Rekindling Lost Connections: Using Art Museum Educational Programs to Strengthen Personal and Community Relationships

"The power of a museum educational program is often not seen so readily, but in this docent's account one can see how art-making can greatly improve the quality of life for the PWDs [persons diagnosed with dementia] and their care partners."

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ABSTRACT

Persons diagnosed with dementia (PWDs) or with an intellectual disability are often marginalized by society, as are their care partners (Innes, Archibald, & Murphy, 2004). In the United States, the dementia community is growing due to the aging population and increasing numbers of persons with brain injuries (Hurd, Martorell, & Langa, 2013; Plassman et al., 2011). There is a need to find better ways to enhance the quality of life for PWDs and their care partners, and art museum dementia programs often provide a solution to this need. Prompted by the author's own observations of the Tucson Museum of Art's (TMA) dementia program, this article examines: (1) museum and art education strategies, (2) the use of other disciplinary theories, and (3) how an art museum dementia program positively influenced the lives of the participants. This article supports the following conclusions: (1) Museum dementia programs are strengthening the relationship between PWDs and their care partners, (2) that shared experiences have a positive effect on both, and (3) museums must continue developing effective educational strategies and creative environments for this population.

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Introduction

Dementia, once described as the silent epidemic, is set to become a worldwide problem due to the combination of longevity and the advancement of the baby boomer generation into senectitude (Larson, Yaffe, & Langa, 2013). It is reasonable to assume that many people will eventually be affected by dementia in their lifetimes, either personally, through a friendship, or because they have become care partners. Dementia is not a specific disease, but rather the umbrella term that describes neurological conditions that affect cognition. There are many different types of dementias, Alzheimer's disease being the most common form. Because of the progressive nature of dementia, personal relationships suffer and may become disconnected due to the stress of care giving and behavioral changes in persons diagnosed with dementia (PWDs). Dementia (Rhoads, 2009) can be treated, managed, and slowed in its progression. However, there still is no known cure that either stops or restores cognitive losses. Because of the uncertainty about how rapidly dementia may develop, many care partners are exploring different ways in which to sustain whatever connections remain between themselves and the PWD. One approach is the use of art museum tours in combination with a studio art-making experience for both the PWDs and their care partners.

Creativity and Dementia

The visual arts may be one of the first vehicles used to initiate the awareness of aesthetics, communicate human feelings, and advance the development of culture (Lewis-Williams, 2002). As early as the Paleolithic period, one finds evidence of humans employing visual depictions to express their emotions about events in everyday life. These artifacts signal the emergence of a human cognition that would evolve into fully developed human intelligence (Gretton & ffytche, 2013; Lewis-Williams, 2002.) Creativity, whether to solve a problem in daily life or to satisfy the need for artistic expression, has been recognized as a human characteristic and a way to express the experience of human existence. Hayes and Povey (2011) wrote that "creativity is stimulated by the pulse of life through our veins: by the very fact that we are breathing living beings" (p. 22). Creativity and the expression of one's creativity is an important aspect of living, and it is needed throughout one's lifespan. In addition, creativity and artistic expression play an important part (Hannemann, 2006; Cohen, 2000) in maintaining brain cells, particularly those associated with memory. Artistic expression has positive influences on emotional health; it is known to help manage depression and anxiety, and to combat feelings of isolation. Essentially, creativity promotes an overall sense of well-being.

For PWDs, the sense of healthy well-being (Cohen, 2000) can be difficult to maintain as cognitive control lessens with the progression of dementia. Maintaining the physical health of PWDs often becomes a priority over their emotional needs, causing an imbalance between physical and emotional states. As Hannemann (2006) wrote, "When addressing the longevity of the elders, especially dementia patients, we have to analyze more than the

current needs of food, shelter, and physical health" (p. 62). Art museum programming for PWDs and their care partners creates a sense of connection with community and supports the feelings of well-being for both (Camic, Baker, & Tischler, 2015; Lamar, Luke, Logsdon, & Morrissey, 2015).

The Complex Relationship Between PWDs and Their Care Partners

A better understanding of this relational dynamic could benefit future studies of gallery touring strategies and refine museum education studies for persons living with dementia. To this end, I examined and analyzed data by using different psychological theories and perspectives of grief, loss, and human development by Kübler-Ross and Boss. Boss's theory of ambiguous loss (2002, 2007) specifically addresses the complex feelings of loss when caring for someone with dementia. Care partners for PWDs face a greater challenge than other care partners because the PWD often appears physically healthy yet cannot connect with them emotionally due to their impaired cognition (Rhoads, 2009). Many times, the relationship between the PWDs and their care partners appears to be intact to outside observers, yet the relationship may be undergoing stress due to unusual behaviors brought on by dementia (Boss & Couden, 2002).   Accrued knowledge of the dynamic between the two would provide the art and museum educators with a better understanding of the behaviors displayed by either the PWD, care partner, or both. This point is supported by the investigation of PWDs and their care partners as participants in art museum dementia programs. Lamar, et al. (2015) stated,

> It is also imperative that the museum staff be properly trained in assessing the PWD's reluctance and aiding the CP in their participation. They should have training from an organization that is well versed in dementia and dementia related behaviors. (p. 40)

The knowledge of theories surrounding ambiguous loss and grieving would help museum and art educators understand what PWDs and their care partners are experiencing in their lives.

Museum Educational Programming and Dementia

One of the first art museums to provide museum education for PWDs was the Museum of Modern Art (MoMA) in New York City. However, it was not until 2006 that MoMA established its "Meet Me at the MoMA" program for PWDs and their care partners, in collaboration with museum educators and experts in the field of Alzheimer's disease. This decision led to a nationwide awareness that prompted art museums to establish their own programs for PWDs.

Several museums have created their own educational and studio programs for PWDs using MoMA's work as a reference point, launching several dementia programs throughout the country: for example, the SEPIA and Memories at the Museum Alzheimer's programs at the Museum of Photographic Arts in San Diego, California; the "here:now" program at the

Frye Art Museum in Seattle, Washington; and the Memories in the Making program at the Tucson Museum of Art in Tucson, Arizona. There are also many variations of programming for PWDs, which often include storytelling, poetry reading, music, and dance. Another development has been the growth of community collaborations between the museums, local arts organizations, and healthcare institutions. For example, the Phoenix Art Museum's Arts Engagement Program is a partnership between the museum, Banner Alzheimer's Institute, and Maricopa Partnership for Art and Culture. The program is based on the work of the Alzheimer's Project at MoMA. Since the advent of that project, there has been a progressive interest in art museums presenting dementia programs, which vary depending on the community the museum serves and the resources that can be found.

Methodology of the Study

This investigation sought to understand how dementia programming in art museums influenced the lives of the PWDs and their care partners by gathering and analyzing observations on their actions and responses while viewing and making art. The study differs from other investigations in that it examines the relationship between PWDs and their care partners through semi-structured interviews, which included care partners, art and museum educators, museum professionals, and dementia experts.

The Present Study

I chose to conduct a qualitative, single case study at the Tucson Museum of Art's (TMA) "Memories in the Making" program" (MIM). In the second year of my graduate studies at the University of Arizona, I accepted a unique internship that allowed me to participate in the MIM program and observe how it operated through a yearlong cycle. This internship also gave me the opportunity to form relationships with the staff of the Desert Southwest Chapter—Alzheimer's Association and the MIM participants, which later allowed me to conduct interviews for this study in greater depth than would have been possible otherwise.

TMA's MIM Program

The TMA and the Desert Southwest Chapter of the Alzheimer's Association formulated their own version of a museum dementia program in the early 2000s. This relationship was formed with the goal of running a seasonal program that would be facilitated by members of the museum's educational staff and populated through the membership of the Desert Southwest Chapter. It would be known to the Tucson community as "Memories in the Making," a museum educational program designed specifically for members of the dementia community. TMA asked that its docents work with the local Alzheimer's chapter to provide and expand the program content. The docents used the existing curriculum but added three new elements: (a) a trained docent to work with PWDs and their care partners, (b) the inclusion of care partners in all activities, and (c) an artist/educator trained in working with people with intellectual disabilities, who would be responsible for studio art-making activities. These additional elements provided by the

docents set the TMA's program apart from other museum dementia programs that did not require dementia training.

Participants

I sorted the participants by their roles in the MIM program: (a) museum professionals, (b) artist/educators, (c) dementia experts, and (d) MIM participants. I chose not to interview PWDs because of the unpredictability of their cognitions and because I felt that care partners, museum professionals, and artist/educators would be a more reliable source of information. I believe that my prior contact with the participants helped me establish a connection and a level of comfort that encouraged them to disclose deeper and more personal insights about their experiences. The University of Arizona Institutional Review Board approved my research investigation in May 2017 and included the approval criteria for all participant selection, information used for recruitment, semi-structured interview questions that would be posed to the various participants, and consent forms. All participants volunteered to be interviewed, and no form of compensation was given to them. Any data that were collected have been stored in a secured location in accordance with the IRB's directive.

In addition, my professional ethics as a licensed professional counselor in the State of Arizona guided my questions and the way I approached each participant. The design of the investigation reduced the risk of any harm or danger to the participants in the study. If the participants felt that they would prefer to stop or withdraw from participating, they could do so at any time, but none of them opted to do so during this investigation. Demographic information about the participants can be found in Table 1.

Table 1. Participant Information

Participant	Sex	Age	Ethnicity	Education PhD=Doctorate M=Masters B=Bachelors	Role	Time/Place
01	F	30-40	White	M/PhD	Museum Educator	120 min/ business office
02	F	30-40	White	M	Artist/Educator	57 min/restaurant
03	F	50+	White	M	Artist/Educator	90 min/studio
04	F	50+	White	M	Artist/Educator	120 min/home
05	F	60+	White	M	Docent Educator	240 min/home
06	M	30-40	White	M	Dementia Expert	105 min/office

Table 1 (continued).

07	F	60+	White	M		Care Partner	58 min/restaurant
08	F	60+	White	B		Care Partner	45 min/restaurant
09	F	60+	White	M		Care Partner	90 min/office
010	M	60+	White	M		Care Partner	60 min/coffee shop
011	F	60+	White			Care Partner	90 min/home

Procedure

I contacted study participants by email, phone, or in person so that I could fully explain the research project. I also gave them an informational sheet with more details about the investigation, along with a copy of the consent form. They were able to review all the materials, including the interview questions that I would be asking, ahead of time. They were given at least two weeks to reflect on how to respond to my questions. The interviews were scheduled for 60 minutes, but the average interview time was 98 minutes. Interviews were conducted at locations where the participants felt most comfortable in discussing information that was personal and potentially sensitive. Many of the participants chose to be interviewed at a coffee shop or restaurant. The other interviews were conducted at participants' homes and business offices, and at my office. To ensure as much anonymity as possible, I used numbers to conceal the identities of the participants.

Data Collection

I interviewed and audio recorded 11 individuals, who participated voluntarily and were associated with the TMA's MIM program. The interviews were recorded in their entirety using a digital recorder and were then professionally transcribed verbatim. I took great care not to disclose any identifying information to the transcriber. Once I received the transcribed interviews, I performed an initial review to begin the data coding and analysis. I continued to review the data for a total of 12 times to formulate a framework or approach to the data analysis. Table 2 shows the type of data, sources, and details of the data that I collected.

Table 2. Different Types of Data Collected

Type of Data	Sources	Specific Info
Interviews	11 participants	1 Museum Education Curator 1 Docent Educator 1 Dementia Expert 3 Artist/Educators 5 Care Partners

Table 2 (continued).

Art Pieces	MIM program and Alzheimer's Chapter Personal Pieces from the collection of PWDs and care partners	Unidentified participants' work—combination of works from both PWDs and care partners
Program Collaterals	Alzheimer's Chapter and TMA Training Docent	Programming Information Training Curriculum

Data Analysis

Early in the process of data collection, I discovered that it was difficult to separate and maintain various emerging themes and their patterns. This issue was addressed by Vasimoradi, Turunen, and Bondas (2013) in an article reflecting their experience with the data analysis process. They wrote that "like other qualitative methods gathering and analyzing data are conducted concurrently in descriptive qualitative approaches, thus adding to the depth and quality of data analysis" (p. 401). This led me to create coding systems that would allow the voice of each participant to be heard.

During the first pass through the data, I highlighted instances where the voice of the interviewee was distinctive in describing their encounters with dementia. As this progressed, I found that other patterns were emerging, so I coupled the highlighting with descriptive coding, which further helped me organize the data into topics or themes.

Later, as I reviewed the data from the first interviews, I realized that I needed to go further to refine my coding system, so I used, NVivo, a qualitative data analysis software program, to help me organize the data so that they could be effectively analyzed. I also incorporated a coding system that would assist me in preserving the voice of the participant by using a process called verbal exchange coding, devised by H. Lloyd Goodall (2000).

Goodall (2000) outlined a coding approach that departs from the traditional coding systems found in qualitative research. Verbal exchange coding uses verbatim transcripts of the conversations with the interviewees. Goodall starts by determining the category of the conversation and then follows with a reflective review of the exchange. These notations (either reflective or analytical) are written directly into the transcription. The transcriptions should include all forms of communication as well as stops and starts, facial cues, and nonverbal cues. Goodall then utilizes one of the five forms of verbal exchanges, which are as follows: (a) phatic communion or ritual interaction, which typically appears in the form associated with societal patterns of communication; (b) ordinary conversation, which focuses more on demographic information; (c) skilled conversation, a focused type of conversation with the intent of using information in a pragmatic manner; (d) personal narratives that disclose information or episodes that were meaningful in the person's life; and (e) dialog that is a higher form of an exchange and that reflects a personal and deeper connection between the interviewer and interviewee. Saldaña (2016) stated that "Goodall advocates a more holistic and truly interpretive approach to the data. . . . His methods are applicable to both transcribed dialogic exchanges or preexisting fictional and non-fictional texts" (p. 36). In my investigation, I compared my notes taken during the interviews with the

notes made during the first pass through the transcribed interviews. Then those comments that I had noted, either during or right after the interview, were entered into a table under the various themes that emerged.

Reliability of the Study

Andrew Shenton (2004) discusses the need to use the highest forms of analytical rigor possible to avoid criticism about reliability in qualitative research. He expands E.G. Guba's work by discussing, in depth, four ways in which a researcher can establish trustworthiness. They are credibility, transferability, dependability, and confirmability. For this study, I established credibility by using sound research approaches. I started with a constructivist paradigm as the foundation of the design and used case study approaches to collect my data. In addition, I reviewed my findings with experts in the fields of museum education and mental health. My background as a licensed behavioral health professional added another layer of credibility to this study since I have had training and cases that involved brain trauma and dementia. The issue of transferability is addressed in the descriptions of each interview and can be found in field notes and weekly research log summaries. I reviewed my data to compare them against well-known models in dementia and museum education in order to ensure their dependability. Finally, I addressed confirmability by describing in depth, in my weekly analytical memos, any research design changes that occurred or updates that I noted.

Yin (1994) recommended that all case study designs should embrace approaches that would ensure the reliability of the analysis. He suggested the use of a four-test strategy to establish reliability: construct validity (established by triangulation of multiple sources of evidence and member checking), internal validity (the use of traditional analytic tools), external validity or analytic generalization, and reliability of the design on which the research is based. In contrast to Yin's framework for establishing reliability, Stake (2005, 2008) had a different perspective on how these issues should be addressed. He offered an umbrella term he called *triangulation*, which uses four strategies: data source triangulation (the cross checking of all sources), investigator triangulation (using multiple investigators,) theory triangulation (the use of two or more theories that would explain the uniqueness of the case), and methodological triangulation (using multiple methods such as observations, questionnaires, and interviews to gather data) (Stake, 2005, 2008). Even with these designs and investigative approaches in case study research, there is not a defined framework for testing that researchers can use to determine the reliability of the study.

Impact of Reconnection Through Participation

The primary purpose of this study was to examine the impact that museum gallery touring and art-making had in strengthening the relational connection between PWDs and their care partners. This purpose was fulfilled by means of information gathered from the perspectives of care partners, museum professionals, and artist/educators.

In the following excerpt, the wife of a PWD reveals how the dementia program affected her life with her husband:

Interviewer: What was the dementia program experience like for you?

Care Partner I: Well, it was wonderful. My husband loved the tours. He listened, and he enjoyed them very much.

Interviewer: Were you able to discuss anything related to what the docent brought out, maybe converse a bit about it afterwards?

Care Partner I: On the way home he would say, "I really had a good time today" or something to that effect. I really liked it.

Interviewer: Okay, but what did you like?

Care Partner I: Well, one thing was being able to get out away from home and sort of socializing with other people—being with other people who understood what was going on. I would try to work with my husband, and sometimes we worked together but sometimes we didn't.

Interview: Did you keep any of the things that you both worked on together?

Care Partner I: Yes, I did. I kept them even after he had passed because they mean a great deal to me. (Care Partner I, Personal Communication, November 11, 2017).

While in this case the experience for the PWD and the care partner was not always completely successful, in the end, however, the encounters were positive and formed a lasting and meaningful memory for the care partner.

For another care partner, the dementia program gave him the ability to work out his own connection with creativity and art while concurrently connecting to his wife, who was in the middle stages of dementia. In the following excerpt, he talks about how attending the program helped him find a creative side, relax with his wife, and make connections with other participants that were meaningful.

Interviewer: What was that experience like, being in the studio with your wife?

Care Partner II: I actually like doing stuff with the clay and painting with watercolors. You know, interestingly enough I got into my stuff and I noticed that I wasn't paying a lot of attention to what my wife was doing. I mean I wasn't a caregiver at that point. I knew she was in good company being cared for by good folks. And I didn't feel like I had to be on duty. I had my piece of art to figure out and that was okay.

Interviewer: What about making relationships with other participants?

Care Partner II: We did find ourselves building relationships and that was probably as important as the art thing itself. It was getting to know some people that kind of became regulars and it was good to see them—the sense of community was good.

Interviewer: What about your wife's experience?

Care Partner II: She did really good stuff in the studio even though it was hard for her more and more to complete the task. But earlier on she was great. In fact, they gave her an award at this annual thing at the last Alzheimer's conference. (Care Partner II, Personal Communication, November 30, 2018)

The lives of many PWDs, and those who care for them, become increasingly difficult due to social isolation. Moreover, people often assume that creativity is no longer possible in dementia. Museum programming for those with dementia destroys this assumption and mitigates social isolation by providing an opportunity to experience once again the joy of art-making and the company of others.

Another perspective comes from an interview with the docent in charge of training other docents to conduct the MIM gallery tours. In this short excerpt she discusses the impact that the program had on the relationships of the participants.

Interviewer: How do you feel that the dementia program affected the participants' lives?
Training Docent: Well, I can tell you what was most gratifying and what I focused on week-to-week were those positive changes happening between the couples. It started out in the studio when we, as a group, were just relaxing doing something fun together with the art materials. No one had to be concerned about what the final product was, so there was a sense of freedom. It was also fun for them because they were able to start to connect with others who were sharing the same experience in managing dementia—this allowed them to make friends sometimes outside of the program.

Interviewer: How did this impact the care partner from your perspective?

Training Docent: Keep in mind that Alzheimer's is the type of disease that is very isolating not only for the PWD but also for the caregiver. There isn't really any opportunity to relax or to have fun or connect for either. I know because the couples would tell me at sessions that they were socializing outside of the program, which was so really great to see those developments! Spouses were finding people who were in the same situation as themselves, and it allowed them to relax so they didn't have to worry so much about the behaviors of their loved one when together, either in the program or outside of the program; it made their lives a little bit easier. (Training Docent, Personal Communication, January 21, 2018)

The power of a museum educational program is often not seen so readily, but in this docent's account one can see how art-making can greatly improve the quality of life for the PWDs and their care partners.

From the perspective of the artist/educator, the TMA dementia program presented another type of opportunity to connect through art. In the following excerpt, one of the artist/educators at TMA recalls a specific case:

Interviewer: Were there any examples you were able to observe where there were positive changes for the participants in the studio?

Artist/Educator I: Well, yes. There was one man, I don't remember his name, but he came with his wife, and he used to be a jeweler years ago and they were from Italy. They loved being in the studio. Yes, so people in the group didn't know him as a jeweler. And I think he had kind of forgotten that connection in his life or that he could be creative now that he had Alzheimer's.

Interviewer: What happened when he got into the studio?

Artist/Educator I: Well, in the studio he got really focused on just drawing. He completely rejected anything that we were doing as a group. He didn't want to do anything that involved color, he didn't want to do this, he didn't want to do that, he just wanted to draw. That happens sometimes with this population. But it was exciting to see the person express himself in a creative way. Sometimes his wife and I would talk about how excited he got working on his pieces. They were fabulous—it was fantastic to watch, you know. His wife said that it made her happy to see him engaged, still active in his mind, and able to produce and create like he did prior to his dementia. She said for that brief time, she had her husband back. (Artist/Educator I, Personal Communication, November 21, 2018)

The museum and studio experience ask nothing more of the PWDs and their care partners than to be in the moment, either experiencing or creating with one another.

Conclusion

This study found that art museum dementia programs provide several important benefits to both PWDs and their care partners. The first finding is that participation in such a program gives the PWDs and their care partners the opportunity to re-establish a lost relational connection. By fostering an experience that is not dependent on memory or skill, but rather on engaging in gallery touring and art-making, the programs provide the opportunity for PWDs and their care partners to come together as equals. The participants in the present study reported an increase of emotional connection, which was important for their emotional health. This benefit is often overlooked, as reported in the research conducted by Hannemann (2006) and Cohen (2000).

In addition, this shared involvement alleviates the sense of ambiguous loss, as described by Boss, which care partners often experience. Such loss is felt by care partners because, while physically present, the PWD is often emotionally and psychologically absent. To bridge that gap, art museums are employing strategies, such as inclusive touring led by docents trained to work with PWDs, to further the participation of the PWDs and their care partners, thereby strengthening and nurturing the reconnection between them. In a wider sense, these shared museum and studio experiences help to create a bond among all the participants, resulting in the formation of community—something that is typically missing from the lives of PWDs.

Implications for Further Study

Museum and art educators are challenged to find additional ways to expand the curriculum for PWDs and their care partners. A further study could examine how to include more effectively all stages of Alzheimer's and other dementia-related conditions. Researchers also need to ask, and seek answers to questions such as: How effective are traditional art education approaches to teaching those with dementia? If these are not effective, can better approaches be created for use in the classroom and studio? Do art and museum educators need to create new approaches to ensure that care partners' needs are being addressed and met in their programming?

More research and development is also needed to (a) provide better education about dementia for art educators and museum professionals, (b) recognize the need for continuous improvement of museum dementia programming, and (c) encourage increased perseverance in assuring that inclusion is sustained in museums for PWDs and their care partners. Also, there should be much more consideration of larger and more comprehensive programs for PWDs—specifically, museum dementia programming for those in the latter stages of dementia or Alzheimer's disease.

At present, there is no cure for most types of dementia, so as the PWD population grows, it will be even more important that museum and art educators respond by creating programming that supports PWDs and their care partners reconnecting and rekindling personal and community relationships.

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