CIVIL MONEY PENALTY (CMP) FUNDED PROJECT REPORT



DEPARTMENT OF HEALTH SERVICES / DIVISION OF QUALITY ASSURANCE QUALITY ASSURANCE AND IMPROVEMENT COMMITTEE

This project report has been prepared by the author under a research grant from the Department of Health Services (DHS) Quality Assurance and Improvement Committee. The views expressed in the report/training are personal to the author and do not necessarily reflect the view of the Department of Health Services or any of its staff and do not bind the Department in any manner.

Grantee

Center for Community Stewardship

Project Title

Alzheimer's Poetry Project

Award Amount

\$ 46,700

Grant Period

8/1/2017 to 7/31/2020 (MM/dd/yyyy) (MM/dd/yyyy)

Additional Information and Resources

ALZHEIMER'S POETRY PROJECT

A Report on Innovative Non-Pharmacological Interventions and Person Centered Care Communication Tools to Help Improve the Quality of Life of those with Dementia and other Psychosocial Needs

The mission of the Alzheimer's Poetry Project is to facilitate the creativity of people living with Alzheimer's disease and related dementia. We work with their care partners, healthcare workers, educators, and students to perform and create poems.

We do not set boundaries in our beliefs in what is possible for people with dementia to create. By saying to people living with memory loss that we value you and your creativity, we are saying we value all members of our community.

On performing poetry:

"A big surprise for me was the laugher. The group really enjoyed laughing.

An hour goes by and they are all engaged. We're still having fun and still laughing.

That has been a surprising and good benefit of the poetry groups."

- Ruth Dabel, Luther Manor

Center for Community Stewardship (Alzheimer's Poetry Project) 116 North Few Street Madison WI 53703 Contact:
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Alzheimer's Poetry Project (APP)

A Report on Innovative Non-Pharmacological Interventions and Person Centered Care Communication Tools to Help Improve the Quality of Life of those with Dementia and other Psychosocial Needs

This report is prepared by Gary Glazner, Project Director and founder of the Alzheimer's Poetry Project, and Daniel Kaplan, Project Research Director and Assistant Professor, School of Social Work, Adelphi University School of Social Work.

GRANT AGREEMENT

This agreement is entered into for the amount of \$46,700 for the period of August 1, 2017 through July 31, 2020, by the State of Wisconsin Department of Health Services on behalf of the Division of Quality Assurance, (DQA), whose principal business address is 1 West Wilson Street, Room 450, Madison, Wisconsin 53703-3445, hereinafter referred to as GRANTOR and the Center for Community Stewardship hereinafter referred to as the GRANTEE, whose principal business address is 116 North Few Street, Madison, WI 53703.



Department of Health Services / Division of Quality Assurance Quality Assurance and Improvement Committee

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F-01593 (08/2015)

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Adelphi University School of Social Work provided in-kind support.

We thank all of our supporters and of all the participating organizations.











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-Katie, Jewish Home, Milwaukee

"I was really impressed

by the vocabulary

the residents used

to describe things."

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About: The Center for Community Stewardship, Alzheimer's Poetry Project, and the Adelphi University School of Social Work

The Center for Community Stewardship

The Center for Community Stewardship (C4CS) brings people together and facilitates their conversations to develop dreams and realize actions for their community. Our mission is to energize and facilitate individuals and groups to be active in matters that affect their lives, cultivating collaborative conversations about visions and activities that can make their community a more wonderful place. Our purpose is to nurture healthy and whole communities capable of innovative, appreciative and collaborative action.

We do this work by:

- Serving as a conduit for funding from a donor to a particular project that otherwise has no legal entity or structure to receiving the funding;
- Offering skillful processes and experienced coaching; and
- Nurturing thoughtful, rational and productive deliberation through facilitation services.

C4CS is the fiscal sponsor of the Alzheimer's Poetry Project.

Alzheimer's Poetry Project

The mission of the Alzheimer's Poetry Project (APP) is to facilitate the creativity of people living with Alzheimer's disease and related dementia. We use classic, well-loved poems to connect with people living with dementia. We engage them in call and response performance and the poems serve as inspiration for the creation of their own original poetry. We do not set boundaries in our beliefs in what is possible for people with memory impairment to create. By saying to people living with memory loss that we value you and your creativity, we are saying we value all members of our community.

Project Director: Gary Glazner



Gary Glazner is the founder and Executive Director of the Alzheimer's Poetry Project, (APP). The APP was the recipient of the 2013, Innovations in Alzheimer's Disease Caregiving Legacy Award and the 2012 MetLife Foundation Creativity and Aging in America Leadership Award. Glazner was the co-recipient of the International Leadership in Arts and Health

Award, 2018. The National Endowment for the Arts listed the APP as a "best practice." NBC's "Today" show, PBS NewsHour and NPR's "All Things Considered" have featured segments on Glazner's work. Glazner is the author of "Dementia Arts: Celebrating Creativity in Elder Care," 2014. Glazner was published in "JAMA: The Journal of the American Medical Association," 2018. The paper includes his most in-depth description of what is happening at the neurological level when you are performing poetry. The APP has provided programming in 32 states and internationally in Australia, Canada, England, Germany, Poland and South Korea.

Adelphi University School of Social Work

From teaching and mentoring to community engagement and field experience, we're constantly working to provide a vast range of high-quality student opportunities. We aim to ensure that every graduate of the Adelphi University School of Social Work is grounded in both theory and practical experience—and thoroughly prepared to make an impact.

Project Research Director: Daniel B. Kaplan



Daniel B. Kaplan, Assistant Professor School of Social Work. In 2015, Kaplan enthusiastically joined the faculty at Adelphi University School of Social Work. He is a clinical social worker with expertise in mental and neurological disorders. Kaplan's research includes both intervention and implementation studies that will optimize care services, clinical

interventions and supportive environments for older adults with mental and neurological disorders living in the community, as well as professional development and training projects to prepare the interprofessional clinical workforce to better meet the needs of older adults and their families.

He is currently the Principal Investigator on a grant-funded project, supported by the Florence V. Burden Foundation and the Health Foundation of Western and Central New York, to build a curriculum and test the delivery of a 36-hour continuing education program entitled Social Work Practice Fellows.

Kaplan holds clinical social work licensure in New York and Massachusetts, as well as an NASW certification in advanced gerontological clinical social work. I earned my doctorate at Columbia University School of Social Work and held an NIMH-funded postdoctoral research fellowship at the Institute for Geriatric Psychiatry at Weill Cornell Medical College.

"The project was different than I expected. First, most residents when you say poetry, they just freak out.

The call and response, the residents really got into it.

They really more into writing the poems than I thought they would.

It was a great success and it helped the residents be able to express themselves."

- Laurie Slagg, Activities Direct, Willowcrest Health Services, South Milwaukee

EXECUTIVE SUMMARY

OVERVIEW

There is a worldwide movement to place the arts at the core of how to best navigate living with dementia. This movement includes acknowledging that creativity is a key drive to what it means to be fully human.

Through much of history, we have seen the arts as primarily individual efforts. We support, and promote here, the inherent value of group-based participatory arts and co-creation as forms of individual and collective self-expression, a platform for the validation of personhood in the context of dementia, and a feasible and acceptable intervention in health and social service settings.

This paper documents the Alzheimer's Poetry Project (APP) training and research project which took place in the period of August 1, 2017 through July 31, 2020 in partnership with numerous health and educational institutions in the state of Wisconsin.

We wish to acknowledge the work and inspiration of Dementia Care Mapping[™] an established approach to achieving and embedding person-centered care for people with dementia, which is recognized by the National Institute for Health and Clinical Excellence, United Kingdom. Dementia Care Mapping[™] was developed at the University of Bradford by the late Professor Tom Kitwood, over twenty years ago and is used in more than 10 countries.

In this project, we place at the core of our work, the observation and studying of a wide-range of arts and other activities with the goal of increasing engagement. For the purposes of this paper we describe this observation as Dementia Engagement Mapping.

Overview

We provided 75 health care staff, at 17 skilled nursing homes, with training on implementing and using the Alzheimer's Poetry Project (APP) methods and techniques, on intergenerational programming and on the implementation and use of Poetry Cards. We also provided training in creating and performing poetry with people living with dementia for 89 students and 6 teachers, at 6 schools in the Poetry for Life component of the project.

COVID-19 Challenge

Reaching our original goal of 20 skilled nursing homes was challenged by the COVID-19 pandemic. Due restrictions on visitation of non-essential personnel we had to pause the project om March, 15th, 152020.

Project Partners

The 17 Skilled Nursing Homes Participating in the Project are:

Bria of Trinity Village, Milwaukee Congregational Home, Brookfield; Crossroads, Waupaca; Luther Manor, Milwaukee; River Pines Altoona; Saint John's On The Lake, Milwaukee; St. Paul Elder Services, Kaukauna: Southpointe Healthcare Center, Greenfield; Terrace at St. Francis, Milwaukee; Villa Loretto, Mt Calvary; St. Mary's Care Center, Madison Bridges of Appleton, Appleton St. Clare Meadows Care Center Jewish Home, Milwaukee The Villa at Bradley Estates Willow Crest Health Services Hales Corner Care Center

APP AND ADELPHI UNIVERSITY SCHOOL OF SOCIAL WORK COLLABORATION Research

The research component of the project was undertaken in partnership with Adelphi University School of Social Work. We received approval from Adelphi University's Institutional Review Board (IRB) for two studies:

- Poetry for Life Study (PFL Study): The PFL Study is an on-going multi-state, multi-year initiative, of which this Wisconsin based project is a part.
 - Alzheimer's Poetry Project-Long Term Care Implementation Study (APP-LTC Study): The APP-LTC Study consists of two parts: an observational study built upon a novel technique called "Dementia Engagement Mapping" and a survey-based "Staff Attitudinal Study."
 - o **Dementia Engagement Mapping-** What are the comparative therapeutic impacts of creative arts therapies relative to other recreational dementia care activities in terms of social engagement, alertness, vocalization, vocabulary, affect, and self-expression?

To answer this question, ethnographic participant observation methods were used to collect qualitative data during diverse routine activity programming in each participating nursing home.

A researcher was immersed in the activity space where he systematically recorded data in written field notes on an ethnographic observational data chart during and immediately following each activity. This effort responds to the need to understand which elements, of which activities, facilitate moments creativity, joy, humor, and personhood among participants.

o **Staff Attitudinal Study**- What are the impacts of APP training and workshop facilitation experiences on participating activities staff members' perceptions, attitudes, and values related to dementia and dementia care, poetry and arts-based interventions, job satisfaction, and interest in ongoing work with older adults, long-term care residents, and people living with dementia?

To answer this question, participating staff members completed our novel Perceptions of Health, Arts, and Dementia survey both before and after participation in the 3-month experience of APP training and facilitation.

The Staff Attitudinal Study builds understanding of how learning APP methods and leading people living with dementia in creative group expression impacts activities staff member's attitudes towards those people in their care and towards their work. Such perceptions may hold implications for quality of care and services for people with dementia living in long-term care settings.

While we are in the early stages of understanding the results of these studies and our goal is to publish those findings, we will report key highlights from the studies in this report. We will describe the research tools and the successes and challenges we learned from this initial implementation of the tools, as well as implications for future work and research.

KEY RESEARCH FINDINGS

- 1) APP is an acceptable and feasible intervention in dementia care settings.
- 2) APP methods and techniques can be successfully learned and adopted by volunteers and long-term care staff members with varied levels of experience in the use of arts and poetry.
- 3) APP methods and techniques can be incorporated into a wide-range of recreational and care-related activities to promote creative self-expression and positive engagement between and among people with dementia and interventionists.
- 4) APP methods and techniques reinforce and enhance skills and confidence in leading recreational activities with people with dementia, soliciting artistic contributions from groups and individuals, and validating personhood in the context of long-term care.
- 5) The novel data collection tools created for these studies, including the Dementia Engagement Mapping guide and the Perceptions of Health, Arts, and Dementia survey, are effective instruments for generating insights about dementia care interventions and their impacts, and may be further enhanced for future use in research data collection and informing care provision to foster meaningful engagement with people with dementia.

HIGHLIGHTS

- In the **APP-LTC Study**, the APP workshops, seem to stand out from other activities in **fostering self-expression**.
- The **Staff Attitudinal Study**, showed that the experience of participating in this program is associated with **notable improvements in staff members' attitudes** about dementia care intervention potential and interaction confidence, knowledge, and comfort.
- The **PFL Study**, showed the experience of students participating in this program is associated with **notable improvements in students' attitudes** about most of the concepts represented in the attitudinal scale with regard to aging and dementia.

RECOMMENDATIONS

"I carry your heart, I carry it in my heart..." -E.E. Cummings

As the worldwide movement in using the arts with people living with dementia builds, we recommend:

- The use of the Dementia Engagement Mapping, an ethnographic observational data chart as a framework for further research, to help strengthen their programs and help improve the quality of life of people living with dementia, for both arts groups and healthcare professionals.
- Encourage healthcare organizations to conduct their own observational studies.
- Disseminate this white paper to a wide range of arts and healthcare organizations.
- Build on this white paper to write and publish research papers.
- Seek additional funding to develop and refine the research tools described in this paper.

"When I first heard the idea of doing poetry, I was like um, okay, really? But it has been so much fun. We got to interact with the residents on a way that we normally don't. They interact with each other when we do this. It makes things cohesive for the residents. The highlights are when you see they are having fun and they are laughing.

My favorite jingle from the poetry party today is "Mama Mia, That's one spicy meatball." Which of course is not about meatballs, but Alka-Seltzer. I love getting animated and using funny voices and faces when I am comfortable and this helps me connect with the residents."

- Gwen, Activities Staff, The Villa at Bradley Estates, Milwaukee

INTRODUCTION

By 2050 the number of people age 65 and older with dementia is estimated to increase from 5.3 million to a projected 13.8 million.¹ Pending effective treatments to alter disease trajectories or prevent cognitive decline,² families and other communities of care must attend to basic needs for assistance, safety, and quality of life. Care and communication techniques are known to meet some of these needs, yet care providers desire tools to promote joy, social connection, and personhood among individuals living with dementia. Participatory group interventions grounded in the cultural arts (e.g., dance, music, poetry, storytelling, and theater improvisation) have been emerging as a compelling approach³.

Alzheimer's disease is the sixth-leading cause of death in Wisconsin and nationwide. In Wisconsin, 110,000 people age 65 and over are living with Alzheimer's disease — a number that is projected to increase more than 18 percent to 130,000 people by 2025. Approximately 194,000 Wisconsinites provide 220 million hours of care for someone with Alzheimer's disease at an unpaid value of more than \$2.78 billion. These figures underestimate the true reach of disorders of dementia as Alzheimer's disease is but one of several common conditions which cause dementia. Other neurocognitive disorders include vascular dementia, diffuse Lewy Body disease, Parkinson's disease, frontotemporal dementia, and many other degenerative and terminal diseases of the brain.

The Alzheimer's Poetry Project (APP) is a non-pharmacological intervention for groups of people with dementia where a trained facilitator uses poetry to inspire creative self-expression, reduce isolation, provide social and intellectual stimulation, and validate the unique personhood of each participant.

APP Four Core Methods and Techniques

A typical APP session is one hour in length. The artistic focus of the APP is on participant creativity. Facilitators and participants recite poems and combine poems and songs with movement. They co-create original works of poetry around themes, for example, springtime, birds and flight, or even whimsically imaging new superheroes. The facilitators build the sessions around well-loved, classic poems. An example would be Emma Lazarus' poem "New Colossus," celebrating the Statue of Liberty, "...Give me your tired, your poor, your huddled masses yearning to breathe free..." Poems utilized in the sessions are grouped by theme.

1) Call and Response

To engage the participants in performance, the session leader begins each session with a call and response technique, reciting a line from the poem and coaching the group to echo the line. This use of repetition builds on poetry's strength as an oral art form. By asking participants to join voices in repeating a line of poetry we encourage participants to shed some measure of isolation, tap established long-term memories, and possibly nurture short-term memory through auditory sense memory pathways of the primary auditory cortex and echoic memory storage pathways involving numerous regions of prefrontal cortex.⁵⁶

One can find call and response across cultures and traditions. Soldiers learn to move in unison with marching cadences. Fans at sporting events chant and cheer for favorite teams. Protest leaders guide demonstrators to repeat calls to action. Religious ceremonies are replete with call and response traditions, including the Catholic liturgy, gospel services, and marriage vows. Call and response is infused in blues, gospel, jazz and hip-hop music.

Importantly, it is often used in teaching 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 programs. Such frequent and effective utility in promoting language development and memory raises the question of the potential value of call and response for language maintenance in the context of dementia.

2) Discussion Starter

APP facilitators use poems to start discussions with and among the participants. This is done by asking questions to engage the group on the subject matter of the poem. As social beings, all people rely on discussion, both through casual chats and more emotionally trusting "heart-to-heart" conversation. These social engagements require communication skills that are learned at a young age, mastered over a lifetime, and eroded by disorders of dementia. APP provides motivation for participants to practice communication skills.

3) Props or Object Handling

Props which reinforce the theme of the workshop include objects that people can smell, feel, hold, hear and taste. An example of a prop for a summer theme would be roses. Visual and tactile engagement with props further stimulates participant cognition throughout APP sessions.

4) Create a Poem

Participants co-create an original poem as facilitators ask open-ended questions around the session themes and write down participant's contributions. One technique is to choose a classic poem as the model and then base the question on the subject matter of the poem. For example, a facilitator using the poem "Daffodils," by Wordsworth, would ask how spring smells, tastes, sounds, looks, and feels.

The answers to these questions come from different participants who speak out or respond when called upon and their words and phrases become the lines of the new poem. Listening skills are crucial in creating the new poem. Using the exact language of the participants instead of paraphrases helps strengthen the text. The session ends with a call and response group performance of the newly created poem.

Additional Techniques

APP facilitators use touch therapy and often hold the hands of the participants, moving their hands lightly to reinforce the rhythm of the poem. Humor is an invaluable element of the APP model as well, as the intervention is designed to bring joy into the experiences of participants. Facilitators use funny poems and encourage the participant's humorous and spontaneous contributions.

Poetry Cards

Poetry Cards have two to four lines of poetry on a business card sized stock, along with a discussion-prompting question. Each pack of cards contains 40 poems. The Poetry Cards were first created for use at the Tallahachie General Hospital in Charleston, Mississippi. In this project, partner organizations each received two packs of Poetry Cards.

The Poetry Cards are designed for healthcare workers to have quick access to a short poem to help with interactions with people. For example a staff member might recite the lines from the Poetry Card, "My love is like a red, red rose, that's newly sprung in June/ My love is like a melody, that's sweetly played in tune," as they move from the resident's room to lunch or during Activities of Daily Living (ADL) such as morning bathing, dressing, and grooming.

The staff member might then engage the resident in talking about the fragrance of roses. Please see: Sample Poems, Poetry Cards, Improvisation Tools and Games for an example of Poetry Cards.

On Using Poetry Cards by a CNA

The poetry helps the resident's spirits and it helped mine too

"The poetry helps the resident's spirits and it helped mine too. I see them everyday, but the little moments will add on to their day.

I love birds, so when I looked through the Poetry Cards I picked bird poems. I was in the room with the resident and she had a bird feeder you could see through the window, to the yard outside the room.

One of the poems was by Maya Angelou and it has a line, 'The bird doesn't sing because it has answers, it sings because it has questions,' that is so beautiful.

When we started there were no birds there. As we read the bird poems, all of sudden there was like a flock of 10 or 15 birds at the feeder. The resident said, 'There were no birds,' and I got goose bumps.

I am a nature person, I love nature and I love birds. It was beautiful."
-Mary Wideman, Trinity Village, Milwaukee

I got goose bumps

Improv Games

As part of the arts training for this project, groups learned theater improvisation games. My first exposure to using improvisation with people living with dementia was from a talk given by Karen Stobbe, founder of "In the Moment," in 2005 at an Alzheimer's Foundation of America Conference.

Karen has a background in the world of improvisational theater, or improv, and what she had to say that day changed my view of caregiving and expanded my understanding of how art could be used as a communication tool.

The games we focused on in our training sessions were, "Pass the Face," and "The Name Game." Please see: Area 9 (Sample Poems, Poetry Cards, Improvisation tools and Games) for an example of Improv Games.

Poetry For Life

In 2013, APP began the pilot-project Poetry for Life. Poetry for Life (PFL) is an intergenerational program that brings students of all ages to perform and create poetry with people living with dementia. In 2017, working with the National Endowment for the Arts and the Poetry Foundation, APP launched the National Outreach of Poetry for Life. Since that time PFL has held programs in 14 states.

Group and One-on-One

To maximize the impact of the training in this project, APP techniques and methods were encouraged for use in both group and individual engagement.

You are initiating conversation, sparking their imagination and making them laugh.

"I do use the Poetry Cards often, for one-on-one. I will read to them the snippet of poetry. I do like the questions that on the cards. For example I am looking at one here, 'There was an old man with a beard, who said it is just as I feared, two owls and a hen, three larks and wren, have all built their nests in my beard.' They would laugh at that and say that would tickle! That is a great example to use one-on-one. You are initiating conversation, sparking their imagination and making them laugh. The Poetry Cards are really helpful with that.

-Jessy Hewitt, Saint John's On The Lake

This Report, "Innovative Non-Pharmacological Interventions and Person Centered Care Communication Tools to Help Improve the Quality of Life of those with Dementia and other Psychosocial Needs," focuses on a number of lessons learned in the course of completing the training and research project, including:

- 1) Using the APP methods in a wide-range of activities.
- 2) Enhancing the use of validation skills with APP methods.
- 3) Building a common base of terms, or taxonomy, to describe "best practices" in dementia arts.
- 4) Designing and testing an observational technique and instrument entitled Dementia Engagement Mapping.
- 5) Using Dementia Engagement Mapping to identify differences among various types of recreational activities in terms of observable impacts on participants.
- 6) Designing and testing an attitudinal survey tool entitled, Perceptions of Health, Arts, and Dementia.
- 7) Using the Perceptions of Health, Arts, and Dementia survey to measure relevant perspectives among trained APP facilitators and to assess changes in perspectives resulting from the experiences of APP training and facilitation.
- 8) Defining "Best practices" for intergenerational arts programs in dementia care.
- 9) Future directions.





Letter from the Project Director

As my friend and colleague the late Richard Taylor, who was a powerful advocate for himself and for others living with memory loss, wrote in his blog, "Alzheimer's from the Inside Out," "If you meet/know one person with dementia you only know one person worth of dementia." I keep Richard in my heart and follow his advice to recognize the person.

My personal journey of using poetry to help people living with Alzheimer's disease and related dementia began in 1997, at an adult day care program in Northern California. This is a story that I have shared hundreds of times since that day.

My moment of inspiration was observing a man with his head down, not participating, seemingly unaware of his surroundings. I recited the Longfellow poem "I shot an arrow in the air," his eyes popped open and he responded, "It fell to earth, I knew not where." Suddenly he was able to participate. This moment showed me how useful poetry could be with this community.

If I had only had that experience, I am sure I would still be doing this work. However, there was another more personal moment, that literary brought home the experience for me. At the same time of that workshop, my mother Frankie had terminal cancer. Brain tumors and morphine were causing dementia-like behavior. My father Billy called to say she was agitated and asking for cherry ice cream. As I arrived with the ice cream, I thought to try the poems from the workshop with her.

My parents were childhood sweethearts and my mother had teased him with, "Can she bake a cherry pie, Billy boy," We all recited the words. It was strikingly clear to me that poetry could be of use to people with dementia. I was and remain inspired to make my life's work serving people living with dementia.

While having a person living with memory loss, remember a poem and shout out the line is powerful, it is also rare. Perhaps it happens 10% of the time in workshops. You can of course increase the chance of this happening by using poems that this age group has a high-recognition with for example, "Trees," by Joyce Kilmer and "The Raven," by Edgar Allen Poe, to name two poems. It is much more likely that the participants, like most people, will not have an affinity for poetry or have any poems memorized.

Most of the healthcare workers that received training in this project, do not have poems memorized either. The responses we see, smiling, laughing, expressions of joy and creativity don't depend on knowing the poems.

In this paper we will explore the concept of participatory and co-creation art experiences. We will look at how attitudes about what it means to living with dementia may shift after watching people engage in moments of creativity and how this may help to alter the stigma of having a diagnosis of Alzheimer's disease and related dementia.

When I went through those experiences back in 1997, I had little language to describe what had happened. In part, this project is a way to build that language. To better understanding what I have observed and experienced.

I want to share with you what one of the amazing health care workers said in an interview for this project.

A highlight for me was seeing the residents become creative. We haven't had many arts projects other than craft projects. It was nice to see them get into the language arts more.

That has never been done here before. It an outlet for them to express themselves, they might not do otherwise. It gets their feelings out in a less restrictive way, telling their opinions where they don't feel they are the only one saying something.

They feel more comfortable in a group saying something than individually. They support each other's opinions and comments.

- Laurie Slagg, Activities Direct, Willowcrest Health Services, South Milwaukee

Slagg's captures the essence and feeling of so many people that participated in this training and research project.

To be in the lives, of the people I have worked with, to share joy, laughter and flashes of creativity with them continues to be an honor.

Sincerely,

Gary Glazner

Project Director

Sanz Glazner

Taxonomy of Arts Interventions for People with Dementia

As a poet, Glazner is obsessed and enamored with words. The words we use to describe our world help to frame our thinking. Describing a person as "a dementia sufferer" or "a dementia patient" may have some accuracy, but saying the person is learning how to best navigate dementia, while not denying the progression of the syndrome, helps frame the experience through a lens of hope, adaptation, and personhood.

It was a very nice way to use words.

"My experience was very rewarding. There are connections being made in a diverse fashion. They feel it is a relationship, rather than just being taught something, they were experiencing something new. I also felt I was experiencing something new and I enjoyed that connection. The highlight for me was the response of one of the residents when we gave her the rose. At the end she said, 'It was a very nice way to use words."

-Carolina Deitrich, Southpointe Healthcare Center

This project builds on more than twenty years work in leading poetry workshop for people living with dementia and training healthcare professionals, family members and teaching artists to use the skills we know to be impactful in those workshops.

In planning this project part of the challenge, was how to describe the powerful responses we observed in the participants. Their expressions of creativity, humor, and joy. We know they change during the workshops, with more smiles, laughter, eye contact, and self-expression, but how should we talk and think about those improvements? How can we define and learn from those moments?

During the time we worked on writing the proposal for this project, Glazner had the good fortune to be invited to take part in an Arts and Dementia Research study, led by Emily Cousins, as part of her completion of a PhD at the University of Nottingham in England. The study was part of the TAnDem (The Arts and Dementia) Doctoral Training Centre, a partnership between the Universities of Nottingham and Worcester, UK.

Cousins published the results of the study in "A Taxonomy of Arts Interventions for People With Dementia," in The Gerontologist.⁷ We draw on Cousins' work and affirm, as she outlines in her paper, the hope that it provides a "foundational model," to further develop our common understanding of terms and concepts to explore dementia arts interventions and participatory art experiences.

Here is the abstract from her paper:

Abstract

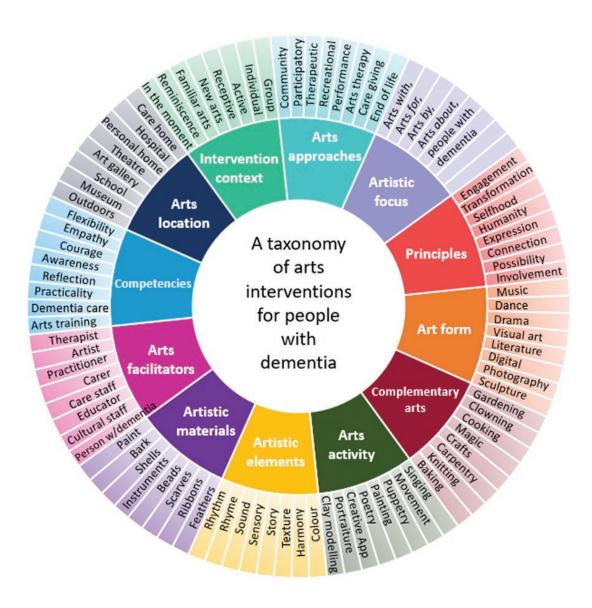
Background and Objectives: The current evidence base for the arts and dementia has several limitations relating to the description, explanation, communication, and simplification of arts interventions. Research addressing these challenges must be multidisciplinary, taking account of humanities and science perspectives. Consequently, this research aimed to produce a taxonomy, or classification, of arts interventions for people with dementia as a contribution to this growing field.

Research Design and Methods: This research was underpinned by taxonomy and realist methodology. Taxonomy, the science of classification, produces a common language to name, define, and describe the world around us. Realist theory explains how interventions "work" and produce their effects. The main findings in this paper were generated from a case study and a Delphi study.

Abstract Continued:

Results: An arts and dementia taxonomy of 12 dimensions was developed: Art Form, Artistic elements, Artistic focus, Artistic materials, Arts activity, Arts approaches, Arts facilitators, Arts location, Comp tencies, Complementary arts, Intervention context, Principles. Discussion and Implications: Arts interventions can be classified according to their contexts, mechanisms, and outcomes.

A range of stakeholders could benefit from the taxonomy, including people with dementia, artists, practitioners, carers, care staff, funders, commissioners, researchers, and academics. Language relating to the arts and dementia can be adapted depending on the audience. This is a foundational model requiring further development within the arts and dementia community.



In analyzing the data collected in our Dementia Engagement Mapping, we particularly paid attention to the Principles category of Taxonomy Wheel from Cousin's paper. That category which includes Engagement, Transformation, Selfhood, Expression, Connection, Possibility and Involvement fit well with the protocols of our Dementia Engagement Mapping.

Our Dementia Engagement Mapping, included a category for creativity with four indicators:

- Originality
- Emotionality
- Using humor or play
- Improvisation

Of particular interest was observing the blending of arts modalities for example engaging in movement, while reciting poems using call and response. Utilizing this multi-sensory approach often showed an increase in the number of people engaged.

During the writing of this paper Glazner was fortunate to take an on-line course, "Dementia and the Arts: Sharing Practice, Developing Understanding and Enhancing Lives," led by Seb Crutch, Professor of Neuropsychology at the Dementia Research Centre, University College London.

We will quote from that course throughout this paper and it forms another step in building a common language to understand and describe when observing people living with dementia engaging in the arts.⁸

Here are a few of the terms and concepts we will incorporate and build on:

- Co-Creativity, (A creativity that happens together with people in which you create together and are created together.)⁹
- Flow, (A state in which you are unaware of time passing and feel no sense of effort to maintain it.)¹⁰
- Micro-Moments, (Those moments that occur just before or after an art experience has taken place. For example the transition between reciting one poem and beginning another.)¹¹
- Multi-sensory stimulation and art experiences, (simultaneous activation of two or more of the senses such as taste, smell, vision, hearing and touch.)¹²
- Object Handling, (A term typically used by museums. Sensory experiences responding to touch and discussion of various artifacts.)¹³

We also want to draw attention to (DEEP), The Dementia Engagement and Empowerment Project. This project and their DEEP Guides provide a powerful tool in helping to frame the lived experience of dementia and people with dementia have helped to write the guides. DEEP stands for the Dementia Engagement and Empowerment Project – it is the UK network of dementia voices. DEEP consists of around 100 groups of people with dementia – groups that want to change things.¹⁴

In the conclusion to her paper Cousin's writes,

Conclusion

The taxonomy of arts interventions reported in this paper, comprised of 12 dimensions, is a foun-dational model for describing, explaining, communicating, and simplifying the arts and dementia. It has attempted to balance generalizability while allowing for interpretation and personalization of the arts. The taxonomy will require further development based on future research. Accepting its limitations, the taxonomy represents novel and innovative work that hopes to make a meaningful contribution to arts and dementia research, theory, and practice.

We are grateful to have been included in Cousin's Taxonomy study for this opportunity to build on that work with the goal of improving the quality of life of people with dementia. We echo her call and hope this white paper will serve as a similar building block with artists, family members, healthcare workers and researchers.

So long as men can breath or eyes can see,
So long lives this and this give life to thee.
-William Shakespeare, Sonnet 18

Observational Study: Dementia Engagement Mapping

In my more than twenty years experience of performing and co-creating poetry with people living with memory loss, I have been honored to witness many extraordinary moments. I have seen thousands of expressions of joy, happiness, and laughter.

Yesterday, in a poetry session, we were creating a poem by asking open-ended questions around the theme of summer. One woman who was seated with us in our circle and had been mostly quiet, with her eyes closed. Another woman had responded to the question, "What does summer look like?" With, "summer is green."

I then told the group we were going to use a poetic technique called a simile, where you use like or as to describe two separate things. This is a challenging technique for any group. I said please fill in the blank, "Summer is green as _____."

For a moment the group was silent and you could feel the tension of trying to search our minds for the answer. Then they woman who had appeared asleep, spoke in a loud clear voice, "A buck." Everyone broke out laughing. Yes! Summer is green as a buck!

Moments like that are what Dementia Engagement Mapping are meant to capture. How can we be better skilled at creating space and opportunity for moment like that to occur?

Here is a quote on the importance of moments, from the on-line course "Dementia and the Arts: Sharing Practice, Developing Understanding and Enhancing Lives," which was offered by the University College London.

"We're interested in the moment because all of our lives are made up of moments. And some of those moments are wonderful and exciting. Others are mundane, and others can be painful and disappointing. And for not only the general population, but people with dementia also have these same moments.

If we can understand, better understand the experiences that people with dementia have in moments in their day-to-day lives, in particular our interest in their experiences with the arts and with cultural activities, I think we'll understand their lived experiences more and will be able to offer them, as researchers and as practitioners, different types of services that more meet their needs.

I think arts-based activities lend themselves particularly well to in-the-moment experiences because they do not necessarily rely on memory or previous knowledge."

-Paul M Camic, Adjunct Professor, Dementia Research Center, University College London, United Kingdom.¹⁵

People talked about things they haven't talked about.

We had a terrific time with this training. We saw people develop using the techniques we learned and we had a lot of fun. Lots of laughter, interesting conversations. People talked about things they haven't talked about. We look forward to continuing to poetry in our weekly schedule as we have done in the training.

- Leslie Kletts, Activities Director, The Villa at Bradley Estates The studies used observation and notes. For the observation we indicated the number of people engaged seven domains:

- Alertness
- Emotional State
- Activity Engagement
- Social Interaction
- Vocalization
- Personhood
- Creativity

Each of the domains had between three and five indicators. (You may see the full list of indicators in Research Tools section of this report.) We noted the number of people in the indicators at increments of five minutes.

The Dementia Engagement Mapping also gathered information on activity type, number of participants being observed, time and location of the activity. We noted if the Activity Type was arts-based with without group socialization, group socialization with arts and an activity without group socialization or the use of the arts.

The Notes section included:

- Introduction
- Engagement Method
- Priming Effect (Priming is the implicit memory effect in which exposure to a stimulus influences response to a later stimulus. We are using it in the study to note techniques used in one part of a session that increase engagement later in the session.)
- Creation Method
- Validation
- Ending

In addition to commenting and tracking if those methods were present in the activity we also made note of highlights occurring in the sessions.

A common theme that emerged from the Observational Studies was that when Artistic Elements were blended in multi-sensory experiences we saw increases in engagement.

For example at Congregational Home, in Milwaukee, we saw the blending of breathing, guided imagery, movement, rhythm, sound and smell in an exercise session built around Tai Chi.

Session Note Highlights:

Movements described as "Carrying the moon," with instructions on how to turn the moon over in their hands. Another movement is called, "Fly like an eagle." These are great example of combining movement with guided imagery and breathing. Other poetic names for movements include, "Fly like a goose," and "Spinning wheel."

Overall, this is an effective session, even when the participants are not able to follow the movements exactly. The session leader expertly combined soft background music, fragrance, with the movements and their evocative poetic names.

During a session of Balloon Volley Ball at Oregon Manor, in Oregon we observed loud laugher and expression of humor. The combined artistic or multi sensory elements were movement, rhythm and color.

Session Note Highlights:

At T5 towards the end of the volleyball game one of the people popped a balloon the laughter that followed in perhaps the strongest spontaneous laughter I have heard during any session in over 20 years of working in this field.

The mix of the explosion, being scared, hearing other people also scared and then immediately laughing built into huge belly laughs. (Other highlights include at T1 and T2 *Hitting balloon playfully, **Great physical improvisation in hitting the balloon. The room was set up with a badminton net, down the middle and the participants were given pool noodles to hit the balloons.

While we are not advocating scaring people as a best practice, we can look at the comedic effect of a setup followed by an unexpected surprise. A first step in developing this type of technique is to see it as a skill.

This tracking of time and highlights helps us explore the micro-moments of engagement.

Another example of using surprise, was in a Poetry Party Culminating event at Luther Manner, Milwaukee. They used the model poem "Bleezer's Ice-Cream," by Jack Prelutsky. We saw a blending of vocalization, rhythm with the sensory experience of food, all in a party atmosphere. The Prelutsky poem features crazy and disgusting ice cream flavors like:

TUTTI-FRUTTI STEWED TOMATO TUNA TACO BAKED POTATO LOBSTER LITCHI LIMA BEAN MOZZARELLA MANGOSTEEN The group created and performed a version of the poem, including incorporating lines from an iconic commercial.



Ice Cream Poem (excerpt) Luther Manner, Milwaukee

Spicy chocolate chicken feet Creamy gorgonzola beet Liver gravy, marinara That's all we have room for Oh and free ... Alka-Seltzer... Plop, plop, fizz, fizz Oh what a relief it is...



The ended the event with an ice cream social. The topping for the ice cream included gummy worms and spiders. They had relabeled the chocolate syrup "liver gravy." They played on the humor of asking the participants, "Would you like more spiders with that?" The participants got into the spirit and enthusiastically asked for, "More liver gravy, please!"

At Villa Loretto, Mt Calvary we observed people participating in the rosary, which combined among other elements sound, rhythm and vocalization.

Session Note Highlights:

A man, whose speech is unintelligible in greeting people as they take their seats, speaks clearly with beautiful deep voice when saying the rosary responses. All five being observed have high engagement with the call and response of the rosary. This is an example of words/text being deeply ingrained in the person through years of participating in saying the rosary. While this happens throughout the hour, we see engagement and vocalization increase in relation to sections of the mass that are listened to and sections that are participatory.

Of particular note was that, even with one of the most known and recognized texts, the highest engagement was when the people are invited to participate. The rosary also offers one of the oldest and most prolific examples of the use of call and response and the transformation in the man's speech was dramatic and moving.

Best Practice Moments as Noted in the Dementia Engagement Maps

- Have an introduction to the activity. This helps mark the shift from every day event to sometime special is going to happen.
- Use multi-sensory or blended arts and co-creativity. In one event, the facilitator used a combination of open-ended questions, call and response and dancing; at one point, one of the participants was inspired to coin a new word, "hap-fully."
- Use enthusiastic praise: In one event, the facilitator shouted "Bravo! Bravo!" at the end of a recitation. In part this captures the micro-moment and power of valadation.
- Encourage validation between the participants, by modeling the giving of complements and praise. Create space for them to validate each other by asking them to comment on what has taken place.
- Be in the moment with the people. Be able to shift the lesson as needed. In one instance, a woman shared that she was not in the mood to create a poem because her brother was ill. The group created a short "get well" poem for him, which led to a noticeable shift in the woman's affect.
- Be creative in developing the themes for your sessions. The facilitators in one session dressed up in costumes that reflected the era of the theme, in another they handed out leis to enhance the feeling that the event was a party.
- Be innovative in object handling or how you use props. In one activity where water was a prevalent theme, the facilitator used a spray bottle and umbrella and passed out cups of water. In another, the group had a "snowball fight," with colorful cloth balls. Both are strong examples of multi-sensory experiences.
- Let the group know what is coming next. The facilitator used the technique of relating the present activity with one in the future; it was an effective way of engaging the participants.

OBSERVATIONS OF IMPACTS OF ACTIVITIES AMONG PEOPLE WITH DEMENTIA: FINDINGS FROM DEMENTIA ENGAGEMENT MAPPING

As described throughout this report, a major component of this study involved research to understand the comparative therapeutic impacts of creative arts therapies relative to other recreational dementia care activities in terms of social engagement, alertness, vocalization, vocabulary, affect, and self-expression.

To answer this question, a novel approach to participant observation called Dementia Engagement Mapping was used to collect qualitative data during diverse routine activity programming in each participating nursing home.

A researcher was immersed in the activity space where he systematically recorded data in written field notes on an ethnographic observational data chart during and immediately following each activity.

The observations of multiple activities, including those which vary in terms of the use of arts, poetry, and group-based interaction, were examined to identify positive impacts on people living with dementia in the domains of cognitive performance, socio-emotional wellness, and self-expression.

A total of 32 activities were observed, including:

- 10 Alzheimer's Poetry Project activities,
- 15 group-based activities without any arts (e.g., Bingo),
- 4 group-based activities with arts (but not poetry; e.g., singing), and
- 3 activities where nursing home residents were engaged individually and without the use of the arts (e.g., Tai Chi).

In each activity, a group of 4-6 residents were systematically observed every 5 minutes in order for the researcher to document the proportion of observed residents who displayed up to 25 indicators of engagement across 7 domains (see Activities Observation Guide).

Observed impacts on Cognitive Performance

The domains of engagement which represent cognitive performance in the Dementia Engagement Mapping method include alertness and activity engagement. In this study, observed impacts on alertness were similar for all types of events and registered between 40 to 43 percent, meaning that about 2/5ths of the observed nursing home residents, on average, demonstrated indicators of alertness during these varied recreational activities.

There is little value in speculating on the potential causes of such subtle variations across activity categories. However, there were noteworthy deficits in the domain of activity engagement among participants in arts-based group activities despite comparable levels of activity engagement across the other activity categories.

While about 28% of observed participants demonstrated activity engagement on average across other categories of activity, only about 15% of participants were seen engaging in the activities defined as arts-based (but not poetry-based) group activities.

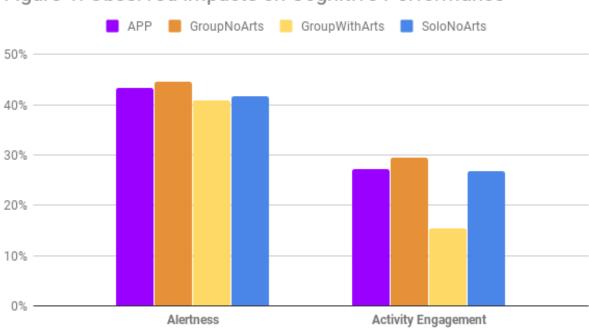


Figure 1: Observed Impacts on Cognitive Performance

Observed Impacts on Socio-emotional Wellness

Positive emotions and social interactions comprise the domain of socio-emotional wellness in the Dementia Engagement Mapping method. The observed impacts on positive emotions were similar across activity types and registered just above or just below 40%, meaning that about 2/5ths of the observed nursing home residents, on average, demonstrated indicators of positive emotions, such as laughing, during these varied recreational activities.

Yet, slightly higher levels of positive emotions were observed during the few activities in which residents were engaged on a more individual level. In terms of social interactions, the overall level of engagement was low, with only about 5-12% of participants demonstrating social engagement.

However, the non-arts focused group activities had the highest levels of social interaction and this likely has to do with the discussion-oriented activities which are captured in this categorization scheme.

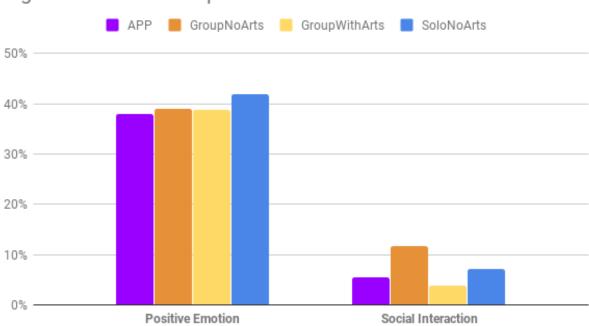


Figure 2: Observed Impacts on Socio-emotional Wellness

Observed Impacts on Self-expression

The domains of engagement which represent self-expression in the Dementia Engagement Mapping method include vocalization, personhood, and creativity. In the area of self-expression, while the other activity types allowed for about 12% of participants to vocalize, the APP activities resulted in about 18% of participants who vocalized during each observation period, and this noticeably higher level of vocalization is likely associated with the call and response techniques and frequent solicitation of content from the group in APP workshops.

Indicators of personhood were low overall, as is commonly reported in dementia care settings, yet the APP workshops yielded noticeably higher levels of impact on average with about 8-9% of observed participants demonstrating personhood indicators as compared to about 5% of participants in other types of activities.

The most profound differences in engagement across all domains were found in the area of creativity. Again, the overall level of engagement in this area was low, but the APP workshops inspired creativity in about 9% of residents while only 1-3% of participants showed creativity during the other types of activities.

Thus, while somewhat comparable findings are noted in the areas of cognitive performance and socio-emotional wellness no matter the type of activity being facilitated, **the APP workshops seem to stand out in fostering self-expression.** It may be that the design of APP techniques are uniquely well-suited to eliciting moments of creativity and personhood among participants.

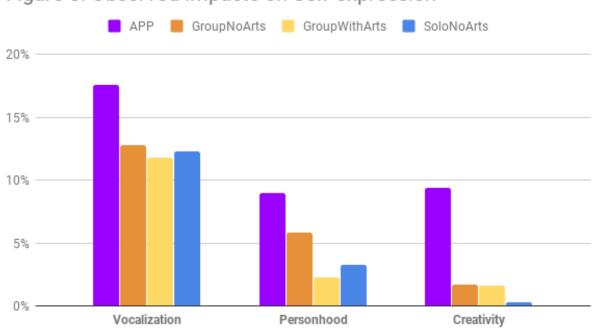


Figure 3: Observed Impacts on Self-expression

PERCEPTIONS OF HEALTH, ARTS, AND DEMENTIA: FINDINGS FROM STAFF ATTITUDINAL SURVEYS

The participating employees at nursing homes in Wisconsin work in the activities departments and are experienced in leading recreational activities for groups of nursing home residents. In consenting to this study, they agreed to complete surveys before and after their involvement in the program, and the findings described here represent comparisons of pre-program survey responses to post-program responses for the same people, matched by person. In other words, each person's pre-program answers were compared to her own post-program answers.

During the time between surveys, participants received in-person training on the techniques of the Alzheimer's Poetry Project and Poetry Cards interventions and gained experience in the use of these techniques while providing services to the residents at their nursing homes.

By comparing their survey responses, we seek to answer the following questions:

- 1. Which beliefs and attitudes are typical among participating employees with regard to aging and dementia, the potential benefits of using arts and poetry in healthcare, their own capacities for leading interventions, their interests in working with older adults and people with dementia, and their job satisfaction?
- 2. What changes in these beliefs and attitudes might be associated with the experience of participating in this program of training and practice with APP techniques?

We got up and danced and they were having a lot of fun clapping and repeating the poem

"It was really nice to get responses from residents. They were really creative. My favorite moment would be, when I had them following along and performing the poem 'Daffodils." We got up and danced and they were having a lot of fun clapping and repeating the poem. It was really nice."

-Amber Freyer, Southpointe Healthcare Center, Greenfield

Employee Ratings from Dementia Attitude Scales

The Dementia Attitudes Scale presents 20 statements about people with dementia and interacting and working with this population, and respondents are asked to rate their degree of agreement with each statement on a six-point Likert-type scale from "Strongly Disagree" (a rating of 1) to "Strongly Agree" (a rating of 6).

Fourteen of the statements are phrased to capture a positive sentiment, such as "It is rewarding to work with people with dementia," where it is desirable to identify strong agreement with the statement and to increase agreement among respondents if possible.

Six statements are phrased in the negative, where lower scores are preferred over higher scores so as to capture disagreement with statements such as "I am afraid of people with dementia."

Among the 26 nursing home activities personnel who completed both pre- and post-program surveys, advanced understanding and positive views about dementia were already common at the time of the pre-program survey. The average responses for each item were agreement or strong agreement, with ratings between 5 and 6 for each positively phrased statement and between 1 and 3 for the negatively phrased statements.

Thus, there was little room for improvement! Changes in average ratings of agreement from 0.0 to 0.3 are not likely as meaningful or valid as changes of a larger magnitude, and the sample size is too small to validly assess the statistical significance of such small changes or to offer generalizable interpretations of findings.

However, in four instances, the difference in mean score registered between 0.5 and 0.7, representing a conceptually meaningful change.

These four statements with noteworthy attitudinal change include:

- 1. "We can do a lot now to improve the lives of people with dementia" -- with a 0.7 point increase from 5.3 to 6.0
- 2. "I feel confident around people with dementia" -- with a 0.6 point increase from 5.1 to 5.7
- 3. "I feel frustrated because I do not know how to help people with dementia" -- with a 0.6 point increase from 2.6 to 2.0 (a negative statement where lower ratings are preferred)
- 4. "I am afraid of people with dementia" -- with a 0.5 point increase from 1.7 to 1.2 (a negative statement where lower ratings are preferred)

Thus, the experience of participating in this program is associated with notable improvements in staff members' attitudes about dementia care intervention potential and interactional confidence, knowledge, and comfort, at least among these activities personnel who already had achieved mature attitudes with regard to dementia care prior to participating in the program.

Experience, capacities, and interests....

One goal of the survey study was to understand the experiences, perceived capabilities, and relevant interests among participating personnel, as well as any changes in these areas over time.

The average pre-program responses reflected moderate levels of experience with reading, writing, and performing poetry--about halfway between no previous experience and extensive prior experience.

While moderate, these levels are likely higher than among people in the general population as professionals working in the field of recreational programming may be more inclined to favor the arts and humanities as meaningful domains of expression and human connection.

Perspectives of participants on their own capabilities reflected a moderate pre-program level of ability in performing poetry and somewhat higher abilities in leading arts-based activities, with a sizeable increase in self-perceived ability in poetry reading after the program.

Perspectives on capabilities in communicating effectively with people with dementia and engaging groups of people with dementia were relatively high at baseline and did not change in any meaningful way by the time of the post-program survey.

These findings likely reflect the existing professional skills among this group of working activities specialists, as well as the important gains in poetry skills that the APP program has added to their repertoire.

In terms of interest in continuing to work with older adults, people living with dementia, or residents/clients in healthcare settings, the pre-test mean levels were so high (rating of nearly 6 across the board), the non-significant gains or losses of 0.0 - 0.2 points across time points likely captures minor episodic shifts in mood among participants instead of any meaningful program impacts.

Similarly, moderately high levels of job satisfaction prior to participation in the program were maintained over time. Yet, moderately high satisfaction with work involving the use of arts increased to a meaningful extent among participants, and this is considered a desirable and anticipated outcome of the program.

Employees' poetry experience, arts and communications capacities, and work interests and satisfaction (matched sample: n=26)

sausiacuon (matched sample, n–20)			
Survey Questions and Scales	Pre-Test Mean	Post- Test Mean	Difference in Mean
Rate your overall previous experience with poetry:			
1= No previous experience at all ; 6= Extensive previous experience			
Reading poetry	3.3	n/a	
Writing poetry	2.6	n/a	
Reciting poetry	3.3	n/a	
Rate your current capabilities in the following areas:			
1= Not capability whatsoever ; 6= Advanced capability			
Performing poetry	3.4	4.3	0.9
Leading arts-based activities	4.6	4.8	0.2
Engaing groups of people with dementia	5.2	5.2	0.0
Communicating effectively with people with dementia	4.9	5.1	0.2
Rate your interest in continuing to work with the following groups: 1= Not at all interested; 6= Extremely interested			
Older adults	5.9	5.8	-0.1
People living with dementia	5.9	5.8	-0.1
Residents/clients in healthcare settings	5.9	5.9	0.0
Rate your satisfaction with your current job in terms of the following: 1= Not at all satisfied; 6= Extremely satisfied			
Your routine job duties	5.1	5.2	0.1
Your work involving the use of arts	4.8	5.4	0.6

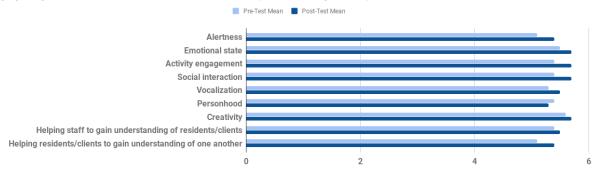
Employee perceived benefits of art-based and poetry-based interventions

Facilitated activities are thought to have potential for positively impacting people living with dementia, including in the domains of cognitive performance, socio-emotional wellness, and self-expression. These potential impacts are the focus of the observational study described throughout this report and which utilized a novel Dementia Engagement Mapping instrument.

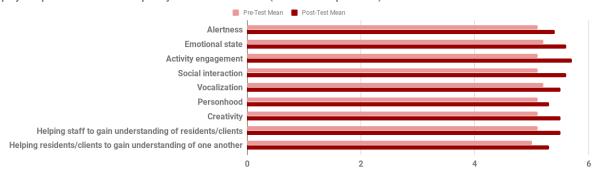
By also asking survey respondents to rate their perceptions of the potential benefits of arts-based and poetry-based interventions, we seek to understand if these interventionists who were trained to use APP techniques believe in the value of such interventions and if those beliefs are influenced by participating in this program of training and practice with APP interventions.

We also included survey questions to capture views on the benefits of arts and poetry interventions in building understanding among nursing home residents and between residents and staff.





Employees' perceived benefits of poetry-based interventions (matched sample: n=26)



Pre-program ratings of the benefits of arts-based and poetry-based interventions were quite high, around 5 or 5.5 on a 6-point scale where 6 indicates a view of "Extremely beneficial." Thus, this group of participating activities personnel already held views of the strong potential for such interventions to benefit nursing home residents across all domains of impact.

Aside from miniscule fluctuations in ratings (0.0 - 0.2) which likely reflect minor episodic shifts in mood among participants instead of any meaningful program impacts, participation in this program seems to have reinforced views of strong potential benefits across domains and for both arts-based and poetry-based interventions.

Of note are the minor differences in pre-program ratings of benefits for arts-based and poetry-based interventions, with slightly lower ratings of perceived benefits of poetry-based interventions across domains.

While the post-program ratings are comparable, this lower pre-program view of benefits of poet-ry-based interventions allowed for more significant gains through the experience of participating in the program.

Again, these variations are minor in degree and should be understood in the context of overwhelmingly positive views of the benefits of both arts- and poetry-based interventions among these activities personnel.

POETRY FOR LIFE: PERCEPTIONS OF HEALTH, ARTS, AND DEMENTIA FINDINGS FROM STUDENT SURVEYS

Another way that we measure project results having the high school students take a pre and post attitudinal survey. While this survey is taken by all of the students we work with in the various states where APP programming takes place and outside of this funding, Wisconsin students make up a large percentage of the students who have participated.

This research component of the project was undertaken in partnership with Adelphi University School of Social Work. We received approval from Adelphi University's Institutional Review Board (IRB) for the study.

While we are in the primarily stages of the research project we may share here some early results. Below are three charts showing primarily results.

Highlight: The PFL Study, showed the experience of students participating in this program is associated with notable improvements in students' attitudes about most of the concepts represented in the attitudinal scale with regard to aging and dementia.

Goals of the Study

By comparing their survey responses, we seek to answer the following questions:

- 1. Which beliefs and attitudes are typical among participating students with regard to aging and dementia, their own capacities for leading interventions, their interests in working with older adults and people with dementia, and their overall self-esteem?
- 2. What changes in these beliefs and attitudes might be associated with the experience of participating in this program of training and practice with APP techniques?

Student Ratings from Dementia Attitude Scales

The Dementia Attitudes Scale presents 20 statements about people with dementia and interacting and working with this population, and respondents are asked to rate their degree of agreement with each statement on a six-point Likert-type scale from "Strongly Disagree" (a rating of 1) to "Strongly Agree" (a rating of 6).

Fourteen of the statements are phrased to capture a positive sentiment, such as "It is rewarding to work with people with dementia," where it is desirable to identify strong agreement with the statement and to increase agreement among respondents if possible.

Six statements are phrased in the negative, where lower scores are preferred over higher scores so as to capture disagreement with statements such as "I am afraid of people with dementia."

Changes in average ratings of agreement from 0.0 to 0.3 are not likely as meaningful or valid as changes of a larger magnitude, and the sample size is too small to validly assess the statistical significance of such small changes or to offer generalizable interpretations of findings.

However, in 15 of the 20 items in this measure, the difference in mean score was higher than 0.3, representing a conceptually meaningful change, and a gain of 0.5 points or more was documented for 10 of the items.

Thus, the experience of participating in this program is associated with notable improvements in students' attitudes about most of the concepts represented in the scale.

Students' ratings from Dementia Attitudes Scale (matched sample: n=33)		
1= Strongly Disagree ; 6= Strongly Agree	Pre-Test Mean	Post-Test Mean	Difference in Mean
I am comfortable touching people with dementia.	3.82	5.00	1.18
I feel confident around people with dementia.	3.97	4.95	0.98
I feel relaxed around people with dementia.	3.97	4.70	0.73
People with dementia can be creative.	4.91	5.63	0.72
I admire the coping skills of people with dementia.	4.63	5.24	0.61
It is rewarding to work with people who have dementia.	4.94	5.47	0.53
We can do a lot now to improve the lives of people with dementia.	4.97	5.42	0.45
People with dementia can feel when others are kind to them.	5.19	5.61	0.42
People with dementia can enjoy life.	5.42	5.79	0.37
People with dementia like having familiar things nearby.	5.12	5.45	0.33
Every person with dementia has different needs.	5.45	5.58	0.13
It is possible to enjoy interacting with people with dementia.	5.76	5.89	0.13
Difficult behaviors may be a form of communication for people with dementia.	4.91	5.00	0.09
It is important to know the past history of people with dementia.	4.97	4.89	-0.08
*I am not very familiar with dementia.	3.48	2.57	-0.91
*I feel frustrated because I do not know how to help people with dementia.	3.18	2.45	-0.73
*I feel uncomfortable being around people with dementia.	2.27	1.58	-0.69
*I am afraid of people with dementia.	2.03	1.50	-0.53
*I would avoid an agitated person with dementia.	3.30	2.95	-0.35
*I cannot imagine caring for someone with dementia.	2.81	2.76	-0.05

^{* =} Item phrasing is negative; thus ratings of disagreement (lower values), as well as decreasing values as a result of program participation, are preferable

Experience, capacities, and interests....

One goal of the survey study was to understand the experiences, perceived capabilities, and relevant interests among participating students, as well as any changes in these areas over time. The average pre-program responses reflected moderate levels of experience with reading, writing, and performing poetry--about halfway between no previous experience and extensive prior experience. While moderate, these levels are likely higher than among people in the general population as students engaged in poetry clubs and competitions will be more inclined to favor the arts and humanities as meaningful domains of expression and human connection.

Students' poetry experience, arts and communications capacitie satisfaction (matched sample: n=33)	s, and wor	k interests a	and
Survey Questions and Scales	Pre-Test Mean	Post-Test Mean	Difference in Mean
Rate your overall previous experience with poetry:			
1= No previous experience at all ; 6= Extensive previous experience			
Reading poetry	4.09		
Writing poetry	3.33		
Reciting poetry	3.06		
Rate your current capabilities in the following areas:			
1= Not capability whatsoever ; 6= Advanced capability			
Engaing groups of people with dementia	3.24	4.37	1.13
Leading arts-based activities	2.45	3.39	0.94
Communicating effectively with people with dementia	3.73	4.55	0.82
Performing poetry	3.21	3.78	0.57
Rate your interest in continuing to work with the following groups:			
1= Not at all interested ; 6= Extremely interested			
Older adults	4.21	4.50	0.29
Residents/clients in healthcare settings	4.18	4.26	0.08
People living with dementia	4.39	4.34	-0.05

Student self-esteem

Another goal of the Poetry for Life study was to investigate if self-esteem might improve when students gain skills for intervention and comfort with people with dementia as a result of the program. To this end, the survey included the Rosenberg Self-Esteem Scale, comprise of 10 items, which has been validated for use with adolescents and young adults.

Students' ratings from Rosenberg Self-Esteem Scale (m	atched samp	le: n=29)	
1= Strongly Disagree ; 4= Strongly Agree	Pre-Test Mean	Post-Test Mean	Difference in Mean
I am able to do things as well as most other people	3.22	3.29	0.07
I take a positive attitude toward myself	3.23	3.29	0.06
On the whole, I am satisfied with myself	3.31	3.37	0.06
I feel that I have a number of good qualities	3.53	3.53	0.00
I feel I am a person of worth, at least on an equal plane with of	3.50	3.45	-0.05
*I feel I do not have much to be proud of	1.66	1.37	-0.29
*All in all, I am inclined to feel that I am a failure	1.69	1.51	-0.18
*At times I think I am no good at all	1.94	1.92	-0.02
*I certainly feel useless at times	2.19	2.26	0.07
*I wish I could have more respect for myself	1.97	2.19	0.22
Total Self-Esteem Score (range 10=lowest; 40=highest)	33	33	0.00

^{* =} Item phrasing is negative; thus ratings of disagreement (lower values), as well as decreasing values as a result of program participation, are preferable

APP Methods in other Arts Interventions

APP shares similarities and yet is distinct from other art interventions. APP draws much of its strength from engaging the participants in co-creating both performances of poetry and original group poems.

The training that healthcare staff receives in recitation and public speaking, enhances communication skills. The training and the co-creation of original group poems emphasize listening skills. All these skills are transferable to other activities.

APP may be added to a range of activities and arts interventions, that the partner nursing homes may already be successfully engaged in. For example reciting poetry may be combined with singing to create medleys.

We have had success in combing APP methods and techniques with:

- Arts and Crafts
- Bible Study
- Bingo
- Current Events
- Cycling Without Age (Rickshaws)
- Exercise sessions
- Memory in the Making
- Music and Memory
- Namaste Care
- TimeSlips
- Wii bowling (and other games)

On Using Jingles

Today we had a poetry party and our theme was TV jingles. We had all the residents singing jingles from old time TV shows and commercials like Chiquita Banana, Slinky, and Almond Joys. People really remembered everything. We had lots of laughs and asking questions about what we like to eat. It was a lot of fun.

- Leslie Kletts, Activities Director, The Villa at Bradley Estates

Strengthening Staff Training

During the Dementia Engagement Mapping we identified a number of activities that the APP techniques and methods may be incorporated into other activities.

Here are a few examples:

- a) During Bingo and Wii Bowling create sports nicknames for the participants and encourage the participants to use call and response, with cheers for the teams.
- b) During manicures and hand massages, use the Poetry Cards to engage the person and saying lines of poetry and having discussions around the poems to enhance the natural flow of conversation.
- c) During chair exercises use call and response to have the participants say lines of poetry or sing songs in rhythm to the exercises.
- d) During reading of the newspaper, often referred to as a "current events," activity, use the vocal skills learned in performing poetry to bring interest to the reading. These public speaking skills, which include articulation, projection, pacing and highlighting the emotional content, may add interest and depth to this and other activities.
- e) During rickshaw rides with Cycling Without Age, you could create poems by asking open-ended questions about what the person is seeing on their ride and writing down the person's answers.
- f) Namaste Care group's have had success sharing poems using call and response.

Music and Memories[™] and TimeSlips[™]

Music and Memories[™] and TimeSlips,[™] which use music and storytelling respectively and are in wide use throughout Wisconsin, most groups we worked with have been trained in both programs.

We want to especially acknowledge Professor Anne Bastings, the MacArthur Award winning, founder of TimeSlips™, for her leadership in the field of Creative Aging.

With TimeSlips[™], we have had success in using call and response to perform the story the group has created. This may include alternating between the practice of reading the completed story and using call and response to highlight and perform parts of the story.

With Music and Memories[™], have had success in asking open-ended questions during the making of the person's play list to create poems and/or stories based on the person's favorite songs.

APP Methods and Validation

In this section we will look at the use of APP methods and how these techniques may be used to increase the opportunities for and improve their skills of using validation. Using validation to interact with people is built into as humans. In the training we encourage people to see the natural use of validation as a skill we can get better at and building on that skill will help us communicate better with residents, staff and perhaps in our personal lives.

In the process of developing a research paper, we hope to publish, we have categorized five domains as a framework for looking at the use of validation in arts programs.

Validation through:

- Collaboration
- Connection
- Communication
- Creation
- Confirmation

Validation in Participatory Arts Interventions for People with Dementia

Validation is a primary focus in group-based participatory arts interventions for people living with dementia, serving as an intended outcome as well as guiding the selection of techniques and activities. These participatory arts programs vary in modality, group size, and degrees of improvisation, performance, and physicality. Compelling and innovative non-pharmacological interventions include those focused on poetry, storytelling, songwriting, and dance, such as the Alzheimer's Poetry Project, Timeslips, Songwriting Works, and Kairos Alive!, respectively.

All emphasize performance, co-creation, and both social and intellectual stimulation. All share a set of core philosophies—respect, authenticity, inclusion, and the assumption of emotional intelligence—which serve as a guiding framework. It is proposed here that the validation that occurs in these programs can be organized into five domains.

Validation through Collaboration

Collaboration during participatory arts activities involves partnership among participants and facilitators in the co-creation of music, stories, poems, and dance. Simply inviting partnerships in these acts of creation and performance sends messages of respect, and expressing respect for another person is an act that is inherently validating of that person's value. Being asked to perform or contribute during these activities—to do something meaningful—acknowledges the active and productive roles that can be assumed by people living with dementia.

APP methods offer collaboration by reciting poems in unison as a group, in discussing the poems and in creating poems by asking open-ended questions.

Validation through Connection

Participatory arts activity programs are collective as well as collaborative. The activities bring people together and break down barriers that typically prevent meaningful connections. Interactions during these activities foster key human validations, including learning one another's names and using social skills to interact with peers. The focus of engagement during participatory arts activities is not on autobiographical reminiscence, but on presence and participation. Thus, all contributions are deemed successful, and the response of the facilitator conveys this powerful validation.

APP methods offer connection through the shared experience of performing poems as a group using call and response.

Validation through Communication

Several barriers to effective communication may contribute to the disablement of people with dementia. Brain disease can lead to impaired expression, understanding, semantic and working memory, attention, and motivation. Environmental barriers, such as the institutional culture, task-focused interactions, and co-residence with other aphasic people in residential care facilities, further impede communication. Participatory arts activities help to establish intimate interactions between individuals, reciprocity among the participants in the group, and continual connectedness during the activity. Intimacy, reciprocity and connectedness are necessary for feeling valued and loved.

APP methods offer a powerful communication tool

During the call and response portion of the Alzheimer's Poetry Project, for example, the group leader recites a line of poetry and has the group repeat back or echo the words. One example of using call and response is with the line, "O Romeo, Romeo, wherefore art thou Romeo?" Participants are asked to say the line with different emotions, love, sadness and anger to name a few. The person then says the line with that emotion and the group listens closely to their voice and tries to say the line back with the same vocal infections and emotion. Often the recitations are quite moving or in the case of saying the line with anger ripe for the use of humor.

All of the various recitations offer the group leader the opportunity to praise the reciter. They give opportunity other participants to offer their encouragement and praise as well. Participants are being heard and are hearing their fellow participants.

In addition, the acts of deeply and actively listening and repeating back the recitation are forms of validation similar to those often used by those who care to demonstrate their attention, interest, and appreciation for the ideas of others. Thus, community building occurs within the participant group and the observer group, but across groups as well.

Validation through Creation

Imagination is necessary for creativity. Imagination is a major achievement of human intelligence, and is not degraded by neurocognitive disorder as we know occurs with other intellectual capacities such as memory and orientation. Acts of creativity are essentially human, so these 42

activities are humanizing, which is restorative in the face of dementia.

The production and completion of the artistic product in each activity is another source of validation. The art represents a vehicle for self-expression, but the piece of art is also created. Be it a poem, dance, or story, it is finished by the end. To only allow the process, to stop before the product is deemed complete, is to deny the participants the full benefits of the activity. It is common for interventionists to draw attention to the finished product or to lead the group in one final recitation of the newly created poem, song, or story. Participants are often able to recognize their own contributions and revisit positive emotions from the recent activity. This closure honors each contribution to the whole, and the recitation of the finished story or dance or poem is a way of thanking and validating each contributor.

APP methods offer the creation of group poems by asking the participants open-ended ques tions around a theme.

Validation through Confirmation

People with dementia are often doubtful about the appropriateness of their thoughts, behaviors, and belongingness in any given setting or group. These participatory arts activity programs foster inclusion, which confirms for participants that their presence and participation are appropriate. These activities are facilitated in ways that are explicitly non-judgmental, where all contributions are witnessed, confirmed, and incorporated into the group dialogue and/or the artistic product. As such, participants are supported in taking risks and overcoming embarrassment. Facilitators incorporate participant contributions into the artistic product and then gesture or move toward the contributor when reciting or reenacting the art. Making sure that everyone in the group has opportunities to participate assures a level playing field where all voices can be heard. These democratizing experiences confirm the innate rights of the members to be present and to express their thoughts. The universal acceptance of each participant and his or her contributions is validating.

APP methods offer opportunities for verbal confirmation at each stage of a poetry session.

Future Studies, Directions and Conclusion

Dementia Engagement Mapping Study

We will seek to introduce and train health care workers in the use of the Dementia Engagement Mapping, an ethnographic observational data chart, to strengthen their programs and help improve the quality of life of people living with dementia.

Certified Nurse Aide (CNA) Study

One direction the findings in this report suggest is to hold a series of stakeholder meetings to determine feasibility of CNAs in using the arts as communication tools. This would be followed by a CNA arts training.

Call for National Arts and Health Study

A larger goal would be to undertake a similar study to the, "Creative Health: The Arts for Health and Wellbeing," which was conducted in the United Kingdom and published in 2017. (See References and Resources for info on the study.)

In Wisconsin there are incredible projects, which have been supported by the State of Wisconsin Department of Health Services on behalf of the Division of Quality Assurance including: Cycling Without Age, Music and Memories™, Namaste Care, and TimeSlips™.

Combining these groups with other "best practice" arts in dementia groups like the dance project Kairos Alive!™, based in Minnesota; the music project SongWriting Works™ based in Washington and the visual arts project, Opening Minds Through Arts, based in Ohio, could form the basis of national study.

(See resources for the "Creative Health: The Arts for Health and Wellbeing," study.)

Conclusion

A challenging aspect of this work, is to fit into the scientific models, especially the gold standard of the double blind study. It would be a hard choice to have a group living with dementia, that you would use as the control group, who would not get the arts intervention.

The question becomes what is the right model for us as artists and healthcare workers to use. Is it more effective to show a photo of the person's reaction? Is it best to show the person experiencing a moment of co-creation in a video?

This project is an attempt to blend the scientific model with poetry.

A major scientific inspiration, that also has art at its core, is the work of Santiago Ramón y Cajal. He was co-awarded a Noble prize, in 1906, for his groundbreaking work as a neuroscientist. His original investigations of the microscopic structure of the brain made him a pioneer of modern neuroscience. Cajal spent thousands of hours observing and making drawings of brain cells. His drawings are still in use for educational and training purposes.

Cajal's imagination was fired by the idea that the nervous system is made up of billions of separate nerve cells. Cajal's work led to the conclusion that the basic units of the nervous system were represented by individual cellular elements (which Waldeyer christened as "neurons" in 1891). This conclusion is the modern basic principle of the organization of the nervous system.

That Cajal was able to intuit the way the brain worked through observation tempered by his drawing and go against the prevailing theory at the time of the idea that the nervous system was made up of a network of continuous elements, is remarkable. Decades later, electron microscopes would confirm Cajal's theory.

In the planning stages of this project, his drawings were first exhibited in the United States. Attending lectures on his work and viewing the breathtaking drawings gave vitality to the concept of using the observational study in this project. What could we learn by looking?

Last year, I co-taught a class on arts and health care at the University of Arizona Medical School. I visited the Gross Anatomy Laboratory and held the brain of a person that had visible deterioration from Alzheimer's disease. I wanted that moment to be imbued with insight, as if the brain were my muse.

As I held this person's brain, it was awe inspiring to think all our hopes; dreams, loves and life experiences are held in this incredible structure. As the formaldehyde filled my nostrils and snapped me out of my reverie, I knew if there was inspiration, it was in the search for knowledge.

This is a call for action and further study, to push forward our knowledge of how poetry works with people living with dementia.

That knowledge quest, coupled with poetry's essence: metaphor, rhyme, rhythm, image, sound and the pleasure of as Coleridge says, "the best words, in the best order," gives us a powerful tool to improve the quality of life, of people trying to best navigate living with memory loss and ultimately a better understanding of humanity.

I would like to end this report with a poem I have written in honor of the people I have worked with in the Alzheimer's Poetry Project.

We Are Forget

-Gary Glazner

We are the words we have forgotten.

We are shifting and pacing.

We wrote this poem.

It's a pretty poem.

Can you bake a cherry pie?

Never more, never more.

We have no horizon.

We don't recall washing or eating

or what you just said.

Ask me my name.

Ask me if I have children?

You're a pretty lady.

You have beautiful eyes.

Wash me, put me to bed clean,

hold me as I fall asleep.

Give me a kiss, brush my hair.

You are my daughter?

Light washing over us moment, moment.

You're a handsome man.

Our hand writing is beautiful

twists and loops of letters

we can't remember our hands.

Our ears are wishful

we can't remember our ears.

We can speak every language,

we can't remember our mouths.

We are porous.

We are the past.

We are forget.

Sample Poems, Poetry Cards, Improvisation Tools

Gallery Night

After being trained in the poetry program, we decided to combine with our TimeSlips and painting programs and set some goals for our activities department to become more of a creative culture community. We planned a culminating experience called "Gallery Night," where we showcased all of our residents including our poems, stories and artwork.

The residents have so many amazing talents and they are so proud of the work they have done. They are proud to show it to their families.

One of our residents loves to read, the paper, magazines, books and he was very excited tonight to see his poems posted in the gallery. I think he thought it was amazing to see his work on the walls, being that he reads all day long and now he could read something that he wrote.

- Erica Bowers, Activities Director, Bridges of Appleton

Flies

Julie & Mary K

The Lord in his wisdom made the fly and then forgot to tell us why.

I think its because he doesn't have his thoughts together.

Flies make buzzing noises, is all they do!

They can lay eggs that look like maggots to feed other animals, and to things they are yummy!

Song

By Julie, Pete & Mary

Has the bright sunset, has Gale grown stronger?
Still we will not grieve yet.
We will sing awhile longer
To make people happy!
My favorite singer is Davy Jones! I love him.
He is so cute too! And tall!
My favorite station is the oldies and I like all songs.

Eels

By Julie, Pete & Mary K

I don't mind eels except as meals! And the way they feel. That is the most unusual food in America. They are always feel. I think the weirdest food is oysters. These poems and song lyrics are from a session at St. Paul Elder Services, which had the theme of the Wisconsin Dariy Cow and ice cream. They added lines to an exsiting poem. This is a great technique to use with many poems.

As they performed the poems using call and response they added movments to the poem and repeated them to excercise movements. At the end one of the paticipants added Tail Swisher and talked about how when you are miling a cow they swish their tail and if you have to duck if you don't want to get hit in the head. That added a ducking movment with a loud swish sound. They also found the original lyrics to the song "I Scream You Scream, We All Scream for Ice Cream." Which a combination song and cheer for iec cream. They also played the recording from 1927 which may be found on YouTube. One of the lyrisists is Howard Johnson, could it be the Howard Johnson from the famous dinner and motel chain? He did sell a lot of ice cream!

I Scream You Scream, We All Scream for Ice Cream

-Howard Johnson, Billy Moll and Robert A. K. King

I scream you scream, we all scream for ice cream! Rah! Rah! Rah!
Tuesdays, Mondays, we all scream for sundaes.
Sis-boom-bah!
Boola-boola sarsaparoolla!
If you've got chocolate, we'll take vanoola.
I scream you scream, we all scream for ice cream! Rah! Rah! Rah!
Frosted, malted, or peppered and salted.
Sis-boom-bah!
Oh, spumonit, oh tartoni!
And confidentially, oh, no baloney.
I scream you scream, we all scream for ice cream!
Rah! Rah! Rah!

Here is an excerpt from "A Cow," -Anthony Helm

Milk Giver Nose Licker Muck walker

The group added on

Cow tipper Hay eater Lip Smacker Bull Watcher Butter milker Tail Swisher

Let's give a round of applause to the Wisconsin Dariy Cow!

Combing Art and Poetry



Our nickname for her was Miss Fluffy Butt, because of the pink pom poms. We spent 4 or 5 days working her. We had baskets of sea shells and odds and ends and stuff. We just started from there. We started with the form and then they just kind of let us loose. We tried and if something didn't work, we took it off and tried something else. With the seashells for her feet, that's where I got the line about coming from Japan, she must be Godzilla, rising from the water. There isn't too much more I can tell you, other than we are very attached to her. It is fun. We started talking about things. We started giggling and we had comradeship, it was really great.

- Colleen, Jewish Home, Milwaukee

First, you give it a look. You look a little askance. You are not really interested in describing every part of it. When you look at it all the way around, there were so many pieces, that everybody was putting a different spin on it. It's so strange and then you are supposed to tell about it! Who knows, it's like down from heaven or something.

- Sherry, Jewish Home, Milwaukee

Improvisation Games

Pass the Face

We have had success in using the theater improvisation games like "Pass the Face," as an ice breaker to start sessions.

In this simple game one person looks at another and "passes," a smile or other emotion.

They then turn to the next person until you have passed the smile around the group.

"Pass the Face," can be quite humorous and fun. Pass the Face," helps build group energy and adds depth to the activity.

We would then typically ask the group to come up with another emotion to pass. A few other examples would be surprise, sadness, anger, and laugher.

The Name Game

This is a call and response game. Each person says their name and does a gesture to show how they are feeling. In unison the group says the person's name back to them and repeats the guesture.

Improvisation as Communication Tool

I felt like a giant light bulb had lit up over my head. I was listening to Karen Stobbe, founder of In the Moment, give a talk in 2005 at the Alzheimer's Foundation of America Conference in Dallas on using improvisational theater techniques in dementia care. In the Moment is a training tool for caregivers that incorporates improvisation. Karen has a background in the world of improvisational theater, or improv, and what she had to say that day changed my view of caregiving and expanded my understanding of how art could be used as a communication tool.

One lesson I learned from her was the concept of "Yes, and . . . " Stobbe says, "There is no more important rule in improvisation." The idea is that you "accept any offer made by another and that accepting helps move the action forward with additional information or action. But beyond that, it is also an important statement when fostering a positive attitude." This concept is central to all types of improv, including comedy.

Below we look at Karen Stobbe's "Tips for working with people living with Alzheimer's disease," and "Some rules for improvisation," in her talks she highlights the simularities between the two lists and their concepts.

You may find our more about Karen Stobbe's work at: http://www.in-themoment.com/

Some tips for working with persons with Alzheimer's disease:

Use gestures when trying to get your message across.

Be aware of what your body and face are saying.

Be aware of the tone and inflection of your voice.

Patience is essential.

Join in the person's world, wherever they are. Agree with their reality.

Creativity and flexibility are key.

Avoid situations that bring on anger or frustration.

Break activities and instructions into simple steps.

Avoid quizzing the person and asking questions.

Try to appeal to the person's sense of humor.

Do not argue. Instead of arguing and reasoning, acknowledge and validate.

Acknowledge what is said. Repeat back key points.

Reframe a situation or give the person a new focus.

Orient the person to person, place, and time.

Be flexible. Be ready for anything.

Limit choices to minimize confusion.

Instead of asking questions, give a kind command.

Redirect when possible.

When needed, define your role.

Important characteristics of the caregiver:

Be spontaneous.

Stay focused.

Be nonjudgmental.

Value the moment.

Respect the basic rights of the person.

Use common sense.

Use your sense of humor.

Be flexible.

Maintain optimism.

Set realistic expectations.

Be a good listener.

Communicate skillfully.

Maintain optimism.

Be creative.

Be able to jump into another world.

Some rules of improvisation:

Say "yes" verbally, physically, and mentally.

Listen with your eyes and ears and face.

Stay in the moment.

Always accept a gift.

Don't say "no," say "yes."

Don't ask questions.

Commit to your actions 100%

Combine ideas, even if they are contradictory.

Give focus to those who take it and take focus from those who give it.

Let others define themselves.

Make your actions big.

Don't hesitate; go with the first thought.

Break the rules to move things forward.

Silence can be golden.

Know your audience and show them respect.

Some benefits of improvisation:

Self-confidence

Trust within a group and trust in your own ideas

Teamwork

Listening to others without prejudgment

Breaking from perfectionism

Committing 100%

Letting go of one's own need to control situations or predetermine outcomes

Problem solving

Creativity

Complex thinking; making sense of chaos

Critical thinking; analyzing and relating ideas

Original thinking

A renewing of playfulness

Self-discovery

Expanding limitations

Poetry for Life

My love is like a red, red rose that is newly sprung in June/My love is like a melody that is sweetly sung in tune.

Red Rose, Robert Burns- Say this poem to the person and then ask them if there is a love song they like to sing. Sing with them.

Poetry for Life

Hand-in-hand on the edge of the sand, we dance by the light of the moon, the moon, the moon the moon.

Owl and Pussy Cat, Edward Lear- If the moon could speak what would the moon say? Bonus, sing the opening lines to "Moon River."

Poetry for Life

The truth I do not stretch or shove When I state that the dog is full of love. I've also found, by actual test, A wet dog is the lovingest.

Dog, Ogden Nash-Which do you prefer dogs or cats?

Poetry for Life

O Romeo, Romeo, wherefore art thou Romeo?

Romeo and Juliet, William Shakespeare-Who said this? Juliet! Where did she say this? On the balcony! What would you say to Romeo? What would you say to Juliet?

Poetry for Life

Full many a glorious morning have I seen Flatter the mountain-tops with sovereign eye, Kissing with golden face the meadows green, Gilding pale streams with heavenly sigh...

Good Morning from William Shakespeare! What makes a good morning for you?

Poetry for Life

"Hope" is the thing with feathers -That perches in the soul -And sings the tune without the words -And never stops - at all -

Hope, Emily Dickenson- What do you hope for?

Poetry for Life

I carry your heart with me (I carry it in my heart) I am never without it
Anywhere I go you go, my dear.
This is the wonder that's keeping the stars apart I carry your heart (I carry it in my heart)

I carry your heart, ee cummings-Is possible to carry someone's heart?

Poetry for Life

A free bird leaps on the back of the wind and floats downstream till the current ends and dips his wing in the orange sun rays and dares to claim the sky.

A bird doesn't sing because it has an answer, it sings because it has a song.

Caged Bird, Maya Angelou- What is your song?

Poetry for Life

I started Early – Took my Dog – And visited the Sea – The Mermaids in the Basement Came out to look at me –

Took my Dog, Emily Dickenson- Where would like to visit with your dog or other pet? What would you see? What would see you?

Poetry for Life

Life's most persistent and urgent question is, what are you doing for others?

Dr. Martin Luther King, Jr.-Thank **YOU**, for what you do for others!



Ethnographic Observation Guide

To be used to collect qualitative data during activities programs in nursing homes and/or other care settings for older adults including those with dementia.

Observations should focus on the shift between residents' behaviors and interactions before, during, and after the activity.

Each activity will occur over 20-40 minutes as is typical of nursing home programming. The observer should be immersed in the activity space where he or she can see and hear nearly all aspects of the activity. Record data in written field notes during and immediately following each activity as described below.

IMPORTANT: Do NOT include any identifying information about nursing home residents. Data will be limited to descriptions of groups and individuals during the activities

Observations should be limited to those clients/residents who are present during activities.

	Activity identification
Activity	y Name:
Activity	y Date and Time:
Activity	y Location (Facility and space within facility):
Numbe	er of participants:
Facilita	ator occupation:
Activity	y Type (select the label which best defines the activity):
	Alzheimer's Poetry Project activity
	Arts-based activity without group socialization (e.g., individuals crafting collages)
	Group socialization activity without arts (e.g., facilitated group discussion of current
	events)
	Activity without group socialization or the use of arts (e.g., answering trivia questions)

Alertness		T1	T2	# at T3	# at T4	# at T5	# at T6	# at T7	# at T8	# at T9	# at T10	# at T11	# at T12
	Sleeping												
	Not focusing												
	Focusing												
	Reacting												
(Notes)													
Emotional State	Feeling Distressed												
	Feeling Upset												
	Non-emotive												
	Feeling Contented												
	Laughing, Feeling joy												
(Notes)													•
Activity	Observing only												
Engagement	Participating at times												
	Fully participating												
(Notes)													
Social Interaction	Physically interacting												
	Cross-talking												
	Addressing group												
(Notes)										ı	1	ı	
Vocalization	Vocalizing infrequently												
	Vocalizing frequently												
	Constantly vocalizing												
(Notes)													
Personhood	Revealing emotions												
	Making spontaneous comments												
	Sharing personal story												
(Notes)		J								•	•	•	
Creativity	Originality												
	Emotionality												
	Using humor or play												
	Improvisation												
(Notes)													

d

Perceptions of Health, Arts, and Dementia

Before proceeding to the survey, you must confirm that you have read the consent information and plan to sign the consent form at the beginning of your first training session.

Informed Consent Document

* Participant Contact Information

(This information will remain protected and will be used for only to connect your responses from this survey to your responses to a future survey)

Name

Company

City/Town

State/Province

--- select state ---

Rate your level of agreement	t with the follow	ing statements:				
	Strongly Disagree	2.	3.	4.	5.	6. Strongly Agree
It is rewarding to work with people who have dementia.					0	
I am afraid of people with dementia.	\circ	\bigcirc	\circ		\circ	\bigcirc
People with dementia can be creative.					0	
I feel confident around people with dementia.	\bigcirc	\bigcirc	\circ	\bigcirc	\circ	
I am comfortable touching people with dementia.	0	\circ	0	0	0	0
I feel uncomfortable being around people with dementia.	\bigcirc	\circ	\circ	\circ	0	0
Every person with dementia has different needs.	0	\circ	0		0	
I am not very familiar with dementia.	0	0	0	0	0	0
I would avoid an agitated person with dementia.	0	\circ	0		0	0
People with dementia like having familiar things nearby.	0	0	0	0	0	0
It is important to know the past history of people with dementia.		0			0	

Perceptions of Health, Arts, and Dementia

	Strongly Disagree	2.	3.	4.	5.	6. Strongly Agree
It is possible to enjoy interacting with people with dementia.	\bigcirc	\bigcirc	\circ	\circ	\bigcirc	\circ
I feel relaxed around people with dementia.					0	0
People with dementia can enjoy life.	\bigcirc			\bigcirc	\circ	\bigcirc
People with dementia can feel when others are kind to them.			0	0	0	0
I feel frustrated because I do not know how to help people with dementia.	\circ			0		\circ
I cannot imagine caring for someone with dementia.			0	\circ	0	0
I admire the coping skills of people with dementia.	\bigcirc	\bigcirc	\circ	\circ	0	0
We can do a lot now to improve the lives of people with dementia.	\circ	0		0		0
Difficult behaviors may be a form of communication for people with dementia.	\bigcirc	\circ	0	\circ	\circ	\circ

	th, Arts, and Dementia					
Rate your overall prev	ious experience with poe	etry:				
	1. No previous					6. Extensive
	experience at all	2.	3.	4.	5.	previous experienc
Reading poetry						
Writing poetry			0	0		
Reciting poetry			0			0
Other (please specify)						

	1. Not at all					6. Extremely
	beneficial	2.	3.	4.	5.	beneficial
ertness				\circ		
notional state					\bigcirc	
ctivity engagement	\circ					
ocial interaction						
ocalization	0					
ersonhood					\bigcirc	\bigcirc
reativity					\bigcirc	
elping staff to gain nderstanding of sidents/clients					0	
elping residents/clients to ain understanding of one nother	0	0	0	0	\circ	0
er (please specify)						

ctivity engagement ocial interaction ocalization ocalization ersonhood reativity elping staff to gain enderstanding of esidents/clients elping residents/clients to ain understanding of one	motional state	motional state
Activity engagement Social interaction Vocalization Personhood Creativity Helping staff to gain understanding of residents/clients Helping residents/clients to gain understanding of one	Activity engagement Social interaction Cocalization Coreativity Co	ctivity engagement
Social interaction	Social interaction	ocial interaction
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Personhood Creativity Helping staff to gain understanding of residents/clients Helping residents/clients to gain understanding of one	Personhood O O O O O O O O O O O O O O O O O O	ersonhood
Creativity Helping staff to gain understanding of residents/clients Helping residents/clients to gain understanding of one	Creativity	reativity
Helping staff to gain understanding of cresidents/clients Helping residents/clients to gain understanding of one	Helping staff to gain understanding of esidents/clients to lain understanding of one onother	elping staff to gain nderstanding of Sain Hard Scients Scient Scien
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gain understanding of one	ain understanding of one unother	ain understanding of one
	her (please specify)	er (please specify)
ther (please specify)		

interested 2. 3. 4. 5. interested Didder adults	emely
People living with dementia	
Residents/clients in healthcare settings her (please specify) ate your satisfaction with your current job in terms of the following: 1. Not at all satisfied 2. 3. 4. 5. satisfied four routine job duties Your work involving the use of arts	
ther (please specify) ate your satisfaction with your current job in terms of the following: 1. Not at all satisfied 2. 3. 4. 5. satisfied four routine job duties	
1. Not at all satisfied 2. 3. 4. 5. Satisfied four routine job duties Our work involving the use of arts	
Your routine job duties O O O O O O O O O O O O O O O O O O O	fied
Your work involving the use of arts	
ate your current capabilities in the following areas: 1. No capability 6. Advance	anced
whatsoever 2. 3. 4. 5. capability	
Performing poetry	
Leading arts-based activities	
Engaging groups of people with dementia	
Communicating effectively with	
people with dementia	

Perceptions of Health, Arts, and Dementia
Why have you chosen to participate in the Alzheimer's Poetry Project-Long Term Care Implementation study?

REFERENCES and RESOURCES

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Resources

Creative Health: The Arts for Health and Wellbeing, https://www.culturehealthandwellbeing.org.uk/appg-inquiry/

The Inquiry Report, Creative Health: The Arts for Health and Wellbeing - Second Edition, presents the findings of two years of research, evidence-gathering and discussions with patients, health and social care professionals, artists and arts administrators, academics, people in local government, ministers, other policy-makers and parliamentarians from both Houses of Parliament, UK.

Forget Memory: Creating Better Lives for People with Dementia, Anne Davis Basting, PhD, 224 pages, Publisher: Johns Hopkins University Press; 1 edition (July 1, 2009) ISBN-10: 0801892503, ISBN-13: 978-0801892509

Based on ten years of practice and research in the field, Basting's study includes specific examples of innovative programs that stimulate growth, humor, and emotional connection; translates into accessible language a wide range of provocative academic works on memory; and addresses how advances in medical research and clinical practice are already pushing radical changes in care for persons with dementia.

The Alzheimer's Poetry Project, Gary Glazner and Daniel B. Kaplan, PhD, JAMA: The Journal of the American Medical Association December 11, 2018 Volume 320, Number 22

Glazner's most in-depth description of his theory of what is happening at the neurological level, when you are performing poetry using call and response.

"Play" and People Living With Dementia: A Humanities-Based Inquiry of TimeSlips and the Alzheimer's Poetry Project, Aagje Swinnen, PhD and Kate de Medeiros, PhD, The Gerontologist cite as: Gerontologist, 2017, Vol. 00, No. 00, 1–9 doi:10.1093/geront/gnw196

This paper is a humanities-based inquiry, to consider "play" in the context of two participatory arts programs.

Medical Students' Perceptions of Dementia after Participation in Poetry Workshop with People with Dementia, Alaina J. Garrie, Shruti Goel, and Martin M. Forsberg, Hindawi Publishing Corporation International Journal of Alzheimer's Disease Volume 2016, Article ID 2785105, 7 pages http://dx.doi.org/10.1155/2016/2785105

We based the staff attitudinal study described in this white paper on this research.

Alzheimer's Poetry Project (APP): Quantifiable and Measurable Goals

The goals and objective of the APP program is to use the performance and creation of poems, improve the quality of life of residents with dementia and other psychosocial needs. To measure resident engagement in activities and compare them to APP methods, we developed "Dementia Engagement Mapping." an observational tool. In over 200 hours of observation, we measured the resident's responses in a wide range of activities. The data indicated a higher level of resident engagement with vocalization, personhood and creativity with APP than with other activities. The results showed the training for the health care workers in APP was effective. We believe the increased engagement and creativity indicates a rich experience and a corresponding improved quality of life for the participating residents. At the end of program 20 nursing homes were certified in the APP program.

