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Systematic review of arts and culture-based interventions for people living with dementia and their caregivers

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Abstract

Aims: To explore and summarize studies investigating the effect of arts and culture interventions for people living with dementia and their caregivers on the well-being and cognition of the person living with dementia and, caregiver strain.

Methods: We carried out a systematic search of five electronic databases (PubMed, PsychINFO, Embase, CINAHL, and Cochrane Library). We included original research published in peer-reviewed journals including both qualitative and quantitative studies. We assessed quality of included studies using the Cochrane Collaboration's Risk of Bias tools. A narrative synthesis was conducted of all included studies.

Results: Of the 4827 articles screened, 34 articles met inclusion criteria. A variety of interventions were identified, with more than half taking place in a museum or gallery. Five RCTs showed improvements in wellbeing outcomes but no cognitive improvements except in some subscales in a music intervention. Most non-randomised studies reported cognitive improvements and well-being improvements for people living with dementia and their caregivers. Studies primarily focused on individuals with mild to moderate dementia.

Conclusions: The use of arts and culture interventions may provide benefits for people living with dementia and their caregivers. However, heterogeneity of the interventions and outcome measures prevented generalization of the results. Further research of arts and culture interventions for people living with dementia and their caregivers should utilize larger controlled trials, standardized outcome measures and include individuals with moderate to severe dementia.

Key words: Dementia, Arts, Culture, Well-being, Cognition

1.1 Introduction:

Dementia is a neurocognitive disorder in which there is a cognitive decline in one or more of the domains of attention, executive ability, learning and memory, language, perception, praxis and social cognition (American Psychiatric Association, 2013). Based on current trends, the number of individuals living with dementia will increase dramatically from 57 million people currently living with dementia worldwide, to 152 million by 2050 (2022). Approximately 40% of people living with dementia (PLWD) suffer from reduced well-being and depression (Alzheimer's Association, 2019; Leung et al., 2021). Well-being comprises of physical, social and mental domains which can be split into 'hedonic' well-being is centred on feelings such as 'happiness' or 'anxiety' and, 'eudaimonic' well-being which centres on the 'thinking' aspects such as 'life satisfaction' or 'quality of life' (CDC, 2018; Clarke et al., 2020; Dolan and Testoni, 2016). Caregivers of individuals living with dementia often experience negative mood changes due to the challenges of caring for someone with dementia, sometimes referred to as caregiver strain (Brodaty and Donkin, 2009). Caregiver strain can present with symptoms including exhaustion, social withdrawal, sleeplessness, irritability, depression, and anxiety (NHS, 2018). As one of the seven targets of the World Health Assembly's action plan, cultivating positive well-being for people living with dementia and dementia caregivers has become a priority for many health, social care and community organisations.

Over the last few decades extensive research has shown the positive effects of creative arts therapies on the mental health and well-being of the general public and of varying patient populations (Regev and Cohen-Yatziv, 2018; Reynolds et al., 2000; Slayton et al., 2010). There have been documented benefits of art therapies in the prevention of cognitive decline in adults living with mild cognitive impairment and on the well-being of people living with dementia (Emblad and Mukaetova-Ladinska, 2021; Lee et al., 2019). Creative arts therapies come in many different forms from visual art therapy, music therapy, to dance therapy. However, creative arts therapies can be differentiated from arts and culture-based interventions. A key aspect of art therapy interventions is that they are delivered and designed by a trained art therapists rather arts and culture interventions are arts activities that are delivered by researchers, trained facilitators, educators or volunteers (Rubin, 2009). Creative art therapies can be defined as, ' a form of psychotherapy that uses art media as its primary mode of expression and communication' (BAAT, 2022). Whereas arts and culture interventions can be defined as any creative activity involving, "collections, combined arts, dance, libraries, literature, museums, music, theatre, and visual arts" to encompass all forms of creativity (Arts Council England, 2021).

Research has shown the arts and creative activities play an essential role in individual health in the general population (Fancourt and Finn, 2019; Fancourt and Finn, 2020). Participation in arts and culture activities have been demonstrated to provide personal, physical and psychological benefits resulting in emotional and cognitive changes such as reduced stress, depression and reduced symptoms and feelings of burden of chronic conditions (Camic, 2008; Lee et al., 2021; Stuckey and Nobel, 2010). In-line with growing calls for non-pharmacological interventions for people with dementia and research on the benefits of the arts on ageing, there has been increasing interest in the role arts and culture interventions can play in dementia care (Camic et al., 2018; Cohen, 2009).

Several systematic reviews have been undertaken to investigate the effectiveness of arts activities for people living with dementia (Cavalcanti Barroso et al., 2020) but have only looked at specific forms of interventions such as art-making activities. A recent review was the first of its kind to examine the benefits of multiple different types of cultural activities on

people living with cognitive impairment, which found significant improvements in general cognition quality of life, emotional wellbeing and reduction in depressive symptoms (Delfa-Lobato et al., 2021). Carers were often excluded from arts and dementia research or are studied separately from the individual they care for, indicating a clear gap in the literature. To our knowledge, there have been no reviews to date that explore a range of arts and culture interventions and their impacts on both individuals living with dementia and their carers. This review aimed to fill the gaps in previous reviews by providing context to the scope of existing arts and culture interventions while examining these interventions for their effects on the cognition of people living with dementia and the well-being of both individuals living with dementia and their carers.

2.1 Methods:

We used Arts Council England's definition of culture to define the various types of arts and culture interventions to be included.

Protocol and registration

The review protocol was registered on PROSPERO, an international prospective register of systematic reviews (Registration ID: CRD42021236325). Methods for this systematic review followed guidelines from Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (Page et al., 2021).

2.2 Search Strategy

We conducted electronic database searches of PubMed, PsychINFO, Embase, CINAHL and the Cochrane Library from inception to February 15th of 2021. Search terms covered six areas listed below and were combined using the AND Boolean operator. We set no limits in terms of language or publication date. Search terms were modified to match terms in each database

- Dementia: Alzheimer's OR AD OR ADRD OR VaD OR dement*
- Caregiver: caretaker OR informal caregiver OR carer
- Intervention: interventions OR strategies OR best practices OR program* OR trial OR study OR education OR training
- Outcomes: Well-being OR wellbeing, OR well being OR QOL OR Quality of Life, caregiver stress OR caregiver fatigue OR caregiver burnout OR caregiver strain OR caregiver burden
- Cultural Institution: Museum OR Heritage site OR library OR archive OR gallery or Theat*

2.3 Eligibility Criteria

- Study Design: Original research published in peer-reviewed journals describing qualitative and quantitative studies (randomised controlled trials and non-randomised pre/post designs, cohort studies, mixed-method descriptive studies, longitudinal studies, or observational studies) were included. Conference abstracts, letters, reviews and non-peer-reviewed articles were excluded.
- Population: individuals living with dementia and informal caregivers. Informal caregivers were defined as non-professionals who care for the person living with dementia full or part-time. No limits regarding age, gender, race or educational background were set. Studies of participants without a dementia diagnosis or included only specific forms of dementia-related neurodegenerative conditions such as Parkinson's, Huntington's, Multiple Sclerosis, etc., were excluded. Studies that included only professional caregivers were excluded.

Studies that did not include relevant outcomes for the person with dementia and/or their caregiver were excluded.

- **Intervention:** All cultural or arts-based interventions, strategies, activities and programming studies for people living with dementia or carers to people with any form of dementia as defined by Arts Council England's definition of culture. Non-arts or culture-based interventions were excluded. Interventions with a therapy-based approach were excluded. Interventions based on 'healthy lifestyles' such as diet or exercise routines were excluded. Pharmacological interventions were excluded.
- **Comparison:** Studies with or without comparison groups, comparisons within the same group pre- and post-intervention or with a group not receiving an intervention were included.
- **Outcomes:** Studies using qualitative methods or quantitative measures such as the mini-mental state examination (MMSE) or QoL-AD to evaluate participant outcomes of cognitive capabilities and psychological health and well-being were included. Studies that did not provide an outcome analysis or without clear outcome measures were excluded. Studies reporting outcomes unrelated to the well-being of people living or carer, or outcomes unrelated to the cognition of people living with dementia

2.4 Study Selection and data extraction

We conducted searches in each online database separately and exported all retrieved articles to Covidence systematic review software (Covidence, 2020). After removing duplicates from the search results, two authors (PL and SA) independently screened all titles and abstracts against pre-specified selection criteria. PL and SA then independently assessed the full text to determine if selection criteria were met. Specific reasons for exclusion were recorded and disagreements between authors were resolved. Reference lists of included papers and related systematic reviews were screened for potentially relevant articles.

One author (PL) extracted data using Covidence systematic review software, and outcome domains were cross-checked by a second reviewer (SA) to ensure completeness of extraction. Extracted data included study and participant characteristics, intervention methods, and outcome measures. A narrative synthesis approach was utilised to summarise the results and accommodate the complexity of the various types of interventions and to provide clear outcome themes.

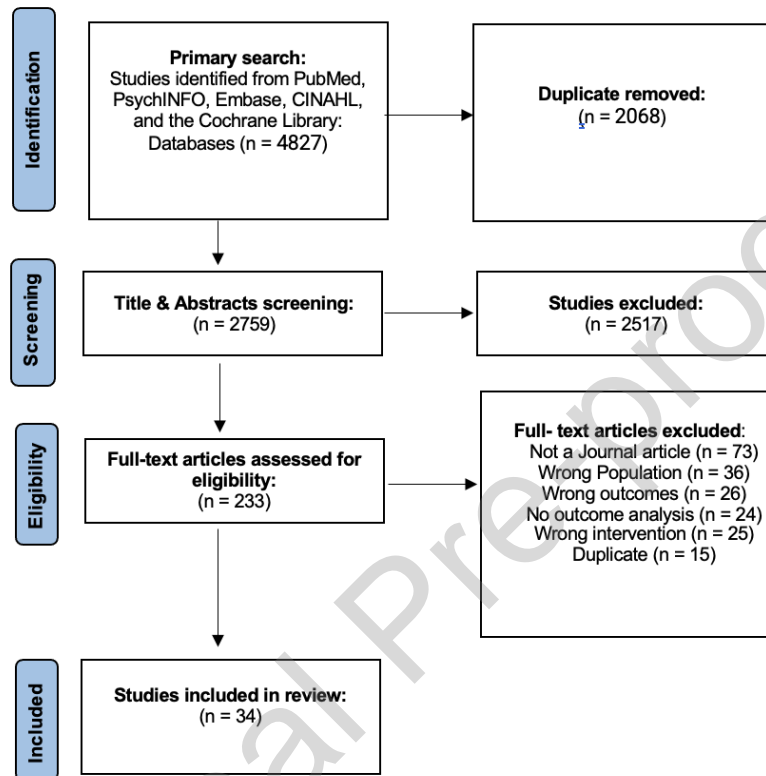
2.5 Quality assessment

Due to broad inclusion criteria, we used two risk of bias tools to assess study quality. To assess randomised controlled trials (RCTs), we used the Cochrane Collaboration's Risk of Bias Tool (The Cochrane Collaboration, 2021), which gauges the risk of bias for sequence generation, allocation concealment, blinding of participants, personnel and outcome assessors, incomplete outcome data, selective outcome reporting and other sources of bias. For non-randomised, mixed-method, and quasi-experimental studies, we used the Cochrane Risk of Bias in non-randomised studies tool (The Cochrane Collaboration, 2021), which gauges the risk of bias due to confounding, selection of participants into the study, classification of interventions, incomplete outcome data, selective outcome reporting, and other sources of bias. Each study was evaluated for each criterion as low, unclear, or high risk of bias. These appraisal tools were selected as they are well-established tools with clear guidance for reviewers, ensuring transparency and minimising bias. After rating each paper independently, the reviewers (PL and SA) met to discuss and resolve any disagreements.

3.1 Results

Study Selection

Our search resulted in 4,827 studies with 2,068 duplicates. 2,759 studies remained for title and abstract screening. 233 full-text articles were assessed, and thirty-four articles fit the inclusion criteria. The PRISMA flowchart is shown in Fig.



1.

Figure 1: PRISMA flow diagram

Study characteristics

A total of 34 studies were included, from the United Kingdom as well as thirteen other countries. Eleven were qualitative studies, 13 used only quantitative assessments and 10 used mixed methods assessments. Five studies were randomised controlled trials. Most studies assessed well-being and cognition for participants living with dementia and assessed the quality of the relationship between the caregiver and the person they care for.

All studies included people living with dementia and informal caregivers of people living with dementia. Eight studies reported the mean age of individuals living with dementia; which was 74.8 to 84.4 years old, three studies reported the mean age of caregivers which was 62.9 to 71.1. Twenty of the included studies disclosed the gender ratios for people living with dementia; seven studies reported the gender ratios for caregivers. Most of these studies had more female than male participants with 63% female participants living with dementia and 75% female carers. Ten studies did not provide caregiver demographics alongside caregiver data, and 9 studies only provided the number of participants living with dementia and caregivers without gender ratios or mean ages. Five studies did not specify

dementia severity. The majority of studies concentrated on individuals living with mild to moderate dementia with only one study centring on people living with moderate to severe dementia. Only seven studies took place in long-term care facilities, with the majority of studies conducted in community settings such as museums, community art centres or day care facilities. The majority of interventions were provided for about six weeks with the longest intervention running seven months and the shortest a one-time session. Four studies did not specify how long the interventions were conducted. Characteristics of included studies are presented in Table 1. Breakdowns of quality assessment and risk of bias can be found in Appendix A.

3.2 Narrative synthesis of intervention effects

All thirty-four studies were classified into five main intervention types: Museum and Gallery interventions with an art-making activity (n=9), Museum and gallery interventions with other activity (n=8), Art-making interventions (n=6), Music-based interventions (n=4), and Other Interventions (n=7) that did not fit into the previous four categories. Of the thirty-four included studies, thirty-two measured for changes in well-being. Of the thirty-four included studies, twenty-five measured for changes in cognition.

Museum and Gallery interventions with an Art-Making activity

Nine studies assessed the impact of Museum and Gallery interventions with an art-making activity. These interventions were delivered by museum or gallery educators or by community artists. In two studies these facilitators received dementia awareness training prior to the intervention (Windle et al., 2018; Young et al., 2015), one study was led by a community artist with previous experience working with people living with dementia (Windle et al., 2020). Five of these studies focused on individuals living with mild to moderate dementia (Camic et al., 2014; Eekelaar et al., 2012; Flatt et al., 2015; Schall et al., 2017; Young et al., 2015), three studies included all dementia severity levels (Belver et al., 2018; Newman et al., 2019; Windle et al., 2018) and one study did not specify dementia severity (Windle et al., 2020). Participants were recruited from aging and dementia services, community venues, and care homes. The number of people living with dementia-carer dyads ranged from six to one hundred. Eight of the nine studies used weekly sessions ranging in duration from 3 weeks to 3 months, and the other delivered a single-session intervention (Flatt et al., 2015). A variety of study designs were employed to evaluate the interventions such as pre- post mixed-methods (Camic et al., 2014; Eekelaar et al., 2012; Newman et al., 2019; Windle et al., 2020; Windle et al., 2018), qualitative (Belver et al., 2018; Flatt et al., 2015), exploratory (Young et al., 2015) and RCT (Schall et al., 2017). Six studies used both qualitative and quantitative measurements such as interviews, Quality of Life questionnaire for people with dementia (DEMQOL)(Smith et al., 2005) and mini-mental status examination (MMSE)(Folstein et al., 1975) (Camic et al., 2014; Eekelaar et al., 2012; Newman et al., 2019; Schall et al., 2017; Windle et al., 2020; Windle et al., 2018). Three studies employed solely qualitative measures such as interviews and session recordings (Belver et al., 2018; Flatt et al., 2015; Young et al., 2015).

Cognitive outcomes

Eight of the nine studies measured cognition in people living with dementia (Belver et al., 2018; Camic et al., 2014; Eekelaar et al., 2012; Flatt et al., 2015; Newman et al., 2019; Schall et al., 2017; Windle et al., 2018; Young et al., 2015). Five studies demonstrated that the intervention was associated with positive changes in cognition, including improvements in memory, verbal fluency and communication for people living with dementia (Belver et al., 2018; Eekelaar et al., 2012; Flatt et al., 2015; Newman et al., 2019; Young et al., 2015). The

remaining three studies reported no improvements to cognition although in one qualitative interview study, caregivers observed the person living with dementia as more present and engaged during the intervention than normal (Camic et al., 2014). Four studies reported improvements in memory, however, these studies used un-coded qualitative measures (Eekelaar et al., 2012; Flatt et al., 2015; Newman et al., 2019; Young et al., 2015). Three studies reported improvements in communication between the person living with dementia and their carer (Belver et al., 2018; Newman et al., 2019; Young et al., 2015) and one study reported a worsening in communication (Windle et al., 2018).

Well-being outcomes

Eight studies measured well-being and quality of life (QoL) (Belver et al., 2018; Camic et al., 2014; Eekelaar et al., 2012; Flatt et al., 2015; Newman et al., 2019; Schall et al., 2017; Windle et al., 2020; Windle et al., 2018). Five studies reported improvements to the overall mood in individuals living with dementia (Belver et al., 2018; Flatt et al., 2015; Newman et al., 2019; Schall et al., 2017; Windle et al., 2018). Three studies reported improvements to self-esteem for people living with dementia (Newman et al., 2019; Windle et al., 2020; Windle et al., 2018). Three studies reported improvements in the relationship between the caregiver and PLWD through qualitative interviews with carers (Eekelaar et al., 2012; Newman et al., 2019; Windle et al., 2020). One study reported no significant changes to well-being for people living with dementia or caregivers, rather well-being remained stable over time (Camic et al., 2014).

Museum and Gallery based interventions with non-art-making activities

Eight studies evaluated the impact of other styles of Museum and Gallery based interventions with a non-art-making activity. Four studies involved a museum or gallery visit accompanied by a discussion of the art and artefacts viewed (Colucci et al., 2010; D'Cunha et al., 2019; MacPherson et al., 2009; McGuigan et al., 2015). Two of these studies included an object handling session as part of the museum or gallery visit (Camic et al., 2019; Johnson et al., 2017). The remaining two studies included immersive reminiscence therapy as part of the museum visit and a story telling activity and art museum visit respectively (Kirk et al., 2018; Loizeau et al., 2015). These interventions were primarily delivered by museum or gallery educators. One study was delivered by specialist volunteers from the host museum (McGuigan et al., 2015). In two studies these facilitators received dementia awareness training prior to the intervention (Camic et al., 2019; MacPherson et al., 2009). Two studies did not specify dementia severity of participants (D'Cunha et al., 2019; McGuigan et al., 2015) and only one study, focused on individuals with any dementia severity (MacPherson et al., 2009). Participants were primarily recruited via local Alzheimer's associations, but were also recruited via local Alzheimer's societies, dementia services and hospitals. The number of person living with dementia-carer dyads ranged from 4 to 80. Six of the eight studies evaluated weekly interventions ranging in length from 6 weeks to 7 months (Camic et al., 2019; D'Cunha et al., 2019; Kirk et al., 2018; Loizeau et al., 2015; MacPherson et al., 2009; McGuigan et al., 2015). Two of the eight studies did not specify the frequency of intervention sessions (Colucci et al., 2010; Johnson et al., 2017). Three studies evaluated the intervention using a quasi-experimental pre-post design (Camic et al., 2019; D'Cunha et al., 2019; Johnson et al., 2017) two employed a qualitative design (Colucci et al., 2010; McGuigan et al., 2015), one a mixed-methods pre-post design (Loizeau et al., 2015), one was a randomized controlled trial (Kirk et al., 2018) and one study used a mixed-subject design (MacPherson et al., 2009). Seven studies used mixed measures such as qualitative interviews, Visual Analogue Scales (VAS)(Wewers and Lowe, 1990) and the Addenbrooke's Cognitive Examination (ACE)(Moisander and Huovinen, 2018) (Camic et al., 2019; D'Cunha et al.,

2019; Johnson et al., 2017; Kirk et al., 2018; Loizeau et al., 2015; MacPherson et al., 2009; McGuigan et al., 2015). One study created a bespoke questionnaire to measure cognitive and well-being outcomes (Colucci et al., 2010).

Cognitive outcomes

Six of the eight studies used cognitive measures for people living with dementia (Colucci et al., 2010; D'Cunha et al., 2019; Kirk et al., 2018; Loizeau et al., 2015; MacPherson et al., 2009; McGuigan et al., 2015). Five studies reported that the intervention was associated with improvements to cognition in individuals living with dementia (Colucci et al., 2010; D'Cunha et al., 2019; Loizeau et al., 2015; MacPherson et al., 2009; McGuigan et al., 2015) and one study reported no significant improvements to cognition (Kirk et al., 2018). Four of these studies reported improvements in memory using varied measurements (Colucci et al., 2010; D'Cunha et al., 2019; Loizeau et al., 2015; McGuigan et al., 2015). Three reported improvements in attention and engagement for people living with dementia (Loizeau et al., 2015; MacPherson et al., 2009; McGuigan et al., 2015). Four studies also reported improvements in communication and verbal fluency for people living with dementia (Colucci et al., 2010; D'Cunha et al., 2019; Loizeau et al., 2015; MacPherson et al., 2009).

Well-Being Outcomes

Seven of the eight studies measured well-being and QoL in people living with dementia and caregivers (Camic et al., 2019; Colucci et al., 2010; D'Cunha et al., 2019; Johnson et al., 2017; Loizeau et al., 2015; MacPherson et al., 2009; McGuigan et al., 2015). Four studies reported improved mood and overall well-being in both people living with dementia and their carers (Camic et al., 2019; D'Cunha et al., 2019; Johnson et al., 2017; Loizeau et al., 2015; McGuigan et al., 2015), one study reported these improvements only for people living with dementia (Camic et al., 2019). Three studies reported improvements to caregiver strain and the relationship between the carer and the people living with dementia (Colucci et al., 2010; Loizeau et al., 2015; McGuigan et al., 2015).

Art-Making interventions

Six studies assessed the impact of art-making activities on people living with dementia and their carers. The majority of studies were delivered by an artist. In one study the artist facilitators received dementia awareness training prior to the intervention (Shoesmith et al., 2020) one artist had previous experience working with people living with dementia (Perez-Saez et al., 2020). One study was delivered by trained student volunteers (Sauer et al., 2016). Two studies focused on individuals with any dementia severity (Kinney and Rentz, 2005; Perez-Saez et al., 2020), two on individuals with mild to moderate dementia (Richards et al., 2019; Shoesmith et al., 2020), one study included only individuals with moderate to severe dementia (Sauer et al., 2016), and one did not specify dementia severity (Pienaar and Reynolds, 2015). Participants were recruited from care facilities or through local Alzheimer's centres. The number of people living with dementia-carer dyads ranged from four to thirty-eight. Two of the six studies took place in a dementia day-care facility (Kinney and Rentz, 2005; Shoesmith et al., 2020), two studies were conducted in a long-term care facility for people living with dementia (Perez-Saez et al., 2020; Sauer et al., 2016), one study was conducted in the arts department of a university (Richards et al., 2019), and one study was held at a healthy aging café (Pienaar and Reynolds, 2015). Five studies used weekly intervention sessions ranging from five weeks to three months in duration. One study did not specify the frequency of the intervention (Kinney and Rentz, 2005). There were two pre-post studies (Perez-Saez et al., 2020; Shoesmith et al., 2020) and one used an ethnographic observational study design (Kinney and Rentz, 2005). One employed a

qualitative evaluation design (Pienaar and Reynolds, 2015) and one study used an exploratory study design (Sauer et al., 2016). Only one study was a randomised controlled trial (Richards et al., 2019). Five of the six studies employed mixed methods such as qualitative interviews, Rosenberg Self-esteem Scale (ROS)(Rosenberg, 1965), GCWBT(Kinney and Rentz, 2005), MMSE, and QoL-AD(Logsdon et al., 2002) (Kinney and Rentz, 2005; Perez-Saez et al., 2020; Richards et al., 2019; Sauer et al., 2016; Shoesmith et al., 2020). One study used qualitative semi-structured interviews to explore participant experiences of the intervention (Pienaar and Reynolds, 2015).

Cognitive outcomes

Only one study measured changes in cognition, reporting that people living with dementia became more social, focused and mentally stimulated through the activities (Shoesmith et al., 2020).

Well-being Outcomes

All six studies measured well-being and QoL for people living with dementia and carers (Kinney and Rentz, 2005; Perez-Saez et al., 2020; Pienaar and Reynolds, 2015; Richards et al., 2019; Sauer et al., 2016; Shoesmith et al., 2020). Two studies reported improvements to mood and overall wellbeing for people living with dementia (Perez-Saez et al., 2020; Sauer et al., 2016) Three studies reported improvements to mood and overall well-being for both people living with dementia and carers (Pienaar and Reynolds, 2015; Richards et al., 2019; Shoesmith et al., 2020). Four reported improvements to self-esteem for people living with dementia (Kinney and Rentz, 2005; Perez-Saez et al., 2020; Richards et al., 2019; Shoesmith et al., 2020). Three studies reported reduced caregiver strain and improvement in the relationship between the people living with dementia and their carer (Pienaar and Reynolds, 2015; Richards et al., 2019; Shoesmith et al., 2020).

Music-based interventions

Four studies evaluated the impact of music-based interventions for people living with dementia and their carers. Three studies evaluated singing (Bourne et al., 2019; Lee et al., 2020; Mittelman and Papayannopoulou, 2018), and the other evaluated music with movement (Cheung et al., 2014). Three of the studies were delivered by experienced musicians (Bourne et al., 2019; Cheung et al., 2014; Mittelman and Papayannopoulou, 2018). One study was delivered by a music therapist, however it was not considered a therapy-based intervention as it was not designed by a music therapist and did not fit within the British Association of Art Therapist definition or arts therapy (Lee et al., 2020). All four studies focused on individuals living with mild to moderate dementia. Two studies recruited participants from care facilities (Cheung et al., 2014; Mittelman and Papayannopoulou, 2018). One study recruited participants from a hospital and one study recruited participants from a pre-existing weekly singing group in the community. The number of people living with dementia-carer dyads ranged from three to fifty-eight. Two studies took place at a local arts centre (Bourne et al., 2019; Lee et al., 2020), one study was held in a church (Mittelman and Papayannopoulou, 2018) and one study was held in a dementia care facility (Cheung et al., 2014). All four studies involved weekly intervention sessions ranging from 6 to 10 weeks in duration. Each of the four studies employed different study designs: a randomised controlled trial (Cheung et al., 2014), pre-post pilot (Mittelman and Papayannopoulou, 2018), pre-post quasi-experimental (Bourne et al., 2019), and phenomenological study design (Lee et al., 2020). All four studies used mixed measures and analysis such as interviews, GDS (Yesavage et al., 1982), ROS, Modified Verbal Fluency Test (MVTF)(Chiu et al., 1997), and interpretive

Phenomenological Analysis (IPA)(Smith et al., 2009) (Bourne et al., 2019; Cheung et al., 2014; Lee et al., 2020; Mittelman and Papayannopoulou, 2018).

Cognitive Outcomes

Three of the four studies measured cognition in people living with dementia (Cheung et al., 2014; Lee et al., 2020; Mittelman and Papayannopoulou, 2018). Two studies (Cheung et al., 2014; Lee et al., 2020) reported improvements to memory. Two studies measured for changes in attention and engagement (Cheung et al., 2014; Lee et al., 2020), and one (Lee et al., 2020) reported non-significant changes. Two studies reported improvements to communication and verbal fluency (Cheung et al., 2014; Mittelman and Papayannopoulou, 2018).

Well-being outcomes

All four studies measured well-being and QoL in people living with dementia (Bourne et al., 2019; Cheung et al., 2014; Lee et al., 2020; Mittelman and Papayannopoulou, 2018). Three of those studies also measured caregiver wellbeing (Bourne et al., 2019; Cheung et al., 2014; Lee et al., 2020; Mittelman and Papayannopoulou, 2018). All four studies reported improvements to well-being and QoL in people living with dementia, although in one study, people living with dementia showed statistically significant increases in composite happiness and optimism scores but not composite overall wellbeing (Bourne et al., 2019). One study reported significant improvements to caregiver self-esteem but not people living with dementia self-esteem (Mittelman and Papayannopoulou, 2018). Only one reported improvements to caregiver strain and the relationship between the PLWD and their carer (Lee et al., 2020).

Other forms of interventions

Seven studies assessed the impact of other arts and cultural intervention types for people living with dementia and their carers: heritage site visit and programme (n=1) (Innes et al., 2021), heritage based activities (n=1) (Li and Li, 2017), performance art (n=1) (Kontos et al., 2017), dramatic performance viewing (n=1) (Maeda et al., 2020), viewing of various types of performance (n=1) (Loewy et al., 2019), theatre activity (n=1) (van Dijk et al., 2011) and creative storytelling activity (n=1) (Vigliotti et al., 2019). Two studies were delivered by trained facilitators (Innes et al., 2021; Vigliotti et al., 2019). Four studies were delivered by professional actors or artists (Kontos et al., 2017; Loewy et al., 2019; Maeda et al., 2020; van Dijk et al., 2011). One study was delivered by the researchers (Li and Li, 2017). Three studies did not specify dementia severity of participants (Innes et al., 2021; Kontos et al., 2017; van Dijk et al., 2011). Another three studies included individuals with any dementia severity (Li and Li, 2017; Loewy et al., 2019; Vigliotti et al., 2019), and one study focused only on individuals with mild to moderate dementia (Maeda et al., 2020). Participants were primarily recruited from dementia care facilities, but one study recruited participants from an existing heritage site programme (Innes et al., 2021), one study did not provide recruitment information (Loewy et al., 2019). The number of people living with dementia-carer dyads ranged from 20 to 103. Four studies took place in a dementia care facility (Kontos et al., 2017; Li and Li, 2017; van Dijk et al., 2011; Vigliotti et al., 2019). The other three studies took place at a heritage site (Innes et al., 2021), performance hall (Loewy et al., 2019) and in the dementia wing of a hospital (Maeda et al., 2020). Six studies included weekly intervention sessions lasting in duration between three and twelve months. One study did not specify if the intervention was multi-session or a single session intervention (Innes et al., 2021). Study designs included pre-post mixed methods design (Innes et al., 2021; Vigliotti et al., 2019), pre-post quasi-experimental design (Li and Li,

2017), pre-post 3-group quasi-experimental design (van Dijk et al., 2011), randomised controlled trial (Maeda et al., 2020), ethnographic observational (Loewy et al., 2019) and qualitative (Kontos et al., 2017) study designs. Five studies used both qualitative and quantitative measures such as interviews, Neuropsychiatric Inventory (NPI) (Cummings et al., 1994) and QUALIDEM (Ettema et al., 2006) (Li and Li, 2017; Loewy et al., 2019; Maeda et al., 2020; van Dijk et al., 2011; Vigliotti et al., 2019). Two studies used only qualitative measures such as specifically designed mood questionnaires, video recordings and interviews (Innes et al., 2021; Kontos et al., 2017).

Cognitive outcomes

Six of the seven studies measured cognition in people living with dementia (Innes et al., 2021; Kontos et al., 2017; Li and Li, 2017; Maeda et al., 2020; van Dijk et al., 2011; Vigliotti et al., 2019). Two of the six studies reported significant improvements in overall cognitive status (Li and Li, 2017; Maeda et al., 2020). Three studies reported improvements in memory (Innes et al., 2021; van Dijk et al., 2011; Vigliotti et al., 2019). Another three studies reported improvements in attention and engagement of PLWD (Innes et al., 2021; van Dijk et al., 2011; Vigliotti et al., 2019). One study reported improvements related to humour including playfulness, ability to co-construct jokes and stories, and demonstrating understanding of humorous acts (Kontos et al., 2017).

Well-being outcomes

All seven studies measured well-being (Innes et al., 2021; Kontos et al., 2017; Li and Li, 2017; Loewy et al., 2019; Maeda et al., 2020; van Dijk et al., 2011; Vigliotti et al., 2019). Five studies reported positive changes to overall well-being and mood (Innes et al., 2021; Li and Li, 2017; Loewy et al., 2019; Maeda et al., 2020; van Dijk et al., 2011). Two studies reported significant reductions to neuropsychiatric symptoms in people living with dementia (Li and Li, 2017; Maeda et al., 2020). One study reported increased self-esteem for people living with dementia (Vigliotti et al., 2019). Four studies reported improvements in the relationship between the caregiver and people living with dementia and caregiver strain (Innes et al., 2021; Kontos et al., 2017; Loewy et al., 2019; van Dijk et al., 2011).

4.1 Discussion

This systematic review identified 34 articles investigating the impact of arts and culture interventions on the well-being and cognition of people living with dementia and their carers. Interventions included museum and gallery visits and activities, performances and performance art, heritage-based activities, storytelling, theatre activities, and music activities. Findings suggest that arts and culture interventions may have beneficial impacts on the well-being of both carers and people living with dementia, the relationship between carer and the person they care for, and improvements to cognitive skills in individuals living with dementia. All included types of arts and culture interventions reported improvements to the relationship quality between the person living with dementia and their carer. The majority of studies also reporting improvements to overall mood and well-being for people living with dementia and caregiver strain in carers. For people living with dementia the majority of studies reported improvements in cognitive domains of attention, engagement, memory and verbal fluency. Our findings are consistent with existing research on the impacts of arts and culture based interventions on the cognition and well-being for people with other forms of neurodegenerative conditions (Barnish and Barran, 2020) and for caregivers of people living with other conditions (Kaimal et al., 2019). Our review adds to existing research by reporting well-being outcomes for both people living with dementia and carers, cognitive outcomes for people living with dementia and improvements to the relationship between the person living

with dementia and their informal carer. To our knowledge this is the first review of its kind to explore the effects of a wide range of arts and culture interventions on the wellbeing and cognition of people living with dementia and caregiver strain within a single review; allowing for a greater understanding of the context of these interventions within the wider field of arts and health.

In qualitative measures, carers and people living with dementia cited that their improved relationship and communication could be attributed to participation in a shared activity outside of a caregiving situation, where they could enjoy the simple act of doing something together. People living with dementia and carers also stated the opportunity to socialise with other people living with dementia and carers as a contributing factor to their improved well-being as it gave them the chance to discuss their experiences and exchange useful information. These qualitative findings suggest that stimulating activities and social interactions are potentially key mechanisms in understanding the cognitive and well-being benefits that arts and culture interventions have to offer. Existing research supports that arts activities that are both mentally stimulating and encourage social interactions are essential to the well-being and cognition of individuals in the general public and people living with dementia (Bosco et al., 2019; Camic et al., 2016; While, 2020).

Evidence from Randomised Controlled Trials

Only five randomized control trials fit inclusion criteria for this review. Detailed information about these studies can be found in Table 1 and information on the quality of these studies can be found in Appendix A. All five RCTs utilized different intervention types: immersive reminiscence in a museum (Kirk et al., 2018), museum visit and art activity (Schall et al., 2017), art making activity (Richards et al., 2019), music with movement activity (Cheung et al., 2014) and a dramatic performance viewing (Maeda et al., 2020). The majority of these studies reported improvements to well-being and cognition for people living with dementia (Cheung et al., 2014; Kirk et al., 2018; Maeda et al., 2020). One reported improvements to well-being in people living with dementia and carers but not cognition in people living with dementia (Schall et al., 2017) and another did not measure well-being and reported no cognitive improvements in people living with dementia (Kirk et al., 2018).

4.2 Implications and recommendations for future research

Given the increasing prevalence of dementia, the benefits of arts and culture interventions for people living with dementia and their informal caregivers must be explored further. The findings of the current review suggest that arts and culture interventions offer benefits for people living with dementia and their carers. The majority of included studies reported the positive effects of arts and culture interventions on the well-being for people living with dementia and their carers. These findings are consistent with broader existing research on the benefits of the arts on health and well-being. Arts and health can help in a variety of health and well-being conditions including ageing, long-term conditions, loneliness, recovery and mental health; even providing relief to carers, health services and social care services (Marmot et al., 2017).

This review indicates apparent gaps in the types of arts and culture interventions offered as there were little no interventions in for some types of arts and culture such as dance, literature or heritage sites. This review also indicates an imbalance in interventions for different severity levels of dementia. Seventeen of the included thirty-four studies focused only on participants with dementia in the mild to moderate range and in the nine studies that included people living with any dementia severity, most of the participants were living with dementia in the mild to moderate range. Five studies did not specify dementia severity of the participants living with dementia. Only one study focused on individuals with moderate to

severe dementia (Sauer et al., 2016). Findings from one study suggest that people living with dementia in the mild to moderate range might experience a greater increase in self-esteem, attention/interest, pleasure and improved cognitive outcomes such as reminiscence than those in the moderate to severe range (Vigliotti et al., 2019). It would be informative to understand the differences, if any, in the impact of these interventions on people at different stages of dementia and how benefits may change with dementia severity level. We recommend that future studies aim to have balanced participation of people living with all stages of dementia and compare impacts across severity levels.

More than half of the included studies took place in a museum or gallery setting, studies that involved a comprehensive range of intervention activities such as going to a heritage site (Innes et al., 2021), viewing a performance (Loewy et al., 2019) and interactive theatre activity (van Dijk et al., 2011) suggested that alternative forms of arts and culture interventions can also provide benefits for people living with dementia and their carers. Only seven studies were delivered at the participants place of residence, suggesting there is a lack of research in out-reach programming for people living with dementia who are unable to travel to a secondary location. Findings from studies suggest that neuropsychiatric symptoms that negatively impact well-being such as agitation and delusions might significantly decrease for people living with dementia when interventions are delivered at their place of residence (Li and Li, 2017; Maeda et al., 2020) compared to a secondary location like a museum (Schall et al., 2017). Additional interventions involving a range of activities separate from visual art and museums and delivered at the participants place of residence should be studied further to explore their potential benefits. Further small-scale studies, particularly in museum or gallery settings, will not add to the knowledge base. Larger studies are needed to fully understand both the effects of these interventions on people living with dementia and their caregivers as well as any differences in the effects of type of arts and culture intervention may have.

Only eight of these studies employed follow-up measurements ranging from one month to six months follow-up. These studies primarily reported continued positive effects on well-being and cognition for people living with dementia and improvements to carer well-being at follow-up. However, given the limited number of studies that conducted follow-up and the range of follow-up times our confidence in the long-term effects of these interventions is limited. Future studies should provide multiple follow-up points over at least six months so that the long-term effects of arts and culture interventions for people living with dementia and their carers can be better understood.

Only one study involved people with lived experience of dementia in the designing of the intervention. Public involvement in health and social care matter is essential to understanding and improving health and well-being (Government, 2012). It would be beneficial to use personal and public involvement (PPI) for future or co-produce interventions in the future to better understand the needs and perspectives of people living with dementia and their carers.

As many studies reported benefits of socialisation and shared activities through qualitative measurements, future studies could benefit from utilising intervention specific measurements to measure outcomes related directly to the aims of the intervention as well as standardised measures such as the MMSE and BI to provide a bespoke understanding of intervention benefits. We also recommend conducting supplementary studies that further explore improvements to negative feelings and emotions, especially measurements for caregiver strain.

Arts and culture interventions for people living with dementia and their carers are varied and complex; a more systematic approach is needed to develop them further and evaluate them. To aid in collecting statistically significant data, we recommend employing

larger sample sizes, including a range of participants in various stages of dementia, determining effect sizes of outcome measures to test efficiency and, given the varied study designs found in this review, we recommend using randomised controlled designs whenever possible to establish effectiveness in a rigorous manner and compare the intervention outcomes to control groups. We also recommend that future studies include a clear and detailed description of the intervention, delivery modes, and any intervention-specific training that practitioners delivering the programme receive, as this information was not provided in the majority of included studies and might help to identify and understand the mechanisms of action by which the intervention might achieve its intended outcomes. When measuring mental health and well-being outcomes, future studies should collect information on any relevant medication prescriptions meant to alter mood, such as antidepressants, as these medications might impact outcome results. We recommend that future studies use arts and health based frameworks such as the INNATE framework to support the design, implementation and evaluation of arts and culture interventions for people living with dementia (Warran et al., 2022). The use of frameworks like INNATE or the WHO's new 'Guide to evaluating behaviourally and culturally informed health interventions in complex settings,' would help to design and evaluate more structured studies and provide a deeper understanding of the mechanisms of change these arts and culture interventions have for people living with dementia (Scott et al., 2022).

4.3 Strengths and limitations of the review

To our knowledge, this is the first review of its kind to assess a broad range of arts and culture interventions currently used within dementia research. We had an inclusive search strategy in five databases, screening and quality rating were carried out independently by two raters and we used robust quality assessment tools.

A meta-analysis was not possible due to the heterogeneity of data. However, the qualitative data provided was sufficient to enable a narrative synthesis that informed recommendations for further research. Limitations of the review were that we did not include search terms for types of interventions or cognition which could have meant we omitted some studies. However, as dementia is a neurocognitive disorder, cognitive outcomes were retrieved in searches. We did search for arts and heritage settings and used other reviews and reference lists to identify more possible studies for inclusion. The limitations of included studies were primarily their inconsistent outcome measures and reporting which affected the confidence of conclusions made in this review. However, we acknowledge that arts and culture interventions for people living with dementia and their informal carers can be challenging to conduct and evaluate due to the complex nature of dementia and challenges associated with working with this population. However, if there is evidence that an intervention can provide improvements to mental health or cognitive skills, then it should be encouraged.

4.4 Conclusion

This narrative synthesis systematic review assessed 34 articles that used art and culture interventions to improve wellbeing and/or cognition for people living with dementia and the wellbeing of their informal caregivers. Our findings suggest that participation in arts and culture interventions improved well-being, QOL, and cognitive skills and functions. Evidence from randomised controlled trials shows that arts and culture interventions may be associated with improvements to cognition and well-being, however these studies were relatively small. Larger scale randomised controlled trials would need to be conducted to provide confidence in the effects of different types of arts and culture interventions for people living with dementia. The most listed positive effects from qualitative measures of these

interventions were improved well-being for people living with dementia and carers, improved communication, and socialisation in people living with dementia and improved person living with dementia-carer relationships. Expanding participation to those living with moderate to severe dementia and their informal carers, larger and additional randomised controlled trials and more robust assessment of outcomes is needed to more thoroughly examine the effects of these interventions.

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Highlights:

- 30 out of 34 studies reported well-being improvements
- 17 studies involved a museum or gallery visit
- Only 1 study focused on participants with moderate to severe dementia