

Observation and interaction: Lessons from a Midwestern retirement home

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Abstract: Dementia, a disease associated with loss, can be a profound teacher. Dementia patients helped a group of students from St. Louis gain insights and develop empathy like no other college class could. Students from the University of Missouri–St. Louis paired with dementia patients from Brooking Park Retirement community to create one-on-one interaction designs. We expected to learn about how primary research strengthens design, but gained insights we never expected.

Introduction

UMSL graphic design ran an undergrad “Design for Dementia” course in 2017 in St. Louis at Brooking Park Retirement Community. In this class, students were paired one-on-one with residents to create patient-centered care systems and experiences that “improved the life of the patient with dementia.”

I was approached by Dementialab’s Andrea Wilkinson about running a version of Dementialab in the United States to compare and contrast European facilities to American ones. This project was of special interest for me because my mother had recently been diagnosed with dementia, and I had watched and participated in her journey from independence with my father in Hannibal, Missouri, to her placement in a skilled nursing facility in St. Louis. We committed to a four-week class in summer 2017, and Andrea was able to travel to Missouri to participate as a co-teacher and mentor, providing us with many insights from her work in Belgium and Europe.

Class goals

This class challenged my undergrad designers to grow. Instead of objects, students were asked to think about designing intangibles: better interactions

for their partner, better experiences that strengthened their sense of personhood. It was a prompt that was initially challenging for these undergraduates, and was left intentionally open-ended, so that students responded to their specific partner's needs and desires (Figure 1).



Figure 1. A student and her partner display their paintings after a watercolor workshop.

Implicit in this project is the act of getting to know each resident partner deeply through more than just a cursory search. Students were asked to help underline the defining features of the residents' personalities with their designs, and we challenged them to see if they could help create interactions that restored the greatest sense of self to each participant.

The first assignment was for each student to develop a persona about his/her Brooking Park partner. Students started collecting information with a general survey, then interviewed caregivers and retirement community staff, and finally they reached out to their partners' family members. These initial surveys not only helped students to fill in the vivid picture of their dementia project partner, but also identified many ways to help dementia patients in general, and their partner specifically.

First Days: Getting Used to the Facility

This experience was overwhelming for many of the students at first. Entering the retirement community was so different than the classroom environment. Brooking Park looked like a hospital, and it became clear the first day that we

didn't know the rules of this facility. Our group's newness, the student's young faces and the speed at which we moved, spoke, and processed information was often engaging to residents, but sometimes overwhelming and over-stimulating.

Approaching partners could be challenging. Students ran into the problem of some patients agreeing to participate one day, but not remembering or wanting to participate the next. Other patients didn't seem to have dementia until we returned and needed to start again with introductions. Some struggled with how to approach partners to send the right message, allowing partners to open up.

Another paradigm shift was thinking of Brooking Park as these residents' homes, their personal space. It was interesting to think about personal space at the nursing home: so much independence is taken away from patients in skilled nursing. They are subject to the facility's schedule, and even private space doesn't feel so private. Personal choice often takes a hit as well. Patients miss controlling their own lives: they miss driving, control over money, and freedom to come and go from the facility as they please. They miss activities and people outside the home; sometimes they even miss taking care of others, instead of being the one who needs care.

We had pleasant surprises as well. We encountered moments while interviewing when partners would strike on moments of lucidity, excitement or animation at a favorite memory. They would come alive, remember and participate for a few minutes at a higher level. It was amazing to see the pleasure wash across residents' faces in moments like these, when they were moved at a favorite song or idea, game or verse. Our group aimed to trigger these moments by activating as many senses as we could. We explored visual, tactile, and olfactory experiences for patients. We also explored sound through music and singing, readings, movies.

Developing Personas and Defining Goals

As the personas developed, we explored how our designs could help our dementia partners to interact and contribute at this higher level. We asked ourselves: "what can we do to increase the occurrence and length of these moments of lucidity and participation?" We realized that in making interactions easier for caregivers or family members, it would be possible for patients to receive more and better-quality visits. This led us to focus on how different groups of people might interact with patients to trigger these moments. We

focused on three groups to design for who might initiate positive interactions: patients, caregivers, and family.

We spent time talking about how to increase the number of orienting experiences and decrease the number of disorienting experiences. Prompts included how to approach residents and introduce one's self each day and how to remove physical barriers to positive interaction through preparation and environmental design. We explored the idea of "hacks" for caregivers to give patients a better quality of daily interaction through timesaving and load-lightening kinds of prompts. For caregivers, our focus was on ways to update or remind staff about a patient's preferences to maximize their limited time with each patient.

We also thought about family members and how to reduce their stress or discomfort by logging a list of activities that the patients enjoy and respond to in this new period of their life. For this group patient "blindness" might be a focus. Family members might experience distortion in their view of patients, expecting them to respond to old prompts that might no longer work, and might miss ways to be close that work better now for patients in their current states. Enabling family to spend better quality time with their loved ones would be a huge positive outcome for the patients. If our prompts made interactions easier, or helped family members reframe what a good experience looks like, then the patients got to interact with a better version of their family members or receive more visits.

As both an instructor and a daughter of a person with dementia, I shared insights about practical communication problems that retirement facilities encounter. Dementia is particularly hard on out-of-state family members. My sisters do not live in St. Louis, and have difficulties reaching my mother or checking on her by phone. Dementia patients may have trouble remembering phone numbers and understanding newer phones or systems. They may be unable to navigate picking up voicemail, and consequently phones can be disorienting, and, in general, less rewarding for patients than video calls, where voice and visuals give them more to read and respond to, and may also give family members more positive feedback.

We discussed the idea that dementia patients may have difficulty learning to participate in contemporary modes of communication. We spent time discussing how social media and home entertainment devices that already exist could be combined and reconfigured to help dementia patients stay in better

communication with loved ones. These kinds of technologies could make retirement communities less isolating, and even allow residents in remoter areas to participate meaningfully, or age gracefully in place.

Another issue we discussed is the American tendency to place retirement communities in the suburbs, inadvertently creating social isolation. I attended a symposium after this class on building more effective and affordable retirement facilities for aging citizens where teams discussed the idea of locating retirement facilities near universities. Here, institutions could share amenities, and create more opportunities for lifetime learning and engagement within the university for retirees. After my experiences with the dementia class, it was clear to me that dementia patients had a gold mine of human talents and resources that they could offer a university campus, in terms of mentorship, time and support of academic units, conversation, and intergenerational affection and empathy.

Final Interaction Designs

We learned a lot about interpreting results from design experiments. Students realized that they needed to re-gauge what success looks like for each individual patient. A smile, a few words, active watching, or five minutes of participation can, for some patients, be a very significant positive outcome. Students saw that even getting up and coming to an activity represented a significant positive outcome for many residents and contributed to their overall health and well-being. Students learned to see, measure, and appreciate these seemingly small behavior changes.

In creating final interactions, we observed that there were many levels at which residents could participate in creative projects. While there were “super users” who would actively paint/draw/carve/manipulate/interact, there were other patients who experienced joy in discussing. For others, who were more intimidated, watching others participate and cheering them on was a positive outcome. For these onlookers, the introduction of coffee and snacks created a party atmosphere around an activity they found stimulating to observe.

One patient, a former university professor in industrial art, was experiencing declining use of her hands and suffered from isolation. She was frustrated when trying to make art, but could still speak at a high level and critically describe artwork. She derived joy from identifying key features, and offering feedback on how to improve the work. Her student partner spent time hunting for and testing artwork that inspired her to look longer and speak more, and created a

book that was meant to inspire her to discuss color theory, pattern, technique, and design. The book was meant to aid and encourage her future caregivers and family members to discuss art with her at a higher level (Figure 2).



Figure 2. A resident admires a discussion book designed to encourage discussions about art and design.

In another final design, a student created a deck of prompts to help caregivers and family to sing her partner's favorite songs, recite favorite bible verses and tell favorite stories. This deck was bound together with a ribbon so that it could hang off the resident's walker and was always handy (Figure 3).



Figure 3. A deck of favourite bible verses, movies, music and memories designed to create quality interactions with family and caregivers.

Another designer created a book to help volunteers produce art workshops that fulfilled her partner's cravings for more complicated and visceral art projects. This book focused on making the new projects less overwhelming to other, more advanced residents by removing barriers and setting up workstations in advance. The book also suggested special workarounds for encouraging dementia patients to participate at many levels, and tips for making tools easier to use for arthritic hands (Figures 4 and 5).



Figure 4. Advertisements for crafts and coffee workshops designed for an artistic resident.



Figure 5. A spread from the Crafts and Coffee project book created to make art programming for dementia patients easier.

Another patient derived her personhood from wordsmithing, and beat all of us at scrabble. Her partner observed that she came alive when she played the game, and while other things were now challenging, she could still beat nearly everyone in our group, and was isolated from scrabble partners who could play at her level. The student created table tents and other environmental pieces to help encourage fellow residents to participate in scrabble playing events by

listing trickier words with unusual letter combinations for high scores, to build a scrabble community for her partner (Figures 6, 7 and 8).



Figure 6. Scrabble event materials.



Figure 7. Scrabble event allowed one resident to share her love of a classic game with residents who remember the game but might be losing their words.



Figure 8. A student helps a resident participate in the scrabble event.

Lastly, one student's partner was in the very early stages of dementia, and only had happy memories to share. She chose to create a biographic jigsaw puzzle of her partner's memories that could be assembled multiple times to help him keep memories and his sense of self as dementia progressed (Figure 9).



Figure 9. A resident studies a memory puzzle made to help him keep defining memories.

Conclusions

My time at Brooking Park as a researcher had a great impact on me. I had anticipated that students would learn about user-testing and primary research.

What I didn't expect was the profound impact these design interactions would have on the students. I realized that students were profoundly moved by the interactions with seniors. The residents offered them rare commodities: time for one-on-one undivided attention, and real immediate, practical needs. This seems so simple, but students, who are used to interacting via social media seemed to respond in heartfelt ways to the real time one-on-one attention and honest reactions of their partners. Being placed into the role of conversation facilitator or activity leader was also extremely powerful. Students reported how good it felt to help their partner.

The experience motivated UMSL students to do some of their best work. Of the 5 students who participated in this first class, all 5 reported it as being a highlight of their college experience. One student is still visiting her partner a year later, and two students reported that the dementia project influenced their senior capstone projects. My students learned that things that are easy for them can be difficult for people raised several generations earlier. They learned that the smallest barriers were enough to create a tipping point that would keep dementia patients from acting. Dementia can make the world a very confusing place, and the students sought ways to help residents keep their bearings. With some care and consideration, design can help dementia patients connect with the world (Figure 10).



Figure 10. A resident is overjoyed to receive his autobiographical puzzle from his partner.

About the author

Jennifer McKnight's design work has been recognized in Print Magazine, and in several international publications including United Designs Annuals and the Golden Bee International Poster Biennial. Her poster work has been exhibited internationally, and her design work has also been published in Becoming a Graphic Designer: A Guide to Careers in Design by Steven Heller and Theresa Fernandes. Her design writing appears in Means by Which We Find Our Way, edited by David Gardner and Andrea Wilkinson, Keep/Delete, edited by Andrea Wilkinson, and Robin Landa's 4th edition of Graphic Design Solutions.