Considerations in Evaluating Technologies in Memory Care Units

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Abstract. As the population ages worldwide, dementia is becoming increasingly prevalent. There is a pressing need to investigate non-pharmacological interventions to meet the needs of people with dementia. Technology may be one tool to enhance the lives of people with dementia without the use of medication. However, conducting studies with people with dementia in memory care units (MCUs) has unique challenges. In this paper, we discuss methodological and logistical considerations in designing, recruiting for, and conducting technology evaluations in memory care units. These considerations are based on a six-month study evaluating a technology system designed to encourage people with dementia to participate in recreational activities. Findings will assist researchers in conducting studies deploying technology tools for people with dementia in memory care units and assisted living facilities.

Keywords: Dementia · Study planning · Computers · Multimedia

1 Introduction

As the population ages worldwide, dementia is becoming increasingly prevalent. In the United States, 14.7 % of adults over the age of 70 were estimated to have dementia in 2010, and the range of dementia care cost for each person was estimated to cost between 41,689 and 56,290 US dollars [1]. In addition to financial cost, dementia can have tremendous psychosocial costs for people with dementia as well as their family members and friends.

1.1 Dementia and Activities

Activities are one non-pharmacological approach to improving the health and quality of life of people with dementia. In one study, Schreiner et al. found that residents expressed happiness more than seven times as often during structured recreation time as opposed to during ‘ordinary time’ [2]. In another study, participants with dementia were observed during three activities: unstructured time, group activities, and group reminiscence therapy (during which memories of the past are revisited). Individuals demonstrated greater levels of wellbeing during both sets of structured activities [3]. Activities have benefits for people other than the individual with dementia: in a study in which staff at a day care center for people with Alzheimer’s disease were interviewed,

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Hasselkus found that facilitating activities served as a source of satisfaction and meaningful purpose for staff [4]. Despite the myriad benefits of engaging in leisure and recreational activities, there are barriers to doing so for people with dementia.

Dementia affects people's abilities to take part in activities of daily living through impairments in memory, language, judgment, and problem solving [5]. Dementia also affects people's abilities to take part in leisure and recreational activities: increased impairment from dementia has been found to be associated with lower participation in staff-led activities in a variety of care settings [6]. In addition, several studies have established that people with dementia in nursing homes and memory care units may lack sufficient activities. In one study, Wood et al. observed residents over several days and found that residents spent the majority of their time unengaged in activities [7]. In another study, 238 people with dementia from various care homes were assessed for unmet needs. The researchers found that while environmental and physical needs were often met, social needs such as company and activities were not sufficiently met [8].

1.2 Technology for Activity Engagement for People with Dementia

Technology has the capability to address some of the needs of people with dementia. Cited in Topo et al. [9], Marshall described nine technology uses for people with dementia: reminders, safety, surveillance, control, service coordination, assistance to relatives, compensation, and stimulation and relaxation [10]. To Marshall's list, Topo adds the use of technology for communication [9]. Wey further suggests five uses for assistive technology in dementia rehabilitation, including supporting cognitive abilities essential for everyday activities, enabling people to carry out difficult tasks, providing access to meaningful occupation, ensuring safety, and supporting caregivers [11]. Newell et al. recommend additional areas for technologies to potentially enhance the lives of older adults with cognitive impairments, including allowing people to retain independence and control, providing monitoring capabilities, keeping people active physically and intellectually, and facilitating communication [12].

Despite the inclusion of needs specific to people with dementia in many of the above lists, Topo points out that the majority of studies focus on the needs of the caregivers of people with dementia rather than the needs of people with dementia themselves. Additionally, Topo stresses the importance of include people with dementia in the evaluation of technologies [9]. Thus, there is a need for studies that involve people with dementia in the design and evaluation of technologies intended for use by or with them, particularly for technologies that support the activity needs of people with dementia.

In a recent six-month study, we evaluated a commercially available multi-functional computer system designed to facilitate access to recreational activities for people with dementia. This system was evaluated in a memory care unit (MCU) and in an activity group for people with early signs of memory impairment. Findings relating to the effect of the system are not discussed here: in this paper, we outline important issues researchers should consider when planning studies that evaluate technologies in MCUs.

2 Related Work

Other researchers have addressed methodological issues in conducting research with people with dementia.

2.1 Considerations in Conducting Studies with People with Dementia

In their study, Hall and colleagues describe the challenges of conducting qualitative interviews with older people living in nursing homes to obtain views on how to preserve dignity. Though the authors do not limit their study to people with dementia, many of the issues they discuss are pertinent in a dementia care setting, such as administering informed consent to residents who forgot they had signed up to participate in the study and difficulty scheduling sessions due to frequent activities and barriers such as residents not feeling well and having unexpected visitors [13].

In a systematic review, Lawrence et al. discuss conditions required for and challenges to successful implementations of psychosocial (as opposed to pharmacological) interventions with people with dementia. Conditions required for successful implementation include staff willing to provide access to and encourage use of interventions, the involvement of family members in notifying staff of likes and dislikes of residents, flexibility of the intervention to accommodate different ability levels of residents, and having an intervention long enough for residents to become comfortable with its use. Challenges to implementation include that psychosocial interventions often placed a burden on staff in terms of time and workload and that staff felt uncomfortable implementing the intervention. In the discussion, the authors emphasize the importance of gaining staff commitment before the intervention is implemented and the importance of collaborating with family members [14]. Despite the pertinence of some of these issues, the projects described above did not deploy a technology tool. Therefore, there are a wide range of issues specific to working with people with dementia and technology deployment that are left unaddressed.

2.2 Considerations in Conducting Technology Deployment Studies with People with Dementia

Several papers discuss methodological and logistical considerations in studies that utilize technology with people with dementia. Andersson et al. describe the importance of setting up a technical help desk, creating user manuals, and checking in periodically to identify issues that were not reported to the help desk. These findings are some of the lessons learned from the deployment of CogKnow, an information and communication technology tool for people with mild dementia [15].

Astell et al. discuss a broad range of findings from seven years of working with people with dementia, family members, and staff to design and evaluate CIRCA (Computer Interactive Reminiscence and Conversation Aid), a computer system designed to facilitate communication between people with dementia and others. The researchers discuss the importance of involving different stakeholders (such as spouses and staff), the particularities of navigating consent with people with dementia, and techniques to evaluate the engagement of people with dementia using verbal and nonverbal behaviors [16].

We build on these previous works by providing additional areas to consider, such as appropriate study time periods, recruitment of staff, and alternate ways to manage technical issues that emerge when using technology systems.

3 Considerations

Below we outline some of the issues researchers should consider when implementing technology studies in MCUs based on our experience.

3.1 Designing the Study

Time Period of Study. Though shorter studies require vastly fewer resources, a longer, six-month study was essential for us to see the ways staff incorporated the system into their activity routine. This was due to a long period during which staff became familiar and comfortable with the system and during which technical issues were resolved. Though the longer time resulted in a more positive view of the system, it is easy to imagine a system that is initially appreciated and then discarded after novelty wears off. We suggest at least three months for technology evaluation studies that involve staff. For the evaluation of systems with people with dementia, the length of a study can be shorter as residents may not be able to remember much from session to session (though they may become more comfortable due to growing relationships with the research team as well as recognizing the system).

We also found it very beneficial to have monthly interviews with staff in order to identify shifting attitudes and capture anecdotal experiences that could have been forgotten over a period of months. Monthly interviews were also beneficial given rapid staff turnover; if a staff member left the facility before the study was completed, we were still able to have more than one interview with them.

Involving Family Members. We found the inclusion of family members to be extremely valuable for several reasons. First, family members have the ability to assist the researcher in evaluating the technology by providing another angle that differs from the observations of the researcher and staff. Second, the family member may be very helpful in figuring out the kinds of applications the residents may like, which is especially useful for residents who have difficulty communicating their interests or appear apathetic. However, family members do not necessarily know residents' current interests; many family members ruled out certain types of application that their relatives actually did enjoy using. Additionally, family members may project their own feelings of fear and failure onto residents and attempt to protect them from experiences where they might fail.

We build on Lawrence et al.'s suggestion to involve family members and take into account their perspectives and advice for interacting with residents [14]. However, we add that it is essential for the researcher to interact with participants with dementia in a manner that is open to additional possibilities, respecting their current status, interests and opinions.

3.2 Recruiting Participants

Though recruitment may be an issue for many studies, studies taking place in MCUs have particular issues such as ensuring informed consent, the need to utilize legally authorized representatives for informed consent, and dealing with staff who are often overwhelmed by responsibilities and may be hesitant to take on the additional burden of participating in a study.

Navigating the Enrollment of People with Dementia Through Others. There are no universally accepted guidelines for what constitutes informed consent for someone with dementia. However, informed consent is a requirement of research involving human participants and necessitates that participants are competent enough to understand the implications of their decisions [17]. To address the lack of ability for people with dementia in middle and later stages to provide informed consent, legally authorized representatives (LARs) are often utilized as proxies for authorizing individuals with dementia to take part in research.

We navigated enrollment in a manner similar to what was described in [16]; however, we did not send recruitment letters to residents due to the level of their cognitive impairment which would make responding to or recalling the contents of the letter impossible. For our study, we sent letters to the people recorded as LARs in resident files asking them to contact us to enroll their relatives if they were interested. Once they signed a consent form, we were able to approach their relative in the MCU to gauge willingness to participate in the study and obtain ‘assent’. Due to us having to go through LARs, some MCU residents who verbally expressed interest in taking part in the study after seeing us use the system with other residents could not take part in the study because their family members did not respond to our letters. In one instance, a resident told the first author she had wanted to use the system but thought that nobody would let her. We felt torn in situations such as these, when residents showed interest in the system yet due to lack of consent from LARs, we were not able to invite them to take part in the study. Unlike studies with the general population, where a person who is interested and meets criteria can take part, people in this population who are interested and would benefit from the study may be excluded due to whether or not their LAR chooses to have them participate.

We caution that the use of technology may make family members more hesitant to enroll their relatives with dementia: one family member wrote to us that he did not think his family member should be in the study as she may be “beyond using any type of technology.” However all participants with the exception of one who had very severe dementia (MMSE score of 2) and was unable to respond to or follow instruction, were able to use the system. As noted by Hellström et al., having a family member serve as a gatekeeper to conduct (non-invasive) research with people with dementia is not optimal, but it is difficult to come up with another way to ensure that people with dementia are not manipulated or treated unethically [18]. Thus, it is important to come up with ways to introduce technology studies to family members so that participants who could benefit are not excluded. As mentioned above, family members often doubted that their relatives would be able to complete the study or interact with the technology, even when this was not the case. Recruitment materials should emphasize that people with all levels of dementia severity may be able to contribute to the study and that researchers will be present to instruct the participant in the use of the technology.

Staff presented another barrier to wide enrollment of residents. After the initial enrollment, during which letters were sent to all LARs, as new residents moved into the MCU, staff would only notify us about residents they saw as cognitively able to take part in studies. It may help to reinforce to staff that the researchers have methods of screening out residents who are unable to take part in research.

Enrolling Staff. It was difficult for us to find a time to speak to staff about the study. During one information session, staff were actively taking care of residents and were not able to fully focus on details of the study and did not express interest in signing up for the study. The staff who did sign up for the study had come to a separate, much smaller session that took place in another area of the facility, away from the residents. Though we believe that the distance from residents helped, the greater participation from this group may also be attributable to the staff members who attended that session having been more interested in the study to begin with. In general, we found that the staff members most likely to be involved were the ones already engaged in conducting and planning activities with residents (whether formally or informally). We suggest targeting these individuals in recruitment as ‘champions’ who may be motivate other staff members to take part in the study.

Staff in MCUs may be extremely busy and unlikely to want to take part in studies that do not have clear benefit to their workflow or practice. In our study, once the tool was in the MCU for several months, staff were much more open to taking part in the study and using the tool. If possible within the study methodology, we suggest letting staff become familiar with the system and its benefits over several weeks before recruiting for the study, as staff commitment before the intervention begins is essential [14]. If this is not possible, another option is to continue recruiting throughout the study. Additionally, some staff members may be willing to do an exit or one-off interview discussing their experience using the system even if they are not willing to be enrolled for the entire duration of the study.

3.3 Conducting the Study

Using the Technology System. Although many products are marketed as ready for deployment with older adults or people with dementia, in our experience, we have found that many have significant usability and technical issues despite being available for purchase. Many issues with the system used for the study were exacerbated by conditions in the memory care unit. For example, staff felt an intense sense of time pressure while conducting activities. They described situations where they would attempt to use an application with residents and it wouldn’t immediately work or they would not know how to use it without multiple attempts, and residents would quickly lose interest and get up and leave the room. One staff member described how she never felt like she had enough time, as she prioritized spending time with the residents over other tasks (including learning to use the system deployed in the study). Although in the long run, learning to use the system might result in more opportunities for beneficial interactions with residents, it could be hard for staff to justify taking time away from interacting with residents to learn to use the system.

To address technical and usability issues, we attempted several solutions. We provided resources to help staff learn to use the system, such as pocket card instruction manuals (attached to the system and given to staff participating in the study) and created web resources, such as videos, to help staff learn how to use certain features. The system manufacturers had technical support staff available, and we left the technical support telephone number in several locations so staff could access them. Additionally, we conducted information sessions where we taught all staff how to use the system. Finally, research staff were on site several times a week to conduct sessions and to address any issues. We also asked staff during monthly interviews if they were having issues with the system.

Unlike Andersson et al. [15], we did not find that technical support staff or instruction manuals were useful for staff members at the MCU. Of all the solutions we attempted, staff mainly utilized on-site researchers as resources for addressing issues. This was useful for staff to notify us about issues that could be addressed, such as broken cables. It was also useful for staff to tell us about processes they found confusing. Based on in-person feedback from staff that this was a very confusing process, we placed a sticky note on the monitor that described how to plug in the system to the monitor. This small change was mentioned as very useful and as leading to greatly increased use. We suggest having researchers on site periodically to resolve issues, as staff did not contact us through email or the system's technical support team through phone.

Another way staff were able to learn to navigate some usability issues was through identifying a staff member that was comfortable using the system and asking them for assistance in the moment. It may be helpful to identify a 'champion' staff member who is willing to spend time with the researchers to learn to use the system and then serve as a person to answer questions from other staff members.

Scheduling. While all studies may experience variability in scheduling weekly sessions, we ran into issues particular to a memory care unit setting. These issues included unpredictable activity scheduling and periodic confusion on the part of residents. In one case, we spent some time with the activity director finding a time to schedule a session with a resident who was especially engaged in activities. Even after this scheduling, some days, staff members would not follow the activity schedule and spontaneously decide to conduct a favorite activity of the resident. Another issue in scheduling sessions occurred with fluctuating cognitive states and disorientation of residents.

In other types of studies, scheduling issues may be resolved through phone calls to avoid having a researcher show up without need. For residents in the MCU, this would not be possible. One solution to dealing with fluctuating cognitive states is identifying best times of the day for residents through talking to staff or family members. Many of the residents were most alert in the morning and experienced some form of "sundowning syndrome" (confusion and agitation which affects some people with dementia as the sun goes down). It was also helpful to be in contact with family members who visited frequently who could let us know if a resident was not feeling well or was experiencing more confusion than usual. We recommend speaking to family members and staff members to minimize scheduling issues.

4 Conclusion

Technology systems have the potential to benefit people with dementia and those that care for them by expanding the types of activities that are available. However, conducting research in memory care units and with people with dementia introduce challenges that are not present in other settings. We present methodological and logistical considerations in deploying technology tools with people with dementia that will assist researchers in conducting similar studies. We address various stages of the research process, such as designing, recruiting for, and conducting studies with this population.

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