

Study shows a rising, but uneven, tide of in-home care for disabled seniors

July 12 2016

More seniors are getting help from family, friends and hired helpers to keep them in their homes, despite disabilities that keep them from total independence, a new study finds.

But that increase isn't happening evenly across all groups. And the rising demand may have implications for the lives and careers of caregivers, and for policies that aim to support at-home caregivers.

In the new issue of *JAMA*, a University of Michigan Medical School team reports that 50 percent of disabled seniors had some form of in-home help in 2012. That's up nearly 20 percent, or 8 percentage points, since the start of the study in 1998.

The sharpest rise was among those who had milder disabilities—suggesting that these seniors may have been trying to avoid entering a nursing home and instead "age in place."

The study included nearly 5,200 people 55 or older who lived at home and had at least one disabling condition, and took part in the Health and Retirement Study, a long-term study run by the U-M Institute for Social Research. Each was interviewed at home or by telephone several times over the course of the study.

"Caregiving is essential for keeping people at home and out of nursing homes. But we were surprised by the size of the increase from 1998 to 2012," says Claire Ankuda, M.D., M.P.H., the study's lead author and a

Robert Wood Johnson Clinical Scholar at U-M's Institute for Healthcare Policy and Innovation. "As we see more of an emphasis by seniors on staying in their homes, and valuing their independence, and as the size of the senior population grows, we need to be thinking as a society about potential ways to help caregivers, and ease the strain it can cause."

The study population aims to be representative of the American public. So, if the rates hold true at a national level, more than 3.1 million more American seniors had in-home help in 2012 than did in 1998.

Differences emerge

Over the study period, people with educations beyond high school and above-average net worth saw greater increases in paid caregiving compared with people with less education and less wealth. This suggests growing socioeconomic disparities in receipt of paid caregiving by disabled seniors.

This may also suggest a trend toward aging in place even among those who might be more likely to afford a nursing home.

Even so, about two-thirds of men and 45 percent of women had no caregiving help at all. That's despite the fact that they all had at least some trouble handling routine daily tasks like preparing meals, getting dressed, going to the bathroom or managing their medications.

As might be expected, spouses and adult children were the most common caregivers, and the percentage of seniors reporting that they got help from these sources rose. So did the percentage who said they received help from other family members.

The largest rise was in paid caregiving, while the percentage who received help from friends stayed flat. Paid caregiving can include help

that's paid for out of a person's savings, or in some cases with Medicaid and Medicare funds for those who qualify.

Next steps and policy implications

Ankuda and senior author Deborah A. Levine, M.D., M.P.H., an assistant professor of internal medicine, are working on other research about caregiver strain.

The demands of caregiving for a disabled spouse or elder may lead to burnout, and in the case of younger caregivers, create missed professional and educational opportunities that could affect their futures.

"Caregivers are critical to maintaining the health and well-being of disabled older adults yet are largely unrecognized in our care systems," says Levine. "Although caregiving can have benefits, it can also have serious risks for the caregiver including depression and worse health. So supporting caregivers is critical to maintain their health and well-being as well."

Some states have begun providing payment to family members who care for disabled people at home, mainly through Medicaid. Other policies regarding guaranteed paid leave from work, and charity programs in the community and through houses of worship, can also assist.

The sizable population of disabled seniors who got no in-home help could also represent another opportunity, they say. It is possible that getting more disabled seniors connected with care could benefit them and reduce healthcare costs from emergency room visits and nursing home care.

Some of these individuals may just need caregiving for a short while—while recovering from surgery, for instance. Others may need

longer-term care to help them stay safely in their homes. Those who are too well-off to qualify for Medicaid, but have no family caregivers available, nor enough money to pay for help, might be especially important to focus on.

"A growing body of research on caregivers really emphasizes that the experience of caregiving is a common experience, especially for middle-aged and older women," says Ankuda. "Caregivers are clearly not unique in their situations, but are often isolated because we don't recognize them as a formal part of the medical system. They're an unseen, unpaid workforce that could be supported better."

More information: *JAMA*, [DOI: 10.1001/jama.2016.6824](https://doi.org/10.1001/jama.2016.6824)

Provided by University of Michigan Health System

Citation: Study shows a rising, but uneven, tide of in-home care for disabled seniors (2016, July 12) retrieved 20 April 2024 from <https://medicalxpress.com/news/2016-07-caregiver-home-dwelling-functionally-disabled-older.html>

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