

Right brain: Art and the restoration of identity in dementia

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What can we do to restore identity in a disease that strips the very essence of personal identity in nearly every individual unfortunate to meet its path?¹

Willem de Kooning (1904–1997) was one of the most preeminent abstract expressionists of the 20th century. He also was diagnosed with likely mixed dementia after developing significant cognitive and functional impairment beginning in his 70s. Throughout his cognitive decline, de Kooning continued to paint productively at a vigorous rate. The juxtaposition from earlier works is evident in de Kooning's art after his diagnosis, with increasing simplicity and clean bands of vivid color.² Another artist with a known dementia diagnosis is William Utermohlen (1933–2007). After his diagnosis of Alzheimer disease in 1995, he continued to paint self-portraits throughout his cognitive decline. There is a striking contrast of late portraits when compared with prior self-portraits, with an intense fear and yearning to understand his condition. Hauntingly, distinct facial features in his self-portraits are obscured toward the end, as if they have withered into the abyss.³

We are fortunate as a society to have had artistic influences like de Kooning and Utermohlen, who have provided us a fundamental glimpse into the mind of dementia. As a neurology resident–physician, I yearn to understand neurologic disease through the lens of patient experience. Indeed, de Kooning's and Utermohlen's paintings are several of the best tools we currently have to understand the perspective of dementia.

Alzheimer disease and the other dementias characteristically lead to a progressive decline in cognition, functional status, and behavior. The memories that strengthen our connections throughout life are ultimately slashed until the only remaining memories are distant recollections from childhood. These are truly some of the saddest diagnoses in all of medicine as the resultant depersonalization steals patients of their lifelong identity.

I have experienced the great gift that art may provide individuals with cognitive impairment. The empowerment and pride that shines from faces of those who have created a painting or written a haiku for the first time is unforgettable. In the following paragraphs, I describe my participation with an arts-based dementia support group and argue that engagement in the arts should be a pillar for the current palliative management of dementia.

In early 2012, I had the opportunity to work with a multidisciplinary team of fellow medical students, geriatricians, and other providers to develop a cognitive support group for individuals with all forms of mild cognitive impairment and dementia. Group participants were community-dwelling adults who varied significantly throughout the spectrum of dementia. Participants included a former aerospace engineer who was functioning independently with no overt signs of cognitive impairment, a former high school teacher and avid landscape painter who needed help with activities of daily living (ADLs)/instrumental activities of daily living (IADLs), and participants with obvious functional decline who necessitated prompting for verbal communication and were dependent in nearly all ADLs/IADLs.

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Our primary outcome measure at group onset was change in Montreal Cognitive Assessment (MoCA). While we realized the likelihood of substantial cognitive improvement was negligible in those with established diagnoses, we searched for an objective measure to quantify group effect. Our groups were designed to run in parallel with a social support group for caregivers. Groups lasted 10 weeks, with monthly maintenance groups for participants who had previously participated in our 10-week sessions.

The initial design of our Brain Fitness group was to focus on classic cognitively enhancing activities. These included tasks that stressed memory performance, attention, and visuospatial skills. After about 2 sessions of co-leading groups it became apparent that traditional cognitively focused activities were poorly fitted for our intended group participants. The frustration and anguish was palpable. I distinctly remember the minutes of silence waiting for group members to answer memory challenge questions or recalling the face of a commonly known 1950s celebrity. I felt horrible. My group co-leader, Gerad, and I wanted to positively affect group participants. We were eager incoming second-year medical students. However, we could not overcome the feeling that providing another source of stress in our group participants was not our ultimate mission—despite our objective goal of cognitive improvement. We had one saving grace...the Ball Game.

When Gerad and I were planning our first group, we added one pure fun activity at the end of each session. This activity for the first week was the Ball Game, which consisted of rolling a tennis ball on a flat boardroom table randomly to group participants. It was groundbreaking for us. Participants loved it, after what seemed like a grueling 60–75 minutes of memory activities. We had the capability to make the game more challenging by adding 2, 3, and 4 balls at a time—or by bouncing the tennis balls instead of rolling them. When we added music from the 1940–1950s, energy flowed through the room like electricity through standing water. Participants who had previously remained mute and emotionless throughout much of the group activities began to dance to the music and fight for incoming balls. It became apparent that we needed to continue with the Ball Game. Activities were planned for each week in advance, but after its resounding success, we incorporated it weekly.

Throughout the first group, we learned that our more intensive cognitive-based activities and memory challenges were a source of profound frustration with participants. MoCA scores were not significantly different pre-vs-post group.⁴ With our current state of tools, altering cognitive endpoints with brain training activities after diagnosis of mild cognitive impairment is a Herculean effort. Given the success of our more creative activities, we reconvened with our mentors and switched to a fully arts-based curriculum for our second 10-week group.

The second rendition of the Brain Fitness group consisted of one longitudinal project supplemented by a weekly curriculum.

Our first longitudinal project was a combined group painting. We decided to dedicate one color to each week. The first several weeks were challenging. We had 1–2 group members who actively participated while the remaining added very few brush strokes to the final canvas. The early adopters were artists themselves or artistically inclined. Yet, with the persistent motivation and encouragement by active participants, we were able to engage every member of the group. Several 80-year-olds from Appalachia who had never picked up a paintbrush in their lives actively participated in theme-altering contributions to the group artwork. The most exciting part of this process was seeing the more artistically experienced group members teaching other participants how to paint. This was all we truly desired to achieve—to facilitate interaction between individuals with similar life experiences, who have largely been isolated from social engagement. We achieved this goal. A satisfaction survey at the end of our first arts-based group resulted in rankings of average overall group satisfaction, enjoyment of arts-based activities, and weekly group painting as “excellent” on a scale of excellent–good–average–poor. All participants would have recommended the group to others.⁵

Our next longitudinal project incorporated several creative tasks. First, we spent 2 weeks teaching participants about photography and specific features in a photograph that makes it appealing. Afterwards, cameras were supplied to group participants with the goal of capturing photographs throughout their daily lives over a week. When participants returned with their photographs, we went through each as a group. Then, participants decided on which of the photographs they would like to print. We eventually painted frames to hold the photographs and wrote a haiku about each photograph with presentation of this project in front of families and friends at group conclusion.

Throughout the 5 years I helped facilitate the Brain Fitness group, I witnessed the personal, social, and skill-building transformation that group participants made. Subjectively, one group participant described our group as “A place where I don’t have to be perfect.” Other feedback included, “My experience makes me want to do more activities at home,” and “I made new friends that have the same interests.”⁵

Despite these encouraging reflections, the clinical decline became clearly evident. Even our most high-functioning participants began to progress in their clinical course. Over months to years in our maintenance groups, several participants returned to group with less vigor and poorer recollection of other group members and our previous group activities.

While we currently lack a disease-modifying therapeutic for Alzheimer disease and related disorders, there is hope to help restore identity throughout the progression of dementia. I strongly encourage every medical student, resident, attending

physician, and other clinicians to participate in support groups if they are present at your institution—or start a group if they are not available. I will never forget the growth our participants experienced and the interaction between group members that were facilitated by creative activities. Art provides individuals with cognitive impairment an outlet to express themselves unlike any other, while restoring identity and meaning in one of the most frightening conditions of our time.

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