

Impacts of Art Museum-Based Dementia Programming  
on the Participating Care Partners

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## Dedication & Acknowledgements

For all the care partners who provide for those with dementia.

I would like to thank Mary Jane Knecht, for being my friend and mentor in the world of dementia programming. In addition, I would like to thank Jessica Luke, who has been my fabulous guide through the entire thesis process. I would also like to thank my sister, Angela, for being my editor throughout graduate school, and my mother for her endless support. And thank you to the staff of the Dallas Museum of Art, the Detroit Institute of Arts and the Frye Art Museum for their enthusiasm and participation in my research. Finally, I would like to thank the rest of my family and friends for their support, advice and stress relief.

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## ABSTRACT

### Impacts of Art Museum-based Dementia Programming on the Participating Care Partners

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The purpose of this study was to describe the impacts of art museum-based dementia programming on participating care partners (CPs). Data were collected through telephone interviews with 29 caregivers who participated in one of three dementia programs: *here: now* at The Frye Art Museum, Seattle; *Meaningful Moments* at the Dallas Museum of Art, Texas; and *Minds on Art* at the Detroit Institute of the Arts, Michigan. Care partners reported that the program afforded them multiple benefits for their well-being, including stress relief and reduced feelings of social isolation. Care partners also reported positive impacts on their relationship with the person with dementia, as they saw this person as more capable, functioning in new ways, and enjoying the art. Results suggest the value of programs such as these within the growing population affected by dementia.

*Keywords:* Dementia, Alzheimer's Disease, Art Museum-Based Dementia  
Programming, Care Partners, Person with Dementia

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## CHAPTER 1: INTRODUCTION

According to the Alzheimer's Association (2014), the number of those afflicted with dementia will increase from 5 million to 16 million by 2050. Most view dementia as a disease when it is more aptly described as a disability (Camp, 2014). The focus should be on what the person with dementia can do, rather than what they cannot do, in order to accommodate their environment accordingly. Viewed as a disability, dementia becomes a community problem, one that can be addressed through multiple and varied programming in community-based organizations, including museums.

The Museum of Modern Art (MoMA) in New York City began a program in 2003 for individuals with dementia and their caregivers. They released their program framework and findings in *The MoMA Alzheimer's Project: Making Art Accessible to People with Dementia*. This guide provided a path for other museums to follow to implement similar programs. These programs are usually restricted to smaller groups during slow or closed hours of the museum so that the environment is calm and welcoming to those with dementia. Typically the program begins with a gallery discussion utilizing Visual Thinking Strategy, an inquiry-based approach that focuses on what participants observe in the painting, rather than art historical facts (Housen, & Yenawine, 2000). The program continues in a studio space with an art-making activity. Now many art museums in the U.S. offer some kind of dementia programming – for example, the Carnegie Museum of Art in Pittsburgh, PA has *In the Moment* and the Museum of Photographic Arts in San Diego, CA has *Memories at the Museum*.

Studies have shown that dementia programming in art museums is beneficial for the person with dementia (PWD), as well as in their relationships with their care partner (CP):

“Challenging activity at inspirational arts venues can re-energize individuals with dementia and their care partners, helping to override stressful symptoms, maximize cognitive function and restore personal esteem, shared interests and the ability to enjoy life in the community” (Gould, 2013, p. 5).

It is known that people’s artistic, imaginative and emotional responses – particularly in Alzheimer’s disease – can remain strong for years after the onset of dementia (Gould, 2013). Within stimulating spaces like museums, there are the chances for memories, conversation and imagination to be aroused.

There is, however, a lack of research on the impact of museum-based dementia programming on participating care partners. The CP is often a spouse or an adult son or daughter, but can also be a professional caregiver. Research has shown that in their roles, CPs can experience stress, financial burden, anxiety and less social engagement and loneliness (Gihooly, 1984). There is good reason to believe that art museum-based dementia programming can play an important role in the life of the CP, in addition to the PWD. These programs can offer a time of reprieve and bonding experiences with the PWD.

## **PURPOSE STATEMENT**

The purpose of this study was to describe the impacts of art museum-based dementia programming on participating care partners. The following research questions guided this study:

1. How do art museum-based dementia programs affect the relationship between care partner (CP) and person with dementia (PWD)?
2. In what ways do art museum-based dementia programs affect the well-being of the care partner (CP)?

## **SIGNIFICANCE**

Five million Americans are living with dementia, which requires five million CPs, whether they are professional caregivers or family members. There is no cure for Alzheimer's disease and other dementias. While there are advances in medicines every day, there are limited medical treatments that can be implemented. Community resources can provide a more meaningful life for both those afflicted and their CPs.

By knowing how these programs positively affect the CPs, we can increase awareness of both the stresses on CPs and the benefits these programs can provide to combat those stresses. Art museums that have dementia programming in place currently can use the results of this research in grant funding opportunities or for arguments towards program expansion. Additionally, results can lead to amendments in current programming to include higher emphasis on areas described as most advantageous to CPs. Museums that do not currently have dementia programming in place can use this research as motive for implementation of their own programming.

## CHAPTER 2: LITERATURE REVIEW

*“Evoked in the museum, individual memories are momentary mirrors; they inspire an instant of reflection and recovery”* (David Carr, 2000, p. 251).

Related research has focused on the effects that art (both viewing and making art) has on those with dementia, as well as on the stress of acting as a care partner (especially in a close relationship such as spouse or son/daughter). This literature review seeks to describe the nature of dementia and the role of care partners, as well as what is known about the effects of visual arts on dementia and how museums are addressing dementia.

### Dementia

Dementia is a general, or “umbrella,” term used to describe diseases that result in a loss of mental ability (Alzheimer’s Association, n.d.). Alzheimer’s disease is the most common type of dementia (Alzheimer’s Association, n.d.). Dementia is an epidemic that affects more than 5 million Americans and is the sixth leading cause of death in the United States, according to the Alzheimer’s Association (n.d.), and that number continues to grow as the American Baby Boomer generation ages. To coincide with those afflicted with the disease there were an estimated 15.5 million caregivers in 2013 alone providing an estimated 17.7 billion hours of unpaid care valued at \$220 billion (Alzheimer’s Association, n.d.).

There is a stigma associated with Alzheimer’s and other types of dementia that causes most to misunderstand the disease and its effects. Individuals with dementia do lose many abilities, including: short term memory, ability to tell time/place/people, language/math/understanding, ability to concentrate, ability to perform familiar tasks, ability to correctly interpret sensory information, ability to control

emotions/mood/impulses and judgment (Alzheimer's Association, 2015). However, they can retain more than most realize, including: memories from long ago, procedural memory, singing/music/rhythm, art, desire to communicate, understanding gestures, and matching like objects (Alzheimer's Association, 2015). Many have argued that it is important to look at dementia as a disability rather than a disease so that you can focus on what the person is capable of doing and modify their environment to accommodate those abilities so that they may still have meaningful experiences (Nuffield Council on Bioethics, 2009; Camp, 2014).

Greg O'Brien, who was diagnosed with early on-set Alzheimer's (a form of Alzheimer's that affects those age 65 and younger), described to National Public Radio what it feels like to have Alzheimer's Disease:

It's like a plug in a loose socket. Think of yourself, wherever you are in the country, and you're sitting down and you want to read a good book, and you're in a nice sofa chair next to a lamp at night. And the lamp starts to blink. You push the plug in and it blinks again and you push the plug in. ... Well, pretty soon you can't put the plug back in again because it's so loose, it won't stay there. And the lights go out forever. (Hersher, n.d.)

### Care Partners

On average, care partners (CPs) provide care for an average of 20 hours per week, though 14% of family care partners provide care for 40 hours or more a week (McCurry & La Fazia, 2015). The CP is frequently a spouse or adult son or daughter, but can also be a healthcare professional. The responsibility of being a CP is a great burden on those performing the role. CP burden is defined by George & Gwyther (1986) as the physical, psychological or emotional, social and financial problems that can be experienced by family members caring for impaired older adults. Chappell & Reid (2002) explain that

burden is a predictor of overall well-being. Well-being is described as including spirituality, health, activity level, social support, resources, satisfaction with personal accomplishments and life situations (Chappell & Reid, 2002).

CPs can feel the weight of their role as both objective and/or subjective burden. Objective burden is the stress that is associated with the physical care of the PWD, such as anxiety, guilt and worry (McConaghy & Caltabiano, 2005). In general, the behavior problems associated with dementia cause the majority of these stressors. Those with dementia are dependent on the CP; they can wander and not know where they are or should be, and they can have sudden mood changes. Gilleard et al. (1982) list these behavior problems as dependency, disturbance, disability, demand and wandering. Gihooley (1984) says "...two aspects of caregiving that are particularly stressful: firstly, the aversive and intolerable behavior of the dementia sufferer, and secondly, the 'daily grind', in which the caregiver experiences no respite from the heavy burden of caregiving."

Subjective burden is the psychological consequences of being a CP, such as fatigue, impaired social interactions, employment conflicts, financial difficulties and family conflicts (McConaghy & Caltabiano, 2005). McConaghy & Caltabiano (2005) argue that those who care for people with dementia spend significantly more hours per week providing care than do non-dementia CPs. Additionally, due to the stigma associated with dementia, the PWD and the CP often have less social interactions and both can feel isolated.

The relationship between the CP and PWD can affect how the CP responds to their role. For example, spouses have reported the greatest degree of physical and

financial strain and were most concerned about the morale of the dementia sufferer (Cantor, 1983). This could be in part due to the fact that spouses are more likely to be co-resident with the PWD and thus more likely to play a greater part in day-to-day caregiving (Morris et al., 1988). Furthermore, women tend to experience more distress and be more emotionally involved in the day-to-day care of the PWD (Morris et al., 1988). Overall, the greater the familial distance between CP and PWD, the better the caregiver's mental health (Cantor, 1983).

Basting and de Medeiros conducted a systematic review of literature on cultural arts interventions in dementia care. They found that studies should not be limited to the PWD, but should include the larger social network (staff, family, CP) due to the group setting these cultural interventions often occur and “the potential for connecting people and improving social environment” (p. 351, 2014).

#### Visual Arts & Dementia

Research shows that dementia will inevitably take away the self-expression of individuals through speaking, writing, and singing (Dowling, 1995). However, a person's artistic and emotional responses can remain strong for years after the onset of dementia (Gould, 2013). Beard found through analyzing the literature that visual arts can create a bridge of non-verbal communication between the PWD and the CP by “enhancing opportunities for reminiscence, providing sensory stimulation and enjoyment, and strengthening the individual's sense of self” (p.639). Parsa (2010), who studied the effects of two art museum dementia programs, adds that while PWDs will lose some memories and facts, it does not mean they have lost the ability to “access creative potential and to engage in meaningful experiences” (p. 219).

For example, Walsh et al. (2011) found that art activities promoted well-being in PWDs through themes that emerged during the process; trusting, thirsting, following, connecting, choosing and reminiscing. Well-being was recorded when illustrated by moments of laughing, talking, creating, smiling, joking, touching and singing during sessions.

Beard (2012) concluded that while studies did report improvement in ratings of pleasure in the PWD and assisted them in “rediscovering obscured abilities and self-worth,” the studies could be made stronger (p. 639). Beard found that studies often lacked consistency in study design and measurement tools, as well as lacked accounts directly from PWD and inclusion of PWD living at home (versus in a nursing facility).

Dr. John Zeisel (2009) states “Art connects people to their culture and to their community. It gives meaning to life and it is meaning that people living with Alzheimer’s so dearly crave” (p.80). Through his art therapy programming at Hearthstone Alzheimer’s Care facilities in Massachusetts and New York, Dr. Zeisel has discovered the different ways that those with dementia/Alzheimer’s can understand visual art:

1. Perceiving and describing – talking about what they see in the artwork
2. Telling a story – narrating the story they see in the painting
3. Linking it to their own lives – describing personal and historical memories
4. Identifying the emotion – naming and expressing the emotions in the artwork
5. Identifying objects that make up the painting – seeing, naming and describing objects

6. Making critical judgments – commenting on moral issues raised in “risqué” artwork (p. 92).

### Museums & Dementia

The American Alliance of Museums (AAM) (2008) outlines the role of museums in their Best Practices by saying that museums should provide programs that “further the museum’s mission and are responsive to the concerns, interests and needs of society, and should be accessible and encourage the widest possible audience consistent with its mission and resources” (p. 26). “Everyone should be able to benefit, as far as is practicable, from the museum’s assets” (p. 22).

The American Alliance of Museums (2013) tells us that “as society has changed, so has the work of museums” (p. 1). AAM continues that “museums play an important role in addressing numerous health issues and the public is warmly embracing – and greatly benefitting from – these initiatives” and that their “service in health care helps them deepen relationships in their community” (p. 11). David Fleming (2014), Director of the National Museums Liverpool and founding member of the Social Justice Alliance for Museums, states that museums are “not the collections but the emotions.” He continues that dementia is the “biggest social issue now” (Fleming, 2014). Parsa continues this idea by saying “Art museums in our time are no longer repositories of artifacts; they are dynamic institutions that position art as a catalyst for navigating one’s relationship with creativity, one’s own life, and the world, in addition to the work itself” (p. 218).

There is no cure for Alzheimer’s disease and other dementias. While there are advances in medicines every day, there are limited medical treatments that can be

implemented. Community resources, such as museums, can provide a more meaningful life for those afflicted, as well as for their CPs, and many have found evidence of the positive impact of these programs. Veronica Gould conducted an evaluation study of Arts 4 Dementia's London Arts Challenge in 2012. Through evaluating 17 weekly projects across a range of art forms and art venues, she found,

Challenging activity at inspirational arts venues can re-energize individuals with dementia and their care partners, helping to override stressful symptoms, maximize cognitive function and restore personal esteem, shared interests and the ability to enjoy life in the community. (Gould, 2013, p. 5)

Research has been done into the benefits of viewing art on well-being. Binnie conducted research at Leicester's New Walk Museum with 22 participants with varying backgrounds in art, from museum staff to frequent art museum visitor to novice (2010). The researcher conducted a semi-structured interview, participants were asked to fill out a mental well being survey and State-Trait Anxiety Inventory. Additionally, eye tracking was conducted while the participant was asked to view an artwork. The eye tracking system is portable equipment that recorded how artworks were visually explored and responded to. Binnie found that "...at least for the museum visiting population, viewing art within a museum does have a positive impact upon anxiety, and thus also well-being" (p. 198). "Museums boost people's quality of life and improve mental and physical health. It is good for well-being to engage closely with collections and ideas in the presence of other people" (Museums Association, 2013, p. 6).

The Museum of Modern Art (MoMA) propelled the awareness of providing dementia programming in museums with the launch of their *Meet Me at MoMA* program in 2006, an educational program specifically for people with Alzheimer's disease

(Rosenburg, 2009). The monthly program “features interactive tours of the Museum’s renowned collection of modern art and special exhibitions for individuals in the early and middle stages of the degenerative disease, along with their family members and caregivers” (p. 1).

New York University School of Medicine was asked by MoMA to conduct a study of *Meet Me at MoMA*, which included joint development with the museum in creating a quality-of-life evaluation (Parsa, et al. 2010). Participants were asked to complete a self-rating quality-of-life scale before and after the participation in the program, take-home evaluations and participate in focus groups that met three months after the program (Parsa, 2010). Researchers report that the “most statistically significant measurement was the change in affect from directly before to immediately following” the program, in which they saw a visible elevation in mood in both the PWD and the CP (p. 225). Additionally, some PWDs reported better self-esteem and CPs reported social connections and reduction in anxiety, depression and irritability (2010).

The subsequent guide, *The MoMA Alzheimer’s Project: Making Art Accessible to People with Dementia*, provided museums with a blueprint to apply the *Meet Me at MoMA* success to their own museum programming. The guide explains how to design, staff, spread the word, plan and discuss the artworks (Rosenburg, 2009). “Placing people with dementia in a resource-rich environment like a museum can promote the health and well-being of people with dementia and caregivers alike” (Rhoads, 2009, p. 238). “The last thing people with dementia lose is their long-term memory – often of things their children can’t relate to. What [patients] want is meaningful things to do to connect with the past, and museums do that every day” (Kendall, 2013, p. 33).

Since MoMA, over 60 museums across the United States and globe have implemented dementia programming for both the PWD and the CP (Parsa, 2010), including prominent programming offered in Australia (*ARTZ: Artists for Alzheimer's*) and the United Kingdom (*Arts 4 Dementia* and *House of Memories*). Through a survey of museum programs addressing dementia, Alejandre found “these museum programs alleviate some of the social issues associated with dementia by disproving misconceptions and respecting the abilities, needs, and preferences of those with dementia” (2012, p. 214). Rosenblatt (2014) tells us that these programs strengthen participants’ sense of community.

Rhoads (2009) explains through her research on varying museum programming for those with dementia that whether you are the PWD or the CP – “everyday conversation sometimes appears to have ended. Using the museum as a starting point for conversation is not only possible, but also highly beneficial to all partaking in the dialogue...Museums can encourage and promote that reflection and reaction, even if words are no longer available” (p. 238).

### Summary

Museums are responding to the call to action in the dementia epidemic in the United States and abroad. They are becoming active participants in addressing the needs of their communities. The growth in museum programming for individuals with dementia and their care partners is in part to the development of *Meet Me at MoMA* and *The MoMA Alzheimer's Project: Making Art Accessible to People with Dementia*. This literature review provides evidence of research into the benefits the visual arts and museum programs have on individuals with dementia and their care partners. However, there is a

lack of research surrounding the CP and how art museum-based dementia programs impact *their* well-being. Past studies focus on the PWD and/or on the relationship between CP & PWD. We need to address how the art museum-based dementia programs affect the relationship between participating CPs and PWDs from the viewpoint of the CP and in what ways art museum-based dementia programs affect the well-being of the participating care partner.

## CHAPTER 3: METHODOLOGY

The purpose of this study was to describe the impacts of art museum-based dementia programming on participating care partners. The following research questions guided the study:

1. How do art museum-based dementia programs affect the relationship between participating care partners (CPs) and persons with dementia (PWDs)?
2. In what ways do art museum-based dementia programs affect the well-being of the participating care partner?

### Sampling

With IRB approval, study participants were sampled from one of three institutions that offer well-established art museum-based dementia programming, free-of-charge and on a monthly basis.

- The Frye Art Museum in Seattle, Washington provides both monthly gallery tours for those with dementia and their care partners, as well a combination tour with an art-making class in their *here:now* programming. Both aspects of *here:now* are designed for those with early onset and early to mid-stage dementia. Museum staff utilizes Visual Thinking Strategies in gallery discussions, which is a line of questioning based on observation (Housen, & Yenawine, 2000).
- The Dallas Museum of Art in Dallas, Texas presents *Meaningful Moments* once a month in their museum. Comparable to the Frye Art Museum, the program involves both a gallery tour/discussion, as well as an art-making activity, and is designed for those with early stage dementia and their care

partners. Museum staff utilizes a combination of Visual Thinking Strategies and Constructivist theory in their gallery discussions.

- The Detroit Institute of the Arts in Detroit, Michigan offers *Minds on Art*. This program is available to those with early stage dementia and their care partners. The program involves gallery discussions led by DIA staff and volunteers, followed by an art making activity. Museum staff utilizes Visual Thinking Strategies in gallery discussions.

Staff from these three museum programs provided contact information for a combined 136 care partners who had participated in one of the programs within the last three years. The researcher sent an email to all 136 CPs; 36 responded; and 29 agreed to participate in the study (see Appendix A for call for participation email). Participants were 72% female (n=21) and 18% male (n=8). Of the 29 CP participants, 66% (n=19) reported living with the PWD while 34% said they live elsewhere.

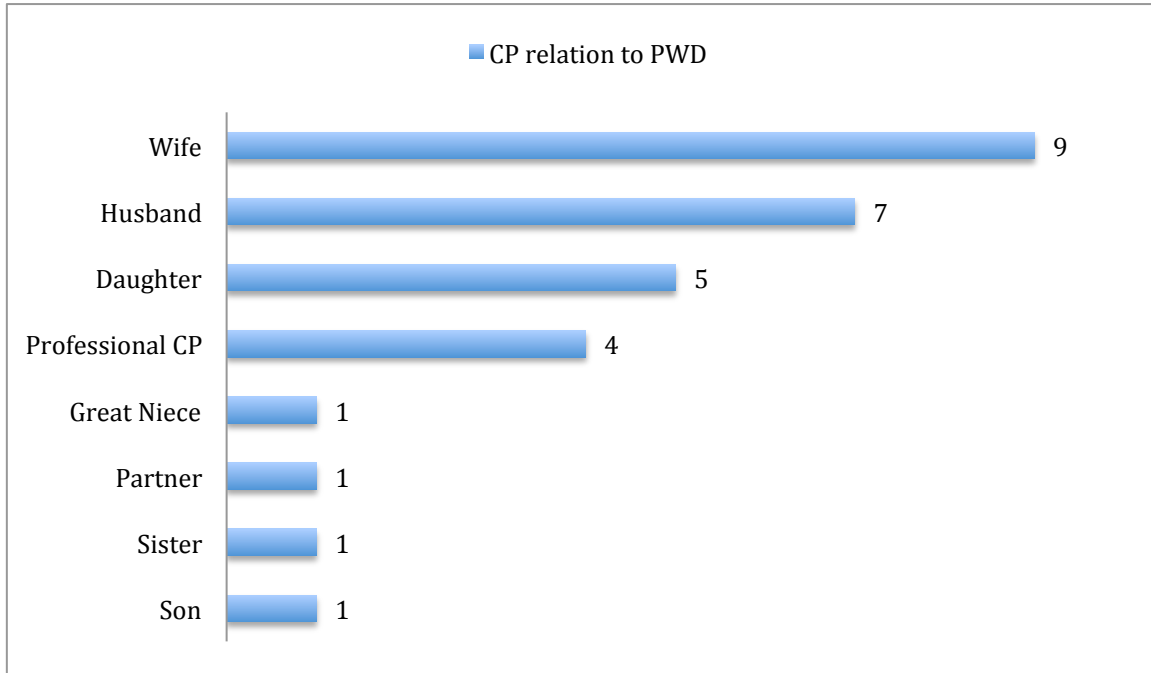
Participants were asked about their prior art museum attendance. Twenty-six of the care partners and persons with dementia had been to an art museum together prior to participation in the program, while two had not (one did not respond to the question). Twelve of the CPs said they would categorize themselves as frequent visitors to art museums prior to participation, with 15 responding they were not frequent visitors (two did not respond). Fifteen of the participants said that they are now attending museums more frequently since participation, while ten said they are not (four did not respond).

Additionally, participants were asked about their involvement in dementia programs after participation. Eighteen of the 29 responded that the museum program encouraged them to participate in other dementia programs in their community, while ten

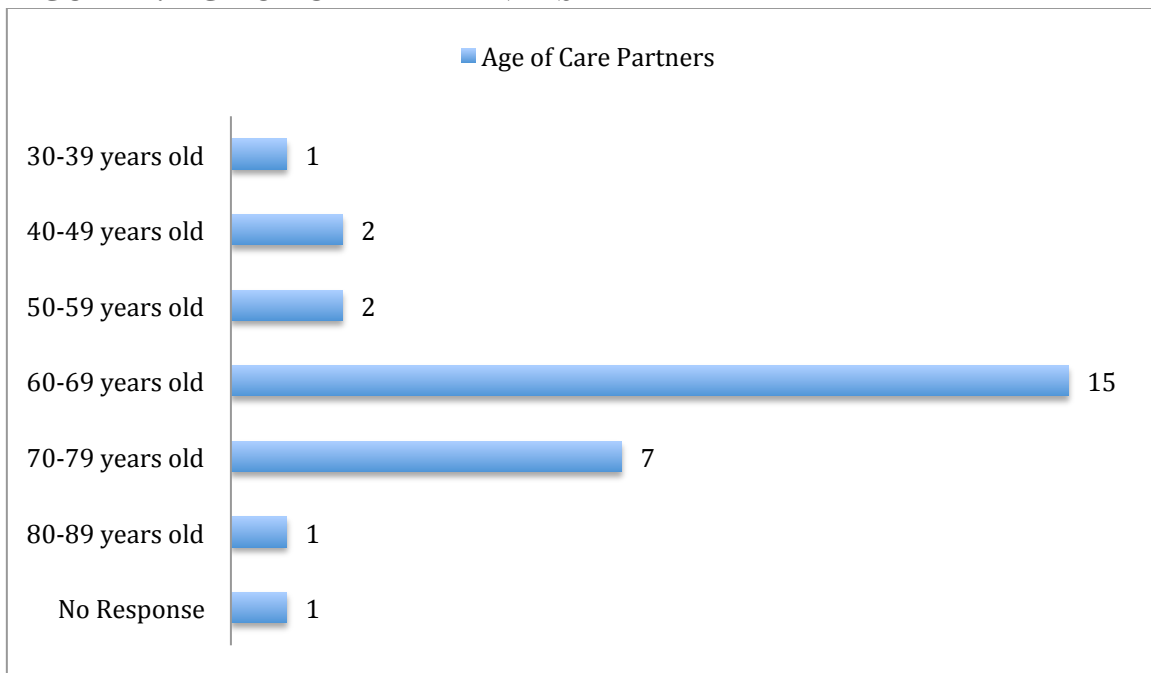
responded that it did not encourage them to participate in other programs (one did not respond).

The following figures further describe the sample.

**FIGURE 1: CARE PARTNERS RELATION TO PERSON WITH DEMENTIA**



**FIGURE 2: AGE OF CARE PARTNERS**



### Data Collection Procedures

Data were collected through semi-structured interviews conducted via telephone and scheduled based on the participants' availability. Interview questions were written to coincide with the research questions guiding this study. Questions were broken down into three sections: a) the participants experience with the program; b) their experience in the role as a care partner; and c) demographic questions. Within the program experience section, participants were asked to describe the program, share moments of interaction with the PWD that stood out and reflect on their relationship with the PWD and any changes they may have noticed. Within the role as a CP section, participants were asked when they felt rewarded or anxious during the program and whether or not the program had an effect on their personal well-being and their stress level after participating in the program. The demographics section asked for their birth year and sex, relation to the PWD, whether or not the PWD lived with them and their museum-going history (see Appendix B for the full interview guide).

Interviews typically lasted between 15 to 45 minutes. All interviews were digitally recorded.

### Data Analysis

Interview responses were analyzed for emerging themes. A coding rubric was designed, identifying emergent themes within responses to each question (see Appendix C). All interviews were reviewed and coded using this rubric.

## **LIMITATIONS**

Limitations within this study include a possible self-selection bias in that those who enjoyed the program or felt it was a rewarding experience may have been more likely to respond to participation requests so results may be skewed in that direction. Further, museum program participants were notified of the study through e-mail only. Some participants may not have e-mail or infrequently use their e-mail accounts, if they do have them. Interviews were conducted via telephone only to create consistency in the methodology, however, some participants may have felt more comfortable with an in-person or written interview and declined to participate because of this. Due to this, the sample does not fully represent all art museum-based dementia program participants.

## CHAPTER 4: RESULTS

In this chapter, resulting themes from the data are summarized by the guiding research questions. Data were analyzed according to the coding rubric found in Appendix C.

### PARTICIPANTS' DESCRIPTION OF THE PROGRAM

CPs were asked to describe the program as they remembered it. The majority gave an account of their activities in the museum (n=26). For example, one CP described the program as follows:

*“[The museum program] was an art program designed for those suffering with dementia or Alzheimer’s. Upon arriving, we would put on nametags and proceed to the museum to view a predetermined painting. We would discuss the painting-how it made us feel, what we thought was the story behind it, and what we liked about it. After viewing the painting, we would go upstairs to an art classroom and paint and/or collage.”*

Another CP said, *“They first have you look at a piece of art and it is discussed, with us and those who we take care of...then there was an art project afterwards. Usually painting or sculpting or something.”*

Several CPs (n=7) noted the way that museum staff led discussions (through Visual Thinking Strategies and Constructivist) within the galleries was beneficial for the group as it allowed both to respond easily and feel equal. One participant noted that seeing the PWD respond *“was almost like seeing a flower open.”* Another said:

*“The person that was leading this group discussion was absolutely marvelous at drawing out, asking questions that people enthusiastically responded to. You could almost not tell who was the caregiver and who was the person with Alzheimer’s. I was really impressed. Since I do this work and I study dementia, I know that people still have an opinion, even if they can’t, their executive function isn’t so great anymore, they still see things and want to, and they have an opinion.”*

Some participants noted the welcome and comfortable environment that the program took place in (n=5): *“Nice way to get people to chat with each other, a nice comfortable setting, well lit, and just a friendly situation.”*

A few CPs (n=4) noted the social aspect of the program, which allowed them to be with others, facing similar issues: *“It meant a lot to me to be with people of similar interests that were dealing with dementia and caregivers. So the program was a social program of mingling with others in the same situation, as well as enriching with the art and discussion of the art that we saw.”*

Other CPs (n=3) discussed behaviors of the PWD during their descriptions of the programs as well. One CP said, *“[PWD] couldn't pay attention enough and tried to leave the building.”* Another mentioned how the CPs were more involved than the PWD. She said, *“Usually the partners were more apt to respond than the patient, goes with the diagnosis. But it was relaxed.”*

CPs (n=2) also mentioned that the program allowed them to be with the PWD on equal footing, which allowed them to enjoy the PWD in that moment. One CP said:

*“One of the wonderful things for a caregiver is that during the program itself, you know, you are not a caregiver, you are just whatever your relationship is...and I really appreciated the fact that there was nothing, I didn't have to do any caregiving of my sister...Things like when they set up the art stuff, we just went into our little world. And that was particularly wonderful. I felt like I got to just enjoy her and also just enjoy side-by-side kind of stuff instead of it being that I have to watch her or take care of her in some way. And that was really wonderful.”*

**1) How do art museum-based dementia programs affect the relationship between participating care partners (CPs) and persons with dementia (PWDs)?**

INTERACTION WITH PERSON WITH DEMENTIA DURING THE PROGRAM

CPs were asked to describe their interactions with the PWD during the program, any moments that stood out in their memory or surprised them. Overall, CPs described more meaningful interactions (n=35) than not (n=13).

Thirteen CPs described interactions in which the PWD was an active participant, responding to gallery discussion questions, interacting with them and others and/or producing art. One said, *"You could just see him beaming [after answering a question]. More than anything that is what amazed me."* Another said, *"The way the program was conducted, drew her out of herself."*

Many CPs (n=12) referred to the art as a catalyst for interactions (both discussions of art in the galleries and the art making activities). Typically these comments referred to the ability of the art to open up conversation between the CP, PWD and within the entire group. One CP said,

*"I think in general, in the conversations about the art, she opened up and just really, you know, shared in the moment, her responses to the art. So it resonated with her and it stimulated her to share more than other times when we just walked through the galleries and she can't slow down enough to look at things."*

Another CP said,

*"Looking at her paintings was a little surprising; they were all ribbons of color. She didn't try to paint any tangible objects. And I asked her about that...it made me think about her and how she sees the world in a way. She doesn't focus on the detail of objects, she focuses on the free flowing motions of things."*

Others (n=5) shared moments in which they learned something new about the PWD. For example, one CP found out that the PWD had grown up near train tracks after she had repeatedly drawn short lines connected by long lines in her artwork week after week:

*“We noticed over several weeks that she would have these little lines, you know? Little short lines, connected by long lines here and there, interspersed in her pictures every week. And it was just an odd thing and I asked her one-day and she has dementia, and I asked her, ‘what are these little marks here?’ And she started telling me about growing up near the train tracks and how that was such a big influence in her life. And it was like she stepped back in time and was really alert.”*

Another CP said, *“Her view of a particular picture brought out that she had lost a child.”*

Some CPs (n=4) discussed how the program provided an equalization of the relationship. One CP said,

*“It gave me time to enjoy time with my husband, in a learning situation, and not be concerned with running the show, so to speak. As a caretaker, you, early on, tend to lose that partnership level. You become the nurse, the advisor, the one responsible for so much, not just in your regular life but now in different financial issues.”*

The social aspect of the program was referred to by four CPs. They discussed the importance of a social situation where both the CP and PWD can feel comfortable together. One CP said,

*“Having that diagnosis, if you have any kind of awareness at all, you realize early on you are going to have issues and not everyone is going to relate well to you, not everyone is going to feel comfortable and in that particular setting, that was sort of put aside.”*

One CP, after describing the financial and banking issues that weigh down on her, explained her enjoyment of the social aspect of the program:

*“This makes your life so difficult [managing the finances], way beyond the pain of seeing your loved one disintegrate. So if you have something you can go to and you can both enjoy it on your own level and have not only the activity but the companionship, what a blessing.”*

One CP found it to be both beneficial and difficult to be in that situation due to her mother’s limited abilities. She said,

*“[It’s] nice to be around other people in similar situations. But it was actually kind of hard; it was kind of like, heartbreaking to watch. [PWD] has a hard time with her vision due to her Alzheimer’s so she had a very hard time seeing what it was we were even looking at and she really had a hard time with it and other people who appeared to be worse off than my mom as far as their Alzheimer’s or dementia, were able to respond better, were able to see the picture and see whatever it was we were looking at and like, respond better to it. So it was actually pretty heartbreaking...the experience. But it was nice to share that time together, to do something, just doing something one on one with her and something different. Nice to have something out of the ordinary to do with her.”*

Some CPs adversely noted how the PWD was not an active participant in the program (n=13). They described that the PWD did not respond to gallery questions and was reluctant to partake in the art making. One CP said, *“It was an observation, not involvement.”* Another said:

*“In a sad way, I guess, the people that respond most to the questions about the art...is naturally the care givers, which is not what they are going for, and we know that’s not what they are going for but otherwise it would be silent. Rarely, rarely, do you hear one of the people that are afflicted with the disease, speak up. Occasionally you do and sometimes I will hear PWD say something, not only say something but say something very astute and that absolutely makes my day.”*

Finally, one CP felt that the program did not contribute the communication between her and the PWD: *“It did not assist in any way with our communication, at any time. I was very aware of that.”*

## INTERACTION WITH PERSON WITH DEMENTIA AFTER THE PROGRAM

When CPs were asked if they talked with the PWD about the museum program after their visit, over half (n=16) said they discussed it as a general, positive experience. One CP said, *“We talked about how much pleasure we were getting out of it.”* Another said, *“She was always so happy to be going.”*

Many (n=8) did not have post-program conversations about their experiences at the museum due to the PWD’s short-term memory loss:

*“She has no short-term memory so I do it, just to see if I can draw something out, but there really is no short-term memory whatsoever. And now she is losing parts of her long-term memory so I make the effort but honestly, there isn’t much forthcoming from her, you know?”*

Another discussed the isolation felt because they could not talk about it:

*“He couldn’t remember, he didn’t connect, and have any capacity to review it afterwards. It was just an experience that he experienced at the moment and that’s what the neurologist told us we would get to with this disease...In the moment I tried to have a conversation afterwards, on several occasions and it never materialized. So I think, that to me reveals a lot about the disease. Its very isolating and a lonely disease for the caregiver. The museum is certainly addressing that by having these experiences.”*

Seven CPs reported that the artwork that participants took home with them gave an opportunity to have conversation about their experiences: *“A day after the museum, she’s really not remembering the paintings...[To PWD] Here’s the project you made. ‘Oh I made that? That’s not that bad’...Then she would look at it and say ‘I remember doing that.’”*

CPs (n=5) also had conversations that revolved around the gallery discussions at the museum: *“She would talk about the piece of art that they looked at or one she saw that they didn’t talk about, then she’d talk about it.”* Another CP said,

*“This happens now every time we go to [the museum], she will point out ‘her pictures.’ ‘Her pictures’ are any pictures that we did the gallery tour with...and I’m really struck by the depth to which she totally knows.”*

Others (n=2) used conversations afterwards as positive reinforcement for the PWD to continue involvement in the program: *“[To PWD] Wow, that was really great, I’m so glad you did it, look at how excited you are.”*

Two CPs recalled the social connection the PWD had within the program. One CP said of her husband,

*“[He] always wants to get back to ‘his people’, and ‘his people’ are those participating in the program or in other programs that he does that are dementia focused. So I know that was a good experience for him because those were ‘his people’. And he’s comfortable.”*

Two CPs mentioned the time spent out of the home: *“Took us out of the house and into an atmosphere that was very much like, um, it was on our level of interest in the arts. It was a very positive experience.”*

#### CHANGES TO HOW CARE PARTNER THINKS/FEELS ABOUT PERSON WITH DEMENTIA

When CPs were asked if the program changed the way they felt about the PWD in any way, many (n=11) said there was no change, often referring to their long relationships and marriages, with responses like: *“We’ve known each other since we were five years old...been married for 46 years.”*

However, some CPs (n=8) saw abilities within the PWD that they thought were already lost. One CP said, *“Dementia has a way of conflicting with communication. But this was like, kind of like, opening another avenue and it made me realize that there are still a lot of switches on in there.”* Another said, *“Appreciation for abilities that I might have thought previously were lost...its nice to see a new insight.”*

Others (n=5) said they felt that they now knew and understood the PWD better as a result of the museum program: *“It helped me to know her better. And it helped me learn to navigate around some of her initial hesitance in other situations too.”*

Others (n=4) mentioned that they now saw the PWD as artistic. Even after a long marriage, one CP said, *“We’ve been married 53 years so it sort of...it regenerated my admiration for his artistic side.”*

#### EFFECT ON THE RELATIONSHIP BETWEEN CARE PARTNER AND PERSON WITH DEMENTIA

CPs were asked if they thought the program had any effect on the relationship they have with the PWD. The majority of CPs (n=23) felt that the program had a positive effect on their relationship and mentioned positive characteristics of the programs by way of explanation. However, some CPs did not feel the program had any effect on their relationship (n=4), though none cited any negative effects.

In a repeated theme, CPs (n=7) reported that the social aspect of the program had a positive effect on their relationships. Both CP and PWD benefitted from the interactions with others in the programs, friendships developed and the relationship between the CP and PWD was given an opportunity to grow outside of the caregiver and care receiver roles. One CP referred to the isolation felt with this disease and said, *“As our social bonds have decreased all over, this is a group to get out without having to explain yourself. So that’s nice.”* Another CP described it as follows:

*“Even afterwards, you know, when we saw some of the people from [the program] outside of the program, it kind of felt like a connection that her and I had. You know? We both knew those people. So yeah, I think it made us closer, in a way.”*

CPs also felt the program brought them closer (n=6), with one CP saying, *"I think it bonded us, brought us closer together."* Another said, *"In a way it brought us closer...the whole experience [contributed to that]."*

The visual art had a reported effect on the relationship for several (n=4): *"It stimulates her in a way that she's not being stimulated otherwise."* One CP whose mother had disapproved of her choice to pursue art found the program brought them closer because her mother *"understood how art can make you feel."*

Three CPs reported the time out of their home as a positive experience, as well.

One CP described the affect on their relationship:

*"Getting out and doing something is so healthy for our relationship, it's not only getting out but seeing him in that context. It is so good for our relationships because it brings back a lot of the reasons why I married him, he was the smartest person I ever knew, and it brings things out of him, brings things out in him that I don't think would come out if we were at home all the time. So I think that it is a real, real good environment for us both to be in."*

The museum programs also allowed for the relationship to be equal (n=3). One CP said, *"We go on equal footing...its great to go on equal footing."*

Others noted that sharing time and an activity together contributed to their relationships (n=3). One CP said, *"It made us do something different that we wouldn't normally do."* One CP whose PWD is active in the dementia community, appreciated a program they could participate in together. She said, *"That was a particular one that I found as interesting as he did so it was good that I could do something with him that, you know, involved other people with dementia and supported us both."*

Additionally, the program gave some PWDs a chance to be the teacher (n=2). One CP whose mother had an art background said, *“It gives her a chance to be the one that knows. Its good for her and great for our relationship.”*

Two CPs (n=2) reported that the stress relief they felt during the program had a positive effect on their relationship with the PWD. One CP said, *“Instead of agony all the time, it was pleasure. It gave me a break.”*

Four CPs (n=4) felt that there was no change to their relationship. One said, *“It didn’t give the results I expected, for me yes, for him no...I am trying to find things that he might be interested in and he’s not.”*

## **2) In what ways do art museum-based dementia programs affect the well-being of the participating care partner?**

### STRESSORS WITHIN THE PROGRAM

CPs were asked if there were any stressful moments within the program. Many CPs (n=7) replied that there were no stressors, that the program actually offered stress relief. One CP noted that it was *“always calming.”* An additional two CPs responded *“no”* without an elaboration.

For those that felt the program did have stressors (n=14), the stressors were mostly due to the PWD being reluctant or not participating (n=5), related to PWD behaviors (n=5) or the logistics of getting to/from and around the museum (n=3). One CP said, *“It was just stressful anyway. You know, getting her there, making sure that she participated, that she came...”* Referring to a PWD’s reluctance, *“It was a little stressful at first because she kept saying ‘I’m not an artist, I’m not talented...’It was stressful for her, you think you are going to be judged I guess.”* One CP who’s husband wandered

throughout the program said, *“There’s this enjoyable experience but you can’t participate in it because your husband is wandering off but then, you know, later you feel guilty for feeling that way. Very confusing.”*

#### EFFECT ON PERSONAL WELL-BEING OF CARE PARTNER

Experiencing relaxation, inspiration and creativity through the visual arts (n=19) were the most repeated response when CPs were asked if the program had an effect on their personal well-being:

*“A big lift emotionally and intellectually, because for preceding our doing the events at [the museum], preceding that time, the feelings of isolation and intellectual, or just, yeah, more academic thinking were disintegrating around my whole being. So getting into [the museum] program and being able to think about the art and what it inspired in other people, how they saw the art differently. It was a huge...not just a relief, it energized me.”*

Another CP said, *“Certainly, I get more out of the gallery experience, I am more inclined to want to pursue artistic endeavors, I feel more creative.”*

Additional repeated themes were the social benefits of the programs (n=10) and the stress relief CPs felt (n=9). CPs reported the programs as a good outlet. One said, *“It’s another social outlet and I enjoy the education aspect of the museum talks also.”* Another said that it reminded them of dinner parties due to the *“good cheer.”* CPs reported feeling *“peaceful”* and *“good”* after the sessions: *“It was a respite from stress, because it was a sort of controlled environment and we were both eager to participate, so there was no stress involved with it, and it gave me a nice outlet, something to do.”*

Further, the museum setting had a positive effect on their well-being (n=7), with one CP noting it was the *“great beauty of the place.”*

For some, the programs provided time for them to not be the CP, the one responsible and in charge (n=5): *"It was just nice to have something that was just the two of us to do that somebody else was responsible for."* One CP described it as follows:

*"Its good to get outside your world of Alzheimer's. Everyday you get up and think 'OK, what am I going to do and how is it going to affect my husband?' And that is kind of how you live so it's nice to get out."*

Also contributing to the positive effect on their well-being, CPs noted the equalization of the relationship (n=3): *"It felt like things were more normal again, you know, for those moments."*

CPs (n=3) also reported they could see the PWD functioning in new ways, which helped to grow their relationship: *"There's so much inside people's heads and if you can find the right key, you can unlock it. That I think about every day. That was sort of a little epiphany."*

While this question was meant to focus on the CP alone, the selfless nature of a CP came out as they often did not focus on themselves but referred back to the relationship they have with the PWD. Three CPs mentioned the importance of time out of the house; one described it:

*"I think it was a great stress reliever in the fact that it was an opportunity to get out of the house together and share something that we both enjoyed and you could be having a fairly stressful morning and then we would go have a nice lunch together and share that great time together and on the way home we had those positive things to talk about. It was a day that we actually looked forward to."*

Additionally, one CP (n=1) felt the program had prolonged the good health of the PWD, which has aided him to be in good spirits due to his wife's better health. He said, *"It has really kept down the quick advance [of the disease]."*

One CP (n=1) reported feeling empowered. She said, *“I guess it made me feel like empowered, I don’t know if that’s right, its like oh I’m doing something to help her. Made me feel like at least I’m doing just a little to help it. I don’t know if empowered is the right word, maybe proud.”*

One CP (n=1) responded with “yes”, that the program had contributed to his personal well-being but did not elaborate.

### FEELING REWARDED AS A CARE PARTNER

More than half of CPs (n=17) responded that seeing the PWD as an active participant within the program was a personal reward for them. One CP said that when the PWD was active in the gallery discussion, *“It was a reflection that the person is not completely gone.”* Another CP discussed the importance the program has in her mom’s life:

*“She calls it going to work. Like, she’ll wake up in the morning...and that to her is a huge thing. She liked working, she was a work-a-holic. And so for her that is a big deal, it is a good thing to say ‘am I going to work today?’ ...So that’s rewarding to me, to have activities that match her, you know, from time to time.”*

One CP said there was some initial reluctance of the PWD, but she said, *“It was rewarding to see...once getting past ‘I don’t want to do this moment’ ...Getting into the project...getting them to the point where they are really enjoying it.”*

CPs (n=10) also noted the PWD enjoyment and/or appreciation of the program as rewarding: *“It’s an overall thing. She really liked to go and still likes to go.... She’s just always really appreciative.”* The finished product from the art activity provided a rewarding feeling as well (n=6): *“When we finished the little craft projects, I felt very good about what I had done.”*

Participating in an activity together (n=3) was mentioned as a reward, as well as the time spent together out of the house (n=2): *“I feel like I’m doing something for my husband every time I go because stimulation is one of the most important things in the world...I think this is the best thing we can do and getting out for crying out loud.”*

One CP described how that could affect their relationship:

*“Not so much rewarded as a care partner but there were times when PWD was having difficulty saying something and the facilitator was able to make sense of it and repeat it, you know, say it in a way, make it feel like that’s what he said, even though it might not have been slightly different but affirmed what he was saying and kept moving...There was not that questioning of what he was trying to say. It was just a given. That’s what he said. And I think that was remarkable, to be able to do that. And a good example for ways that I need to respond to him sometimes. With total neutrality.”*

One CP felt rewarded that her community was offering the programs to her, free of charge. She said:

*“Rewarded in the fact that [the city and museum] were offering programs that were somewhat stimulating to me so that I could grow just a bit during this down hill slide. So yes, I’d say that it provided me a mental avenue that there were activities that we could both participate in and both get something out of.”*

### FEELING ANXIOUS AS A CARE PARTNER

CPs were asked to share any feelings of anxiety they felt during the museum programs. Responses were divided with 14 CPs reporting that they did not experience any feelings of stress and 15 describing instances of feeling anxious.

For those who did not feel any stress (n=14), they often referred to the safe environment, museum staff, and the fact that they were not responsible for the activities.

One CP said the museum and staff are *“like family, close family.”* Another said there

were no feelings of anxiety because *“they are taking care of everything”* and another said, *“there’s nothing asked of me.”*

Some CPs (n=4) reported the PWD’s reluctance to participate in the program caused them to feel anxious: *“Anxiety in the early parts in the art making because she would tense up.”* Some CPs found that the PWD was reluctant at first but became participatory as the weeks went on: *“Initially because she was reluctant to participate.”*

CPs (n=4) felt stressed during the program due to the PWD’s behaviors, as well: *“Those moments are a little bit, um, disconcerting, I guess. But they’re brief. Once she settled in everything was great.”* Another CP described an event where her husband wandered from the group and to the front doors of the museum. *“One time he actually did make it to the door and I had to try to talk him into coming back in...that’s a bit frustrating.”* Other responses (n=3) explained, *“At this point you are always anxious.”*

Two CPs (n=2) noted the logistics of getting to the museum or maneuvering through the museum caused them anxiety: *“Pretty much all the time, moving around the museum, through the crowd and helping her sit down. Working on the art in the production room.”*

Finally, CPs (n=2) reported anxiety during the program, as it was a confrontation with reality:

*“Anxious only in that when he’s not making sense, then I realize that this is real. That’s the only anxiousness, that I can’t get away from this disease. Not anything that the program created, any interaction, any time when I see PWD failing in a standard social sense, is stressful because I know that’s the reality for him.”*

### UNEXPECTED EXPERIENCES DURING THE PROGRAM

CPs were asked if they experienced anything unexpected during their participation in the museum programs. Several CPs (n=7) mentioned how the museum program was a positive experience for them. One CP said it was a *“higher quality than I expected.”*

Another said, *“Beyond my expectations of a pleasant experience.”*

Having a community and social outlet was again mentioned within the scope of this question (n=6). One CP said,

*“You can’t have expectations when you are a care giver. You learn that real fast, those go away...so I didn’t go into that program with any expectations but what came out of it...she loves the people who helped out with that class and some of the participants we see at other things and she is so happy to see them when she sees them. She may not consistently remember we ever did the program but she remembers the people and I just, I love her having new friends at her level now that, um, she loves being with.”*

Another said, *“It’s good because everyone understands the dementia component of it, and what stresses us, and what we are able to do and not do, and its still fun...Everyone kind of knows what’s going on.”* Others said they became friends with those in the program: *“We became close with some of the participants, it was unexpected and very positive.”*

There were several CPs who did not feel there were any experiences that were unexpected within the program (n=5), partially due to the unpredictable nature of dementia: *“I don’t think I had expectations at that point, about anything, you know? I just was ‘let’s get through today. Let’s make today a happy day, a good day.’”*

Having creative inspiration from the art was repeated too (n=4). One CP particularly mentioned the quiet time spent just looking at the painting prior to the group discussion.

She said it was “*very rewarding to do that.*” Another CP said the program inspired her into “*getting back into my own work.*”

Several CPs (n=4) noted that seeing those with dementia as active participants was unexpected to them:

*“I think how many of the people with dementia, memory loss, would open up and talk about...seeing the progression.... and talk about the piece of art they were working on or what they saw or sometimes even open up a little bit more personally about things. I think that was a surprise to me.”*

Two CPs (n=2) noted the welcome and comfortable environment the museum provided: “*I feel a tremendous amount of support [from museum staff].*”

Others did not have the same positive unexpected experiences (n=2). One CP said, “*I was surprised at how hard it is for her to do something new or different.*”

Two CPs (n=2) mentioned how they now see the PWD as artistic: “*I’m kind of amazed when he goes in there and does art. I think his is better than most. He doesn’t come from an art background.*” Additionally, seeing the PWD’s pleasure in the program was unexpected (n=2): “*Sometimes I didn’t expect the level of her delight.*”

One CP (n=1) noted how the museum setting was a positive he and his wife felt: “*A lot of times when I made a few efforts to take PWD to senior centers and that was extremely depressing in several instances, and we did not experience that at all [at the museum].*”

#### ALLEVIATION OF STRESS DUE TO PROGRAM PARTICIPATION

CPs were asked if they felt the museum program they participated in helped to alleviate stress felt as a CP to a PWD, added to the stress or a bit of both. The responses were 72% positive, with most saying the program alleviated the stress they felt as a CP (n=21). CPs said it was “*relaxing*” and “*refreshing.*” They mentioned the “*non-*

*judgmental atmosphere*” and the feeling of “*creating community*.” They did not feel they had to be in charge for that time of the day: “*It just allowed me to be his wife. Go there and just be a wife. Wasn’t his nurse...I was his wife. We were partners in that activity.*”

One CP said,

*“It alleviated stress. I felt like I was relieved of burden...maybe? Because I kind of felt like I was floating on the clouds afterwards, and maybe for a day or two afterwards, I just kept thinking of that wonderful feeling of being lifted out of that... of my thorn. It was a very, very positive. And it lasted more than just that afternoon.”*

Another said,

*“It can’t take care of the bigger problems but it can sure take care of that in the moment, you know it is just wonderful to get back to the present moment. Right now, here, at [the museum] we are fine. You know? And I think I need that as much as PWD does. Because it is a place where you are OK. So it is really valuable to me.”*

Some CPs reported that they felt both anxiety and stress relief (n=6). One CP said, “*It was a pleasant relief to have something social to participate in but with the anxiety that tempered it a little bit.*” Another said, “*Only because there was another responsibility...and I lost my time.*” Others noted the logistical difficulties as a stressor during the program (n=2):

*“Oh well you know, just getting to the program, the logistics - all that stuff is stressful, but any outing is that way, so nothing particular about this program. And once you got there, you had the sense... that you can sort of sit back because they were directing things and providing the activity and so it was an opportunity to have a break.”*

Through twenty-nine interviews, this study has found that there can be positive impacts on the participating CPs on both their relationship with the PWD and their own well-being. The results are further discussed in the conclusions section.

## CHAPTER 5: CONCLUSIONS

The purpose of this study was to describe the impacts of art museum-based dementia programming on participating care partners (CPs). Data were collected through 29 interviews and responses were coded to emerging themes. Those themes represent what art museum-based dementia programs are contributing to the well being of CPs and their relationships with the person with dementia (PWD). Through these themes, we can strengthen and amend current programs so that they can become even more beneficial for participants.

### DISCUSSION

The results from this study show that art museum-based dementia programs can have a positive influence on the relationship between the CP and PWD. There was an equalization of the relationship in which many felt they were in a partnership again. They reported enhanced interactions with the PWD, as well. There were instances in which the PWD revealed something the CP did not know about them. The PWD showed an artistic side the CP had not seen before or for some time, which in some cases, led to the CP seeing the PWD as more capable than before. The art gave CP and PWD something to discuss after the program, either the gallery discussions or perhaps the finished artwork they took home with them. Many thought the museum programs brought the two of them closer. This could be because of the shared time in the museum or because of the social interaction with new friends in the program. Basting and de Medeiros support the results of the social aspect being particularly important in their review of cultural arts interventions in dementia care (2014). They tell us “not only do cultural arts interventions

involve meaningfulness, creativity and imagination, they involve social connectedness and engagement with the outside world” (p. 351, 2014).

Further, the results of this study show an impact on the well being of the CP. Overall, the majority of CPs who participated in this study reported an alleviation of stress due to museum programming. They discussed the importance of having a safe and welcome environment to go to on a regular basis. They appreciated the time spent out of the home and saw it as a “break.” They especially valued interacting with others in similar situation as themselves. CPs reported the importance of the art within the program. They felt the gallery discussions and the art making were positive, relaxing and welcome activities. These findings are supported by Binnie, who found that well-being could be affected by viewing art within a museum (2010). Some CPs who participated in this study have even had a revival of their own art making at home. And for those who were the spouse or family member of the PWD, they were allowed to just enjoy time with their loved one and not feel the stress of being the caregiver. Rhoads backs these findings in her summary of museum dementia programs (2009). Rhoads tells us that CPs in the *Meet Me at MoMA* program reported that joyful experiences and a social avenue were of the utmost importance (2009).

#### Contributions to Positive Program Impacts

The environment was often cited in CP responses as a beneficial component of the art museum-based dementia programs. This includes the museum setting (n=8), feeling welcome and comfortable atmosphere (n=7), time spent outside of the home (n=10) and the visual arts within the museum (n=39). This shows that the impact these programs may be specific to their location within the museum walls. It gives the CP and

PWD a chance to change their setting and step out of the house to appreciate art in person.

Equally important is that the museum staff and teaching artists who conduct the programs are perceived as patient and respectful of all involved. Additionally, many participants (n=7) noted the effectiveness of the gallery discussions led by museum staff. This shows the efficiency of utilizing Visual Thinking Strategies and Constructivist in bringing out participation in this particular audience.

A majority of responses (n=32) mentioned the importance of the social aspect and sense of community they felt while participating in these programs. They cited the importance of interacting in a group who are all cognizant of dementia and in similar situations as themselves, the new and lasting friendships founded. CPs often feel isolation and have less social interaction due to the stigma associated with dementia (Basting & de Medeiros, 2014). To have those whom you feel you can turn to or have a social gathering with, without the worry of all involved understanding how the PWD may act, is incredibly important to the well-being of the CP, as well as the PWD.

## RECOMMENDATIONS

Findings from this study are intended to identify and describe the impacts of participating in art museum-based dementia programming which could contribute to future studies, grant funding, expansion/amendments of current programming and implementation of new programming.

Results have implications for practice relative to the ways in which dementia programs in museums are structured and delivered. As it has been shown through the data collected, the environment and social/sense of community aspect were highly valued, and

thus there is value in continuing and even expanding these elements, if possible. Museum staff should be welcoming and respectful to all involved. The environment should be kept clean and minimal so that those with dementia are not overwhelmed.

With the stressors cited within CPs responses, programs could be doing more to aid CPs in the initial participation reluctance of the PWD. One recommendation would be that the programming takes place over the course of two additional weeks so that the first two meetings could be a shorter, more introductory event. This would allow more time for the PWD to feel comfortable and ease into the program, as well as keep the first two meetings shorter so that the CP does not feel overly anxious for an extended period of time if the PWD is reluctant from the start.

As previously mentioned, 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. In addition to this, the teaching artists should be well versed in ways to overcome any difficulties the PWD may have (i.e. due to vision loss or loss of motor function) with the materials presented for the art activities.

The other stressor reported by CPs was the logistics of getting to the museum. Many said that this is how it is with any experience outside the home, but how can museums help in those logistical challenges? Again, museum staff training would be beneficial, as well as an increase in staff present for the programs. With more staff on hand, there could be more assistance in moving through the museum from the gallery to the art activity rooms. Additionally, amenities like wheelchairs and free parking could help with the logistical challenges.

While this research sheds light on the benefits art museum-based dementia programs can have on CPs, additional research should be pursued. A similar study could be conducted in which participants would be contacted through multiple avenues for participation in the hopes of a larger sample size. In addition, research could measure the impact of different genres of art (i.e. contemporary versus more traditional landscape paintings) on those participating within the gallery discussions. Further, a study could measure the impact of differing themes discussed within the sessions to see if any are more conducive to responses from the PWD or aid in relaxation for the CP. For example, perhaps in one session there is a theme of water within the paintings discussed in the galleries and another session focuses on flowers or landscapes. In the same vein, research could be conducted to see which art materials and art making activities provide more relief to both the CP and the PWD (i.e. watercolor or clay/sculpting). In these instances, interviews with CPs would need to be conducted either on site or within a day or two of the programs to measure any changes from week to week.

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## APPENDIX A: CALL TO PARTICIPATE

### RESEARCHER'S EMAIL INVITATION TO PARTICIPATE

Greetings,

I am a museum studies graduate student at the University of Washington in Seattle, and I am conducting my Master's Thesis research on the impacts of art museum-based dementia programming on participating care partners. I became interested in this topic through my own family's history with Alzheimer's disease and after helping my mother to care for my grandfather.

**Since you participated in [insert museum and program name here], I am emailing to ask you to participate in my study.** If you agree, I would schedule a telephone interview with you in the next two weeks. Interviews will be scheduled at your convenience, and will take approximately 20 to 45 minutes. The interview will be recorded, however, the recording will only be used by my research team and your responses will be confidential. Your name will not be identified and while I may quote you, that quote will not be attributed to you or to the museum where you participated in the program.

Please email me at [katielamar@mac.com](mailto:katielamar@mac.com) if you are willing to participate. Your experiences will help me to document the importance of these programs in our communities.

Thank you for your time,  
Katie

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## APPENDIX B: INTERVIEW GUIDE

### **Impacts of Art Museum Public Programs for Individuals with Dementia on their Participating Care Partners Interview Guide**

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Thesis Advisor: Dr. Jessica Luke, Museology Graduate Program, University of Washington  
Phone: 206.685.3496 // Email: [jjluke@uw.edu](mailto:jjluke@uw.edu)

#### Consent Script

I am asking you to participate in a research study that is part of my Master's Thesis work at the University of Washington. The purpose of this research is to describe the impact of art museum-based dementia programming on the participating care partners. I became interested in this topic due to my family's history with Alzheimer's disease and after helping my mother to care for my grandfather.

Your participation is voluntary. Refusal to participate will involve no penalty or loss of benefits, and you may discontinue participation at any time. This interview will be recorded. However, the recording will only be used by my research team and your responses will be confidential. Your name will not be identified and while I may quote you, that quote will not be attributed to you or to the museum where you participated in the program. If you have any questions now or in the future, you may contact me or my advisor using the contact information I shared in my email to you. Do you have any questions? Do you agree to participate in this interview?

#### Interview Questions

The goal of this interview is to establish an understanding of what, if any, impact your participation in [insert program name] has had on your own personal well-being, and on your relationship with [insert name of Person with Dementia]. I will ask you first about your experience with the program, then your experience as a care partner, and finally a few questions about you personally. Each section will consist of about 6 questions. If there are any questions you wish to skip or if you would like a break at any point, please let me know. Do you have any questions before we get started?

Let's begin!

My first few questions are about the nature of your experience in the program.

1. When did you participate in [insert program name]? (Probe: From when to when?)
2. Describe the program, as you remember it.

3. I'm particularly interested in your interactions with [insert person's name] during the program. Do any particular moments you shared with [insert person's name] stand out in your memory? Did you share any moments in which they shared something that surprised you? Were there any particularly stressful moments within the program?
4. What about your interactions with [insert person's name] after the program – for example, when you were walking/driving home, or talking over dinner. Did you ever have any conversations about your experiences in the program? (Probes: If yes, what did you talk about? What prompted that conversation?)
5. Do you think that your participation in this program changed the way you think or feel about [insert person's name]? (Probes: If yes, in what way? And what was it about the program that you think contributed to that change?)
6. Do you think that your participation in this program had any effect on your relationship with [insert person's name]? (Probes: If yes, what effect do you think it had? What do you think it was about the program that resulted in that effect?)

My next set of questions are about you as a care partner.

7. Do you feel that participating in this program had any affect on your personal well-being? (Probes: If yes, in what way? What was it about the program that you think contributed to that effect?)
8. Can you tell me about a time in this program when you felt particularly rewarded as a care partner?
9. Can you tell me about a time in this program when you felt particularly anxious as a care partner?

10. Did you experience anything unexpected while participating in this program?

(Probes: If yes, can you describe that experience? What did it mean to you?)

11. I know that providing care for someone with dementia can be very stressful at times.

Did participating in this program add to that stress, alleviate that stress, or a bit of both?

This last set of questions are about you personally. Answers to these questions help me to understand who has participated in this study.

12. In what year were you born?

13. What is your sex? Male/Female/other

14. How are you related to [insert person's name]?

15. (If not previously mentioned) Does [insert person's name] live with you?

16. Before you started participating in this program, had you and [insert person's name] been to an art museum together?

17. Before you started participating in this program, were you a frequent visitor to an art museum?

18. Have you been more frequently to an art museum since your participation in this program?

19. Did this program encourage you to participate in any other dementia programs or activities in your community?

20. Is there anything else you would like to tell me about your experience in this program?

## APPENDIX C: CODING RUBRIC

	<i>Describe the program, as you remember it.</i>	
<b>Code</b>	<b>Description</b>	<b>Example</b>
1	Welcome/comfortable environment	<i>"Nice way to get people to chat with each other, a nice comfortable setting, well lit, and just a friendly situation."</i>
2	Discussion in the gallery then an art activity	<i>"One section we did was a 6 week course on looking at art then going into the studio and creating art, with four other couples."</i>
3	Social - Sense of community - New friends	<i>"I really try to keep her involved socially in any kind of situation so that's kind of what we get out of it, you know what I mean?" "Not sure what my wife gets out of it, keeps her involved socially."</i>
4	Visual Thinking Strategies/Constructivist gallery discussions	<i>"They were so good at getting the participants to look, think and speaking up." "It was basically no right or wrong answers, just look at the painting and tell us what you see. No art history or anything."</i>
5	PWD behaviors (i.e. wandering, attention)	<i>"Usually the partners were more apt to respond than the patient, goes with the diagnosis. But it was relaxed."</i>
6	Equalization of the CP/PWD relationship	<i>"During the program itself, you are not a caregiver." "It was almost hard to tell who was the person with dementia and who was care partner."</i>
	<i><b>I'm particularly interested in your interactions with [insert person's name] during the program. Do any particular moments you shared with [insert person's name] stand out in your memory? Did you share any moments in which they shared something that surprised you?</b></i>	
<b>Code</b>	<b>Description</b>	<b>Example</b>
1	Stress relief	<i>"[It was] great for me" "[The program was] always calming"</i>
2	Social - Sense of community - New friends	<i>"Nice to be around others in similar situations."</i>

3	PWD was not an active participant - Quiet and/or reluctant	<i>"It was actually quite heartbreaking [to watch them struggle]." "What I saw in [PWD] was observation, not involvement."</i>
4	PWD was an active participant	<i>"You could just see him beaming [when answered a question]. More than anything that is what amazed me." "...to see PWD do something you didn't realize they could do."</i>
5	Equalization of the CP/PWD relationship	<i>"It gave me time to enjoy time with my husband, in a learning situation, and not be concerned with running the show, so to speak. As a caretaker, you, early on, tend to lose that partnership level."</i>
6	Learn something new about PWD	<i>"Her view of a particular picture brought out that she had lost a child."</i>
7	Art	<i>"It really really struck me how creative people are...it is just like taking a key and unlocking a door to people's minds." "[PWD] values the artwork."</i>
8	Other	<i>"She felt very valued."</i>
	<b><i>Were there any particularly stressful moments within the program?</i></b>	
<b>Code</b>	<b>Description</b>	<b>Example</b>
1	No, it provided stress relief	<i>"[The program is] a good outlet for any caregiver, as well as the person with dementia."</i>
2	Logistics (i.e. getting to the museum, parking, PWD participation)	<i>"It was just stressful anyway [not specifically during the program]. Ya know, getting her there, making sure that she participated, that she came..."</i>
3	PWD was not an active participant - quiet - reluctant	<i>"Stressful at first because she kept saying 'I'm not an artist, I'm not talented.' You think you are going to be judged." "It was stressful in the production room."</i>
4	No (without elaboration)	<i>"Not for him and I, no."</i>
5	PWD behaviors (i.e. wandering, attention)	<i>"There's this enjoyable experience but you can't participate in it because your husband is wandering off but then, ya know, later you feel guilty for feeling that way. Very confusing."</i>

	<i>What about your interactions with [insert person's name] after the program – for example, when you were walking/driving home, or talking over dinner. Did you ever have any conversations about your experiences in the program? (Probes: If yes, what did you talk about? What prompted that conversation?)</i>	
<b>Code</b>	<b>Description</b>	<b>Example</b>
1	Limited or no discussion due to no short term memory	<i>"[PWD] enjoyed it but they don't have any short term memory so it is hard to discuss it afterwards."</i>
2	Conversation about the gallery discussions	<i>"We talked about looking at the art in the galleries and discussing with the others in the group."</i>
3	Positive reinforcement	<i>"[to PWD] Wow, that was really great, I'm so glad you did it, look at how excited you are."</i>
4	Finished product	<i>"I think the big takeaway for her was that she had something that she could look at, that she could see that she did. It gave her some validity, she still had a reason to be involved."</i>
5	Positive experience	<i>"We talked about how much pleasure we were getting out of it."</i>
6	Social - Sense of community - New friends	<i>"She felt, I think, enlivened by having an emotional connection to the painting and to the people in the room."</i>
7	Special day out/time out of the house	<i>"Took us out of the house and into an atmosphere that was very much like, um, it was on our level of interest in the arts. It was a very positive experience."</i>
8	Other	<i>"PWD seemed to be more relaxed than usual after each meeting."</i>
	<i>Do you think that your participation in this program changed the way you think or feel about [insert person's name]? (Probes: If yes, in what way? And what was it about the program that you think contributed to that change?)</i>	
<b>Code</b>	<b>Description</b>	<b>Example</b>
1	No change	<i>"No change to how I feel about [PWD], but it is nice to participate in something together."</i>
2	PWD is artistic	<i>"Watching [PWD] be engrossed in art is a beautiful thing."</i>

3	PWD capable - CP sees abilities thought lost in PWD	<i>"Appreciation for abilities that I might have thought previously were lost." "Made me realize to just enjoy her how she is, not be so worried, you know, about stuff she can't do."</i>
4	CP knows/understands PWD better	<i>"It helped me to know her better. And it helped me learn to navigate around some of her initial hesitance in other situations too."</i>
	<b><i>Do you think that your participation in this program had any effect on your relationship with [insert person's name]? (Probes: If yes, what effect do you think it had? What do you think it was about the program that resulted in that effect?)</i></b>	
<b>Code</b>	<b>Description</b>	<b>Example</b>
1	Brought PWD and CP closer	<i>"In a way it brought us closer...the whole experience [contributed to that]."</i>
2	Sharing time/activity together	<i>"[The program] gave us time together." "Spending time together, she and I had never done an art project together before, I gained a better understanding of how she can enjoy herself."</i>
3	Stress relief	<i>"If I didn't have some kind of outlet like that... so healthy for our relationship"</i>
4	Equalization of the CP/PWD relationship	<i>"Incredibly safe, nurturing atmosphere for her. We go on equal footing, great to have something where you are equal partners."</i>
5	Allows PWD to teach	<i>"Gave her a chance to share with me what she thought I should be doing."</i>
6	Social - Sense of community - New friends	<i>"...it kinda felt like a connection that her and I had, you know? We both knew those people" "Extended the time for PWD to feel a part of the community."</i>
7	Special day out/time out of the house	<i>"Good for both of us to get out of the house."</i>
8	Art	<i>"She understood how art can make you feel."</i>
9	No change	<i>"It didn't give the results I expected, for me yes, for him no...I am trying to find things that he might be interested in and he's not."</i>

<b>Code</b>	<b>Description</b>	<b>Example</b>
	<i>Do you feel that participating in this program had any affect on your personal well-being? (Probes: If yes, in what way? What was it about the program that you think contributed to that effect?)</i>	
1	Social - Sense of community - New friends	<i>"Interaction with other people with similar issues." "Definitely, my mood, wonderful for me to be around the other people in similar situations, very supportive."</i>
2	CP doesn't have to be CP	<i>"Gave me time to be with her and not stressed. I didn't have to watch her, it was a refreshment, where I can appreciate her. Gave both opportunities." "It was just nice to have something that was just the two of us to do that somebody else was responsible for."</i>
3	Museum setting	<i>"Great beauty of the place." "We never regret going to an art museum."</i>
4	Stress relief	<i>"Rejuvenated me." "Great stress reliever." "Big lift emotional."</i>
5	Empowerment	<i>"Made me feel empowered... made me feel like at least I'm doing just a little to help it."</i>
6	Special day out/time out of the house	<i>"We get out of the house together, something we both enjoyed. It was a day that we actually looked forward to."</i>
7	Equalization of the CP/PWD relationship	<i>"Everybody is equal."</i>
8	PWD functioning in new ways	<i>"Allowed me to see her functioning in a different way than I had before. " "Definitely, definitely reminds me how complex people are and how there is so much in people's heads. These people who are almost unreachable and see what they produce."</i>
9	Art & Creative inspiration	<i>"Certainly, I get more out of the gallery experience, more inclined to want to pursue artistic endeavors, I feel more creative." "Helped me to really appreciate art." "The power of art in of itself to take the mind to a new dimension."</i>

10	Prolonged good health for PWD	<i>"I think this has prolonged her good health. It has really kept down the quick advance [of the disease]."</i>
11	Yes (without elaboration)	<i>"Yes, definitely."</i>
	<b><i>Can you tell me about a time in this program when you felt particularly rewarded as a care partner?</i></b>	
<b>Code</b>	<b>Description</b>	<b>Example</b>
1	Special day out/time out of the house	<i>"I think it's the best thing we can do and getting out for crying out loud."</i>
2	Sharing time/activity together	<i>"Activities that we both could participate in and get something out of."</i>
3	PWD as an active participant	<i>"When he saw things and he responded." "Seeing the painting my wife was doing" "Not worrying about the final project, but the process of watching my mom paint or do the clay."</i>
4	Finished product	<i>"When we finished the little craft projects, I felt very good about what I had done." "Surprised at how good what we did."</i>
5	PWD's appreciation/enjoyment for the program	<i>"It's an overall thing. She really liked to go and still likes to go.... She's just always really appreciative."</i>
6	Other	<i>"Rewarded in the fact that [the city and museum] were offering programs that were somewhat stimulating to me so that I could grow just a bit during this down hill slide."</i>
	<b><i>Can you tell me about a time in this program when you felt particularly anxious as a care partner?</i></b>	
<b>Code</b>	<b>Description</b>	<b>Example</b>
1	No stress/anxiety experienced	<i>"Never." "I can't think of a time that I felt anxious."</i>
2	Logistics (i.e. getting to the museum, parking, PWD participation)	<i>"Pretty much all the time, moving around the museum, through the crowd and helping her sit down. Working on the art in the production room."</i>
3	Confrontation with reality	<i>"Anxious only in that when he's not making sense, then I realize that this is real."</i>

4	PWD was not an active participant - Quiet and/or reluctant	<i>"Anxiety in the early parts in the art making because she would tense up." "Initially because she was reluctant to participate."</i>
5	PWD behaviors (i.e. wandering, attention)	<i>"[PWD] wandering, but that was only the first one or two visits." "[PWD] made it to the door one time."</i>
6	Other	<i>"At this point you are always anxious."</i>
	<b><i>Did you experience anything unexpected while participating in this program? (Probes: If yes, can you describe that experience? What did it mean to you?)</i></b>	
<b>Code</b>	<b>Description</b>	<b>Example</b>
1	Positive experience	<i>"Higher quality than I expected." "Beyond my expectations of a pleasant experience." "I never felt like it was a waste of time."</i>
2	Social - Sense of community - New friends	<i>"We became close with some of the participants, it was unexpected and very positive." "Maybe seeing [PWD] interact with other gentlemen he didn't know."</i>
3	Art & Creative inspiration	<i>"Getting back into my own work." "Eye opening about art."</i>
4	PWD as an active participant	<i>"[PWD] level of engagement."</i>
5	Museum setting	<i>"A lot of times when I made a few efforts to take PWD to senior centers and that was extremely depressing in several instances, and we did not experience that at all [at the museum]."</i>
6	PWD is artistic	<i>"I'm kind of amazed when he goes in there and does art. I think his is better than most. He doesn't come from an art background."</i>
7	PWD's pleasure	<i>"Sometimes I didn't expect the level of her delight."</i>
8	Welcome/comfortable environment	<i>"Everyone understands the dementia component, and it's still fun, everybody kinda knows what is going on."</i>
9	Nothing unexpected experienced	<i>"I don't think I had expectations at that point, about anything, you know? I just was 'let's get through today. Let's make today a happy day, a good day.'"</i>
10	Other	<i>"I was surprised at how hard it is for her to do something new or different."</i>

	<i>I know that providing care for someone with dementia can be very stressful at times. Did participating in this program add to that stress, alleviate that stress, or a bit of both?</i>	
<b>Code</b>	<b>Description</b>	<b>Example</b>
1	Stress relief	<i>"It has given us a bright spot...it has made all the difference in the world to us." "To me it was very much a relaxing experience."</i>
2	Both - added to and alleviated stress	<i>"Bit of both, only because there was another responsibility and I lost my time."</i>
3	Logistics (i.e. getting to the museum, parking, PWD participation)	<i>" Oh well you know, just getting to the program, the logistics - all that stuff is stressful, but any outing is that way, so nothing particular about this program. And once you got there, you had the sense... that you can sort of sit back because they were directing things and providing the activity and so it was an opportunity to have a break."</i>