
Addressing Empathy during research in Memory Care Units

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Abstract

Technology can provide opportunities for activity engagement for people with dementia, but technology studies in this population can be difficult due to impairments arising from the disease. Empathic issues often arise when conducting research with a population with dementia. It may be difficult for researchers to balance the appropriate amount of empathy while carrying out their study design. This paper will describe empathic issues that we have seen arise while conducting a technology study in a population with dementia in a memory care unit (MCU) and conclude with recommendations for researchers.

Author Keywords

dementia; empathy; memory care unit

ACM Classification Keywords

J.3. Life and Medical Sciences (Health)

Introduction

Research involving people with dementia has a series of well-documented challenges such as dealing with communication impairment, memory loss, and difficult emotions [1]. Utilizing technology in an HCI study introduces additional challenges, such as fear of breaking the technology or making an error [2]. Removing people with moderate or severe dementia

from their regular environment may introduce disorientation and agitation, as well as eliminate the context in which people with dementia would actually use technology. This means the researcher may have to go where people with dementia reside, bringing specific considerations they must consider to minimize disruptions to the life of the study participant while maximizing what they learn. Many empathic issues arise in studying people with dementia in an MCU.

Study Description

In March 2013, we began an ongoing field study examining the use of a mobile computer system in an MCU. This system, designed to be used by older adults with dementia, has applications to facilitate entertainment, communication, information access, and cognitive training. We gather data through observations during one-on-one sessions using the unit with residents enrolled in the study, as well as interviews with staff and family members. Quantitative data are gathered through standardized instruments on facets such as the quality of life, mood, cognition, and health care resource utilization of residents. The goal of the study is to understand feasibility issues in using this system in the dementia care setting, as well as evaluate the effect of using the system on the lives of study participants. Next, we discuss empathic issues that arise from working with people with dementia and study designs for this population.

Empathic Issues Arising from Working with People with Dementia

In this section, we discuss ways empathy can be managed and channeled during interactions with people with dementia.

Avoiding paternalism

One of technology's greatest potentials for this population is allowing people with dementia to initiate, select, and carry out interactions of their choosing. This is of importance because people with dementia are sometimes treated like children. However, during a feasibility study, technology may not be perfectly designed for use by the population. We were initially hesitant to give detailed instructions during observations (e.g., "press here and then there"), as we felt that we were treating the participants as if they were unable to use the system on their own. However, without instructions the participant was more likely to make an error or spend most of the time on navigation instead of using an application. Eventually, after we heard a participant referring to the first author (AL) proudly as "my teacher", it became clear that, as with any other population, it was appropriate to give instructions as long as people were not instructed on how to do what they already knew to do. For the resident who referred to AL as her teacher, it was empowering to be taught to use a new technology.

Avoiding projection

AL found herself trying to protect participants from situations where she thought they might feel poorly, for example giving hints for the right answer. Instead of listening to what participants were actually feeling and expressing, she imagined how she might feel in their situation and acted based on that. Due to the many images and mental models we have of people with dementia from media and the strong priority Western culture places on complete independence, it can be easy to project feelings into participants that they may not be having, but it can lead to bias and prevent the researcher from seeing the situation as it actually is.

Channeling empathy appropriately

Some behaviors people with dementia engage in that might be difficult for researchers to know how to deal with. People with dementia may tell the same story many times, and we have found that salient details may be added each time, and it is therefore beneficial to the participant to repeat their stories even if it may fatigue the researcher. During one session, a resident revealed that her parents had divorced when she was very young and she had moved to a farm with her aunt and uncle, where having a horse had made the experience bearable. She revealed this story in pieces throughout the session, as the slideshow played over and over. We have found that empathizing with the need for telling stories- sharing something personally relevant- has helped. Another situation where it can be beneficial to pay attention to the feelings of a participant is when factually inaccurate statements are made, such as with one participant who believed that her sister had just passed away (she had passed away several years before). We have found that rather than focusing on the facts, tapping into our empathy and understanding that to the person speaking, the event feels as if it had just occurred, helps us communicate with them empathically.

Ending a Study

By conducting an on-site long-term research study with a vulnerable population, the researcher often establishes a relationship with study participants and the study procedures and technologies become a part of their life routine. Ending the study may present ethical challenges, especially when the researcher and participant establish a relationship or the technology seems to be beneficial. For example, one participant's daughter is concerned that her mother will have a hard

time getting used to AL not coming weekly. While it is not feasible to continue a study indefinitely, it is important to prepare participants instead of abruptly ending the study. Based on a conversation with the daughter, we plan to begin telling the participant a month in advance that the study is ending soon.

Empathic issues arising from study designs with people with dementia

In this section, we discuss ways study designs and setups can affect both the participant with dementia and the researcher.

Administering standardized instruments

It may be important to administer standardized instruments measuring cognition or mood to determine the success of the intervention and to allow for comparability and meta-analysis of the study. However, people in an MCU are regularly assessed with standardized instruments, some of which may be intrusive. One resident asked AL why people were always asking her questions while we administered one of the instruments. Another issue is that cognitive screeners have questions that someone with dementia knows they should know, but is not able to come up with the answer. Imagining what it might be like to be asked questions that one doesn't know the answer but knows that they should know (such as the date or name of the building) can highlight the need to minimize intrusive questioning.

Studies in an MCU

As mentioned earlier, it is complicated to remove people with dementia from where they live to do a controlled lab experiment. Therefore, the researcher may have to be on site, which may be an MCU or

assisted living. Even with extensive reading on conducting studies with people with dementia and best practices for interaction, to a novice researcher with no familiarity with the target audience, the experience can be a shock at first, as people can behave in ways not seen in other environments- crying, yelling, and conveying agitation. It took AL several months of observations to understand the nuanced presentation of emotions. Her preconceptions of what it must be like to live in an MCU had initially overridden the evidence of people laughing and participating in activities.

Recommendations

Below are recommendations for ways to address empathy in ways that will benefit both researchers and participants with dementia.

- By interacting with the participants in our study in an empathic manner, we realized that they felt overwhelmed when asked some questions from standardized instruments and uncomfortable when they didn't know the answers. While these measures are important for assessing outcomes and measuring clinical relevance, be cognizant to the many intrusive questions that people with dementia are asked and how it might feel to not be able to answer them. Minimize the length and number of questions asked. If possible, use measures that have already been administered to participants by nurses or staff.
- Although it is important to empathize with participants, bias can occur when projecting one's own idea of how it might be to live with dementia onto the person. Awareness of what participants actually say and do can help a researcher avoid a biased approach.

- Spending time in an MCU can raise difficult emotions. A researcher should allow for time to gain an understanding of the whole picture in which people with dementia live. Understanding the actual context and circumstances of behaviors is difficult, but important, to meet participants' needs.

Conclusion

Technology can provide people with dementia with meaningful engagement and social interactions. However, the studies to prototype and evaluate technology with this population can raise questions regarding empathic ways to engage with study participants. Our recommendations include minimizing intrusive questions, avoiding projection, and giving oneself time to appreciate the complexity and intricacies of individuals with dementia.

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