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A Comprehensive Measure of the Costs of Caring For a Parent: Differences According to Functional Status

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Abstract

Providing unpaid care for an older parent has costs that go well beyond a caregiver's lost wages. A new estimate suggests that the median direct and indirect costs of caregiving are \$180,000 over two years, about the same as full-time institutional care. This estimate accounts for lost earnings as well as non-tangible factors, such as lost leisure time and changes to the caregiver's well-being. It suggests that informal care cost caregivers at least \$277 billion in 2011, which is 20 percent higher than estimates that only consider lost wages.

Keywords

informal care, long-term care, caregiving

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Research BRIEF

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A COMPREHENSIVE MEASURE OF THE COSTS OF CARING FOR A PARENT: DIFFERENCES ACCORDING TO FUNCTIONAL STATUS

Norma B. Coe, Meghan M. Skira, Eric B. Larson

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KEY FINDINGS

Providing unpaid care for an older parent has costs that go well beyond a caregiver's lost wages. A new estimate suggests that the median direct and indirect costs of caregiving are \$180,000 over two years, about the same as full-time institutional care. This estimate accounts for lost earnings as well as non-tangible factors, such as lost leisure time and changes to the caregiver's well-being. It suggests that informal care cost caregivers at least \$277 billion in 2011, which is 20 percent higher than estimates that only consider lost wages.

THE QUESTION

Unpaid care provided by family and friends, or 'informal care', is a cornerstone of care and support for older people in the U.S. In 2015, more than 35 million Americans provided informal care to relatives or dependents over age 50, the majority being daughters caring for their mothers. Placing a dollar value on the cost of caregiving, and fully accounting for the impact of care on the caregiver's well-being, is a complicated and difficult task. Most studies calculate foregone earnings, or consider the cost of replacing informal care with a formal home health care provider.

What would the cost be if the value of lost leisure time, the long-term impact on earnings and work, and any intrinsic benefits to the caregiver were taken into account? In this study, the researchers use multiple waves of the national *Health and Retirement Study* to observe and monetize the choices made in the most common informal caregiving situation – daughters caring for their mothers. They identified 3,400 women between 40 and 70 who had a living mother at the start of the study period (1998-2012), and estimated the total impact on the caregiver's well-being, comparing costs by the hours of caregiving (light or intensive) and the mother's health (e.g., whether she has a memory-related disease, or needs help with activities of daily living such as eating or bathing).

THE FINDINGS

DIRECT IMPACT OF CAREGIVING ON WELL-BEING

Caregiving can have a direct effect on well-being in both negative and positive ways. Caregivers might derive some intrinsic benefit, like fulfilling a familial duty. But caregiving is also difficult, and could directly decrease well-being.

The direct impact on well-being differs by the intensity of care and by the mother's health, as shown in Figure 1. Providing informal care to a relatively healthy mother decreases the daughter's well-being, regardless of the hours of care provided. Light caregiving (less than 1,000 hours of care over two years) positively affects the daughter's well-being when her mother has memory and/or activity of daily living (ADL) problems, but not when her mother is so ill that she cannot be left alone for more than an hour. This suggests that light caregiving may yield a net benefit to the caregiver when the parent is not too dependent, but when health impairments become severe, caregiving becomes particularly burdensome.

These effects are quite different for intensive caregiving (providing 1,000 hours or more of care over two years). Intensive caregiving for mothers with ADL limitations increases well-being, whereas caring for mothers with a memory-related disease decreases well-being. This difference could be driven by a clearer understanding of how to care for someone with ADL limitations as opposed to a memory-related disease. When the mother has both conditions, or when she cannot be left alone, intensive caregiving increases the daughter's well-being.

TOTAL COSTS OF INFORMAL CAREGIVING TO A DAUGHTER'S WELL-BEING

When only considering foregone wages, the median cost of informal caregiving is \$24,500 over two years, with relatively little variation by the health of the mother (Figure 2). However, when taking into consideration the monetized effects on the caregiver's well-being, or what economists call 'welfare costs', the median cost of informal caregiving is about seven times more – \$180,000 over two years.

The authors also compared costs by the mother's functional status. The median costs are similar if the mother has only ADL limitations or a memory-related disease (\$163,000 and \$167,000, respectively). However, when memory problems are paired with ADL limitations, the median costs of caregiving to the daughter's well-being decrease to \$144,000, likely due to the positive effects of caring for a mother with both conditions already noted. When mothers cannot be left alone, costs again rise to \$200,000 (Figure 2).

This estimate suggests that informal care cost at least \$277 billion in 2011, which is 20 percent higher than current estimates.

THE IMPLICATIONS

Increasingly, states are promoting home and community-based services as a cost-effective replacement for institutional care in their Medicaid programs. An expert national panel recently [recommended](#) making the home the nexus of dementia care. To the extent these changes increase the amount of informal care, the cost in terms of caregiver well-being should be considered. While policy changes may appear to reduce costs on a societal level when only foregone wages are considered, accounting for the caregiver's well-being may alter the calculation. The median cost of a daughter providing informal care to her mother—about \$180,000 over two years—is nearly the same as the two-year cost of a semi-private bed in a nursing home (just above \$170,000 in 2017). This suggests the need for more research on the benefits and drawbacks of these two very different care options. These findings should inform long-term care strategies that more fully account for the well-being of informal caregivers.

THE STUDY

The authors used 1998-2012 *Health and Retirement Study* data to identify female respondents between ages 40 and 70 who had a living mother at the start of the study, to focus on those most likely to be providing informal care. The final sample included 3,427 women and 14,645 observations, and includes information about working status, education, non-labor income, family structure, siblings, and the parent's health.

The authors estimated the impact of informal care on well-being by observing the daughters' decisions about how they split their time

Figure 1. Direct impacts of caregiving on well-being by health of mother

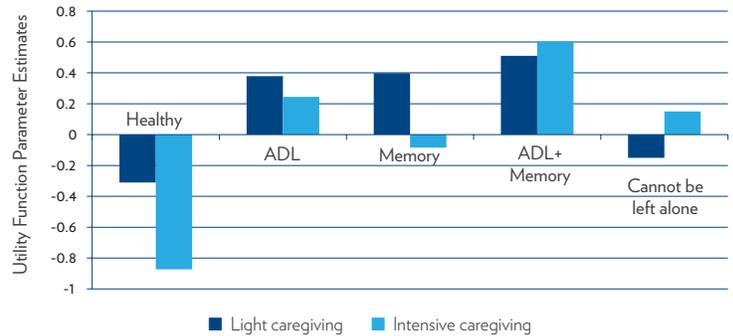
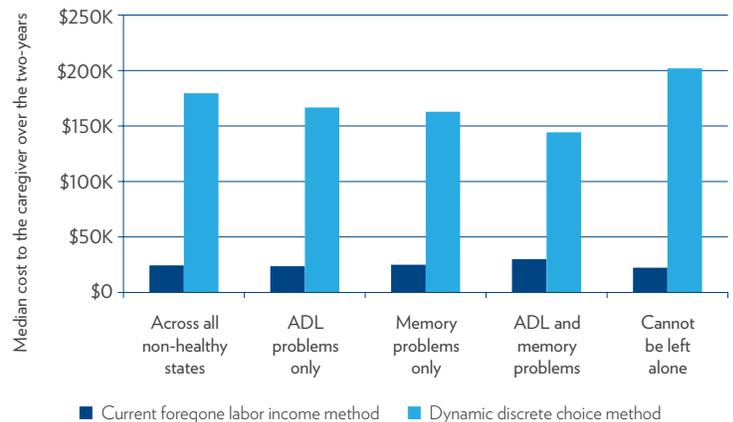


Figure 2. The median costs of providing care by health of mother



Source: *Journal of the American Geriatrics Society*

between leisure, work, and informal caregiving over a two-year period as their mothers progressed through various health states. The authors use the estimated model parameters to calculate each daughter's well-being when she has the choice to provide informal care compared to when she has to provide care, and observe how the model predicts differences in work, leisure, and wages. They calculated the costs to well-being as the lump-sum amount a woman would have to receive to be at the same level of well-being in the two scenarios, and reported the median costs.

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