

Leveraging information technology to support caregiver medication management for individuals who live with dementia

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More than 21 million people provide unpaid care for millions of people living with dementia in the U.S. With input from caregivers, researchers

from Regenstrief Institute, Indiana University, the University of Wisconsin and Purdue University are developing and testing Helping the Helpers, a user-centered, evidence-based app to support dementia caregivers as they help manage medications—very often multiple drugs for various conditions—of individuals who cannot do so independently.

In one of the first studies leveraging app-based [information technology](#) to help [caregivers](#) with medication management for individuals living with dementia, and with the goal of sharing their research with others who are developing or adapting technology to help caregivers, the Regenstrief, IU, Wisconsin and Purdue research scientists have published their gold standard methodology related to:

- Remote assessment of the needs of caregivers who manage medications for people with dementia.
- Co-design, including input from caregivers, of a prototype app to support caregiver-assisted medication.
- Feasibility testing of the prototype app.

Among other innovations, the researchers added a virtual component to contextual inquiry to learn what caregivers go through during the day as they tackle medication management.

"We want to know what's going on," said study corresponding author Richard Holden, Ph.D., M.S., human factors engineer, social cognitive psychologist and implementation scientist. "So we ask participants to record what they are going through during the day related to medication management and send something to us twice a day. It can be a photo, a video, an audio file or a written memo. It might be a photo of the large number of medications that have to be managed. It might be a video of a patient refusing to take medications. We analyze this input and its an important component of our participatory co-design with caregivers' innovation."

Managing the medications for individuals with dementia is often confusing, time consuming and difficult, especially if the cognitively impaired patient is resistant, belligerent or both. Caregivers, many of whom have other responsibilities inside or outside the home, are typically under-trained, under-resourced and under-supported in their role as medication manager. This can lead to significant caregiver burden, stress and potentially mistakes which might be life threatening to the individual with Alzheimer's or related dementia.

"My family and I understand the daunting challenges of caring for someone with dementia. My mother and brother are the primary caregivers for my father, and I am a remote 'tele-caregiver.' We know that caregivers need support," said Dr. Holden. "As the U.S. population ages, the need for user-centered support for caregivers, like our Helping the Helpers app, becomes even more necessary. My colleagues and I are presenting the methodology of our study in this paper so other researchers and developers will have access to the innovative methods framework we devised to produce technology meeting the needs of the intended end users—actual caregivers."

According to the Alzheimer's Association, an estimated 6.5 million Americans age 65 and older are living with Alzheimer's [dementia](#) in 2022. That number is predicted to rise to an estimated 7.2 million in 2025 and is projected to reach 13.8 million in 2060, barring the development of any medical breakthroughs to prevent, slow or cure Alzheimer's.

"There are countless numbers of [medication](#) management apps currently available that support a variety of tasks, but very few are developed and designed for caregivers with specific attention to caregiver needs," said Noll Campbell, PharmD, M.S., of Regenstrief Institute and Purdue University College of Pharmacy.

The Helping the Helpers paper concludes that "ultimately, if successful, our IT (information technology) intervention should be useable and acceptable to a range of users across the U.S, who could benefit immediately from IT without directly or indirectly incurring the costs associated with clinician-intensive treatments."

The research is published in *Research in Social and Administrative Pharmacy*.

More information: Nicole E. Werner et al, Helping the Helpers—A research protocol for user-centered technology to aid caregiver management of medications for people with Alzheimer's disease and related dementias, *Research in Social and Administrative Pharmacy* (2022). [DOI: 10.1016/j.sapharm.2022.03.014](https://doi.org/10.1016/j.sapharm.2022.03.014)

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