

# The biggest financial, legal and functional challenges of caregivers of persons living with dementia

October 10 2023, by Ann Kellett

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A [new study](#) published in *JMIR Aging* identifies the major challenges and needs of the 11 million Americans who act as caretakers for family members with dementia.

The study findings will be used to refine a national, digital platform for [caregivers](#).

About [6.5 million Americans](#) age 65 and older live with Alzheimer's disease and Alzheimer's-related dementias, and this number is expected to grow to 13.8 million by 2060. These diseases lead to the loss of memory, [motor function](#) and other debilitating conditions. The causes of [dementia](#) remain unknown, and there is no cure.

Most caregivers for Americans living with this disease are patients' spouses, children and children-in-law, and most are female. They are also mostly older and have significant additional professional and [family responsibilities](#). Combined, they contributed more than 16 billion hours of care with an estimated economic cost of nearly \$272 billion in 2021 alone.

These dementia caregivers often face challenges in finding caregiving information and services in general, and finding services that are high-quality, trustworthy and flexible more specifically. This can lead to [chronic stress](#) and increase their risk of developing depression, anxiety, social isolation and physical health problems.

In the new study, a team of researchers led by Texas A&M School of Public Health Regents and Distinguished Professor Marcia Ory, Ph.D., asked caregivers for relatives with dementia about their challenges and needs, as well as their ideas for a digital platform that would provide advice and support for caregivers. Qiping Fan, a recent Texas A&M DrPH graduate in health behavior, led this research effort.

Other studies have identified caregivers' broad challenges and the importance of developing innovative technology solutions. This study, however, is the first to drill down into the three main challenge areas—financial, legal and functional—and to also ask for dementia caregivers' ideas for a "magic wand" [digital platform](#) that could reduce their stress and improve their quality of life.

"We explored caregivers' specific concerns, such as where to get help to pay for caregiving services, how to navigate the issue of guardianship and how to cope with everyday activities," Fan said. "Their input will be used in the design of a digital health platform that they would find useful and tailored to their specific needs."

For the study, 30 dementia caregivers participated in interviews and a follow-up survey that asked about their biggest challenges in caregiving, if they got help from professionals and what kind of features they most needed in an online platform for caregivers. Most participants were over the age of 50 (83.3%), female (76.7%), White (83.3%), non-Hispanic (90%), and held a bachelor's degree or a graduate degree (73.4%).

Collectively, all participants acknowledged financial, legal and functional challenges in caring for their [family members](#) living with dementia. The most common challenges included balancing other family obligations and work, managing financial burdens, finding reliable services, navigating the legal or financial process, and seeking emotional health support.

The study found that the relationships between all the individuals involved are significant factors in care decisions, so elder care services should engage not just individual caregivers but entire families in a holistic decision-making process. In addition, participants noted that reliable information about caregiving is hard to find online, indicating a significant demand for programs, tools and services that integrate mental

[health](#) support, educational resources, an information database on elderly care services and other quality features.

"This study was only possible through the unique partnership combining the creativity of Aggie students, faculty and alumni," Ory said.

"We now have a comprehensive view of this population's current challenges and a clear vision of potential resources and interventions that may support caregivers," said Logan DuBose, one of the principals at Olera.care who has worked closely with the School of Public Health.

**More information:** Qiping Fan et al, Financial, Legal, and Functional Challenges of Providing Care for People Living With Dementia and Needs for a Digital Platform: Interview Study Among Family Caregivers, *JMIR Aging* (2023). [DOI: 10.2196/47577](https://doi.org/10.2196/47577)

Provided by Texas A&M University

Citation: The biggest financial, legal and functional challenges of caregivers of persons living with dementia (2023, October 10) retrieved 27 April 2024 from <https://medicalxpress.com/news/2023-10-biggest-financial-legal-functional-caregivers.html>

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