

Pain limits family caregivers' daily activities, finds study

November 28 2023, by Marijke Vroomen Durning



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Researchers from Weill Cornell Medicine provide the first national estimate of caregivers' pain and arthritis experiences that can limit their ability to perform necessary tasks while caring for older family

members.

The study suggests screening [caregivers](#) for pain issues and offering interventions, particularly to populations that are traditionally underserved. This may help avoid higher health costs and improve the quality of life for both caregivers and their care recipients.

This is one of the few studies focused on quantifying how pain affects caregivers. The [paper](#), published on Sept. 1 in *The Gerontologist*, analyzed data collected from 1,930 caregivers, with a [median age](#) of 62, who participated in the 2017 National Study on Caregiving.

"Research on family caregivers' pain is really scarce," said lead author Shelbie Turner, a postdoctoral fellow in the division of geriatrics and palliative medicine at Weill Cornell Medicine. Earlier studies indicated that about 40% of caregivers have arthritis and 50% have pain they identify as "bothersome."

"I wanted to take it a step further and determine how many of those caregivers have pain that routinely limits their [daily activities](#)," Turner said. "This could help us determine the extent of the issue, with a longer-term goal to explore the effect of caregiver pain on care recipients' unmet needs. For instance, a caregiver having a high pain day could struggle with tasks like getting their relative in and out of bed."

The results of the new study validated earlier findings that 40% of caregivers were diagnosed with arthritis. Delving deeper, the researchers found that 75% of those caregivers had "bothersome pain," and 30% said the pain was activity-limiting. Among all respondents, regardless of arthritis diagnosis, 51% had bothersome pain, 24% of whom had activity-limiting bothersome pain. Older age was closely correlated with arthritis and pain-related disability.

Given that caregivers of older adults are often spouses who are themselves older, or [older children](#), they may find it challenging to carry out everyday duties effectively and consistently. The researchers found that caregivers with physical difficulty providing care were more likely to have activity-limiting pain.

"This finding raises new questions about the ways in which certain caregiving activities may exacerbate existing pain or be associated with the development of new pain conditions," Turner said. She and her team are planning future studies to answer such questions.

Pain that forces caregivers to curtail certain activities, from hands-on care (such as bathing and dressing) to preparing a meal or driving a relative to a doctor's appointment, not only affects the care recipient directly but also contributes to caregiver stress, Turner said, "Many people with pain also struggle with high negative emotions and mental health conditions such as depression. The stress of pain may compound the stress of caregiving in ways that make caregivers' daily lives quite challenging."

While some results were expected, Turner and her colleagues were surprised to find that reported pain among caregivers of people with dementia didn't differ from other study participants.

"I'm really interested in figuring out what's going on because we anticipated that caregivers of recipients with dementia would be more likely to have activity-limiting pain," she said. Navigating care for relatives with dementia can be more stressful and more physically demanding than with someone without cognitive impairment. "It's possible that even though dementia caregivers are no more likely to have pain, they may face more care-related challenges when they do experience pain," she said.

With the U.S. population age 65 and over growing nearly five times faster than the [total population](#), according to the 2020 census, the need to study this phenomenon is crucial.

"Dr. Turner's study shows that pain in family caregivers is an important but neglected topic in the field of gerontology. Further studies will define the scope of pain in caregivers, as well as, initiate interventional studies to mitigate [pain](#) in this target group," said senior author Dr. Cary Reid, the Irving Sherwood Wright Professor in Geriatrics, division of geriatric and palliative medicine at Weill Cornell Medicine and a physician at NewYork-Presbyterian/Weill Cornell Medical Center.

More information: Shelbie G Turner et al, Prevalence Estimates of Arthritis and Activity-Limiting Pain Among Family Caregivers to Older Adults, *The Gerontologist* (2023). [DOI: 10.1093/geront/gnad124](https://doi.org/10.1093/geront/gnad124)

Provided by Cornell University

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