

## Research In Focus: A Weekly Digest of New Research from the NIDILRR Community

### Understanding Care Approaches May Help Shape the Future of Technology to Support People with Dementia

*A study funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR).*

About 5-8% of adults over age 60 worldwide have dementia, that's 50 million people worldwide, according to the World Health Organization. People with dementia may benefit from supports to help them remain engaged in meaningful activities, such as hobbies, volunteering, or activities of daily living. Assistive technologies may provide supports to people with dementia that can augment the supports provided by family and professional caregivers. Differing philosophies about dementia care may influence the technology design priorities held by researchers, designers, and service providers. In a recent NIDILRR-funded study, researchers asked practitioners serving people with dementia about their strategies for supporting their clients to engage in meaningful activities. The researchers wanted to find out what supports the practitioners provided and their underlying philosophies in understanding and responding to the needs of their clients with dementia. They also wanted to understand how technology could support meaningful activities for people with dementia.

Researchers working with the [Inclusive Information and Communications Technology Rehabilitation Engineering Research Center](#) interviewed 19 practitioners who served people with dementia in skilled-nursing facilities, at adult day programs, or in their homes. The practitioners included occupational and speech therapists as well as activities directors and others who facilitate group or individual activities for people with dementia. During the interviews, the researchers asked the practitioners about the types of meaningful activities in which they support their clients, the strategies they use for supporting their clients, and any technologies they use in their work.

The researchers found that the practitioners described supporting their clients with dementia in a variety of meaningful activities. Most described asking their clients to collaborate in setting goals and identifying meaningful activities, if they were able to clearly communicate their preferences. For clients with greater communication impairments, the practitioners described incorporating what was known of the client's history to estimate their wishes. For example, if a client had previously worked as a postal employee, the practitioner might provide them with a task of delivering mail to other residents.

When the researchers asked the practitioners about their professional strategies, they found that there was a tension between two differing philosophies of dementia care. Specifically, the practitioners described two opposing ways of interpreting the actions of people with dementia, each with an associated approach to engaging with their clients:

1. Interpreting actions as symptoms of disease (disease-focused): Some of the practitioners described attributing behaviors such as emotional outbursts, aggression, or disengagement to the dementia itself. The term Behavioral and Psychological Symptoms of Dementia (BPSD) was sometimes used to explain these behaviors. Some of the practitioners used this language to comfort or reassure their clients' family members that the unusual or distressing behaviors they observed were "the disease, not the person." The practitioners following this philosophy reported using strategies such as distracting or redirecting their clients if they expressed upset and focusing on meaningful activities that kept their clients safe and comfortable. These practitioners emphasized a practical approach to reducing unwanted behaviors and safeguarding their clients' well-being. Some of the practitioners described engaging their clients in simple activities, such as coloring pictures or folding a basket of towels, to help them feel a sense of accomplishment without struggling.
2. Interpreting actions as meaningful (meaning-focused): Other practitioners described interpreting the actions of their clients as attempts to communicate desires, rather than as symptoms of the disease. The practitioners explained the need to "be a detective" and look for the meaning conveyed by the client's behavior. For example, if a client repeatedly walked out during a particular activity, the practitioner might try to determine what the client disliked about the activity and how to better meet their needs. The practitioners holding this view emphasized a "respect" approach which included treating their clients like adults, avoiding childlike activities such as coloring, and instead offering their clients meaningful opportunities to give back to their communities, such as making art for patients in the hospital.

Although each practitioner tended to favor either disease-focused or meaning-focused interpretation when working with their clients, many of the practitioners also reported changing their interpretations of their clients' actions based on several factors. These included:

- Stage of dementia: Some of the practitioners reported taking a more disease-focused interpretation with clients in the later stages of dementia, and a more meaning-focused interpretation with clients in earlier stages of dementia who could still communicate their wishes more clearly.
- Evolving thought: other practitioners reported that their interpretations changed as they advanced in their careers, learned more about dementia, and met self-advocates with dementia who emphasized the importance of respect and dignity.
- Time pressure: The practitioners emphasized sometimes needing to respond to a resident's actions quickly. During these periods, they reported that it was faster to simply attribute resident's actions to the disease rather than taking the time to investigate its deeper meaning.

- Emotional distancing: The practitioners described the emotional toll of caring for individuals with dementia. They reported that attributing clients' behaviors to their dementia helped to create some needed emotional distance to prevent burnout.

The authors noted that people with dementia may benefit from participation in person-centered activities with the support of practitioners who recognize their clients' high-level needs such as esteem and a sense of purpose. However, practitioners may face time pressures and emotional challenges that may lead them to focus on ameliorating the behavioral symptoms of dementia rather than fully listening to the desires that their clients are communicating through their actions.

Based on the study results, the authors recommended two areas for assistive technology development and future research. First, they recommended the development of new technologies to support people with dementia in actively contributing to their communities. For example, technology to support volunteering in the community, or virtual reality for simulated activities like cooking. Second, they recommend the development of assistive technologies that support emotional distancing for professional and family caregivers, to mitigate the emotional impact of caring so that they can better support people with dementia in continuing to live meaningful lives.

#### [To Learn More](#)

Study author Emma Dixon discussed [part of this study and the role of sensory changes in everyday technology use by people with mild dementia in this video](#).

The Rehabilitation Engineering Research Center (RERC) on Technologies to Support Aging-in-Place for People with Long-Term Disabilities conducts research and development on technologies for use in the home and in the community, such as smart home technologies, falls prevention tools, and more. This center also works with developers to help them understand the technology needs of older users. [Learn more about this research and some of the technologies under development](#).

The [RERC on Wireless Inclusive Technologies](#) are investigating the use of Pepper, a socially assistive robot, to provide social, physical, and emotional support for older adults and people with disabilities. [In this video, Pepper teaches a person how to do a fist bump, reads a story, and plays a game](#). Socially assistive robots like Pepper may offer an innovative approach for significantly increasing the capabilities and social participation of people with disabilities across environments of their choice.

#### [To Learn More About this Study](#)

Emma Dixon and Amanda Lazar. (2020) [Approach matters: Linking practitioner approaches to technology design for people with dementia](#). Proceedings of the SIGCHI Conference on Human Factors in Computing Systems. This article is available from the NARIC Collection under Accession Number J84887.

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