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EXPLORING ARTS-BASED METHODS IN UNPAID CAREGIVING CONTEXTS: A SCOPING REVIEW

ABSTRACT

Introduction:

Unpaid caregiving plays a crucial role in supporting older adults, requiring innovative approaches to understand and enhance caregivers' experiences.

Research Objectives:

As a response, this scoping review investigates the application of arts-based methods in understanding the caregiving experience, as well as the advantages and limitations of these methods in providing care to diverse populations.

Methodology:

Building on Arksey and O'Malley's framework, our methodology draws from the Joanna Briggs Institute approach. Eligibility criteria encompassed peer-reviewed publications in English from 2007 to 2022, focusing on unpaid caregivers, arts-based methods, and caregiving experiences. Six comprehensive databases were queried, with the initial searches yielding 761 articles. Full text screening of 66 papers resulted in 19 papers for inclusion in the scoping review.

Results:

Analysis of the literature revealed the multifaceted applications of arts-based methods in understanding and supporting unpaid caregivers. These encompassed a wide range of creative techniques, such as visual arts, photo elicitation, storytelling, and performance – which provided insights into the emotional, psychological, and social dimensions of caregiving. Findings highlighted the potential for arts-based methods to enhance caregiver well-being, foster self-reflection and self-care, and promote dialogue. Nonetheless, there were notable gaps. Racial and ethnic diversity was often neglected in the studies (addressed in 3 of 19), underscoring the necessity for tailored interventions and methodological considerations for diverse populations. Importantly, dementia caregiving received substantial attention (12 of 19).

Final Considerations:

This scoping review highlights the growing interest in integrating arts-based methods into caregiving research and interventions amongst qualitative and mixed methods approaches. By mapping out the landscape of existing literature, this review underscores the need for further exploration and methodological refinement to harness the full potential of creative techniques in advancing our understanding of unpaid caregivers' lived experiences. Arts-based approaches hold promise in providing a nuanced and holistic perspective on unpaid caregiving experiences.

Keywords

Arts-based; Unpaid caregivers; Methods; Interventions; Scoping review.

1. Introduction

Public healthcare systems worldwide are undergoing profound transformations as they grapple with the challenges posed by an aging population (Cristea et al., 2020). One notable trend is the escalating reliance on unpaid caregiving to meet the ever-growing care needs (Lindt et al., 2020; Medicine et al., 2008). This shift reflects a broader societal expectation that families should bear the responsibilities of caregiving, often without adequate financial and other support structures in place (Willert & Minnotte, 2019). As the global demographic shift towards an older population intensifies, these demands on unpaid caregivers are poised to rise exponentially, raising important questions about unpaid caregiving arrangements. Unpaid caregivers are defined as family members, neighbours, and/or friends who provide unpaid care to someone experiencing a diminishing physical or mental ability, or chronic illness. Unpaid caregivers often find themselves navigating a complex web of responsibilities encompassing emotional support, medical assistance, and daily living activities (del-Pino-Casado et al., 2021). This multidimensional role can place immense responsibility on caregivers who often grapple with the lack of formal training and resources required to address the diverse needs of care recipients. The assumption that caregiving is a natural extension of familial obligations neglects the intricate and demanding nature of the tasks involved. This oversight results in unpaid caregivers being ill-equipped to handle the complex medical, emotional, and logistical aspects of providing care, leading to potential negative consequences for both the caregiver and the care recipient (Broxton & Feliciano, 2020; Schulz et al., 2012).

Unpaid caregivers play a crucial role in supporting individuals in need. Research exploring the experiences and needs of unpaid caregivers is essential to understand their caregiving challenges and support them in their role as caregivers. While quantitative studies may provide a macro-level understanding of caregiving dynamics, they often fail to capture the intricacies and subjective dimensions of the caregiver's journey. The lack of in-depth qualitative exploration hinders our ability to comprehend the diverse challenges, coping mechanisms, and emotional toll experienced by caregivers. Arts-based methods have emerged as a unique approach to delve into the world of unpaid caregivers, offering a creative and expressive avenue to capture their lived experience (Bourne et al., 2020; Lang et al., 2014; Yoon Irons et al., 2020). This scoping review sets out to explore what is known about how arts-based approaches are being used in the context of unpaid caregiving research.

1.1 Background of Arts-Based Methods

Barone and Eisner define arts-based research as “an approach to research that exploits the capacities of expressive form to capture qualities of life that impact what we know and how we live” (2012, p. 5). According to the authors, arts-based research uses the strengths of the arts to produce new information, insights, and perspectives in a variety of fields and disciplines, such as the humanities, social sciences, education, health, and community development. Through this strategy, deep and nuanced aspects of the human experience can be explored in a way that is frequently not achievable through conventional research approaches alone.

Arts-based approaches and practices can encompass a diverse range of methods and practices, but some of the most common methods include, according to Patricia Leavy (2019, p. 4), are:

- Literary forms: essays, short stories, novellas, novels, experimental writing, scripts, screenplays, poetry, and parables;
- Performative forms: music, songs, dance, creative movement, theatre;
- Visual arts: photography, drawing, painting, collage, installation art, three-dimensional art, sculpture, comics, quilts, and needlework;
- Audiovisual forms: film, video;
- Multimedia forms: graphic novels; and
- Multimethod forms (combining two or more art forms).

These methods can be applied individually or in group settings.

1.2 Arts-Based Methods in Caregiving Research

Arts-based methods in research with unpaid caregivers have gained attention due to their potential to provide a deeper understanding of the caregiving experience. Within health research more broadly, incorporating creative arts elements into research has been found to help tap into the emotional and psychological aspects of lived experience that may not be easily expressed through traditional research methods (Fraser & Sayah, 2011).

Three existing reviews explore the use of specific creative methods with caregivers of individuals with neurological conditions, dementia, and patients in a radiation oncology unit. Bourne et al. (2020) conducted a systematic review focusing on dyadic arts interventions for individuals with dementia and their caregivers, finding that participants enjoyed the activities and reported positive effects of participating. Lang et al. (2014) carried out a systematic review exploring the effects of art therapy on caregivers of cancer patients, indicating that this kind of approach effectively reduced stress among caregivers. Yoon Irons et al. (2020) conducted an integrative systematic review of creative arts interventions for older unpaid caregivers of individuals with neurological conditions, underscoring the psycho-social benefits of creative arts interventions for caregivers in this specific demographic. These reviews provided important information on the effectiveness of specific arts-based methods and interventions amongst unpaid caregivers of particular populations. However, to date, there is no comprehensive review that focuses on all art forms and methods to understand unpaid caregivers' experiences. Therefore, this scoping review aims to synthesize available evidence of all arts-based and creative methods more broadly with unpaid caregivers.

As a review method, a scoping review is able to address broader questions than a systematic review, offering the possibility to identify knowledge gaps and map out current evidence (Peters et al., 2020). Scoping reviews allow for the inclusion of different study designs, making it possible to capture an overview of current literature on a particular topic (Arksey & O'Malley, 2005). This is thus a suitable method given the exploratory nature of the question being considered in this review.

This scoping review examines existing research to analyse the impacts of arts-based methods on research with unpaid caregivers. The review included 19 English language peer-reviewed journal articles published between 2007 and 2022.

2. Review Question

The overarching research question guiding the scoping review is: What arts-based methods are used to explore unpaid caregiving experiences in Canada and internationally?

Sub-questions:

1. What are the impacts of arts-based methods on research with unpaid caregivers?
2. What are the advantages and challenges of using arts-based tools in interventions for unpaid carers?

Within the JBI's recommended PCC (population, concept, and context) framework (Pollock et al., 2023), this review's population is unpaid caregivers, the concept of focus is the use of arts-based methods, and the context is caregiving research.

Keywords: arts-based, unpaid caregivers, research, interventions

Eligibility Criteria

The scoping review limited inclusion to peer-reviewed publications published in English between 2007 and 2022. Given the scarcity of available literature on arts-based approaches to caregiving research, a 15-year eligibility was deemed appropriate to maximize the number of eligible papers while remaining current. The review was limited to English language publications as this is the only language all authors have in common. Peer-reviewed publications were exclusively considered in order to maintain a high-quality review. Additionally, to be included, papers needed to discuss both the provision of unpaid care to older adults by unpaid, informal and/or family caregivers and the use of arts-based methods related to caregiving (either as a research method or in the context of an intervention). Papers were excluded if they only addressed paid caregivers. Likewise, papers were excluded where the provision of care for children (unless adult children) was discussed. Papers that discussed both recipients of care and caregivers were included so long as they discussed outcomes for caregivers.

3. Methods

Building on the methodological work of Arksey and O'Malley (2005), this review followed the Joanna Briggs Institute (JBI) methodology for Scoping Reviews (Peters et al., 2020; Pollock et al., 2023) to conduct a scoping review of arts-based methods used with unpaid caregivers. The Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) (Trocco et al., 2018) was followed for reporting. No protocol was registered.

3.1 Search Strategy

A Trent University research librarian was consulted in the development of the search strategy. The strategy was then refined through discussion among the authors. Six bibliographical databases were chosen to be both comprehensive and feasible (Levac et al. 2010). To capture both research-based and intervention-based papers, both medical and social science databases were consulted, namely: MEDLINE, PsycINFO, CINAHL, ProQuest, Sociological Abstracts and Web of Science.

Database searches took place in the month of December 2022. Final search results were exported to Mendeley, and duplicates were removed.

Databases were searched for key terms of caregiver (carer/caregiv*/informal caregiv*/family caregiv*) and arts-based methods (arts-based methods/creative methods), as well as a publication date filter for 2007-2022. Where possible, limits for adult participants were also used. The database searches were conducted by the first author. Following the JBI search process (Peters et al., 2015), the reference lists of all identified papers were searched for additional relevant papers.

3.2 Source of Evidence Selection

Following the search, all identified citations were collaged and uploaded into Mendeley 2.105.0/2023 (Elsevier, Amsterdam, Netherlands) and duplicates were removed. Manuscript titles and abstracts were then screened by First Author and Second Author for assessment against the inclusion criteria for the review. Potentially relevant sources were retrieved in full, and their citation details were imported into Mendeley 2.105.0/2023 (Elsevier, Amsterdam, Netherlands). The full text of selected citations was assessed in detail against the inclusion criteria by First Author and Second Author. Reasons for the exclusion of sources of evidence are noted in Figure 1. Any disagreements that arose between the reviewers at each stage of the selection process were resolved with the input of Third Author.

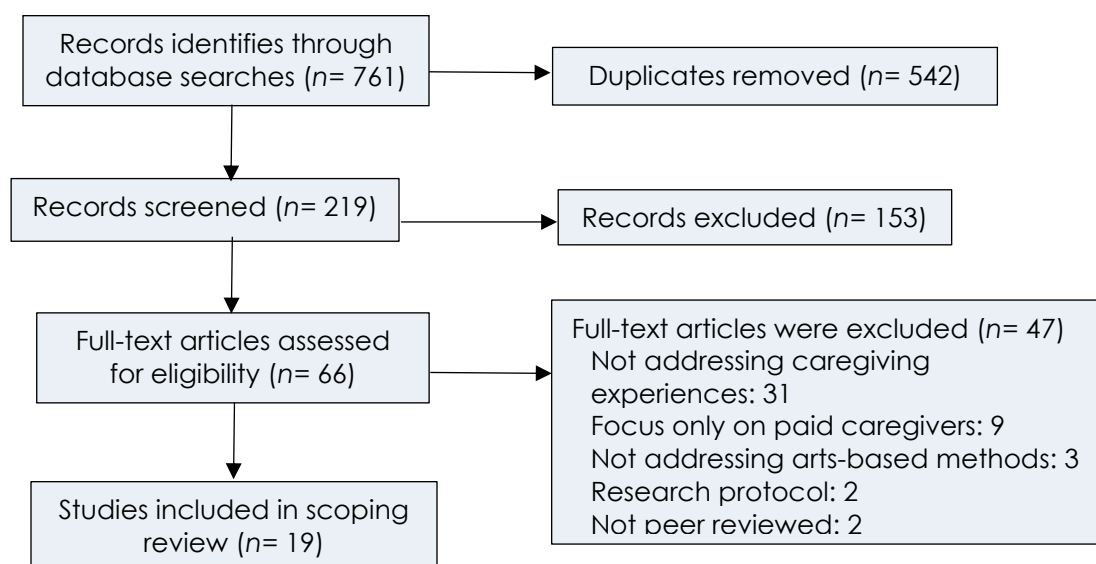


Figure 1. Article screening and exclusion, based on PRISMA 2020 guidelines

4. Data Extraction

A data-charting form was jointly created to determine what data to extract. Using Excel, two reviewers charted the data independently, calibrating the form together in an iterative process.

Data items charted included characteristics of articles as well as key findings. Descriptive data included publication details such as authors names, year of publication, country in which the research took place. Data about the population were also charted, including number of participants, population of care recipients, relationship between care recipient and caregiver, age of caregiver/care recipient, ethnicity of caregiver/care recipient and years of caregiving experience. Whether the article presented findings from an intervention or outcomes of a research process were also charted. Details about the aim/purpose of the article were also charted, along with overall methodology as well as the type of arts-based method used. Finally, key findings were charted (see appendix 1).

5. Findings

The review yielded studies where arts-based methods were used as data collection tools ($n = 9$) and intervention research where arts-based methods were used as part of the intervention itself ($n = 14$), with some including both unpaid caregivers and care recipients ($n = 5$) while others focused on unpaid caregivers ($n = 9$).

Of the 19 studies reviewed, the majority were carried out in the United States ($n = 6$), followed by Australia ($n = 4$), Canada ($n = 3$) and the United Kingdom ($n = 4$), with few from Singapore ($n = 1$) and The Netherlands ($n = 1$).

Most of the studies reviewed come from the caring professions, most prominently from psychology ($n = 7$). Nursing studies also figured prominently ($n = 3$), followed by health sciences ($n = 2$), oncology ($n = 2$) and palliative care ($n = 2$). Other disciplines represented in the reviewed studies include geography ($n = 1$), digital design ($n = 1$) and education ($n = 1$) was also analysed.

Table 1. Methodological Characteristics Findings

Methodological Characteristic	Findings
Use of Arts-Based Methods	Arts-based intervention ($n = 14$) Arts-based method as data collection tool ($n = 9$)
Geographic Location	United States ($n = 6$) Australia ($n = 4$) Canada ($n = 3$) Singapore ($n = 1$) Netherlands ($n = 1$)
Discipline	Psychology ($n = 7$) Nursing ($n = 3$) Health Sciences ($n = 2$) Oncology ($n = 2$) Palliative care ($n = 2$) Geography ($n = 1$) Digital Design ($n = 1$) Education ($n = 1$)

The majority of the studies addressed experiences of unpaid caregiving for a person living with dementia (n= 12), and cancer (n= 3). Studies explored caregiving for a variety of chronic and palliative conditions (n= 2), and other studies were unspecified with respect to the condition of the care recipient (n= 2).

Race and/or ethnicity of participants was not always addressed in the reviewed studies. Where this data was available, it showed limited diversity across the unpaid caregivers included in these studies. The unpaid caregiver participants in the majority of the reviewed studies are predominantly Caucasian from Australia, Canada, the United Kingdom and the United States. The exceptions to this are: Hammond et al. (2017) focus on First Nations cancer survivors and their caregivers in Canada, Petts and Urnton (2022) explore the experiences of participating in a community dance program for family caregiver where two of the three participants were South Asian, Walsh et al. (2007) undertake art-making classes amongst caregivers of cancer patients in the United States where 20% of their participants are Caucasian, Wharton et al. (2018) undertake a photojournalism pilot project to explore caregiver burden with two African American participants and one Hispanic participant, and Tan et al. (2022) who are studying an arts and dementia program among predominantly (93.8%) Chinese participants in the Singapore context.

Gender was more consistently reported on than race and/or ethnicity in the reviewed studies. Most reviewed studies had more female participants than male (n = 12), with many reporting more than twice the number of female to male participants (n = 7). One study consisted of an equal number of female and male participants and two studies had only female participants.

Table 2. Demographic Findings

Type of Demographic	Findings
Diagnosis of Care Recipient	Dementia (n = 12) Cancer (n = 3) Chronic and palliative conditions (n = 2) Unspecified (n = 1)
Race/Ethnicity of Participants	Majority Caucasian/white (n = 5) Majority non-Caucasian/white (n = 5) Unspecified (n = 9)
Gender of Participants	Majority female (n = 12) Only female (n = 2) Equal female-male (n = 1) Unspecified (n = 4)

The results of the thematic analysis are described in the following subsections.

5.1 Arts-Based Methods Used in Reviewed Papers

Returning to Leavy's (2019) categorization of arts-based methods, the following is a breakdown of the forms of arts-based methods used in the reviewed studies (interventions have been indicated in *italic*).

Table 3. Forms Of Arts-Based Methods Used in Reviewed Studies

Forms of arts-based methods	Arts-based method used
Literary forms (n= 3)	<ul style="list-style-type: none"> - Appreciative inquiry (i.e. experimental/narrative art or storytelling) (Graham-Pole & Lander, 2009) - Poetry writing (<i>Kidd et al., 2011</i>) - Song writing (<i>Baker & Yeates, 2018</i>)
Performative forms (n= 5)	<ul style="list-style-type: none"> - Groups singing (<i>Clark et al., 2018; Davidson & Almeida, 2014; Osman et al., 2016</i>) - Research-based drama (<i>Dupuis et al., 2016</i>) - Community dance (<i>Petts & Urmston, 2022</i>)
Visual forms (n= 3)	<ul style="list-style-type: none"> - Participant Produced Graphic Elicitation (i.e. drawing) (<i>Lowe et al., 2022</i>) - Colouring or open-studio art therapy (<i>Kaimal et al., 2019</i>) - Photojournalism (<i>Wharton et al., 2019</i>)
Audiovisual forms (n= 1)	<ul style="list-style-type: none"> - Carer administered a music listening program (<i>Hanser et al., 2011</i>)
Multimedia forms (n= 1)	<ul style="list-style-type: none"> - Graphic novel (<i>Haan et al., 2022</i>)
Multimethod forms (n= 6)	<ul style="list-style-type: none"> - Art viewing and art making (<i>Camic et al. 2016; Tan et al., 2021</i>) - Photography and journaling (<i>Hammond et al., 2017</i>) - Four visual methods (photo-elicitation, documentary photography, cartoons, and drawings) and one story-telling approach (research poetry) (<i>Miller & Zelenko, 2022</i>) - Participant's artwork of choice (<i>Fraser et al., 2014</i>) - Art-making activities (i.e. decorating jewelry boxes, monoprints, watercolour painting, silk scarf or wall hanging making, mandala creations) (<i>Walsh et al., 2007</i>)

Multimethod forms, including two, or more, arts-based methods, were the most popular amongst reviewed studies, with an even split between intervention research and arts-based

methods research. This is followed by performative forms which included only intervention research, of which singing was the most common. Literary and visual forms were also well represented.

5.2 Using Arts-Based Methods for Data Collection or Data Creation

The scoping review findings suggest that the use of arts-based methods for data collection can have a positive impact on caregivers and the caregiving experience. Arts-based research methods were also noted to help nurture a safe environment for participant expression, particularly in the emotionally charged context of caregiving (Fraser et al., 2014; Lowe et al., 2022; Graham-Pole & Lander, 2009). Lowe et al. (2022), who carried out their interviews remotely, credit their graphic elicitation method for allowing participants to be vulnerable despite the physical and social distance involved in phone interviews.

Arts-based methods can help caregivers gain a deeper understanding of themselves and their caregiving experiences and lead to increased self-awareness and self-care for caregivers (Miller & Zolenko, 2022). The non-verbal nature of visual methods is also reported to offer participants opportunities for reflection (Hammond et al., 2015).

5.3 Using Arts-Based Interventions

The use of arts-based tools within caregiving interventions has been reported to offer a myriad of benefits, contributing significantly to the well-being of both caregivers and care recipients. One prominent advantage is the enhancement of contentment and social engagement (Clark et al., 2018; Davidson & Almeida, 2014; Hanser et al., 2011; Osman et al., 2016; Tan et al., 2021; Warton et al., 2018). Through artistic activities, individuals involved in caregiving experience a positive influence, with stress reduction being a notable outcome (Clark et al., 2018; Davidson & Almeida, 2014; Hanser et al., 2011; Kaimal et al., 2019; Kidd et al., 2011; Osman et al., 2016; Tan et al., 2021; Walsh et al., 2007). This positive impact extends to fostering a reconnection between caregivers and the individuals they care for, as evidenced by studies conducted by Clark et al. (2018), Petts and Urmston (2022), Osman et al. (2016), and Tan et al. (2021).

Furthermore, the use of arts-based tools has been recognized for providing caregivers with a sense of being seen and heard, as elucidated by Baker and Yeates (2018). Additionally, these interventions facilitate the creation of connections among caregivers, offering them a supportive network, as emphasized in studies by Kidd et al. (2011) and Warton et al. (2018). The process of engaging in artistic activities also promotes self-reflection for caregivers, aiding in personal growth and understanding, as observed in works by Baker and Yeates (2018), Kaimal et al. (2019), and Kidd et al. (2011). Moreover, arts-based caregiving interventions are acknowledged for providing respite to caregivers, allowing them a moment of reprieve from their demanding responsibilities (Camic et al., 2016; Petts & Urmston, 2022; Warton et al., 2018).

Despite the extensive exploration of the benefits, it is noteworthy that challenges or drawbacks associated with the use of arts-based methods in caregiving interventions were rarely discussed in the reviewed literature.

The focus has primarily been on the positive impacts, suggesting a need for further research to comprehensively understand the potential limitations and to then address them in the implementation of these innovative approaches.

Of note, two intervention studies reviewed employed arts-based methods as tools for raising awareness about illness and caregiving experiences (Dupuis et al. 2016; Haan et al., 2022).

6. Discussion

Data about the race and/or ethnicity of participants was often absent in the reviewed studies. When this data was available, participants were predominantly caucasian/white, with 3 notable exceptions. This suggests both that more nuanced reporting about race and/or ethnicity, and that arts-based research and intervention work is needed amongst a more diverse population of unpaid caregivers.

While the gender of participants was often reported on, the strong majority of female participants present in most of the reviewed studies reflected the gendered reality of care work (Ophir & Polos, 2021). The reviewed studies did not address the ways in which experiences of caregiving are profoundly shaped by gender, suggesting that applying a gender analysis in future research could be worthwhile.

Though unpaid caregivers were often included in interventions, where unpaid caregivers and care recipients were both included, studies often had care recipients as their primary focus. While this generated some interesting insights, more arts-based research and interventions which seek to explicitly address caregiving concerns and experiences are needed.

Additionally, 12 of the 19 studies reviewed focused on caregivers of people living with dementia. Though dementia is an important focus, new research or intervention work could broaden the application of arts-based methods to a greater range of caregiving experiences.

Lastly, within literature on arts-based methods, there seem to be an emerging discussion on the distinction between active and passive forms of arts-based methods (Yoon Irons et al., 2020). This discussion draws attention to the differences that might arise between the use of methods where the participant is doing/making and where the participant is listening/watching. Two of the studies reviewed would be considered passive (Hanser et al., 2011; Wharton et al., 2019). From the reviewed studies, it appears that the experiential element of the active forms of arts-based methods have the added benefits of more fully engaging participants. It would be worthwhile exploring whether, and if so how, this distinction is useful for the design and implementation of arts-based methods and interventions.

7. Final Considerations

The use of arts-based methods in research with unpaid caregivers aligns with the broader goal of enhancing caregiver and care recipient experiences. By incorporating creative approaches, researchers can not only document the challenges faced by caregivers but also highlight their resilience and coping strategies. Understanding the multifaceted experiences of caregivers through arts-based methods can lead to more tailored and effective support programs that address their unique needs.

The use of arts-based methods in research with unpaid caregivers offers a promising avenue to explore the complexities of the caregiving journey. Future research can shed light on the impact of creative interventions on caregiver well-being and pave the way for more comprehensive and empathetic support systems.

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New Trends in Qualitative Research

Appendix

Articles															
Author(s)	Title	Year	Country of Origin	Discipline	Aim/purpose	Population(s) of care recipient	Relationship to care recipient	Number of participants	Years of caregiving for Informal Caregivers	Age of Informal Care Giver/ Recipients	Ethnicity	Type: Intervention or Research	Methodology	Type of Arts-based Method	Key Findings
Baker & Yeates	Carers' experiences of group therapeutic songwriting: An interpretive phenomenological analysis	2018	Australia	Music therapy	Exploratory study examining the benefits of collective therapeutic songwriting for carers of persons with dementia, exploring their caregiving experiences	Persons with dementia	Spouse (n=2), adult child (n=2)	Informal carers n=4 (F=2; M=2)				Intervention	Qualitative; focus group and individual interview about songwriting sessions	Songwriting	Participant experience exceeded expectations, co-creating a song was reported as found to be meaningful, participants learned throughout the experience, and reported feeling like their voice was heard.
Camici et al.	Theorizing how art gallery interventions impact people with dementia and their caregivers	2016	United Kingdom	Psychology	This study sought to develop a theoretical understanding of how the process of viewing and making art in the social and physical context of an art gallery environment impacts people with dementia and accompanying caregivers	Persons with dementia	presumed family, though not actually specified in study	n=24, PWD n=12, carer n=12 (F=15, M=9)			17 White-British, 4 White-Europeans, 2 British-Asian, 1 Black-British;	Intervention	Qualitative; 8-week program, 2 hours per week with one hour of art-viewing and one hour of art-making	painting images and shapes, building abstract and figural sculpture, making lino prints, and constructing collages relating to feelings and emotions evoked by the art	Study found that the museum-based program provided respite and support for carers.
Clark et al.	Community-Dwelling People Living With Dementia and Their Family Caregivers Experience Enhanced Relationships and Feelings of Well-Being Following Therapeutic Group Singing: A Qualitative Thematic Analysis	2018	Australia	Psychology; music therapy	Presenting findings of pilot study aimed to explore how community-dwelling PwD and their FCG experienced therapeutic group singing over 20 weeks	Persons with dementia	Spouse (n=8), adult child (n=1)	n=18, PWD n=9 (F=5, M=4), carer n=9 (F=5, M=4)	PWD age range 57-89, carer age range = 61-90	8 dyad = Australian-born, 1 dyad = immigrated from Ukraine		Intervention	Qualitative	Group singing	Study suggests that therapeutic facilitation by music therapists, with design features tailored for PwD and FCG dyads, provided supportive structure, which when coupled with affinity between group members and the fact that PwD and FCG could attend together, mediated improved accessibility to group singing, the formation of empathic friendships, benefits within PwD/FCG relationships, and wellbeing for both as individuals

Davidson & Almeida	An exploratory study of the impact of group singing activities on lucidity, energy, focus, mood and relaxation for persons with dementia and their caregivers	2014	Australia	Psychology	Exploratory quantitative and qualitative study to examine the benefits of a weekly singing program on people with dementia and their carers	Persons with dementia	Group a (community-based group)= child and spouse Group b (LTC group)= professional carers	Group a: PWD n=6 and family carers n=6, Group b PWD n=11 and paid carers n=4	Age range: Group A: 42-86; and, Group B: 44-63	Intervention	Exploratory quantitative and qualitative study	Group singing	Quantitative and qualitative data suggests weekly participation in this kind of singing groups decreases stress for carers (benefits not disaggregated by type of carer) and increased connection
Dupuis et al.	Igniting Transformative Change in Dementia Care Through Research-based Drama	2016	Canada	Community and Long-term Care Settings (e.g., social work, nursing, primary health care, educator)	To examine how personal images, understandings, and actions of family members (FMs) of persons with dementia and health care professionals (HCPs) change after the introduction of a research-based drama about the experiences of living with dementia called I'm Still Here	Persons with dementia	Family members of persons with dementia and Health care Providers; Family members cared for: parent, parent-in-law; spouse; sibling; grandparent and other relative	N= 106 Family members = 48; (F= 36; M= 12); Health Care Providers = 58 (F= 46; M= 12)	2 or less years = 15 3-5 years = 16 6-10 years = 13 11-15 years = 2 Not indicated = 2	Intervention	Longitudinal research project; interpretive phenomenological research	Live performance of a research-based drama "I'm Still Here" Focus groups pre and post-performance; Telephone interviews	The study's findings revealed that witnessing suffering evokes compassion, gaining new awareness leads to expansion, finding comfort and courage enables changes, and envisioning new possibilities facilitates action.
Fraser et al.	Uncovering the Meaning of Home Care Using an Arts-Based and Qualitative Approach	2014	Canada	Nursing	To uncover the meaning of the home care experience	Wide variety of chronic and palliative conditions, and many had multiple health problems	Family caregivers of persons who received formal home care services, had experience in the hospital and with assisted living facilities	N= 11 (one client and 10 family caregivers) (F=9, M=2)		Research	Qualitative Arts-based methods	Participant's artwork of choice (a wall quilt, a drawing, a story, three poems, and one short story); In-depth individual interviews	The study's findings highlighted six significant themes regarding family caregivers' experiences and the impact of formal home care services: understanding the effects of caregiving, coping strategies employed by caregivers, accessing available home care services, navigating bureaucratic systems, examining qualities and relationships with formal caregivers, and adapting to life with home care support.

Graham-Pole & Lander	Metaphors of loss and transition: An appreciative inquiry	United States	Pediatrics	<p>Four objectives: (1) elicit information about caregivers' use of art in care; (2) explore its social and cultural contexts; (3) explore its benefits for caregivers and recipients; and (4) identify cross- and intra-cultural commonalities and differences.</p>	<p>General - explore healing of caregivers and care recipients involved in formal/institutional and informal/family health care settings</p>	Personal caregivers	<p>Personal caregivers = 6; Professional = 6; Artists in residence = 9; F = 18 and M = 3</p>	<p>Canadians = 7; Americans = 8, British = 3, and Africans = 3</p>	Research	Qualitative; Action research/narrative methodology	Experiential/narrative art	<p>The study identified 13 interrelated themes revolving around loss and healing, emphasizing the integration of art into care practices, the search for meaning in narratives of loss, the discovery of positivity amidst adversity, and the importance of self-care for caregivers. Additionally, it highlighted reciprocal support between caregivers and recipients, the potential for personal growth through challenges, and the role of art in both breaking barriers and addressing spiritual aspects of healing.</p>
Haan et al.	<p>Facilitators and barriers in using comics to support family caregivers of patients receiving palliative care at home: A qualitative study</p>	Netherlands	<p>Health Sciences - nurse, social worker, hospice employee, nursing home physician, family caregiver consultant, spiritual counsellor</p>	<p>To identify facilitators and barriers in using Naasten (Loved ones), a Dutch research-based graphic novel about family caregivers providing care at the end-of-life.</p>	<p>People receiving palliative treatment</p>	<p>N = 23 (palliative care volunteers, and healthcare professionals who supported family caregivers); F = 22; M = 1 N = 4 (family caregivers); F = 3; M = 1</p>	<p>Caregivers mean age = 65.75 ; Care Recipients mean age = 77.3</p>	Intervention	Qualitative	<p>Comic - Graphic novel; Focus groups</p>	<p>The findings highlighted barriers and facilitators across various dimensions: the family caregiver's role, its impact, the dynamics of communication between support providers and caregivers, their relationship dynamics, and the impact on the support provider. "Naasten" was recognized as supportive and emotionally evocative, facilitating meaningful conversations and awareness. However, barriers included concerns about the book's style, its guidance in conversations, and doubts regarding its added value.</p>	

Hammond et al.	Cycles of silence: First Nations women overcoming social and historical barriers in supportive cancer care	2015	Canada	Oncology	Explores survivorship experiences of First Nations women with cancer and their caregivers.	75% - People with cancer; 25% - colon, kidney or skin cancer, or Non-Hodgkin Lymphoma.	Caregivers of cancer survivors	N= 43 (24 cancer survivors and 19 caregivers)	Caregivers mean age; Community 1 = 61 years; Community 2 = 56 years; Community 3 = 49 years; Community 4 = 61 years	People from 4 First Nations Communities- British Columbia, Ontario, and Quebec	Research	Participatory arts-based methods	Qualitative interviews, sharing sessions, photovoice, and other creative activities	The findings revealed two key themes: firstly, the cycle of silence perpetuated by suffering without support, and secondly, the potential disruption of these cycles through community-based supports. Social, historical, and institutional barriers hindered discussions about cancer and accessing support, but these barriers were mitigated through the voluntary and unsolicited provision of support.
Hanser et al.	Home-based music strategies with individuals who have dementia and their family caregivers	2011	United States	Psychology; Music therapy	Feasibility study to test a caregiver administered music program with a family member who has dementia, exploring benefits for care recipient and carer	Persons with dementia	Spouse (n=6), adult child (n=2)	Family carers n=14 recruited (F=5, M=3)		White	Intervention	Qualitative and quantitative, Visual analog scale used to measure subjective experiences of relaxation,	Carer administered music listening program	Both caregivers and care recipients improved self-reported relaxation, comfort, and happiness, when mean scores were compared between baseline and music conditions. Caregivers showed the most benefit.
Kaimal et al.	Outcomes of art therapy and coloring for professional and informal caregivers of patients in a radiation oncology unit: A mixed methods pilot study	2019	United States	Oncology	To compare the effects of two brief visual arts interventions (open studio art therapy and coloring, as the active control group) for caregivers of patients undergoing radiation oncology treatment on measures of stress, anxiety, affect, self-efficacy, creative agency, and burnout	Cancer Patients	Personal caregivers of patients undergoing radiation oncology treatment; Included spouses (3), children of patients (3); parents of patients (2); and siblings.	N= Thirty-four (F= 27; M = 7) Health care professionals (n=25) and informal caregivers; (n=9)	22-72 years (does not separate ages of formal and informal caregivers)		Intervention	Mixed-method study	Single sessions of coloring or open-studio art therapy	Caregivers in both interventions demonstrated improvements across all psychological outcomes - improved affect, decreased anxiety and stress, reduced caregiver burnout, improved self-efficacy, and improved creative agency. Both coloring and open studio conditions improved the effect in the participants. Feelings of pleasure and enjoyment were voiced throughout the findings.

<p>Kidd et al. for family caregivers 2011 Benefits of a poetry writing intervention of elders with dementia</p>	<p>United States</p>	<p>Nursing</p>	<p>pilot clinical trial tested effectiveness of a poetry writing intervention for family caregivers of elders with dementia</p>	<p>Persons with dementia</p>	<p>Family caregivers</p>	<p>n=20 (F=17, M=3)</p>	<p>Mean age was 60.2 years, with a range of 41–80 years of age</p>	<p>Majority Caucasian (95%), with only one participant being African American</p>	<p>Intervention</p>	<p>Qualitative analysis of in-depth interviews conducted with participants following their poetry writing experience</p>	<p>Poetry writing</p>	<p>The primary finding of the study centered around self-affirmation. From this emerged nine subthemes: achievement, catharsis, increased acceptance, greater empathy, reflection, enhanced self-awareness, enjoyment and creativity, positive challenge, and altruistic endeavors.</p>
<p>Lowe et al. 2022 Remote graphic elicitation: A critical reflection on the emotional affordance and disruption management in caregiver research</p>	<p>United Kingdom</p>	<p>Geography</p>	<p>Methodology paper that explores how participant-produced graphic elicitation activities support the sharing of more challenging emotional caregiving experiences by participants from a distance</p>	<p>Persons with dementia</p>	<p>Informal caregivers (spouse and adult child mentioned, but not specified for all care dyads)</p>	<p>Informal carers n=17 (F=12; M=5)</p>	<p>age ranging from early 50s to mid-80s</p>	<p>Research</p>	<p>Qualitative Arts-based methods</p>	<p>participant-produced graphic elicitation</p>	<p>The study discovered that conducting graphic elicitation remotely was effective in exploring the emotionally charged topic of informal caregiving. This method facilitated reflection and expression of experiences and emotions, creating a safe space for participants to be vulnerable. Additionally, it contributed nuanced visual outputs that enhanced understanding of informal dementia caregiving journeys. The method played a crucial role in the success of the interview process, both in terms of content and preparation.</p>	
<p>Miller & Zolenko 2022 The Caregiving Journey: Arts-Based Methods as Tools for Participatory Co-Design of Health Technologies</p>	<p>Australia</p>	<p>Digital</p>	<p>To explore the value of design and arts-based methods in exploring the caregiving experience and co-designing an app, with and for end-users.</p>	<p>Living with illness, disease, or chronic disability</p>	<p>Informal and Formal caregivers</p>	<p>9 female caregivers (informal caregivers (n = 7), paid (n = 2))</p>	<p>Research</p>	<p>Mixed arts-based research methods; co-design workshops</p>	<p>Multiple arts-based methods, including visual experience mapping tools, storytelling, photo-elicitation, documentary photography, cartoons, drawing, and research poetry.</p>	<p>The study uncovered insights into informal caregiving, highlighting the daily challenges faced by caregivers, their pragmatic yet loving approach to caregiving, feelings of isolation and exhaustion, and interest in utilizing technology to aid in their responsibilities.</p>		

Osman et al.	'Singing for the Brain': A qualitative study exploring the health and well-being benefits of singing for people with dementia and their carers	2016	United Kingdom	Music Therapy	Examines impact of an intervention based on group singing activities developed by The Alzheimer's Society for people with dementia and their carers	Persons with dementia	Spouse (n=7), adult child (n=3)	n=20 (F=13, M=7)				Intervention	qualitative study with semi-structured interviews was used to gather in-depth information about the experiences of people with dementia and their carers	Singing program called 'Singing for the brain'	The study identified six key themes from the data, including social inclusion and support, a shared experience among participants, positive impacts on relationships and memory, lifting of spirits, and acceptance of the diagnosis.
Petts & Urmston	An exploration into the experience of family caregivers for people living with dementia in a community dance class	2022	United Kingdom	Dance research; Education	To present findings of semi-structured interviews conducted with informal caregivers to understand how participation in community dance programs has impacted their caregiving experiences.	Persons with dementia	Spouse (n=2), adult child (n=1)	Family carers n=3 (F = 3)	minimum 3 years	42 to 57 years (M = 50.3 years, SD = ± 6.24)	Nationality: Indian, British, Belgian	Intervention	Qualitative	Community dance	The study findings underscored how community dance provided caregivers with opportunities to reconnect with their care recipients, fostered a socially engaged environment among caregivers, and allowed for temporary respite from caregiving responsibilities.
Tan et al.	Enhancing the caregiving experience of family care partners in Singapore through an arts programme for persons with dementia: an exploratory study	2021	Singapore	Psychology	To broaden the sociocultural perspectives of arts-based programmes by investigating the impact of a locally developed Arts & Dementia programme for persons with dementia on their family care partners	People with dementia from the New Horizons Centres	Primary family care partners (those who accompanied their loved ones to the programme) of the persons with dementia; Spouse and Adult Child	N= 32 care partners (M= 12; F = 20); *10 care partners for the qualitative interviews;	Care partners mean age = 54.87	Chinese 30 (93.8%) Malay 2 (6.2%)	Intervention	Mixed-method approach: quantitative pre- and post-programme data and qualitative data from semi-structured group interviews	Arts & Dementia programme	The study did not find any self-reported short-term changes in perceived caregiving difficulties and gains, but semi-structured interviews revealed potential benefits of community-based arts activities for caregivers. These benefits included feelings of contentment and social engagement, reconnection and development of new interests, positive influences on caregiving, suggestions for program improvements, a desire for more arts programs, and increased support for families living with dementia.	

Walsh et al.	A Pilot Study to Test the Effects of Art-Making Classes for Family Caregivers of Patients With Cancer 2007	United States	Oncology; Nursing	To test the effects of an art-making class (AMC) on reducing anxiety and stress among family caregivers of patients with cancer.	Cancer patients	Family caregivers	n=69	The 69 enrolled caregivers were aged 18–81 years, with a mean of 48 years (sD = 14.47).	The 69 enrolled subjects were primarily female (80%); 38% were Hispanic, 23% were islanders (Caribbean), and 20% were caucasian.	Intervention	pretest and post-test quasi-experimental design	Art-making activities: decorating jewelry boxes, monoprints, watercolour painting, silk scarf or wall hanging making, mandala creations	A significant reduction in anxiety and stress was noted among family caregiver participants in the study results	
Wharton et al.	Photojournalism-Based Intervention Reduces Caregiver Burden and Depression in Alzheimer's Disease Family Caregivers 2018	United States	Nursing	The pilot study aimed to holistically reduce caregiver burden and depression and provide a nonverbal outlet for participants to portray their lives as AD caregivers.	Persons with dementia	Persons living with dementia	Informal/unpaid caregivers N= 10 (F= 7; M =3)	An average of 6.2 years	Caregivers mean age = 63.4 ; Care Recipients mean age = 77.3	African Americans = 4; Hispanic =1	Intervention	Four session - Pilot Photojournalism intervention program	Quantitative pre and post-program intervention; Qualitative exploration included sessions' observations, viewing caregivers' photographs, and recording caregivers' accompanying comments.	The study demonstrated clinically meaningful reductions in caregiver burden and depressive symptoms through quantitative analysis. Qualitative findings revealed three themes: caregiver emotional health, shared experiences, and caregiver classroom engagement.