

The contribution of museum programmes in supporting caregivers of people with life-limiting illnesses: A systematic literature review

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Abstract

This review aimed to explore and synthesize the benefits that museum programmes offer to caregivers of people with life-limiting illnesses, and to critically assess the level of support provided in light of the attention to an alternative public health approach of EoLC. In pursuit of this goal, systematic searches were conducted in various databases. According to the PRISMA guidelines, this resulted in 11 unique entries. The benefits identified across studies were associated with cognitive, social, and particularly psychological benefits for caregivers, especially those caring for people with dementia. However, none of the studies investigated long-term benefits. Therefore, future research is needed to allow for a more robust synthesis of findings and to maximize benefits and minimize risks, ensuring that these programmes become more widely available to caregivers of people with life-limiting illnesses.

Keywords: literature review; informal caregivers; end-of-life care; museum programmes

Introduction

Caregiving is a crucial and delicate task to carry out in palliative and end-of-life treatment (EoLC). Informal caregiving, that is to say, unpaid caregiving performed by a family member or a close friend, is often equivalent to a full-time job, and implies financial costs, considerable physical work, and emotional burden (Rabow et al. 2004). Research has shown that caregivers' social, cognitive, psychological, and emotional needs often remain unmet before and after bereavement, and that there is a lack of adequate information to deal with practical caregiving (Aoun et al. 2021), as well as support and resources (Kepic et al. 2019). A caregiver often experiences care burden as a result of long-term caring responsibilities for a loved one (Liu et al. 2020; Rabow et al. 2004). Bom et al. (2019) revealed that this so-called care burden negatively affects both the mental and physical health of caregivers. While caregiving can be equally rewarding and can mitigate the negative effects resulting from the burden of responsibilities (Ratcliffe et al. 2013), it can also lead to loneliness and isolation (Cross et al. 2018). Having access to and involvement in social activities appears to play an important role in reducing the burden and stress level of caregivers (Tuncay and Fertelli 2019). Moreover, according to Horsfall (2018), caregivers' burden eases when they have a functioning caregiving network around them. Some caregivers explicitly acknowledge the need for support and time for respite (Cross et al. 2018; Hashemi et al. 2018). This highlights the importance of a public health perspective, as emphasized by Kellehear (2013), which relies on supportive communities and places the responsibility of individuals to care for each other in times of serious illness, death, dying, loss, or bereavement at its centre. In general, communities can be defined as "social units, groups of individuals that share something in common and may vary in scope, size, scale and strength of within-group ties" (Vanderstichelen et al. 2022: 12). Among the different types, compassionate communities (CCs) entail a community whose members actively provide care for one another, especially at the EoL stages (Kellehear 2013). Within this model, community care and support can be provided by strengthening supportive networks of people, by connecting people to useful resources to deal with caregiving, dying, or grieving, and by raising awareness about EoL issues (BC Centre for Palliative Care et

al. 2020).¹ Everyone, including both caregiver and care recipient, should receive support regardless of the type of illness, age or cause of death (Abel 2018). By going beyond the conventional clinical approach to care, provided mainly by healthcare professionals, CCs can lead to more timely and sustainable community care in the social, psychological, spiritual and physical spheres (Kellehear 2013). How the CC model can be implemented, for instance, is clearly illustrated by 'Seven Hospice' in Shropshire, England, that called for and trained 14 volunteers to visit and support frail people, including those with life-limiting illnesses, in their local area (Cronin 2016). This initiative aimed to reduce loneliness and isolation among the older and vulnerable people of the community. At the same time, it also helped reduce anxiety and panic among them, and led to a consistent reduction in the use of unplanned healthcare services that could instead better serve more complicated cases (Cronic 2016).

Kellehear (2016) has highlighted the relevance of museums and art galleries to the CC movement, offering exhibitions about EoLC experiences, for instance, as pinpointed among the 13 social changes in the Compassionate City Charter (Wegleitner et al. 2016). Camic and Chatterjee (2013) concluded that the cultural heritage sector, in particular museums and art galleries, present an asset for an alternative public health care approach to deliver programmes to promote the well-being of the community they serve. Museums, art galleries, and arts centres are not medical institutions where one might feel pressured and embarrassed, but rather non-stigmatizing places where one feels more at ease. In this regard, there is evidence that museums, art galleries, and arts centres can play a role in promoting support and care for caregivers (Rosenberg 2009; Camic and Chatterjee 2013; Irons et al. 2020). MoMa was the first museum in the United States to host Meet Me, a community-based, open art programme for people with Alzheimer's disease and their caregivers. By actively engaging with works of art facilitated by a museum educator, caregivers can not only connect with one another and share stories and concerns, but can also explore their artistic interests and find space for respite (Rosenberg 2009). Most literature on the beneficial role of programmes in museums, art galleries, and arts centres focuses on P/EoLC recipients (e.g., Hartley and Payne 2008; Lee et al. 2021; Rodeyans et al. 2021). A critical note here is that people with life-limiting illnesses are often not involved in the research. In terms of the benefits for their families or informal caregivers (hereinafter referred to as caregiver) participating in such programmes, the attention is generally limited. Although the programmes are often designed for dyads, the caregiver is often given a passive role during the activity or is not part of the research sample (Hendriks et al. 2018; Schall et al. 2017). Against this background, this review provides a systematic body of empirical studies on museum programmes encompassing museums, art galleries, and arts centres that offer benefits to those who provide care for people with life-limiting illnesses. Learning from existing museum programmes through a comprehensive review of studies, and critically evaluating the state of support for informal caregivers, are both essential, especially when an alternative public health approach is being implemented, wherein museum programmes can play a role in supporting caregivers in the communities they serve.

Review question

Against this background, the following review question will be addressed by this article: what are the benefits of museum programmes in supporting caregivers with life-limiting illnesses?

Methodology

A systematic literature review was conducted to ensure a comprehensive and unbiased search and assessment of studies relevant to the research questions (Petticrew and Roberts 2006). The electronic databases Scopus and PubMed, as well as all databases on the Web of Science platform, were searched until April 2022. The search string included the combination of the following keywords: search 1: museum OR museum program* OR art gallery OR art exhibition OR arts center; AND search 2: care OR support OR aid OR assistance OR supportive care OR supervision OR compassionate care; AND search 3: Caregiver* OR carer* OR care partner* OR caretaker* OR family carer* OR parent carer* OR informal caregiver* OR informal carer*; AND search 4: compassionate communities OR CC OR public health

OR community network*; NOT search 4: art-therapy OR art therapy.

Inclusion and exclusion criteria for eligibility and rationale

The studies to be included had to meet two inclusion criteria. Firstly, they had to be empirically or conceptually peer-reviewed articles written in English. Secondly, they needed to focus on museums, art galleries, or arts centres that either offered programmes for the care recipient and the caregiving dyad, or only for caregivers. This criterion was included because such programmes are often designed to involve dyads. The studies to be excluded had to meet one of three exclusion criteria. First of all, studies should be based on art therapy interventions for caregivers carried out by an art therapist. Art therapy is defined as therapeutic treatment facilitated by art therapists who use artistic means to work on anxiety, self-awareness, and traumatic experiences, among others (American Art Therapy Association 2014, cited in Schouten et al. 2018). Secondly, studies in which the programme for caregivers was not delivered by or linked to a museum, art gallery, or arts centre, were excluded. This criterion does not limit the nature of the programme. Thirdly, studies in which the caregiver accompanied the care recipient, but in which the museum programme focused only on the latter, were also ruled out.

Identification of studies

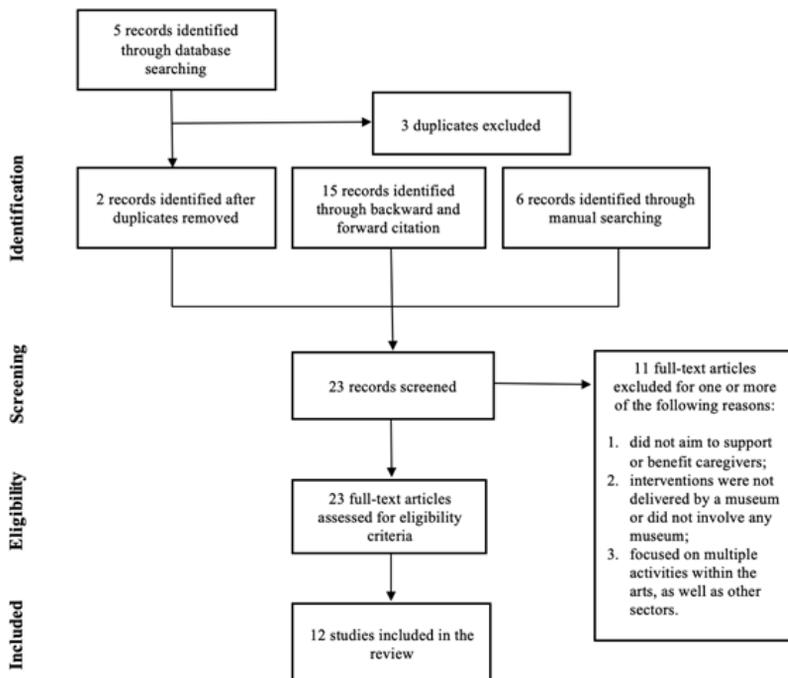


Figure 1: Flow of information through the review (adapted version based on Moher et al. 2009).

As shown in Figure 1, the search process followed the PRISMA guidelines of Moher et al. (2009). The first search led to the identification of five records, of which three were deleted given that they were duplicates. As this first search yielded only two eligible articles, it was chosen to expand the search through secondary channels so that no relevant studies would be missed (Cooper 2017). Therefore, the reference list and the citation* indexes of these two

selected papers were scanned, by reading titles and abstracts. This process led to the selection of 15 additional studies. As the identified studies only related to caregivers of people with dementia, a further manual search was conducted by exploring the related records proposed by each of the databases. This process of manual search led to six additional studies, including two studies targeting caregivers of people with diagnoses other than dementia. In total, the identification phase resulted in 23 records to be screened, which, based on the exclusion criteria, ultimately led to 11 unique peer-reviewed articles that were included for review.

After extracting the data according to PRISMA guidelines, the quality of all studies was critically assessed using two criteria: (i) validity using the checklist for qualitative research (Lockwood et al. 2015) based on 10 methodological criteria and the checklist for quantitative (descriptive/case series) studies (The Joanna Briggs Institute 2011), which are based upon nine methodological criteria, and (ii) relevance (i.e. whether the study contributed to new knowledge or increased confidence in existing knowledge) (Mays and Pope 2000). The first author was in charge of synthesizing the findings for the selected categories, while the second author checked and validated the research results. Differences in individual assessments were discussed until reaching consensus.

Coding procedure and data analysis

To systematically analyse the selected studies, a coding procedure was followed, and the most relevant information was tabulated to make the review more transparent (Petticrew and Roberts 2006). Following Cooper's (2017) guidelines, the first code sheet was created with the most generic but relevant information for each of the categories (research design, participants, study setting and country, and study purpose), which are carefully reported in Table 1, in chronological order. The second code sheet was then used to record specific information in view of the research questions (Cooper 2017). After re-reading the studies, two main elements were reported (see Table 2): (i) the type of programme; and (ii) the benefits for caregivers. Table 2 facilitated the process of conducting a thematic analysis, consisting of extracting, grouping, and synthesizing data into the three themes used to answer the research question (Xiao and Watson 2019). This process took place in close consultation between the two authors, in which differences in individual judgements were discussed until a consensus was reached.

Table 1: Methodological features of the study.

| Study | Research design and method | Participants | Study setting and country (when applicable) | Scope of the study |
|---------------------|---|---|---|--|
| Camic et al. (2014) | Mixed-method design. Standardized questionnaires and interviews | People with dementia (PWD) (mild to moderate) and their caregiver (not specified) | Two art galleries: Dulwich Picture Gallery (UK), and Nottingham Contemporary (UK) | Exploring how two art viewing interventions in two art galleries would affect the care burden, the relationship between PWD and their caregivers but also other domains of quality of life of the PWD. |

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| Flatt et al. (2014) | Cross-sectional qualitative study. Satisfaction survey, focus groups | Older adults with early-onset Alzheimer's disease or related cognitive disorders (ADRDs) and their family caregivers | The Andy Warhol Museum, in Pittsburgh, Pennsylvania (US) | Examining the subjective experience of the target group participating in a one-off art engagement activity at a museum. |
| Camic et al. (2015) | Qualitative study. Semi-structured interviews, grounded theory | PWD (mild to moderate) and their caregivers (not specified) | Two art galleries in two different regions of the UK (not specified) | Theorizing how an intervention of art viewing and making in an art gallery can have an impact on PWD and their caregivers. |
| Johnson et al. (2015) | Quantitative study. Visual analogue scales and open-ended feedback questionnaires | PWD and their family or informal caregivers | A museum in the south-east of England (UK) | Investigating the impact of three museum activities (art viewing, object handling, and refreshment break) on the well-being of PWD and their caregivers. |
| McGuigan et al. (2015) | Quantitative and qualitative study. Time sampling observation, focus group, interviews | PWD (not severe stage) and their family caregivers | Auckland Museum (New Zealand) | Examining a six-week art programme at Auckland Museum for PWD and their caregivers to identify the most appropriate way to deliver art in an engaging and enriching way for the target group. |
| Pienaar and Reynolds (2015) | Qualitative study. Semi-structured interviews | Caregivers of family members with dementia | A local art gallery, Healthy Ageing Café, London (UK) | Exploring the value of a creative arts leisure programme for caregivers of a family member with dementia. |

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| Hazzan et al. (2016) | Qualitative study. Observations, questionnaires | PWD (mid to late stage) with behavioural symptoms and the professional or family caregivers | Art Gallery of Hamilton, Ontario, and the hospital setting of the Behavioural Health Program (BHP) (Canada) | Exploring whether the 'Artful Moments' programme promoted positive engagement in the moment for PWD and its impact on care partners. |
| Wharton et al. (2018) | Qualitative and quantitative study. Questionnaires, observations, field notes | Family caregivers of people with Alzheimer's disease | Emory University campus and Emory University's Schwartz Center for Performing Arts, Atlanta (US) | Examining the impact of a photojournalism workshop for family caregivers of people with Alzheimer's disease on their psychological well-being (care burden and depression). |
| Ganga and Wilson (2020) | Mixed methods design. Online surveys, participant observations, field notes, feedback | Family caregivers of PWD | Museum of Liverpool, with New Walk Museum in Leicester and Art Gallery, Salford Museum and Art Gallery (UK) | Developing an empirical understanding of how the 'House of Memories' (HoM) programme affected caregivers' care practices and how they perceived their own well-being. |
| Levy et al. (2020) | Mixed methods study. Surveys | Pediatric palliative caregivers (PPCGs) | Online platform and a local art gallery, Western New York (US) | Evaluating how the 'Photographs of Meaning Program' (POM) impacted pediatric palliative caregivers' meaning and purpose, well-being and perceived social support. |
| Innes et al. (2021) | Mixed methods study. Data sources, mood questionnaires, post-session interviews | PWD and their caregivers (mostly spouses) | Two heritage sites also used as museums (Kew Palace and Hampton Court Palace) (UK) | Exploring the impact of the 'Sensory Palaces' (SP) programme on PWD and their caregivers. |

Table 2: Descriptive features of the study.

| Study | Type of programme | Benefits for caregivers |
|------------------------|---|---|
| Camic et al. (2014) | The art galleries' intervention consisted of eight two-hour sessions for PWD-caregiver pairs over an eight-week period and were composed of two activities: art viewing interactively (one hour) followed by art making (one hour). | <ul style="list-style-type: none"> - Slightly reduced care burden (non-significant trend towards) - Improved well-being due to the social aspect of the intervention and its impact on the caring relationship between caregiver and PWD |
| Flatt et al. (2014) | One-off art museum activity (guided tour followed by an inquiry-based discussion and a two-hour art making activity) at the Andy Warhol Museum in Pittsburgh (Pennsylvania), for community-dwelling elderly people with onset ADRD and their family caregivers. | <ul style="list-style-type: none"> - Cognitive stimulation (creativity, reminiscing about the past, learning new skills) - Improved social connectedness and self-esteem (feeling normal, special/important) |
| Camic et al. (2015) | The eight-week intervention (two hours per session) consisted of art viewing sessions with interactive guided discussions, followed by art making sessions using various tools for both the PWD and their caregivers. | <ul style="list-style-type: none"> - A sense of 'normalcy' as the art gallery remained open to the public - Cognitive stimulation (doing/ learning and engaging in something different, appreciating art) - A break (respite) from care obligations through peer support and interaction - A more positive view of dementia |
| Johnson et al. (2015) | Three museum-based activities: art viewing, object handling, and refreshment break (social activity) for dyads (PWD and their caregivers). In particular, six sessions started with object handling and five with art viewing, with the social activity in between. | <ul style="list-style-type: none"> - Significant increase in subjective well-being |
| McGuigan et al. (2015) | A six-week programme (two hours per session) for PWD and their caregivers, conducted at the Auckland Museum by both specialist volunteers and outreach staff from Alzheimer's Auckland, a local organization. Six sessions in which participants handled objects, viewed images, and visited galleries. | <ul style="list-style-type: none"> - Enhanced socialization (connecting and exchanging experiences with other caregivers) - Re-engagement with museums and arts - Doing something new |

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| Pienaar and Reynolds (2015) | Four sessions (weekly one and a half hours) of art making for caregivers attending the Healthy Ageing Café (London), and a visit in duo to the local gallery where their group's art products were displayed with the gallery's artworks. | <ul style="list-style-type: none"> - Sense of freedom and respite - Strengthening of their identity - A deep sense of self-affirmation - Improvement in their mood - Social support - Increased resilience to cope with care by knowing that the loved one was in a safe space and being cared for |
| Hazzan et al. (2016) | Art making and art appreciation sessions both in the art gallery (one hour) and in the hospital setting (one hour) for PDW with behavioural problems and their caregivers, covering various themes (eight weeks in total). | <ul style="list-style-type: none"> - Enjoyment of engaging in meaningful activities together with their partner - Learning new care skills (more positive approach towards providing care) - Reduced stress |
| Wharton et al. (2018) | Four photojournalism sessions (within three months) and a final exhibition of photographs they took individually, capturing their caregiving experience, especially aspects that non-caregivers may not be familiar with. | <ul style="list-style-type: none"> - Reduced care burden and depression - Sense of community among the participants |
| Ganga and Wilson (2020) | The 'House of Memories' (HoM), an eight week-long programme, occurred in three museums in England. Each session included a character-based documentary to give an introduction to dementia and what being a caregiver entails; dementia-friendly museum activities (using social history collections and objects); the opportunity to use the <i>My House of Memories</i> application. | <ul style="list-style-type: none"> - Learning more about dementia led to dementia awareness and reduced stigma on dementia - Learning more about care practices in dementia helped people understand how to live well with dementia and fostered values such as compassion, dignity and respect that should be taken into account in care practice - Improving their 'in the moment' well-being - Increasing socialization with other caregivers |
| Levy et al. (2020) | The eight-week 'Photographs of Meaning Program' (POM) for PPCGs consisted of a social media dimension where caregivers posted weekly content based on a selected theme (e.g., identity exploration) and a closing community exhibition where each participant's favourite photograph was displayed. | <ul style="list-style-type: none"> - Positive impact on the search for meaning in their lives - Increased well-being, overall social support, attachment areas, social integration, reassurance of value, and guidance |

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| Innes et al. (2021) | ‘Sensory Palaces’ is a heritage programme in a dementia-friendly location. It offers sensory stimulation, storytelling, and space exploration for dyads and includes a variety of artistic disciplines like sculpture, dance, and music. | <ul style="list-style-type: none"> - Getting the opportunity to continue learning - Improving their mood and well-being - Improving their interpersonal relationships, both with the person they care for and with the community of visitors |
|---------------------|--|---|

Results

Design and methods

The search yielded articles published between 2014 and 2021 (see Table 1). All peer-reviewed studies (n=11) were empirical in nature, applying mixed methods (n=6), qualitative (n=4) and quantitative (n=1) methodology.

Participants and settings

Studies were conducted in the United Kingdom (n=6), the United States (n=3), New Zealand (n = 1), and Canada (n=1). A total of seven studies focused on dyads where the care recipient is living with dementia (different types and in different levels of dementia severity), while four studies targeted only caregivers, specifically pediatric palliative caregivers (PPCGs) (n=1) and caregivers of PWD (n=3). The study (Levy et al. 2020) focused on PPCGs did not specify the children’s diagnosis. The set-up of the programme, and therefore the context in which the studies took place, varied significantly: one art gallery (n=2), two art galleries (n=2), one museum (n=3), three museums with one art gallery (n=1), one art gallery with one hospital (n=1), one university campus with one university performing arts centre (n=1), and two heritage settings that functioned as museums (n=1).

Aims and programmes

Study aims commonly sought to examine the effects of museum programmes on various aspects of participants’ quality of life. We identified four types of museum programmes (see Table 2) that contribute in different ways to specific benefits for caregivers in terms of activities and aims. Firstly, the majority of the studies (n=7) involved museum programmes consisting of art engagement activities (i.e., art viewing and/or art making sessions) of varying length and format, mainly targeting dyads with the aim of supporting them to experience art. A second type of museum programme was for caregivers only, with a closing exhibition featuring their photographs organized for the wider community. This aimed to support caregivers and raise awareness of caregiving among them, as well as within the community. A third type of museum programme, aimed at supporting dyads, consisted of art-making sessions for caregivers only, followed by a gallery visit for dyads in which the artworks of caregivers were displayed together alongside items from the gallery’s collection. A fourth type of museum programme consisted of several activities with a focus on dementia for caregivers only: a documentary with an introduction about dementia and what it means to be a caregiver, intended to reduce stigma; dementia-friendly museum activities; and the opportunity to try out an app for PWD. This fourth type of programme aimed to make caregivers more aware of dementia.

In terms of duration, the majority of the programmes (n=5) lasted a maximum of eight weeks, while other programmes lasted between four and six weeks (n=3). Two studies (Innes et al. 2021, and Johnson et al. 2015) did not mention the official duration of their programme, as seen in Johnson et al.’s study (2015), for example, which only stated that all participants attended a total of eleven sessions. The shortest programme lasted only three hours, which was noted as a limitation by the authors (Flatt et al. 2014). In general, the duration of all programmes was relatively brief, which has the disadvantage that studies lack insight into the post-session benefits for dyads.

Themes

Although the museum programmes differed greatly in terms of approach, duration, and scope, they all produced very similar effects. No study reported any disadvantages associated with museum programmes in supporting caregivers, but they all documented a wide range of benefits for caregivers, which can be clustered across studies into three themes: cognitive, social, and psychological, none of which were mutually exclusive. These three themes were generated from caregivers' self-report.

Cognitive sphere

The opportunity to continue learning something new about art through art-based activities and appreciating art, was perceived as beneficial (Flatt et al. 2014; Innes et al. 2021; McGuigan et al. 2015). During post-intervention interviews in a study by Camic et al., one interviewee stated: "I didn't have any knowledge of art and I think it was fun, enjoying, discovery, learning" (2015: 1036). Moreover, by learning something new together with their care recipients, caregivers experienced a change of perspective about dementia in a more positive way (Camic et al. 2015). Through art-viewing and art-making sessions involving dyads, eight caregivers reported via a questionnaire that they gained a deeper understanding of dementia. This was because they observed how PWD improved their creative competences, communication skills, and attention span. They also learned some new activities that both parties could enjoy together (Hazzan et al. 2016). In the HoM programme, documentary videos showcasing personal stories about dementia were presented alongside historical collections and objects, as well as the opportunity to engage with a dementia-friendly app. Pre- and post-surveys conducted in a small group of caregivers showed an increase in awareness regarding dementia and the different stages of the condition, as well as an enhancement in knowledge concerning dementia care and the significance of compassion, dignity, and respect in improving the quality of care they deliver (Ganga and Wilson 2020).

Additionally, through focus group interviews Flatt et al. (2014) found that a one-off art engagement activity stimulated caregivers' cognitive functions: the paint and silkscreen printing session enhanced their creativity as it allowed them to give expression to impressions of experiences in a personal way, and the guided tour and discussions enabled them to recall memories.

Social sphere

Some articles (n=9) reported museum activities providing social benefits – that is to say, benefits through socialization with others – which we could classify into three groups.

Improving peer-to-peer care networks

Taking part in the programmes was particularly helpful in creating social connections with other caregivers. They also felt supported by these peers because of the mutual exchange of experiences about caregiving. In the study of Flatt et al. (2014), a caregiver stressed the role of art to enhance social bonds: "other caregivers and the patients, it's just developing that bond, you know, art's a good medium to do that for us... I think that's an important part of the journey that we're on" (Flatt et al. 2014: 385).

Strengthening social ties

In addition to social bonds between caregivers, some studies also pointed to the beneficial role of the museum programme in terms of building or strengthening the relationship between the caregiver and the person they were caring for (Camic et al. 2014; Camic et al. 2015; Hazzan et al. 2016; Ganga and Wilson 2020). During a focus group referred to in the study of Flatt et al. (2014), one caregiver even stressed the importance of art as a means of strengthening social ties: "other caregivers and the patients, it's just developing that bond, you know, art's a good medium to do that for us... I think that's an important part of the journey that we're on" (385). The study by Innes et al. (2021) zooms out even further by highlighting the social bonds

between caregivers and others from the wider community that were also strengthened when the museum was open to other visitors during their activity.

Psychological sphere

In most studies (n=11), the benefits reported by caregivers belonged to the psychological sphere and were all linked to impact on their well-being.

Well-being

A few studies used different evaluation scales to measure caregivers' perceptions of their overall well-being, which improved after their participation in the museum programme. For instance, Levy et al. (2020) used the Flourishing Scale (Diener et al. 2009) to measure caregivers' subjective well-being, which significantly increased after taking part in the activities. Ganga and Wilson (2020) measured participants' subjective well-being using three evaluation scales – a modified WEMWB, 12-items ZBI, and Smiley-face Assessment Scale (Ballesteros et al. 2010) – through baseline and follow-up questionnaires. Only the Smiley-Face Assessment Scale reported a statistically significant improvement in caregivers' mood following the activities. None of the other results were statistically significant, for which the authors offered no explanation.

Well-being related benefits

Other studies, although they did not explicitly focus on it, nevertheless reported benefits related to well-being. These benefits included reduced stress, which were measured through qualitative questionnaires (Hazzan et al. 2016), and (although not statistically significant) reduced depression for some caregivers, which was measured via the Patient-Reported Outcomes Measurement Information System (PROMIS) questionnaire (Wharton et al. 2018). Another important benefit related to well-being experienced by caregivers, albeit only temporarily, was a sense of normalcy fostered by curators and other staff (e.g., Camic et al. 2015), which enhanced their self-esteem. For example, in the study of Flatt et al. (2014), interviews and focus groups after a one-off activity at an art museum showed that caregivers' self-esteem improved because they felt normal, special, or important. Care burden was measured by Wharton et al. (2018) using pre- and post-programme questionnaires among 10 caregivers who followed the programme alone, showing a significant reduction. In contrast, Camic et al. (2014) found a non-significant reduction in care burden among caregivers after participating in the programme as dyads, as indicated by pre- and post-standardized questionnaires. However, the authors of this study suggest that the lack of significance may be attributed to the small sample size of 12 caregivers. A final reported benefit related to well-being focuses on caregivers who experienced respite through participation in museum activities. For example, Camic et al. (2015) conducted interviews with caregivers who indicated that they experienced 'respite' by taking a break from their usual caring duties. This was also highlighted when caregivers participated in activities alone, knowing that their loved ones were being cared for by professionals. A direct quote from a caregiver in the study of Pienaar and Reynolds illustrates this: "it gave me a couple of hours away from Harry, you know, sort of like respite really, which I know, I won't normally get ... It was sort of like a respite thing" (2015: 6).

Discussion

The current review identified 11 studies with the aim of investigating the benefits that museum programmes provide for caregivers of people with life-limiting illnesses, and with the aim of evaluating museums' contribution to a new public health approach that best serves the community during the most challenging moments of a person's life. The review found that although museum programmes differed in approach, duration, and scope, they all produced similar effects for caregivers. Reported benefits were multiple and related to one or more of the following domains: cognitive, social, and psychological, which could occur together or separately. Cognitive benefits mainly related to gaining more knowledge in the artistic field, on

the one hand, and the specific disease of dementia and new care practices for better quality of care, on the other. Social benefits led to social inclusion, more specifically relationship building among caregivers, and between caregivers and the people they cared for. Moreover, in a museum programme studied by Innes et al. (2021), caregivers felt connected to the wider community when the institutions involved were also open to other visitors during the programme activities. According to research by Lamar and Luke (2016), museum programmes for groups with life-limiting illnesses such as PWD, as well as their caregivers, are often restricted to specific visiting hours when no other visitors are present, with the aim of creating a calmer environment for these people in situations of vulnerability. This indicates that the museum sector still sees these programmes as an 'extra' rather than a fully integrated part of the museum's offer. In these circumstances, there is also no opportunity to connect with the broader community. Furthermore, keeping access open to other visitors is in line with the belief that EoLC should not be something provided privately but should instead involve everyone (Kellehear 2005). Therefore, if an alternative health approach is implemented, it is important to tailor museum programmes to the needs of individuals while simultaneously making sure not to isolate them from other visitors. However, the review highlighted that most of the benefits were related to caregivers' psychological health. This pertained to both the perceived well-being of caregivers, and to other benefits related to well-being. One of the most severe psychological issues that caregivers face is care burden. Two studies in this review focused on this, with care burden only significantly decreasing after participation in a museum programme that involved photojournalist sessions and a photo exhibition designed exclusively for caregivers (Wharton et al. 2018). Exploring this further, as well as programmes for dyads – this time with a larger sample size – could contribute significantly to the understanding of care burden and the support needed. Closely related to care burden, studies in the review have shown that caregivers experienced 'respite' when participating in activities alone (Pienaar and Reynolds 2015), as well as alongside their care recipients (Camic et al. 2015). According to Kinsey et al. (2019), the rationale behind this lies in the idea that engaging in activities in which caregivers are relieved of caregiving responsibilities, and/or where the care recipient also gains from the programme, can offer caregivers equal respite. Conversely, it becomes less favourable when caregivers are not as involved in the museum programme (Kinsey et al. 2019). Therefore, it is advisable for museum practices to equally involve dyads in their programmes.

The benefits found are consistent with the type of community support promoted in the CC movement by Kellehear (2013). Specifically, the review points to the importance of museums as community resources for promoting the well-being of caregivers of people with life-limiting illnesses, expanding the care network within the community, and raising knowledge about caregiving. However, a recent scoping review (Dumont et al. 2022) that examined the implementation and evaluation of CCs found a wide range of organisational stakeholders involved in activities to support people requiring long-term care and their caregivers, but did not mention museums or other actors from the cultural sector.

Findings of this review showed that, although no clusters of conditions were excluded in the search string, the majority of studies focused on museum programmes targeting caregivers of people with dementia. According to Gronemeyer and Rothe (2016), the dominant focus on dementia could be a consequence of the increase in the number of people living with dementia, as well as the awareness to address this condition through community-based initiatives using arts and culture. Thus, although museum programmes have emerged that are tailored to other life-limiting illnesses, these have received less attention in research. For example, a recent scoping review (Lee et al. 2021) found only seven studies that examined the effects of arts engagement facilitated by artists on individuals with life-limiting illnesses other than dementia. Therefore, consideration is advised when adapting museum programmes to health conditions. Additionally, the authors recommend advancing research in these areas. Taking an independent research approach rather than a broad one across all life-limiting illnesses is advisable due to the nuanced nature of care. This enables a thorough analysis of literature and practical considerations specific to changes in the life circumstances of both the caregiver and the care recipient. Moreover, this research approach should take into account the way that the museum programme is set up in terms of activities, target groups, and aims.

Developing a research agenda that assesses risks for caregivers, in order to anticipate and address issues with museum programmes, is also recommended.

Finally, this review only included 11 studies focused upon the effects of museum programmes on caregivers. These programmes were relatively short-lived, and none of the studies examined what happened to them after the programme to assess any long-term benefits. This underscores the insufficient evidence available to determine whether museum programmes effectively support caregivers of people with life-limiting illnesses. To arrive at a robust synthesis of findings, it is necessary for future research to investigate whether these benefits persist after the programme ends and therefore have the potential to improve caregivers' overall quality of life. Moreover, future studies could benefit from consistency in the duration of the programme. Even so, this review can serve as a starting point for museum programme development and further research, aiming to understand how to maximize benefits, minimize risks, and address challenges, so that these programmes become more widely available to caregivers of people with life-limiting illnesses and museums become full partners within an alternative public health approach.

Limitations of the review

One limitation stems from the fact that the searches were limited to peer-reviewed journals and English-language papers only. Books, grey literature, and papers written in languages other than English could have yielded further relevant information, which was deliberately excluded in this review. A second critical remark is that only 11 studies were identified. This resulted in a lack of diversity in terms of life-limiting illnesses faced by the study participants and targeted by the museum programmes, thereby affecting generalizability.

Conclusions

This systematic literature review synthesized evidence and evaluated the state of support for caregivers with life-limiting illnesses by museum programmes through 11 studies. The museum programmes differed in their approach, scope, and duration. Findings highlighted a diverse range of benefits for caregivers, primarily those of people with dementia, in social, cognitive, and/or particularly psychological areas. However, among the extant studies, no significant differences were identified between the various museum programmes, nor did they assess long-term benefits after the programme ended. Given the limited number of studies, there is insufficient evidence to conclude whether such programmes provide support to caregivers of people with life-limiting illnesses. Future research is therefore recommended, with studies potentially benefiting from consistency in programme duration to obtain a more robust synthesis of findings. Also, building a research agenda focusing on other types of life-limiting illnesses than dementia is advisable. This review is a step towards gathering existing evidence to further efforts aligned with an alternative public health approach to EoLC, in order to make museum programmes more widely available to individuals supporting people with life-limiting illnesses.

Disclosure of potential conflicts of interest

The authors report no actual or potential conflict of interest.

Notes

¹ BC Centre for Palliative Care, Pallium Canada and HPCO, 'Compassionate Communities Evaluation Toolkit', Pallium Canada 2020. <https://www.pallium.ca/evaluation-toolkit/>, accessed 17 March 2023.

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