall verbal fluency seemed to improve slightly during the art gallery sessions. The thematic analysis findings also supported improvements in episodic memory and verbal fluency. Individual variations, such as the two PWD whose disfluencies increased dramatically at the post interview, may be accounted for by fluctuations in cognitive ability, which is commonly seen in dementia (Bradshaw, Saling, Hopwood, Anderson, & Brodtmann, 2004).

These findings on episodic memory and verbal fluency reflect previous findings on arts-based interventions for PWD, which indicated increased memory access (MacPherson et al., 2009) and improved communication (Kinney & Renz, 2005; Musella et al., 2009; Rosenberg, 2009). In the thematic analysis findings, family carers reported increased attention and engagement in PWD, which was also reported in the previous studies. The carers also described improved mood, confidence, increased social contact, and value of the shared experience among PWD following the art gallery sessions. This is similarly supported by previous studies (MacPherson et al., 2009; Rosenberg, 2009; Musella et al., 2009), and may account for the carers' positive response and endorsement of the gallery intervention.

It is beyond the scope of this exploratory study to attribute the results to any one specific factor. There were a variety of elements in the intervention, any of which could have contributed (e.g. art-viewing, art-making, social interaction, educational components). The remainder of the discussion will consider some aspects of these elements: engagement in

visual arts, social interaction, shared experiences between participants, and learning opportunity.

Engagement in visual arts

The theoretical literature on art and aesthetics may provide some explanation for the observed changes in episodic memory and verbal fluency in PWD during the intervention. Psychological theories about visual art include ideas about the cognitive, affective, and neurological processes that occur when perceiving an aesthetic stimulus (e.g. a painting). According to Leder, Belke, Oeberst, and Augustin (2004), cognitive and affective procedures occur during an experience of viewing visual art and the perceiver accordingly experiences a cognitive and emotional reaction. Therefore, visual art may stimulate the viewer's cognitive and affective responses (see also Kreitler & Kreitler, 1984; Camic, 2008).

Interestingly, factual observations and opinions about the paintings dropped considerably during the gallery sessions, while emotional responses rose slightly. Rose (1996) observed that affect can be induced in the viewer from an interaction between object and viewer, and other theorists have described an emotional arousal when viewing aesthetic stimuli (Berlyne, 1974; Leder et al., 2004). Therefore, it is possible that the experience of the gallery, surrounded by visual art and striking architecture, stimulated affective responses in the PWD. High affect was also observed within Musella et al.'s (2009) study, in which PWD viewed paintings in a group at a museum. Participants rated highly on anxiety, and the authors wondered whether viewing the visual arts facilitated the release of trapped emotion. Therefore, PWD in the current study may have experienced a stronger affective response in the gallery compared with at home.

Recent developments in brain imaging technology have enabled researchers to identify increased neuron activity in areas of the brain when viewing art (e.g. Zeki, 1999; Kawabata & Zeki, 2004). It may be that areas of the brain affected in dementia are stimulated during art-viewing, awakening some residual abilities. Zaidel's (2005, 2009) research about artists who develop dementing diseases indicates that, although cognitive and physical deficits become marked as the disease progresses, often the artists' creativity remains intact until the latter stages of the illness. This suggests that elements in the brain responsible for artistic endeavours may not be localised to specific areas of the brain and so be more accessible even as a dementia progresses. Therefore, it could be that an arts-based intervention can inspire creativity and artistic ability, although other cognitive abilities have diminished.

The modality of visual art may be particularly accessible to PWD as it is less demanding than language (which often becomes impaired in dementia). Zaidel (2010) described how brush strokes on a canvas have no meaning outside the context in which they exist, as oppose to the fixed meaningful units of language (e.g. words). This is reflected in Carer E's comments about the art-making session providing a physical and sensory stimulus for his mother so that she did not need to rely on memory or language ability to engage in the activity.

Social interaction

Family carers observed a reduced sense of isolation for the PWD, which has been an outcome in previous art gallery projects (e.g. Shaer et al., 2008; Rosenberg, 2009; Roberts et al, 2011). Not only did participants in the current study report the importance of meeting others with similar experiences to them, there was also a sense of feeling less remote from the wider community and more connected to the outside world. This also seemed the case in

Howells and Zelnik's (2009) arts-studio project, in which the community that arose from the project bridged a gap for members to access the wider community, as it increased participants' self-esteem and confidence.

Social interaction is particularly important for PWD and their family carers because stigma towards dementia in the Western world has greatly reduced PWDs' presence in society, which has led to disempowerment and invalidation (Sabat, 2001; Kitwood, 1997). This social interaction in itself could have contributed to the cognitive changes observed, and indeed these changes might have arisen in a different environment from an art gallery.

Shared experience between participants

Family carers reported the value of sharing the experience of the gallery intervention with the PWD, in particular the art-making aspects. Shaer et al.'s (2008) project for people with mental health problems and their carers found that the gallery space almost took on a therapeutic quality as participants used the gallery's work as a tool for processing difficult personal experiences. Colbert et al. (under review) had similar findings in an art gallery project for people with psychosis. In the current study, the shared experience of the PWD and family carer appeared to allow for some meaningful communication and understanding, be it through art-making, discussing paintings in the gallery, or having the opportunity to socialise during the sessions.

Shared experience is particularly beneficial for PWD and family carers, for whom the onset of dementia places major demands on the coping resources of the individual and their loved ones, often leading to fraught relationships (e.g. Clare, 2002). Furthermore, the cognitive difficulties experienced by PWD make it difficult for them to retain a sense of identity (Woods, 1998). Therefore, a shared activity in which both members are equal can

provide non-pressured and relaxed valuable time together (Roush, Braun, Basting, Winakur, Rosenberg, & McFadden, 2010). These beneficial effects of the shared experience might also have contributed to the PWDs' cognitive changes.

Learning opportunity

Participants in the current study often remarked on the opportunity to gain knowledge about the paintings and their narratives, and to learn new art skills. Three of the PWD showed high rates of seeking knowledge during the gallery sessions, which suggests a sense of curiosity and desire to learn. A national survey in Britain revealed that people over 65 considered that engaging in mentally stimulating activities was important for their quality of life, and some perceived old age as a time to learn new skills (Gabriel & Bowling, 2004). The role of the art educator was therefore integral to the participants' experience, and her lively and warm approach was paramount to their engagement in the group, which was also identified as a crucial element at the Meet Me at MoMA project (Rosenberg, 2009). Therefore, it might be that this mental stimulation through learning contributed to the cognitive changes.

Limitations

The study did not aim to determine a causal link between the art gallery intervention and cognitive changes; therefore conclusions as to any association can only be speculative. Findings from the thematic analysis suggest that components other than art-viewing and art-making were important (e.g. social interaction), which may have affected the cognitive changes measured in the content analysis. Furthermore, family carers also reported improved mood and confidence in PWD; it may be that elements such as these influenced cognition.

This study attempted to explore episodic memory and verbal fluency in PWD using audio-recorded gallery sessions. It was observed, however, that participants engaged at various levels and for different lengths of time during the intervention. This differential engagement of participants has implications as it may be that more vocal PWD, who preferred to engage in discussion rather than art-making, are over-represented, and that these PWD are more likely to display increases in episodic memory recall owing to the larger quantity of speech recorded. Participants' varying levels of engagement also have implications for the intervention itself and may suggest that the beneficial effects observed during the gallery sessions are, to some extent, dependent on individual cognitive abilities, interest in art, and personality characteristics.

The study did not specify a type of dementia for inclusion and so, while all PWD were in the mild to moderate stages of a dementia, it may be that particular subtypes could respond differently to this type of intervention. Participants volunteered to take part after reading information about the study; the study may therefore have recruited those who already had an interest in art. This needs to be considered in future research.

It was impractical to record any speech during the art-viewing stage of the intervention,² which was unfortunate as these occasions provided a wealth of responses to the images through facilitated discussions by the art educator. It would be valuable to facilitate data collection during the art-viewing in future projects, for example, by the use of individual microphones. Related to this was the short duration of the gallery sessions. Participants reported that three weeks was not enough time for them to fully acclimatise to the group, which could also have affected the findings.

² The sessions were conducted during times the gallery was open to the public.

Despite these limitations, some useful aspects have presented themselves from this exploratory study. The structure using a combination of art-viewing and art-making with PWD and their carers in an art gallery has not been reported in the existing literature to date. The combination of the two may facilitate the engagement of a wider range of PWD as some may prefer art-viewing and others art-making. The combination of the two processes may also encourage the beneficial elements of sharing an activity with a carer and having the opportunity to learn new things which were observed by family carers in this study.

The study has also attempted to gauge episodic memory and verbal fluency using idiosyncratic measures rather than standardised measures. It was unrealistic for the current study to use standardised psychometric tests because small changes over the short timeframe would be unlikely to be detected (e.g. Mayes & Warburg, 1992). In addition, standardised measures for this population are often difficult to administer and have varying reliability and validity. Furthermore, lengthy questionnaires have been found to be problematic in research with PWD owing to their cognitive difficulties (e.g. Rosenberg, 2009). The unique measures of cognitive abilities used in the current study could be further explored in future research and potentially provide an alternative way of qualitatively assessing episodic memory and verbal fluency in PWD.

Research and clinical implications

This project demonstrated that it is feasible to use a multiple-session art gallery-based intervention for PWD and family carers, and that using audio-recordings to measure episodic memory and verbal fluency warrants further study. Future research might first consider lengthening the number of sessions and also adding a control group in order to ascertain whether cognitive changes can be more confidently attributed to the intervention than to other

variables (e.g. simply leaving the house or the exercise from walking around the gallery). Components of the art gallery intervention could be compared in future research by offering a similar art-viewing and art-making group in a more ordinary setting, such as a community centre or hospital, alongside an art gallery group for comparison, or providing just the art-viewing or just the art-making sessions for comparison, in order to extrapolate further what components may be most beneficial to cognitive ability and overall experience.

The findings have potential implications for improving community care for PWD within the NHS and supporting family carers. The recent DoH strategy for caring for PWD (DoH, 2009) emphasises improving quality of life through developing community resources and providing meaningful, therapeutic social activity. NHS professionals, such as clinical psychologists, may wish to forge positive relationships with resources in the community, such as local art galleries, in order to facilitate community provision for PWD. Clinical and clinical health psychologists would be well placed to offer training to art educators and set up self-supporting groups using a community psychology approach to intervention (Holmes, 2010; Camic, 2008).

Conclusion

The results suggest that PWDs' episodic memory and verbal fluency improved during the gallery-based intervention. Family carers corroborated these findings and highlighted their observations of improved mood, confidence, reduced isolation, and the shared experience among PWD at the gallery sessions. While the study was exploratory and did not aim to attribute the findings to specific causes, it does seem that engagement in the visual arts, social interaction, the shared experience, and learning opportunity were all important to participants. There is therefore a need for further research into this area. Strengths of the

study include the creation of an original gallery-based intervention and a unique way of measuring cognitive function in PWD. It has clinical implications regarding facilitating the establishment of more arts-based community projects for PWD and their family carers.

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SECTION C

Critical Appraisal

This section describes the critical appraisal of the research and reflection on the process of carrying out the study. It answers four questions posed by the course.

What research skills have you learned and what research abilities have you developed from undertaking this project and what do you think you need to learn further?

This was the first research project of this scale that I have undertaken and I learned a great deal during the process. Firstly, I developed an awareness of and learning about the benefits of working within a wider research community. I liaised with other researchers and art gallery staff who were interested in exploring the use of art gallery resources for people with a dementia (PWD) as the research area is currently very limited. It felt daunting to be carrying out a project on which there is very little written, and so collaborating with art therapists, staff at the gallery where the study took place, art educators, and an assistant to the Meet Me at MoMA project (Rosenberg, 2009) on a visit to New York, proved invaluable. I think my confidence and communication skills developed as a result of needing to clearly articulate my objectives. I had to learn to communicate without jargon and confusing language as many professionals I encountered had very different backgrounds from psychology.

I also learned the importance of sensitive communication with different professionals outside the NHS, which is something I had little experience of prior to this study. Joint ventures between the NHS and community organisations can be problematic owing to

political agendas (White, 2009), and I became aware of two cultures potentially clashing in their objectives and practice (e.g. conflicting views on the use of funding). Fortunately, my personal experience with this was positive and I found that collaboration meant a wealth of perspectives and expertise that would not have been achievable without effective joint working.

I learned about the value of building on previous studies to develop a coherent evidence base. I learned that a solid understanding of the literature pertaining to arts and health, particularly relating to PWD, was paramount before I was able to formulate my own research questions and design a project. Although there was a temptation to hasten the process without full awareness of the research area, I feel that the work that went into familiarising myself with the wider literature has meant that the study (even though it is small-scale) can more meaningfully contribute to the research area.

I think I need to further develop my interview skills for research. The semi-structured interview (Appendix F) was intended to prompt free speech from the participants. Occasionally, however, I found myself getting drawn into a conversation about a painting or the story behind it. While it could certainly be argued that interaction with the researcher was an important means of eliciting speech for analysis, I was mindful that my responses could influence PWDs' episodic memory recall and verbal fluency. I feel that with more experience with research interviews, I will be able to improve my awareness of my role in the interview and potential interviewer bias issues.

If you were able to do this project again, what would you do differently and why?

Practically, I would approach the community mental health team for older adults earlier than I did, in order to facilitate the recruitment process. I failed to anticipate how

lengthy this stage of the project could be, which involved working with a highly busy team of practitioners whose first priority was not finding participants for the study. Owing to the risk of drop-out among participants, I would have ideally recruited eight dyads rather than six. Unfortunately, ill health meant that not all participants were able to attend every session or post interviews; therefore more participants would have ameliorated this slightly.

It was unfortunate that I was unable to record during the art-viewing aspect of the intervention in the art gallery. This was due to impracticalities as the gallery was open to the public during the sessions. Now with an awareness of how rich the discussions in the gallery were, I might have discussed with the gallery staff whether it might have been possible to open the gallery up for the sessions after hours (as the Meet Me at MoMA project does), so that recording could have been viable. Of course this might not have been possible to implement; however, I would have investigated this further.

Methodologically, I perhaps would have considered a case study design. As this was a pilot study, another way of exploring the impact of the art gallery-based intervention on PWDs' cognition could have been a more in-depth analysis of each individual case. Yin (2009) maintained that the scope of case study research allows for exploration of individuals within interventions, communities, or relationships. Furthermore, case studies emphasise the investigation into the individual's context. Therefore, more contextual issues could have been analysed, for example the individuals' diagnosis, level of cognitive abilities, previous educational attainment, and pre-existing interest in art.

Clinically, as a consequence of doing this study, would you do anything differently and why?

I feel that my approach to clinical work has been greatly influenced by this research project. By undertaking a community arts project and seeing observable benefits for the participants, I have begun to think more about community psychology approaches to meet the needs of vulnerable people in society. Psychology is largely engaged with offering clinical interventions within a medical model framework for what are often social and economic problems, rather than adopting socio-political interventions (Duckett & Pratt, 2001). My contact with the gallery staff and their enthusiasm and commitment to offering programmes for a number of vulnerable groups in society enabled me to envisage the reality of developing more community projects, as an alternative and less stigmatising way of improving wellbeing compared with more traditional psychological services.

I found my clinical work with PWD has been affected by my work on this research project. The study and the literature that supports it emphasise the isolation that some PWD and their carers can feel, which is exacerbated by the stigma that dementia receives in modern society (Sabat, 2001; Kitwood, 1997). On my clinical placement in an older adult service, I was able to spend some time expanding on the service's links with community groups such as the Alzheimer's Society and social groups for older people in order to develop more joined-up working with these valuable resources. This was something considered of value to the service; however, limited staffing meant that liaising with these agencies was often not prioritised.

I have an interest in using art and creativity in my clinical work and this study has certainly strengthened my awareness of the therapeutic benefits of creativity. I was struck by the observation from the family carers about the artwork (either art-viewing or art-making) forming a means of communication between PWD and family carers, and this has been identified in previous gallery work (e.g. Shaer et al., 2008; Colbert, Cook, Camic, &

Springham, under review). Literature from the creative therapies field has long maintained that expressive art is a form of language (e.g. Gladding, 1997; Mills & Daniluk, 2002; Rogers, 1993). As a result of this study and my growing interest in arts and health, I have allowed myself to be more creative in my clinical work by encouraging the use of art if this seems appropriate, as a means of enhancing the therapeutic alliance and communicating potentially difficult thoughts or feelings.

If you were to undertake further research in this area what would that research project seek to answer and how would you go about doing it?

I would like to continue researching this area and expand the literature on art gallery interventions for PWD and their carers. Given the committed research community interested in art gallery interventions, it feels important to disseminate the current study's findings in order to provide a base on which future research can develop. Therefore, I presented some preliminary findings of the study at the Art Galleries, Wellbeing, and Health Conference: New Directions in Research (Appendix M), held on 29th March 2011. There is already a newly funded project, on which I am consulting, that builds upon the current study by extending it from three sessions to eight sessions across two different gallery sites, and will involve art-viewing, handling of art objects, discussion, and art-making (Appendix N). The study will invite 20 PWD and their family carers to the gallery, with the aim to assess quality of life among participants using standardised measures. The increase in sample size and the use of standardised measures will provide more robust data, which can be analysed for statistical significance.

I would also be interested in extending the current study with a similar design to the above described study, in order to more formally assess cognitive function. I would look at

other cognitive domains in addition to episodic memory and verbal fluency (for example attention and executive function) as it may be that overall cognitive functioning and not just specific deficits improves during or after this type of intervention. The research question would ask whether an art gallery-based intervention impacts on general cognitive functioning. I would increase the number of participants to 20 PWD and their family carers so that statistical analyses could be undertaken. As 40 participants would be too many for one gallery intervention, using two galleries (as above) would be advantageous as the results would also indicate whether gallery programmes can be replicated in different galleries.

The study would carry out a battery of cognitive tests with the PWD, pre and post intervention. This could also be followed up three and six months after the intervention to monitor for longer-lasting effects. Tests could include the Hamilton Depression Rating Scale (Hamilton, 1960) as this has been validated on older people with cognitive problems. It is important to assess for depression because cognitive deficits are a core feature of depression and are particularly prevalent in memory, executive functioning, and processing speed (Thomas & O'Brien, 2008). Thus it might be mood that could impact on cognitive ability rather than dementia symptoms. Cognitive functioning could be assessed using a global scale such as the Mattis Dementia Rating Scale (Mattis, 1988), which yields a total score as well as scores on five discrete cognitive areas (attention, conceptualisation, construction, initiation/perseveration, and memory). Other variables, such as subtype of dementia and medication being taken, may need to be controlled for. Statistical analyses would provide quantifiable, and potentially replicable, evidence that this type of intervention can improve cognitive function across a variety of domains for PWD.

As in the current study, family carers could provide qualitative feedback on the experience. From my experience, family carers' perspectives are equally important to acquire

as they share their lives with PWD, delay entry to care homes, and ultimately contribute to their quality of life (Selwood, Johnston, Katona, Lyketsos, & Livingston, 2007). A separate future study should perhaps focus more on family carers' experience of an art gallery-based intervention. This could be evaluated in relation to carer burden, as caring for a family member with a dementia can lead to emotional and physical health deterioration in carers (Wills & Soliman, 2001). Therefore, a joint activity such as visiting an art gallery may have a positive impact on carer stress, which may then increase positive outcomes for PWD as well.

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Appendix A: Search terms

Search	Search Term	PsycINFO	Medline	Web of Science	Cochrane database
1	“view* art” OR “museum*” OR “art education” OR “art museum*” OR “art galler*” OR “art program*” OR “art project” OR “community art*”	1632	373	37 135	18
2	“dementia” OR “Alzheimer*”	39 376	761 162	>100 000	9347
3	1 & 2	3	3	9	0

(Search conducted on 4/1/11)

Appendix B: Excluded articles

Article	Aim	Reason for exclusion
Silva, A.M.R.E., Geldsetzer, F., Holdorff, B., Kielhorn, F.W., Balzer-Geldsetzer, M., Oertel, W.H.,...Dodel, R. (2010). Who was the man who discovered the “Lewy bodies”? <i>Movement Disorders</i> , 25, 12, 1765-1773.	To summarise Fritz Heinrich Lewy’s life and present his contribution to German and American neurology.	The paper does not discuss art and dementia.
Musutani, T., Yamamoto, Y., Konishi, J., & Maeda, K. (2010). Effects of music and art education in early life and oral functions on the QOL of the Takarazuka Revue Company OG compared with general elderly females. <i>Psychogeriatrics</i> , 10, 1, 4-14.	To examine the effects of art education in early life on older people’s current QOL and oral functions.	The study does not examine the effects of art activities that older people may currently be engaged in. The study does not use a population with dementia.
Dicks, M., Bird, M., & Warren, L. (2009). Art gallery access programme for people with dementia – residential aged care perspective. <i>Australasian Journal on Ageing</i> , 28, 2, A97-A97.	To pilot a programme for older people with dementia attending an art gallery and evaluate its effects.	While relevant, the paper is not a full empirical study but an abstract for an upcoming meeting.
Brownell, C. (2008). Art therapy as a means to decrease passive behaviors in patients with dementia: An intergenerational art program. <i>Gerontologist</i> , 48, 3, 639-639.	To evaluate an intergenerational art programme for people with dementia.	While relevant, the paper is not a full empirical study but an abstract for an upcoming meeting.
Garcia-Marina, V., Garcia-Lopez, P., & Freire, M. (2007). Cajal’s contributions to the study of Alzheimer’s disease. <i>Journal of Alzheimer’s Disease</i> , 12, 2, 161-174.	To review Santiago Ramon y Cajal’s work on the nervous system and Alzheimer’s disease.	This paper does not discuss art and dementia.
Cohen, G.D., Perlstein, S., Chapline, J., Kelly, J., Firth, K.M., &	To measure the impact of community-based cultural	This study does not specify participants with

<p>Simmens, S. (2006). The impact of professionally conducted cultural programs on the physical health, mental health, and social functioning of older adults. <i>The Gerontologist</i>, 46, 6, 726-734.</p>	<p>programmes on the physical health, mental health, and social activities of older adults.</p>	<p>dementia and the programme intervention is not visual art.</p>
<p>Banack, S.A., & Cox, P.A. (2003). Biomagnification of cycad neurotoxins in flying foxes – implications for ALS-PDC in Guam. <i>Neurology</i>, 61, 3, 387-389.</p>	<p>To examine neurotoxins in flying foxes and their impact on the Guam ecosystem.</p>	<p>This paper does not discuss art and dementia.</p>

Appendix C: Ethics and R&D approval

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Appendix D: Information sheets and consent forms



Centre for Applied Social & Psychological Development

Participant Research Information Sheet

Art at [name of gallery] Project for Older People

What is the project about?

The [name of gallery] and [name of NHS Trust] have agreed to be part of a project that is investigating the benefits of viewing and making art in an art gallery for people with memory problems and their carers. The study is a student research project for partial fulfilment of a Doctorate in Clinical Psychology.

Why have I been chosen?

You have been given this information because your care co-ordinator has suggested that you might be interested in taking part in the art project. This is an information sheet that explains what the project involves to help you decide whether you would like to take part.

What is the project?

The art project is a three week group consisting of five to eight people with memory problems and their carers, for a total of up to sixteen people. Most participants will have received a diagnosis of early stage memory problems. The group will meet once a week for one and a half hours. Refreshments will be provided. The group will consist of looking around the [name of gallery] with a trained art therapist and guide, and you will have the opportunity to make your own art in the gallery. Looking at art and making art has been found to be beneficial for people with memory problems and their carers, as people enjoy themselves, socialise, and art can help improve attention, concentration, and memory. Before and after the group, participants will meet the researcher individually to look at some art, and talk about it.

Will everyone interested in joining the art project be included in the project?

No, not everyone, but hopefully most people who decide that they want to take part will be offered a place. Those who are well enough to attend the group, are able to travel to [name of location of gallery], and are experiencing mild to moderate memory problems will be offered a place.

Do I have to take part?

You do not have to take part if you do not want to. You may also withdraw from the project at any time and you do not need to give your reasons. This will not affect the care you receive

now or in the future. In this situation, we would still like to use the information you have provided to us.

Do I have to be good at art?

No, you do not need to be good at art! The group is designed so that you enjoy yourself. You will not be asked to do anything during the art-making session that you do not want to do.

What will happen if I choose to take part in the project?

If you are interested in taking part, the researcher will meet you to discuss the project further and answer any queries you may have. The researcher will ask for your permission to access a pre-screening tool score (Mini Mental State Examination; MMSE) if this has been carried out by your clinician recently. You will also be asked to sign a consent form and attend the project at [name of gallery] for three weeks in a row.

Each session of the group will last for one and a half hours and refreshments will be provided. You will be invited to go around the gallery and look at pieces of artwork. You will also be invited to make your own artwork. The group will be run by a trained art therapist with support from a guide from the gallery and the researcher.

As part of the evaluation of the sessions, you will be interviewed by the researcher on an occasion before the art gallery sessions. You will be asked to look at some art work and to talk about this process (about 1 hour in total). You will be asked to do this again one month after the group has ended. The researcher will discuss with you what time and place suits you best for these interviews.

The interviews and the gallery sessions will be tape recorded in order to have an accurate record of what you said. Only the researcher and a transcriber will listen to the tape.

Will I receive payment to take part or have to pay any expenses?

Unfortunately we are unable to provide payment. However, we can pay some amount of travel expenses to [name of gallery] and the interviews before and after the group. If travelling is a problem for you, please discuss this with us and we will try to assist you.

What are the possible benefits of taking part or any risks involved?

Hopefully you will enjoy the experience and benefit from meeting people with similar difficulties and find the process of art stimulating and interesting. However we cannot promise this. We do not anticipate any disadvantages from taking part although, sometimes, people might at first be a little anxious about joining a new group and about doing art. This will hopefully not be the case after the first group session. If you remain anxious or uncomfortable then we will make sure to offer you further advice and support.

What happens when the project is finished?

You will receive a brief written report about the results. We will also provide you with the names and locations of other art groups if you would like to continue doing art.

Will my taking part be kept confidential?

Yes, all information you give us and the content of the sessions will be confidential. Information you give us will be stored in a locked filing cabinet and will be anonymised when the project is being written up so that you will not be able to be identified. All information from the interviews will be destroyed when no longer needed or after 10 years from when the project is finished.

Direct quotations of what you have said in the tape recordings may be used in the final write up of the project. However, these will be anonymised and you will remain unidentifiable.

What will happen to the results of the project?

The results will hopefully add to our understanding of memory problems and the benefits of an art group in an art gallery for people with memory problems and their carers. The project report will be shared with local practitioners and published in a national or international journal. It is possible that some of the data might be shared with other colleagues who are researching art, memory problems, and interventions in an art gallery. You will also receive a summary of the results.

Who has reviewed the study?

All research in the NHS is reviewed by an independent group of people in a Research Ethics Committee in order to protect your rights, safety, well-being, and dignity. This study has been reviewed and approved by the North London Research Ethics Committee on 10th May 2010.

How can I contact you?

Please get in contact if you wish to discuss the project further or receive more information:

Catherine Eekelaar: **01892 507 673**

Trainee Clinical Psychologist

Salomons, Canterbury Christ Church University

Thank you for reading about this new project and we look forward to meeting you.

Carer Research Information Sheet

Art at [name of gallery] Project for Older People

What is the project about?

The [name of gallery] and [name of NHS Trust] have agreed to be part of a project that is investigating the benefits of viewing and making art in an art gallery for people with memory problems and their carers. The study is a student research project for partial fulfilment of a Doctorate in Clinical Psychology.

Why have I been chosen?

You have been given this information because you are considered to be a carer of someone with memory problems. We use the term “carer” to describe the person who regularly supports somebody with memory problems. We understand if you would prefer to be called something different to the term “carer”, and you will have the opportunity to specify how you would like to be referred to during the project.

The care co-ordinator of the person you care for has suggested that you might be interested in taking part in the art project. This is an information sheet that explains what the project involves to help you decide whether you would like to take part.

What is the project?

The art project is a three week group consisting of five to eight people with memory problems and their carers, for a total of up to sixteen people. Most participants will have received a diagnosis of early stage memory problems. The group will meet once a week for one and a half hours. Refreshments will be provided. The group will consist of looking around the [name of gallery] with a trained art therapist and guide, and you will have the opportunity to make your own art in the gallery. Looking at art and making art has been found to be beneficial for people with memory problems and their carers, as people enjoy themselves, socialise, and art can help improve attention, concentration, and memory. Before and after the group, participants will meet the researcher individually to look at some art, and talk about it.

Will everyone interested in joining the art project be included in the project?

No, not everyone, but hopefully most people who decide that they want to take part will be offered a place. Those who are well enough to attend the group, are able to travel to [name of location of gallery], and are experiencing mild to moderate memory problems will be offered a place. If you, as a carer, also agree to accompany the person you care for and take part in the group, you will also be invited to participate.

Do I have to take part?

You do not have to take part if you do not want to. You may also withdraw from the project at any time and you do not need to give your reasons. This will not affect the care that you, or the person you care for, receive now or in the future. In this situation, we would still like to use the information you have provided to us.

Do I have to be good at art?

No, you do not need to be good at art! The group is designed so that you enjoy yourself. You will not be asked to do anything during the art-making session that you do not want to do.

What will happen if I choose to take part in the project?

If you are interested in taking part, you will be asked to sign a consent form and attend the project at [name of gallery] for three weeks in a row.

Each session of the group will last for one and a half hours and refreshments will be provided. You will be invited to go around the gallery and look at pieces of artwork. You will also be invited to make your own artwork. The group will be run by a trained art therapist with support from a guide from the gallery and the researcher.

As part of the evaluation of the sessions, you will be interviewed with the person you care for by the researcher on an occasion before the art gallery sessions. You will be asked to look at some art work and to talk about this process (about 1 hour in total). You will be asked to do this again one month after the group has ended. The researcher will discuss with you what time and place suits you best for these interviews. The interviews and the gallery sessions will be tape recorded in order to have an accurate record of what you said. Only the researcher and a transcriber will listen to the tape.

Continued capacity to consent to participate in the project

Although _____, the person whom you are caring for, has given informed consent to participate in this research as of _____ (date), we realise that, because of the nature of his/her difficulties _____ (name) may not be able to freely decide to continue to consent to participate over the course of the interviews or art group. As someone who knows _____ very well, we are asking that you become a personal consultee for the person you care for in order to inform us if you believe the wishes and feelings of _____ would likely lead him/her to withdraw from the project if he/she had the capacity to do so.

If you are concerned that _____ may no longer wish to participate in the project please contact Catherine Eekelaar and we will discuss with you if it is best to withdraw _____ from the project. If this were to be the case, we would completely respect and support your decision in the matter.

Will I receive payment to take part or have to pay any expenses?

Unfortunately we are unable to provide payment. However, we can pay some amount of travel expenses to [name of gallery] and the interviews before and after the group. If travelling is a problem for you, please discuss this with us and we will try to assist you.

What are the possible benefits of taking part or any risks involved?

Hopefully you will enjoy the experience and benefit from meeting people with similar difficulties and find the process of art stimulating and interesting. However we cannot promise this. We do not anticipate any disadvantages from taking part although, sometimes, people might at first be a little anxious about joining a new group and about doing art. This

will hopefully not be the case after the first group session. If you remain anxious or uncomfortable then we will make sure to offer you further advice and support.

What happens when the project is finished?

You will receive a brief written report about the results. We will also provide you with the names and locations of other art groups if you would like to continue doing art.

Will my taking part be kept confidential?

Yes, all information you give us and the content of the sessions will be confidential. Information you give us will be stored in a locked filing cabinet and will be anonymised when the project is being written up so that you will not be able to be identified. All information from the interviews will be destroyed when no longer needed or after 10 years from when the project is finished.

Direct quotations of what you have said in the tape recordings may be used in the final write up of the project. However, these will be anonymised and you will remain unidentifiable.

What will happen to the results of the project?

The results will hopefully add to our understanding of memory problems and the benefits of an art group in an art gallery for people with memory problems and their carers.

The project report will be shared with local practitioners and published in a national or international journal. It is possible that some of the data might be shared with other colleagues who are researching art, memory problems, and interventions in an art gallery.

You will also receive a summary of the results.

Who has reviewed the study?

All research in the NHS is reviewed by an independent group of people in a Research Ethics Committee in order to protect your rights, safety, well-being, and dignity. This study has been reviewed and approved by the North London Research Ethics Committee on 10th May 2010.

How can I contact you?

Please get in contact if you wish to discuss the project further or receive more information: Catherine Eekelaar: **01892 507 673** (this is an ansaphone so please specify that you are leaving a message for Catherine and please leave your name and number, and I will get back to you)

Trainee Clinical Psychologist
Salomons, Canterbury Christ Church University

Thank you for reading about this new project and we look forward to meeting you.

Information Sheet for Referrers

Art at [name of gallery] Project for Older People with a Dementia

What is the study about?

The [name of gallery] and [name of NHS Trust] have agreed to be part of a project that is investigating the benefits of viewing and making art in an art gallery for people with a dementia and their carers. The people involved in the project are Catherine Eekelaar (Trainee Clinical Psychologist at Canterbury Christ Church University, Salomons campus), supervised by Dr Paul Camic (Canterbury Christ Church University, Salomons campus) and Neil Springham (Art Therapist, Community Mental Health Team, [name of NHS Trust]). The study is a student research project for partial fulfilment of a Doctorate in Clinical Psychology.

What is the project?

The art project is a three week group consisting of five to eight people with a dementia and their carers, for a total of up to sixteen people. Most participants will have received a diagnosis of an early stage dementia. The group will meet once a week for one and a half hours. Refreshments will be provided. The group will consist of looking around the [name of gallery] with a trained art therapist and participants will have the opportunity to make their own art in the gallery. Looking at art and making art has been found to be beneficial for people with a dementia and their carers, as people enjoy themselves, socialise, and art can help improve attention, concentration, and memory. Before and after the group, participants will meet the researcher individually to look at some art, and talk about it.

Who is eligible?

Older people aged 50 and over who are in the early to mid stage of a dementia and a carer who lives with the person or sees them daily. Carers can be a spouse/partner, family member, or close friend. The person will need to be able to provide informed consent to take part, and will need to commit to a three week group.

What are the possible benefits of taking part or any risks involved?

The experience will hopefully be enjoyable and we hope that participants will benefit from meeting people with similar difficulties and find the process of art stimulating and interesting. We do not anticipate any disadvantages from taking part although, sometimes, people might at first be a little anxious about joining a new group and about doing art. This will hopefully not be the case after the first group session.

Who might the project not be suitable for?

The project is not suitable for people who are experiencing psychosis, severe depression, or mania. It is also not suitable for people who might be unable to participate due to severe attentional or communication problems, or if they have a significant cognitive impairment

that will make participation difficult. The project is unsuitable for people who are unable to bring along a carer to the group.

How do I refer someone?

1. Please check that your client meets the eligibility criteria outlined above.
2. If your client is suitable, please discuss the art project with them when you next see them. If you are not due to see them for a while, please could you consider contacting them to see if they might be interested in having some further information about the project sent to them. If they are, please ask for their permission to give us their name and address so that we can send further information.
3. If your client is interested in being considered for the project, please ask their permission to give us their contact details. Alternatively, if they prefer, they can contact us (contact details below).
4. Following the referral, the researcher will arrange to meet the client in order to discuss the project further, and to complete a short pre-group interview. Potential participants will be asked for consent to allow the researcher to access a recently administered MMSE score in the notes if there is one so that the participant need not undertake the measure again.

Contact details

Please send any written referrals to:

Neil Springham

Community Mental Health Team

[Address]

If you have any questions about the project, please contact Catherine Eekelaar on **01892 507 673**.

CONSENT FORM – for participants

Art at [name of gallery] Project for Older People

Please tick box

1. I confirm that I have read and understood the Information Sheet 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 needing to give any reason, and without my health care or legal rights being affected.
3. I agree that the researcher has access to a pre-screening tool score (Mini Mental State Examination; MMSE) if this has been carried out by my clinician recently.
4. I agree to have a session before the art group where I will talk about some artwork, and another similar session one month after the group.
5. I understand that the sessions will be tape-recorded and the tapes transcribed. I understand that the tapes will be kept strictly confidential and destroyed when no longer needed.
6. I understand that anonymised direct quotations of what I have said in the interviews may be used when the study is written up. I understand that the

interviews during the research will not identify me in any way in the write-up of the study.

7. I understand that if my care co-ordinator referred me to the group I agree to he/she being informed of my participation in the study.

8. I agree to take part in the above study.

9. I would like to be sent a copy of the overall evaluation of the project when it is available.

Name of participant

Date

Signature

**Name of researcher
taking consent**

Date

Signature

CONSENT FORM – for carers

Art at [name of gallery] Project for Older People

I support someone with memory problems. I am a professional carer / family member / friend / other (please circle)

If other, please specify how you would like to be referred to during the project:

Please tick box

1. I confirm that I have read and understood the Information Sheet for carers 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 needing to give any reason, and without my health care or legal rights being affected.
3. I agree to have a session before the art group where I will view some artwork, and another similar session one month after the group.
4. I understand that the sessions will be tape-recorded and the tapes transcribed. I understand that the tapes will be kept strictly confidential and destroyed when no longer needed.
5. I understand that anonymised direct quotations of what I have said in the interviews may be used when the study is written up. I understand that the interviews during the research will not identify me in any way in the write-up of the study.

6. As someone who knows _____ very well, I agree that I understand my role as a personal consultee, which has been explained to me by the researcher. Part of my role as a personal consultee is to inform the researcher if I believe the wishes and feelings of _____ would likely lead him/her to withdraw from the project if he/she had the capacity to do so.

7. I agree to take part in the above study.

8. I would like to be sent a copy of the overall evaluation of the project when it is available.

Name of participant

Date

Signature

**Name of researcher
taking consent**

Date

Signature

Appendix E: MMSE

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Appendix F: Interview schedule

Semi-structured interview schedule

The following questions are a prompt. The aim is to elicit free speech about art-viewing and art-making from PWD and their family carers.

Pre interview

Response to viewing paintings

1. What do you think/feel about this painting?
2. What do you like/dislike about this painting?
3. How does the painting make you feel?
4. What do you think is going on in the painting?

Gallery art-making sessions

1. What are you doing? [If participant is engaged in art-making]
2. How did you find the art-viewing in the gallery today?
3. What did you like/dislike about the paintings we saw?
4. How did the paintings make you feel?
5. What did you think/feel about the paintings?

Post-group interview

Response to viewing paintings

1. What do you think/feel about this painting?
2. What do you like/dislike about this painting?
3. How does the painting make you feel?
4. What do you think is going on in the painting?

Experience of the group

1. How did you find the gallery sessions?

2. What did you enjoy?
3. What did you not enjoy?
4. What did you find difficult?
5. How did you find the setting (art gallery)?
6. Was there anything that affected you from being able to participate in the group?
(prompt: memory problems, communications difficulties, mood problems, problems with being in a social context, confidence, physical difficulties etc)

Appendix G: List of paintings

Paintings viewed at the interviews and gallery sessions

Pre interview

Sir Joshua Reynolds (1789) – Mrs Siddons as the tragic muse

Thomas Gainsborough (c. 1779-1785) – Mrs Moody with her sons Samuel and Thomas

Pieter Nason (c. 1663) – Portrait of a man

Session 1 of gallery sessions – Portraits

Thomas Gainsborough (c. 1779-1785) – Mrs Moody with her sons Samuel and Thomas

Sir Joshua Reynolds (1789) – Mrs Siddons as the tragic muse

John the Elder De Critz – (c. 1606) James VI and I

Session 2 of gallery sessions – Landscapes

Giovanni Antonio Canal) Canaletto (1754) – View from Walton Bridge

Adam Pynacker (c. 1665) - Landscape with sportsmen and game

Claude Lorrain (1676) – Jacob with Laban and his daughters

Session 3 of gallery sessions – Narratives

Charles Le Brun (c. 1642-1643) -Horatius Cocles defending the bridge

Adriaen Van Der Werff (1716) – The judgement of Paris

Nicolas Poussin – (Mid-1630s) – The nurture of Jupiter

Post interview

Giambattista Tiepolo (c. 1733-1735) – *Joseph receiving Pharaoh's ring*

Jacob Van Ruisdael (Late 1660s) – A waterfall

John the Elder De Critz (c. 1606) - James VI and I

Appendix H: Initial codebook

CODEBOOK

1) SEMANTIC CLUSTERING

Description

Statements in which semantically-related words (or group of words describing a single concept e.g. “cup of tea”) are produced rapidly one after another.

Inclusion criteria

Any statement from PWD where two or more semantically-linked words or concepts are uttered in quick succession with at the most one word separating them (such as “cat and dog”).

Exclusion criteria

Strings of words are separated by more than one word, or are not semantically linked.

Example text

“All these, err, God of this and God of War and God of Love, and God of Marriage”.

“I love livestock and to draw livestock. Just like dog, cattle, sheep, anything like that”.

2) FACTUAL OBSERVATIONS OF PAINTING

Description

Statements about the painting that reflect observations about the physical qualities of the painting (e.g. colour, content, shape, characters).

Inclusion criteria

Any statement from PWD about the physical characteristics of the painting, either a painting seen during the session or recollections of a previously seen painting.

Exclusion criteria

Statements about feelings about paintings, or subjective opinions of the paintings (such as “I like it”).

Example text

“There is no white colour in that one”.

3) LIFETIME MEMORY

Description

Content of speech includes reference to a memory about the life of PWD.

Inclusion criteria

Any statement from PWD that includes recalling specific events, activities, people, or animals from the person's life.

Exclusion criteria

Any statement that recalls more recent memories from the previous art sessions or the pre interview (as these would be coded as memory of previous session).

Example text

"I think I probably told you but when my parents gave me a present and I thought it was going to be a cat...I opened up this great, you know, splendidly, um, produced box. And in there was a corgi!".

4) MEMORY OF PREVIOUS SESSION

Description

The content of speech includes reference to a memory about any aspect of the previous gallery sessions, or the pre interview.

Inclusion criteria

Any statement from PWD that includes recalling specific events, activities, people, or paintings from previous areas of the study (gallery sessions or pre interview).

Exclusion criteria

Any statements that recall more retrospective memories, such as from before the gallery sessions, or memories of events or activities that occurred outside the gallery sessions and pre interview (as these would be coded as lifetime memory).

Example text

"You know the painting with the man with the skull?" (Seen last session).

5) OPINION OF PAINTING

Description

Statements about the painting that offer an opinion or judgement about the painting and/or its characteristics.

Inclusion criteria

Any statement from PWD that includes a subjective opinion or judgement about a painting pertaining to its content, physical qualities, or context.

Exclusion criteria

Statements that do not hold a subjective opinion, or statements that offer a description or observation of characteristics of the painting, or an emotional reaction to a painting.

Example text

“Portrait, you know...I know it’s a very refined work but...um, you’ve got to be expert. You cannot afford to make any mistake on that one. But here, you can afford to make a mistake, You can paint it your own way”.

6) SEEKING KNOWLEDGE

Description

Statements in which more information or knowledge about a painting is being requested.

Inclusion criteria

Any statement where PWD actively requests or seeks more information or knowledge about a painting, such as about the artist, the period during which the painting was painted, the characters in the painting, or the context.

Exclusion criteria

Any statements where PWD is actively requesting information about other members of the group, the facilitators, or matters pertaining to outside the gallery, rather than the paintings.

Example text

“And when was it painted?”.

7) DISFLUENCIES

Description

Statements where speech is characterised by false starts, revisions, prolongations, hesitations, and/or repetitions.

Inclusion criteria

Statements where more than 3% of the speech contains disfluencies such as “um” “uh” “err”, and pauses “...”.

Exclusion criteria

Extracts of text containing less than 3% of disfluencies.

Example text

“Well no...I was just interested to...no...if any...no...that one...hmmm. Yes, I think that one...I’ve lost my attention...”.

8) EMOTIONAL REACTION TO PAINTING

Description

A statement with an emotional response to a painting.

Inclusion criteria

Any statement where PWD offer a positive or negative emotional reaction to a painting by naming emotions they are feeling, or a non-verbal expression of emotion (e.g. crying).

Exclusion criteria

Any statement that includes PWD offering an opinion about a painting, or factual observations about a painting without any emotional content.

Example text

“...but I mostly love this landscape...for some reason. I don’t know why!”.

9) EMOTIONAL REACTION TO GROUP

Description

A statement with an emotional response to the art-viewing or art-making parts of the gallery sessions.

Inclusion criteria

A statement in which PWD expresses a positive or negative emotional reaction to the art-viewing or art-making parts of the gallery sessions, or a non-verbal expression of emotion (e.g. crying).

Exclusion criteria

Any statement that includes PWD offering an opinion about the group, or factual observations about the group, and does not have any emotional content.

Example text

“Thank you very much. I really enjoy it here”.

10) REQUESTING GUIDANCE

Description

Direct requests for guidance about what to do either in the gallery sessions or at the pre or post interview.

Inclusion criteria

Any statement where PWD are directly asking for guidance or reassurance as to what to do in the gallery sessions or at the pre and post interview. These can be directed at carers, facilitators, or other members of the group.

Exclusion criteria

Statements where PWD are not directly asking for guidance, even if they may seem slightly confused.

Example text

“I don’t know...have I got it the right way up?”.

11) PERSONAL DESCRIPTIVE INFORMATION

Description

Statements pertaining to personal descriptive and current information.

Inclusion criteria

Any statements where PWD articulate descriptive information about their current life (e.g. number of children they have, where they live).

Exclusion criteria

Statements that pertain to the past rather than the person’s present situation.

Example text

“No he is not a...he [my son] is a Deputy Head of the school now”.

12) ART ACTIVITIES AFTER GROUP

Description

An expression of a wish to continue to paint or undertake other art activities either at home or at an art class, once the gallery sessions have finished.

Inclusion criteria

Any statements where PWD express a desire to continue their relationship with art either at home, at an art class, or at an art gallery, or express that they have already continued to engage in other art ventures during the same period as the gallery sessions. Art activities could include art-viewing or art-making.

Exclusion criteria

Statements where PWD state past involvement with art.

Example text

“You see, I have a [art] class once a week over there, but that is not enough. I really want at least a couple every week”.

13) SHARING FACTUAL KNOWLEDGE

Description

Statements involving learned factual knowledge about a subject, either to a carer, facilitators, or other members of the group.

Inclusion criteria

Any statements where PWD express learned factual information. This could include information about a painting's historical context, the characters in the painting, or the artist.

Exclusion criteria

Statements where information expressed pertains to PWDs' personal life, rather than learned general knowledge about a subject.

Example text

“Sistine, yes the Sistine...yes. But it was fascinating to learn about and of course crikey how high it was. 50 metres I think it is, you know”.

Appendix I: Inter-rater reliability

	INDEPENDENT RATER														
		1	2	3	4	5	6	7	8	9	10	11	12	13	TOTAL
RESEARCHER	1	1	0	0	0	0	0	0	0	0	0	0	0	0	1
	2	0	8	0	0	1	0	0	0	0	0	0	0	0	9
	3	0	0	8	0	0	0	0	0	0	0	0	0	0	8
	4	0	0	0	0	0	0	0	0	0	0	0	0	0	0
	5	0	3	0	0	7	0	0	0	0	0	0	0	0	10
	6	0	0	0	0	0	6	0	0	0	0	0	0	0	6
	7	0	0	1	0	0	0	21	0	0	0	0	0	0	22
	8	0	0	0	0	0	0	0	10	0	0	0	0	0	10
	9	0	0	0	0	0	0	0	1	6	1	0	0	0	8
	10	0	0	0	0	0	0	0	0	0	11	0	0	0	11
	11	0	0	0	0	0	0	0	0	0	0	2	0	0	2
	12	0	0	0	0	0	0	0	0	0	0	0	1	0	1
	13	0	0	0	0	0	0	0	0	0	0	0	0	3	3
TOTAL	1	11	9	0	8	6	21	11	6	12	2	1	3	91	

Calculation of “proportion agreement, observed” (PA_O)

$PA_O = \text{Total of agreement}/n$

$PA_O = 84/91 = 0.92$ (92% agreement)

Calculation of “proportion agreement, expected by chance” (PA_E)

$PA_E = \sum P_i^2$ (where P_i = each joint marginal proportion)

Category	N for Researcher	N for Independent Rater	Product of marginals (pm_i): Researcher x Independent rater	Sum of marginals: Researcher + Independent rater	Joint marginal proportions P_i
1	1	1	1	2	$2/182 = 0.01$
2	9	11	99	20	$20/182 = 0.11$
3	8	9	72	17	$17/182 = 0.09$
4	0	0	0	0	$0/182 = 0.00$
5	10	8	80	18	$18/182 = 0.10$
6	6	6	36	12	$12/182 = 0.07$
7	22	21	462	43	$43/182 =$

					0.24
8	10	11	110	21	21/182 = 0.11
9	8	6	48	14	14/182 = 0.08
10	11	12	132	23	23/182 = 0.13
11	2	2	4	4	4/182 = 0.02
12	1	1	1	2	2/182 = 0.01
13	3	3	9	6	6/182 = 0.03
TOTAL	91	91	1054	182	1.00

$$\text{Cohen's kappa} = \frac{PA_O - PA_E}{1 - PA_E} \quad \text{where } PA_E = (1 - n^2)(\sum pm_i)$$

n = number of units coded in common by coders

pm_i = each product of marginals

$$\begin{aligned} \text{So } PA_E &= (1/84^2)(1+99+72+0+80+36+462+110+48+132+4+1+9) \\ &= (1/7056)(1054) \\ &= 0.15 \end{aligned}$$

$$\begin{aligned} \text{Cohen's kappa} &= \frac{PA_O - PA_E}{1 - PA_E} \\ &= \frac{0.92 - 0.15}{1 - 0.15} \\ &= \frac{0.77}{0.85} \\ &= 0.91 \end{aligned}$$

Appendix J: Sample coded transcripts

This has been removed from the electronic copy

Appendix K: Finalised codebook

CODEBOOK

1) SEMANTIC CLUSTERING

Description

Statements in which semantically-related words (or group of words describing a single concept e.g. “cup of tea”) are produced rapidly one after another.

Inclusion criteria

Any statement from PWD where two or more semantically-linked words or concepts are uttered in quick succession with at the most one word separating them (such as “cat and dog”).

Exclusion criteria

Strings of words are separated by more than one word, or are not semantically linked.

Example text

“All these, err, God of this and God of War and God of Love, and God of Marriage”.

“I love livestock and to draw livestock. Just like dog, cattle, sheep, anything like that”.

2) FACTUAL OBSERVATIONS OF PAINTING

Description

Statements about the painting that reflect observations about the physical qualities of the painting (e.g. colour, content, shape, characters).

Inclusion criteria

Any statement from PWD about the physical characteristics of the painting, either a painting seen during the session or recollections of a previously seen painting.

Exclusion criteria

Statements about feelings about paintings, or subjective opinions of the paintings (such as “I like it”).

Example text

“There is no white colour in that one”.

3) MEMORY

Description

Content of speech includes reference to a memory about the life of PWD, memory about a previous art gallery session or the pre interview, personal descriptive information about current life, or articulating learned factual knowledge.

Inclusion criteria

Any statement from PWD that includes recalling specific events, activities, people, or animals from the person's life, including previous gallery sessions or the pre interview. Any statement that recalls anything about PWDs' current life situation (e.g. number of children), or statements articulating learned general factual information about a topic.

Exclusion criteria

Statements that reflect PWDs' current observations, opinions or emotional reactions to paintings.

Example text

"I think I probably told you but when my parents gave me a present and I thought it was going to be a cat...I opened up this great, you know, splendidly, um, produced box. And in there was a corgi!"

"You know the painting with the man with the skull?" (Seen last session).

"No he is not a...he [my son] is a Deputy Head of the school now".

"Sistine, yes the Sistine...yes. But it was fascinating to learn about and of course crikey how high it was. 50 metres I think it is, you know".

4) OPINION OF PAINTING

Description

Statements about the painting that offer an opinion or judgement about the painting and/or its characteristics.

Inclusion criteria

Any statement from PWD that includes a subjective opinion or judgement about a painting pertaining to its content, physical qualities, or context.

Exclusion criteria

Statements that do not hold a subjective opinion, or statements that offer a description or observation of characteristics of the painting, or an emotional reaction to a painting.

Example text

"Portrait, you know...I know it's a very refined work but...um, you've got to be expert. You cannot afford to make any mistake on that one. But here, you can afford to make a mistake, You can paint it your own way".

5) SEEKING KNOWLEDGE

Description

Statements in which more information or knowledge about a painting is being requested.

Inclusion criteria

Any statement where PWD actively requests or seeks more information or knowledge about a painting, such as about the artist, the period during which the painting was painted, the characters in the painting, or the context.

Exclusion criteria

Any statements where PWD is actively requesting information about other members of the group, the facilitators, or matters pertaining to outside the gallery, rather than the paintings.

Example text

“And when was it painted?”.

6) DISFLUENCIES

Description

Statements where speech is characterised by false starts, revisions, prolongations, hesitations, and/or repetitions.

Inclusion criteria

Statements where more than 3% of the speech contains disfluencies such as “um” “uh” “err”, and pauses “...”.

Exclusion criteria

Extracts of text containing less than 3% of disfluencies.

Example text

“Well no...I was just interested to...no...if any...no...that one...hmmm. Yes, I think that one...I’ve lost my attention...”.

7) EMOTIONAL REACTION TO PAINTING

Description

A statement with an emotional response to a painting.

Inclusion criteria

Any statement where PWD offer a positive or negative emotional reaction to a painting by naming emotions they are feeling, or a non-verbal expression of emotion (e.g. crying).

Exclusion criteria

Any statement that includes PWD offering an opinion about a painting, or factual observations about a painting without any emotional content.

Example text

“...but I mostly love this landscape...for some reason. I don’t know why!”.

8) EMOTIONAL REACTION TO GROUP

Description

A statement with an emotional response to the art-viewing or art-making parts of the gallery sessions.

Inclusion criteria

A statement in which PWD expresses a positive or negative emotional reaction to the art-viewing or art-making parts of the gallery sessions, or a non-verbal expression of emotion (e.g. crying).

Exclusion criteria

Any statement that includes PWD offering an opinion about the group, or factual observations about the group, and does not have any emotional content.

Example text

“Thank you very much. I really enjoy it here”.

9) REQUESTING GUIDANCE

Description

Direct requests for guidance about what to do either in the gallery sessions or at the pre or post interview.

Inclusion criteria

Any statement where PWD are directly asking for guidance or reassurance as to what to do in the gallery sessions or at the pre and post interview. These can be directed at carers, facilitators, or other members of the group.

Exclusion criteria

Statements where PWD are not directly asking for guidance, even if they may seem slightly confused.

Example text

“I don’t know...have I got it the right way up?”.

10) ART ACTIVITIES AFTER GROUP

Description

An expression of a wish to continue to paint or undertake other art activities either at home or at an art class, once the gallery sessions have finished.

Inclusion criteria

Any statements where PWD express a desire to continue their relationship with art either at home, at an art class, or at an art gallery, or express that they have already continued to engage in other art ventures during the same period as the gallery sessions. Art activities could include art-viewing or art-making.

Exclusion criteria

Statements where PWD state past involvement with art.

Example text

“You see, I have a [art] class once a week over there, but that is not enough. I really want at least a couple every week”.

Appendix L: Individual frequency data

Frequency of codes for PWD A

	Pre	During	Post
Memory	23.08%	73.69%	45.45%
Semantic Clustering	0%	10.53%	9.09%
Disfluencies	19.23%	5.26%	9.09%
Factual observation of painting	11.54%	0%	12.12%
Opinion of painting	26.92%	0%	18.18%
Emotional reaction to painting	19.23%	0%	0%
Emotional reaction to group	N/A	5.26%	3.03%
Art activities after group	0%	5.26%	0%
Seeking knowledge	0%	0%	3.03%
Requesting guidance	0%	0%	0%

Frequency of codes for PWD B

	Pre	During	Post
Memory	4.35%	22.22%	25.00%
Semantic Clustering	0%	0%	0%
Disfluencies	0%	0%	0%
Factual observation of painting	47.83%	22.22%	8.33%
Opinion of painting	17.39%	0%	25.00%
Emotional reaction to painting	17.39%	11.11%	8.33%
Emotional reaction to group	N/A	22.22%	8.33%
Art activities after group	0%	0%	0%
Seeking knowledge	13.04%	22.22%	25.00%
Requesting guidance	0%	0%	0%

Frequency of codes for PWD C

	Pre	During	Post
Memory	0%	24.25%	16.13%
Semantic Clustering	0%	6.06%	0%
Disfluencies	4.00%	4.55%	22.58%
Factual observation of painting	36.00%	15.15%	9.68%
Opinion of painting	52.00%	9.09%	12.90%
Emotional reaction to painting	4.00%	15.15%	9.68%
Emotional reaction to group	N/A	7.58%	12.90%
Art activities after group	0%	6.06%	12.90%
Seeking knowledge	4.00%	12.12%	3.23%
Requesting guidance	0%	0%	0%

Frequency of codes for PWD D

	Pre	During	Post
Memory	5.00%	0%	21.67%
Semantic Clustering	0%	11.11%	1.67%
Disfluencies	5.00%	11.11%	30.00%
Factual observation of painting	45.00%	11.11%	18.33%
Opinion of painting	40.00%	11.11%	23.33%
Emotional reaction to painting	5.00%	0%	3.33%
Emotional reaction to group	N/A	11.11%	0%
Art activities after group	0%	0%	0%
Seeking knowledge	0%	44.44%	1.67%
Requesting guidance	0%	0%	0%

Frequency of codes for PWD E

	Pre	During	Post
Memory	5.88%	0%	N/A
Semantic Clustering	0%	0%	N/A
Disfluencies	23.53%	15.38%	N/A
Factual observation of painting	5.88%	0%	N/A
Opinion of painting	0%	0%	N/A
Emotional reaction to painting	0%	0%	N/A
Emotional reaction to group	N/A	0%	N/A
Art activities after group	0%	0%	N/A
Seeking knowledge	58.82%	0%	N/A
Requesting guidance	5.88%	84.62%	N/A

Frequency of codes for PWD F

	Pre	During	Post
Memory	0%	19.23%	N/A
Semantic Clustering	0%	3.85%	N/A
Disfluencies	5.88%	15.38%	N/A
Factual observation of painting	47.06%	11.54%	N/A
Opinion of painting	29.41%	19.23%	N/A
Emotional reaction to painting	0%	7.69%	N/A
Emotional reaction to group	N/A	0%	N/A
Art activities after group	0%	0%	N/A
Seeking knowledge	17.65%	23.08%	N/A
Requesting guidance	0%	0%	N/A

Appendix M: Conference information

Art Galleries, Wellbeing and Health Conference: New Directions in Research – London - 29 March

29 March 2011

An afternoon conference that explores new research findings about how art galleries can offer communities experiences to enhance wellbeing and increase quality of life.

The conference is the result of a research partnership between Dulwich Picture Gallery, Oxleas NHS Foundation Trust and Canterbury Christ Church University.

Programme:

Welcoming remarks: Social Action through Art – A Perspective

Gillian Wolfe CBE: Director of Learning and Public Affairs, Dulwich Picture Gallery

The Role of Galleries in overcoming the Effects of Social Exclusion on Mental Health

Mr. Neil Springham: Head of Art Therapy, Oxleas NHS Foundation Trust

The Community Programme at Dulwich Picture Gallery

Ms. Michelle Douek: Community Programmes Manager, Dulwich Picture Gallery

What Research is Telling Us about Galleries and Wellbeing

Prof. Paul Camic: Canterbury Christ Church University

Developing Positive Personal and Community Stories of People's Experiences of Psychosis through Art

Dr. Susie Colbert: Canterbury Christ Church University & Oxleas NHS Trust

A Museum-based Art Intervention for People with Dementia and their Carers

Ms. Catherine Eekelaar: Canterbury Christ Church University

Conference participants are welcome to visit the permanent collection and special exhibition in the Gallery.

There is no fee for the conference but pre-registration is required by **15 March**.

To register: please send an email with your name, address and institutional affiliation (if any) to Viv Cousins at viv.cousins@canterbury.ac.uk. In the subject line of your email please type: DPG Conference. Alternatively, please send your name and postal address to: DPG Conference c/o Ms. Viv Cousins, Dept of Applied Psychology, Canterbury Christ Church University, Broomhill Rd., Tunbridge Wells, Kent TN3 0TG

Appendix N: Proposal for future study

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Appendix O: End of study information to ethics

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Appendix P: Summary of study's findings for dissemination

An art gallery-based intervention to enhance episodic memory and verbal fluency in dementia: An exploratory study

There are currently 750 000 people with a dementia (PWD) in the UK and as the ageing population increases, this number is expected to rise to over a million by 2025 (Alzheimer's Society, 2011). Therefore, there is a growing need to address the wellbeing of this population and those who care for them. Arts and health projects may be a particularly valuable way of addressing the needs of PWD. There is some compelling evidence emerging that suggests that PWD who engage in an arts-based activity show improvements in social and psychological wellbeing (Rentz, 2002; Kinney & Rentz, 2005), increased confidence, enthusiasm, enjoyment, and social contact (MacPherson, Bird, Anderson, Davis, & Blair, 2009, Rosenberg, 2009), and decreased ratings of depression (Musella, Carloni, de Marino, di Bartolo, Gaeta, di Maggio, & Fasanaro, 2009; Rosenberg, 2009). Although not deliberately investigated, there has been anecdotal evidence to suggest that some PWD also experience short-term cognitive improvements while attending an arts-based intervention, such as increased memory recall (MacPherson et al., 2009) and increased sustained attention, engagement, and communication (Kinney & Renz, 2005; Musella et al., 2009; Rosenberg, 2009).

The current exploratory study invited PWD and their family carers to attend an arts-based intervention at Dulwich Picture Gallery for three sessions over three weeks, in which they engaged in art-viewing and art-making with an art educator and art therapist. Using audio recordings, the study sought to explore possible changes in cognition of PWD during the intervention, namely episodic memory and verbal fluency. In order to help identify changes that might occur in the Gallery, each PWD and family carer also participated in pre and post interviews at home which involved commenting on reproductions of paintings. Family carers' observations of PWDs' response to the art gallery-based intervention was also explored.

The findings suggested that episodic memory and verbal fluency appeared to improve during the art gallery-based intervention and that this appeared to be maintained at the post interviews one month later. Family carers corroborated these findings and reported that PWD showed increased mood, confidence and social interaction, and that they valued the shared experience and learning opportunity.

It is unclear whether these changes in episodic memory and verbal fluency can be attributed to the intervention as the study was exploratory and did not aim to control for other elements that could have affected the findings. It seems that engagement in the visual arts, social interaction, the shared experience, and learning opportunity were all important to participants. Encouragingly, both PWD and family carers valued the experience, demonstrated through positive emotional reactions to the sessions and a desire to continue with art-related activity following the project. There is therefore a need for further research into this area. Strengths of the study include the creation of an original gallery-based intervention and a unique way of measuring cognitive function in PWD. It has clinical implications regarding facilitating the establishment of more arts-based community projects for PWD and their family carers.

Appendix Q: Research diary

Research Diary

Spring 2009 – preliminary ideas

An art therapist working in the NHS emails the course with potential research ideas involving joint working between NHS mental health services and art galleries. I am immediately curious to learn more as I have a passion for art and visiting art galleries. I have not ever considered the role an art gallery could take in the lives of people with mental health problems and their carers, and I email the art therapist for more information. We arrange a meeting.

6th March 2009 – meeting with art therapist

His enthusiasm in this research area is infectious and we spend some time talking about our own relationships with art and its meaning in our lives. I think about how, for me, art can be a form of escapism from the stress and pressures of life. I also consider my experience of art galleries and am reminded of feeling awed by the artwork and architecture of prolific art galleries I have visited in the past. I also think about how there is a quietness about an art gallery, in which I feel I can reflect on and be thoughtful about my emotional responses to the artwork.

We discuss the possible expansion of an existing project in an art gallery for people with psychosis, which is being undertaken by a second year trainee clinical psychologist. The art therapist encourages me to meet with this trainee and to think about how I would possibly like to expand on this project.

The art therapist talks about a project in an art gallery in which people with mental health problems created podcasts that are available for members of the public to listen to at the gallery about their experiences with art and their own mental health. There has also been a similar programme for carers to discuss their experiences of caring for someone with mental health problems. This leads me to think more about how art galleries could play a role in destigmatising mental health problems in society.

March 2009 - Listening to podcasts

I listen to some of the podcasts and watch some of the videos from these sessions in the art gallery. I am particularly struck by some footage of carers discussing a painting (The Saltonstall Family by David Des Granges), which then facilitates an open and honest conversation about the difficulties of caring for someone with mental health problems and the challenges that the carer and their family face. I start to consider whether the role of the art gallery could be to provide a unique space for honest reflection on difficult issues between carer and cared for.

12th March 2009 - Meeting with second year trainee clinical psychologist

Her project involves inviting people with psychosis to an art gallery to participate in a group reflecting on paintings that speak to their life experience. This resonates with my initial

thoughts about the gallery providing a unique forum for communication. As I think about communication and communication problems, I start wondering about how this kind of space might impact on people with communication difficulties, such as people with learning disabilities or people with dementia.

19th March 2009 - Visit to the gallery, in which the project could potentially take place

I meet with the art therapist again and he agrees to be my external supervisor. He suggests that visiting the art gallery he has made links with may clarify my thoughts about which direction I want to take the project. That afternoon, I visit the gallery. I have never visited this gallery before and I am immediately impressed by the building and grounds. The gallery is fairly small, which gives it a friendlier vibe and contrasts with the intimidation of larger art galleries that I sometimes feel. I am immediately drawn to the temporary exhibition displaying the works of Paul Nash and I recognise a set of hills he famously painted which are not far from where I grew up. I have a strong emotional, nostalgic reaction to this, which makes me reflect on the powerful effect art can have on an individual. I also start to wonder whether art could be a means of prompting lifetime memories for people with memory problems and I make a note to investigate whether there has been any work on the effects of art galleries on people with cognitive problems like dementia.

When I leave the gallery, I think about how refreshing it has been to spend an afternoon in an art gallery during my working week. It certainly does not feel like work! I begin to think about my days on clinical placement, and how medicalised and stigmatising the setting of a mental health team can be. I muse about whether more psychological work could be done in other settings in the community, and how this could be on a group level rather than always on an individual one.

Summer 2009 – further reading

I don't find much in the way of research with art galleries and people with dementia but a project at the Museum of Modern Art (Meet Me at MoMA) emerges from an internet search. It seems novel and interesting and there is a lot of helpful advice on the website about how to set up an art programme for people with dementia and their carers at an art gallery. The research paper (Rosenberg, 2009) had not come out at this point but the website reported the following potential effects on PWD:

1. Decreased social isolation
2. Enhanced self-esteem
3. Reduced symptoms of depression
4. Enhanced quality of life
5. Some reports of improvements in memory and attention (although short-term)
6. Beneficial impact on carers as the programme strengthens their relationship, as well as being a form of respite in a sense.

I suggest to my supervisors that our project could investigate further the observed improvements in cognitive functioning through neuropsychological tests. Both supervisors are supportive of this idea. The art therapist says that a new art therapist has been recruited into the dementia service and so she may be interested in linking with the project.

19th November 2009 – meeting with Laurel Humble at MoMA

I happen to be going on holiday to New York and so take the opportunity to get in touch with the Meet Me at MoMA staff. I meet with Laurel Humble (assistant on the programme) at MoMA who is very enthusiastic about the programme and supportive of my proposal to replicate a similar project in the UK. She gives me practical advice, such as ensuring there are chairs for participants to sit on in front of the paintings and being aware of short levels of concentration (which impacts on ability to focus on the paintings for long periods of time and ability to fill out questionnaires for evaluation). She is keen to hear how our project goes and is happy to provide any more advice or help during the process.

November/December 2009 – discussions about design

I discuss my idea of using neuropsychological tests with a clinical psychologist at the university who is experienced in neuropsychological testing in older people's services. She advises me that cognitive neuropsychological assessments would be unable to detect subtle changes over such a short period of time and suggests I think about a qualitative design. She also advises that I do not ignore carers during this process because they can provide valuable observations of PWD as they know them across many settings. She also recommends that I think about the impact on the carers as well, as carer burden is a huge issue in dementia care. In discussion with my supervisors, we agree on a qualitative design using content analysis to detect changes in episodic memory and verbal fluency. We also agree to combine art-making and art-viewing at the art gallery within the intervention as previous literature has suggested that both interactions with art have beneficial outcomes. The project is approved by the university.

During this time, I make initial links with the community mental health team for older adults I wish to recruit participants from. The team leader is interested and recommends that I get in touch when I have firmer practicalities about the project.

19th February 2010 – visiting the gallery

Meeting with Community Outreach Manager of the gallery. She informs me about the array of community projects the gallery runs, which surprises me. Target groups include harder to reach young people, young families, and older people. While I am there, she takes me to the studio to see an art-making session for older people (with and without dementia) run by an art educator. It is a weekly, drop-in group. The atmosphere feels lively and it is clear to see that there is huge importance on the social component for the group members as they catch up with each other and comment on each other's artistic creations. I wonder whether I've forgotten this aspect of the project as I have felt so bogged down with the practicalities relating to the art. I wonder whether the social aspect may seem the most significant for a group of people for whom going out and engaging in activity has become more difficult as they have got older.

Spring 2010 – ethical approval

I start applying to NHS ethics and R&D for approval for the project. This process makes me acutely aware of the vulnerability of PWD as I consider things like loss of capacity to consent to the study because of cognitive problems and inability to travel to the gallery owing to poor

physical health. I find myself wondering whether the project is practically feasible, then I speculate that my doubts are reflective of society's attitude towards older people and PWD (in that "it's too much hassle". "keep them tucked away in a home"). Fortunately, this realisation makes me feel more motivated to make the project work and I start investigating things like the possibility of NHS patient transport and travel expenses.

After liaising with the art gallery, the three art gallery session dates are booked for August 2010 and suddenly it all seems very real. I start to worry about how the actual sessions are going to run.

Spring 2010 – meeting with supervisor and art therapist

I meet with my external supervisor and the art therapist who works in the dementia service and is happy to be involved in the gallery art-making sessions. We talk about how the art gallery sessions are new to all of us, as none of us have run an art gallery intervention for PWD before. Therefore, there will be some trial and error, and learning from the process each week. This both reassures me and raises my anxiety! We think practically about how to structure the sessions and consider how difficult it will be recording data in the art-viewing component in the art gallery.

May 2010 - recruitment

I start to get anxious about recruitment and contact the community mental health team for older adults. It is difficult to get responses back as people are on annual leave or too busy. Therefore, I speak to the art therapist who works in the dementia part of the service about recruitment and she kindly offers to speak with the team about the project. Furthermore, a meeting is set up for me in July to present the project to the team at a team meeting.

2nd July 2010 – meeting with all those involved in the project

Meeting at the gallery with the Community Outreach Manager of the gallery, the art educator, my external supervisor, and the art therapist. There is an air of excitement about the project as more practicalities are discussed. Having the full support from the gallery is invaluable, as art materials, refreshments, and even complimentary tickets to the temporary exhibition for participants are offered.

14th July 2010 – meeting with community mental health team for older adults

I meet with the community mental health team for older adults and present the study in a team meeting. Despite the clear work pressures on staff, I am struck by how supportive and enthusiastic they are. Several staff members comment on how hopeful it feels to know there is interest from a research angle in improving quality of life for PWD and carers. I wonder whether there are high levels of burnout in this team because of the nature of their work in which the losses of old age are so prevailing. It feels that by presenting a potentially new resource for PWD and carers in the community, the mood in the team brightens. This draws my attention back to the effects such an intervention may have on the carers. Perhaps they will feel more hopeful and less "forgotten" in the community through this project.

July/August 2010 – recruitment and pre interviews

Fortunately, interest in the project emerges from potential participants identified by the team and the art therapist. I speak to potential participants on the phone and arrange for to visit their homes to answer further questions they may have and to embark on the pre interviews if they consent to taking part. I enjoy these visits and feel welcomed at each home. There is excitement about the gallery sessions but also a sense of anxiety for a lot of the participants. I realise that the distance to the gallery is fairly far for some and that many participants seem to rarely leave the house unless it is to attend hospital appointments. Therefore, a visit to an art gallery seems very new and unknown.

The art educator and I communicate via telephone and email to plan the themes for the gallery sessions. I enjoy our conversations and feel I am learning a lot about the richness of the stories behind the paintings she has chosen to show participants. We decide on the themes of portraits, landscapes, and narratives within paintings.

August 2010 – the art gallery sessions

At the first session, I am relieved when all the participants arrive. The art therapist, art educator, gallery staff and I do our best to welcome them. During the art-viewing session, we acquire a lot of interest from members of the public in the gallery and a couple of participants comment that they feel “very special” to be having their own tour of the paintings led by the art educator. In the art-making session, I soon realise that having one digital recorder for data collection is not enough. I feel I am missing valuable conversations around the table and so I later discuss with my supervisors about bringing multiple recorders to the next two sessions.

After the first art-making session, the art therapist, art educator and I wonder whether we should take some time at the end of the next art-making session to acknowledge that the session is ending and have a final group discussion. We agree to try this next week.

At the second session, the participants appear less anxious and more vocal, particularly during the art-viewing component. I notice that a couple of PWD point out the paintings we viewed in the first week as we walk through the gallery. At the art-making session, we attempt a five minute group discussion at the end. This does not work so well because some participants want to continue with their own art activities. This makes me think that perhaps we have not allocated enough time for the art-making session as it does feel fairly rushed.

There is an air of melancholy at the final session from participants and also myself, the art educator, and art therapist. The participants are appreciative of the sessions and express sadness that they will not be continuing. It feels like we have just established a routine with the sessions and so it is a shame to be finishing. The art therapist, art educator and I meet for coffee afterwards to discuss how the sessions have gone. We reflect on how much participants’ confidence had grown over the course of the sessions. At the last session, it was difficult to get them to stop talking and move into the studio for the art-making. We also wondered whether portraits seemed to have the most powerful effect on participants as each of us observed that participants seemed to remember the portraits the most and found the background stories of the characters particularly appealing.

September 2010 – post interviews

I meet with each dyad for the post interviews. I am particularly touched by one carer, who (together with her husband) provides a great amount of positive feedback about the sessions during the post interview. After I leave their home, the carer calls me on my mobile. She says she wants to thank us again for the project and emphasise just how moving it had been to spend this time with her husband in a different context to the frustrations of everyday life of caring for a loved one with a dementia. Perhaps she felt it difficult to express how important the group had been for her in front of her husband but I really feel a sense of desperateness about her situation. I am pleased to hear that she and her husband intend to continue with art classes in the future. This experience makes me question who this intervention is actually for. Although the study is focusing on cognitive improvement in PWD, I wonder whether actually the intervention is more beneficial for the carers. I think about the impact of carer stress on the ability to care for PWD and I wonder whether a positive and enjoyable interaction with PWD (such as through the art gallery intervention) will positively affect the quality of care carers are able to provide, which then in turn may improve PWDs' quality of life and even perhaps their cognitive abilities as a result.

19th Oct 2010 - symposium at The Royal Academy

I attend a symposium organised by The Royal Academy of Arts with the art educator and art therapist involved with the project. It is entitled: Access for All: Making Art Accessible to People with Dementia. It is held in association with The MoMA Alzheimer's Project. It is useful to hear more about the Meet Me at MoMA project and it is lovely to see Laurel Humble, who I met in New York about a year ago, and inform her of how our project went. It feels exciting to hear about more projects involving arts and dementia and I feel a genuine enthusiasm in the area from people presenting. I start to feel part of a community with this specific interest in arts and dementia, and I look forward to hearing more about other projects and how they develop.

October 2010 – March 2011

I start my clinical placement in an older people's community mental health service. I feel more confident working with PWD after the project. I have the opportunity to get involved in a singing group for people with dementia in the local area, which is also being evaluated for quality of life benefits for the PWD and their carers. I attend the weekly sessions for six weeks as a co-facilitator. I experience the group to be similar to the gallery sessions; there is an energy as the PWD and carers begin to get to know each other and enjoy each other's company. I witness some seemingly intimate moments between some couples, especially when they are both singing a favourite song, through smiling at each other and holding hands. I am very moved by one man, who appears greatly impaired by his dementia. As he sings one particular song, tears stream down his cheeks. After a while, I feel concerned and ask him if he is OK. He does not respond and just continues singing. His wife tells me that sometimes he cries during this group but he cries because he is being touched by the music and is connecting with something, which is something he is unable to do anymore in his everyday life. I find this very poignant and I feel that her words sum up everything that the art gallery project was trying to achieve: to enable individuals with a dementia to connect, through creativity and art, to their carers, to others, to their memories, to their emotions, and, ultimately, to themselves.