

## **The impact of including carers in museum programmes for people with dementia: A realist review**

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## **Abstract**

**Background:** 'In the moment' museum programmes for people with dementia (PwD) are an increasingly popular way of supporting people to live well. Most programmes include carers, though it is not well understood what effects, if any, their inclusion has. This review aimed to understand how including carers in museum programmes impacts the PwD, the carer, and the relationship between them.

**Methods:** A realist review of peer-reviewed and grey literature was conducted to develop theory in answer to the research questions.

**Results:** Twenty-three documents were included and 15 theory statements were developed within four themes: seeing the PwD in a new way, shared respite, excess disability, and reduced social isolation.

**Conclusions:** As both positive and negative impacts were found, it is important to consider that programmes may not be beneficial for all dyads. The review offers recommendations to support positive outcomes for dyads, highlights gaps in the literature, and suggestions for further research.

## **Keywords**

Dementia; museums; carers; realist review

## **Introduction**

There is increasing interest in finding ways to support both people with dementia (PwD) and carers to live well. Recent research suggests the relationship between the PwD and their main carer, and social engagement or connectedness, may be important factors in wellbeing in dementia (Martyr et al., 2018; O'Rourke, Duggleby, Fraser, & Jerke, 2015).

Cultural arts interventions may improve general wellbeing and quality of life, communication, and cognitive function (Mental Health Foundation, 2011). Shared community-based arts activities for both PwD and their carers, may support connectedness within their relationship and the wider community (DiLauro, Pereira, Carr, Chiu, & Wesson, 2017). Shared activities include singing (Camic, Williams, & Meeten, 2013), drama (Lepp, Ringsberg, Holm, & Sellersjö, 2003), and art-making (Eekelaar, Camic, & Springham, 2012).

Museums are one place providing shared arts activities. In the early 2000s, New York's Museum of Modern Art developed an art-viewing programme for PwD and their carers in which the focus is on 'the moment', rather than reminiscence (Rosenberg, 2009). Many museums have since started their own programmes, with some including different activities such as art-making and object handling. Though memories may be triggered by the activities, the focus is not on 'remembering' but on the person's views and feelings in that moment, with the aim that this way of questioning and discussing allows people with and without dementia to participate on an equal basis. Additionally, although the activities are designed and adapted for PwD, it's not about dementia or explicitly talking about dementia. In most, a carer, friend, or family member attends with the PwD and everyone takes part on an equal basis. This 'enjoying together' as a dyad is often one of the explicit aims.

There has been some evaluation of museum programmes (e.g. Burnside, Knecht, Hopley, & Logsdon, 2017; Camic, Baker, & Tischler, 2016) and many studies assess outcomes for the carer as well as the PwD, or outcomes for the dyad as a whole. Most studies report positive outcomes but two studies described negative outcomes related to including carers. MacPherson, Bird, Anderson, Davis, and Blair (2009) found that, during their museum programme, professional carers created "excess disability" (Brody, Kleban, Lawton, & Silverman, 1971) in participants with dementia in that carers answered and did tasks for PwD that they were able to do themselves once the carers left. On this basis, a recent large-scale evaluation of visual arts programmes (Windle, Joling, et al., 2017) made the participation of carers optional. They noted that "the presence of staff and carers on occasion required careful management by the artist-facilitators" (p13), but did not give further detail on what extent facilitators needed to intervene, how, or what impact it had.

There may also be negative impacts on carers themselves. For example, a dyadic reminiscence therapy trial found carer stress increased with the number of sessions they attended (Woods et al., 2016), and some models of family caregiving suggest that at times carers need to detach emotionally from the relationship to avoid negative impacts on mental and physical health (Ablitt, Jones, & Muers, 2009), a finding that is at odds with the intention of these programmes to enable closeness.

Since most programmes include carers, it is important not to overlook the impact of including them. This review aims to synthesise current research to examine how including carers in museum programmes for PwD impacts the PwD, the carer, and the dyad as a whole.

## **Review questions**

1. How does including carers in museum programmes for PwD impact the PwD, the carer, and the relationship between them?

Secondary questions:

- a. Is this different for different levels of impairment, for family vs professional carers, or for types of museum activities (such as art-making or art-viewing)?
- b. Do the impacts extend beyond the 'moment' of the group, or are they only or mainly experienced while at the museum?

## **Methods**

A realist approach to synthesis was chosen for a number of reasons. Realist approaches are designed to answer explanatory questions – rather than whether something works, it asks how, why, and in what circumstances (Pawson, Greenhalgh, Jarvey, & Walshe, 2005), which is a better fit with the review aims. Additionally, the approach includes an underlying assumption that programmes will not work for everyone at all times or in all circumstances, and the research aims to consider both positive and negative impacts. Finally, a key difference between realist and conventional systematic reviews is the product of realist reviews is evidence-based theory in answer to the research questions. Little research explicitly examines the impact of including carers, and this approach aims to identify underlying theories which may not be explicit.

Realist theorising is conceptualised using context-mechanism-outcome (CMO) configurations, where the interaction between the context and mechanism leads to the outcome. Contexts are factors outside the programme, such as participant characteristics or social environment. Mechanisms are participants' reasoning and reactions to the programme's resources (e.g. Pawson & Tilley, 1997; Wong et al., 2016).

No changes were made to the protocol on PROSPERO (ID: CRD42018092399).

### **Developing initial theory**

The initial rough theory to guide the review was developed through spending time as a participant and volunteer on a programme at a local museum and informal stakeholder conversations with staff at three museums. Additionally, an initial informal scoping of the literature was undertaken to find existing research and theories on how the inclusion of carers may impact on outcomes. This initial scoping was combined with the informal stakeholder discussions and experience on the programme to create the initial theory to frame the review. Initial theories are given in Supplementary File 1.

### **Search strategy**

The search strategy was iterative; as relevant studies were located, initial theories were refined and refuted and new theories created, which in turn led to new areas of literature.

The first stage was a broad search of museum programmes and PwD in electronic databases chosen as most likely to include relevant literature, including Web of Knowledge, Medline, and PsycInfo, using the keywords (museum\* OR "art gallery" OR galler\*) AND (dementia OR Alzheimer's OR "Alzheimer's Disease" OR "mild cognitive impairment" OR MCI). Forward and backward citation searching of included papers was conducted, and authors of documents were contacted for unpublished supplementary material. A grey literature search was performed through email lists for the arts in dementia or museums, searching museums' websites, and searching ProQuest for dissertations. Grey literature was included to reduce the risk of publication bias (Paez, 2017), particularly as in-house museum evaluations may not be published academically.

After synthesising evidence from included studies from the first searches, gaps in theory development were identified. This led to one further iteration of searching – outcomes for PwD

when carers were not included. Results from the first search were reviewed to identify programmes that did not include carers as these outcomes were not included from the first search.

### Inclusion and Quality Appraisal

Documents were included if they had relevance to the research questions. Specifically:

1. The programme explicitly included PwD, as the way programmes are organised and facilitated may differ significantly for people without cognitive impairment or acquired progressive illness;
2. It included outcomes or processes related to the impact of including carers in non-remembrance museum programmes for PwD;
3. The programme, or part of, took place in a museum, art gallery, or similar setting.
4. Written in English;
5. Dissertations were included if they met the above criteria and provided insights additional to those in any published articles derived from the work.

Consistent with a realist framework, there were no inclusion criteria based on study methodology, to avoid missing pertinent evidence.

All papers in the first stage 'museums and dementia' search were assessed for inclusion by two reviewers independently (DK, DP) and any discrepancies discussed and agreed upon. The remainder of documents were assessed by one reviewer (DK).

Quality appraisal in realist review is not based on a hierarchy of methodology (such as randomised control trial versus case study), but is judged on the relevance and rigour of evidence within studies. According to the RAMESES guidelines (Wong, Westhorp, Pawson, & Greenhalgh, 2013, p9) this is defined as:

- "Relevance - whether it can contribute to theory building and/or testing; and
- Rigor - whether the method used to generate that particular piece of data is credible and trustworthy".

The RAMESES guidelines do not recommend using a strict checklist to assess methodological quality given a wide range of documents and parts, rather than the whole, of a paper may be included. Each fragment of evidence is considered within the synthesis as a whole, rather than in isolation – relevant data that has lower trustworthiness may be supported by other data with higher trustworthiness (for example, a theory put forward in a discussion section may be supported by empirical data in another paper). The quality of the review as a whole is based on this data trustworthiness, but also on the coherence of the theories developed. 'Coherence' is judged by explanatory breadth, simplicity, and analogy (fitting with existing knowledge and substantive theory; Wong, 2018). Appraisal of document quality therefore occurred in parallel with synthesis, and was related to the relevance and rigour of the section being used in the context of how it was used (Pawson, 2006a).

### Data Extraction

Included documents were imported into NVivo and coded for contribution to theory in relation to the research questions. Nodes were not created in advance. Documents were coded thematically, for example for outcomes such as "shared respite" or for proposed theory. Each document was reviewed at least three times to ensure new themes found in other papers could be assessed, and

that evidence was not missed. This process enabled the identification of a number of themes which linked to evidence in sections of included documents.

### Data Synthesis

The synthesis aimed to develop theory in relation to the research questions, and identify gaps in the literature. Patterns of mechanisms, contexts, and outcomes were identified across included papers, and, as per Pawson (2006b), evidence was juxtaposed, adjudicated, reconciled, consolidated, and situated, to refine and develop theory. This was completed both within and across themes, but always within the context of the particular document to ensure contexts, mechanisms, and outcomes were assessed in configuration (Pawson & Manzano-Santaella, 2012). For example, 'shared respite' may be an outcome in one configuration but a context in another, as its function in explanation may be different for different theories. Iteratively examining the data at both the level of quotes from the documents and the level of broader themes integrated categorising and connecting analytic strategies (Maxwell, 2012).

### Search results

#### First search – museum programmes and dementia

Searching electronic databases yielded 54 unique citations. Titles and abstracts were reviewed against the inclusion criteria, and 33 were reviewed as full text. Following full text review, 13 papers were included. Forward and backward citation searching led to a further seven documents, and searching ProQuest led to two relevant dissertations. No further relevant documents were found through museum email lists or websites, or contacting authors.

#### Second search – programmes not including carers

Using the results from the first search, 11 citations were reviewed as full text. Of those, three papers describing museum programmes for PwD that did not include carers were identified, which included 1 document not included after the first search.

In total 23 documents, reporting on 21 separate studies, were included (18 journal articles, three non-peer-reviewed reports, and two dissertations). The included documents are summarised in Supplementary File 2. A flow diagram of the search process is given in Figure 1.

*Figure 1: Search and inclusion flow diagram*

### Results

The synthesis resulted in 15 programme theory statements within four themes. These are presented below with supporting evidence. Unless the mechanism could not be separated into resource and reasoning, the theory statements use Dalkin et al's (2015) method of structuring CMO configurations whereby the mechanism's resource (M/res) is introduced into a context (C), which together change the participants' reasoning or behaviour (M/rea), leading to the outcome (O). Elements of the statements which were not apparent in the included literature but have been theorised are presented in italics for transparency.

#### Theme 1: Seeing the PwD in a new way and relationship-building

The outcome 'the carer seeing the PwD in a new way' is supported for family carers (Clarke-Vivier, Lyford, & Thomson, 2017; Johnson, Culverwell, Hulbert, Robertson, & Camic, 2017; Mittelman & Epstein, 2006), professional carers (Roe et al., 2016), and in programmes with mixed or unspecified carer types (Baker, 2014; Burnside et al., 2017; Camic et al., 2016; Gould, 2013; Hazzan et al., 2016;

Humphrey et al., 2017; Lamar, 2015; Lamar & Luke, 2016; Mangione, 2013). However, one study (Lamar, 2015) reported some carers specifically stated the programme did not change how they saw the PwD due to having long-standing relationships.

'Building relationships' as an outcome is supported for family carers (Clarke-Vivier et al., 2017; Eekelaar et al., 2012; Gaugler, Mojsilov, & Gerber, 2010; Mittelman & Epstein, 2006; Schall, Tesky, Adams, & Pantel, 2017), professional carers (Roe et al., 2016), and in programmes with mixed or unspecified carer types (Baker, 2014; Burnside et al., 2017; Camic et al., 2016; Camic, Tischler, & Pearman, 2014; Gould, 2013; Hazzan et al., 2016; Humphrey et al., 2017; Lamar, 2015; Lamar & Luke, 2016; Livingston, Fiterman Persin, & Del Signore, 2016; Mangione, 2013). One study (Lamar, 2015) reported that, while a majority of carers reported a positive impact on their relationship, four carers felt it had no impact.

*Theory statement (a)*

**When the facilitation enables the PwD to 'maximise capacity' to participate (M/res) and the carer's expectations of the PwD are low (C) and/or others in the group highlight the PwD's capabilities (C), the carer perceives the PwD to have achieved competency (M/rea), so the carer sees the PwD in a new way (O), which also helps to build their relationship (O).**

Baker (2014) explicitly theorises that the carer seeing the PwD in a new way is contingent on the carer perceiving the PwD to have achieved 'competency'. On the basis of participant and facilitator interviews, Baker (2014) (and Camic, 2016, based on Baker) suggests sharing an engaging experience in a stimulating environment and the carer seeing the PwD making competent contributions allows the carer to see the PwD in a new way. Other studies also support this theorising. Mangione (2013) includes quotes from carers discussing seeing their partners with dementia making astute or insightful contributions and describing themselves as marvelling or feeling emotionally overwhelmed at the experience. Similarly, Lamar (2015) includes quotes from carers about learning something new about the PwD, and reported that in some cases the emergence of the artistic side of the PwD led the carer to see the PwD as more 'capable' than before. Johnson et al. (2017) discuss the idea that carers gain new understanding of the PwD's abilities. Baker (2014) also includes comments by facilitators suggesting a carer was able to see her partner in a new way through seeing his contribution through others' perspectives.

However, no studies report on whether these effects (both the carers' new perceptions and resulting relationship-building) are maintained long-term. None of the studies suggest what it is about the context of the dyad which generates the mechanism. It has been theorised here that the carer having lower expectations of what the PwD is capable of than they are actually able to achieve is the context. However, this is likely inadequate and will be examined in the discussion.

*Theory statement (b)*

**Professional carers only have a relationship with the PwD in a work context (C) but take part in a shared activity outside of the work context (M/res) and are able to get to know the PwD beyond dementia (M/rea), which builds their relationship (O)**

Following interviews and observation, Roe et al. (2016) describe how the programme enables care staff to see those they care for in a social, rather than care, context, and gives staff new things to discuss with residents which helps bonding. The interviews were held one month after the end of the programme, which suggests at least short-term effects. However, this was the only study in the review which included participants without dementia as well as PwD without differentiation, so the results are only suggestive of applicability to PwD.

*Theory statement (c)*

**Where dyads have little opportunity for meaningful/leisurely activity (C), sharing a meaningful experience on an equal basis (M/res), means they have meaningful communications and interactions (M/rea), which helps the carer to see the PwD in a new way (O) and build their relationship (O).**

Eekelaar et al. (2012) theorise the stimulating activity and environment allow for meaningful communications. Burnside et al. (2017) defined their outcome of 'relationship growth' as being related to meaningful experience, and, similarly, Lamar (2015) and Camic et al. (2016) suggest the shared experience builds the relationship. Lamar (2015) and Clarke-Vivier et al. (2017) discuss the art product itself opening up dyad communication, and helping the carer to learn or see something new about the PwD. Clarke-Vivier et al. (2017) and Lamar and Luke (2016) both link this 'seeing/learning something new' with relationship-building.

*Theory statement (d)*

**In dyads where the carer is unsure about how best to support the PwD or is struggling with communication (C), modelling by the facilitators (M/res) means carers learn new ways to interact with the PwD and new strategies (M/rea), which builds relationships through improved communication and a focus on process rather than product (O).**

Six papers discuss carers learning new ways of interacting with the PwD. Humphrey et al. (2017), Hazzan et al. (2016) and Lamar (2015) give examples of carers reporting using skills modelled by the facilitators in other, unrelated, situations, such as helping the PwD eat, and to focus on the process of activities rather than the end product. Camic et al. (2016) and Mittelman and Epstein (2006) both report at least one carer in their programmes who intends to make changes in the way they interact with their partner at home. Mangione (2013) includes one quote from a physician working with the programme about how it opens up new ways of coping and reacting to behavioural difficulties, which may also be linked with this modelling by facilitators. However, none of the studies have enough long-term follow-up to determine if this effect is lasting, or if those with intentions to interact in different ways actually do so.

*Theory statement (e)*

**Where the PwD is anxious about new activities (C), the carer reassuring or taking part in a shared activity (M/res) helps the PwD to feel comfortable/able to take part (M/rea), so the PwD is able to participate without anxiety (O).**

One study (Hazzan et al., 2016) suggests carers being involved helped PwD to engage with the programme through the reassurance of their presence.

Theme 2: Shared respite

Shared respite as an outcome was supported for family carers (Eekelaar et al., 2012; Flatt et al., 2015; Johnson et al., 2017; McGuigan, Legget, & Horsburgh, 2015), professional carers (Roe et al., 2016), and in programmes with mixed or unspecified types of carers (Baker, 2014; Burnside et al., 2017; Camic et al., 2016, 2014; Hazzan et al., 2016; Lamar, 2015; Lamar & Luke, 2016). One study (Baker, 2014) reported respite had not been experienced for one carer, in contrast to others in the study.

*Theory statement (f)*

**Where the dyad's home interactions are mainly around caring (C), enabling facilitation in a non-medical setting in which the carer has no caring responsibilities (M/res) means the dyad**



**can enjoy the activity together on an equal basis (M/rea), which leads to the dyad experiencing shared respite from dementia roles/life (O), which also helps to strengthen their relationship (O).**

The carer not having caring responsibilities as a context is suggested by five papers reporting on three studies (Baker, 2014; Camic et al., 2016; Lamar, 2015; Lamar & Luke, 2016; McGuigan et al., 2015). Four of these (Baker, 2014; Camic et al., 2016; Lamar, 2015; Lamar & Luke, 2016) also linked the lack of caring/cared-for roles with the ability to enjoy the activity on an equal basis, which was supported by a further three studies (Camic et al., 2014; Eekelaar et al., 2012; Mittelman & Epstein, 2006). The activity not being about dementia, and so not about individuals' caring/cared-for roles related to dementia, was linked to shared respite or enjoyment by four papers reporting on three studies (Baker, 2014; Burnside et al., 2017; Camic et al., 2016; Flatt et al., 2015). Shared respite helping to build relationships is suggested in three studies (Burnside et al., 2017; Camic et al., 2016; Lamar, 2015). The importance of the non-medical context was highlighted in three studies (Camic et al., 2014; Johnson et al., 2017; McGuigan et al., 2015).

*Theory statement (g)*

**Shared respite (C) means the dyad can interact and communicate outside of dementia roles (M), which builds their relationship (O) and also feeds back into enjoying the activity together (O).**

Eekelaar et al. (2012) discusses the shared experience allowing meaningful communication to occur. The shared respite described in theory (f) above also feeds back into enjoyment of the activity (Eekelaar et al., 2012; Lamar, 2015; Lamar & Luke, 2016). In this way, (f) and this theory are mutually reinforcing processes – enjoying the activity on an equal basis leads to shared respite, and this shared respite further enables the dyad to enjoy the activity together.

*Theory statement (h)*

**The participatory activity with a 'product' e.g. artwork/verbal contribution (M/res), in the context of high carer expectations or a dyad struggling to accept dementia (C), means the carer compares the PwD's current to their past abilities or negatively with other PwD in the group (M/rea), which leads to the group highlighting losses or reinforcing limitations (O).**

Five papers reporting on four studies discussed the group highlighting losses or negatives about dementia for the carer, particularly where current and past abilities were compared. Humphrey et al. (2017) discuss some carers feeling initially discouraged by PwD's artwork being less skilled than that they had produced in the past. Lamar (2015) and Lamar and Luke (2016) report two carers who found the programme anxiety-inducing as a 'confrontation with the reality' of dementia, another who found it difficult that her mother seemed to have greater difficulties than others, and another who discussed feeling isolated because they could not talk about the shared experience of the programme afterwards as the PwD had forgotten it. Burnside et al. (2017) found the carer expressing frustration with the PwD's limitations was a barrier to the dyad's engagement. Baker's (2014) theorising regarding carer-perceived competency, described in (a) and (i), also relates to this theory. As in theory (a), carer expectations are theorised as context, but here where the carer has higher expectations of the PwD than they are capable of achieving.

*Theory statement (i)*

**Where the carer has high expectations of the PwD (C), or the group highlights losses (C), the carer does not perceive the PwD to have achieved competency (M), so the carer does not feel respite (O) and the carer does not see the PwD in a new way (O).**

Related to theory (h), and in contrast to (a), Baker (2014) theorises the reason one carer did not experience a sense of respite was that they did not perceive the PwD to have achieved 'competency', so could not step out of their caring role. As theory (a) suggests, if the carer cannot step out of their caring role, they also cannot see the PwD in a new way.

*Theory statement (j)*

**When the carer has caring responsibilities in the group (C), the dyad cannot enjoy on a completely equal basis (M) so the carer does not get respite (O) and feels increased stress (O).**

Lamar (2015) reports some carers felt the programme had stressors related to caring responsibilities, such as the PwD's behaviour. This implies carers feeling a caring responsibility inhibits stress relief, which is suggested in the same study to be related to a lack of responsibility and the safe environment. In theory (f), five papers reporting on three studies (Baker, 2014; Camic et al., 2016; Lamar, 2015; Lamar & Luke, 2016; McGuigan et al., 2015) suggested the carer not having caring responsibilities in the group is a context for enjoying the activity together equally. This implies *having* caring responsibilities inhibits enjoying equally.

In four studies which explicitly described carers having responsibilities for the PwD within the programme, one did not report carer outcomes (MacPherson et al., 2009), while the remaining three suggested some positive outcomes for the carer or relationship building (Gould, 2013; Livingston et al., 2016; Roe et al., 2016) due to the social context. However, as none of the three focussed on carer outcomes, and other studies which highlighted responsibilities as an issue did not report how much responsibility the carer had, it is not clear if there is a 'threshold of responsibility' that impacts on carer outcomes, or if it is about the carer's perceptions of responsibility, rather than the actual. This CMO configuration may be more usefully conceptualised as a 'dimmer switch', with activation of the mechanism operating on a continuum rather than an on/off switch (Dalkin et al., 2015).

### Theme 3: Excess disability

*Theory statement (k)*

**Anxious carers (C) intervene on PwD's behalf (M), so the PwD cannot engage fully (O) and the carer has no respite (O).**

MacPherson et al. (2009) specifically focus on the idea of excess disability. They found, for PwD from residential care, anxious professional carers intervened and the PwD seemed to lose confidence. When the carers were not involved, the PwD showed greater capacity and positive affect. On this basis, Windle et al. (2017) did not recruit dyads, though some carers attended, and suggested facilitators needed to intervene at times to stop carers inadvertently taking over and preventing the PwD from doing tasks at their own pace.

*Theory statement (l)*

**PwD may find it more difficult to speak up in a group setting (C), so where there is poor facilitation (M/res) carers dominate the conversations (M/rea), so the PwD cannot engage and does not have a sense of belonging in the group and cannot gain potential positive outcomes (O).**

'Poor facilitation' in this context means that not all participants are enabled to participate or contribute in the discussions. A carer in Lamar (2015) suggested carers spoke up most in the group, and Mittelman and Epstein's (2006) evaluation states carers could be enthusiastic which may have discouraged PwD from taking part. Mittelman and Epstein (2006) also measured the number of spontaneous comments made by PwD and found no difference between comments to the group and

those to carers, so it may be that PwD spoke less in general rather than simply due to carers' presence in the group setting. However, it also suggests the importance of facilitation that encourages PwD to participate, rather than relying on spontaneous involvement. In the 'hints and tips' section of their report, Gould (2013) specifically states a general question to the group is usually answered only by carers. Relatedly, as discussed in theory (k), MacPherson et al. (2009) and Windle et al.'s (2017) studies suggest the importance of facilitation in ensuring carers do not dominate.

#### Theme 4: Social isolation

##### *Theory statement (m)*

**Where carers are not in contact, or have limited contact, with other carers (C), the activity happening in a group means carers meet others in similar situations (M/res) and feel connected to others in a similar situation and the wider community (M/rea), so feel less socially isolated (O), and leads some to continue friendships outside the group (O) or join other dementia-friendly groups (O).**

Although mainly carers, not PwD, were asked about this, the social aspect of the group and peer support were highlighted as important to participants. Ten documents reporting on eight studies report participants saying social interaction and connections with others in similar situations was important and helpful (Baker, 2014; Burnside et al., 2017; Camic et al., 2016; Eekelaar et al., 2012; Flatt et al., 2015; Gaugler et al., 2010; Lamar, 2015; Lamar & Luke, 2016; McGuigan et al., 2015; Mittelman & Epstein, 2006). Eekelaar et al. (2012) specifically found the programme reduced feelings of social isolation, while four studies reported participants informally socialising after the programme or at other events (Baker, 2014; Burnside et al., 2017; Lamar, 2015; Roe et al., 2016). Lamar (2015) reported participants joining other dementia-friendly activities after the programme. The importance of the group as a social space was highlighted by Flatt et al. (2015), who found overall satisfaction with the programme was related to a greater sense of belonging to the group. However, the programmes cannot be wholly reduced to being a social group, as in another study wellbeing significantly increased to a greater degree during the programme than in a purely social break (Johnson et al., 2017).

##### *Theory statement (n)*

**A positive experience in the museum (M/res), in the context of a 'shrinking world' for the dyad (C), makes the dyad feel the museum is a 'safe' place they can return to (M/rea), so they intend to return outside of the group (O) and feel less socially isolated (O).**

Three studies (Camic et al., 2016, 2014; Mittelman & Epstein, 2006) report participants discussed an intention to return to the museum following their programmes, though none had long-term follow-up to determine whether they actually did. Gaugler, Mojsilov, and Gerber (2010) measured additional participation in museums during the programme and found dyads attended an average of 1.2 additional museums. However, as they did not measure whether people attended museums prior to the programme, it is not clear if this is more or less than usual.

##### *Theory statement (o)*

**A positive experience in the museum (M/res), in the context of a 'shrinking world' but where the carer does not have capacity to include leisure in day-to-day life (C), means the carer does not see the museum as a place they can return to (M/rea), so they do not intend to return and do not feel less isolated (O).**

One study (Camic et al., 2016) included quotes from two carers specifically discussing the demands of caring and lack of practical value of the programme, one calling it an ‘indulgence’, as a reason they would not return.

#### Outcomes when carers are not included

The second search was conducted to compare outcomes for PwD when their carers were or were not included. One study (Camic, Hulbert, & Kimmel, 2017) was specifically designed to see if the programme was still effective without carers present. They found an increase in wellbeing for all participants, but that people with mild dementia had greater increases than those with moderate. Windle et al.'s (2017) study did not specifically recruit dyads, though does not state how many carers participated. They also found PwD had increased wellbeing following the programme. These two studies suggest increased wellbeing is not dependent on the presence of carers, though caution must be taken given little research without carers.

#### Interaction of CMO configurations

Some of the theories interact with each other, and more than one mechanism can lead to the same outcome. The mapping of CMOs has been split into sections according to interaction for ease of comprehension, and are visually depicted in Figures 2, 3, and 4.

As shown in Figure 2, dyads may experience relationship building in one or more ways. The outcome of shared respite is also self-strengthening, as it feeds back into enjoying together on an equal basis which is a mechanism for shared respite.

*Figure 2. Interaction of CMOs related to positive outcomes, including references to theory statements*

A reduction in feeling socially isolated is not only about feeling connected to others, but may also be due to the museum as a public space that can be re-visited outside of the group. However, where the dyad does not have capacity to return, this contribution to reducing social isolation is lost. As presented in Figure 3.

*Figure 3. Interaction of CMOs related to social isolation, including references to theory statements*

A lack of respite can be achieved via three mechanisms, including where the outcome of the group highlighting losses becomes a context for the carer not perceiving the PwD's competency. Two mechanisms can lead to the PwD being unable to engage fully. See Figure 4.

*Figure 4. Interaction of CMOS related to negative outcomes, including references to theory statements*

#### Discussion

This review aimed to examine how including carers in museum programmes for PwD has an impact on the PwD, the carer, and the relationship between them. Four themes of outcomes were identified: seeing the PwD in a new way and building relationships, shared respite, excess disability, and reduced social isolation. Fifteen evidence-informed programme theory statements were developed within these themes, some of which interacted with each other. Including carers had both positive and negative aspects, and the same outcome could occur through a number of different mechanisms.

The results may indicate an overarching impact that including carers in programmes contributes to outcomes which extend beyond the moment of the group, such as relationship building, whereas, without the carers' presence, the PwD can experience wellbeing outcomes but these are ‘in the

moment'. However, there is inadequate research on long-term outcomes and on programmes which do not include carers, so this can only be tentative. There is also not enough evidence to propose theory for the secondary aims of the review. Issues related to these gaps will be considered throughout the discussion.

In this review, shared respite refers to respite from caring/cared-for roles, with a focus on the relationship not defined by dementia (Burnside et al., 2017). This was well supported as an outcome. However, it may also be that some carers do not want *shared* respite, and would like more traditional breaks from caring responsibilities. The studies included in this review had participants who either specifically volunteered or were already attending programmes, so would likely be more interested in shared activity. Additionally, most studies interview dyads together which could make it difficult for participants to discuss negative aspects related to their relationship (Pesonen, 2011). Furthermore, as both relationship dynamics and symptoms of dementia can fluctuate, what each individual in the dyad wants in terms of respite may also fluctuate over time. Most included studies used a cross-sectional design, which may not capture a fluctuation of outcomes and dyad preferences. Further research should consider following dyads through a number of sessions, and consider that outcomes may not be static so individuals may need different kinds of support at different times.

Studies interviewing dyads together may also have had an impact on the focus of the developed theories. As carers' voices were dominant, it is unsurprising that most of the theories centre the carer, rather than the PwD. For example, there may be similar processes of losses being highlighted for the PwD, as well as the carer (theory (h)), but this is not apparent in the current literature.

The theories could be further strengthened, resulting in more nuanced practice implications, if the mechanisms within the context are also investigated to understand why particular mechanisms fire in particular contexts (Westhorp, 2018). This issue of what it is about the context that generates the mechanisms, is a gap in a number of areas. For example, although reduced feelings of social isolation was discussed in a number of studies, it is unclear how socially active participants were prior to the programme. This outcome, as well as shared respite, may be influenced by the amount and quality of other social activities the dyad takes part in, both together and as individuals. The current evidence base does not allow for theorising on what it is about a dyad that means the programme reduces social isolation compared to those for whom it does not.

There is also a lack of evidence about the context of the dyad in terms of their relationship dynamics and type. In this review, relationship dynamics have been conceptualised as 'high/low carer expectations' of how the PwD would contribute, as it made most sense in terms of the framing given in included studies. However, this is inadequate to explain why it is some dyads experience positive outcomes and others negative, which means recommendations cannot be given about which dyads may benefit and how. Realist review methodology includes scope to search widely to fill theoretical gaps, however there is a lack of research generally in how the dyadic relationship in dementia has an impact (e.g. Edwards et al., 2018), rather than the impact of dementia on the relationship. Some evidence suggests it does have an impact, such as current and past relationship quality having positive and negative effects on emotional wellbeing and coping (Ablitt et al., 2009), but not on how this may affect programme outcomes (Rausch, Caljouw, & Van Der Ploeg, 2017). Further research examining the dyadic context within programme evaluation could provide better understanding of for whom these programmes work, and provide potential practice implications for those who do not benefit, such as a differing kind of support during the programme.

There is also a lack of consideration given to the type of caregiving dyad, such as spousal, parent/child, or paid professional, and if there are differences in outcomes in differing relationship contexts. This may be important given the socio-relational challenges faced by different dyad types are likely to be different (Rausch et al., 2017). The evidence gap is particularly apparent for professional carers. One review found some residential care staff were hesitant to engage with interventions promoting closeness because they feared getting emotionally attached to the PwD (Rapaport, Livingston, Murray, Mulla, & Cooper, 2017). This suggests, in museum programmes, some professional carers may not engage fully and this may impact outcomes. Further research should consider the socio-relational contexts of the dyad to better understand outcomes.

Relatedly, most participants in studies were white, had previous arts experience, and, in the case of couples, in a heterosexual relationship. There may be differing contexts, mechanisms, and outcomes in different demographics. For example, whether the museum becomes a 'safe place' to return to (theories (o) and (p)) may not simply rely on the context of having capacity return, but also on previous experience with museums. Although museums can be non-stigmatising, non-medical settings (Camic & Chatterjee, 2013), they are also more likely to be attended by people from higher socio-economic groups without a disability or long-term illness (Matthews, Xu, Matusiak, & Prior, 2016). A dyad that has capacity to return but do not feel they 'belong' may not return, or, conversely, the programme may help them to feel they belong, having a greater effect than if they already felt comfortable in the setting.

As well as dyadic context, facilitation was a key factor as both a resource (e.g. theory a) and a context (e.g. theory m). The importance of facilitation as a contextual factor has also been found in a review of visual arts programmes (Windle, Gregory, et al., 2017) and singing groups (Unadkat, Camic, & Vella-Burrows, 2017) for PwD and their carers. Windle et al. (2017) suggest good facilitation requires an understanding of dementia alongside general facilitation skill. Further research could examine the elements of facilitation which contribute to outcomes to enable better training of facilitators.

As most theories developed in this review do not refer to the museum or the type of activities specifically, but rather to the facilitation style, they may have applicability to other activities where the PwD and carer take part together on an equal basis, without a focus on reminiscence, and to museum activities in other settings. However, there may be different dynamics involved in taking museum activities into, for example, a care home. When people go to the museum, they are in a space separate from their home/work environment, whereas in a care home they are in their usual care environment. This could have implications for how easily dyads are able to step outside of their carer/cared-for roles, and for facilitation (for example whether the museum or care staff feel they have a lead role). Windle, Joling, et al. (2017)'s visual arts intervention was equally beneficial across different settings, but found some differences in communication and social behaviour, which may have particular significance when considering the impact of including carers.

A synthesis is inevitably limited by the scope of the current literature and this review is limited by a lack of research on the dyadic context and long-term follow-up. As a result, some of the theories are better supported than others. Further research addressing these issues would strengthen the theories developed. The theories will be used as the basis for an evaluation of museum programmes following this review.

This is the first review to examine the impact of carers on outcomes in museum programmes for PwD. As both positive and negative impacts were found, it is important to consider programmes may not be beneficial for all dyads. The review suggests that to enable positive outcomes for dyads,

programmes need: (1) good facilitation which enables all to participate as equally as possible, (2) few caring responsibilities for the carer, and (3) management of carers' expectations of PwDs' spoken comments or artwork. These recommendations may be applicable to other arts programmes for PwD and their carers. Further research examining the dyadic context within museum programmes in more detail may enable more detailed recommendations about who would most benefit and how to facilitate positive outcomes.

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