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## Subjective Experiences of an Art Museum Engagement Activity for Persons with Early Alzheimer's disease and their Family Caregivers

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## Abstract

**Objective**—To describe the subjective experiences of older adults with early-stage Alzheimer's disease or related cognitive disorders (ADRD) and their family caregivers who participated in an art museum engagement activity.

**Methods**—Four focus groups were conducted with 10 persons with ADRD and 10 family caregivers following the completion one-time, three hour engagement activity. Participants also completed a brief satisfaction survey, and associations were examined using nonparametric statistics.

**Results**—Three key themes were identified: cognitive stimulation, social connections, and a sense of self. In addition, we identified programmatic issues such as activity-specific concerns and program logistics that could help improve future art program offerings. Past experience with art

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and perceived social cohesion were correlated with participants' overall satisfaction with the program.

**Discussion**—Efforts aimed at improving the quality of life of those with Alzheimer's and their family caregivers should consider the potential role of art museums.

#### Keywords

Alzheimer's disease; art museums; caregivers; social activities; quality of life

More than 5 million people age 65 and older in the U.S. have been diagnosed with Alzheimer's disease (AD) and other dementias.<sup>1</sup> These individuals as well as their family caregivers encounter many barriers and challenges that can result in lowered quality of life. Of particular concern, persons with dementia and their family caregivers are at an increased risk for social isolation and withdrawal.<sup>2–4</sup> One way to foster social interactions among this population is by encouraging participation in arts and cultural programs, such as visiting art museums. Very few studies have examined the potential role that cultural venues like art museums may play in improving the quality of life for persons with AD and their caregivers. This study explores the subjective experiences of older adults with early stage Alzheimer's disease or related cognitive disorders (ADRD) and their family caregivers who participated in an art engagement activity at The Andy Warhol Museum.

## Background

Individuals with early-stage dementia and their family caregivers often encounter stigma associated with the recent disease diagnosis and symptoms.<sup>5</sup> This often results in withdrawing from everyday social opportunities and an increased risk of socially isolation.<sup>6</sup> Social isolation in this population has been found to be associated with decreased quality of life, including increased depressive symptoms, reduced activity participation and poorer health and cognitive function.<sup>7,8</sup>

Arts and cultural programs, specifically participatory-based art interventions, may provide unique opportunities to enhance the quality of life of those living with AD and other dementias and their family caregivers. Participatory-based arts typically involved more interactive and hands-on participation, while non-participatory arts tend to be more passive activities (e.g., art making and discussion versus observing art only).<sup>9</sup> The majority of research on art-based interventions for persons with dementia tends to focus on participatory-based art interventions as these are believed to be more beneficial for overall health and well-being.<sup>10,11</sup> Further support for the positive health outcomes in late-life associated with art engagement comes from research on a myriad of participatory-based arts interventions.<sup>9</sup> including music and singing in choirs.<sup>12,13</sup> theatre programs.<sup>14</sup> and art making.<sup>15</sup> There is also a substantial amount of research on participatory-based art interventions for those with dementia; however, the majority of these interventions have been done in in-patient or long-term care settings and often they don't include caregivers. Art therapy programs for older adults with dementia are typically comprised of music, art, dancing/movement, drama or mixed modes,<sup>16,17</sup> and there is some evidence for the potential positive effects on behavioral and psychological health outcomes. For example, some

Reasons for the potential beneficial effects of art interventions remain unclear; however, there seems to be evidence that being creative could have healing effects, especially with regards to adverse physiological and psychological outcomes, in younger populations and in those with diverse diseases.<sup>11</sup> For older adults with dementia, engaging in art activities may provide opportunities for self-expression, mastery, pleasure, and social interactions; and perhaps it is a holistic approach that helps to treat various dimensions of health and wellbeing.<sup>19</sup> For instance, a recent study by Ullan and colleagues found that art education workshops with individuals with dementia resulted in several positive aspects, including active engagement, learning, enjoyment and a better self-image.<sup>20</sup> Another communitybased art program, Memories in the Making, involves an expressive art program for persons with early and middle stages of AD. <sup>21,22</sup> This program has found improvements in several domains of well-being, including pleasure, self-esteem, and sustained interest. There is a need for further research on participatory-based art programs, including those in community-based settings, such as art museums and galleries. Further research is also needed to identify what makes these programs meaningful to those with dementia and their family caregivers.<sup>17</sup>

Art museums are an under tapped resource for public health interventions and health promotion,<sup>10</sup> and these cultural venues could also be especially relevant for those with AD and other dementias and their family caregivers. Further, providing health-based interventions in museums may offer unique advantages in that they may be less stigmatizing for participants and caregivers since they focus less on the disease diagnosis and treatment. Art museums may also offer a unique community setting that is engaging, socially inclusive and may enhance emotional well-being.<sup>10</sup> Several recent studies have found that older adults with dementia were able to actively engage in art discussions and activities at museums and galleries.<sup>23–25</sup> These studies have suggested that making art accessible to participants with dementia and their family caregivers may offer several potential benefits, such as increased self-esteem, cognitive stimulation, and social interaction.<sup>23,26</sup> For instance, a recent study by Camic and colleagues found that an 8-week gallery-based intervention for persons with dementia and their caregivers provided opportunities for social inclusion and interactions, reinforced the relationship between caregivers and persons with dementia, and created opportunities for learning and cognitive stimulation.<sup>23</sup>

Many art museums have started to reach out to individuals and families affected by dementia. Since 2006, The Museum of Modern Art (MoMA) in New York has been offering Meet Me at MoMA, a model program for other museums that involves private, small group tours for individuals with early to middle stages of AD and their caregivers.<sup>27</sup> These monthly, guided tours are for 90-minutes and include an interactive discussion of modern art from all over the world. Findings from an evaluation of Meet Me at MoMA have suggested

that the program provides individuals with dementia and their family members with greater opportunities for intellectual stimulation, social interactions, shared experiences, as well as opportunities to interact in a supportive and an accepting environment.<sup>26</sup>

Despite previous findings on the feasibility and potential benefits of art museums and art programs, less is known about the important aspects of these programs for persons with early-stage AD and their family caregivers. Satisfaction with art programs most likely varies based on older adults with early-stage AD and their family members' previous experiences; and there is a need for a greater understanding of factors that may influence their overall interest and satisfaction with art museum programs. Thus, the purpose of this study was to describe the subjective views and experiences regarding participation in a one-time, art museum engagement activity by community-dwelling older adults with early-stage ADRD and their family caregivers. Our specific research aims were to: 1) Identify aspects of the art museum engagement activity that participants found enjoyable; 2) Determine how the activity could be improved for future participants; 3) Explore whether group cohesion shaped participants' satisfaction with the program; and 4) Examine whether past experience with art was associated with participants' overall experience.

## Methods

#### Design

This study investigated the experiences of individuals with early-stage ADRD and their family caregivers who participated in a one-time art museum engagement activity at The Andy Warhol Museum in Pittsburgh, Pennsylvania. This was a cross-sectional, qualitative research study, which involved participants with early-stage ADRD and their family caregivers completing a brief satisfaction survey and then participating in a focus group interview. A total of 4 focus groups were held during the study period. Verbal informed consent was obtained from all participants prior to completing the satisfaction survey and focus group interviews. This study was approved by the University of Pittsburgh's Institutional Review Board.

#### Art Museum Engagement Activity

The art museum engagement activity was established through an existing partnership between The Andy Warhol Museum and the University of Pittsburgh Alzheimer's Disease Research Center (ADRC), which is a part of a broader collaboration between the University of Pittsburgh Schools of the Health Sciences and the Carnegie Museums of Pittsburgh. This partnership was initiated by an artist residency project engaging a contemporary Brazilian artist, José Rufino, who deals with issues of memory and loss in his work. During Rufino's artist residency project, he met and worked with persons with dementia and their family members, as well as staff and researchers from both the ADRC and The Warhol Museum. In parallel to the planning the Rufino's artist residency project, a number of workshops and staff training sessions were held to establish further collaborations and to familiarize respective staffs with both the museum and the ADRC. This included select staff of The Warhol Museum observing a diagnostic evaluation at the ADRC and meeting with ADRC

staff members who answered questions about dementia and provided additional insight on what to expect and possible behaviors with this population.

These earlier collaborations during Rufino's residency project resulted in staff from The Warhol Museum working with the ADRC's Education and Information Core to develop a small group-based art museum engagement activity for patients and families affected by dementia. The art engagement program was modeled after New York's Meet Me at MoMA program with regards to the guided art discussions, but it was also enhanced by adding an art making project. The art engagement activity began with a guided tour where participants spent about an hour looking at four different artworks by Andy Warhol. Participants were provided with a stool to sit upon while viewing the paintings. Elevators were accessible for those with mobility impairments. As participants together viewed a work of art, an inquirybased discussion was led by one of the museum's education curators or staff. The inquirybased discussion involved encouraging participants to look at an artwork and describe what they saw. To foster richer discussions, additional guiding questions were used, such as "What word first comes to mind when looking at this artwork?"; "What is the mood of this artwork?"; "Do the colors make you think of a certain era?"; and "How would you describe Andy's personality based on this artwork?" These questions tended to be context specific with regards to the individual artworks at The Andy Warhol Museum, and participants with ADRD did not seem to have any challenges with understanding and responding to the questions. Further, the pieces of artwork were carefully chosen by the curators so that they would stimulate discussion.

Following the guided tour, participants were led to the art studio where they participated in a 2 hour art-making activity inspired by Andy Warhol. Participants created their own unique canvas tote bags using the same photographic silkscreen technique Warhol used to underpaint and screen print his own iconic artworks. Immediately following the completion of the art-making activity, older adults with ADRD and their family caregivers were asked to first complete a brief satisfaction survey and then participate in a focus group interview.

#### Sample and Setting

Participation in the art engagement activity was limited to dyads (person with early-stage ADRD and their family caregiver) seen at the ADRC. Family caregivers tended to be a spouse/significant other or a related family member, such as a son or daughter. Participants were notified about the art engagement activity by telephone and asked if they would also be willing to participate in a brief focus group interview following the activity. All participants approached to participate in this study agreed to participate. Four art engagement activity sessions were held between March 2011 and September 2011. No exclusion criteria were in place; however, the sample was limited to those dyads with their own transportation to the museum and those who were physically able to participate in the walking part of the guided tour. All satisfaction surveys and focus groups were conducted in The Warhol Museum's art studio. Participants were provided with light refreshments and free parking.

A total of 20 participants participated in the art engagement activity during this time and focus groups following the activity. All focus group participants were current ADRC participants or family caregivers. Ten participants had early-stage AD (n = 8) or related

cognitive disorders (n = 2) based on a prior ADRC evaluation, and none of the family caregivers (n = 10) had impaired cognition. Each focus group was conducted with between 4 and 7 participants. Of the 10 older adults with ADRD, 8 were 60 years or older, half were female, and 7 were Caucasian and 3 were African American. For the 10 family caregivers, 6 were 60 years or older, more than half were female (n = 6), and 8 were Caucasian and 2 were African American.

#### Satisfaction Survey

Our satisfaction survey was designed to assess participants overall satisfaction with the program, and was not previously administered or validated prior (Table 1). The survey was comprised of 18 self-report items: three demographic questions (age [<60 or 60], and experiencing memory loss or being a caregiver), 9-items on satisfaction with program, including questions on aspects that were most enjoyable to participants and past experience with art, and a 6-item perceived social cohesion scale (PCS). The PCS was developed to examine an individual's sense of belonging to a group and his or her feelings (morale) about being a member of the group.<sup>28,29</sup> All questions were assessed on a Likert scale (1 to 5, strongly disagree to strongly agree).

## **Focus Group Procedure**

Focus groups were conducted by a trained facilitator using a script to guide the interview. Specific questions were chosen to elicit thoughts and feelings about the experience and generate ideas for how to improve the activity for future participants. Sample questions included: "What were your expectations for today?" "What do you think about discussing the paintings as a group?", and "What things can we do to improve this activity?" (See Table 1 for further details). Throughout the interview the facilitator encouraged participants with ADRD and their family caregivers to talk and share their views. The focus group interviews lasted about 30 minutes on average. Field notes were taken by an ADRC staff member to provide further contextual detail. All interviews were audio recorded and transcribed verbatim.

#### **Data Analysis**

We used descriptive and nonparametric statistics to analyze the demographic and satisfaction survey data. We used a Mann-Whitney U test to determine whether responses to aspects of the art museum engagement activity that participants found enjoyable differed by participant type; and to test correlations between the PCS and program satisfaction, we used a Spearman rank-order test. The significance level was set at p < 0.05. Our analysis of the focus group data involved thematic analysis of the transcriptions from each focus group and the handwritten notes taken by the ADRC staff member, informed by methods of grounded theory.<sup>30,31</sup> The research team reviewed focus group transcripts and developed a coding scheme, which involved an iterative process of coding and reviewing the data until saturation was reached. Analysis began with an open-coding process that involved reading the transcripts and labeling phrases, sentences or larger chunks of text. Codes were assigned based on the important concepts that emerged from the interviews rather than specific interview questions or predefined categories. The next step involved axial coding where codes were condensed and/or combined into larger categories to reflect the major themes.

During this process, investigators discussed identified codes and themes in order to resolve code divergence and decide upon final themes. This led to further revision and refinement of themes until the core categories and final themes were decided upon.

## Findings

## **Satisfaction Survey Results**

Nineteen of the 20 participants completed all questions on the satisfaction survey (Table 2). About 68% of participants had past experienced with visiting art museums or making art. Regarding participants' satisfaction with the art engagement activity, 84% of participants said that the experience met their expectations, and 89% said they would like to attend the program again. On average participants rated the program highly at 4.51 out of 5.00. Looking at aspects that participants enjoyed most, participants rated art making highest (M = 4.74 out of 5.00) followed by the group interactions (M = 4.53) and the guided art discussion (M = 4.16).

Exploring for any differences between older adults with early-stage ADRD and family caregivers, we found that persons with ADRD rated the group interactions higher (4.90) than caregivers (4.11), (p = 0.028, Mann–Whitney U Test). There were no other significant differences between participant type and ratings for the other aspects of the art museum engagement activity. Next, we looked at whether past experience with art was correlated with participants' overall satisfaction with the program. We found that past experience with visiting art museums or creating art was associated with greater overall program satisfaction (23.54) compared to those without previous experience (20.33), (p = 0.029, Mann–Whitney U Test).

Examining group cohesion via the PCS, participants' average level of cohesion for belonging and morale were 4.15 and 4.31, respectively. There were no significant differences between participant type and their ratings for feelings of belonging and morale (p-values > 0.50); persons with ADRD rated their level of belonging at 4.27 and morale at 4.33 compared to 4.03 and 4.30, respectively, for family caregivers. Exploring whether cohesion was related to participants' overall satisfaction with the program, we found a correlation between overall satisfaction with the program and feelings of belonging and morale (Spearman's r = 0.79, p < 0.01, r = 0.65, p < 0.01, respectively).

#### **Key Themes from Focus Group Interviews**

There were five overall themes that were identified from the thematic analysis of the focus group interviews (Table 3). Three key themes represented the aspects of the art museum engagement activity that participants found most enjoyable: cognitive stimulation, social connections, and self-esteem. There were also two additional themes that reflected the programmatic concerns or ways to improve future art engagement programs: activity-related concerns and logistical issues. Further, participants' comments were specific to how the art engagement activity was tailored for those with AD and other dementias.

**Cognitive Stimulation**—This theme consisted of three categories that represented the mental stimulation provided by the art engagement activity: the novelty of the experience,

the learning of new skills, and how the artworks at The Andy Warhol Museum provided opportunities for participants to reminisce about the past (i.e., nostalgic). When talking about the art engagement activity, participants spontaneously speculated about how the activity was novel and could be important for stimulating their minds by teaching them new things. Older adults with ADRD noted that the guided art discussion was something very novel to them. After being asked about what they liked most about the art discussion, one participant with ADRD stated the following about the guided discussion: "[T]hat kind of opened your eyes a little bit to interpreting something new or how you look at things." Family caregivers also noted that the art engagement activity was a new experience and would most likely be cognitively stimulating:

My wife died of dementia.... The family was constantly trying to find ways, particularly in the earlier stages, to find ways to stimulate her. Trying to keep her interested in life, you know? It seems to me that the kind of way that we went around today was a great stimulator. It was done in a group and it had a lot of different ideas being suggested to make it more interesting... Suppose when my wife was in her early stages, if some organization would take five or six or tens victims of dementia and bring them around in that kind of way, that would be a great stimulator.

Both family caregivers and participants with ADRD remarked favorably about the artmaking activity that involved painting and silkscreen printing. Most participants mentioned the activity as one of their favorite aspects of the program. They also talked about it being cognitively engaging in regards to allowing them to be creative and learn a new skill. For instance, one participant with ADRD said the following:

It just feels so good to be creative. It feels, and to just, I like to look at other people and see what they are doing. And um, we're all doing the same thing when you think about it, but it came out... If there were eight people around here, eight people did eight different things.

Another participant with ADRD also talked about learning how to do the silk screening process. They mentioned the following: "We knew that we were going to do a silk screen and make, put is on the tote bag. I was just trying to figure out how to do it, and I never knew how to do it. So that's something I learned today."

Several of the artworks that participants viewed and discussed during the guided tour included iconic paintings, such as Jacqueline Kennedy Onassis and Muhamad Ali. Participants commented on how these artworks reminded them of the past. For instance, one family caregiver commented that the material evoked feelings of nostalgia. For example: "Andy Warhol was somebody special though, his work ... fascinates you. Also he's dealing with subject matter that is very common and open. We all have lived through some of this, you know." Participants with ADRD also seemed to agree with the activity being nostalgic and evoking a personal meaning. For instance, one individual with ADRD said that "Everybody connects to an experience like this with something in his personal life." While another participant with ADRD had the following to say: "Yea, Jacqueline, the picture upstairs. When I saw that picture with her little pill box, I got teary eyed because that really brought back memories of when that originally happened."

**Social Connections**—This theme represented the social connections or bonding that participants experienced during the art engagement activity. Categories identified within this theme included participants' feelings of being connected with others and how participants' experiences were shaped by others. Several participants mentioned that being connected or bonding with others was an important aspect of the art engagement activity. This seemed to be common for both older adults with ADRD and their family caregivers. Participants with ADRD reflected on how the activity allowed them to bond with others that were similar to them. For instance, one older adult with ADRD said, "Closeness, there's a closeness. That you know that you experience and somebody experience so you know what each other's experiencing." This bond was also reflected in participants' reflections on the sentiment of camaraderie and commonality with others through a shared disease and experience.

And I love her [another participant with ADRD] so much and we met before, and we both have the same disease; and I am younger than you, but you're doing great, and so now I think, 'Well, I'm gonna do great too because you're my inspiration!' You are!

A number of caregivers also talked about the importance of the social aspects of the art engagement activity and the opportunity to bond and connect with others who are facing similar challenges. For instance, one caregiver said, "Other caregivers and the patients, it's just developing that bond, you know, art's a good medium to do that for us... I think that's an important part of the journey that we're on." Another family caregiver also expressed how the art engagement activity allowed them to connect with others. "We weren't just talking about art, we were talking about life. So many things that...connecting the artists to it, connecting other people to it, and talking about the motives of the persons who were being painted."

The social interactions also helped to shaped participants overall experience. For instance, one older adult with ADRD specifically talked about how the experience was socially rewarding and that their experience was shaped by other members in the group.

I liked that there are different kinds of people here. So there's younger, there's older, there's professionals, there's retired people. And you kind of get a feel, if I am looking at something, I might look at it from my age and who I am, where as a younger person may look at it totally different. So it's kind of like learning different things about the art through different people. So I kind of like that.

Caregivers also mentioned that doing the activity in the group provided for a much richer experience and made it more enjoyable. One family caregiver stated:

I think the element of the group makes it easier to work on something of this kind. I think you do get a feeling of recreation that's involved and interpersonal relationships; where as if you do it on your own, it's more stilted.

**Self-esteem**—This theme was characterized by the positive feelings that were expressed by participants when talking about the art engagement activity. Three overall categories were identified: feelings of being accepted or normalcy, feelings of autonomy, mastery or control, and having a sense of importance or feeling special. Many of the older adults with

ADRD and family caregivers seemed to stress that the activity also provided a sense of normalcy and acceptance. One family caregiver said the following, "She [curator] let all of us talk and she was very, uh, accepting of what people were saying was worth talking about." This sentiment of acceptance was also expressed by family caregivers. The art engagement activity seemed to be particularly welcoming to older adults' with ADRD and it allowed them to participate in a meaningful way.

[P]eople with Alzheimer's you know you can be a part of art and be part of the process. Mildly impaired or even more impaired, you know you can have an opinion if you like something or not, so it's a way to involve a lot of different... art touches a lot of different people, you can even express themselves.

The activity also provided opportunities for autonomy or to be independent from the rest of the group. For instance, one older adult with ADRD highlighted that an important part of the activity was the opportunity to have a different perspective than the rest of the group.

[Y]ou can have a different opinion and I can disagree with you, and I like that. Instead of everyone agreeing, I like seeing different challenges and opinions. I just think that's good.

In addition to the autonomous aspect of the activity, there also seemed to be a sense of pride from completing the art-making activity. It seemed to provide participants with a sense of mastery and an opportunity to practice a newly learned skilled. One participant with ADRD mentioned,

To know how to do it [art making]! You never think how they do get this done. But to see how it gets done and do it ourselves makes you feel good because you did it. Nobody painted this for us. We did it ourselves! You know, and when people look at this. I made this. I made this at The Andy Warhol Museum. I'm real tickled about that.

Older adults with ADRD frequently mentioned how the activity made them feel special. One older adult with ADRD shared, "I felt special because these other people, they pay to come in...but we had guides. Makes you think you're real special today." Family caregivers also talked about how the activity made them feel special and important. Attending the art engagement activity may have provided an escape for family caregivers from everyday stressors and challenges of caring for a loved one with ADRD. For instance, one family caregiver said, "I think that's really important how we feel, feeling special. You know, on a day to day basis life is kind of a drag. It's like, it's not special. Finally, I feel special." Similar to other participants' depictions of feeling special, many of the older adults with ADRD and family caregivers alike conveyed how the opportunity to participate in the art engagement activity gave them something to look forward to. One caregiver talked about this in detail,

What was good for us was, because [my husband with ADRD], I think that you'll admit that your memory is somewhat short. Three minutes max. Okay, so he kept asking me "Why? What are we doing today? Where we going?" So I'd say, "You're my ticket to The Andy Warhol Museum! Because of you, I'm getting

there." And because of that he felt that was okay, right? And then he was willing to come. That was really nice.

**Programmatic Concerns**—Participants who attended the art engagement activity also discussed several programmatic concerns, specifically **activity-related concerns** and **logistical issues**. Activity-related concerns include those aspects that seemed important for designing the activities for older adults with ADRD. This theme included four categories: the small group setting, the hands-on art-making activity and having trained facilitators. Doing the activities in small groups seemed to be one of the aspects that were especially important for older adults with ADRD. Several suggested that it made participants feel more comfortable and allowed participants to interact more closely.

It's the small-group setting that's definitely a plus; as opposed to a big group where there is a lot of confusion, information can't be processed real well, so it's definitely in the best interest to have small, intimate groups.

Another important aspect of the activities involved having the hands-on aspects. Most of the participants spoke highly of the silkscreening process and some mentioned that they would have liked to do more or paint other images. Family caregivers especially liked that it was a hands-on activity; and several mentioned that they hadn't been to a museum or painted in quite a while. Furthermore, several participants expressed that they would have liked to see and discuss more artworks during the guided discussion.

The Museum curators and staff also seemed to be a vital part of the experience. Both older adults with ADRD and family caregivers mentioned that the Museum staff played an important role in keeping the activity interesting and helping them to feel comfortable and accepted. One participant with ADRD mentioned, "Young people, they are really good. [The Museum staff] are really good. I enjoy them so much. They're real nice, and courteous and kind. And make you feel real welcome here."

With regards to how the art engagement activity could be improved, some participants mentioned that it would have been helpful to have a better communication. Improving communication or a more detailed description of the activities may have eased some of the participants' reservations about participating; and it might help to minimize concerns about the inability to actively participate. One family caregiver suggested that it might also be helpful to customize the activities based on older adults with ADRD's disease stage.

Logistical issues represented planning or other related issues that made the activity more feasible for participants. This theme was comprised of three categories: timing and length of program, transportation and parking, and access to refreshments. With regards to timing and length of the program, starting the program later in the morning (10:30 a.m.) seemed important to participants, especially family caregivers, because it allowed them to avoid city traffic and get home at a reasonable time (the program ended by 1:30 p.m.). Several family caregivers mentioned that transportation could be an important barrier for other families. For instance, one caregiver said, "[I]f they had a bus that would bring them down and pick them up. Some people just don't want to leave their house...." Participants also highlighted that the refreshments were nice, and while not necessary, they provided a more social feeling.

## Discussion

Our findings support that art museums and art engagement activities are valuable to and provide a unique social and cultural experience for individuals with memory challenges and their family caregivers. From our focus group interviews with older adults with early-stage ADRD and family caregivers, we identified three major themes that reflected the key aspects of the program that were important for participants: cognitive stimulation, social connections, and self-esteem. In addition, several programmatic concerns were identified, such as the small-group setting, having hands-on activities, and thinking about timing and access to transportation.

We also found that persons with ADRD rated enjoying the group interactions more than their family caregivers. This highlights the potential importance of social interactions for those with dementia. Other studies examining the potential impact of art programs for persons with dementia and have found that social interactions were important for shaping the experience<sup>20</sup> and creating bonds between the person with dementia and their caregiver.<sup>23</sup> Participants' overall satisfaction with the program was also related with perceived social cohesion, including a greater sense of belonging to the group and positive feelings of morale. This may suggest the importance of overall group dynamics in the art engagement activity, and further supports our qualitative findings on the importance of the small-group setting and how the participant's experience was shaped by other group members during the activity.

A unique aspect of the art museum engagement activity was that older adults with ADRD and their family caregivers consistently indicated that the experience provided them with cognitively stimulating opportunities, such as being creative, reminiscing about the past, as well as learning, practicing and mastering new skills. Further research is needed on whether museum-based arts interventions could offer cognitive benefits to those with dementia. There is some evidence from art therapy interventions showing improvements in attention, concentration, and verbal communication; however, these findings are based on small samples and non-experimental research designs.<sup>32</sup>

Often the behavioral and cognitive symptoms associated with dementia result in older adults with dementia and their family caregivers withdrawing from social activities and becoming social isolated.<sup>4</sup> Art museums may provide an environment where individuals with ADRD and their family members can interact with others; this environment should be welcoming and supportive of their unique needs while allowing them to be independent and expressive. We also found that this environment can facilitate cohesion among older adults with ADRD and their caregivers, especially when activities are done in small groups, which is supported by findings from other qualitative studies.<sup>23</sup> This could be an important element to consider when designing art-related programs for those with cognitive challenges; it may also allow for more meaningful social interactions and greater satisfaction with the program.

This study offers preliminary evidence that the art engagement activity at The Andy Warhol Museum may also have the potential to promote older adults with early-stage dementia and their family caregivers' psychological and emotional well-being. Past research on the

benefits of art therapy have suggested that these art-related activities could have important implications for improving older adults with dementia's mood, self-esteem and other emotional health outcomes. Further, several studies have demonstrated potential emotional health benefits from participatory-based art interventions, including those offered in museum and gallery settings.<sup>23–26</sup> These studies suggest that the social setting of museums and galleries is ideal for interventions aimed at promoting social inclusion, a positive self-image and improved mood. Hence, art museums should be considered as a possible avenue for promoting psychological and other quality of life outcomes in those with dementia and their family caregivers, and future research on these efforts is greatly needed.

These findings also apply to those interested in designing a museum-based intervention for older persons with dementia. Researchers and community stakeholders should consider art museums as a potential setting for community-based interventions as they may help to encourage learning and mental stimulation, meaningful social connections and promote quality of life, such as self-esteem and mood. It may also be important to consider using a small-group setting for the intervention activities. Training staff on how to tailor art activities for those with dementias and maintaining a collaborative relationship with clinicians and researchers also seem important. For example, one determinant of this program's success may have had to do with the early and sustained collaborations between the University of Pittsburgh ADRC Education and Information Core and The Andy Warhol Museum. Both older adults with ADRD and family caregivers stated that The Warhol Museum curators and staff played an important role in making them feel at ease and that the activities were designed in a way that kept them engaged. Thus, those designing art museum-based interventions for older adults with dementia and their family caregivers should consider collaborating with trained providers to better tailor programs. Further, we found that this collaboration has allowed the program to be sustained and it continues to be well received.

Future museum-based interventions for persons with ADRD and their family caregivers may also want to consider multiple sessions. For example, this study was limited in that it was based on a one-time visit. Other studies have utilized multiple sessions,<sup>20,23</sup> which might have more lasting effects on quality of life outcomes as well as aid in identifying important long-term programmatic issues. In order to better assess the potential effectiveness of the art engagement activity, a comparison group, such as a wait-list control group, should also be considered as it would allow for a comparison and more definitive findings on the programs' impact.

There are several additional strengths and limitations of our study that should be noted. Our study was primarily inductive and based on accounts from a small sample of older adults with early-stage ADRD and their family caregivers; this is also a strength since we were able to collect richer and more detailed descriptions of participants' subjective experiences. It should also be noted that participants in the art museum engagement activity most likely attended because they had a personal interest in art or visiting museums. This participation bias most likely influenced our findings, such as a favorable opinion of the program and key themes on the enjoyable program aspects. Further, our conclusions about the potential program aspects are suggestive of positive benefits, but future research using more objective

measures is needed to substantiate these claims. In preparing for our study, we found that there were very few assessment tools currently available to evaluate the impact of art-related interventions. Other evaluation tools should be considered, and it is possible that our findings may have influenced by a ceiling effect since the majority of responses were "agree" or "strongly agree." There is a need for developing new measures and tools that are more sensitive to the potential impact of art interventions for those with dementia and their family caregivers.<sup>33</sup>

#### Conclusion

With the expected rise in the number of older adults with dementia, there is a need for rethinking about how we treat individuals with dementia and their families; it most likely requires a greater focus on more holistic and non-pharmacological approaches.<sup>34</sup> Social and cultural programs, such as those offered at art museums, seem to be an important community resource that could be leveraged to enhance quality of life in those with dementia and their family caregivers. However, there is need for a further research to identify measures and assessment tools that can adequately evaluate the impact of arts and cultural interventions for those with dementia and their family caregivers. Our study has shown that a local art museum engagement activity for those with early-stage ADRD and their family caregivers was feasible, and provided participants with opportunities for socialization, creativity, learning, and enjoyment. Art museums may offer a protected space where older adults with cognitive challenges can interact in an environment where it is less about the illness that frames them and more about connecting with the art and other people.

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## Table 1

## Focus Group Script

1 2		vere you overall impressions of this group activity?		
2	What w			
		What were your expectations for today's visit?		
	a.	Probe: How did today's experience meet your expectations?		
	b.	Probe: How did today's experience differ from your expectations?		
	c.	Probe: Did anything surprise you about your experience today?		
3	How has today's visit changed your thinking about looking at art?			
	a.	Probe: Would you want to do this activity again?		
	b.	Probe: Do you think you will visit other art museums now?		
4	What aspects of today's visit to the Warhol Museum did you find the most enjoyable?			
	a.	Probe: What aspects of this activity did you like?		
	b.	Probe: What did you think about art-making in the studio?		
	c.	Probe: What did you think about the group discussion?		
	d.	Probe: How did looking at art in a group impact your experience?		
5	How did you and your love one enjoy this activity?			
6	Are there things that could improve this activity?			
7	Would you recommend this activity to others like yourselves?			

a. Probe: Why or why not?

#### Table 2

## Satisfaction Survey Results by Participant Type

Questions	Overall Mean, (SD)	ADRD Mean, (SD)	Family Caregivers Mean, (SD)
Program Satisfaction Question			
I enjoyed the interactions that I had with other members of the group.	4.53 (0.70)	4.90 (0.32)	4.11 (0.78)*
I enjoyed discussing art as a group.	4.16 (0.96)	4.30 (1.06)	4.00 (0.87)
I have past experience with visiting art museums or creating art.	3.68 (1.29)	3.80 (1.32)	3.56 (1.33)
I would like to come to another Warhol Artistic Expression activity.	4.53 (0.70)	4.60 (0.70)	4.44 (0.73)
This experience met my expectations.	4.53 (0.77)	4.70 (0.68)	4.33 (0.87)
My guest or family member enjoyed the activity.	4.53 (0.61)	4.70 (0.48)	4.33 (0.71)
I enjoyed the discussion of the art pieces.	4.47 (0.61)	4.60 (0.70)	4.33 (0.50)
I enjoyed the art making activity.	4.74 (0.45)	4.70 (0.48)	4.78 (0.44)
I enjoyed the Warhol Artistic Expression activity.	4.63 (0.50)	4.60 (0.52)	4.67 (0.50)
Overall Satisfaction Score	22.53 (2.65)	23.10 (2.85)	21.89 (2.42)
Perceived Cohesion Scale			
I feel that I belong to this group.	4.10 (1.12)	4.20 (1.03)	4.00 (1.25)
I am happy to be part of this group.	4.60 (0.68)	4.50 (0.71)	4.70 (0.68)
I see myself as part of this group.	4.25 (1.16)	4.30 (1.16)	4.20 (1.32)
This group is one of the best anywhere.	3.95 (0.83)	4.00 (0.94)	3.90 (0.74)
I feel that I am a member of this group.	4.10 (1.17)	4.30 (0.95)	3.90 (1.37)
I am content to be part of this group.	4.40 (0.88)	4.50 (0.71)	4.30 (1.06)
Total Score	21.88 (4.76)	22.20 (4.53)	21.56 (5.19)
Belonging	12.45 (3.35)	12.80 (2.97)	12.10 (3.81)
Morale	12.95 (2.16)	13.0 (2.16)	12.90 (2.28)

Notes: Questions were rated on a 5-point Likert scale (1 to 5, strongly disagree to strongly agree);

p-value < 0.05

## Table 3

## Themes and categories from focus group interviews

Themes	Definition	Categories
Enjoyable aspects		
Cognitive Stimulation	Aspects of the activity that were considered to be mentally stimulating	Learning Novelty of the experience Reminiscing about the past or being nostalgic
Social connections	Represents the social connections or bonding that participants experienced.	Connecting with others How others shaped the experience
Self-esteem	Positive feelings or emotions expressed by participants when talking about the art engagement activity.	Feeling accepted or a sense of normalcy A sense of autonomy, control or mastery Feeling special or important
Programmatic Concerns		
Activity-related concerns	Aspects that seemed important for designing the activities for older adults with dementia	Importance of small groups Hands-on art-making activity Trained facilitators Better communication Customizing to disease sage
Logistical issues	Planning or related issues that made the activity more feasible for participants.	Timing and length of program Transportation and parking Access to refreshments