

New study estimates the caregiving costs for families

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"Informal care" is the term used in medicine to describe unpaid care provided by family and friends. It's an important lifeline for millions of older adults in the U.S. who need day-to-day help with shopping, cooking, cleaning, eating, taking medicine, looking after their own daily well-being, and many other activities essential to our health and quality of life as we age.

In the U.S., more than 35 million people provided informal care to someone 50-years-old and older in 2015. We usually understand the costs associated with a doctor, nurse, or other healthcare worker providing professional care to [older adults](#). However, we don't understand what the true costs are when older adults are cared for by family members or friends. In part, that's because most studies have focused on "direct" healthcare costs (the expenses associated with professional help/treatment). However, these studies have ignored the "indirect" costs associated with informal care.

When the costs of informal care are accounted for, most studies usually multiply the hours of informal care by the wage that a formal home healthcare provider would earn. But this doesn't reflect the true cost of informal care. Informal caregivers often give up other activities such as leisure or employment, for example. Studies haven't examined the value of leisure time and the other important aspects of life people may give up when they care for a friend or family member.

In a new study, researchers focused on one of the most common

caregiving arrangements: daughters between the ages of 40 and 70 who were likely to need to provide informal care to their mothers at some point in the near future. Participants were identified using the Health and Retirement Study, a survey conducted by the University of Michigan since 1992. Findings from this new analysis were published in the *Journal of the American Geriatrics Society*.

The researchers totaled the time the daughters spent in caregiving. They distinguished between light caregiving (providing fewer than 1,000 hours of care over a two-year period) and intensive caregiving (providing 1,000 or more hours of care). The daughters were also asked whether they worked full- or part-time outside their caregiving role.

The survey also asked the daughters about their mothers' health. For example, it asked if their mothers needed help with "instrumental activities of daily living" (IADLs). IADLs include activities such as taking medicine or grocery shopping. The survey also asked if their mothers needed help with more general "activities of daily living" (ADLs), such as eating, bathing, and getting around. Daughters were also asked whether their mothers could be left alone for an hour or more, and whether their mothers were ever told by a doctor that they had a memory-related [disease](#).

The researchers used these measures to define six states of health for the mothers:

- Healthy
- Has difficulty performing [daily activities](#) only
- Has a memory-related disease only
- Has difficulty performing daily activities and has a diagnosed memory-related disease
- Cannot be left alone for an hour or more
- Dead

The researchers noted that while there is a variety of health concerns that could make it difficult to leave an older person alone, two-thirds of the daughters said they could not leave their [mothers](#) unattended because of a doctor-diagnosed memory-related disease.

The researchers also said that the costs associated with care for a memory-related disease varied a great deal depending on whether the mother also had trouble performing daily activities. For example, caring for someone with memory-related disease but no ADL limitations cost approximately \$163,000 over a two-year period. This is similar to the costs of providing care for a mother who only had ADL limitations (\$167,000). However, when memory issues were paired with having difficulty performing ADLs, the costs of caregiving actually decreased to \$144,000. On the other hand, when a mother cannot be left alone for more than one hour, caregiving costs rise to more than \$200,000.

To put these costs in perspective, the average cost of a semi-private bed in a nursing home in 2017 was \$85,775. This suggests that two years of [nursing home care](#) would cost \$171,550.

The researchers concluded that their results suggest the costs of informal care to a daughter's well-being are similar to the costs associated with full-time institutional care. Based on their study, the researchers believe that the impact of having unpaid family or friend caregivers differs depending on the health needs of the person receiving care. This is important for three reasons:

- Providing informal care for someone with a memory-related health condition may be a different (sometimes more complex) experience than caring for someone who only needs assistance with physical limitations.
- Memory-related diseases, such as [Alzheimer's disease and related dementias \(ADRD\)](#), use a very large share of informal care.

- Memory-related diseases currently affect more than 5 million Americans, and cases are predicted to double within the next 30 years.

More information: Norma B. Coe et al, A Comprehensive Measure of the Costs of Caring for a Parent: Differences According to Functional Status, *Journal of the American Geriatrics Society* (2018). DOI: [10.1111/jgs.15552](https://doi.org/10.1111/jgs.15552)

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