

Original Paper

Group-Based Participatory Arts Interventions Validate Personhood for those Living with Dementia

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Abstract

Participatory arts-based interventions for people living with dementia involve the collaborative creation and performance of poetry, story, song, dance, and visual arts. These programs are designed to support self-expression and productive collaboration among people living with dementia while stimulating positive social interactions and feelings of empowerment and validation. In this commentary, we explore the use and potential benefits of validation in the implementation of person-centered participatory arts interventions in the context of dementia care. We offer a novel framework for understanding validation as a common intervention method during these activities, organized into five themes: collaboration, connection, communication, creation, and confirmation. These validation opportunities are suggested to offer direct benefits for participants as well as indirect benefits when modeled in the presence of formal care providers and family members. Clinicians and other transdisciplinary care providers are encouraged to understand, use, and teach these and other validation-focused arts interventions with persons living with dementia.

Keywords

participatory arts, validation, dementia, creativity, poetry, personhood

1. Introduction

In this practice-informed commentary, we explore the use and potential benefits of validation in the implementation of person-centered participatory arts interventions in the context of dementia care, including The Alzheimer's Poetry Project, TimeSlips, Songwriting Works, and Kairos Alive! We aim

first to articulate the ways in which dementia threatens personhood and creative expression serves to affirm personhood, and second to offer a novel framework for understanding validation as a common intervention method during these interventions, organized into five themes: collaboration, connection, communication, creation, and confirmation.

2. Background

2.1 Dementia and Threats to Personhood

Dementia is a lay term for neurocognitive disorder, an acquired syndrome encompassing a range of clinical symptoms typically caused by neurodegenerative illnesses like Alzheimer's disease, most of which are terminal and progressive with increasing numbers and intensities of symptoms over time. It involves losses in cognition, functional capacity, and communication, as well as distressing behavioral changes. These losses can be gradual or rapid, impacting just a few areas of functioning or more comprehensively destructive across abilities. Each contributing illness has its own profile of symptom progression, and even within one particular disorder it is expected that any one person will have a unique experience because of their baseline abilities and health status.

The symptoms of the dementia syndrome result in numerous invalidating experiences over the course of years and thereby pose considerable threats to personhood. For example: family members and health professional may exclude the individual with dementia from conversations about prognosis and care; increasing frequency of mistakes in routine tasks may create feelings of embarrassment; friends and extended family members may restrict the frequency and authenticity of conversations with the individual; and personal freedoms may be restricted due to safety concerns. In these examples, the individual with dementia is perceived to be "less than" and is treated by others as incapable, incompetent, and in need of protection. Tom Kitwood's work and writing brought significant attention to the problems of invalidation of personhood by those who interact with individuals living with dementia—invalidation on the basis of perceived limits in rationality and autonomy for those with cognitive impairment—and promoted an alternative focus on relationships and the intrinsic worth of each person (Kitwood, 1997). Higgs and Gilleard review the concepts of personhood in Kitwood's work and much of the scholarship which has since tackled personhood in the context of dementia, and acknowledge that these concepts can be confusing, misdirecting, and distracting from conversations about care practices and policies (2015). In this paper we adopt the stance that each definition of personhood makes a valuable contribution to our broad understanding of this complex construct and that the accumulated experiences of people living with dementia too often challenge or threaten perceptions of personhood for people with dementia and/or those in their lives and surroundings.

The psychological impacts of such experiences, while difficult to understand fully because of communication challenges, are believed to be profoundly distressing (Luxenberg, 2000). Knowledge of this distress should, and usually does, compel close family members, friends, and other caregivers to address the emotional needs as well as the physical and basic needs of people living with dementia.

Many people with dementia withdraw from routine socialization with friends and family for reasons, including depression and apathy, lack of opportunity, impaired communication and functional skills, and feelings of embarrassment and stigma (Kane & Cook, 2013), particularly those living with frontotemporal dementia (Snowden et al., 2001) or vascular dementia (Honda, Meguro, Meguro, & Akanuma, 2013). They are also known to reduce engagement in the routine tasks and activities that formerly served as indicators of productive engagement in their personal lives and communities (Vikström, Josephsson, Stigsdotter-Neely, & Nygård, 2008).

A further threat to personhood resulting from care needs associated with the dementia syndrome is the common necessity to spend time during the latter stages of illness as a resident in healthcare facilities such as nursing homes. About 40% of the total number of years lived with Alzheimer's disease are spent in the most severe stage of illness (Arrighi, Neumann, Lieberburg, & Townsend, 2010). As such, nursing home admission by the age of 80 is anticipated for 75% of individuals with Alzheimer's disease as compared to just 4% of the general public (Arrighi, Neumann, Lieberburg, & Townsend, 2010). Nearly half of all nursing home residents have a diagnosis of dementia in their medical record (American Health Care Association, 2011). Institutional care settings are mandated with assuring safety and optimal health for residents, and many have developed innovative approaches to succeed in these goals. Litwak (1985) advanced the idea that formal organizations are more efficient in achieving technical knowledge and expertise than primary social groups such as families. However, this efficiency model of care is not designed to offer the personal attention and strengths-based approaches that are most effective at helping people with dementia to feel validated as individuals.

People with dementia struggle to preserve self-identity as well as functional abilities, and the experience of living in long-term care facilities exacerbates these losses and creates feelings of diminished self-determination, fear of loss of involvement and exclusion from activities, and upset over unrecognized needs and staff attitudes which devalue personhood (Clare, Rowlands, Bruce, Surr, & Downs, 2008; Cohen-Mansfield, Pappas-Gill, & Golander, 2005; Thompson, 2015). Experts and advocates promote helping people with dementia in maintaining a sense of self in order to combat the dehumanizing process of *othering* that accompanies cognitive decline (Petrescu, MacFarlane, & Ranzijn, 2014). Significant positive outcomes such as a meaningful sense of purpose and increased activity engagement are derived from person-centered and strengths-based interventions in dementia care (Gitlin et al, 2010; Parker, 2001; Ronch, 2003). Such approaches are known to undergird both clinical mental health work and quality dementia care. A compelling complement to is to offer non-traditional participatory arts-based interventions to promote personhood, productive activity engagement, and other positive benefits for people living with dementia in long-term care settings.

2.2 Validation of Personhood for Those Living with Dementia

In her seminal work on validation techniques, Feil (1982) sought to support the emotional needs of people with moderate-to-severe dementia through humanistic communication techniques. By referencing the person's feelings instead of commenting on the accuracy of statements, Feil intended to

affirm personhood and honor the dignity of the individual living with dementia. Feil's work focused on the confirmation and affirmation of the emotional state of the person with dementia (Benjamin, 1995). Validation is conceptualized here as defined by Marsha Linehan, who articulated multiple levels of validation through the acknowledgement, understanding, and acceptance of the thoughts, feelings, and behaviors of another person (1993). Linehan promoted the value of active observation, reflection, and direct validation as means to convey genuine acceptance (1993).

When used with people living with dementia, validation techniques have been shown to support improved orientation to communication partners and physical participation (Benjamin, 1995; Testad et al, 2014). The participatory arts-based interventions for people with dementia that are discussed here utilize basic validation techniques that are easily learned and can be incorporated into a broad diversity of dementia care strategies including activity programs designed to stimulate cognitive, physical, and communicative abilities. Ideally, such programs serve to validate participants through the very nature of the activities being facilitated, and thereby supplement the validation techniques used in communications during the program. Thus, the use of validation techniques in dementia care is driven by knowledge of the needs, strengths, and challenges of people with dementia. For example, Benjamin (1995) suggested that engaging the external environment becomes less desirable for people with dementia as opportunities diminish for meaningful interactions with others. Thus, by creating opportunities for successful social interactions from which people with dementia can derive meaning, interventionists and caregivers seek to reinforce connections between the person and their environment. Treatment can be conceptualized as having several purposes including the reduction of symptoms, improvement of coping capacity and experiences of comfort, and curing illness. Each purpose has value, yet dictates unique combinations of approaches, both pharmacological and non-pharmacological. In addition, de Medeiros and Basting (2013) have demonstrated that drug therapies yield little positive benefit when compared to psychosocial and arts-based interventions. In dementia care, even the activities of care can be understood to serve as treatments by helping to reduce any number of symptoms and improving quality of life, goals which surely deserve pursuit. As such, the terms "intervention" and "treatment" used throughout this paper are intended to affirm this therapeutic capacity which is proposed to be inherent in dementia care activities including those which are grounded in the arts. The goals of such activities certainly do not include cure, but instead celebrate the capacity of care providers to positively impact emotional states, functional capabilities, communications, self-awareness and self-esteem, and continuity of personhood. These outcomes and others are proposed here to be counted among a number of important benefits of arts-based activities of care.

2.3 Creative Expression and the Therapeutic Value of Arts

Moreno's seminal book *Who Shall Survive?*, published in 1953, proposed the theory of spontaneity-creativity which inspired decades worth of subsequent theory development and research in mental health and psychology with the aim of understanding what makes life fulfilling (Kipper, 2006).

Moreno suggested that spontaneity is a state of mind, a readiness to act creatively. Warming up to the spontaneity state involves a process of arousal that can be triggered internally or by receiving external stimulation, as may be the case when participating in activities that provide opportunities and encouragement for creativity. Studies by Kipper and colleagues (2006) found that spontaneity is positively correlated with well-being, and that a spontaneity deficit is correlated with anxiety, obsessive-compulsive behavior, and an orientation to the past—all of which are common challenges for people living with dementia.

Frequent engagement with arts and cultural activities is known to yield positive impacts on cognition, emotional wellbeing, self-esteem, and social contact, particularly among older adults (Arts Council England, 2014). In a recent systematic review of arts on people living in care homes, Curtis, Gibson, O'Brien & Roe found evidence of positive outcomes including increased verbalization, reduced apathy, increased expressions of positive affect and decreased negative affect, and increased self-awareness (2018). Critics of arts-based programs for people with dementia may question if cognitively impaired participants are capable of contributing to the creation of artistic products. Yet, organized, linear thought and sustained intellectual focus are not prerequisites of creativity or for making meaning through art. As noted by Anne Basting (2001) in a discussion of the benefits of TimeSlips, "...staff and facilitators were no longer looking for symptoms of the disease in the spoken word. Language was suddenly free to carry emotional, rather than literal, meaning." Anatole France, the 19th century poet, journalist, and Nobel Prize winning novelist, wrote "In art as in love, instinct is enough" (1894). Petrescu, MacFarlane and Ranzijn (2014), reflecting on the results of their exploratory study to understand if poetry writing interventions complement other activities to help people with dementia meaningfully engage with life, report that participants in the study created works of poetry expressing unique emphases ranging from the desire for competence and self-efficacy to overcoming the embarrassment of social blunders; from aspiring to maintain roles of beneficence to accepting engagement efforts of others in order to battle apathy. Additionally, they suggest that creativity is a strength that remains in people struggling with numerous cognitive losses and capitalizing on this strength celebrates what people with dementia can do instead of examining only those functions they have lost.

Weiss, an early pioneer in geriatric art therapy, summarized the therapeutic goals for working with older adults as: 1) Rediscovering interpersonal and intrapersonal meaning in life; 2) Enhancing interaction and communication with others; 3) Developing and enhancing self-worth and self-esteem; 4) Reviewing life events, coming to terms with one's self, and seeing value in one's life; and 5) Experiencing "wholeness in one's being" through fulfillment of one's potential and finding meaning in one's life (1984, p. 27). Frequent moments of awareness of oneself and one's surroundings remain valid and important, even when a person struggles to maintain longer trains of thought. The success of poetry, for example, in allowing people with dementia to feel content and happy, to express their spontaneity, humor and wisdom, reveals how the disorder is not, in fact, uniform and total in its devastation. Instead,

the sense of self persists, and the person remains a person even while particular capacities are diminished. Creative arts activities and therapies, such as those which are central to the participatory arts-based interventions described here, can therefore serve an important function in dealing with dementia by mediating losses to personhood.

3. Purpose

Validation is a primary focus in group-based participatory arts interventions for people living with dementia, guiding the selection of techniques and activities. 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. The Alzheimer's Poetry Project was founded in 2003 by poet Gary Glazner to facilitate the creativity of people living with dementia as participants are first engaged in a call-and-response performance of classic, familiar poems and the group is then supported to create an original, communal poem that the group performs at the end of the session. TimeSlips is a well-known program built upon an improvisational storytelling method, developed in 1996 by theater artist and educator Anne Basting. The focus of storytelling in the TimeSlips process is on imagination, and people in various stages of dementia are able to collaboratively build stories that aren't limited to words but can include sounds and gestures as well. Judith-Kate Friedman, award-winning vocalist, producer, and composer, developed Songwriting Works in the early 1990s. Each project brings older adults and families together with trained professional songwriters to collectively compose and perform their own original songs. Kairos Alive! is an intergenerational dance company that was founded by noted dancer, choreographer, and artistic director Maria Genné in 1999 to create a sense of community and well-being among participants and to explore the "language of dance" through movement improvisation, the interweaving of dance and story, and the collaborative development of choreography that draws on their memories and life experiences.

These participatory arts programs vary in modality, group size, and degrees of improvisation, performance, and physicality. Yet each of these programs emphasizes 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. Importantly, the activity facilitators do not have access to the medical charts. So, whereas in the classic intervention paradigm a facilitator would review the chart to determine which interventions are possible considering the roster of known diagnoses, the facilitators of these participatory arts activities enter the space with a lack of assumptions about the participants and must therefore take them each at face-value. The only assumption that these artists bring into their work is that something good is going to happen. It is proposed here that the validation that occurs in these programs can be organized into five domains, including collaboration, connection, communication, creation, and confirmation.

4. Major themes

4.1 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 roles that can be assumed by people living with dementia. Furthermore, these requests for action are taken seriously by the facilitators, the invitations offered with sincere expectation for participation. In fact, the success of the activity depends on collaboration, and so participation is understood to be of meaningful importance. Participants are therefore helped to believe that they matter at least in this particular way on this particular day.

The collaboration that is facilitated during these group activities shifts the role of the person with dementia from audience member to co-creator and performer. The kinds of contributions that can be expected from participants include vocalization and verbal content in general, improvisation, affective expression, rhythmic sound, lyrical song, narrative text, bodily movement, social interaction, reminiscence, and active listening, to name a few. We see a common theme in the Alzheimer's Poetry Project, Song Writing Works and TimeSlips in the use of asking open-ended questions around a theme to collaborate with the participants to create poems, song lyrics and stories. In specific, TimeSlips uses for inspiration and theme a photograph about which the facilitator asks a series of open-ended questions and writes down the group's answers to create the text of the story. For example, one photograph shows a baby in a doctor's bag. A section of the story created on December 8th, 2011 by Rose Villa reads, "This is a prize. This boy is a schemer; you can just tell from the expression of his eyes, he's got something cooking. Somebody put him in the bag. Maybe the bag was turned over and the baby just walked in" ("Story: The Baby in the Bag" 2019). Validation occurs when participants' contributions change the event or the artistic product.

People with dementia may feel empowered by contributing or observing the contributions of others during these activities and honored to be considered capable of making meaningful contributions. The positive, validating affirmation described here flows from facilitator to participant, from participant to participant, and from participant to facilitator, and at times to and from those family members and staff who are observing the programs. In addition, facilitators themselves may experience validation as skillful providers of the intervention as well as co-creators of the artistic product that is joyfully performed at the end of the session. Peers and other observers witness this impact and therefore experience the implicit validation of all contributors and potential contributors. Validating personhood and capacity in these ways helps to counter the experiences of dementia that are so often associated with role restriction, passive dependence, and the marginalizing assignment into the categories of *residents* or *patients* in a healthcare facility. Importantly, the mutual validation among all collaborators

seemingly reinforces a social environment in which all parties are on equal terms in their capacity to contribute both content and affirmations of others, an achievement which likely allows for shared experiences of inter-subjectivity.

4.2 Validation through Connection

Participatory arts programs are collective as well as collaborative. Interactions during these activities foster key human validations, including learning one another's names and using social skills to interact with peers. Participants may be more likely to talk and interact with peers after the activity. Thus, participants validate one another both during and after the activity.

Connections are fostered through the facilitators' behavior, engagement, and purposeful use of self. During the activity, facilitators are witnessing interactions, listening to participants, and responding to words, emotions, and gestures. They are clearly, and without question, paying attention to the person with dementia. Facilitators also build upon the contributions of participants and purposefully connect to participants' experiences and preferences. This may include shaping the content to touch on topics that are culturally or even geographically relevant, so that the subject matter resonates somehow with the participants. The facilitator tries to draw out enough information from every participant, especially those who are not extroverts, to achieve this goal.

In *Kairos Alive!* we see an example of this in their Intergenerational Dance Hall™ programs. The programs bring together people of all ages, family members and the general community to dance with people living with dementia. Participants are encouraged to talk about their experience with dance and tell stories of that experience. In one session held in Washington DC a person talked about their experience of watching the dance show, "Soul Train," when they were growing up. The facilitators then led the group to form the familiar Soul Train "line," in which all the dancers form two lines with a space in the middle for dancers to strut down and dance in consecutive order. In this example we saw the participants boogie down the middle, some in wheelchairs, and buoyed by shouts of encouragement and validation. Both the facilitators and participants experience the validation of the co-created dance among cheers of the collective group. The validation of personal stories also gives honor to participants, who may want to know that their stories make a difference.

Families hunger for techniques to build bridges to their loved one. These activities stimulate memory functions involved in recall and recognition and offer glimpses into the inner thoughts of people with neurocognitive disorder who struggle to express themselves. The interventionists use the themes of the artistic project to elicit discussion. The act of engaging people in discussion around the art allows validation through the simple act of caring about participants' opinions. The facilitator may repeat back the words of participants to let them know they have been heard and to offer praise for interesting ideas and points of view or for the way the person phrased the ideas. Over time, some participants learn the routines of the activity, recognize the facilitator, and understand how to respond to cues during the activity. Even during single activity sessions, participants seem to improve in their ability to respond with longer and longer phrases during call and response. Such observations support the theory that

these activities stimulate several memory functions, including echoic, sensory, procedural, episodic, and semantic memory functions (Glazner & Kaplan, 2018).

The focus of engagement during participatory arts activities is not on autobiographical reminiscence, but on presence and participation. Even if autobiographical reminiscences are inaccurate, it is likely that the experience of sharing personal stories supports feelings of continuity or maintenance of self. When people with dementia offer stories about their past or present lives, the accuracy of the contribution is irrelevant. Responding to each contribution offered throughout the activity honors these stories at face value. Thus, all contributions are deemed successful, and the response of the facilitator conveys this powerful validation.

4.3 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.

Communication techniques employed by facilitators during participatory arts activities are purposefully affirming. Appropriate methods of interacting with persons with dementia are modeled for participants and observers, including kneeling and leaning in to overcome hearing impairments. Additional communication techniques useful in establishing a caring and empathetic environment include using vocal tone to match the emotional state of the person with dementia, maintaining eye contact, mimicking movements to nonverbally demonstrate understanding, allowing for the use of ambiguous or vague pronouns, and avoiding any discussion of the veracity of statements (Benjamin, 1995). Physical touch during the activity offers another essential form of human socialization, which validates the person's humanity and helps to counter the "othering" which inevitably occurs in industrial healthcare settings.

In the Alzheimer's Poetry Project, one technique is to ask permission to hold the person's hand and explain you are going to move their hand to the rhythm of the recited poem. This opens the possibility of using teasing and flirtation to engage the participants. For example, with a male participant the facilitator may comically lower their voice, to mimic hyper masculinity and couple this with giving the person an exaggerated handshake and saying lines of a poem such as from Wordsworth's poem "Daffodils," "...Then my heart with pleasure fills and dances with the daffodils." The facilitator may add humor by rephrasing the line, "...Then my heart with pleasure fills and dances with the Buffalo Bills." The setup of using repetition and call and response for a participatory performance and then the surprise of the humorous word substitution often evokes laughter in the group. Another example is when a male facilitator kneels before a female participant and says, "May I ask you a question please?"

The woman will respond with, “Well you can ask, but I’m not going to marry you!” Again, this setup evokes group laughter. These anecdotes serve as brief descriptions of how communicative validation may play out in the sessions and reinforce how both the facilitators and participants may benefit from communication through touch and humor.

Facilitators also utilize verbatim copying of participants’ movements, words, and phrases. This replication of participant contributions is validating because it acknowledges the witnessing of participants’ gestures and articulations. Observers are also helped to see the importance of the stories and thoughts of people with dementia. 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 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 inflections 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 the various recitations offer not only the group leader the opportunity to praise the reciter, but for the other participants to offer their encouragement and praise as well. Participants are being heard and are hearing their fellow participants.

The unique social setting of these activity programs helps to nurture better communication within the larger context. For example, facilitators demonstrate the large amount of time that can be spent eliciting engagement from people with dementia, and peers and observers may learn that such investments are necessary for establishing interactive transactions with people who struggle with aphasia. These activities are models of the enactment of the person-centered philosophy which undergirds appropriate dementia care. Yet, these activities are community-centered as well as person-centered. The programs are designed to create a context for community building. Observers, including family members of individuals with dementia, begin to form relationships, leading to supportive communities where interactions carry out beyond the boundaries of the facility. Thus, community-building occurs within the participant group and the observer group, but across groups as well.

4.4 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 activities are humanizing, which is restorative in the face of dementia. Using remaining intellectual abilities likely creates feelings of competence and validates a person’s sense of self-efficacy and is therefore likely to boost self-esteem. The use of imagination draws upon each person’s individuality. Imagination is one of the most individualizing aspects of cognition. Whereas many people may come to similar conclusions when confronting a challenge of deduction, the act of induction or imagination is achieved through the discrete experiences, thoughts, and feelings of the individual. Eliciting imaginative contributions

celebrates this diverse creativity in a failure-free environment.

The production and completion of the artistic product in each activity is another source of validation. In Song Writing Works, the *WWII Homecoming Song* tells of the bond between twin brothers who served in and survived the war together. The song ends, “The big day is when the ship comes home/ We wait on the dock to meet the ship/ Family together, Celebrating/ Home on the front porch – Big orange soda/ and some moonshine/ Aaaah.../Home Again/ Hallelujah Hallelujah Hallelujah” (“World War II Homecoming Song,” 2019). This song was created “during a songwriting workshop with more than 30 elders and their loved ones and care partners at Dungeness Courte Memory Care community in Sequim, WA. When four veterans of World War II shared their stories of service in the Marines, the group began to compose a stirring anthem both from the perspective of the veterans returning home and the families who greeted them” (“World War II Homecoming Song,” 2019). As with this example, 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.

4.4.1 Alzheimer’s Poetry Project Example

Poet Gary Glazner and the poets of the New York Memory Center created this poem on January 25, 2018 during a workshop of the Alzheimer’s Poetry Project. The inspiration was, “To a Mouse,” by Roberts Burns. We created this poem by collecting participant responses to open-ended questions. For example, “What would the mouse say to the farmer,” gave us our first line. We asked, “What would the house look like?” and the answers generated the powerful poetic image of the house “made of straw, shaped of cupped hands.”

Shaped of Cupped Hands

You ruined my house.

You have to buy me another house.

Made of straw.

Shaped of cupped hands.

A large cup.

With munchies inside.

Lentil soup.

Tomato soup.

You can go inside and have
some breakfast.
The mouse teaches us survival.
I don't need a house!

I would like a tiny suit and baseball cap.
I like any kind of cheese,
whatever you can find.
Munster with Pinot Noir!

4.5 Validation through Confirmation

People with dementia are often doubtful about the appropriateness of their thoughts, behaviors, and belongingness in any given setting or group. Disorientation and short-term memory limitations make it nearly impossible for many people with dementia to have confidence that they are in *the right place*, doing *the right thing*. One participant said after a poetry session, "To me, and I think to many people, poetry brings out the best in us. For people like us with Alzheimer's, we get nervous, and poetry helps calm us. You ask us to do things." 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.

5. Discussion

The authors propose a framework which situates validation as a common method to be used within arts-based interventions, with validation opportunities built into the design of the interventions and transmitted through collaboration, connection, communication, creation, and confirmation. The resulting experiences seem to offer direct benefits for participants as well as indirect benefits when modeled in the presence of formal care providers and family members, although the relationship between validation approaches and outcomes has not yet been tested. We suspect that improved interactions resulting from validation techniques also allow care partners to believe they have provided a worthwhile contribution to boosting quality of life. The potential outcomes of such validation likely include: empowerment and bolstered self-esteem among participants; the expression of participants'

memories, thoughts and feelings; positive social interactions; and the artistic product itself. However, it is appropriate to test if validation occurs as intended and if these desirable outcomes are realized.

The observations reported here suggest that clinicians and artist-interventionists should be encouraged to consider the potential value in seeking to understand, use, and teach these and other validation-focused interventions with those facing disorders of dementia or engaged in their care. Suggested practices to be implemented as drawn from The Alzheimer's Poetry Project, TimeSlips, Songwriting Works, and Kairos Alive! include the use of "call and response" to engage participants in verbal performance and the use of asking participants open-ended questions around a theme and writing down their answers to create poems, song lyrics and stories. In addition, we suggest including dance and movement as exemplified by Kairos Alive!

Equipping family members and care providers with methods for engaging the inner world of the person with dementia provides techniques which may succeed in reducing stress during conversations, potentially leading to more frequent and comfortable interactions and family visits. Similarly, formal and informal caregivers may be assumed to gain knowledge and skills by witnessing these activities and these newly acquired or reinforced attitudes and communication skills among caregivers could be of benefit to their care recipients/partners. Modelling methods for interaction which communicate beliefs in the emotional intelligence, creative capacity, and inherent personhood of individuals with dementia, as well as effective communication techniques to compensate for the impairments caused by neurocognitive disorder, likely leads to distal validating experiences when family members and formal care providers adopt similar attitudes and behaviors. These assumptions should also be carefully examined and explored through research.

During the Alzheimer's Poetry Program workshop at the New York Memory Center, described above, participants celebrated the Robert Burn's poem "To a Mouse," the final stanza of which praises the mouse for living in the moment without past regrets or future fears. "*Still, thou art blest, compar'd wi' me! The present only toucheth thee.*" The poets in the Memory Center responded in verse, writing, "*The mouse teaches us survival. I don't need a house!*" While captured during moments of spontaneity and joy, the lines of the new poem offer powerful subtext, as is often the case during these interventions. The facilitator typically becomes aware of such subtext. While it is unlikely that the poets of the Memory Center would be able to be articulate, if asked about the connections between the themes from Burn's poem and their experiences of living with memory loss, we often find this type of subtext to creating poems, song lyrics and stories with people living with memory loss. This phenomenon warrants further study. In this example of co-creation, we see that the group's spontaneous responses to open-ended questions include the poetic image highlighting that survival does not depend upon something so physical as shelter, it necessitates something more. We propose that the survival of persons with dementia requires that which allows all persons to thrive—roles with purpose and meaningful experiences.

The activities in residential care environments are predominately centered on care tasks. Invitations for

residents' spontaneity and creativity are an important counterbalance to the institutional and medical demands in such environments. The social and recreational activities programs that can be introduced to supplement formal care services as nonpharmacological interventions are intended to meet the emotional needs of people with dementia. Such interventions comprise a compendium of dementia treatments with great potential for positive benefits. As activity programs based in creative arts help to support self-expression among participants and serve as a vehicle for generating feelings of self-efficacy, such activities are well suited to fostering the person-centered goals of dementia care programming. The intervention programs discussed here are designed to inspire, connect, and validate people living with dementia. These participatory arts programs offer tools for connecting to personhood in a population for whom such connections are under constant threat of erosion.

References

- American Health Care Association. (2011). *Nursing Facility Patient Characteristics Report*. Table 12: Medical Condition: Mental Status.
- Arrighi, H. M., Neumann, P. J., Lieberburg, I. M., & Townsend, R. J. (2010). Lethality of Alzheimer disease and its impact on nursing home placement. *Alzheimer Disease & Associated Disorders*, 24(1), 90-95. <https://doi.org/10.1097/WAD.0b013e31819fe7d1>
- Arts Council England. (2014). *The Value of Arts and Culture to People and Society, An Evidence Review*. London: Arts Council England. Retrieved from https://www.artscouncil.org.uk/sites/default/files/download-file/The_value_of_arts_and_culture_to_people_and_society_an_evidence_review.pdf
- Basting, A. D. (2001). "God is a talking horse": Dementia and the performance of self. *TDR: The Drama Review*, 45(3), 78-94. Retrieved from <https://www.jstor.org/stable/1146913>
- Benjamin, B. J. (1995). Validation therapy: An intervention for disoriented patients with Alzheimer's disease. *Topics in Language Disorders*, 15(2), 66-74.
- Clare, L., Rowlands, J., Bruce, E., Surr, C., & Downs, M. (2008). The experience of living with dementia in residential care: An interpretative phenomenological analysis. *The Gerontologist*, 48(6), 711-720. <https://doi.org/10.1093/geront/48.6.711>
- Cohen-Mansfield, J., Parpura-Gill, A., & Golander, H. (2005). Salience of self-identity roles in persons with dementia: Differences in perceptions among elderly persons, family members and caregivers. *Social Science & Medicine*, 62, 745-757. <https://doi.org/10.1016/j.socscimed.2005.06.031>
- de Medeiros, K., & Basting, A. (2013). "Shall I compare thee to a dose of Donepezil?": Cultural arts interventions in dementia care research. *The Gerontologist*, 54(3), 344-353. <https://doi.org/10.1093/geront/gnt055>
- Feil, N. (1982). *V/F validation: The Feil method*. Cleveland, OH: Edward Feil Productions.
- France, A. (1894). *Le Jardin d'Épicure* (The Garden of Epicurus). Public Domain.
- Gitlin, L. N., Winter, L. W., Dennis M. P., Hodgson, N., & Hauck, W. W. (2010). A biobehavioral

- home-based intervention and the well-being of patients with dementia and their caregivers. *Journal of the American Medical Association*, 304(9), 983-991. <https://doi.org/10.1001/jama.2010.1253>
- Glazner, G., & Kaplan, D. B. (2018). The Alzheimer's Poetry Project. *The Journal of the American Medical Association*, 320(22), 2294-2295. <https://doi.org/10.1001/jama.2018.16340>
- Honda, Y., Meguro, K., Meguro, M., & Akanuma, K. (2013). Social withdrawal of persons with vascular dementia associated with disturbance of basic daily activities, apathy, and impaired social judgment. *Care Management Journals*, 14, 108-113. <https://doi.org/10.1891/1521-0987.14.2.108>
- Kane, M., & Cook, L. (2013). *Dementia 2013: The hidden voice of loneliness*. London, England: Alzheimer's Society. Retrieved from https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/dementia_2013_the_hidden_voice_of_loneliness.pdf
- Kipper, D. A. (2006). The canon of spontaneity-creativity revisited: The effect of empirical findings. *Journal of Group Psychotherapy Psychodrama & Sociometry*, 59(3), 117-125.
- Kitwood, T. (1997). *Dementia reconsidered. The person comes first*. Buckingham: Open University Press.
- Linehan, M. M. (1993). *Cognitive-Behavioral Treatment of Borderline Personality Disorder*. New York, NY: Guilford Press.
- Litwak, E. (1985). *Helping the elderly: The complementary roles of informal networks and formal systems*. New York: The Guilford Press.
- Luxenberg, J. S. (2000). Clinical issues in the behavioural and psychological symptoms of dementia. *International Journal of Geriatric Psychiatry*, 15, S5-S8. Retrieved from [https://psycnet.apa.org/doi/10.1002/\(SICI\)1099-1166\(200004\)15:1+%3CS5::AID-GPS161%3E3.0.CO;2-H](https://psycnet.apa.org/doi/10.1002/(SICI)1099-1166(200004)15:1+%3CS5::AID-GPS161%3E3.0.CO;2-H)
- Moreno, J. L. (1953). *Who shall survive?* Beacon, NY: Beacon Press.
- Parker, J. (2001). Interrogating person-centered dementia care in social work and social care practice. *Journal of Social Work*, 1(3), 329-345. <https://doi.org/10.1177/146801730100100306>
- Petrescu, I., MacFarlane, K., & Ranzijn, R. (2014). Psychological effects of poetry workshops with people with early stage dementia: An exploratory study. *Dementia*, 13(2), 207-215. <https://doi.org/10.1177/1471301212456279>
- Ronch, J. L. (2003). Caring for people with Alzheimer's disease and related dementias: Strengths-based approaches. In Ronch, J. L., & Goldfield, J. A. (Eds.), *Mental wellness in aging: Strengths-based approaches* (pp. 315-342). Baltimore: Health Professions Press, Inc.
- Snowden, J., Bathgate, D., Varma, A., Blackshaw, A., Gibbons, Z., & Neary, D. (2001). Distinct behavioral profiles in frontotemporal dementia and semantic dementia. *Journal of Neurology, Neurosurgery & Psychiatry*, 70, 323-332. <https://doi.org/10.1136/jnnp.70.3.323>
- Story: *The Baby in the Bag*. (n.d.). Retrieved from <https://www.timeslips.org/stories/7818>

- Testad, I., Corbett, A., Aarsland, D., Lexow, K. O., Fossey, J., Woods, B., & Ballard, C. (2014). The value of personalized psychosocial interventions to address behavioral and psychological symptoms in people with dementia living in care home settings: A systematic review. *International psychogeriatrics*, 26, 1083-1098. <https://doi.org/10.1017/S1041610214000131>
- Thompson, R. (2015). Transforming dementia care in acute hospitals. *Nursing Standard* (2014+), 30(3), 43-48. <https://doi.org/10.7748/ns.30.3.43.e9794>
- Vikström, S., Josephsson, S., Stigsdotter-Neely, A., & Nygård, L. (2008). Engagement in activities: Experiences of persons with dementia and their caregiving spouses. *Dementia*, 7(2), 251-270. <https://doi.org/10.1177/147130120809116>
- Weiss, J. S. (1984). *Expressive therapies with elders and the disabled: Touching the heart of life*. New York: Haworth Press.
- World War II Homecoming Song*. (n.d.). Retrieved from <http://songwritingworks.org/world-war-2-homecoming-song/>