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ARTS INTERVENTIONS IN DEMENTIA CARE.

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Summary of the portfolio

Section A

This section reviewed the literature on creative arts interventions and dementia with a specific focus on evidence of psychological benefit. An introduction to the area summarises the significance of non-pharmacological interventions and how creative arts have been used within dementia care. A critical appraisal of peer-reviewed literature relating to interventions for people experiencing dementia was divided by artistic area: music engagement; creative expression and visual arts. A discussion of the research confirms evidence of psychological benefits but provides a rationale for expanding the evidence base and highlights the need to develop a theoretical understanding of how creative arts interventions impact participants.

Section B

This study investigated arts-based interventions at two art galleries, where 12 people with dementia and their carers were engaged in art-viewing and art-making. Post-intervention interviews with participants and facilitators, field notes and written communication between the facilitator and research teams were analysed using a grounded theory approach. Three key aspects; a valued place, intellectual stimulation and social relationships facilitated positive affect in participants and a different view of people with dementia for carers and facilitators. The resulting theory has potential implications for the use of arts by health and social care professionals as well as community services.

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SECTION A

**Creative Arts Interventions as Non-Pharmacological Approaches to Dementia
Care**

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Abstract

The following review summarises the literature on creative arts interventions and dementia with a specific focus on evidence of psychological benefit. An introduction to the area summarises the significance of non-pharmacological interventions and provides a rationale for the review. Various models of dementia are described and lead to an exploration of the role of arts interventions within contemporary dementia care. Theoretical perspectives are considered that offer ways of understanding the psychological benefit of arts interventions. A critical appraisal of the current peer-reviewed literature relating to creative arts interventions for people with a dementia follows and is divided by artistic area: music engagement; creative expression and visual arts. A discussion of the research summarises the psychological outcomes evidenced, including improved quality of life, communication and mood. It also provides a rationale for the importance of expanding the evidence base and highlights the need to develop a theoretical understanding of how creative art intervention impact participants to continue to develop and refine future interventions.

Keywords: dementia care, the arts, community, creativity, non-pharmacological.

Introduction

Dementia has become a key health and social care issue for the 21st century as a result of increasing life expectancies (Alzheimer's Society, 2013; Wimo, Winblad, Aguero-Torres, & von Strauss, 2003). There is no cure for dementia, so an important aspect of care is improving quality of life and this means attending to individuals' social and psychological wellbeing as well as medical symptoms. Cohen (2000, p 1-3) argued that "too often one hears the unqualified statement that, 'There is no treatment for Alzheimer's disease'", a common form of dementia. Cohen states that this misrepresents the numerous clinical interventions that can alleviate "symptoms and suffering and maximize coping." Thus, whilst no cure has been discovered and medical treatments at best delay progression of dementia (Raina et al., 2008; Sink, Holden & Yaffe, 2005), non-pharmacological approaches are showing promise in promoting psychological wellbeing throughout the experience of dementia (Beard, 2012; Douglas, James, & Ballard, 2004; Salisbury, Algar, & Windle, 2011).

The following review considered a subset of the non-pharmacological interventions currently offered: creative arts. Increasing evidence has shown that participation in creative arts enhanced the psychological wellbeing of people with a diagnosis of dementia and their carers (Camic, 2008; Clift et al., 2009). Cummings and colleagues (2008) noted that to study participation in art was to recognise the strengths, and not only the weaknesses, of people with a dementia. Interventions based around creative arts can promote wellbeing and provide support to those with a dementia in non-stigmatising community settings (Camic & Chatterjee, 2013; Wali, Severson, & Longoni, 2002).

This review aimed to explore the types of creative arts interventions currently on offer to people with dementia, and their carers, and to assess the evidence of

psychological benefit of these various interventions. The aim was to provide an overview of current findings and highlight gaps in research and knowledge in order to provide a better understanding of the use of creative arts activities as psychological interventions for people with a dementia and carers.

Methodology

This article is a traditional overview (Grant & Booth, 2009) of the peer-reviewed literature (in the English language) investigating the psychological benefits of creative arts-based group interventions for people with a dementia and carers. Five databases (ASSIA, Web of Knowledge, Medline, Psycinfo, Cochrane) were searched for the period (2000- 2013) to explore the most contemporary evidence. Search terms were based upon previous research in the area (Appendices A, B).

Arts interventions included musical engagement, creative expression and visual arts as identified in previous reviews within the area (Beard, 2012): dance and movement-based interventions were excluded since outcomes attributable to the “arts” aspect are difficult to distinguish from the impact of physical activity (Potter, Ellard, Rees & Thorogood, 2011). Studies were included if they reported upon some form of psychological impact. The criteria were not further defined in order to include as many psychological aspects as possible including mood, quality of life, carer burden and wellbeing, which again follows the precedent of previous reviews (Beard, 2012). Studies were excluded (Appendix C) where interventions were identified as “therapy” for instance art therapy, defined as “a form of psychotherapy that uses art media as its primary mode of communication” (British Association of Art Therapists, 2011) in order to focus on interventions that do not require trained therapists to facilitate them.

The search revealed 21 relevant articles (Appendix D). Critique of the studies was directed by the guidelines on appraising various types of research produced by the

“Critical Appraisal and Skills Programme” (CASP, 2013). Other researchers’ advice was drawn on regarding the consideration of more specific aspects such as triangulation and respondent validation (Golafshani, 2003; Mays & Pope, 2000).

Dementia

Dementia is a cluster of symptoms related to neurological changes that contribute to cell death and impaired functioning of brain cells. Various diseases (such as Alzheimer’s disease and vascular dementia) are associated with such symptoms and these are considered to be “dementias”. The biological and psychological symptoms associated with dementia include: cognitive difficulties (for instance, executive function deficits, memory problems and language difficulties), an overall decline in daily living skills (Knapp & Prince, 2007), changes in behaviour, such as agitation or aggression (e.g. Burns, Jacoby, & Levy, 1990; Fairburn & Hope, 1988), and changes in mood (Ownby, Crocco, Acevedo, John, & Loewenstein, 2006), all of which are associated with reduced perceptions of quality of life (Beard, 2011).

Research in interventions for dementia has been a focus for biomedical disciplines and healthcare professions for more than a century (Innes & Manthorpe, 2012). The relatively recent input (1980s) from social psychology prompted a reorientation to investigate the impact of dementia above and beyond the biological symptoms (Kitwood, 1997; Sabat, 2001).

Models of dementia

Biomedical model. The biological model of dementia included three key characteristics: a pathological, abnormal condition, an aetiology that progressed through stages and a diagnosable condition using biomedical assessments (Lyman, 1989). This pathological nature of dementia has been challenged as it required a definition of “normal ageing” (Downs, 2000). Similarly, the classification of stages of

dementia implied a linear transition from a “normal” cognitive status to severe cognitive impairment (Crisp, Gelder, Rix, Meltzer, & Rowlands, 2000) which was criticised as over-reductionist, since progression and interpretation of symptoms could be highly variable (Downs, 2000).

The biomedical model promoted medical treatment of dementia, with no consideration of psychological or social issues (Bond, 2001). Estes and Binney (1989) suggested that a biomedical conceptualisation promoted negative attitudes towards ageing by reinforcing a view of ageing as inevitably leading to the need for medical care due to physical decline and disease.

Biopsychosocial model. Kitwood (1997) developed an influential model of dementia that underlined the interaction between neurological impairment, psychological factors, and the social context in which the individual exists. The model suggested that people with a dementia experienced psychological responses to their cognitive difficulties differently depending upon their physical and social environment. In adopting a more holistic biopsychosocial understanding of dementia, mediating aspects (e.g. perception of loss, feeling disabled within their physical or social environment) were seen to affect the experience of dementia and the likelihood of developing comorbid mental health difficulties.

Kitwood (1997) theorised that the key psychological needs of people with a dementia comprised occupation in activities of interest, comfort, identity (knowledge of who one is), bonds or attachments to others and inclusion within a group. Clare (2008) therefore proposed a holistic approach to treatment which included medical treatment and physical care at the biological level, therapeutic, supportive interventions that promote adaption and coping with dementia at a psychological level, as well as education and support for carers.

Social-gerontological model. Gerontology specifically considers the place and status of older people in society and complements the biopsychosocial model. The gerontological position described that those with dementia frequently faced the double stigma of ageing and dementia (Benbow & Reynolds, 2000; Katsuno, 2005). Western society's attitudes to ageing were considered negative (e.g. Clare, 2008; McConatha, Schnell, Volkwein, Riley, & Leach, 2003) leading to disempowerment and invalidation, which Kitwood (1997) termed "malignant social psychology" (p. 46). These attitudes diminished the opportunities for individuals with dementia to present themselves in society (Sabat, 2001). The consequence of a malignant social environment was the potential for excess disability, the "gap between actual function and judged potential function" (Brody, Kleban, Lawton, & Silverman, 1971, p. 125). Individuals with dementia may be considered to be more impaired than they actually are, or their intact abilities overlooked, leading to them being engaged in activities inappropriate to their level of functioning (Buettner & Fitzsimmons, 2003).

Influence on Policy and Practice

In the United Kingdom (UK), National Institute for Research and Clinical Excellence (NICE, 2011) guidelines for interventions remain mainly pharmacological and reflect the dominance of biomedical research. However, Kitwood's holistic model of dementia has resulted in an awareness of the significance of person-centred dementia care and became one of the underlying principles of the Department of Health's (DoH) National Service Framework for Older People (DoH, 2001). The more recent, *Living Well with Dementia: A National Dementia Strategy* (DoH, 2009), also prioritised person-centred care and cited among its objectives: raising awareness of inappropriate use of antipsychotic medications, access to personalised social activity, therapeutic and meaningful activity in care homes (including creative arts),

improving the general public's knowledge and understanding, as well as engaging the community.

The biomedical model of dementia has been strengthened with the addition of psycho-social and gerontological understandings. Accordingly a growing interest in associated interventions has developed. Community interventions in particular offer a cost-effective manner by which to support those affected by dementia with the potential to challenge societal attitudes, re-integrate individuals into community settings and celebrate strengths that facilitate personal self-worth and societal value.

The role of Arts and Health

A review completed by the Arts and Health Working Group (DoH, 2007), recommended that arts and health were integral to healthcare provision, and that interventions across the country were reporting benefits to health and wellbeing.

Camic (2008) suggested that the role of psychology within the field included developing community arts and health promotion interventions and participation in research that examines the impact of art engagement on biopsychosocial factors.

The arts may be particularly pertinent in the healthcare and wellbeing of those with dementia as diverse studies have revealed a positive relationship between participation in activities related to the arts and health and wellbeing throughout the ageing processes (Cohen, 2009; Cohen et al., 2006; Fisher & Specht, 1999; Wikström, 2002). The skills required to participate in creative arts have been shown to be relatively preserved for a prolonged period despite a diagnosis of dementia (Baird & Samson, 2009; Halpern et al., 2008) so offers an area in which people have the opportunity to feel empowered and have their psychological needs met (Kitwood, 1997).

A Psychological Perspective

Creativity and ageing. The application of gerontological frameworks to ageing enabled theories, such as “creative ageing” (Cohen et al., 2006), to be considered in relation to dementia. Gerontological research underlined the significance of a “sense of control” (Jermyn, 2004; Rodin, 1986, 1989) and “social engagement” (Bennett, 2002) for older people which was reminiscent of Kitwood’s (1997) model for successfully coping with dementia (Innes & Hatfield, 2001). Cohen argued that art had a “natural appeal” (p. 9) which ensured sustained engagement and the opportunity for feelings of mastery (and thus a sense of control). Sustained engagement ensured social connections could be made within a group and presented opportunities for meaningful social contact.

Creativity’s potential for health promotion in ageing, whilst not specific to dementia, had clear links with a gerontological perspective and in meeting the basic needs of individuals with dementia (Kitwood, 1997). Cohen’s insights into the link between participation in cultural programmes and health promotion offered a useful theoretical model by which to understand how the arts could be beneficial to those with dementia. Harris and Keady (2008) maintained that more positive conceptualisations of dementia were needed to change images of dementia; mastery through participation in the arts could offer a chance to dissolve some of the stigma (Miller and Cohen, 2010).

Community psychology. A complementary position to that of a gerontological perspective would be that of community psychology. Rather than considering only the individual and their immediate interpersonal context, community psychology emphasises a broader level of analysis and intervention. In attempting to define community psychology principles, Nelson and Prilleltensky (2005) highlighted three

levels: personal wellbeing- self-determination, care and compassion, health; relational wellbeing- respect for diversity, participation and collaboration and collective wellbeing- support for community structures. The British Psychological Society paper “psychological health and wellbeing: a new ethos for mental health” (2009) stresses the importance of a public health or social approach to supporting well-being with an “innovative use of psychological expertise” (p14.).

Wellbeing was a key target for intervention by community psychologists and a commonly evaluated target for creative arts interventions. Definitions of wellbeing vary considerably but Swindells et al. (2013) argue that creative arts interventions are compatible with a eudaimonic framework of wellbeing. Eudaimonic wellbeing is commonly characterised in terms of “the realisation of inner potential through meaningful relationships and purposeful activity” (p. 2). Eudaimonic, as opposed to a hedonic model (focussing more on happiness/ pleasure) is considered less transient and more dynamic (Ryan & Deci, 2000). However, a significant criticism of eudaimonic constructs is that there remains no clear consensus as to appropriate objects/units of measurement (Diener, Kashdan & King, 2009). Creative arts may offer activities which promote eudaimonic wellbeing and aligns with Kitwood’s model (1997) to meet the psychological needs of those with dementia.

Community psychology offers a holistic approach to improving wellbeing and whilst applicable to all areas of work may be particularly helpful in thinking about oppressed or disadvantaged groups, of which those affected by dementia are one (Clare, 2008; McConatha et al., 2003). A focus on the person-environment interaction, social inclusion, social justice and empowerment enables a wider perspective on the potential of creative arts approaches, particularly in community settings.

Reviewing the Evidence

Music engagement

While language and cognitive functions deteriorate during the course of dementia, many musical abilities, such as general musical and rhythmic skills have appeared to be preserved (Aldridge, 2000; Baird & Samson, 2009). Music has been shown to positively impact mood (Kumar et al., 1999), decrease stress hormones such as cortisol (Leari et al., 2007) and improve coping with stress (Vink, 2012). In a review, Clément, Tonini, Schiaratura and Samson (2012) found that music engagement had specific positive effects relevant to dementia such as improvement in language abilities (Thompson, Moulin, Hayre, & Jones, 2005), autobiographical memory (Irish et al., 2006) and verbal memory (Haslam & Cook, 2002). This evidence related to music “therapy,” but further research has demonstrated similar benefits without a reliance on professional therapists as discussed next.

Cooke and colleagues reported two studies with 47 individuals with early to mid-stage dementia (or symptoms consistent with a diagnosis) that investigated the effect of a live music group programme on agitation and anxiety, and quality of life and depression (Cooke, Moyle, Shum, Harrison, & Murfield, 2010a, 2010b). Both studies involved song-singing and listening, three times a week for eight weeks. A randomised cross-over design was adopted, with a music group and a reading “control” group with a five week gap between cross-over to minimise carryover effects. Researchers blind to the treatment group interviewed participants using standardised measures (see Appendix D) that have been shown to be valid with this population (Sansoni et al. 2007) to assess the effect of the treatment on the variables mentioned above.

The results of the two studies suggested no overall effect of the programme on ameliorating agitation or anxiety, but unexpectedly, participation in both groups was related to a significant increase in the frequency of verbal aggression over the course of the study. The increase in verbal aggression may at best indicate positive benefits to expressive communication (as the authors concluded) but at worst reflect negative reactions to the intervention and further research must be mindful of the potential for harm. However, of those who attended over 50 per cent of the sessions, there were improvements in self-esteem and a reduction in depressive symptoms (in both conditions). The lack of significant results may be explained in part by low levels of aggression and anxiety from the outset of this study.

This study did not use a “usual treatment” control group which would have aided interpretation of the findings by contextualising results in regard to an average pattern of change. It was significant that both music and reading activities were shown to improve self-esteem and depression in those with dementia as well as stimulating verbalisations. This suggested that factors beyond the musical component were important in the changes. It should be noted that this study only included individuals with a dementia who demonstrated aggressive behaviours and this may represent a specific subgroup and limit the generalisability of the findings.

Camic, Williams and Meeten (2011), using standardised and well-accepted measures, assessed mood, quality of life, behavioural and psychological problems, activities of daily living and the cognitive status of ten people with dementia (or mild cognitive impairment) and their family carers who participated in a “Singing Together Group” for ten weeks. The results showed that those with dementia were deteriorating slowly over the course of the study on all measures except quality of life, where they and their carers’ scores remained relatively stable. Although some cognitive decline

was noted, participants reported the group as “enjoyable”, “interesting” and “supportive” while citing no negative impact. The deteriorative nature of dementia presents a particular challenge to researchers attempting to demonstrate intervention outcomes and as in the previous study a control group would have aided interpretation of the results.

The authors used Nolan’s “Senses Framework” (2002) which is based upon a systemic relationship model of good dementia care to guide exploration of qualitative feedback captured via interviews. The importance of a sense of security, of feeling “valued” and “belonging” were highlighted and demonstrated the strength of the qualitative approach in capturing psychological outcomes that were not evident in the quantitative analysis. The application of Nolan’s framework guided a theoretical understanding of the intervention and thus contributed something new to the area and the ten week follow-up demonstrated consideration of the potential for longer-term impact which previous studies had dismissed.

The small sample size and heterogeneous group (diagnoses of participants were reported but not compared) were a shortcoming of the study. Whilst the study adopted commonly used standardised measures for the quantitative analysis allowing comparison with other research in the area, further research is needed to elucidate the insignificant quantitative results alongside the positive qualitative findings. As a pilot study a key aim should be to initiate novel theoretical links (Mays & Pope, 2000) and this was the main contribution of this study which highlighted the possible application of Nolan’s framework (2002) to understand the impact of the intervention.

Van der Vleuten, Visser and Meeuwesen (2012) assessed quality of life during a live music intervention. The authors conceptualised quality of life as consisting of two key domains: participation (dimensions included: human contact, care relationship and

communication) and mental wellbeing (positive affect, negative affect and communication). A sample of 45 people with dementia completed the study and the authors developed an observational rating scale (un-validated but with good internal consistency) that was completed by caregivers and family. No data on inter-rater reliability were given. Positive effects on care relationships, and the expression of positive and negative emotions were reported. Statistically significant results were achieved for the total group, but separate analysis of data relating to those with severe dementia ($n = 16$) revealed that only the subscale of positive affect showed significant improvement. This finding may indicate that interventions have different effects depending upon participants' stage of dementia; the researchers concluded this may be due to lower cognitive abilities.

Both Cooke and colleagues (2010a, 2010b) and Van der Vleuten et al. (2012) demonstrated improved quality of life according to their measurement of the concept however the lack of consistency in measures weakens the ability of the literature to demonstrate a conclusive argument (Golafshani, 2003). Camic et al. (2011) used the same carer rated, standardised and validated measure as Cooke et al. (2010b) (Dementia Quality of Life [Brod, Stewart, Sands, & Walton, 1999]), but the reported results varied. This may reflect inconsistencies in reporting, or the effect of different interventions (live group music/reading vs. group singing); unfortunately the numerous discrepancies (diagnoses, duration and frequency of intervention) limit the ability to directly compare the results.

A further study investigated the effects of musical interventions on various emotional measures for five individuals with Alzheimer's disease (Clément et al., 2012). The study was designed as a randomised trial which included matched participants within a French residential home. A musical intervention ($n = 5$) was

compared to a cooking control intervention ($n = 6$). The intervention lasted four weeks (two one-hour sessions per week) and effects were assessed up to four weeks post-intervention. Positive and negative expressions of emotion in facial expressions, discourse content, and overall mood of the patients were measured. The music was reported to be more effective than cooking in improving the emotional state of participants. Music had statistically significant positive effects shortly after the intervention on all three emotional indices (facial expression, discourse content and overall mood). This effect remained significant up to two weeks after the end of the intervention on discourse valence and up to four weeks on mood. No overall significant benefit of cooking interventions on emotional state was found.

Like much of the research regarding musical interventions the study lacked a theoretical framework and the participants were at no point invited to offer qualitative feedback (or at least this was not reported) which would have strengthened the validity of the findings (Mays & Pope, 2000). Arguably a “usual treatment” control group would have been preferable to the cooking control. Despite these limitations, the study quantitatively measured and demonstrated benefits of musical engagement and showed these to be maintained up to four weeks post-intervention, thus adding something new to the literature.

Sarkamo et al. (2012) completed the largest scale study to date, involving 89 individuals considered to have mild to moderate dementia and their carers (59 family carers and 30 nurses) who were randomly assigned to a singing group, a music listening group or a usual care control group. The control group were given instructions to continue with their normal everyday activities. The cognitive abilities, mood, and quality of life of those with dementia and the psychological wellbeing of

their family carer were assessed at three time points: baseline, immediately after the intervention and six months post-intervention using common standardised measures.

Numerous analyses of variance were completed to measure change during and after the intervention and demonstrated significant positive short-term cognitive effects: listening to music was associated with improvement on overall cognitive abilities, executive functioning and attention; whilst singing was associated with short-term and working memory improvements. Both music groups demonstrated a highly significant short-term positive effect on mood although the trend failed to reach significance long-term. This was the first intervention to report a long-term improvement on quality of life, although this was only in the music listening group. Singing was found to reduce the psychological burden experienced by the family carers six months after the intervention.

Sarkamo et al. (2012) reported robust quantitative evidence of numerous cognitive and mood benefits related to the musical interventions for those with dementia as well as reduced burden in the singing group reported by carers. The intervention included homework and ongoing use of the intervention beyond the end of the set groups (ten week duration) as integral to the study and this appeared to have enabled long-term (6-months post-intervention) results. One explanation for the music listening intervention having resulted in longer-term effects on quality of life was that carers continued to implement the intervention more frequently and for longer durations than the singing group. This highlighted the importance that researchers consider the long-term feasibility of interventions for carers. The studies' strength was the randomised-controlled design and a larger sample size than other research in the area, however the duration of the group was relatively short and as, with some of the earlier studies, the type of dementia was not taken into account as a variable.

Creative expression (story-telling and drama)

It has been reported that storytelling and reminiscence activities have numerous positive psychological health benefits for older adults in general (McKee et al., 2005), including increased wellbeing (Snow, Damico, & Tanguay, 2003), increased communication/interaction (Byres, 1995; Thorgrimsen, Schweitzer & Orrell, 2002) and improved relationships with professional caregivers (Basting, 2001 in Beard, 2012). Some studies emphasise the potential for relational, or co-constructed, encounters to help express inner worlds and validate experiences (Pendzik, 2006 in Beard, 2012). Drama has been shown to empower people with dementia by promoting activity through the “quality moments” resulting from activities such as mime, storytelling, role-play, object work, movement and music, games and play (Batson, 1998 in Beard, 2012).

The trademarked “TimeSlips” programme was developed in 1996 in the United States by Basting and remains one of the most well-known story-telling programmes. TimeSlips encourages those with dementia to express themselves through group-generated stories which stem from the imagination rather than on factual reminiscence (TimeSlips, 2014). A study using the TimeSlips storytelling programme (Fritsch et al., 2009) compared ten nursing homes randomly selected for TimeSlips training and implementation, with ten control nursing homes (taken as treatment as usual). Time sampling was used over the ten-week intervention to observe resident engagement and affect across different types of activities, rather than specifically during TimeSlips sessions.

Researchers found significant improvement in residents’ general alertness, engagement, quantity and quality of staff-initiated interactions, and staff attitudes toward the residents in treatment homes compared to the control homes. Eight trained

research assistants completed the observations and in general inter-rater reliability was shown to be good, however reported Kappa values of between .25 and .92 demonstrated significant variation in reliability across codes. The study design was unusual and arguably offered less robust evidence than a more traditional pre/post design making use of standardised quantitative measures would have. Staff in the TimeSlips-trained facilities reported more frequent staff-resident interactions and a more positive view of their patients compared to the staff in the control facilities.

Fritsch et al. (2009) provided evidence of benefits for those with dementia and demonstrated these to be apparent outside the intervention group itself (i.e. during other activities). This was a novel finding but did limit the specificity of the findings since it was unclear that all residents included in the time sampling would actually have attended the story-telling group. A further problem with reporting changes observed outside the intervention was the difficulty demonstrating a direct link between the story-telling and resident outcomes; it may have been for example, that the staff training promoted the change rather than being intervention specific. The results were unique in considering the impact on staff and consideration of promoting “grassroots culture change” (p. 119) in how staff interacted with residents.

A significant finding of this study was that alongside the positive improvements on various measures, observations of those in the intervention group revealed significantly more sadness, anger, behaviour considered to be challenging and anxiety than those at control residences. This difference was ascribed to the general increased awareness but raises ethical issues as to whether such an intervention offers sufficient positive outcomes to counteract possible negative outcomes.

A further study used individual participant level measures (Phillips, Reid-Arndt, & Pak, 2010) to evaluate the effect of TimeSlips on communication, neuropsychiatric

symptoms and the quality of life of 56 (mainly women) long-term care residents with dementia. The programme was delivered for a period of one hour on six consecutive weeks; groups ranged from 6-12 participants in three different facilities. The control group participated in another activity of their choice. A range of validated rating scales for mental health, cognitive function and quality of life were repeated over the course of the intervention (see Appendix D). The evaluation findings indicated that participation in TimeSlips was associated with statistically significant increased expressions of pleasure and better communication, compared with the control group. The pleasure effect persisted one week post-intervention (although had declined three weeks later). No intervention effect was found for depression or on behavioural scales.

The small size of the sample makes drawing wider conclusions from this study difficult (CASP, 2013) although alongside Fritsch et al. (2009) the findings clearly indicate beneficial outcomes for those with dementia. One of TimeSlips' benefits was its ability to be administered by trained nursing home staff and the researchers concluded that the benefits warranted the cost of training the staff (Phillips et al., 2010). TimeSlips was aimed at individuals with more advanced dementia (middle to late-stage) and so introduces evidence of benefits at a later stage than some of the previously reported research. The measures used reflected a broad range of potential outcomes which reflects the exploratory state of the research in this area.

Lepp, Ringsberg, Holm and Sellersjo (2003) investigated the experience of professional caregivers in a drama and story-telling programme for people with dementia and their professional carers (the intervention also included singing and dance). A phenomenographic approach was adopted to understand the experience of participating in the arts project (Marton, 1986). Twelve participants with moderate to severe dementia and their seven carers participated in weekly ninety minute sessions

for two months, with a focus group interview being conducted with the caregivers one month later.

A thematic analysis of the interview data resulted in two themes: “interaction” and “professional growth”. Carers described how fellowship developed between participants enabling them to talk about their emotions. People with dementia communicated with each other and the leaders, and the programme was reported to aid memory by making associations with situations experienced earlier in their lives. Carers were clearly affected by the experience, seeing those they cared for differently and demonstrating a plan to continue to implement ideas from the intervention. The credibility of the themes was apparent by the examples the authors gave (Mays & Pope, 2000) in this research and demonstrated an insightful qualitative appraisal of the intervention. However, further explanation of the analysis of data would have aided interpretation of the validity of the results (CASP, 2013). In addition, it was unfortunate that evidence drew on a focus group with carers from the whole project, including those who participated in singing and dance, limiting the ability to compare the various interventions involved in the study.

Holm, Lepp and Ringsberg (2005) later reported on the storytelling intervention as an independent study. The study used stories designed around Erikson’s (1982) eight development phases in order to create the opportunity to reflect upon and create reality as described by Goodwin (2001 in Holm, Lepp & Ringsberg, 2005). The data analysed were the facilitator’s contemporaneous diary entries using a phenomenographic approach. The study concluded that storytelling triggered emotional and verbal reactions considered to be therapeutic. The lack of triangulation, and respondent validation limited the ability to appraise these findings as valid (Mays & Pope, 2000). The facilitator was a registered nurse trained as a symbol

pedagogue/teacher and the amount of reflexivity in the notes she kept was impossible to determine since no examples were given. The study used a more prescriptive approach to storytelling compared to an approach such as TimeSlips which promoted greater creativity by participants. The dramatically different designs and analyses inhibit comparison but research which compares a productive vs. recipient storytelling intervention would help to guide further exploratory research.

Walter et al. (2007) adopted humorous stories and anecdotes to stimulate conversation with ten people with Alzheimer's (ten in the intervention, ten in a "usual pharmacotherapy treatment condition"). This study described "humour therapy" but was included since the content of sessions was similar to those of story-telling interventions but with an increased focus on humour. Quality of life was measured before and after the intervention but no change was found for participants. This study relied on self-reported quality of life by participants with a dementia using a tool (Anamnestic comparative self-assessment [Bernheim & Byse, 1983]) without reported reliability or validity with this population (i.e. individuals with a dementia). Some evidence suggests self-report measures to be appropriate for individuals experiencing dementia (Fuh & Wang, 2006) however, most of the studies reported here chose to use carers' feedback. It may be that the self-reported quality of life tool was problematic or that this particular approach to storytelling did not provide therapeutic benefit. This was the first known empirical study in to the use of humour with people with dementia which highlights a new area for possible interventions, but the non-specific measure used and limited sample size inhibit the value of the study.

Later research that included humour was Stevens (2011) qualitative study where he described and investigated the effect of a programme of stand-up comedy and improvisation workshops for people with early stage dementia. Interviews from

participants (n = 6), their carers (n = 6), and the comedian facilitator, field notes and observational notes of the participants kept by the researcher were analysed using constant comparative analysis to develop themes. The findings indicated that dementia did not prevent participants from laughing appropriately or successfully creating and performing comedy. Carers reported improvements in the memory of those they cared for as well as sociability, communication and self-esteem. The triangulation of data and examples given gave a good summary of the study findings but there was a lack of clarity regarding the nuances of how the data was analysed and little evidence of quality assurance. This was a small pilot study, which may best be considered as an exploration of whether humour can be integrated in dementia care rather than a study with definitive outcomes.

Visual arts (viewing and making)

Aesthetic response appears to be preserved for some time in dementia (Halpern et al., 2008; Stewart, 2004) making visual art appreciation and art making a further area for intervention development. In a pilot programme Rentz (2002) evaluated an art intervention for individuals in the early to middle stages of dementia entitled *Memories in the Making*. The sessions were facilitated by artists who encouraged participants to expression using a variety of artistic materials. Ratings completed by staff observers demonstrated that participants were able to sustain attention and engagement as well as experiencing positive social interaction. Qualitative recordings of participants spontaneous comments demonstrated that participants valued the experience, one participant stated that “in here I feel like a person again” (p. 178). However, the study had considerable methodological limitations with the use of un-validated measures that were not clearly defined, raters who were involved in the study potentially biasing the findings and a lack of control group.

Kinney and Rentz (2005) later used the Memories in the Making programme in comparison with a structured activity (such as word games) and made some improvements to the rating measure which was reported to have adequate inter-rater reliability (Kappa coefficient 0.65). The authors reported significantly higher levels of pleasure, normalcy, sustained attention, interest and self-esteem during the programme (as measured by their tool) compared with the other activity. The two studies provided evidence for art viewing improving quality of life which in this case was measured based on Lawton's (1991) conception of "wellbeing". The latter study improved upon the methodology of the former (including a control group, improving the reliability of the rating tool) but the art activity always preceded the control activity thus neglecting the influence of participant fatigue. The studies offered a useful platform from which to consider how such interventions should be evaluated but the unique measure limited comparison with other studies and further evidence would be required to justify the use of a new measure over existing alternatives used in aforementioned studies.

Another well-known American programme, the Meet me at MoMA project (Mittelman & Epstein, 2009; Rosenberg, 2009) was the first reported art gallery-based programme. This added an important new dimension to the research area as the physical environment could be seen as integral to the intervention. The study took place at New York's Museum of Modern Art (MoMA) in 2006. Here, 37 individuals with dementia and their carers attended a once monthly, 90-minute gallery tour, which included discussion and interpretation of visual art. Self-rating scales (validated and used in other studies of this cohort) were filled out by participants and their carers, including measures of social support, mood, self-esteem and quality of life, before and after each session.

The data in this study suggested that individuals affected by dementia and their family carers expressed a significantly more positive mood and improved self-esteem following the session compared to prior to the session. Participants were reported to have valued learning new things and sharing a new experience with loved ones. Mittelman and Epstein (2009, p. 104) stated that the programme provided an “increase in intellectual stimulation, social interaction and improved mood within an accepting environment” for the person with dementia. The carers reported valuing the opportunity to share a pleasant and stimulating experience with the person they cared for. Inclusion of carers demonstrated the application of art viewing interventions to include not only those suffering with dementia but their carers too. The statistically significant results highlighted the potential and value of using empirical measures to produce robust empirical findings with the additional benefit of qualitative data enabling a more in depth description of the observed and reported benefits (Golafshani, 2003). Like much of the research, the study did not include a control group and the qualitative findings should be interpreted cautiously given the potential for demand characteristics or the “good-subject effect” (Nichols & Maner, 2008).

Other studies have been inspired by the work of the MOMA project, although have failed to follow the empirical standard and depth of reporting. Colucci, Musella, Finizio, Maggio and Fasanaro (2010) built on the work of Musella et al. (2009) to explore the effectiveness of an art project on the psychological health of people living with dementia in Italy. In this study the researchers introduced a comparison group who were engaged in “computer-based cognitive stimulation.” It was reported that behaviour considered challenging by staff (i.e. agitated or aggressive) decreased after the art intervention and conversely increased after the cognitive stimulation. The carer’s stress was also reported to decrease after the intervention and increase after the

alternative activity. In addition, there was a high abandoning rate in the computer activity which may suggest the tasks were too difficult but the authors do not explore the finding. Although empirical measures were used, they were inadequately reported prohibiting replication, assessment of the validity of measures or intervention as a whole (CASP, 2014). In addition, this study took place mainly in individual sessions in residential settings with seemingly only one group session occurring, therefore failing to build on the previous evidence regarding the significance of the gallery setting.

Other researchers have more successfully applied models similar to the MoMA project (MacPherson, Bird, Anderson, Davis, & Blair 2009). MacPherson and colleagues developed a six-week programme at the National Gallery of Australia. Individuals diagnosed with a dementia and their professional carers attended the gallery to view and discuss artworks. Sessions were videoed and analysed using time-sampling methods where a range of behaviours provided indicators of affect. Focus groups following the programme indicated that participants felt that the programme had been enjoyable, facilitated the discovery of residual abilities, sparked new interest in art and increased social contact. No long-lasting changes were reported. The art educators reported that participants' memory was stimulated within the group and that they appeared enthusiastic and more confident in the gallery compared to a different context. Whilst not able to demonstrate long-term impact post-intervention, the authors cited the importance of social, cognitive and emotional benefits even if they occur "only in the moment" (MacPherson et al., 2009, p. 751).

Like all of the reported studies there is difficulty in identifying specifically what components of the programme were beneficial. Whilst qualitative data imply enhanced positive affect and social engagement, a lack of baseline and control group

makes these assertions impossible to demonstrate empirically. The qualitative data reported were exhaustive although the methodology for analysis was not clearly defined. The strength of this research was the extension from one-off sessions (in previous studies) to a programme of six sessions. Further quantitative data may have enabled a more objective view of benefits and the potential to assess longer-term impact of the intervention.

Ullán et al. (2011) conducted an exploratory study which involved an artistic educational programme (viewing art) in addition to making art based on photographic cyanotype techniques. The intervention took place with individuals in the early stages of dementia in care facilities in Spain. Data were collected by participant observation, assessment by the educators, a focus group with those with dementia and a focus group with professional carers providing good-quality triangulated qualitative data (Golafshani, 2003). Results demonstrated interest and commitment to the activity, and interest in learning new things: “I didn’t think I could learn things like this at this point” (p.12). Participants reported satisfaction in the creative process and a positive effect on communication and social relations was evidenced. The study was also reported to reinforce feelings of capacity: “see how well it turned out” (p.13) and transmitted a positive image of individuals with dementia: “I made it!” (p. 16). Quantitative measures used to record observational data demonstrated attention throughout (81%) and enjoyment (67%).

Ullán and colleagues (2011) chose to base their study in a day centre setting, did not invite carers and chose a very specific type of art making, photographic cyanotype. Whilst the study was framed as an exploratory study it did not build on nor develop the findings of previous research, rather introduced a slightly different artistic focus without the benefits of a gallery setting or the inclusion of carers. The triangulation of

the data gathered offers a helpful qualitative design, which enabled a more complete view of the impact of such an intervention. However the reporting of the analysis fails to explain the way in which themes were established. In summary, the study demonstrated a good example of triangulated data collection (Golafshani, 2003) that offered a multiple perspective account (participants, carers and facilitators) but the qualitative results echoed those of previous studies- reinforcing the evidence-base but adding little new understanding of the impact of such an intervention.

Two further studies have altered the MoMA model to include an art-making component (Camic, Tischler & Pearman, 2014; Eekelaar, Camic, & Springham, 2012). The first intervention primarily explored the impact on verbal fluency and episodic memory for people with mild to moderate dementia over three sessions. The results suggested that episodic memory could be enhanced through aesthetic responses to visual art, while effects on verbal fluency were more ambiguous but indicated some improvement. Thematic analysis of post-intervention interviews highlighted social benefits of being with the group, personal effects of “becoming their old selves” (p. 7) and the value of sharing an experience between the participant with dementia and the carer. This was a small study of six dyads (an individual with dementia and carer) and just three pairs attended every session, so the results must be interpreted with caution, but like other studies reported individual and social benefits of the intervention.

Camic et al. (2014) completed a mixed-methods study that built on the work of Eekelaar et al. (2012) but was more intensive and took place over a course of eight weeks. The study compared an art intervention across two very different art galleries, one housing mostly 17th/18th century European art and the other contemporary international art. The intervention sought to explore the effect on carer burden, the cared for–carer relationship, social and cognitive domains, social inclusion and quality

of life of those with dementia adopting common and validated measures to do so. The varying contexts of the galleries and arts added an exploratory dimension to assess whether the variable would impact upon findings and guide future research.

Standardised measures did not demonstrate significant differences to carer burden, quality of life or daily living activities nor was any difference between the gallery contexts found. The authors suggested that lack of significant quantitative findings may have been due to an insufficient sample size (12 people with dementia, 12 carers) or lack of specificity of the standardised measures. Thematic analysis, though, drew out three key themes; social impact; cognitive capacities and the art gallery setting. The social impact captured the significance of sharing an experience with others as well as enhancing the caring relationship between carers and the person they cared for. Cognitive capacities were mentioned by the interviewees who reported cognitive engagement, new learning and for some, memory enhancement. The gallery setting enabled people to feel empowered, engaged with the art work and they valued both the viewing and making aspects. Carers reported high levels of enthusiasm and interest despite ratings of carer burden failing to show significant reduction. This would suggest that as with some of the other studies, quantitative measures have failed to capture changes that the participants or researchers have noticed.

The qualitative analysis and findings were clearly reported (although with no quantitative measure of reliability) and reflexivity was apparent in the process. One drawback was that in attempting to improve validity the study included only themes relevant to all respondents, which diminishes the significance of dissonant findings. The study offered a robust measure of pre/post scores on various measures and introduced an interesting variable relating to the type of art within the intervention, but

as with most previous studies offered no theoretical conceptualisation of the processes at play.

Discussion

Music engagement

Music interventions were shown to improve the quality of life of individuals with dementia and carers (Camic et al., 2011; Clément et al., 2012; Cooke et al., 2010b), as well as decrease negative and increase positive emotions (Clément et al., 2012; Van der Vleuten et al., 2012). Evidence that music performed only as well as a reading intervention (Cooke et al., 2010a, 2010b) seemingly undermined any unique benefits of music, although where cooking was introduced as a control, music was shown to be superior (Clément et al., 2012).

The exploratory nature (due to this being an early stage in the research area) was evident in the disparate measures adopted, the small sample sizes and the inconsistent findings across studies. However, the most recent study (Sarkamo et al., 2012) marked a progression in the research area toward larger scale research with clear aims, the use of standardised measures and a robust experimental design. Sarkamo and colleagues were able to demonstrate clear positive effects on mood of singing and listening to music, as well as a reduction in carers' sense of burden.

Future research would need to provide further evidence of a similar quality to that of the most recent study to promote the use of music as beneficial for individuals with a dementia and their carers. The different forms of music intervention, including singing, music listening or engaging with live music also require further comparison to guide the development of interventions. Theoretical conceptualisations, as Camic et al. (2011) included, would also be required to develop a clearer understanding of how music interventions affect participants.

Creative expression

The study of drama and storytelling appeared to be a more recently developed intervention with a smaller evidence-base compared to music and art (at least within peer-reviewed journals). Studies were largely exploratory, with small sample sizes and disparate measures. The qualitative study designs (Lepp, Ringsberg, Holm & Sellersjo, 2003; Holm, Lepp & Ringsberg, 2005; Stevens, 2011) contributed to tentative hypotheses regarding how such interventions affected participants, but the lack of quality assurance and clarity in analysis made their validity questionable. It was the widespread TimeSlips programme that provided the best evidence of psychological benefits including improved communication, client-staff interactions and staff attitudes toward dementia sufferers (Fritsch et al., 2009; TimeSlips, 2014).

The inclusion of humour in storytelling was a novel area, in which the two reported studies showed that individuals retained the ability to laugh and engage in the interventions but were less clear in demonstrating psychological benefit. Stevens (2011) demonstrated a triangulated and robust qualitative study in which observational data, carer views and the perspective of the facilitator were captured. The evidence base in this area would benefit from further good-quality mixed-methodology designs. Comparison between the use of storytelling with or without humour, the addition of stand-up comedy or drama will allow a better understanding of the importance of the various aspects of interventions.

Visual arts

The evidence base for visual arts demonstrated improvement in various measures of quality of life (Camic et al., 2014; Kinney & Rentz; 2005; MacPherson et al., 2009; Rentz, 2002), interaction (Ullán et al., 2011), mood (Mittelman & Epstein, 2009; Rosenberg, 2009), aspects of cognitive symptoms (Eeklaar et al., 2012) and on

some behavioural measures (Colucci, 2010). Many of the studies included qualitative measures that captured difficult to quantify effects such as changes in how carers view the person they care for, individuals rediscovering abilities, “becoming their old selves” (p. 7, Eekelaar et al., 2012) and enjoyment. These benefits were on top of the indirect effects of community-based interventions which promoted a different way of viewing dementia, for example seeing retained creative abilities rather than disabilities and the community education inherent in conducting groups in communal places during normal opening times. Further research examining different variables (setting, participants, type of carer, type of intervention) was needed, as well as more experimental designs. Although the qualitative evidence was compelling, larger studies that make use of control groups would be more likely to demonstrate changes on quantitative measures which would be important in securing funding for further research.

General discussion

The review of the literature pertaining to arts-based activities and dementia highlighted the scope of activities taking place. In this review, similarities across creative art approaches were apparent but the unique elements and the modes of change needed further delineation. The quality of research methods varied and a lack of consistency across aims, measures and findings made direct comparison difficult. This may have been due to a lack of theoretical conceptualisation that underpins the area, since most studies evaluated various art programmes with no clear rationale for projected findings. Indeed, whilst some studies included carers and took place in community settings with clear applicability to a community psychology perspective, others focussed on more individualistic goals around cognition or individual conceptions of wellbeing. Applying creative ageing research or community

psychology concepts would help to establish theoretical models allowing the area to develop working understandings of the processes at play.

In order to convince commissioning bodies of efficacy, randomised controlled trials with active controls as well as usual care groups are needed. However, quantitative studies struggled to encapsulate the benefits of artistic endeavour. Well thought out qualitative studies could offer convincing evidence and a platform for developing theoretical conceptualisations (e.g. using a grounded theory approach). Longitudinal studies were absent and these would be important to demonstrate potential longer-term benefit.

Other variables need to be explored such as the similarities or differences between types of art intervention, venues of interventions, cultural differences (with studies occurring worldwide), facilitators and types and stage of dementia. Benefits for family carers compared to professional or voluntary carers were largely unexplored. Studies should also take more consideration of the context in which interventions take place. These interventions could play an important part in reinforcing a benign and non-stigmatising social environment, which could positively affect psychosocial functioning (Kitwood, 1997).

This area of research has the potential to be questioned in regard to age-appropriateness which raises ethical dilemmas when working with individuals who may lack capacity to consent to such interventions. All of the studies included sought ethical approval from relevant professional bodies and most sought consent of participants, if not, carers/ family members were approached where a lack of capacity for informed consent was established. Whilst it is unlikely that participation in art viewing, for example, would be questioned in regard to its age appropriateness, it is possible that some interventions such as creating a story, or the use of humour, might

be thought to be age inappropriate. None of the studies reported any dissatisfaction from participants/carers although it is unclear whether individuals' views were solicited. In research where the participants may be vulnerable to social stigma or infantilisation it is especially important to consider the appropriateness of interventions. Kitwoods' (1997) concept of "malignant social psychology" should be considered alongside such interventions to pay attention to how they might promote or negate this issue. Further research should ensure these ethical dilemmas are named and considered even where there is no clear resolution.

Implications for clinical psychology research and practice

Creative arts programmes appear to result in numerous positive effects and have the potential to become a part of community-based, non-clinical dementia care policy across different countries (e.g. Living well with dementia, DoH (2009)). Cost benefits (Cohen, 2009) of one art intervention with older adults in the United States (not experiencing dementia) demonstrated a saving of \$172.91 per year for each participant compared to control group spending on medication and doctor visits. It seems safe to assume the saving would be more for someone with dementia but thus far no research has evaluated this. Beyond ethical considerations, the fiscal benefit of such interventions would be primary to secure funding for the future.

The field of the arts represents an innovative area and unique opportunity for clinical psychologists to broaden the spectrum of evidence-based interventions on offer to those with dementia and carers. Psychologists are well placed to evaluate the evidence base as well as developing theoretical conceptualisations of the effect of arts interventions. Involvement at this early stage of research will enable clinical psychologists to undertake interdisciplinary work and ensure future consultative roles in the development of interventions. These interventions show potential in challenging

current practice and developing programmes which meet the biopsychosocial needs of those affected by dementia and carers, with potential further benefit at a community level.

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SECTION B

Theorising how Art Gallery Interventions Impact People with Dementia and their Carers.

WORD COUNT: 7,767(1122)

For Submission to: Dementia

Abstract

Dementia refers to a variety of diseases that are characterised by cognitive difficulties and an overall decline in daily living skills. Psychologically-informed arts and health interventions may be particularly beneficial ways of improving the lives of people with a dementia and their carers. This study investigated arts-based interventions at two, London and Nottingham, art galleries where 12 people with mild to moderate dementia and their 12 carers were engaged in art-viewing and art-making. Post-intervention interviews with participants (n = 24) and facilitators (n = 4), field notes and extensive written communication between the facilitators and research team were analysed using a grounded theory approach to establish how the intervention impacted upon those involved. Three aspects: a valued place, intellectual stimulation and social relationships facilitated a positive affect in participants and there was evidence of a different perception of those with dementia by carers and facilitators. The resulting theory has potential implications for the use of arts within health and social care by applied psychologists, health, social care and museum professionals, as well as community services.

Keywords: dementia care, art galleries and museums, creativity, carers.

Introduction

Dementia

Dementia has become a key health and social care issue for the 21st century as a result of increasing life expectancies (Alzheimer's Society, 2013; Wimo, Winblad, Aguero-Torres, & von Strauss, 2003). It is classified as a cluster of symptoms related to neurological changes that contribute to cell death and impaired functioning of brain cells. The biological and psychological symptoms associated with dementia include: cognitive difficulties (e.g. executive function deficits, memory problems, language difficulties and visuospatial issues), and an overall decline in daily living skills (Knapp & Prince, 2007). In addition to cognitive symptoms, those with dementia may experience changes in behaviour, such as agitation or aggression (e.g. Burns, Jacoby, & Levy, 1990; Fairburn & Hope, 1988), and mood (e.g. Eekelaar, Camic & Springham, 2012; Ownby, Crocco, Acevedo, John, & Loewenstein, 2006). There is no cure for dementia and medical treatments at best delay progression (Raina et al., 2008; Sink, Holden & Yaffe, 2005). Thus, an important aspect of care is improving the quality of life of those with the condition and this means attending to social and psychological wellbeing as well as medical symptoms (Beard, 2012; Cohen, 2000; Douglas, James & Ballard, 2004; Salisbury, Algar, & Windle, 2011).

In addition to a more holistic approach to the care of dementia, the needs of carers have been increasingly recognised (Crombie, Irvine, Elliot, & Wallace, 2007). A recent UK government policy document, *Living Well with Dementia* (Department of Health (DoH), 2009), acknowledged that "family carers are the most important resource available for people with dementia" (p. 12) and estimated that "they provide over £6 billion a year of unpaid care" (p. 50). Evidence shows that being a family caregiver of someone with dementia is associated with higher levels of anxiety,

depression and isolation (Jones & Peters, 1992) compared to the general population. Thus, carers need to be supported due to their role as irreplaceable resources to those with dementia as well as their own increased risk of psychological distress.

Living Well with Dementia (DoH, 2009) also responded to the need to reduce stigma associated with dementia and increase community awareness. These far-reaching objectives highlighted the importance of working with individuals with dementia and their carers as well as the general community. The policy suggested that to meet these aims “requires us to transcend existing boundaries between health and social care and the third sector, between service providers and people with dementia and their carers” (p.7). Community psychology studies have for some time advocated that therapeutic activity (distinct from therapy) should take place in community contexts, rather than being limited to service settings (Alcock, Camic, & Barker, 2011; Levine, Perkins, & Perkins, 2005). There is growing evidence that community-based interventions have the capacity to reduce social exclusion and benefit health (Camic & Chatterjee, 2013; Mittelman & Epstein, 2012).

Community-based art interventions

Art galleries have proven to be popular settings for community-based interventions for individuals with various mental health issues (Camic & Chatterjee, 2013; Roberts, Camic, & Springham, 2011; Shaer et al, 2008). Art may be a particularly useful form of intervention for those with dementia since aesthetic responses appear to be preserved for some time (Halpern et al., 2008; Stewart, 2004), thus visual art appreciation and making offers an area where dementia need not restrict an individual (Cummings et al. 2008). Participation in creative arts has been shown to enhance the psychological wellbeing of people with a diagnosis of dementia and their carers (Clift et al., 2009). Benefits have been demonstrated in social and

psychological wellbeing (Kinney & Rentz, 2005; Rentz, 2002), increased enthusiasm, confidence, enjoyment, and social contact (MacPherson, Bird, Anderson, Davis, & Blair, 2009), and decreased depression (Musella et al., 2009).

Whilst such interventions demonstrate some of the benefits of creative arts participation, there is further evidence to show that art projects can promote a sense of community and challenge stigma (Howells & Zelnik, 2009) and this may require re-considering the use of traditional care settings. Interventions based around creative arts offer the opportunity to provide support to those with a dementia in non-stigmatising community settings (Camic & Chatterjee, 2013; Wali, Severson, & Longoni, 2002) and thus work at an individual, carer and community level. However, only a small number of studies have applied visual arts interventions within art gallery settings and none have developed a theoretical understanding of the process.

The Meet me at MoMA project (Mittelman & Epstein, 2009; Rosenberg, 2009) was the first reported gallery-based programme for dementia. The intervention involved 37 individuals with dementia and their carers attending a once monthly, 90-minute gallery tour which included trained facilitators engaging participants in discussion and interpretation of art. People with dementia and carers valued learning new things and sharing a new experience with loved ones and both their self-esteem and mood significantly improved following the session compared with before. Mittelman and Epstein (2009, p. 104) stated that the programme provided an “increase in intellectual stimulation, social interaction and improved mood within an accepting environment”.

MacPherson et al. (2009) developed a six-week programme at the National Gallery of Australia that included a similar sample. Findings implied that the intervention prompted the discovery of residual abilities, enjoyment, sparked new

interest in art and increased social contact. Carers described participants to have enjoyed the sessions and been enthusiastic, but no long-lasting changes were reported. The facilitators reported that participants' memory was stimulated within the group (e.g. recognising paintings and other participants), and they appeared more confident and enthusiastic in the gallery compared with a different context. The social, cognitive and emotional benefits were evident but it was noted these were "only in the moment" (MacPherson, Bird, Anderson, Davis, & Blair, 2009, p. 751).

Two further studies have altered the MoMA model to include an art-making component (Camic, Tischler, & Pearman, 2014; Eekelaar, Camic, & Springham, 2012). Eekelaar et al. (2012) primarily explored the impact on verbal fluency and episodic memory for people with dementia over three sessions but also reported on themes arising from post-intervention interviews, highlighting: social benefits of being with the group, personal effects of "becoming their old selves" (p.7) and the value of sharing an experience between the person with a dementia and the carer. Camic et al. (2014) used a mixed-methods design that built on the work of Eekelaar et al. (2012) but was more intensive and took place over a course of eight weeks.

Camic et al. (2014) compared an art intervention across two very different art galleries, one housing mostly 17th/18th century European art and the other contemporary international art. As in the aforementioned study, participants took part in an art viewing and art making intervention facilitated by artists or art educators at one of the two galleries. The study reported non-significant quantitative results but a thematic analysis demonstrated three key themes: social impact; cognitive capacities and the importance of the art gallery setting. These themes captured the significance of sharing a social experience and enhancement of the caring relationship; cognitive engagement, new learning and memory enhancement as well as a sense of

empowerment, engagement with the art work and the value of the multi-faceted viewing and making aspects. Whilst a mixed method, pre/post design, the study did not attempt to offer a theoretical understanding of the process which led to the outcomes reported. In addition the thematic analysis only represented themes true of all participants, which potentially neglects less generalisable but important aspects of the intervention.

The present study

Previous research has demonstrated that community-based art interventions have the potential to produce positive psychological, social, and relational outcomes for those with dementia and carers. The research has, however, yet to develop a theoretical understanding of the intervention process and associated outcomes. A theory able to describe and explain the benefits, challenges and changes gallery-based art interventions precipitate will allow the refinement of future interventions. Perhaps more importantly, a theoretical understanding could inform how best to further develop the involvement of third sector organisations in community-based health improvement programmes as outlined in the Health and Social Care Act (2012) and the ongoing Living Well with Dementia strategy (DoH, 2009).

The current study drew on the participant interview data collected by Camic et al. (2014) as well as field notes and a contemporaneous blog between researchers and facilitators of the intervention. New interviews with facilitators of the intervention also added to the dataset to enable triangulation. Triangulation is the practice of collecting data on a particular phenomenon using more than one research method or source (Jick, 1979) to provide a broader database on which to form interpretations (Myers, 2008). The study sought to develop a theoretical conceptualisation to answer: how does a

community-based art gallery intervention impact people with a dementia and their carers?

The research question supports using a qualitative methodology (Smith, 2003). Grounded theory (Glaser & Strauss, 1967; Strauss & Corbin, 1998) is a well-established qualitative analytic tool (Henwood & Pidgeon, 2003) that is especially appropriate for research where there is little empirical literature available and the area is under-theorised (Burck, 2005; Willig, 2001). Previous literature, particularly Camic et al. (2014) provided “sensitising concepts” (Strauss & Corbin, 1998). These enabled the researcher to narrow the focus of data gathering sufficiently to make the research practicable, whilst remaining open to new areas of participant experience. In this case the interviews and themes in Camic et al.’s study guided the questions issued to facilitators and provided possible avenues of analysis.

Method

Participants

Archival data. Much of the data were drawn from a previous study (Camic et al., 2014) at two sites, Dulwich Picture Gallery and Nottingham Contemporary; recruitment occurred through the Alzheimer’s Society, Extra Care Charitable Trust and the host galleries (Appendix F). Twenty-four participants completed the intervention (dementia participants’ age range = 58–94 years; 17 White-British, 4 White-Europeans, 2 British-Asian, 1 Black-British). Inclusion criteria were a diagnosis of dementia within a mild to moderate range and aged over 55 years. Exclusion criteria were physical incapability to attend, a severe mental health problem or life threatening illness. To determine inclusion within a mild-to-moderate range of dementia, the Addenbrook’s cognitive examination revised (ACE-R) (Larner, 2007), incorporating the mini-mental status examination (MMSE, Folstein, Folstein & McHugh, 1975), was

administered along with the neuropsychiatric inventory (NPI-Q, Kaufer et al., 2000).

At initial screening there were no statistically significant differences between participants at either site, on MMSE, ACE-R or NPI-Q scores.

Facilitators. Four individuals who facilitated the gallery intervention (two from both galleries) completed post-intervention interviews. The interviewees were a psychologist, who co-facilitated each making and viewing session (in Nottingham) and the artist who facilitated both the viewing and making aspects of the study in Nottingham. The art educator who facilitated the viewing aspect and participated in the art making sessions, and the head of community programmes who was involved in facilitating throughout the intervention at Dulwich Picture Gallery, were also interviewed.

Procedure

The original intervention consisted of eight two-hour sessions over an eight-week period at both sites. The sessions were divided into two sections: one hour of art viewing and discussion followed by one hour of art making. In the art viewing, an art educator guided discussion about two or more pieces of art within the gallery. After art viewing the group moved to a studio for art making which was facilitated by a professional artist. Each week different materials were provided depending on the art-making task and included water-based paints, pastels, coloured pencils, collage material, glue, quick-drying modelling clay and printmaking supplies. Completed work was stored at the gallery and given back to the participants at the final session.

Semi-structured interviews were conducted by the authors of the previous study (Camic et al., 2014) with participants with dementia and carers 2–3 weeks after the groups ended; the interviews, which were audio recorded and transcribed, occurred in the participant's home and lasted 50–90 minutes. Topics included participation in the

viewing and making of art components, relationships, communication and gallery context. Field notes (Simonds, Camic, & Causey, 2012) including detailed observational data, were kept by the researchers who attended each session and a frequent email blog discussing the research took place amongst the facilitators and researchers; these archival data sources had not been previously analysed.

For the present study, semi-structured interviews were conducted with four members of the original facilitator team (two from each gallery). Interviews lasted between 30-60 minutes and took place in June and July of 2012, approximately a year and a half after the cessation of the intervention. Questions were guided by the topics highlighted in the post-intervention interviews with participants (Appendix G) however participants were encouraged to add to this. A summary of the data can be seen in Table 1.

Table 1. Data sources (* indicates archival data)

Data Type	Participants	Length of interview/ word count
Interviews with carers and individuals with a dementia*	12 dyad interviews (7 from Dulwich, 5 from Nottingham)	50 - 90 minutes each
Interviews with facilitators	Four facilitators (as described above).	30 - 60 minutes each
Email blog (facilitators and researchers)*	4 facilitators, as well as the researchers contributed to a contemporaneous email blog	32,818 word count
Field notes*	Written by 2 of the researchers	Approx. 5,800 words (42 hand written pages)

Data analysis

Analysis in grounded theory is considered to be an inductive process where meaning is co-constructed by participant and researcher, and emergent theory is 'grounded' in the data rather than imposed upon it (Charmaz, 2006). This process is enabled by 'constant comparison' (Glaser & Strauss, 1967), the technique of concurrent data collection and analysis, moving back and forth between the raw data

and each subsequent level of coding in order to ensure that the emerging theory is true to the original data. In the present study extensive unanalysed archival (historic) data were available in addition to four interviews. Corbin and Strauss (2008) describe how researchers should analyse archival data “exactly as they would their own data” (p.316), suggesting scanning the data in order to find an aspect of interest to them in order to begin initial coding before progressing to theoretical sampling; selecting data of relevance to emerging categories (see Appendix L for an example of the initial sampling decision processes).

Coding followed the practice set out by Urquhart (2013), which draws on the work of Strauss and Corbin (1990) and Glaser (1978, 1992):

1. Line by line open coding. In vivo codes, using the participants’ own language, were used where possible to help capture subjective meaning. This was carried out for the first three data sources (including two participant interviews (one from Dulwich and Nottingham) and one facilitator interview (from Nottingham) resulting in 155 open codes. Computer program Nvivo 9 was used to manage coding.
2. Selective coding. Following the first three transcripts, analysis began with selective coding. This involved focusing on the more frequent open codes relevant to the research question and re-coding the data to synthesise larger sections of data at a more conceptual level. The initial open codes were elevated to become more analytic and directional (Appendix M for full list of selective codes, Appendix N for example of transcript with selective codes).
3. Theoretical coding. Substantive codes were developed and assimilated into conceptual categories and the relationships between them explored. Constant comparison technique (Glaser & Strauss, 1967), the technique of moving back

and forth between the raw data and each subsequent level of coding was used to ensure that the emerging theory was true to the original data. Memo writing was used to further define and explore emerging concepts (Appendix L and N for examples). Theory generation was facilitated by memos and initial diagramming of the relationships between concepts (Appendix J).

Most qualitative analysis using this method continues until theoretical saturation of emerging categories is achieved (Corbin & Strauss, 2008, p. 263). There is some debate about whether theoretical saturation or “theoretical sufficiency” (Dey, 1999, p. 117) should be aimed for. Theoretical sufficiency is described as, “the stage at which categories seem to cope with new data without requiring continual extensions and modifications” (Dey, 1999, p.117) and provides a clearer point at which to cease analysis compared to the exhaustive implication of theoretical saturation. Strauss and Corbin suggest that, particularly for a small-scale study, “sufficient saturation” (Strauss & Corbin, 1998) is adequate. As theoretical sufficiency was achieved on the 16th of 18 data sources available (as described in Table 1.), the two remaining sources (participant interviews) were analysed for expediency.

Quality assurance

Bracketing. In conducting qualitative research the researcher should be aware of their own perspective and its potential impact on the research (reflexivity): “It is not possible to view without viewing from somewhere. We do our best to become aware of what that somewhere is, questioning it, owning it or changing it, and including it in our reports” (Fischer, 2009, pg. 584). The research diary was used to record the author’s views and monitor impact on analysis (Appendix J).

Independent data audit. Each stage of analysis was systematically recorded and the records and samples of coded transcript were discussed with 1-2 colleagues in

a grounded theory study group until all parties were satisfied that the interpretation of the data and that the conclusions drawn were plausible.

Credibility check. Themes identified through the analysis and the overarching model were explained to the study group and feedback sought. Colleagues were in agreement that the themes and model were representative of the data, supporting the validity of the study. In addition an individual working outside the clinical psychology field (with no prior knowledge of the area) was able to understand the model and felt it helped to explain potential benefits of the intervention.

Ethical considerations. The archival data were accessible due to the original participants consenting to the use of their data for further research. The principal investigator of the study provided data in an anonymous form and without identifiable information (Appendix E). Approval to conduct the current study was sought from a Canterbury Christ Church University ethics panel and was approved on 5th October 2012 (Appendix K). Particular consideration was given to the provision of clear information for participants, making anonymous and the storage of data and the proposed course of action should a participant become distressed during the interview.

Results

The analysis led to the construction of 48 selective codes, 12 subcategories and 5 categories in table 2 (see appendix M for illustrative quotes). Selective coding within quotation marks denotes in vivo codes that were elevated to selective codes. Quotes are attributed to place and type of participant with an assigned number to distinguish individuals e.g. Dulwich- Carer (D-C1), Nottingham-Facilitator (N-F2), Dulwich-Person with a dementia (D-P3), Researcher (R). Quotes from the field notes (fn) and email blog (b) are further distinguished.

Table 2. Superordinate categories, subcategories and selective coding.

Superordinate categories	Subcategories	Selective coding	
Gallery Setting	“Ordinary users of an ordinary facility” (N-F1)	“part of a larger group...appreciating the art” (D-C1)	
		Equal	
		Getting the pitch right	
		Normal	
	Somewhere “different” (D-C5, 8, N-C3,4)	“Something to look forward to” (D-C5)	
		“Lifts you” (D-P5)	
		A break from the every day	
		Special event	
	A special and valued place	“Luxurious surroundings” (D-C5)	
		“Felt valued” (NF2)	
		Inviting atmosphere	
	Intellectual Stimulation	Art feels inclusive	“a subject everyone is interested in” (D-P1)
			Learning experience
“You can look at something and if it’s nice you just know” (N-P3)			
It’s not about dementia or being a carer			
Competency		Art becoming accessible	
		Confidence	
		“Finding that I knew more than I thought I did” (N-P5)	

		Learning from the person with a dementia (PWD)
		A “challenge” (N-C2)
		Overwhelming
		Highlighted some losses in capabilities
	Engagement	“opened one’s mind” (D-P1)
		“absorbed” (D-C1)
		“doing something” (D-C3)
		Facilitators surprised by engagement
		“It did wake me up a bit” (D-P5)
	Social Relationships	Carer respite and support
Different relationship with PWD		
People rather than PWD and carer		
A shared experience		
Peer support		
Difficulty finding the time		
Intellectual discussion		
Interaction		Confidence speaking
		Self-expression
		Stops dyad “becoming isolated” (D-C3)
		“group of people...that’s what makes it” (D-C4)
		Normalising carer feelings
		Warmth

Positive Affect	Enjoyment	Comfort
		Relaxation
		Visual aesthetics
		Fun
	Empowered	Freedom
		Confidence
A new perspective	Carers	Carer saw something new in PWD
	Facilitators	Dispelled some commonly held beliefs

The goal of any research utilising full grounded theory methodology is to generate theory (Charmaz, 2006). Urquhart (2013) and Straus and Corbin (1998) emphasise that demonstrating the relationships between categories moves an analysis from descriptive to theoretical. Figure 1 displays in diagrammatic form the proposed relationships between the categories. Categories are bold and underlined, with their properties (subcategories and selective codes) in plain font.

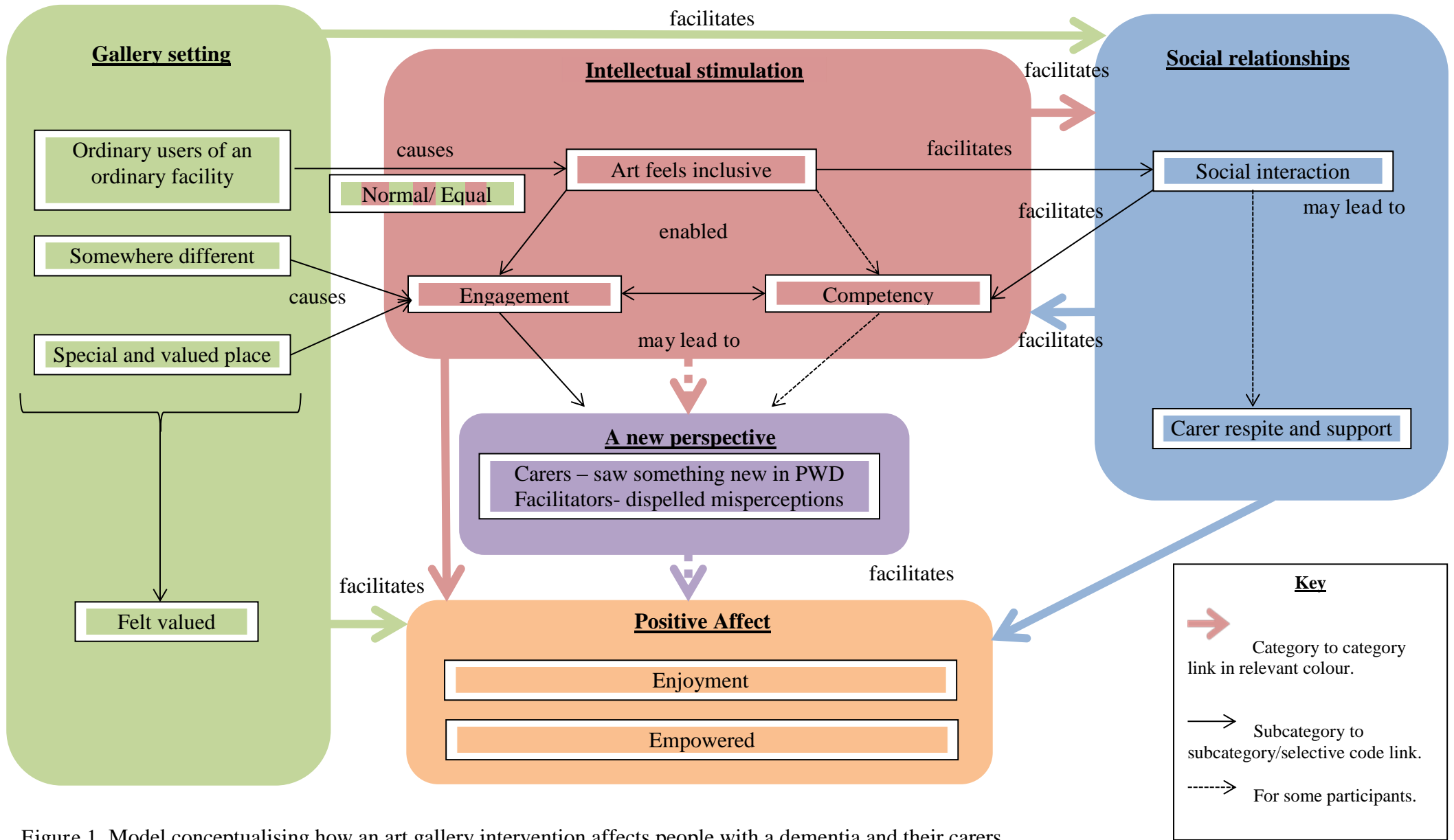


Figure 1. Model conceptualising how an art gallery intervention affects people with a dementia and their carers.

Theory summary

The gallery setting, including the physical environment and interactions with staff, helped to contribute to an overall experience of people feeling special and valued, and thus was an important aspect of the intervention. Feeling special and valued was something different compared to participants' day-to-day lives and not something generally experienced in healthcare settings. The sense of being valued and the inviting atmosphere, promoted relaxation and comfort within an accepting social environment. This helped individuals to engage with the intellectual aspects of art viewing and making in a safe space where they could become absorbed in the art and express their thoughts without fearing judgement. This opportunity for social interaction and intellectual stimulation was considered enjoyable and empowering.

The galleries, being "ordinary" (N-F1) community settings, contributed to an idea of art being inclusive and accessible to all. The fact that "you can look at something and if it's nice you just know" (N-P3) meant that art was something anyone could engage with and appreciate, whether or not the person had a dementia, promoting a sense of normalcy and equality. This engagement and accessibility enabled a sense of competency, although for those found comparing their current abilities to former abilities this sense of competency was diminished or not achieved.

The intellectual stimulation facilitated social interaction that for most led to a feeling of enjoyment from being part of a group where support could be sought. In contrast to health or social care, the community setting and "normal learning" (D-C4) ensured these interactions were not about dementia but about the stimulation, challenges and enjoyment of visual art; this helped to develop more balanced social relationships, minimising the differences between caring and cared for. In addition, the

intellectual experience facilitated a sense of respite for carers where they were not primarily a “carer” but an active participant.

For at least one carer, a sense of respite was not experienced and this was best explained by the person she cared for having failed to achieve a sense of competency (or her carer not perceiving this), undermining the ability of the carer to step out of the caring role. Carers who benefited the most had an experience of seeing those with dementia in a new perspective. The new perspective appeared to be contingent on those with dementia having achieved a sense of “competency”, even if that competency was only in the moment. Facilitators too shared this experience of seeing those with dementia in a new way.

Subcategory descriptions

The following information presents a detailed exploration of key elements of the analysis.

Gallery setting.

Ordinary users of an ordinary facility. Participants noted benefits of the art gallery being open to the public at the time of their group: “I think it was OK that there were other visitors there...it made you feel part of a larger group that were appreciating the art” (D-C1). There was a sense of normalisation with one facilitator mentioning “I liked the way it wasn’t closed because passers-by would often slow down and benefit from the exchange that was going on and it stops people from feeling stigmatised” (N-F1). Indeed one dyad literally “bumped into” someone they knew:

And she was there just because they like going to the gallery...it’s just those little touches, that although they are away from and glad to be away from the world at large, there are still other people there, and they were there because as [D-P5] said they enjoyed it (D-C5).

The nature of the public setting led to members of the public listening to what the group were saying. One facilitator noted that “lots of the general public started to get involved as well, which for me was reassuring because it made me feel that what I was doing with them wasn’t for ‘simple’ people or people who were ill or different” (D-F1b). The setting enabled the facilitators to have confidence that they were not patronising group members but presenting information that any user of the facility also found interesting; underlining the significance of the community setting. This aspect was key in participants with a dementia and carers considering the intellectual aspects (gallery viewing, discussion and making art) to be both inclusive to all, but also enabling a sense of competency. In other words, facilitators achieved a “pitch” (R-fn) for the content that was considered appropriate for people with or without a dementia.

The contrast between the gallery environment and more usual clinical settings was also noted:

Very often...activities...might be tailored to reminiscence or at day centres or up at clinics, people are often talking to you, to both of us, as we are people in the situation we are in, rather than as equals, people on a day-to-day basis. And I was very conscious I think at Dulwich ...People were treating you courteously as equals with something to contribute, so there was equality there (D-C4).

In this sense the people as well as the place enabled a sense of normalcy, equality and personhood which participants reported facilitated their confidence to offer verbal contributions.

Somewhere different. Numerous participants commented on the significance of being somewhere “so different” (D-C5, 8, N-C3, 4), “It lifts you into another world... I just felt released from the humdrum stuff at home” (D-P5).

Significantly there was a sense that it was about departing from the usual everyday activities/settings, “It gave them a structure that was beyond their everyday structures” (D-F1). This sense of difference was also linked to an event of value “It was nice to do something that’s different from being at ... going into Nottingham especially you know, um getting, you know lipstick on” (N-C4).

A special and valued place. Although the setting was considered “ordinary,” in the sense that it was a public place open to all, it was also considered a special setting. “It was a really luxurious experience...we were really privileged, because the number of people facilitators to the number, you know our number – a very high ratio, and very luxuriously treated, and being showed around, and the food, and the chocolate biscuits!” (D-C4), “It’s a beautiful space...it’s not just the art, it’s the space and all people being, behave in the museum, it’s very... people are very respectful I find in museums” (D-C5). This sense of a special and valued place seemed to generalise to the participants feeling special and valued, “And when you’re sort of our age there’s not many people really want to be bothered with you to be quite honest. But there you felt really welcome” (N-P2). Facilitators also commented on this “they said that they felt valued and, a lot of them had never been in the gallery and they really liked it” (N-F2). This linked to the category of positive affect as participants enjoyed the special setting and how this made them feel valued. This sense of being valued also facilitated individuals expressing their views without fear of being judged, this is discussed later as a dimension of the subcategory “empowered”.

Intellectual stimulation

Almost all participants commented on the learning experience of the group, “It was enlightening” (N-P1), “I didn’t have any knowledge of art and I think it was fun, enjoying, discovery, learning” (D-C8), “I absolutely loved it. It opened almost a new,

almost in a small way, a sort of life changing experience, because I have never had any real interest beyond being aware that it's there" (D-C5). Participants frequently juxtaposed expressions of enjoyment with intellectual aspects of the intervention demonstrating the direct link between the intellectual stimulation and positive affect.

One family carer underlined the significance of learning as opposed to reminiscing (a focus they had experienced in other support groups): "even when your memory is not quite as good as it should be, your life isn't only about reminiscing ... So that's the difference with this kind of activity, because you feel its forward looking, it's learning" (D-C4). The same carer went on to vocalise the importance of the learning despite the fact that the knowledge may not be remembered, "retaining what you have learnt becomes more difficult, but that doesn't necessarily devalue the whole learning process, because the learning is an end in itself and it is enjoyable at the time... You are enhancing your life at the time" (D-C4). This highlighted how learning was primarily a transitory experience rather than long-lasting.

Art feels inclusive. A participant with a dementia reflected on why the art engaged her:

Because it was a very natural thing to... the fact is that it is a subject, everybody is interested in. Art what you see, it doesn't usually require, you can appreciate it, because the whole of our existence in life is appreciating a view, what we see out of our eyes (D-P1).

This is reminiscent of the research evidence demonstrating that dementia does not restrict a person's aesthetic preferences or ability to appreciate art (Cummings et al. 2008). One commented on how art acted to enable a "normal" experience of learning rather than emphasising the caring relationship due to the experience of dementia:

It's a triangular relationship isn't it, it's between you, the facilitator and the object, and the object is the art. So here are two people functioning at the same level and exchanging conversation and having jokes and one of them is learning and the other is helping the learning...not just here am I with a problem, and here am I working with you and your problem (D-C4).

This quote articulates the way in which the art acted as a means by which to shift the focus from dementia and the caring relationship to the subject of art. This interacted with the "ordinary facility" to promote a sense of inclusion and normalcy and the sense of the intervention being a respite from the normal caring-cared for relational dynamic.

Competency. Various participants appeared to achieve a sense of competency through the experience: "the team was very encouraging. Some were not very.... I know there was a man who was always belittling himself, then he stopped doing that" (D-C8). Some reflected on their own surprise at their abilities "learning with others and finding that I knew more than I thought I did. You can pull things up out of your mind can't you given the right stimulus" (N-P5). The growing sense of competency was noticed by facilitators, "The participants are beginning to enjoy using discourse-specific terminology, especially the carers (especially...who will exclaim: 'listen to me!' or 'how about that!' after stringing together a convincing exposition)" (N-F1b).

There were clearly two sides to the intellectual stimulation, as some evidently compared themselves to their previous abilities, or those of others, with one individual reflecting on how "you probably feel you can't do what you could of done earlier" (D-P1). This demonstrates that where the art viewing or making highlighted reduced abilities, an individual could be left feeling dispirited and suggests grading the art activity to the abilities of an individual is important and that the "pitch" (Rfn) wasn't

always right for everybody. Despite the experience highlighting difficulties for some, all participants remarked on some aspect in which they felt more competent.

Engagement. Participants with dementia described how the experience “opened one’s mind really” (D-P1) and “I was never bored at any point” (N-P1). Carers too noticed differences in the person they cared for: “he got absorbed in things in a way that he probably doesn’t so much these days...I think he was certainly concentrating more than usual, both on the pictures and when he is doing the creative thing” (D-C1). The engagement in the activity was considered particularly valuable given that carers reported deterioration in motivation to participate in activities, “that is all peeling away you see, her interest in anything is going, and of course she is not doing anything domestic as I am doing it. So actually it’s much more valuable than you might think...I think its inherently empowering as she is doing something, it must be” (D-C3).

The level of engagement appeared to be a surprise to facilitators:

It has been incredibly exciting to work on this project. I have been struck by the level of engagement of the group, who almost all remained fully focused for the whole 45-50 minutes of the tour (...they have been my most engaged group of adults to date, and I mean of...400 groups I have given tours to including students, ladies who lunch, art historians, tourists, this group has been the most engaged) (D-F1b).

This surprise at the engagement of the participants linked in to changes in how carers and facilitators’ perceived those with dementia which is described later.

Social relationships.

Carer respite and support. Carers valued the time as an opportunity for a break from every day care obligations as well as peer support from those going through similar experiences:

It has certainly helped me... you see others who have equal and worst problems than I do, it was relief for me in many ways, as it has been the only outing I would get....the rest of time it's just the two of us. For me it was an absolute gift, it really was (D-C6).

Another carer said "support, well, that made all the difference...everybody was so kind... there are days when you feel, boom! Your chin hits the floor, this support I am talking about is very important" (D-C5). "They seemed to particularly like the contact with other carers and you know some of them started swapping numbers with each other so we found that they were kind of meeting independently of the group" (N-F2).

Facilitators spoke about how carers found a sense of respite at the gallery and were able to have a relationship with their loved one that was different to the caring role:

One carer...said that she enjoyed her relationship with her mother more, because she was relaxed when she was there. She didn't feel as though she was a carer. So it was respite time for her...she could chat with her mother as an equal about whatever it was they were doing...So they were sort of communing as mates (N-F1).

Interaction. The social and verbal interactions with others were valued by participants even if their memories of the intervention were hazy... "It was a chat really and a discussion mostly with...I can't remember his name?" (N-P5). Facilitators

and the field notes revealed that “the novelty of a new session from week to week isn’t there...there is familiarity even though there is not a definitive memory” (R-fn). This familiarity seemed to contribute to a growing confidence to participate and interact that facilitators and participants noted (discussed later as a dimension of “empowered”).

Carers commented on the importance of the social interaction and group nature for the success of the activity:

there are a lot of activities which are good for people in our situation... that you should be doing. But it isn’t very easy to do it, sitting in your little place at home. The impetus isn’t there. So to get together with a group of people and to interact like that, that’s what I think makes it successful (D-C4).

“I think the most important thing for mum was to go out and do things with other people, as there is this danger to become quite isolated” (D-C3). This interaction also held a different importance for carers by normalising their feelings, “for me sometimes I can get cross or frustrated and I feel guilty, and when I saw ...I thought I am not alone in feeling this way” (D-C8).

A new perspective.

Carers. Carers saw new aspects of their loved one “she sang a song in the gallery inspired by the skeleton of an armadillo, which was delightful and it took her daughter by surprise because she was so extrovert. Her daughter enjoyed that change in her” (N-F1b). Another commented on how other people had been surprised when seeing what their loved one had achieved: “ she was one of the few who showed her talent, she sat and drew me one day, many people since have seen it and remarked, “oh gosh this is terrific!” (D-C5). The interaction of the place, social relationships and intellectual stimulation facilitated an environment in which a new side to individuals

with a dementia was often seen, such as the engagement and competence described above.

Facilitators noticed how this often changed the way the pair interacted, “she was seeing her husband through other people’s eyes and I think that changes things when you are so use to that dynamic between the two of you and then she was in a position where others suggested why don’t we listen to what he has to say and present his work” (D-F2). “She also seemed to respond much more jokingly to her partner, whereas she normally seems a bit exasperated” (D-F1b).

Facilitators. Facilitators were clear about how the project had dispelled some commonly held beliefs about dementia “the level of engagement of this group...is really, really remarkable...because...the stereotype of people with dementia is that they have low attention levels. This really is not the case with respect to this group on this project” (D-F1b).

Perhaps the most impactful session for me was when two people with dementia did it [facilitated a discussion]... it was amazing how...they were interacting with each other and the group. I couldn’t have imagined at the beginning that two people with dementia would not only make work and take part in the group but would be able to talk about it and facilitate a discussion about the works...not just take part but to lead as well (N-F2).

Positive affect.

Enjoyment. All individuals with a dementia who attended reported a variation on it was “very enjoyable” (D-P1, N-P 2,4,5) and how relaxing the experience had been “it’s a nice little place for quietness to work, your brain will work” (D-P8).

Carers spoke of their partner enjoying it but also themselves:

I think she really liked being there, to the extent where she was quite happy. I thought it was actual fun, the doing of the stuff wasn't quite as..... it wasn't important that it came out like a Picasso, it was just a fun process, that you were trying something different each time... I am amazed how much I liked it, and really without going over the top how much I did like it (D-C3).

One facilitator reported that during the intervention a participant had said "I don't know what I'm doing here, but I'm enjoying it!" (N-F1b). This aptly demonstrates how the intervention was enjoyable in the moment whether or not the experience as a whole was recalled. Enjoyment was linked by participants to the setting, social aspect and intellectual stimulation, as well as seeing a new side to those with dementia and carers where relevant.

Empowered. Participants reflected on growing confidence "Getting more confident, yes there was no judgement" (D-P8) and that facilitators "made you feel as if you were welcome and not stupid if you know what I mean (laughter)" (N-P2). This confidence led to them being more outspoken about what they wanted, "as people became more comfortable they would talk more. They would begin to call the shots" (N-F2).

Facilitators also made links to more traditional conceptions of empowerment in which the gallery setting was thought to "stop people from feeling stigmatised" (N-F2). The field notes too made reference to the non-stigmatising setting: the "socially inclusive aspect of a gallery open during regular opening hours helps participants to blend in and not be cordoned off and kept away from the general public" (R-fn).

A sense of being empowered was also linked to the making of art where those with a dementia and carers expressed satisfaction in the art work they produced, "their

surprised by the artwork themselves, when they have done the artwork, when they see it on the wall there – they are quite amazed. It is an empowering process, none of them felt that they were particularly talented but quite quickly they are able to produce some quite good things” (D-C3). The carer describes the empowering nature of making art and provides an example of how the challenge of creating art (a part of the intellectual stimulation) facilitated positive affect, in this case surprise and amazement.

Discussion

Theoretical conceptualisation

The theory notes the significance of the “valued” setting, suggesting that whilst social interaction was key to the experience, it alone did not explain the impact upon participants. The importance of the galleries as valued places within a community context, the latter being a key tenet of community psychology theory and intervention (Alcock, Camic, & Barker, 2011; Levine et al., 2005), suggests that non-clinical settings have a role to play in dementia care, promoting normalcy and equality. Winn’s (2000) view that a gallery should provide relief from roles or associations with sickness and become a source of pleasure and beauty helps to explain the art gallery as a valued setting that is “somewhere different”.

Facilitators (and carers) expressed new perspectives which appeared to be related to the opportunity to share an engaging experience with individuals with dementia and witness them making competent contributions in an intellectually challenging setting. The intellectual aspect interacted with the group environment to offer an opportunity for individuals with dementia to be seen differently. The facilitators reported this change in perspective over a year post-intervention implying a long-lasting outcome. Whilst carers reported having seen a different side to the person they cared for at the time, this research did not capture whether this led to a long-lasting change in the way

the person with a dementia was seen. It was commented upon that members of the public attempted to join the group at times. Although speculative, it is possible to consider that public attitudes toward those with dementia might be positively affected as was the case with facilitators (and indeed carers), if people with dementia were witnessed making insightful contributions in group discussions. Further research would help to establish potential benefits at this more community level.

The significance of “intellectual stimulation” has a familiarity in light of the increasing use of cognitive stimulation therapy (CST, Spector, Orrell, Davies, & Woods, 2001; Spector et al., 2003). A benefit of a gallery intervention, over CST for example, is that the focus is not explicitly on dementia. This shift of focus appeared to enable carer respite, the opportunity to see new aspects of those with dementia, contributed to a sense of competence and feelings of being “normal”. These effects are well explained by Liebenberg (2009) who suggested the mutual co-construction of meaning of images (i.e. visual art engagement) contributes to a flattening of hierarchies and reduction in power imbalances. Thus, the gallery setting and engagement with art (intellectual stimulation) enabled a different relationship compared to carer-cared for.

It was notable that not all participants appeared to develop a sense of competence. For the two (one reported by the person with a dementia, one implied by the carer), where this was not apparent both had a history of having artistic talent. It may be that the art making aspect in particular highlighted areas where people would have performed better previously and thus accentuated changes that have occurred as part of a dementia. Where those with dementia did not achieve a sense of competency, carers appeared not to find the intervention a form of respite. It is significant that even these participants expressed positive affect in relation to the intervention, but it

underlines the significance of getting the “pitch” of tasks right in order to minimise threats to a sense of competency.

The superordinate category of “social relationships” was perhaps the least surprising. Social engagement has been recognised as an important component of wellbeing in older adults (Cherry et al., 2013) and supports the use of groups for people with dementia and carers. In the United Kingdom (UK), older adult services often offer groups to carers and individuals with dementia separately. One reason for separate carer groups may be that such groups are considered to be an opportunity for carer respite and peer support. However, this theory would imply that carer respite and peer support can be achieved even with the person with dementia present and in fact can have a positive impact on the caring relationship.

The components described above facilitated the final two superordinate categories: positive affect and new perspectives. Positive affect fits well with previous outcomes-based research within the area that has demonstrated enhanced social and psychological wellbeing (Kinney & Rentz, 2005; Rentz, 2002) and increased enthusiasm, confidence, enjoyment, and social contact (MacPherson, Bird, Anderson, Davis & Blair, 2009). The current research was not outcome-based but the superordinate category “positive affect,” could be considered to capture the outcomes reported in previous studies which would support the application of the current theory to previous gallery-based research as well as that of Camic et al. (2014).

Previous research

The MoMA project (Mittelman & Epstein, 2009; Rosenberg, 2009), MacPherson (2011), Eekelaar et al. (2012) and Camic et al. (2014) have all identified psychological and social benefits from gallery-based art interventions for people with dementia and carers. Camic et al. (2014) highlighted three key themes from their

thematic analysis: social impact; cognitive capacities and the art gallery setting. Similarly, Mittelman and Epstein (2009, p. 104) stated that their programme provided an “increase in intellectual stimulation, social interaction and improved mood within an accepting environment” and that carers valued the opportunity to share a new, pleasant and stimulating experience with the person they cared for. The similarities in these findings are striking and suggest consistent themes across this type of intervention. However, these studies failed to conceptualise how these factors integrated to affect participants and provide a theoretical conceptualisation of the process.

This research was unique in the broad range of perspectives that were included: people with a dementia, carers and facilitators (as well as field notes from the researchers). Triangulation of data provides a broader database on which to form interpretations (Myers, 2008). The theory integrated these perspectives and different experiences to form a coherent, single model of the impact of the intervention. In this way, the experiences of those with dementia were captured from their own perspective, that of their carer as well as the observations of facilitators. Facilitators were also able to comment on their observation of carers experience to compliment the carer perspective as well as accounting for the facilitator’s own experiences which is generally neglected. This broad dataset can be seen to improve the validity of the research through a “search for convergence among multiple and different sources of information to form themes or categories in a study” (Creswell & Miller, 2000, p. 126).

Research implications

The grounded theory resulting from the present study suggested three critical components of the intervention: a “valued place,” “intellectual stimulation” and “social interaction”. All three of these aspects could be manipulated in experimental research

to evaluate the robustness of the theory and direct future research. For instance, the “valued setting” may be manipulated, making use of a museum or theatre in comparison to a place deemed not to be valued. It would also be useful to establish whether other types of interventions for people with dementia, such as support groups, could be improved simply by changing the setting, or if places of value could be created in a hospital for example. In addition, the positive affect and new perspectives may be targets for outcome measurement, helping to refine the way such interventions are assessed.

A unique aspect of Camic et al.’s (2014) study was the use of two distinctly different settings, a contemporary and a traditional art gallery. In that study, participants spoke relatively little about the content of the art itself, nor were they specifically asked about this during interviews. Likewise in the present study the participants, field notes and email blog revealed no significant information about the impact of contemporary art compared to traditional art. During the analyses it did appear that there were more comments about specific pieces of contemporary art than traditional art but it was beyond the scope of this research to investigate further. It may imply that contemporary art was more stimulating and hence more memorable than the traditional art. Further research into this variable would be important for refining future interventions.

The theory highlighted a few areas important to consider in further work, namely, ensuring the “pitch” is correct to avoid feelings of incompetency and the significance of “not remembering the intervention.” The lack of recall seemed to limit the potential for long-lasting benefits to those with dementia so future outcomes-based research would need to explore the implication of not remembering the experience. In addition, whilst many participants intended to continue visiting galleries, many did not

intend to pursue making art. It will be the role of future outcomes-based research to acknowledge these aspects and consider how interventions could be made to be more enduring since benefits may cease upon the termination of projects.

Clinical implications

The theory offers an explanation of how a gallery-based art intervention has the potential to provide an inclusive therapeutic intervention. It promotes offering groups conjointly to those with dementia and their carers, since both can benefit, thus attending to the need to provide support to carers, as identified in Living Well with Dementia (Department of Health (DoH), 2009), alongside attending to the needs of those with dementia. It also highlights the unique benefits of community-based programmes, since the setting was integral to the psychosocial benefits, and this demonstrates the need for clinical psychologists to make links with local third sector organisations.

Drawing on specific components of the intervention may also be of use to clinical psychologists. For instance, therapy, CST or support groups could be offered in community settings, such as an art gallery or museum. The way the shared intellectual task facilitated social interaction or how feeling valued directly impacted upon engagement, are further aspects clinicians could learn from and apply to other interventions or settings. Where similar interventions are not possible, clinicians could still broaden guidance offered to nursing or care homes; it may be that advising the use of art or music groups would have psychosocial outcomes for those with dementia and carers that belie a need for more intensive psychological intervention.

Limitations

The study had various strengths in regards to novelty, the use of triangulated data, rigorous grounded theory analysis and numerous examples of data to ensure

transparency. However, there were of course limitations, one of which was the sample which included people with mild to moderate stages of a dementia over the age of 55. It may be that the age of participants (i.e. early-onset dementia), type and stage of dementia would respond differently to a gallery-based intervention. Participants also volunteered after reading information regarding the study, so those recruited may already have had an interest in art, biasing results to those for whom art is of interest (although when asked during interview most participants did not express previous significant interest in art). Future research should attend to such variables.

Corbin & Strauss (1998) acknowledge that the use of archival data can be “difficult” (p.150) when undertaking a grounded theory analysis and cautions that “gaps in the research may occur when analysing previously collected data because there isn’t the opportunity for further exploration.” They go on to reassure this does not mean analysis will “lack significance or be superficial.” In this study, facilitators were available to clarify gaps or discuss ideas; however carers and participants were not able to, which potentially limited aspects of theory development. For example, the category “new perspectives” may have been elucidated by going back to carers to see if the new perspective on the person they cared for remained or if this was only evident during the intervention itself. In addition, some of the themes of the current analysis were similar to those of Camic et al. (2014) who had previously analysed one aspect of the dataset. It may be that in collecting wholly new data the analysis would have resulted in less repetition of previous findings and more novel aspects. The historic data also limited the suitability of respondent validation (with the original intervention having taken place over 2 years ago). It would be helpful to present the theory to participants of future gallery interventions to improve credibility (Elliott, Fischer & Rennie, 1999).

Conclusion

Whilst this study has its limitations, the resultant theory offers a good basis for further research within the area. The theory outlines how offering an intervention to people with dementia and their carers in a valued place that facilitates intellectual stimulation and social relationships promotes positive affect and new perceptions of dementia. The theory supports the use of community facilities as non-stigmatising environments which add to the psychological and social benefits of an intervention. It also challenges commonly held misperceptions about the capacity of those with dementia to engage in complex material and offers new ways of thinking about psychologically-informed dementia care. Healthcare professionals should pause for thought regarding the types of intervention offered, settings used and the scope to act beyond an individual level to benefit carers and the community.

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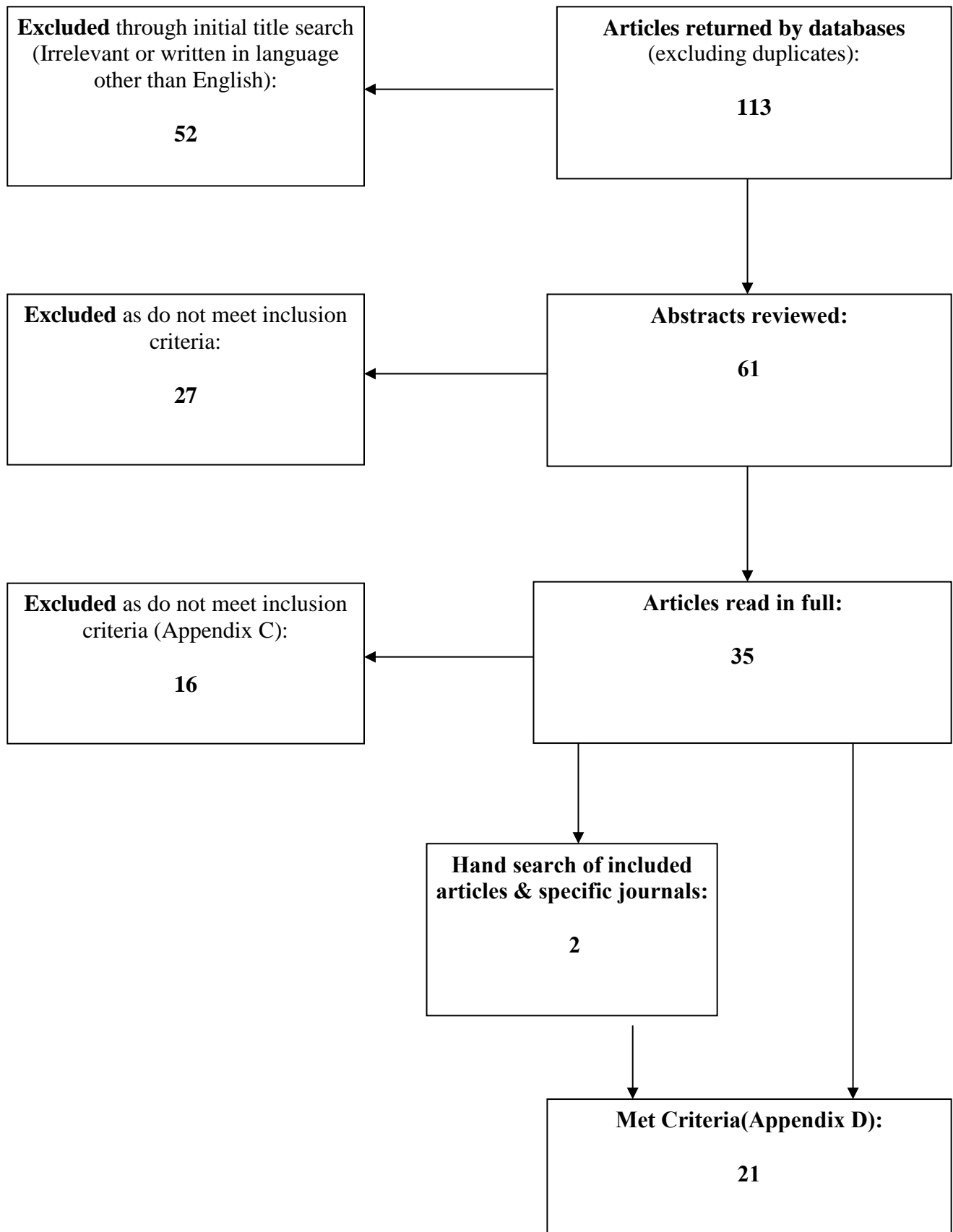
SECTION C: Appendices of supporting material

Appendix A: Literature Search

Completed 30/12/2012 (repeated 01/11/13)

Database	PsycINFO	Medline	Web of Knowledge	ASSIA	Cochrane
Search 1.	Search Terms: view* art OR museum* OR art education OR art museum* OR art galler* OR art program* OR art project OR community art* OR art group* OR music OR sing* OR danc* OR creat* OR story OR perform* OR drama*				
	4227	10010	75843	632	2401
Search 2.	Search Terms: “dementia” OR “Alzheimer*”				
	10886	10155	444,687	6051	9901
Search 3.	Search Terms: 1 & 2				
	12	16	25	8	75

In addition: The Community Psychology UK website was also searched and links explored. Google scholar was used to check for specific terms: dementia/ Alzheimer and community/art/creative interventions. Specific journals were searched for research related to dementia: Arts and Health, Journal of Applied Arts and Health, Museum and society, Curatorial management.

Appendix B: Flow chart depicting literature search

Appendix C: Exclusion Table Summary

The following articles lacked a focus on clients with dementia or focussed exclusively on the carers of PWD:
<p>Kidd, L., Zauszniewski, J. A., & Morris, D.L. (2011) Benefits of a Poetry Writing Intervention for Family Caregivers of Elders with Dementia, 32(9),598-604.</p> <p>Kontos, P. C., Mitchell, G. J., Mistry, B. & Ballon, B. (2010), Using drama to improve person-centred dementia care. <i>International Journal of Older People Nursing</i>, 5, 159–168. doi: 10.1111/j.1748-3743.2010.00221.x</p> <p>Kontos, P. C., & Naglie, G. (2007). Expressions of personhood in alzheimer's disease: An evaluation of research-based theatre as a pedagogical tool. <i>Qualitative Health Research</i>, 17(6), 799-811. doi:http://dx.doi.org/10.1177/1049732307302838</p> <p>Rancour, P. & Barrett, T. (2011). Art Interpretation as a Clinical Intervention Toward Healing. <i>Journal of Holistic Nursing</i>, 29(1), 68-80. doi: 10.1177/0898010109358768</p>
The following articles include interventions termed as “therapy”:
<p>Hattori, H., Hattori, C., Hokao, C, Mizushima, K. & Mase, T. (2011). Controlled study on the cognitive and psychological effect of coloring and drawing in mild Alzheimer’s disease patients. <i>Geriatric Gerontology International</i>, 11, 431-437.</p> <p>Wall, M., & Duffy, A. (2010). The effects of music therapy for older people with dementia. <i>British Journal of Nursing</i>, 19(2), 108-113. Retrieved from http://search.proquest.com/docview/742728415?accountid=9869</p>
The following articles had no (or very limited) inclusion of psychological aspects:
<p>Bannan, N. & Montgomery-Smith, C. (2008). Singing for the brain': reflections on the human capacity for music arising from a pilot study of group singing with Alzheimer's patients. <i>Journal of the Royal Society of the Promotion of Health</i>, 128(2), 73-78.</p> <p>Brownell, C.A. (2008). An intergenerational art program as a means to decrease passive behaviors in patients with dementia. <i>American Journal of Recreation Therapy</i>, 7(3), 5-12.</p> <p>Cox, E., Nowak, M., & Buettner, P. (2011). Managing agitated behaviour in people with alzheimer's disease: The role of live music. <i>The British Journal of Occupational Therapy</i>, 74(11), 411. doi:http://dx.doi.org/10.4276/030802211X13204135680866</p> <p>McLaren, A.N., LaMantia, M.A. & Callahan, C.M. (2013). Systematic review of non-pharmacologic interventions to delay functional decline in community-dwelling patients with dementia. <i>Aging & Mental Health</i>, 17(6), 655-666.</p> <p>Riley, P.J., Alm, N. & Newell, A.F. (2009) An interactive tool to support musical creativity in people with dementia. <i>Journal of Computers in Human Behaviour</i>, 25, 599-608.</p> <p>Sung, H., & Chang, A. M. (2005). Use of preferred music to decrease agitated behaviours in older people with dementia: A review of the literature. <i>Journal of Clinical Nursing</i>, 14(9), 1133-1140. Retrieved from http://search.proquest.com/docview/57147374?accountid=9869</p>
The following studies included studies pertaining only to individual use of music,

limiting application to group-based interventions:

Asplund, K., Melin, E., & Norberg, A. (2003). Reactions to music, touch and object presentation in the final stage of dementia: An exploratory study. *International Journal of Nursing Studies*, 40(5), 473-479. Retrieved from <http://search.proquest.com/docview/57042513?accountid=9869>

Lancioni, G. E., O'Reilly, M.F., Singh, N. N., Sigafoos, J., Grumo, G., Pinto, K., . . . Groeneweg, J. (2013). Assessing the impact and social perception of self-regulated music stimulation with patients with alzheimer's disease. *Research in Developmental Disabilities*, 34(1), 139-146. Retrieved from <http://search.proquest.com/docview/1430187679?accountid=9869>

Seifert, L. S., & Baker, M. K. (2002). Art and alzheimer-type dementia: A longitudinal study. *Clinical Gerontologist*, 26(1), 3-15. Retrieved from <http://search.proquest.com/docview/57172708?accountid=9869>

Sixsmith, A., & Gibson, G. (2007). Music and the wellbeing of people with dementia. *Ageing & Society*, 27(1), 127-145.

Appendix D: Inclusion Table

Authors/ Year	Population details	Art Form	Variables and Measures	Study Design	Findings
Musical Interventions (6)					
Cooke et al (2010a)	47 PWD (2 aged care facilities) Australia	Singing and listening	Agitated behaviour (Cohen- Mansfield Agitation Inventory) and anxiety (Rating Anxiety in Dementia Scale).	Randomised, controlled cross-over design- music compared to reading intervention. Repeated –measures.	No significant effects, increased verbalization.
Cooke et al (2010b)	“ ”	“ ”	Quality of life (QoL. Dementia Quality of Life, DQoL) and depression (Geriatric Depression Scale, GDS).	“ ”	Improved self-esteem, those with depressive symptoms reduced over time, sense of belonging developed but no different to reading group.
Camic et al. (2011)	10 PWD or MCI (& 10 carers) UK	Group singing	Mood (GDS), activities of daily living (Bristol activities of daily living scale, BADL) and QoL (DQoL). Semi-structured interviews captured qualitative information.	Mixed methodological repeated measures design.	Decline on all measures but QoL remained constant. Qualitative feedback indicated improved wellbeing.
van der Vleuten, Visser & Meeuwesen (2012)	54 PWD (6 nursing homes) across the Netherlands	Live music singing performance.	Participation and mental wellbeing (measured by an observation instrument developed by the authors based on previous literature).	Quasi-experimental. Observational rating scales (after intervention).	Improved human contact and communication, relationship with carer and less negative emotions.
Clément et al. (2012)	14 people with (severe) Alzheimer’s diagnosis in	Singing, playing music and movement.	Short and long term effects on mood (adapted version of State- Trait Anxiety Inventory for Adults completed by one of the	Randomised, controlled design: music compared to cooking intervention. Repeated –measures.	Significant short-term benefit demonstrated on all 3 emotional indices after the music intervention. No significant effect of cooking other than increased

	residential care. France.		authors using only the 10 positive and negative statements). Facial expressions and discourse contents were measured quantitatively by 5 independent observers.		mood after the 4 th session (mid-point). Long-term (1 month post-intervention) improvement of mood following music intervention.
Sarkamo et al. (2013)	89 PWD (89 FC or nurses) Finland	Singing vs. music listening (& control)	Cognitive abilities, mood, QOL of PWD & family carer psychological wellbeing. Neuropsychological measures included: Cornell-Brown Scale for Quality of Life in Dementia, General Health Questionnaire, Quality of Life in Alzheimer's Disease (QOL-AD), Zarit Burden Interview (ZBI).	Randomised, controlled design: repeated measures with baseline.	Singing and music improved mood (and some cognitive abilities) over control condition. Singing enhanced carer wellbeing, music improved QoL.
Authors/ Year	Population details	Art Form	Variables Measured	Study Design	Findings
Creative Expression (6)					
Lepp et al., (2003)	12 PWD (and 7 professional caregivers) Sweden	Storytelling, conversation as well as dance, rhythm and song.	Qualitative experience of group described by carers in a focus group interview	Qualitative design- post-intervention focus-group interview analysed using a phenomenographic approach.	Carers reported that PWD showed their feelings, both joy and sorrow, more openly, their self-confidence grew and they showed greater interest in their surroundings. Key themes reported to be 'interaction' and 'professional growth'.
Holm et al., (2005)	6 PWD (and 3 professional caregivers) Sweden	Storytelling.	Potential therapeutic application of storytelling with PWD.	Contemporaneous diary kept by the facilitator and analysed using a phenomenographic	Storytelling triggered emotional and verbal reactions considered therapeutic. Conversations mirrored PWD's previous skills and knowledge enabling a sense of

				approach.	‘wisdom’.
Walter et al., (2007)	20 people with Alzheimer’s (10 in intervention, 10 in usual care group)	Humorous stories and anecdote used to stimulate conversation.	QoL (Anamnestic Comparative Self Assessment Scale- scores measured in relation to best time in life to worst time in life)	Repeated-measures design. QoL measure before admission and after the intervention.	No change in QoL for dementia group (although a group of older adults with depression did show improvement).
Fritsch et al., (2009)	10 nursing homes for PWD (10 nursing homes with no intervention) U.S	TimeSlips storytelling intervention.	Engagement, affect (mood), staff attitudes. Generally, assessed via observation conducted by eight trained research assistants. Measures included: the Philadelphia Geriatric Center Affect Rating Scael, a modified version og the Quality Interactions Schedule, Maslach Burnout Inventory Human Services survey (a measure of carer burn-out).	Quasi-experimental, two-group design: intervention vs. normal care group. Time-sampling observations of interactions measured engagement and affect.	Improvement in residents’ general alertness, engagement, quantity and quality of staff-initiated interactions, and staff attitudes in the intervention group. Also, significantly higher levels of anger, sadness, anxiety and challenging behaviour in the interventions group which was ascribed to the higher general alertness.
Phillips et al., (2010)	56 PWD (n=28 in intervention group). Long-term care residents U.S	TimeSlips storytelling intervention.	Mood (Cornell Scale for Depression in Dementia and Observed Emotion Rating Scale), Communication (Functional Assessment of Communication Skills complete through an interview with a carer), neuropsychiatric symptoms (Neuro-psychiatric Inventory-Nursing Home Version), and QoL (QoL-AD) in long-term care	Quasi-experimental, two-group (intervention vs. normal care), repeated measures design (baseline, one week post-intervention and four weeks post-intervention).	Increased positive affect and improved communication skills in intervention group. No significant differences between treatment and control group on long-term effects and other outcomes.

			residents with dementia.		
Stevens (2011)	15 people with mild dementia (15 family carers) living in the community. Australia	Stand up comedy and improvisation workshop.	Qualitative experience of group described by all involved.	Semi-structured interviews post-intervention with 6 PWD & 6 carers) and field notes thematically analysed.	Improvements in memory, learning, sociability, communication and self-esteem were demonstrated.
Authors/ Year	Population details	Art Form	Variables Measured	Study Design	Findings
Art (9)					
Rentz (2002)	41 PWD attending day programs or in assisted living/nursing home. U.S	Making art	Objective and subjective measures of wellbeing including: affect and self-esteem. Measure completed by one trained member of staff during a 60 minute observation.	Observational measures completed during intervention as well as qualitative data (spontaneous comments).	Sustained engagement, wellbeing and self-esteem perceived to be enhanced although there was no baseline measure.
Kinney & Rentz (2005)	12 PWD from 2 adults day centres U.S	“ ”	Wellbeing (Greater Cincinnati Chapter Wellbeing Observation Tool based on measure above)	Measures of wellbeing c/o to alternative activity. Measure repeated in each condition but alternative activity always took place after art intervention.	Wellbeing score greater during intervention c/o alternative activity.
Rosenberg, (2009) Mittelman & Epstein (2009)	37 PWD (37 carers) US	Art Viewing	Mood (smiley face assessment scale), communication/interaction (Family Assessment Measure), self-esteem (Rosenberg self-esteem scale) & QoL (QoL-AD). Staff also completed observer rating scales i.e.recording how long participant looked at	Mixed-methodological repeated measures, focus group and evaluation completed by caregivers post-intervention.	Improved mood, engagement and interaction. Participants felt intellectually stimulated.

			facilitator.		
Colucci (2010)	10 people with mild to moderate AD Italy	Art Viewing	Behavioural and neuropsychological measures- unspecified.	Repeated measures c/o computer-based cognitive stimulation group.	No cognitive changes but improved behavioural aspects (unspecified). Positive emotions reported from authors and carers observations. Reported decline in carer stress although it was not apparent how this was recorded.
MacPherson et al. (2009)	15 PWD living at home or in residential care Australia	Art viewing	Quantitatively recorded behavioural observation of engagement, focus groups for assessment of qualitative experience.	Observational measures completed during intervention & post-intervention focus groups analysed using Grounded Theory.	Participants were engaged, qualitative evidence of enjoyment, feelings of normalcy, intellectual stimulation, and social benefits- feeling a part of a group.
Ullán et al. (2011)	21 people with mild to moderate dementia Spain	Viewing and making art	Qualitative experience measured (see design) as well as educators completing an 8-item summary form of each participant each session i.e. did PWD pay attention to the process? Followed by a 4 point likert scale.	Qualitative review based on observation, videod focus groups (with PWD and carers) & field notes.	Engagement, interest in learning new things, satisfaction & improved communication.
Eekelaar et al., (2012)	6 PWD (6 carers) UK	Art viewing and making	Episodic memory, recall & verbal fluency and qualitative experience were assessed via asemi-structured interview.	Pre-post mixed methods design – content analysis of audio recording of semi-structured pre/post/follow up interviews as well as recordings during of sessions.	Social benefits and ‘becoming old selves.’ Episodic memory (and to a lesser degree verbal fluency) improved during and after intervention.
Camic et al. (2014)	12 PWD (12 carers)	Art viewing and making	PWD QoL (DQoL), activities of daily living (BADL)and carer	Mixed-methods repeated measures design.	No significant difference on quantitative measures. Qualitative feedback implied

UK	in a gallery setting.	burden (ZBI). Qualitative data via semi-structured interviews.	positive social impact, enhanced cognitive abilities and improved QoL.
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Appendix E: Permission to Access Dataset

This has been removed from the electronic copy.

Appendix F. Poster for Participants

Volunteers Needed!

'Viewing Together'

A new art-based group for people with a memory problem and their family carers

A new research project to be conducted at the Dulwich Picture Gallery in London and the Nottingham Contemporary Gallery in Nottingham and supported by Canterbury Christ Church University and the University of Nottingham Medical School

We are seeking volunteer pairs (person with a memory problem and family carer (or live in friend) to participate in a research project to help us understand the benefits of viewing art in a gallery

Interested in hearing more?

Please contact:

**Prof. Paul Camic 01892 507 773 or
paul.camic@canterbury.ac.uk**

What does the Project involve?

- **8 two-hour sessions at the Dulwich Picture Gallery looking at and talking about art**
- **Completing questionnaires and an interview**
- **No previous art experiences needed!**
- **Refreshments provided**



**The University of
Nottingham**

Appendix G: Semi-structured interviews**Questions to participant pairs (historic data)**

1. What was your general experience of the art intervention?
 - What specific aspects did you like/ dislike?
2. Did you notice any positive/negative outcomes?
 - How did FC perceive the experience of the person they cared for?
 - Did the person with a dementia notice any benefits or difficulties?
3. Will you continue with any aspect (viewing or making)?
 - Will you visit art galleries/ museums more?
4. Were any changes in the person with a dementia's concentration or attention noticed?
5. Did the intervention have any impact on your relationship?
 - During or after?

Questions to facilitators

1. What do you think participants got out of the project?
 - Was it different for PWD and carer ?
 - Were there longer-term effects ?
 - Positive or negative effects?
2. What did you notice about the different experiences of art viewing compared to the art making?
 - Was it different for PWD and carer ?
 - Did the type of art affect the experience?
3. Over the 8 weeks, did you notice anything else?
 - Changes in PWD or carer?
 - Social relationships or interaction ?
4. If you did it again, what would you do differently?
 - How did the setting affect the experience?
 - How did the type of art/ gallery impact upon the experience?
 - How did the length or content of sessions affect things?
5. What was your experience of participating in the project?

Appendix H: Information Sheet to Original Participants (Historic, participants with a dementia received a shorter version excluding irrelevant material)

Participant number FCD_____

Version 1: 13.6.11

**'Viewing Together' Art Group Project for Older People
at the
Dulwich Picture Gallery**

Research sponsor: Canterbury Christ Church University

**INFORMATION SHEET
for FAMILY CARERS**

Viewing Together Art Group Project for Older People

Dates: 2.30-4.30pm Tuesday 18 October - Tuesday 8 December
Venue: Dulwich Picture Gallery, Gallery Road, Dulwich, London SE21 7AD

What is the study all about?

The Faculty of Social and Applied Sciences at Canterbury Christ Church University is supporting a research project investigating the benefits of viewing art in a gallery for older people with memory problems and their partners, families or key supporters. A companion project is also being conducted at the Nottingham Contemporary Gallery supported by the University of Nottingham Medical School.

Why have I been chosen?

We are providing you this information because you are a carer of someone with a memory problem. One of the charities we work with or the person you care for has put your name forward as someone who might be interested in participating in an art viewing programme along with the person they care for. This is an information sheet explaining what is involved to help you decide whether you would like to participate.

What is the Viewing Together project?

The Viewing Together project is an eight-week group consisting of up to 10 people with mild to moderate memory difficulties and their carers, for a total of 20 people. Most participants will have received a diagnosis of a dementia in the early to mid stages.

The group will meet once per week for about two hours at the Dulwich Picture Gallery and include refreshments. Viewing and discussing art in a gallery has been found to be a helpful way for people to enjoy themselves, help relax, increase concentration and socialise with other people.

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

No, not everyone, but most people who decide to participate in the Viewing Together project will likely be offered a place. Those people who have a mild to moderate memory problem that are well enough to come once per week for about two hours for eight weeks will be offered a place in the group. We are also asking that you, as a carer, also agree to accompany the person you care for and take part in the group.

Do I have to take part?

Participation in the study is completely voluntary and you may withdraw from it at anytime without giving your reasons and with no affect on the care you, or the person you care for, receive now or in the future, or in your being welcomed to come back to the gallery. In this situation, we would still like to use the information you have provided to us.

Do I have to be knowledgeable about art?

No, not at all. This is a group designed to be enjoyable. People who join the group do not have to know anything about art history or ever had made any art. No one will ever be required to do anything they do not want to do.

What if I want to join the art group but not be part of the research project?

In this case, we can advise you on art groups that run at the gallery or in the community.

What will happen to me should I choose to take part?

If you are interested in taking part in the research project you would be asked to sign a consent form and be expected to join the art group, along with the person you care for, which will run for eight weekly sessions.

Each session of the Viewing Together project will last for about two hours, with refreshments provided. During the course you and the person you care for will be looking at and talking about different pictures in the gallery. This will be followed by further discussion and the opportunity to

make art, if you'd like to give that a try. The group will be run by two facilitators with support from a research assistant.

As part of the evaluation for the group you will be interviewed by a researcher and asked to complete an interview (lasting about 30 minutes) and questionnaires (about 45-60 minutes) about your mood, overall wellbeing and about your daily activities. You will be asked to do this again after the group has ended.

At the end of the group questions will also include your general views of the group and whether it has been helpful. The two interviews (1 before the group begins and 1 immediately after the group has finished) will be audio recorded in order to have an accurate record of what you say. The researcher will discuss what venue and time suits you best for these interviews. Only the researchers and the person who transcribes the tape will listen to the tape.

The art groups will also be audio recorded so the researchers can listen to each group meeting to better understand if it is helpful.

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 dementia _____ (name) may not be able to freely decide to continue to consent to participate over the course of the art group or at the ten week follow-up period. 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 Dr Paul Camic and we will discuss with you if it is best to withdraw _____ from the project. If this were to be the case, please know that we would completely respect and support your decision in the matter.

Will I incur any expenses by taking part or receive any payments?

Unfortunately, we cannot provide payment or pay travel expenses. If travelling is a problem for you, please discuss this with us and we will try and assist you.

What are the possible benefits of taking part and are there any disadvantages or risks?

We hope that you will find the experience enjoyable, that you will benefit from having the opportunity to meet other similar people, and that you will learn ways to use viewing and making art to help increase enjoyment of daily living, but cannot promise this. We do not anticipate any negative side-effects but, sometimes people can at first be a little nervous about joining a new group and about talking about art. This usually stops by the end of the first group meeting. If you remain nervous or uncomfortable we would take care to offer you further advice and support.

What happens when the research study finishes?

We will provide you with a brief written report about the results. We will also provide you with the names and locations of other art groups should you wish to continue.

What if there is a problem?

Should you have any complaint or concern about any aspect of the study or how you have been treated, then please do contact any member of the research team who will do their best to answer your questions.

If you remain unhappy and wish to complain formally, you can do this through the university complaints procedures and contact Professor Margie Callanan, the Chair of the ethics panel that approved this project in the Department of Applied Psychology at Canterbury Christ Church University on **01892.507.672** or by email at margie.callanan@canterbury.ac.uk.

Will my taking part in the study be kept confidential?

Yes, we will not inform anyone you are taking part without your permission. If you like, and with your written permission, we can inform your GP about your participation in the group.

What will happen to the information I give?

Your information will be kept confidential, stored in a locked filing cabinet at the university and will be anonymised when the study report is written so you will not be identified. Information from the questionnaires and

interviews may be made available to other qualified researchers after this study is completed. Information identifying you or the person whom you are caring for will not be disclosed, however. Information from the project will be destroyed 10 years from when the project is completed.

Only in exceptional circumstances, such as if you or someone else was at risk of harm in anyway, would information be disclosed. In such situations, any further action would always be discussed with you first.

What will happen to the results of the research study?

The results will hopefully help us improve our understanding of how group art viewing and art making can help people with memory difficulties and their carers increase the quality of their lives.

The project report will be shared with professionals working in this area as well as published in national or international journal. It is possible that information from the interviews and questionnaires could be used for future collaborations with other colleagues in the UK who are researching in this area. A summary of the findings will also be offered to you.

Who has reviewed the study?

The project is examined by an independent group of people called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by University's Research Ethics Panel on 8 July 2011.

Further information and contact details: Do contact any member of the research team for information and advice about the study:

Project Lead: Professor Paul Camic: 01892.507.773 or
paul.camic@canterbury.ac.uk
(Canterbury Christ Church University)

Art Educator: Sarah Ciacci ciacci.sarah@googlemail.com

**We thank you for all your help with this new project and
look forward to meeting you**

Appendix I: Information Sheet to Researchers/ Facilitators

Participant number _____

A follow-up to 'Viewing Together' Art Group Project for Older People at the Dulwich Picture Gallery

Research sponsor: Canterbury Christ Church University

**INFORMATION SHEET
for Researchers and Facilitators****What is the study all about?**

In October 2011- February 2012 you took part in the 'Viewing Together' project at: Dulwich Picture Gallery, Gallery Road, Dulwich, London SE21 7AD.

You may remember that during the original project participants consented to the data collected being used for further research studies.

To follow on from the research you were involved in, I would like to develop a theory of the affect of the intervention on participants. As part of this I have brought together what participants said about the project in interview. I would also like to know what you, as researchers and facilitators, of the project observed and noticed during the project. This, alongside notes kept during the original project will be used to develop a theory of the potential benefits of such art gallery interventions for people with a dementia and their carers.

Who is the researcher?

I, Erin Baker, will be conducting this research under the supervision of Professor Paul Camic and Dr Victoria Tischler who were involved in the original study. I am a Trainee Clinical Psychologist at Canterbury Christchurch University.

Why have I been chosen?

I am providing you this information because you helped to conduct the original study. This is an information sheet explaining what is involved to help you decide whether you would like to participate.

What will the follow-up interview involve?

I would like to ask you what you thought participants experience of the project was like, for instance, any beneficial aspects or difficult parts

that you noticed. I will ask about your observations about the project and your thoughts about its impact on participants.

The interview will last approximately half an hour and will take place at a venue and time that suits you best e.g. the gallery. The interviews will be audio recorded in order to have an accurate record of what you say. Only the researcher and the person who transcribes the tape will listen to the tape.

Do I have to take part?

Participation in the study is completely voluntary and you may withdraw from it at any time without giving your reasons.

What will happen to me should I choose to take part?

I will contact you to arrange a convenient time and place for the interview (e.g. the gallery).

What are the possible benefits of taking part and are there any disadvantages or risks?

I hope that you will find it interesting to consider what you thought about the gallery intervention and share your observations. I do not anticipate any negative side-effects but, if you feel uncomfortable at any point during the interview, we can take a break or finish the interview. I will take care to offer you further advice and support in case of any distress associated with the interview.

What happens when the research study finishes?

I will provide you with a brief written report about the results.

What if there is a problem?

Should you have any complaint or concern about any aspect of the study or how you have been treated, then please do contact me, I will do my best to answer your questions.

If you remain unhappy and wish to complain formally, you can do this through the university complaints procedures and contact Professor Margie Callanan, the Chair of the ethics panel that approved this project in the Department of Applied Psychology at Canterbury Christ Church University on **01892.507.672** or by email at margie.callanan@canterbury.ac.uk.

Will my taking part in the study be kept confidential?

Yes, I will not inform anyone you are taking part without your permission.

What will happen to the information I give?

Your information will be kept confidential, stored in encrypted and password-protected files on a computer and will be anonymised when the study report is written so you will not be identified. Information from the project will be destroyed 10 years from when the project is completed.

Only in exceptional circumstances, such as if you or someone else was at risk of harm in anyway, would information be disclosed. In such situations, any further action would always be discussed with you first.

What will happen to the results of the research study?

The results will hopefully help to improve our understanding of how group art viewing and art making can help people with memory difficulties and their carers increase the quality of their lives.

The project report will be shared with professionals working in this area as well as published in national or international journal.

Who has reviewed the study?

The project is examined by an independent group of people called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by University's Research Ethics Panel on_____.

Further information and contact details: Feel free to contact me for information and advice about the study:

Project Lead: Erin Baker - eb281@canterbury.ac.uk.
(Canterbury Christ Church University)

Thank you for all your help with this project and I look forward to meeting you

Appendix J: Research Diary

Pre June '12

The research idea was presented as an option for MRP's- I was hooked! The prospect of an intervention in a community facility really appealed to me. I was concerned that perhaps a lack of art knowledge would affect my chances of doing the project but going to see the supervisor he was confident that wouldn't be a problem and offered me the project then and there. After that it was the process of getting university approval. It was fairly straightforward but they specified I must not only consider the 'benefit' as I had written but any negative aspects as well. It reminds me how easy it is to get swept up in what's good about an intervention and not appreciate any drawbacks.

June- Sep '12

Scanning the archival data- Corbin & Strauss (2008) suggest that when using archival data you should sample in the same way you would if you were collecting the data from scratch. However, you need a starting point so I am starting to scan the interviews to get an idea of content and find a transcript that interests me to start off with. It's engaging to read through them but it feels quite detached from what was actually going on. I'm aware of the drawbacks of having not been there and collected this data myself as, for instance, when they reminisce about a particular painting I don't know what it is! I was perplexed as to how to manage that dilemma at first but having looked at the email blog between the facilitators and researchers, and field notes, they summarise the content of different sessions and there are links to the art online. This is really helpful from a practical point of view but will also be helpful when I come to theoretical sampling if anything specific to the art comes up.

At this early stage I'm also aware that I need to acknowledge that these interviews have already been analysed using thematic analysis by Camic et al. (2014) so I need to use those themes as sensitising concepts. Charmaz (2006) said that sensitizing concepts "give you initial ideas to pursue and sensitize you to ask particular kinds of questions about your topics and conceptual emphases." I'm mindful not to be overly influenced by the thematic results since they had only one aspect of the data compared to mine and this is a much more in depth process of analysis, however they may help guide initial coding and sampling.

In scanning the interviews and the facilitator/researcher blog I'm already starting to see areas of interest, particularly around relationships and the environmental aspects of the setting. I will need to bear this in mind when I interview the facilitators to understand what they noticed about carer-PWD relationships and indeed their relationships with the participant which isn't captured in the archival data. The setting/environment intrigues me as I'm noticing both participants at Dulwich and Nottingham contemporary are talking about being relaxed or feeling special at the gallery and yet the galleries and the art could not be more different! Again- something to consider at the facilitator interviews.

Sep- Jan'13

In supervision with my supervisor he advised that interviews with the facilitators should take place ASAP so I arranged them as soon as my project was approved. Now I'm scanning the data and know grounded theory better I'm aware that this pragmatic decision may affect my ability to develop categories (i.e. I may not ask the right questions at interview as I haven't started the analysis). Normally, the analysis would guide the collection of data. I will have read through all the participant interviews and facilitator/researcher blog prior to speaking with the facilitators myself

but I am now questioning whether it would have been wiser to begin coding first. I will ensure that I request permission to contact facilitators should I have questions as I analyse the data. Scanning the archival documents at least has given rise to thoughts about questions to the facilitators so this will have to suffice.

February '13

There are 6 of us using a grounded theory methodology for our MRP's so we have come together as a grounded theory study group! It's great to know we will all be struggling through the process together. We have been discussing the intricacies of grounded theory but also agreed that once a few more of us have started coding then we can have regular meetings to go through examples of coding together. This will be really useful to keep us on track with our coding and to see how our theories go down with one another.

March-April '13 - Interviews

I found myself surprised that the artists involved didn't have a specific motivation to work with PWD but were asked to do it so did so. Talking to N-F2 (and to a lesser degree D-F1) there was a sense of excitement and wonder about such interventions but N-F1 seemed much more pragmatic about it all. It was harder to see an emotional attachment to the intervention. Perhaps this relates more to the professional backgrounds and how people perceived the 'interview' rather than a lack of emotional attachment/investment. I issued an information sheet but perhaps I wasn't clear enough about the aims of the interview, or too clear and limited people. I wonder if people were trying to give academically valid responses rather than just their own personal responses which is what I was really after. I'll think again about this as I transcribe and analyse interview data.

I have asked about the relationships and the implications of other people being around which most interviewees seem less interested in. I'm aware I'm specifically asking about these areas because I'm interested in understanding the process from a Critical Community Psychology perspective but it also came up in Camic et al. (2014) themes and whilst I don't want to be overly influenced I also don't want to ignore potentially important aspects. I am and need to continue to be aware of my bias towards wanting to understand the interventions and for them to be effective in this way. I will need to work hard to monitor this bias and ensure I understand other theories/ ways of thinking about the intervention to create a theoretical understanding that is truly grounded in the data rather than my preconceptions.

Reading

I'm surprised by the interest in measurable outcomes of the interventions. I suppose this is because of the need to demonstrate efficacy but it troubles me. I very much have the idea that this sort of intervention is inherently valuable in and for the moment in which it exists- with or without any resultant outcomes. Is that psychological though? It seems important to me but how does that fit with the medical model the NHS seems tied to?

Reading Eekalar's MRP I again feel distanced from a more holistic conception of the intervention and the reporting of numbers and outcomes seems cold and scientific. My interest in the area is the normality and accessibility of such interventions. I'm drawn to the sense of wellbeing and joy that seem, in a common-sense manner, to be linked to such an intervention. An assessment of the outcomes in a quantitative form therefore feels devoid of the sentiment and 'real' associations I have of these types of intervention. Again my tendency to think in a more community

psychology-based manner is affecting how I'm absorbing and understanding the studies.

May '13

Finishing off transcription of the interviews with facilitators. Really struck by Dulwich facilitators talking about how reminiscence work seems to be focussed upon in literature and in participants experiences of other interventions and how that aspect was disliked. Perhaps because a resounding feature of dementia is memory loss we have become too focussed on memory and making the most of the residual memories, whereas other faculties involved in the present moment are not being made the most of.

D-F1 talked about a project combining music and art and I wondered whether I'm looking at it from a too art-focussed perspective and maybe there are lots of other collaborations that would be good. However, I'm developing a theory about the art so need to stay focussed whilst not blinkered. Should there have been a group discussion about the project at the end...would have been useful for a grounded theory...

July '13

I have started the initial open coding. I have begun with a Nottingham participant interview- N-F2 was infectious with her enthusiasm for the intervention and I wanted to see if the participants were too. This decision is already part of theoretical sampling in that I'm choosing to go to a Nottingham interview because of the engaging interview with the facilitator. Obviously this has the potential to bias my analysis- I need to be open to negative aspects as well as positive, but this seems an appropriate starting point since Strauss & Corbin (2008) indicated you should start at a point of interest when beginning analysis of pre-existing data.

I browsed the Nottingham interviews and started with N2 because the PWD is very vocal about her experience and the setting as she used to work there. There are

some sections that are not particularly relevant, there is a lot of reminiscence which of course is interesting in itself but I can't be sure if this will be relevant to others or just this person. I'm also aware that Nottingham contemporary is fairly newly built so participants will have memories of what was there before or just thoughts associated with the city centre previously. I am astonished how many open codes I'm establishing, I have 40 just from that interview- I can't see how all of them can come together in to something but then I am only on the first interview!

I make the decision that given the importance of the setting and reminiscence about it that it would be helpful to contrast this with a Dulwich interview. N2 had worked in a factory that used to be where the gallery now is- Dulwich was the world's first purpose built art gallery (1811) so the reminiscence will certainly be different from those that participated in the study there. At this stage I have no idea if the setting or the history of the setting is significant to theory development but it provides an avenue to explore and the open codes around place far outnumbered those on any other area in the N2 interview. Strauss and Corbin talk about how sampling should be guided by developing emerging categories and part of that is looking to possible contrasts within the dataset.

I can't know which Dulwich interview will add to this area of coding but opening the first one, D1, by line 12 the PWD says "I first went to the gallery probably about the age of eleven..." Interestingly the FC and the interviewer quickly bring the PWD back round to discussing specifically the 8 weeks but I think it's marvellous that the PWD links the intervention in to the rest of his experience with the gallery. This is a good example of where I would have done something quite differently compared to the interviewer in this existing data and where collecting the data contemporaneously alongside the analysis would have been helpful.

After D1 I moved on to a facilitator interview because of links to differences in the type of art and to introduce a different perspective (facilitator). This led me down a different coding route but t's all adding together now. I'm at 155 open codes and I'm seeing similarities. I have loads of open codes that are similar are seem to link to other codes so I'm making notes of these as I go. I've started to bring these together to form selective codes based on theoretical memos in the previous transcripts. It's time consuming going back and forth between the data but I can see it helps you to make sure your selective codes build on all the examples of an open code rather than just the most recent ones. With all this repetition, and categories starting to emerge I'm moving up to selective coding. It's much quicker and I'm getting few new open codes now, I will still use open coding if I find new codes.

Getting to grips with coding. N-vivo is a bit tricky to use but I want to persevere because I want all my coding to be available to me and anyone else. Supervision with my supervisor made me re-think some of my initial coding- I was trying to get what I considered 'usable' codes- influenced by my reading, my own perceptions and knowledge of speaking to facilitators etc. but this had led me away from the data. My supervisor has re-focussed me on just coding what is in the data- I'm amazed how easy it is to veer away from it and not notice. It's made me think about the quality of previous qualitative research I've done and how difficult it is to know the quality of someone's coding and therefore conclusions.

As I code I'm noticing the importance of the galleries to PWD- they are familiar to some of the individuals and it's allowing them to reminisce and maybe feel more comfortable? I'm not sure what part this plays in it all yet but it's being commented upon and that feels important. Reminiscence → comfort?

August '13

Continuing to code- really starting to enjoy it and feels much easier now that I have moved on to selective coding. I have realised that a lot of the information in the interviews that isn't specifically around the intervention feels really important because it orients you to the person speaking (i.e. the type of person, their relationship with the person who accompanied them) as well as the wider context (how they see themselves, how they consider society to see them etc.) This feels really important in terms of how the theory of the intervention might fit with wider theoretical models and understanding i.e. how is this intervention helpful in the context of how society sees PWD or how they see themselves etc. It feels important to capture this in the theory but at the moment I'm not clear how it all links together and whether most people felt this or not. It occurs to me that the facilitators views on the participants might elucidate possible societal attitudes and I remember NF1 mentioned this in the email blog so I will analyse that source next.

September '13

Focussing on writing Section A before continuing with the coding. My supervisor advised that reviewing the literature would help to direct the analysis and write-up of Section B. This makes sense but I'm already aware that by reading the findings and rationale of other researchers I can't help but identify similar aspects within my own research. This obviously has pros and cons but somehow I can't help feeling it makes the whole process less organic and directed purely by the data and more influenced by the work of others. It will certainly help with the write up of Section B but part of me is curious to know how different my resulting theory would have been had I finished my analysis prior to my literature review and writing section A.

November '13

I have a draft of Section A. I'm aware that the pressure of needing to write the literature review has taken some of my interest out of the research. I'm looking forward to re-focussing on the analysis because I know my interest will be re-captured once I'm absorbed in the actual data again. Constant comparison is key to the analysis- constantly going back to open codes or selective codes that I have already established to ensure the developing theory is truly based in the data- all of the data! I recall that new codes were getting less and less and the theoretical memos were getting more and more familiar. Something was beginning to emerge...

December '14

I'm continuing with selective coding. I'm noticing how easy it is to get caught up in certain engaging perspectives. The coding has become focussed just on the pre-existing codes- I haven't found anything new in the last two transcripts (participant transcripts). It makes me think back to the initial transcript I coded where the participant reminisced on their memories of what use to be there, of Nottingham during the war, of the heritage of the place and associated personal memories. This was compelling and I recall meeting with my supervisor raving about how the place seemed so important and how this might fit with the intervention. I was soon reigned in, reminded that it may be significant but it was too early to tell. Indeed, as I have coded further it seems less and less important, although clearly it was of great significance to that individual.

The iterative and subjective process of coding appeals to me and enables a connection to the research I have not felt before in previous, largely quantitative research. One thing I am wary of is my desire to keep the coding to myself and get lost within it without the interference of others, however I'm aware I need support to

ensure I keep on track and for quality assurance and it may highlight aspects I have overlooked or offer an alternative perspective. The grounded theory group is good for this- it can feel a bit intimidating asking my supervisor to look at it because I feel quite defensive about my coding but when it's peers and you can give insights in to their coding too it feels less intrusive.

January '14

I really need to upscale the selective codes in to categories now using much more theoretical coding. Initially it was quite easy to establish 15 categories just grouping together selective codes. Theoretical memos are really helpful at this point because they help you to see links you saw between data or just thoughts that help you see how things relate. Using constant comparison I was then able to go back and see where there was overlap in categories, how people experiences were different extensions of one aspect. So for instance I had the selective codes: art becoming accessible, overwhelming, feelings of discomfort which might seem quite disparate but actually these are different experiences of one aspect: "competency." So competency has now become a subcategory under "intellectual stimulation".

This process has also involved deletion of categories that were not relevant to the theory, for example, one category was "practicalities" in which participants reflected on ways to improve projects practically such as seating and accessibility. Whilst informative for future interventions this doesn't really contribute to developing a theory around the experience. It feels quite difficult to just discard a category which lots of people talked about but the nature of theoretical sampling is that you are following theoretical conceptualisations and the practical category just doesn't add to this.

This feels like one of the most difficult stages; developing a theory and next examining each category to determine whether it is comprehensible, distinct from other categories, and can be considered to have sub categorical properties. This aspect of the analysis, which again made use of the constant comparative method (Glaser & Strauss, 1967), resulted in the elimination of some categories and the incorporation of others in to superordinate categories. I now have three very distinct categories which reflect different aspects of the intervention: intellectual stimulation, the gallery setting and social relationships. I had respite (i.e. carer's feeling the intervention was break from care) as a category but looking back at the data this is a subcategory of "social relationships." The intervention highlighted the way that the nature of the shared activity enabled a different relationship with the person with dementia, which was in turn experienced as a form of respite from the caring role.

Shared activity/intellectual stimulation = different relationship → respite

February '14

Building the theory- I've turned to pieces of paper with the 7 categories which seem to encompass the important aspects of the intervention:

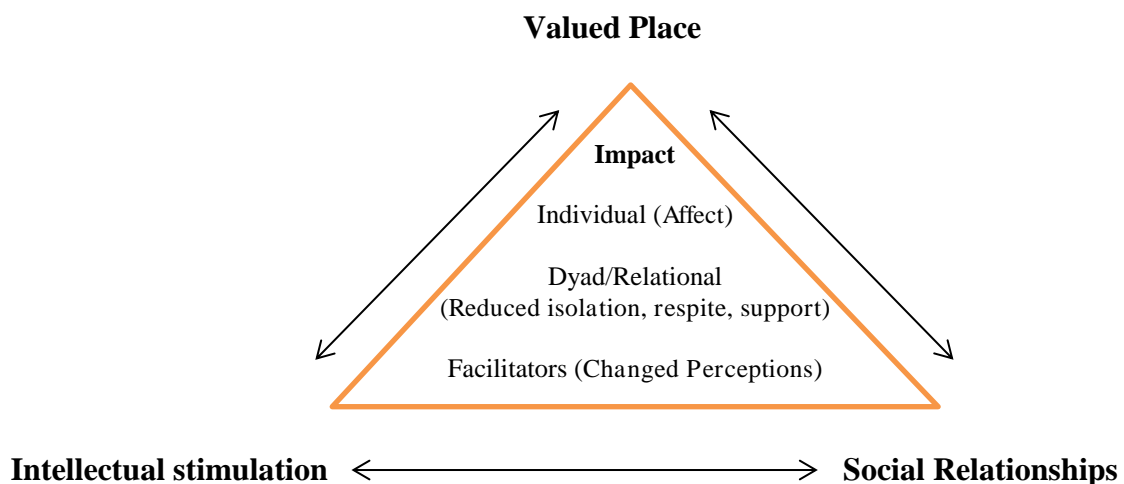
Categories		
Gallery setting	Intellectual stimulation/Learning	
Notable impact...'Wind beneath our sails now'	Positive Affect	
Relationships	Respite for carer	Social interaction

I'm not happy with the titles such as "notable impact" as this tells the reader nothing about what this code means but I can't find a more satisfactory title- I need to capture the changes that PWD, carers and facilitators have noticed- it's that process of having been changed in some way by the experience I want to capture. At the moment I have the categories laid out in a way which I'm not sure how related to GT protocol it

is but it makes sense to me... The unique, special and valued gallery setting facilitated positive affect, intellectual stimulation, respite and social interaction all of which affected relationships of PWD, carers and facilitators and led to a notable impact of changes at individual, dyad, facilitator and wider levels.

Going back to the data the relationship, social interaction and respite are all dimensions of social relationships and positive affect is linked to the impact of the other components so fits under the notable impact category.

There is something about the intellectual, social and setting aspects coming together to facilitate the notable impact:



This diagram demonstrates the three key aspects that come together to produce a result. Here, I have divided them by participant i.e. the individual, dyad and facilitators were impacted as different levels. It's important to develop a clear model that would act as an explanatory blueprint for the impact of a gallery intervention and a basis from which to engage in further research. According to this model there are 3 key components which produce the "notable impact". All of the categories include disparate subcategories but as a whole I think it enables a story about the effects of such an intervention. I will test this out with my supervisor and a non-Psychology colleague to see if this makes sense. Throughout I have made use of the grounded

theory study group to discuss coding to assure the quality of my practice, however when it comes to the wider theory I want to make sure it's accessible to... anyone- not just Psychologists or academics but anyone.

July – Aug '14

Conditions for the MRP stipulate that the theory is not “complex” and needs further working up. I can see how the triangular diagram failed to demonstrate the intricate links between the categories and the subcategories were not included. I think in trying to keep it simple I kept it too simple and the complexity hasn't come across. I need to go back to the data and have a re-think. The examiners suggested I may need more data (!) but I think I just haven't made clear enough the extent of data I had and the fact that I analysed all of it. I definitely did reach theoretical sufficiency, I think where the problem lies is I have not explained it adequately. I have spent so much time with this data the links between the categories seem obvious and I don't think I have demonstrated the depth of analysis nor complexity of the theory. That's not to say I won't go back to the data- I need to do further analysis to develop the theory further and make sure all the connections and explanatory power are clear.

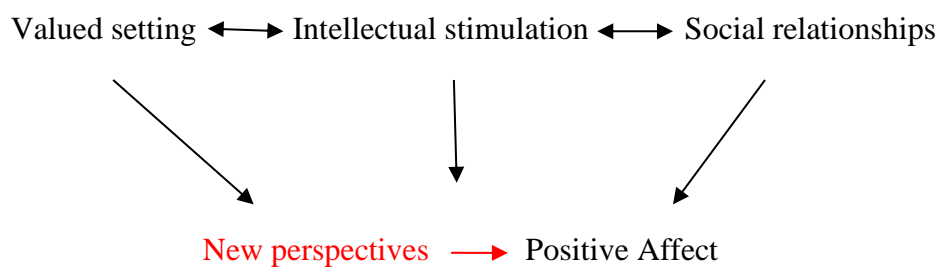
I have tried to create a more complex diagram based on my previous analysis which adequately shows all the links. I'm finding the connections complex and confusing, for one participant it works and for another the arrows don't work. There is a problem with the category “notable impact”- it had always troubled me but I wasn't clear how to resolve the disparateness of the category. Going back to the original data, especially the participants interviews, I can see that notable impact doesn't work as a category- because for some they talked about positive affect but no change in perceptions of the person with a dementia but others don't talk about this aspect. That

doesn't mean it can't be one category but they seem different aspects when I go back to the data.

The three components of gallery setting, intellectual stimulation and social relationships work. It is in the data, it is integral to the experience and they culminate to produce the impact, so these aspects can't change although the subcategories of these need to be illuminated to demonstrate how they precipitate an effect. The examiners seemed concerned that these were too similar to the themes of Camic et al. (2014) study and previous research but to me that's spot on- this theory should be explaining that research so it bodes well if the findings are similar. But I understand that my theory has to say something more- it has to explain why these components come together to produce something. Going back to the data has helped me divide out the category of notable impact in to: positive affect and new perspectives.

The valued and accepting context of the gallery setting was a break from every day life that enabled an intellectually stimulating learning experience to take place for both the person with a dementia and their carer. This stimulation was characterised by engagement and a growing sense of competency and again this was true for both PWD and their carer. The gallery and intellectual aspect facilitated supportive (because the group was like minded and going through similar experiences) social interactions and for some carers enabled an experience of respite from participants' daily lives. The shared experience was often a new way of being with one another and carers saw something different in their loved one which positively affected the caring relationship. Similarly facilitators saw something different in those with dementia because they saw engaged and competent individuals which didn't always fit with a stereotypical view of a PWD. For everyone on the project the culmination of these aspects was positive affect which included enjoyment but also empowerment due to increased confidence

during the intervention and freedom to be creative which they didn't get in other aspects of life.



There is a lot more complexity within each category than I am capturing here- within these dimensions participants spoke about different facets and there was a complex interplay of how these facets affected experience. Participants considered the setting to be special and somewhere different from their day to day lives which resulted in them feeling engaged. Yet the fact that the setting was a community setting also contributed to an idea of art being inclusive and accessible. This engagement and accessibility enabled a sense of competency in some, although others found themselves comparing their current abilities to old ones. I have put new perspectives in red as this wasn't true for all people but I need the model to explain alternative responses to a gallery intervention too i.e. why did some not feel competent? Perhaps the theory can't explain every possible avenue but it should make room for it and allow me to hypothesise why.

Sep '14

The model is a lot more complex and quite a challenge to follow. But at least it better encapsulates all the experiences. The problem of some people not feeling competent is illuminated by the idea of art being accessible- for most this was the case and that was a part of enabling competency. The data suggested that for some the physical deficits stopped art being as accessible and those that felt least competent

were those that had previous art experience so they may have come in expecting more of themselves. For them it wasn't an escape from the impact of a dementia it was a reminder. That affected the carer's perspective too. This isn't an aspect my simpler model could have explained and although I don't venture this model is perfect I think it is sufficient to explain the impact of a gallery intervention and as a theoretical basis for ongoing research. It also better captures the new perspective of carers and facilitators. It's disappointing that I can't capture whether or not the different perspective was ongoing for carers after the intervention but this is a limitation of using the archival data. I can think about this in the discussion.

Appendix K: Ethics Approval Letter

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Appendix L: Example of theoretical memos and sampling decisions

Research diary extract describing initial sampling choice:

I have begun with a Nottingham interview- NF2 was infectious with her enthusiasm for the intervention and I wanted to see if the participants were too. I suppose this decision in some ways is already part of theoretical sampling in that I'm choosing to go to a Nottingham interview because of the engaging interview with the facilitator. Obviously this has the potential to bias my analysis- I need to be open to negative aspects as well as positive, but this seems an appropriate starting point since Strauss & Corbin (2008) indicated you should start at a point of interest when beginning analysis of pre-existing data. I browsed the Nottingham interviews and started with N2 because the PWD is very vocal about her experience and the setting as she used to work there.



Interview transcript NC2 – Theoretical memos:

Line 80 – The participant is having difficulty answering the interviewer's question as they don't seem to be able to remember their hopes about what they would get from participation. This is important as it reflects a problem with post-intervention interview for people with a memory impairment. It may be really difficult for the PWD to express how they felt or what they thought of an intervention as they may not remember it- this may mean interviews are biased toward the carers perspective, the thoughts expressed by the PWD may not be reflective of how they felt at the time (although this could be said for any population) and at worst the process might be upsetting for the individuals if they can't recall the experience.

Line 97- The PWD is talking about the place, the location where the gallery is. They mention going down in to the caves but also that this was where they hung people. It's not clear if this person has positive or negative (or both) connotations with the location. Is this part of the experience/intervention? Is it important? It's a form of reminiscence and shared local memories of the location and was obviously of significance to this person. It's not clear how this links to the intervention or whether this would be of significance to others.

Line 129- The interviewer gives a third prompt to get back to the question they were asking. The participant seems more comfortable talking about memories of the place, this may be because they have little memory of the actual intervention. Is remembering the intervention important? It may not be in regard to the intervention but in regard to collecting feedback from interviews it seems relevant. In this case she promptly talks about a mask she made at the gallery which is relevant to the question- she clearly does remember aspects and the physical souvenir (i.e. having bought this mask home) may have helped her retain something of what they did.

Line 172- 187- There is a reliance on the carer to attend with PWD, so I wonder if this means that the carer is still responsible/burdened? However, the carer acknowledges that she facilitated the PWD to go and that without her she would not have gone. It's not clear how the carer feels about this, whether she minded being there, got something out of it...hopefully this will be considered later in the interview.

Line 252- 279 There is a lot of laughter around the mask that the participant made .It obviously brings positive emotions when the carer and PWD talk about making it. There is some pride in showing it to the interviewer and talking about the facilitator who they based it on. This section of interview is filled with laughter which is stimulated by reminiscence about the project, a physical souvenir they made and the social aspect and humour about having based in on the facilitator (without him knowing). I'm wondering if the physical souvenir is important or this reflects the enjoyment and humour of creating the item or the interactions during the intervention. It's unclear but I can contrast with whether other participants talk about the things they made and things they have kept.

Line 330- 347: The dyad talk about their relationship but this follows numerous prompts by the interviewer. I wonder if this was something the dyad would have spoken about independently or whether the prompts forced the issue.

Sampling decision note: "There are numerous potential areas to pursue, a dominant aspect of this interview was the reminiscence about the setting. The Nottingham gallery is in stark contrast to Dulwich in regard to it's modernity. Dulwich was the world's first purpose built art gallery (1811). As I can't know which Dulwich interview will add to this area of coding I begin scanning the first chronological interview, D1. Strauss & Corbin (1998) recommend the use of chronology for initial sampling as a way to get started. Line 12 the PWD says "I first went to the gallery probably about the age of eleven..." I decide to continue coding this manuscript.



> Interview transcript D1: Theoretical memos.

Line 16: The PWD talks about memories of the gallery prior to the intervention, this is similar to the previous participant who reminisced about the gallery and local surroundings. Is this significant to the impact of the intervention or is this not relevant?

Line 23: The PWD is speaking about the historical aspects of the paintings during the art viewing and the new knowledge they gained. The individual clearly has difficulty remembering the project as they ask 'did someone come around with us?' but then is very eloquent talking about the 'pleasant ambience' of the gallery. I wonder how relevant it is that he has difficulty remembering the project. He goes on to talk about 'dozing off' there is a sense of the environment being relaxing and tranquil. This is adding to the codes regarding the setting but it's quite different to the more reminiscing nature of the previous participants input.

Line 53-80: There is a lot of talk about the paintings themselves, they are remembering details and using these as examples to demonstrate how engaged and focussed they were. There are a lot of codes around learning, the history of art, details about particular pictures which suggest a possible category might be something about the learning aspect. This is another area that can be picked up in future interviews.

Line 84: The setting is mentioned again in regard to it being small compared to bigger galleries where they sometimes feel “overwhelmed”. This may be something else about the place feeling safe? This adds to codes around the place.

Line 166: They are talking about the level of engagement being different at home compared to the gallery, it’s not clear what factors engaged him but it seems linked to the intellectual stimulation?

Line 183: The PWD described the art reminding him he is “inept” although he then goes on to talk about how his maturity gives him a wiser perspective than younger people who might see less in the art. There seems to be something about competency. The art could highlight a lack of competency or competency.

Line 242: The couple talk about increased attention. Both looking at the pictures and making the art. However the interviewer bought this on not the participant so I’m mindful that this might have been the interviewer’s perception rather than something the couple would have bought up naturally.

Line 274: The carer talks about the “shared activity” and how positive it was to do something together. This reminds me of Eeklaar’s work, one of her themes was “shared activity”. I wonder if this will come up for others.

Line 294: The couple talk about how enjoyable the activity was and again link back to learning. This was the cause of their enjoyment. There seems to be a causal link between the learning aspect and enjoyment, at least for this couple.

Sampling decision- This participant talks about the setting as the previous participants from Nottingham did but it’s in a different way. They talked about the empowering nature of a small gallery which felt safe and helped them come out of their shell. This adds to the open codes which relate to the setting but it’s a different dimension to that which N2 spoke about. However, they talked more about it as a social experience and the enjoyment of being with other people. The most notable aspect of this interview is the focus on being stimulated intellectually- feeling really engaged with the interesting artistic material. Learning about something they found interesting. This intellectual aspect was less focussed upon by N2 and it makes me think again about the differences between the galleries. I want to expand my understanding of the intellectual aspect that has come out of the D1 coding and see if this is something that others experienced- if so maybe I’ll go back to the first interview to see if I missed intellectual aspects. I recall in my interview with NF2 she spoke about the difference between the art at Dulwich and Nottingham and wondering how the different types of art would affect people’s experience. Also, having coded two participant interviews I’m curious how the facilitator perspective will illuminate or contrast with the participant data so far.



>Interview transcript NF2: Theoretical memos.

Line 14-27: Facilitator speaks about how even getting to the gallery was a rewarding experience for people as it was going to a “special event.” She goes on to describe it as a “normal sort of social activity,” a break from the normal day to day activities. The

value of the context, of the social support, or the art and intellectual experience has been in both previous interviews but there has been less about the journey and the intervention as an event. Is this another dimension of those aspects or is this different?

Line 31- 34: The value is being linked back to the setting so these codes seem to be linking back to the gallery setting being one of value.

Line 37- 53: The stimulation of the art is spoken about- the abstract nature of the art was of concern in regard to how participants would react but she talks about the engagement and learning of a new vocabulary. The team put together a glossary of terms related to modern art. This really links back to the learning aspect the previous interview underlined. "There seemed to be something going on cognitively, for the PWD".

Line 65: Ownership and growing confidence are talked about in regard to the participants. The facilitator links this to comfort and feeling comfortable in the situation. Does this link back to the relaxing environment the earlier participants described? Or is this about time spent on the project? Or the social aspect?

Line 108: The social aspect is being spoken about more with participants sharing numbers. This frames the social interaction as facilitating social support. The social aspect has come up, as has a break from day to day life but this seems a new aspect.

Line 139: The facilitator mentions the physical souvenirs of the making aspects and how the feedback was stronger for the making i.e. it was more memorable to participants and they enjoyed it more. I'm not sure how this fits with a theory of the intervention...

Line 186: Facilitator spoke about a particularly impactful session and how this surprised and changed her perceptions. It reminds me of how carers have seen different aspects of those they care for. Is this the same or different? For this facilitator it was about seeing those with dementia curate a part of the session. She spoke about their growing confidence to talk- so is it related to the PWD gaining in confidence?

Line 246: Facilitator talks about the participants gaining in confidence and the facilitators giving them more choice to support their growing ownership of the sessions and empowerment.

Sampling decision- The facilitator spoke a lot about confidence, empowerment, social support and relationships. I recall an interview with some participants where the carer seemed concerned the PWD had felt lost at times and that the intellectual aspect was too challenging. That doesn't fit with this idea of participants becoming empowered and increasing in confidence. I will go to this interview next.



Interview transcript D3 – See Appendix N.

I've got 155 open codes now and they are starting to get very similar and themes have started to emerge around place, intellectual aspects, social aspects and feelings of

happiness evoked by the project so I'm starting to escalate my codes to selective coding. This involved taking the most frequent or significant codes forward and using more conceptual codes. I will use open codes where needed for anything new but there are some clear areas emerging now. Coding of D3 will begin at a selective coding level.

Appendix M: List of categories with selective coding and illustrative quotes

Superordinate categories	Subcategories	Selective coding	Illustrative quotes
Gallery Setting	“Ordinary users of an ordinary facility”	“part of a larger group... appreciating the art”	DC4: the fact that sometimes people would come and sit down came and sat down on the chairs sometimes.
		Equal	DC4: People were treating you courteously as equals with something to contribute, so there was equality there – you don’t get it in every situation.
		Getting the pitch right	NP5: He was good at that... ..gaging what we could answer and asking, that sort of thing...
		Normal	NF1: they were with just other people in a normal public space and a couple of people had commented how nice it was to be not in a hospital or some kind of medical centre, so they were doing what everyone else, every other normal person in there was doing and looking at work-that was positive.
	“Somewhere different”	“Something to look forward to”	DC1: Well, I found that they were a very pleasant thing to look forward to on a Tuesday afternoon. Seeing something and learning something about the pictures and paintings plus doing something creative was an interesting one.
		“Lifts you”	DC6: very creative, and uplifting. I would never have guessed that it could be psychologically so uplifting as I found it. It was extraordinary.
		A break from the every day	DP7: It was a different atmosphere then my – here. It was a different atmosphere when we were in the gallery because we were concentrating on those pictures at that time, and we were out, then we were thinking something else, what we had seen when we were inside
		Special event	DF1: a sense of something important, like when you go to the theatre or something you might get a bit more dressed up, and you plan your day differently, so I know

			that's been a big thing.
	A special and valued place	“Luxurious surroundings”	DC5: Its a very comfortable, almost luxurious surroundings and I am not one, we as a family, aren't in for luxury or extravagance at all, but I think this is one instance where a bit of luxury actually makes all the difference.
		Felt valued	NF2: You could see that people in the gallery they felt valued, hence that whole thing of it being a sense of occasion, of getting dressed up, of going in a taxi, of walking around town and it made them feel special.
		Inviting atmosphere	DC4: I think I just generally like to be there, I think its worthwhile place to be looking at paintings.
Intellectual Stimulation	Art feels inclusive	“a subject everyone is interested in”	DP1: And I think the fact is that it is a subject, everybody is interested in. Art what you see, it doesn't usually require, you can appreciate it, because the whole of our existence in life is appreciating a view.
		Learning experience	DC6: I enjoyed the whole learning experience. And for me it was very much that.
		“You can look at something and if it's nice you just know”	DP1: Because it was a very natural thing to, go along and see something, you don't have to use your, you know, you go in there with no pre conceived ideas, and you look along a whole load of paintings, and this must surely apply to anybody, one or two of them stand out and impress you more than others.
		It's not about dementia or being a carer	NF1b: what I saw as giving people an opportunity and a space to re-engage with each other. To not have to work and not be a carer or not be an ill person but to be two people enjoying a painting together and exploring a painting together.
		Competency	Art becoming accessible

		Confidence	NC2: I think she had more confidence there. I think when you'd come back you'd got more confidence.
		"Finding that I knew more than I thought I did"	DC5: I tried and [REDACTED] came round, and she showed a little surprise, I said its no good. Oh she said its better than I expected you to do, and little remarks like that, and that gave me a warm feeling you know. An then each and every week when we went, with the exception of one, where I got in a muddle, it got better.
		Learning from the PWD	DC1: there was a carpenter there who told us about how the chest of drawers were made and he became the expert for a few minutes with all this technical information.
		A "challenge"	NC5: I learnt that you can do whatever you want you know have a go and see what comes out and have another go and that you know it's important. NC2: I enjoy the challenge.
		Overwhelming	NC1: there was one particular time when I was trying to help mum decide what she was going to do with the artwork and she said I just suddenly feel like I can't do anything at all.
		Highlighted some losses in capabilities	DP1: I suppose I was trying to see, it probably takes some time to get back into doing drawing and things like that if you haven' done any for years. Getting back into the experience and reminded possible how inept one was!
	Engagement	"opened one's mind"	NF1: It gave them, those that didn't have it before an entrée in to the world of contemporary art and most of them really didn't know much about contemporary art, so most of them enjoyed that process, being immersed in that world.
		"absorbed"	NC3: You know he was much more happier when he's in that situation. He'll come here and he'll just sit down you know he can look at things here but it doesn't engage him so much.
		"doing something"	NC1: she doesn't get the chance not at home anymore. And it I don't know it just created an opening that wasn't there.
		Facilitators surprised by engagement	Rfn: What struck me was how attentive all the participants were doing the gallery discussion.

		“It did wake me up a bit”	NP5: Well I felt a bit sort of woken up by it and willing to try something else given the opportunity.
Social Relationships	Carer respite and support	Break from every day care	NF2: It was really nice to see how relaxed the carers were as well. Some of them said it was really like respite for them.
		Different relationship with PWD	DF2b: I loved watching some couples just enjoy spending time together as couples, rather than as carer and cared for, while this time, as it was a longer project, it was also wonderful seeing some couples begin the project very tense and stressed and not really communicating positively, but by the end seeming to be communicating with each other differently, perhaps more light-heartedly.
		People rather than PWD and carer	DF2b: it wasn't that someone with dementia was creating their own piece of work and someone was assisting them, they were all being creative.
		A shared experience	DC4: Well I would say I have found it an activity that we have both enjoyed together a great deal. And we have been able to talk about it and look forward to it....
		Peer support	NF2: They were kind of meeting independently of the group so obviously there was some kind of social support mechanism going on for them.
		Difficulty finding the time	NC1: there in lies the issue um I can't deny it wasn't difficult to find the time. I mean it was half the day basically lost so that's half a day's... but I think there's a trade-off.
		Intellectual discussion	NC2: You [PWD] spoke about what you wanted to speak about while we was there didn't you? You always saw something within the [art].
	Interaction	Confidence speaking	NC5: very kind of eloquent about what you saw sometimes...
		Self-expression	DC3: I am talking about the empowering experiences, self expression of course, is my feelings as much as other peoples.
		Stops dyad “becoming isolated”	DC6: you see others who have equal and worse problems than I do, it was relief for me in many ways, as it has been the only

			outing I would get. Apart from where there were others with the same problem, the rest of time it's just the two of us.
		“group of people...that's what makes it”	DP5: I loved to be with other people who had an interest in art and procedure of looking at paintings, and observing, making observations.... So it was lovely to be part of a group who were all similarly interested. That was very, very nice.
		Normalising carer feelings	DC8: And seeing all the other people as well. I watch the pairs... yes.... Because sometimes you feel isolated, less and less, because we get used to it now, but interesting to see..... The first day I saw a mum and daughter and I could see the daughter getting impatient with, but as the times we went she was more patient with her mum.
		Warmth	NP1: Well it was a nice warmth was a part of it straight away there was none of I don't think she might like it, you know. No I quite liked everything straight away.
Positive Affect	Enjoyment	Comfort	NP2: Well it was so interesting what we was doing below which at my time would have been like the dungeons (laughter) I'm sorry but... it were down there and it was so , so nice that everybody you felt comfortable with all the staff and everything.
		Relaxation	DC5: She seemed very relaxed and very comfortable, definitely so in that atmosphere. She was almost like at home. It wasn't strange surroundings at all. She was very unflustered, as time went on she got more so, more relaxed definitely.
		Visual aesthetics	DP5: I just loved to look at paintings. It's hard to say anything particular about it....And emmmhhh, they are so beautiful to see.
		Fun	NP1: I liked having a laugh with the others and getting to know the others was good fun.
	Empowered	Freedom	NP4: Well that was so interesting, it really was. And um you felt as if you were free to do it. You could do what you liked and enjoy it. So I enjoyed it.
		Confidence	NP2: Oh I loved it yeah I thought it was really to me it was sort of um giving you a challenge that I could probably have

			done sort of thing but I've lost a lot of my confidence so that gave me back quite a bit of me confidence.
A new perspective	Carers	Carer saw something new in PWD	NC1: It was nice to see her engaging in answering the question and giving insight in sharing her own knowledge you know and what she thought about stuff. Yeah that was nice.
	Facilitators	Dispelled some commonly held beliefs	DC2: there are a lot of assumptions that PWD can't learn new things, wouldn't be able to take part in something that was so process-led... following quite an in-depth process to get to a final result. Erm and I know that a lot of people who work in art practice veer towards something quite simple just like line drawings or something, or colouring something in, to actually viewing art and making art and being an active learner so to speak. So, I think that has been really interesting for me to see with the participants.

Appendix N: Example of Coded Transcript (D3)

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Appendix O: Summary of Research Findings for Submission to Ethics Panel

A follow-up to 'Viewing Together' Art Group Project for Older People at Dulwich Picture Gallery & Nottingham Contemporary Research sponsor: Canterbury Christ Church University

Dementia refers to a variety of diseases that are characterised by cognitive difficulties and an overall decline in daily living skills. Psychologically-informed arts and health interventions may be particularly valuable ways of improving the lives of people with a dementia and their carers.

This study investigated arts-based interventions at two art galleries where 12 people with mild to moderate dementia and their 12 carers were engaged in art-viewing and art-making. The original intervention consisted of eight two-hour sessions over an eight-week period. In the art viewing an art educator guided discussion about two or more pieces of art within the gallery. After art viewing the group moved to a studio for art making which was facilitated by a professional artist. Each week different materials were provided depending on the art-making task and included water-based paints, pastels, coloured pencils, collage material, glue, quick-drying modelling clay and printmaking supplies.

Post-intervention interviews with participants (n=24) and facilitators (n = 4), field notes and extensive written communication between the facilitators and research team were analysed using a grounded theory approach to establish how the intervention affected those involved.

Results

The significant components of the intervention could be divided in to three key aspects: the gallery setting, the intellectual stimulation and the social relational aspect. The combination of these aspects facilitated both new perspectives on those with a dementia by carers and facilitators and positive affect for those with a dementia and carers.

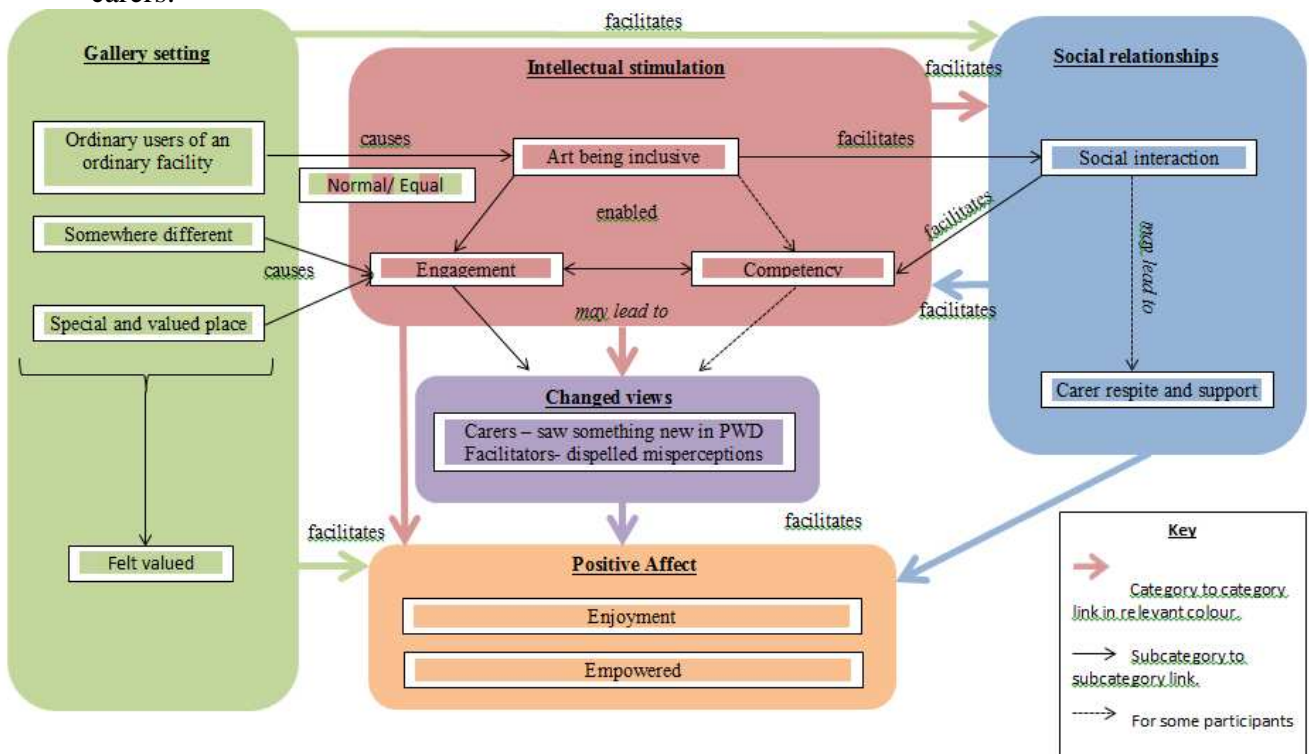


Figure 1. How an art gallery intervention affects participants.

The gallery setting, including the physical environment and interactions with staff, helped to contribute to an overall experience of people feeling special and valued, and thus was an important aspect of the intervention. Feeling special and valued was something different compared to participants' day-to-day lives and not something generally experienced in healthcare settings. The sense of being valued and the inviting atmosphere promoted relaxation and comfort within an accepting social environment. This helped individuals to engage with the intellectual aspects of art viewing and making in a safe space where they could become absorbed in the art and express their thoughts without fearing judgement. This opportunity for social interaction and intellectual stimulation was considered enjoyable and empowering.

The galleries, being community settings, contributed to an idea of art being inclusive and accessible to all. The fact that "you can look at something and if it's nice you just know" meant that art was something anyone could engage with and appreciate, whether or not the person had a dementia, promoting a sense of normalcy and equality. This engagement and accessibility enabled a sense of competency, although for those found comparing their current abilities to former abilities this sense of competency was diminished or not achieved.

The intellectual stimulation facilitated social interaction that for most led to a feeling of enjoyment from being part of a group where support could be sought. In contrast to health or social care, the community setting and "normal learning" experience ensured these interactions were not about dementia but about the stimulation, challenges and enjoyment of visual art; this helped to develop more balanced social relationships, minimising the differences between caring and cared for. In addition, the intellectual experience facilitated a sense of respite for carers where they were not primarily a "carer" but an active participant.

For at least one carer, a sense of respite was not experienced and this was best explained by the person she cared for having failed to achieve a sense of competency (or her carer not perceiving this), undermining the ability of the carer to step out of the caring role. Carers who benefited the most had an experience of seeing those with dementia in a new perspective. The new perspective appeared to be contingent on those with dementia having achieved a sense of "competency", even if that competency was in the moment and always cumulative. Facilitators too shared this experience of seeing those with dementia in a new way.

Future

The resulting theory has potential implications for the use of arts within health and social care by applied psychologists, health and social care professionals, museum professionals, as well as community services. Professionals should consider the use of community facilities as non-stigmatising environments which can add to the psychological and social benefits of an intervention. Groups that are open to individuals with dementia alongside their carers would offer relational benefits that may be lost in groups that divide the carer-cared for dyad. In addition, the theory challenges commonly held misperceptions about the capacity of those with dementia to engage in complex material and warns against underestimating intellectual abilities. The current theory should give healthcare professionals pause for thought regarding how interventions can be effective at an individual, dyad and societal level.

Appendix P: Submission guidelines for intended journal Section A – Journal of Aging (Impact Factor 1.139)

Retrieved from <http://www.elsevier.com/journals/journal-of-aging-studies/0890-4065/guide-for-authors#20100>

NEW SUBMISSIONS

Submission to this journal proceeds totally online and you will be guided stepwise through the creation and uploading of your files. The system automatically converts your files to a single PDF file, which is used in the peer-review process.

As part of the Your Paper Your Way service, you may choose to submit your manuscript as a single file to be used in the refereeing process. This can be a PDF file or a Word document, in any format or lay-out that can be used by referees to evaluate your manuscript. It should contain high enough quality figures for refereeing. If you prefer to do so, you may still provide all or some of the source files at the initial submission. Please note that individual figure files larger than 10 MB must be uploaded separately.

References

There are no strict requirements on reference formatting at submission. References can be in any style or format as long as the style is consistent. Where applicable, author(s) name(s), journal title/book title, chapter title/article title, year of publication, volume number/book chapter and the pagination must be present. Use of DOI is highly encouraged. The reference style used by the journal will be applied to the accepted article by Elsevier at the proof stage. Note that missing data will be highlighted at proof stage for the author to correct.

Formatting requirements

There are no strict formatting requirements but all manuscripts must contain the essential elements needed to convey your manuscript, for example Abstract, Keywords, Introduction, Materials and Methods, Results, Conclusions, Artwork and Tables with Captions.

If your article includes any Videos and/or other Supplementary material, this should be included in your initial submission for peer review purposes.

Divide the article into clearly defined sections.

Figures and tables embedded in text

Please ensure the figures and the tables included in the single file are placed next to the relevant text in the manuscript, rather than at the bottom or the top of the file.

Article structure

Subdivision - unnumbered sections

Divide your article into clearly defined sections. Each subsection is given a brief heading. Each heading should appear on its own separate line. Subsections should be used as much as possible when cross-referencing text: refer to the subsection by heading as opposed to simply 'the text'.

Essential title page information

- **Title.** Concise and informative. Titles are often used in information-retrieval systems.

Avoid abbreviations and formulae where possible.

- **Author names and affiliations.** Where the family name may be ambiguous (e.g., a double name), please indicate this clearly. Present the authors' affiliation addresses (where the actual work was done) below the names. Indicate all affiliations with a lower-case superscript letter immediately after the author's name and in front of the appropriate address. Provide the full postal address of each affiliation, including the country name and, if available, the e-mail address of each author.
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Abstract

A concise and factual abstract is required. The abstract should state briefly the purpose of the research, the principal results and major conclusions. An abstract is often presented separately from the article, so it must be able to stand alone. For this reason, References should be avoided, but if essential, then cite the author(s) and year(s). Also, non-standard or uncommon abbreviations should be avoided, but if essential they must be defined at their first mention in the abstract itself.

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Highlights are mandatory for this journal. They consist of a short collection of bullet points that convey the core findings of the article and should be submitted in a separate file in the online submission system. Please use 'Highlights' in the file name and include 3 to 5 bullet points (maximum 85 characters, including spaces, per bullet point). See <http://www.elsevier.com/highlights> for examples.

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Immediately after the abstract, provide a maximum of 6 keywords, using American spelling and avoiding general and plural terms and multiple concepts (avoid, for example, 'and', 'of'). Be sparing with abbreviations: only abbreviations firmly established in the field may be eligible. These keywords will be used for indexing purposes.

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Define abbreviations that are not standard in this field in a footnote to be placed on the first page of the article. Such abbreviations that are unavoidable in the abstract must be defined at their first mention there, as well as in the footnote. Ensure consistency of abbreviations throughout the article.

Acknowledgements

Collate acknowledgements in a separate section at the end of the article before the references and do not, therefore, include them on the title page, as a footnote to the title

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- Make sure you use uniform lettering and sizing of your original artwork.
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Section B: Dementia (Impact factor: Not established)

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