

ON THE BRAIN

Sujal Manohar, BS, BA
Baylor College
of Medicine,
Houston, Texas.

Repairing Our View of Dementia

It is a rewarding experience each time I lead a virtual art gallery tour for adults with dementia. Though we are over 1000 miles apart physically and multiple decades apart in age, we connect over artwork through the Reflections Program at the Nasher Museum of Art at Duke University. However, I did not expect that one comment from a participant—sparked by an art piece—would lead me to reconsider societal expectations and our care of adults with dementia.

All Reflections tours have a theme and today was no different. This morning's theme of "reuse and recycle" highlighted works of art from the Nasher Museum collection created with found objects. The other gallery guide and I led lively discussions about an industrial glue bottle covered with gold paper-mache, chair legs fashioned into a stallion sculpture, and a public art project called the Radical Repair Workshop.¹ The brainchild of Durham, North Carolina, artist Julia Gartrell, the Radical Repair Workshop encourages participants to bring in broken objects to be repaired or repurposed. Each time she sets up the workshop in a vintage camper, Gartrell aims to spark dialogue about consumerism and our attachment to our possessions.

As I shared images of the Radical Repair Workshop, 1 participant was intrigued by the idea of broken objects. He asked the group what we do with things when they are broken. Reflecting on his own experience, he questioned what we could do with him now that he was broken. He paused for a moment, then wondered aloud whether he had any use.

He was well aware of his cognitive changes, insidious yet undeniable; the participant knew he was not functioning the way he once did. Perhaps he was alluding to feeling like a burden on his wife, who helped him connect to the Zoom call on his computer.

I was stunned by the insightfulness of his comment and its relevance to his own condition. The other gallery guide and I took a moment to listen, then thanked him for sharing. As a medical student, my coursework had taught me about the neurofibrillary tangles and amyloid plaques of Alzheimer disease, the visual hallucinations that accompany Lewy Body dementia, and the differentiation between delirium and dementia. But it was my background as an artist that allowed me to respond.

I explained that these artworks showed us that all objects are valuable, even if they do not serve their original purposes. They can come together to make something beautiful. I emphasized that objects can be used in various ways and everyone has challenges and differences—that does not mean they aren't valuable.

The conversation moved on, but my mind remained focused on the participant's comment. When considering how society and caregivers must adapt to the changes that come with dementia, it is critical to

listen to people with dementia themselves. Especially in long-term care facilities, care professionals need training to improve communication with people with dementia and understand their preferences.² While some patients may not be able to articulate their challenges due to anosognosia, others, like this participant, are cognizant of the impact of their illness on themselves and those around them.

The participant's comment indicates that adults with dementia need a purpose—even if it is different from their previous roles in life. They must know that they are not broken or useless. People with dementia can create collaborative projects, share their stories, or help medical professionals better understand the intricacies of their condition. Creative storytelling programs that encourage participant input and do not rely on memories can improve quality of life, especially for those with milder dementia.³ In this case, an art piece and group discussion served as stimuli that prompted deeper reflection and insight. There is also tremendous value in fostering intergenerational connections through initiatives at universities and schools, which allow students to interact with older adults.⁴ Building relationships with children can lessen stress and perseverations about physical health among people with dementia.⁵

This much is clear: people with dementia must have a purpose. Purpose is not only fundamental to an individual's happiness, but also to their health and longevity.⁶ And while all of us need a purpose, it is especially important for people with dementia, who may find themselves unable to participate in the roles and activities that previously brought them joy. However, there are ways to create continuity for people with dementia, even if their current activities differ from their previous ones. One group of people with dementia highlighted the importance of staying active and involved, whether through leisure activities, household chores, or other social commitments. These activities had many positive effects, including a heightened sense of autonomy and personal identity.⁷ As the US population ages, helping people with dementia find meaning in their lives is more important than ever. The 6.1 million individuals today living with Alzheimer disease, the most common form of dementia, will more than double by 2060.⁸ Society is largely unprepared for this increase, with few medical interventions that can slow the disease's progression and none that can cure it.

When caring for a person with dementia, members of their support system must explore their social history, finding ways to give them purpose that accentuate their strengths rather than illuminating their challenges.⁹ Helping an individual with dementia find meaning in their life may also benefit caregivers, who experience high rates of depression and need better training to manage their own feelings while providing support.¹⁰

Corresponding

Author: Sujal Manohar, BS, BA, Baylor College of Medicine, 1 Baylor Plaza, Houston, TX 77030 (sujal.manohar@bcm.edu).

Serving as a Reflections gallery guide has demonstrated that people like this participant see things through a new lens. Having dementia and being insightful are not mutually exclusive. When considering how to care for those with memory loss, we must include the per-

spectives of not only caregivers and health care professionals, but also those who experience the disease itself. We must help people with dementia realize that there is indeed purpose and meaning in their lives. I am grateful that the Reflections participant was able to show me that.

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