Agency Restored, Dignity Preserved: Lessons Learned as an Art Historian About Enhancing Quality of Life for People with Dementia

By Susan Shifrin, PhD

"Carl D. (right) and ARTZ Philadelphia facilitator Justine Stehle, engaging with works by artist Jes Gamble in Main Line Art Center exhibition [ital: Happily Ever After], October 2017. Photo credit: ARTZ Philadelphia."

I. *"We conceive of [a person] as a special kind of agent, an agent-plus, who can also make life plans, hold values, choose…"*

— Charles Taylor[i]

This article at its core is about reinventing what agency within cultural settings—indeed, within their worlds at large—should look and feel like for people living with dementia. It is about rehabilitating our approach to and understanding of people who have experienced the stigmas of dementia diagnoses, about purposefully setting aside what some have referred to as the "master status"[ii] of the diagnosis and restoring the status of human identity and dignity.

AGENCY CONSTRAINED WITHIN MUSEUM WALLS

As a young professional working in art museums in Boston and New York in the 1980s, I was often struck—and made uncomfortable—by the ways in which museums routinely deprived their visitors of agency, just as they did so many of the communities in which the objects displayed in museum galleries had lived their first lives. Didactic labels hung near objects too often emphasized through exclusionary language the specialized knowledge of the museum staff who had written them and - by implication - the innate and inevitable ignorance of the visitors who found themselves more outside-the-know after reading them than they had been before they started. Viewers were not brought into closer connection with the objects this way, but distanced from them even more, reminded uncomfortably of their lack of expertise and agency in making sense and meaning of culture.

By contrast, my doctoral dissertation in art history examined how the responses of viewers to the visual and textual portraits of a boundary-crossing 17th-century woman shaped the narratives around her portraits and—equally—the stories told about the woman they pictured. The exhibitions I curated during the 1990s and 2000s were often structured around questions that called for active interventions by the people who visited them. For example, an exhibition about censorship, Drawing the Curtain (Who or What Are We Protecting?), co-curated with students and an art historian colleague, asked viewers to choose whether or not to push curtains aside or awaken sleeping laptops in order to see works that had been declared obscene by arbiters of one political persuasion or another. The paramount agency of the viewer—honoring the integrity and power of viewer response—was the driving force in my practice of art history as a researcher and educator.

In very practical ways, prioritizing viewer agency shaped the programs that I oversaw for more than a decade as the museum educator at the Philip and Muriel Berman Museum of Art at Ursinus College, located in a suburb of Philadelphia, PA. From 2002 to 2013, we trained K-12 and college students through our peer docent program to look slowly, closely, and thoughtfully at works of art and then, moving backwards through self-reflection, develop questions and prompts based on their own observations that might help to engage other students in interacting with the same works of art. The process was designed to help young viewers build meaningful relationships with those works grounded in active insights rather than passive reception of information. The peer docent program became one of the museum's hallmark initiatives.[iii]

MAKING THE MUSEUM PERMEABLE TO AGENCY

In 2002, the Board of Directors of the American Alliance of Museums passed a "Museums & Community Resolution" that characterized museums as "community cornerstones, …treasured places where memories are created and shared. [They] can also transform the way people view the world and encourage the expression of differing points of view," and thus might "assume an expanded civic role in society."[iv] The AAM's new list of operating principles called for museums to create new relationships with communities "based upon expanded mutual understanding, recognition of common concerns and interests, and a desire to collaborate for the benefit of the community [my emphasis]."[v]

This newly codified challenge to museums to collaborate with their communities seemed to call out the centuries of exclusionary museum practices that kept visitors at arm's length rather than setting a place for them and their life experiences at the table. This formal acknowledgement of the professional and ethical obligations of museums to their communities became the inspiration for a course I taught on "Museums and Their Communities," in which we investigated the theoretical underpinnings for the notion of the museum as a site of civic engagement, and then put these theories into action in a series of community-based projects.[vi]

In 2010, Debby D., a social worker from a local continuing care retirement community (CCRC), knocked on my office door to make me aware that while the residents of the community's independent living units routinely enjoyed opportunities to visit the

Museum, residents on their memory care floor had no such opportunities. She asked, could we not develop a program for those people in her care living with dementia? "They have nothing," she said bluntly. My own mother had been living with dementia for almost a decade by then and I had been directing students' independent study projects exploring the principles of accessibility and inclusion for several years. So here it was: a personal and institutional crossroads where I could make real and practice what I had been preaching for so many years, and make the Museum of, by, and for one of our underserved communities. (This particular way of articulating the prioritization and realization of community agency within the milieu of cultural organizations—"of, by, for all"—would not become formalized until 2018, when then director of the Santa Cruz Museum of Art and History and arts activist Nina Simon founded what would become a year later the non-profit organization Of/By/For All, of which my own organization ARTZ Philadelphia became a founding member.)[vii]

REINVENTING AGENCY AND ACCESSIBILITY

What started as a narrowly-focused mission to welcome people with dementia from the local CCRC into our museum for the first time evolved into a much broader and more profound project: to reinvent what agency within the museum would look and feel like for visitors living with dementia. In 2011, with trainings for staff and students provided by the only 2 organizations in the country at the time who provided research- and evidence-based workshops for arts institutions seeking to be fully inclusive of and accessible to visitors with disabilities—Art Beyond Sight[viii] and Artists for Alzheimer's[ix]—we launched a series of accessibility initiatives that would ultimately lead to the 2012 exhibition Access-Ability: Deconstructing and Reconstructing Art for Access.[x] (The principles and practices developed and advocated by Sean Caulfield with John Zeisel, his co-founder of ARTZ/Artists for Alzheimer's (no longer in existence), are detailed in Zeisel J. I'm Still Here: A New Philosophy of Alzheimer's Care. Avery; 2009. ARTZ Philadelphia was founded in 2013 as the first mid-Atlantic affiliate of Artists for Alzheimer's, but became an independently operated 501(c)3 in 2015.)

A GROUNDBREAKING EXHIBITION

The selection of objects for the exhibition, co-curated by two students majoring in psychology, was made largely on the basis of a series of arts-centered conversations with a focus group of people living with dementia on the memory care floor at the local CCRC. The more responsive, engaged, and vital the residents became when looking at and discussing photographs of works of art from the museum's permanent collection, the more certain those particular works were to appear on the walls of the museum's galleries.[xi]

When the same group of residents visited the museum to see the exhibition, several of them were amazed to see a large text panel acknowledging each of them by name as essential contributors to the exhibition. They visited the exhibition several times during Fall 2013, with several "accessibility docents" trained both in the peer docent program and in workshops led by Artists for Alzheimer's and Art Beyond Sight. They engaged in far-ranging intergenerational conversations that drew out our visitors and generated smiles and laughter during their hour-long visits. The social worker who had originally approached us about providing an outlet for her community's residents with dementia observed after one of the visits:

"I've been a social worker all my life. But I have to say, this experience has been the best. …just celebrating the joy of the human person with Alzheimer's, with dementia, with whatever problems exist—there is still joy, there's still wonder, still connection to other people.

One of the residents who clearly had dementia but had been an art teacher and was interested in the exhibit of a painting of Paris in the rain. She was looking at this painting and Susan led the discussion … And the woman says, 'I know where that is. I've been there. I painted that with my students.' She died a couple weeks later; it was right before she died she had a chance to … revel in the memory and the pleasure of being in Paris. It was so amazing, it was just a wonderful experience. We know people with dementia, we know people have terrible things, but to attain the quality of life you want for yourself and for people you care about—that's the hard part. And that was really monumental. One of the lady's friends was encouraging her to paint again, which clearly was too much for her. But being able to go to an exhibit to talk about her experiences—to hear her; she had very definitive ideas about art… and to really clearly explain them. …[T]there was no question about what she was saying or what her opinion was. And she had such a good time. There was a sparkle in her eye…" (Phone interview, November 2014).

II. *"The most important [thing] is that they listen to what I have to say…"*

—Heggestad et al[xii]

OPENING THE DOORS TO DIGNITY

In July 2013, I made the transition from academic and curator to founder and executive director of ARTZ Philadelphia, a community-based non-profit organization dedicated to enhancing the quality of life and well-being of people living with dementia and their care partners through joyful interactions around arts and culture. The organization connects people with dementia and those they love with artists, cultural organizations, and each other and helps to build caring, supportive communities that restore and preserve the self-esteem and dignity of our constituents, regardless of their color, culture, where they live, or their economic resources.[xiii]

My focus as an art historian and museum educator on examining and promoting viewer agency translated readily to our organization's emphasis on enhancing quality of life and preserving dignity for people living with dementia through interactions around art that prioritize above all the agency of program participants.

There has been extensive research and much written in the last decade regarding the various ways in which people across the globe living with dementia define quality of life. A number of studies have specifically focused on the role of dignity preservation as a prime contributor to quality of life. For instance, Van Gennip et al noted in 2014 that "a number of [qualitative] studies have indicated that the way in which individuals with dementia are treated by others has a significant impact on their experience of the disease and that the views of and treatment by others can perhaps be seen as the primary cause of the loss of self and self-esteem."[xiv]

A 2010 study by Heggestad et al assessing Norwegian nursing home residents' experiences of dignity by means of interviews with residents living with dementia yielded recurring theoretical themes relating to dignity, such as "dignity related to confirmation," "dignity related to freedom," and "dignity related to belonging." One interviewee declared, "The most important is that they listen to what I have to say." The study's authors conclude that our societal predilection to assume that people with dementia diagnoses are incapable of autonomy is driven by our conflation of their diagnoses with their very identity. We supplant their status as individual persons, the authors suggest, with an identity that derives solely from being understood as part of a group: in this case a group with the status "dementia." This, the authors argue, "may be experienced as violation of a person's dignity. To avoid this threat to dignity, we should to a greater extent ask the persons with dementia what they think is important in order to live a good life, and see them as experts on their own lives. We should confirm the person and his or her individual identity, which exists behind the disease [my emphasis]."[xv]

DESIGNING PROGRAMS TO PROMOTE AGENCY

It is against the backdrop of, and in direct response to, the research regarding dignity preservation (and other crucial quality-of-life factors) that we have designed our programs and projects at ARTZ Philadelphia, and in relation to which we assess their efficacy and impact.

ARTZ Philadelphia's flagship programs include several small-group conversation-based programs in which works of art in our partner museums' and arts centers' collections and exhibitions serve as the initial jumping-off point for facilitated conversation, connection, and engagement among people with different kinds and in different stages of dementia, as well as their care partners. It offers similar facilitated conversation-based programs in CCRCs, nursing homes, and community day centers; hands-on art-making programs led by artist-facilitators, also in CCRCs, community day centers and senior centers; and programs designed exclusively to provide respite and stimulation for care partners.

The daughter and primary care partner of one of the longtime participants in our ARTZ @ The Museum programs described in an email the impact of attending these programs with her father:

"I look forward to these days as much as my dad. I know I've said this before, but I have never appreciated art so much (and I even went to school for graphic design for a little while!). I honestly feel that it's the entire group that make the experience so wonderful—your amazing facilitation skills and the discussions that take place. Those with the 'memory impairments' only enhance my experience and I feel so lucky to be able to participate in these programs alongside everyone. I've learned so much from the entire group that I am continuously blown away by the experience." (Email communication, April 2015.)

In another email, she reflected on the way in which her shared experiences with her father at the programs had changed the patterns of their relationship and enabled her to perceive in him the father she had not previously felt to be present to her:

"Funny thing is that I feel like this whole experience has really been my father taking care of me because it has connected me to so many wonderful people (like you) and taught me more than I ever could have imagined. My father may not have the same memory he used to, but he certainly is still filled with an extensive amount of wisdom. I think he has been more of a father to me this past year than in the other 33 years of my life. So I think we both get caretaker designations in our situation." (Email communication, August 2015.)

REHABILITATING AGENCY, CHANGING HEALTHCARE ONE MENTOR AT A TIME

"ARTZ @ Jefferson" is one of several special initiatives that demonstrate most clearly ARTZ Philadelphia's commitment to reestablishing the agency, rebuilding the self-esteem, and preserving the dignity of our constituents living with dementia and their care partners. This educational initiative, which we now deliver as a program under the umbrella of Jefferson Elder Care in the College of Rehabilitation Sciences at Thomas Jefferson University in Philadelphia, was designed and launched by ARTZ Philadelphia under the auspices of the Office of the Provost at the Sidney Kimmel Medical College at Jefferson in Spring 2016.

Through this program (subtitled "Opening Doors to Empathy Through the Arts"), people living with dementia and their care partners serve as mentors to Jefferson's medical and other health professions students. The students meet with their mentors in dyads, over a period of months, learning who they were prior to the diagnosis, who they understand themselves to be post-diagnosis, and what it means to them to live with dementia. Students engage with them not as patients, but as people, and as the students' guides to learning.

While under the umbrella of the Provost's Office, the impact of the initiative on the students was front-and-center from the institution's perspective. How might the program enhance the empathy and well-being of the students who took part in it? How might it complement their studies, humanize their approaches to patients? All of these questions are of course highly relevant and remain fundamental to the program to this day. However, once under the umbrella of Jefferson Elder Care, the impact of the program on the program's mentors—people with dementia and care partners—was suddenly understood by the institution as every bit as crucial as its impact on the students. (Indeed, without the mentors, the very things that made this program so unique would be lost.) The dignity-preserving, quality-of-life-enhancing priorities inherent to occupational therapy and other rehabilitation sciences similarly infuse this program, even though it is arts-and humanities-based.

TURNING HIERARCHY UPSIDE-DOWN

This initiative turns upside-down the historically hierarchical relationship between doctors (or other healthcare providers) and patients with dementia. In this setting, those living with dementia and their families are venerated for the richness of their experiences and their intimate knowledge of navigating illnesses the students know they would not be able to learn about from any other source, in any other way. Here, agency and dignity preservation come together for the mentors, as they find admiring and respectful protégés who want to listen to their life stories and learn from them. Fundamental learning goals for the students include:

- Developing through recurring interactions with program mentors a skill base centering on "being present to/with," "listening to," and "learning from" patients.
- Developing a more nuanced and grounded understanding of the importance of empathy and compassion.
- Developing an understanding of the importance of dignity preservation for people living with chronic illness.
- Developing a greater awareness of, and level of comfort with, the efficacy of non-pharmacological interventions.

Mentors participate in 6 sessions over 2 months. Students participate in 9 sessions over 2 months, including one 3-hour seminar that takes place at the end of the program and focuses on the intersections of empathy and practice in the health professions.

INSIGHTS GAINED

Our data to this point have yielded the following insights regarding the student experiences:

- 121 students have taken part over 9 semesters plus an initial half-day pilot.
- In post-course surveys, nearly 100% of the students noted that the course had enhanced their ability to listen to others and value listening; and to think differently about the healthcare provider/patient relationship.
- 97% of students noted that the course had increased their understanding of the role of empathy in healthcare and that they had developed a more nuanced understanding of the practice of empathy.

The following insights were obtained regarding the experiences of mentors:

- 42 unique mentors have taken part over 9 semesters plus an initial half-day pilot.
- In post-course surveys, 70% to 80% of mentors responding noted that their interactions with the students added substantively to their quality of life, social engagement, and sense of purpose.
- 50% of mentors with dementia said that participating in course sessions made them feel better than they had earlier in the day, and 75% said they were looking forward to the next time.
- Close to 100% said that participating as mentors made them feel that they were making an important contribution.
- 75% of mentors who were care partners reflected that they felt confident they had enhanced their students' understanding of what it means to live with dementia.
- More than 90% of mentors who were care partners said that they would definitely recommend mentoring in the program to people in their own circles who were living with dementia or caring for someone with dementia.

IN THEIR OWN WORDS

Mentors have commented on their experiences in the program through formal survey responses and in informal conversations and emails. Donald K., a retired cardiologist in the early stages of dementia, wrote after his first semester as a mentor:

“The value of this mentorship is very personal. It's privileged passage into the life of ‘me.’ It's a teaching opportunity to ‘confess’ who I am and what I was. It forces me to accept the reality of what I can't control and reveal this change in myself so that a student can experience firsthand what I'm going through as an individual with early cognitive decline, and how it affects those close to me. In these exchanges there is opportunity to appreciate the need for compassion, empathy, and the importance of being supportive; essentials that should never be lost in any professional relationship in providing healthcare. What is of paramount importance is that a patient with dementia is an individual who should be encouraged to be as productive mentally, physically, and socially as possible so as to maintain their dignity as a human being." (Email communication, November 2018.)

Carl D., a retired physicist who first came to our programs shortly after he received a diagnosis of Alzheimer's Disease and who continued to participate in our programs until months before his death (from COVID-related complications) 5 years later, said of the programs in general, "...how wonderful it's all been....it's really changed me, given me an opportunity and a sparkle that I didn't have before. If there weren't this [program], I do not know what I would have done." (Transcribed by care partner in email communication, July 2016.) [Figure.]

Several years on, when asked if his just-completed fifth semester of serving as a mentor in ARTZ @ Jefferson had met his expectations, Carl captured figuratively the experience of dignity preservation by responding that it had, "in the sense of people coming to a place of equality with each other." (Verbal response to post-program survey, transcribed by care partner, May 2018.)

Meg O., one of the students in the mentoring program, who completed her nursing degree in a single, accelerated year and opted to participate in ARTZ @ Jefferson for 2 successive semesters that same year, reflected on the gift of working with a mentor whose primary progressive aphasia made it very difficult for her to communicate verbally. "[My mentor] gave me humor and brought out the humor in me. I think we had our own way of meeting each other and our own way of communicating and dancing together." (Transcribed from comments during wrap-up session with students and mentors, November 2018.)

As she looked back in her final journal entry for the course, Meg wrote, "I reflect back on my first day with Mary Anne. I wondered how I would connect with her. I saw it as an obstacle. Today, I no longer see such moments as obstacles to overcome, but as opportunities to grow, learn and share new experiences with another [person]." (Excerpt from final entry in course journal, November 2018.)

In 2017, "ARTZ @ Jefferson" (then known as "ARTZ @ Jeff") was recognized for its contributions to advocacy and policy by the Family Caregiver Alliance with its Innovations in Alzheimer's Caregiving Award.[xvi]

LESSONS LEARNED

The majority of ARTZ Philadelphia's programs and projects—including "ARTZ @ Jefferson" and a new, condensed iteration of it, "ARTZ-Connect @ PCOM," in which first-year medical students from Philadelphia College of Osteopathic Medicine are able to complete required humanities course credits by participating in a 3-week arts and dementia mentoring program with us—moved online with the outbreak of the COVID-19 pandemic in March 2020. In addition to adapting pre-existing in-person programs for online delivery, we have also launched new programs online that will remain hybrid in 2022 when we restart some of our in-person programs again.[xvii]

The most significant lesson I have learned through my journey from art historian, museum curator, and educator to non-profit founder, director, and advocate for the dignity preservation and agency of people living with dementia is this:

If we listen—truly listen—to people living with dementia, we will learn. And when we learn from the people who are the experts at lived experiences around dementia, we cannot help but become better care partners to them, better advocates, better human beings. People with dementia should be our authorities and our guides in determining what quality of life means—of, by and for them.

About the Author

Susan Shifrin, PhD is the founding director of ARTZ Philadelphia. She is an art historian, museum educator and curator, and arts accessibility advocate. She received her PhD in the History of Art from Bryn Mawr College and has worked on the curatorial and education staffs of a number of large and small museums. Her understanding of the arts and humanities as vehicles for human connection is core to her scholarly, curatorial, and service work.

Susan's most recent publications include: "Addressing the Whole Person: The Arts as a Conduit to Community for People Living with Alzheimer's," In the Media, *Journal of Pastoral Care and Counseling*, vol. 67, no. 3, September 2013; and "The Museum as a Site of Caring and Regeneration for People Living with Dementia" in Hamish Robertson, ed, *The Caring Museum* (Museums Etc, 2015). She is currently editing a volume titled *The Museum As Experience* comprised of essays authored by contributors from around the world (publication forthcoming 2022, ARC Humanities Press).

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