



EDITORIAL

Participatory Arts: Reflections on the Benefits of Creativity-Based Interventions in Dementia Care

Daniel B. Kaplan ¹, Gary Glazner ²

¹ Adelphi University

² The Alzheimer's Poetry Project



OPEN ACCESS

PUBLISHED

30 April 2025

CITATION

Kaplan, DB., and Glazner, G., 2025. Participatory Arts: Reflections on the Benefits of Creativity-Based Interventions in Dementia Care. Medical Research Archives, [online] 13(4).

<https://doi.org/10.18103/mra.v13i4.6462>

COPYRIGHT

© 2025 European Society of Medicine. This is an open-access article distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

DOI

<https://doi.org/10.18103/mra.v13i4.6462>

ISSN

2375-1924

ABSTRACT

In this editorial, we present an overview of arts programs used in dementia care that have at their core the objectives of performing and creating art with people living with dementia. We look at the commonalities between leading arts programs and provide a case study of one such program conducted with elderly nuns at convents in Milwaukee, Wisconsin, and articulate the potential benefits of these arts programs as worthy of pursuit and aligned with essential goals of intervention. We offer comments on the current state of relevant research in the United States and reflect on future directions for continued programming and study.

Introduction

Dementia is a general term for neurocognitive disorders resulting in a syndrome defined by intellectual losses, psychiatric features, and psychological disturbances. The effects on functional capacities can gradually or rapidly accumulate to the point of severe disability, loss of independence, and extreme challenges in maintaining quality of life. Worldwide, 47 million people live with dementia, and by 2050, the number is expected to increase to 131 million.¹ Dementia symptoms of note for this editorial are confusion, memory impairment, language difficulties, and impaired reasoning², as these cognitive impairments interfere with many occupational and instrumental activities yet do not preclude the possibility of personal fulfillment and quality of life derived from creative forms of recreation and self-expression.

Participatory arts, as a long-standing genre of recreational activity used across the continuum of care settings³, grew out of the universally familiar and valued presence of arts across cultural contexts. Artists are found in every community, and multiple forms of art are infused into models of care and education for people of all ages and ability levels. Art can utilize a vast array of media and materials. It can be done as an independent activity in isolation or in the company of others, or it can be structured as a group-based participatory activity with multiple people collaborating in the creation of artistic products. For these reasons, it has been a time-tested feature of daily life for older adults who receive care services in the community or in residential facilities⁴. As such, clinical providers, artists, and scholars have become aware of the compelling effects of arts in dementia care.

The participatory arts in dementia care involve collaborations between trained facilitators and participants, including older adults with varied levels of cognitive capacity and sometimes also including care workers, family members, program staff and volunteers. Participants are supported to engage in creative storytelling, dance, music, poetry, and visual arts⁵. As an activity to include in the daily schedule of care for people living with dementia, participatory arts offer many benefits to formal and informal care providers alike, including convenience, low cost, efficiency of effort, and rapid implementation. However, the most compelling benefits in the views of many medical and clinical professionals are those experienced by the participants themselves.

A key feature of participatory arts is the use of imagination as opposed to memory⁶. Imagination draws upon aspects of human intelligence that are not so severely impaired by neural losses resulting from diseases of dementia. Executive functioning and memory recall are often irrelevant in the making of art. As such, participation in the cultural arts is nearly failure-free as an activity for people with dementia. There is no right or wrong way to improvise a stroke of the paintbrush or the phrasing of a line of poetry. People can experience the artwork of others and make artwork of their own far longer into their journey through dementia than they can engage in other modes of activity. Importantly, each person's contributions to the artistic product have value.

These contributions are expressions of the person's thoughts and feelings, and we validate that person whenever we witness, acknowledge, or celebrate their art.⁷

Participatory arts tap into the essential personhood of human beings and therefore allow for the fulfillment of the highly prioritized goal of person-centered dementia care. Arts allow people to be at the center of the activity, revealing their personhood to others, and honoring the personhood of one another—both participant and facilitator, caregiver and care recipient.⁸ Proponents of participatory arts suggest that people can achieve a state of relative well-being if they are able to maintain their personhood through person-centered care⁹. Anne Basting, the pioneering scholar behind the TimeSlips storytelling model of participatory arts in dementia care, promotes the motto “Forget Memory, Try Creativity,” and this simple phrase has become a touchstone for envisioning new priorities for therapy. What is therapy after all if not an activity designed to achieve relief from discomfort and disability? Five decades into a concerted scientific effort to relieve dementia patients from their cognitive impairments have yielded only limited gains. This relief is a truly noble goal that should continue to be sought. Yet, what of other goals and other forms of relief? Shall we invest in the widespread availability of activities that allow for dramatic increases in quality of life? Shall we further study the relationships between hours spent in joyful expression and outcomes such as appetite and cooperation with tasks of care—outcomes with significant medical and financial implications?

Interventions drawing from artistic traditions

Offered below are six examples of participatory arts formats and best practice programs. These practices typically take place in adult day care programs, care homes, and Memory Cafes.

- Visual Arts: Painting, Drawing, and Coloring: Simple and accessible activities that allow for self-expression. Best practice: Open Minds Through Arts¹⁰.
- Singing and Music Groups: Participating in singing or playing instruments can boost mood and memory. Best practice: SongWriting Works¹¹
- Dance: Movement and rhythm can be a great way to express emotions and engage physically. Best practice: Kairos Alive!¹²
- Drama and Theatre: Acting out scenes or creating plays can encourage social interaction and storytelling. Best Practice: In the Moment¹³
- Creative Writing: Creating stories on the basis of prompts such as photographs can inspire imagination. Best Practice: TimeSlips¹⁴
- Poetry: Creating and reciting poems can be a way to express thoughts and feelings. Best Practice: Alzheimer's Poetry Project.¹⁵

In the workshops of the program Open Minds Through Arts, people living with dementia (artists) are paired with volunteers (students, families, caregivers) who are trained to rely on imagination instead of memory and focus on remaining strengths instead of lost skills. They are paired one-on-one and often will focus on creating abstract art.

This reduces the need for the skill to create figurative art. In this program's training sessions, they show a Jackson Pollack piece next to a work created by a dementia artist. The quality is so similar it is hard to say which is which.

Singing, storytelling, and poetry programs all share a common technique in using open-ended questions to create artistic contributions such as lyrics, stories, and poems. This technique, which Basting calls "Beautiful Questions," focuses on being in the moment with the person, rather than asking, for example, "Remember the time we went to the lake?" An example of an open-ended question might be, "What does the sun feel like on your skin?" Dancing has a similar focus on being in the moment and has the added benefit of being able to work with less verbal and nonverbal participants.

In the Alzheimer's Poetry Project, participants chant lines of poems and alternately sing songs. Movement is created by asking participants to show with their hands, arms, and bodies what a line of poetry would look like. For example, in "The Eagle," by Tennyson, people are asked to demonstrate the line, "The wrinkled sea beneath him crawls," resulting in wave-like motions of the arms and upper body. The Alzheimer's Poetry Project is unique among these best practices in using Call and Response as a core way to perform poems with people. This technique, where the session leader recites a line of poetry and the group echoes or repeats it, allows participants to be fully present with the group.

An emerging body of research knowledge

Anecdotal reports on the observed impacts of participatory arts programs in dementia care are truly compelling. Non-communicative people are stirred to speech and song. Disengaged people become socially active. Boredom is eliminated. Affective state is visibly improved. Reviews of articles in academic literature often conclude that such anecdotal evidence and the results of small observational studies warrant further study, including the need to better define intervention components, context, and dose.

In *The benefits of community-based participatory arts activities for people living with dementia: A thematic scoping review*, Ward et al conclude, "There is strong evidence in support of using participatory arts for dementia, regardless of art form. In-the-moment and person-centered approaches were deemed impactful. Further research is needed to explore the importance of setting, material culture, and the methodological or theoretical perspectives in participatory arts and dementia research"¹⁶. This scoping review explored relevant literature published from 2008 to 2019 and examined a sample of 26 articles reporting on dementia care interventions employing visual arts, literary arts, comedy, music, and dance.

In *The participative arts for people living with a dementia: a critical review*, Zeilig, Killick, and Fox write, "According to the literature reviewed, the participative arts can contribute positively to the lives of those living with a dementia in manifold ways. These include: aiding communication; encouraging residual creative abilities;

promoting new learning; enhancing cognitive function; increasing confidence, self-esteem, and social participation; and generating a sense of freedom... There is widespread agreement that non-pharmacological interventions are important for people living with a dementia"¹⁷.

While the state of science in this field of study is premature, likely due to the paucity of both public and private funding for high-quality, large-scale, randomized intervention trials for non-medical dementia interventions, there is at least a growing body of evidence demonstrating compelling benefits from participatory arts interventions. In other words, something important is happening in these spaces, and it needs to be better understood. With a better understanding, it will be possible to define the best practices that drive desired outcomes.

Poetry for Life: A Case Study

From July 4, 2023 to October 8, 2024, supported by funding from the American Rescue Act administered by the Wisconsin Department of Health, the Alzheimer's Poetry Project worked in partnership with the managed care organization Community Care, Inc. to offer the Poetry for Life program to 86 older adults including some attending day care programs as well as a number of catholic Sisters and Brothers living in convents and friaries. Poetry for Life is a participatory arts intervention that has three components: 1) Poetry Parties, 2) Poetry on Wheels, and 3) Art Support Calls. All three components utilize participatory arts to help older adults, including those living with dementia, create and perform poems, stories, and songs. Built into the Poetry for Life program model are activities of training to enhance interventional capacity among staff and family members based on the core Alzheimer's Poetry Project techniques, described below.

Poetry Party is the name used for Alzheimer's Poetry Project workshops. By using this name, a sense of fun and playfulness is invoked, suggesting a pleasurable event rather than an educational or academic activity. Poetry on Wheels uses "Poetry Booklets," which are standard letter-sized sheets of paper folded in four. This result is a small booklet with a front cover displaying a logo and project name, a back cover showing contact information. Opening the first fold reveals an inspirational or well-loved poem. Opening the full page gives a list of open-ended questions on the theme of the poem. The Poetry Booklets are delivered to the participants much like a "Meals on Wheels" delivery of food. Art Support Calls are phone calls made by teaching artists who speak with participants about the recently delivered Poetry Booklets and ask participants to perform and create poems. The frequency of the Art Support Calls is determined collaboratively by the teaching artists and the participants, typically weekly to daily calls.

BACKGROUND

The Alzheimer's Poetry Project was founded by poet Gary Glazner in 2003 and has since done programming in 36 states and internationally in Australia, Canada, England, Germany, Malaysia, Mexico, Poland, South Korea, and Turkey. The Alzheimer's Poetry Project began

a slate of program activities across the state of Wisconsin in 2010, holding 1,190 poetry workshops, serving 14,228 elders and people living with dementia in nursing and care homes, adult day programs, memory cafes, museums, and intergenerational programs statewide.

TECHNIQUES

The Alzheimer's Poetry Project uses four main techniques to guide participants in performing and creating poetry, including: A) Call and Response; B) Discussions around the themes of the poems; C) Props the person can hold, smell, touch and sometimes taste; and D) Asking open-ended questions on a theme to create lines for new poems that are then performed by the group. These methods are used in Poetry Parties and are the basis for the prompts included in Poetry Booklets. The same techniques are used when interacting with participants in Arts Support Calls. Staff and caregivers are taught these techniques so they may continue to incorporate the method within their work. They build confidence and skills in using the arts as a communication tool as well as an activity.

"Call and Response" is a technique where one person says a line of poetry and another person or group repeats or echoes back the words. One can find call and response in numerous activities in many communities. Soldiers learn to move in unison with marching cadences. Fans at sporting events use chants to cheer for their favorite teams. People echo significant phrases in religious ceremonies, including the Catholic liturgy, gospel services, and marriage vows. Audiences are called upon to repeat lines of song in blues, gospel, jazz, and hip-hop music. Importantly, it is often used by teachers to facilitate language mastery across all ages and is the central tool of secondary language acquisition, both in face-to-face classroom instruction and self-study programs¹⁸.

EXAMPLE OF 'POETRY FOR LIFE' METHODS

Through the program element called Poetry on Wheels, poetry booklets are brought to the places where participants live. Each poetry booklet offers a series of well-known and loved poems, along with simple prompts to help create poems. One page provides an inspirational poem, such as "*Hope is a thing with feathers*," by Emily Dickinson¹⁹. The next page displays a series of discussion prompts. After hearing and performing the poem, participants would be prompted, for example, to answer the question, "What do you hope for?" They are further encouraged to explore the sensation and significance of hope: "What is the fragrance, sound, taste, look, and feel of hope?" "If you could speak to hope, what would you say?" "If hope could talk, what would it say to you?" In answering these questions, participants create lines for a new original poem for which the facilitator invites the person or group to perform through call and response. The delivery of the Poetry Booklets is followed by Art Support Calls that are facilitated by trained program staff to inspire participants to create and perform poems, stories, and songs.

OUTCOMES

From 2017 to 2023, the Alzheimer's Poetry Project developed and tested an observational method, Dementia Arts Mapping, in a project providing training for staff at 23 nursing homes throughout Wisconsin. It was

hoped that this approach would lead to a better understanding of how the Alzheimer's Poetry Project's methods may be used in a wide range of activities, including Arts and Crafts, Bible Study; Bingo, Current Events, Exercise sessions, Wii bowling, and other games. Dementia Arts Mapping is adapted from Dementia Care Mapping, a caregiving-focused observational method devised at the University of Bradford by Professor Tom Kitwood and Dr. Kathleen Bredin in the late 1980s. Dementia Arts Mapping monitors participant activation in seven domains: Alertness; Emotional State; Activity Engagement; Social Interaction; Vocalization and Creativity. There are 3-4 indicators of each domain for a total of 25 indicators, including, for example: Sleeping; Focusing; Feeling Contented; Laughing; Feeling joy; Observing only; Participating at times; Fully participating; Addressing group; Vocalizing frequently; Sharing personal story; Originality; Emotionality and Improvisation. For each 5-minute segment of an activity, observers note the number of participants activated in these 25 areas.

In the Poetry for Life project, Dementia Arts Mapping was employed both before training the staff members of Community Care Inc. and afterwards at culminating events to explore if the creativity training resulted in increased participant engagement. Participants in Poetry on Wheels completed a survey to gauge if the Art Support Calls and use of the Poetry Booklets resulted in reduced feelings of social isolation. Both Dementia Arts Mapping and Poetry on Wheels surveys offer insights into the potential success of the project.

Engagement increased by more than 100% in the areas of sharing personal stories and using humor, and increased by over 50% in improvisation. In fact, engagement increased in all of the domains of activation that were observed through Dementia Arts Mapping, indicating that the Recreation Specialists working in these sites had successfully learned the methods of the Alzheimer's Poetry Project, and those methods were impacting participants in positive ways.

Thirty-six people completed the social isolation surveys. Responding to the question asking if engagement with poetry helps you to feel socially connected to others, 47% reported very high connection to other people and 38% reported somewhat high connection, and 86% reported they felt bonded to the facilitator. Only two people reported a very low or somewhat low connection. Survey data also showed positive views of the program activities, with 88% reporting enjoyment from performing poems, 86% from creating group poems, and 72% from hearing the lines they contributed performed in the new group poem. These findings suggest that participating in poetry activities helps reduce social isolation and provides enjoyment. One Catholic Sister said, "*What it has meant to me is the exploration of poetry, but also of my life. Creating a poem together is integral to who I am. When we were talking about the earth, how the earth feels and smells, to create the poem... I think about it all the time. It's not just during the phone calls. It's a whole different way of exploring emotionally what I really think about. That part has given me such energy. I am very grateful to be part of this.*"

For the staff who completed surveys, all of the Recreation Specialists indicated they would continue poetry programming, with 66% indicating they would do so on a regular or monthly basis and 33% once in a while. When asked if poetry activities help staff to feel connected to the residents in their care setting, 66% indicated somewhat high and 33% very high levels of connection.

In participatory arts programs, artistic products are another kind of outcome. They are not to be overlooked in terms of cultural significance. The Poetry Parties of this project led to the creation of 84 original poems, and the people participating in Poetry on Wheels created over 100 poems.

Comments on the state of science

While outside the scope of this editorial, the authors acknowledge their recognition of two facts: First, the book “Doctored: Fraud, Arrogance, and Tragedy in the Quest to Cure Alzheimer’s,” by Charles Pillar²⁰ has just been published. It seeks to expose a scandal through which hundreds of important Alzheimer’s research studies have been based upon false data. It shows that the amyloid hypothesis, on which most research has been funded over recent decades, was based on falsified images. Second, among a general assault on science by the current U.S. administration, in February of this year, lawsuits have been filed by the Association of American Medical Colleges and the American Association of Colleges of Pharmacy, among others, to stop the cut in federal funding for research²¹. If such funding is not reinstated, universities may ultimately be forced to lay off staff, close laboratories, and shutter certain research programs altogether, cutting off treatment for patients and the promise of intervention evidence. It is in these contexts that we must reflect not only on the research that has been misdirected and the leading biomedical research that is

being shut down, but also ask what research on psychosocial therapies and care-based activities may never be prioritized for funding or done at all.

Conclusion

We seek to promote and model the recommendations put forth in the groundbreaking paper, *Shall I compare thee to a dose of donepezil? Cultural arts interventions in dementia care research* by De Medeiros and Basting: “In moving forward, cultural arts intervention research must not be limited to the tools of the clinical trial model. Instead, researchers should carefully rethink what constitutes rigorous and effective research for interventions aimed at creating a meaningful personal experience for the participant rather than measurable change”⁵. To this end, one direction for extending the research about Poetry on Wheels and other participatory arts interventions is to persist in documenting cases where programs lead to observable outcomes.

The proliferation of gold standard randomized controlled trials will not be funded by small grants from community foundations and state government initiatives. Scholars, clinicians, and artists must continue to define appropriate indicators of quality of life as realistic targets for therapy. Importantly, the executives and practitioners who work in care settings should be encouraged to experiment with the safe, accessible, and affordable programs where people with dementia participate in the cultural arts to experience joy, self-expression, and validation of their personhood. This seems like good medicine, does it not?

In our work, we are ever hopeful, or as Emily Dickinson says, “Hope is a thing with feathers, that perches in the soul and sings the tune without the words and never stops at all”¹⁹.

References

1. Arvanitakis Z, Shah R, Bennett D. Diagnosis and management of dementia: Review. *JAMA*. 2019;322(16):1589. doi:10.1001/jama.2019.4782
2. Cerejeira, J, Lagarto, L, Mukaetova-Ladinska, EB. Behavioral and psychological symptoms of dementia. *Frontiers in Neurology*. 2012; 3:73. doi:10.3389/fneur.2012.00073
3. Swinnen, A, de Medeiros, K. Participatory arts programs in residential dementia care: Playing with language differences. *Dementia*. 2018; 17(6):763-774. doi:10.1177/1471301217729985
4. Curtis, A, Gibson, L, O'Brien, M, Roe, B. (2018). Systematic review of the impact of arts for health activities on health, wellbeing and quality of life of older people living in care homes. *Dementia*. 2018; 17(6):645-669. doi:10.1177/1471301217740960
5. de Medeiros K, Basting A. "Shall I compare thee to a dose of Donepezil?": Cultural arts interventions in dementia care research. *The Gerontologist*. 2013;54(3):344-353. doi:10.1093/geront/gnt055
6. Basting AD. *Forget Memory: Creating Better Lives for People with Dementia*. Johns Hopkins University Press; 2009.
7. Kaplan DB, Glazner G, Drake C. Group-based participatory arts interventions validate personhood for those living with dementia. *Advances in Social Science and Culture*. 2023;5(2). doi:10.22158/assc.v5n2p1
8. Cousins, E, Tischler, V, Garabedian, C, Dening, T. A taxonomy of arts interventions for people with dementia. *The Gerontologist*. 2020;60(1):124-134. doi:10.1093/geront/gnz024
9. Kitwood T, Bredin K. Towards a theory of dementia care: Personhood and well-being. *Ageing and Society*. 1992;12(03):269-287. doi:10.1017/s0144686x0000502x
10. Levenberg K, George DR, Lokon E. Opening minds through art: A preliminary study evaluating the effects of a creative-expression program on persons living with dementia and their primary care partners. *Dementia*. 2021;20(7):2412-2423. doi:10.1177/1471301221997290
11. Friedman JK. The Songwriting Works™ Model: Enhancing Brain Health and Fitness Through Collaborative Musical Composition and Performance. In: Hartman-Stein P, LaRue A, eds. *Enhancing Cognitive Fitness in Adults*. Springer; 2011:325-360.
12. Genné MD, Anderson C. Coming Alive: Kairos Dance Theatre's Dancing Heart™ – Vital Elders Moving in Community. In: Hartman-Stein P, LaRue A, eds. *Enhancing Cognitive Fitness in Adults*. Springer; 2011:285-300.
13. Holzman L, Fridley M, Massad S. Creating a New Performance of Dementia. In: Lester JN, O'Reilly M, eds. *The Palgrave Encyclopedia of Critical Perspectives on Mental Health*. Palgrave Macmillan; 2021.
14. Vigliotti AA, Vernon MC, George DR. Evaluating the benefits of the TimeSlips creative storytelling program for persons with varying degrees of dementia severity. *American Journal of Alzheimer's Disease & Other Dementias*. 2019;34(3):163-170.
15. Swinnen A, de Medeiros K. "play" and people living with dementia: A humanities-based inquiry of TimeSlips and the alzheimer's poetry project. *The Gerontologist*. 2017;58(2):261-269. doi:10.1093/geront/gnw196
16. Ward MC, Milligan C, Rose E, Elliott M, Wainwright BR. The benefits of community-based participatory arts activities for people living with dementia: A thematic scoping review. *Arts & Health*. 2020;13(3):213-239. doi:10.1080/17533015.2020.1781217
17. Zeilig H, Killick J, Fox C. The participative arts for people living with a dementia: A critical review. *International Journal of Ageing and Later Life*. 2014;9(1):7-34. doi:10.3384/ijal.1652-8670.14238
18. Glazner G, Kaplan DB. The Alzheimer's poetry project. *JAMA*. 2018;320(22):2294. doi:10.1001/jama.2018.16340
19. Dickinson E, "Hope" is the thing with feathers. In: Higginson TW, Todd ML, eds. *Poems by Emily Dickinson: Second Series*; 1891.
20. Piller C. *Doctored: Fraud, Arrogance, and Tragedy in the Quest to Cure Alzheimer's*. One Signal Publishers, Atria; 2025.
21. Jewett C, Rosenbluth T. Court pause on Trump cuts to medical research funds is expanded nationwide. The New York Times. February 11, 2025. Accessed March 29, 2025. <https://www.nytimes.com/2025/02/11/health/nih-research-funding-lawsuit-injunction.html?searchResultPosition=2>.