

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

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Approximately 34 million family and friends provided unpaid care to individuals aged 50 and older in 2015. It is difficult to place a value on that time, because no payment is made to the caregiver, and multiplying caregiving hours by a wage does not account for the value of lost leisure time, implications for future employability and wages, or any intrinsic benefits accrued to the care provider. This study used a dynamic discrete choice model to estimate the costs of informal care provided by a daughter to her mother, including these other costs and benefits not typically accounted for, and compared these cost estimates for 4 categories of the mother's functional status: doctor-diagnosed memory-related disease, limitations in activities of daily living (ADLs), combination of both, cannot be left alone for 1 hour or more. We studied women aged 40 to 70 with a living mother at the start of the sample period (N=3,427 adult daughters) using data from the Health and Retirement Study (1998–2012). The primary outcome was the monetized change in well-being due to caregiving, what economists call “welfare costs.” We estimate that the median cost to the daughter's well-being of providing care to an elderly mother ranged from \$144,302 to \$201,896 over 2 years, depending on the mother's functional status. These estimates suggest that informal care cost \$277 billion in 2011, 20% more than estimates that account only for current foregone wages. *J Am Geriatr Soc* 66:2003–2008, 2018.

Key words: memory-related disease; ADL limitations; costs of caregiving; informal care

Informal care, unpaid care that family and friends provide, is a cornerstone of the care and support system of elderly adults in the United States. More than 35 million Americans provided informal care to someone aged 50 and older in 2015.¹ Most studies focus on the direct healthcare costs of aging, ignoring the costs associated with informal care. When the costs of informal care are computed, studies tend to use relatively straightforward methods, primarily relying on a replacement cost or forgone wage approach. Replacement cost methods multiply the hours of informal care by the wage of a formal home healthcare provider. The foregone wage approach uses the caregiver's own potential market wage to value each hour of informal care provided.

Both of these methods ignore important aspects of the true cost of informal care. Individuals providing informal care are affected beyond current forgone earnings. For example, all caregivers provide care at the cost of some other activity—leisure or employment. Forgone wage approaches do not incorporate the value of forgone leisure. For individuals who leave work or decrease their work hours to provide care, future labor market opportunities can be affected, making it difficult to return to work at their previous wage or hours. Finally, people who provide informal care might do so because it gives them some intrinsic benefit, such as fulfilling a family duty.² Neither the replacement cost nor the forgone wage approaches consider these long-term costs and nontangible benefits.

Furthermore, these methods do not capture heterogeneity in the costs of care due to the health status of the care recipient. There are 3 reasons this is important: (1) Providing informal care for someone with a memory-related disease may be a different experience than caring for someone with only ADL limitations. (2) Memory-related diseases, such as Alzheimer's disease and related dementias (ADRD),

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use a disproportionate share of informal care. In 2014, one-third of caregivers providing care to someone aged 65 and older reported that their loved one has a memory problem. (3) Memory-related diseases currently affect more than 5 million Americans, and their prevalence is predicted to double within the next 30 years.³ It has been estimated that informal care increases the cost of ADRD by 50% to 100% over the healthcare costs^{4–9} but, again, use static methods that ignore the dynamic nature of the cost to the caregiver's well-being.¹

This study estimated a more comprehensive cost of informal care that includes the value of time, the implications for future employability and wages, and any intrinsic benefits that accrue to daughters who provide care to their mothers. Economists refer to this collection of costs as “welfare cost.” Using a dynamic discrete choice model, we allow those costs to differ according to whether the mother has a memory-related disease, with and without accompanying ADL limitations, allowing us to more directly compare our cost estimates with those that focus on ADRD care using more traditional, static methods.

METHODS

Data

Survey data from the Health and Retirement Study (HRS), a longitudinal survey with information on labor supply, family structure, intergenerational transfers, health, income, and assets, were used. Baseline interviews occurred in 1992, with biennial follow-up. We used data from 1998 to 2012, when questions about parental memory-related diseases were asked. All HRS data used were de-identified, and all respondents provided informed consent under protocols that the University of Michigan institutional review board approved.

For two reasons, we focused on daughters at risk of providing informal care to their mothers by limiting the sample to female respondents aged 40 to 70 who had a living mother at the start of the sample period. First, the effect of caregiving on well-being may differ based on the characteristics of the caregiver and the care recipient, such as sex concordance.¹⁰ Second, the most prevalent intergenerational caregiving arrangement, nationwide³ and in survey data,¹¹ is daughters providing care to their mothers. The final sample consisted of 3,427 adult daughters and 14,645 person-wave observations.

Measures

In the HRS, respondents are asked whether they or their spouses had spent 100 or more hours in the past 2 years helping their parents with “basic personal needs like dressing, eating, and bathing.” Follow-up questions are asked about who was helped and how many hours of care the respondent and her spouse separately provided. Respondents were also asked whether they helped with “household chores, errands, transportation, etc.,” with similar follow-up questions. A woman is defined as a caregiver if she provided either type of care, and the hours she spent providing both types of care are summed to determine the amount of care provision. We distinguish between light (<1,000 hours

of care over 2 years) and intensive ($\geq 1,000$ hours of care) caregiving. In implementing the model, we assigned the median number of hours of care to each group: 200 hours of care per period for light and 1,560 hours for intensive care.

In the model, women could not work, work part-time, or work full-time. Those who worked part-time were assumed to work 2,000 hours per 2-year period, and those who worked full-time were assumed to work 4,000 hours per 2-year period. Additional covariates include the woman's education, nonlabor income, and family structure. In particular, in each wave, the woman reported her marital status and the number and sex of living siblings.

The HRS asks each respondent about her parent's health. In particular, the respondent is asked whether her mother needs help with activities of daily living (ADLs), whether she can be left alone for 1 hour or more, and after 1996, whether a doctor has ever told the mother that she has a memory-related disease. We used these measures to define 6 health states: healthy, ADL limitations only, a memory-related disease only, ADL limitations and a diagnosed memory-related disease, cannot be left alone for 1 hour or more, and death. Although a variety of ailments could lead to an individual not being able to be left alone, two-thirds of this group were reported to have a doctor-diagnosed memory-related disease.

Analysis

Discrete choice models describe and predict the choices people make when deciding between 2 or more alternatives, for example, working or not, providing informal care or not. Dynamic discrete choice models recognize that these decisions are not static, one-time decisions but have implications for future periods, particularly future well-being. We used a dynamic discrete choice model that follows directly from previous work.¹¹ Details of the model can be found in Appendix S1. The main point of departure from the earlier model is the more granular classification of maternal health.¹¹

This methodology allowed us to perform the following mental exercise. In each 2-year period, the adult daughter makes decisions about how to spend her time between leisure, work (no work, part time, full time), and informal care (no care, light care, intensive care) to maximize her well-being not just today, but also over her lifetime. For example, a daughter who decides to work full or part time today knows her expected wage offer will be higher in the next period because of the returns to experience and human capital formation. If she decides to work part time today rather than full time, her hourly wage may be lower if part-time jobs earn less than full-time jobs, and her ability to find a full-time job in the future may be lower if there are difficulties moving between full- and part-time employment. Finally, if she opts not to work at all, working in the future may be difficult because it is likely that she will have limited job offers and lower wages because of the loss of human capital.

Informal care can affect individual well-being in the following ways:

Direct utility effect: Caregiving can directly affect well-being—one could like it or dislike it. Caregiving effects on

well-being can vary according to duration (first time providing care vs continuing providing care), parent's health (ADL limitations, memory-related disease, combination of the two, cannot be left alone), and whether there is a sister who could share the responsibility.

Indirect effect through change in leisure time: Some individuals may value leisure more than others, and this valuation may change with age (e.g., after retirement, individuals may value each additional hour of leisure more or less).

Indirect effect through change in labor market opportunities and earnings: Providing informal care may affect how much one works today, affecting consumption today, as well as their wages and employability in the future.

The value of these effects is determined by observing a daughter's decisions about caregiving, work, and leisure as a mother progresses through these health states.

The daughter's well-being is measured by observing her choices, what economists refer to as "revealed preference." Individuals choose the options that give them the highest expected lifetime well-being. Variation in choices between individuals and over time allows us to estimate the preference parameters (along with functional form assumptions, distributional assumptions, and normalizations), and well-being is quantified using these parameters and observed choices about caregiving, work, and leisure as the mother's health status and the daughter's work opportunities change.

We used the estimated model to calculate the well-being of each daughter when she had the choice of providing informal care (baseline model). In a separate simulation exercise, for all women aged 55 and 56 with an ill mother, we removed the choice of not providing care and "forced" them to provide informal care in that period. When we "forced" women to provide care, they still optimized their well-being through their remaining choices regarding time spent working and time spent on leisure. We then compared the daughter's well-being between the two scenarios. For women who provided care in the baseline scenario, their change in well-being was 0.

We calculated the costs of informal care for women whose caregiving behavior changed from not providing care in the baseline scenario to providing it in the simulation. We calculate costs to well-being, which is the lump-sum amount of money a woman would have to receive to be equally well off in the 2 scenarios, and report the median costs. We calculated labor earnings forgone because of caregiving by limiting the sample to women who changed their caregiving behavior and their work decisions when we removed the option not to provide care.

RESULTS

Table 1 displays descriptive statistics for our (unweighted) sample of women based on their current caregiving status (with a mother no longer alive), noncaregiver (with a mother alive), light caregiver, intensive caregiver). Not surprisingly, caregiving becomes more prevalent with age. There was also a positive relationship between not working and caregiving intensity, which suggests difficulty in combining work with caregiving responsibilities, but education is less correlated with caregiving activity. Caregiving frequency and intensity increased as the mothers' health

declined. The percentage married varied across these categories, likely reflecting an increase in widowhood as women age and resulting differential time and availability to provide care.

In Figure 1, we present estimates of the direct utility effects of care provision according to the health state of the mother and the intensity of care provision. (Main model parameter estimates are available in Supplementary Table S1.) Providing informal care to a mother who has neither ADL limitations nor memory-related disease decreases the well-being of the daughter no matter how many hours of care are provided. Light caregiving has a concave relationship with well-being across the health states, positively affecting the well-being of the daughter across all health states except the healthiest and the sickest.

Intensive caregiving does not exhibit the same concave pattern. The most noteworthy difference is between ADL limitations (only) and memory-related disease (only). Intensive caregiving for mothers with memory-related disease decreases well-being, whereas caregiving for mothers with ADL limitations increases well-being. Only when memory impairment is combined with ADL limitations does intensive caregiving yield positive direct effects on well-being.

Figure 2 presents 2 estimates of the cost of care provision according to the health state of the mother; median current forgone earnings and median cost to well-being. The first methodology leads to an estimate of \$24,500 over 2 years over all health states, with little variation over the health states. These estimates align with those found in the literature, which range from \$21,220 to \$26,043 (in 2008 dollars).^{11–14}

The estimate of the median cost to well-being over all health states is approximately \$180,000 over 2 years, approximately 7 times the cost estimate using the current forgone wage approach. In addition, there is variation in the cost to well-being across health states. The costs to a daughter's well-being of caring for someone with memory-related disease varies considerably, depending on whether there are also ADL limitations. For example, caring for someone with memory-related disease but no ADL limitations costs approximately \$163,000—similar to the costs of providing care for a mother who has only ADL limitations (\$167,000)—but when memory problems are paired with ADL limitations, the costs of caregiving decrease to \$144,000 because of the direct positive utility effect of caregiving for mothers with memory-related disease and ADL limitations (Figure 1). When the mother cannot be left alone for more than 1 hour, the costs again rise to more \$200,000 over 2 years.

DISCUSSION

Focusing on the most prevalent caregiving dyad, we estimate the effects of caregiving on the well-being of the informal care provider. We compare forgone wages because of caregiving with a more comprehensive measure of cost that accounts for the dynamic nature of caregiving, the long-term effect on earnings and work, the effect on leisure, and the direct effect of caregiving on well-being. Our preferred method suggests that the median cost to well-being is approximately \$180,000, 7 times the forgone wage estimate. To put these costs into perspective, the average cost

Table 1. Characteristics of Women According to Caregiving Status

Characteristic	Mother No Longer Alive, n=5,610	Noncaregiver, n=5,640	Light Caregiver, n=2,714	Intensive Caregiver, n=681
Employment, %				
Not working	55.3	37.1	38.1	52.6
Working part time	17.4	18.2	21.1	19.4
Working full time	27.3	44.7	40.8	28.0
Mother's health, %				
Healthy		76.9	64.9	37.2
ADL problems		6.9	12.7	18.4
Memory-related disease		2.6	5.6	5.1
ADL problems and memory-related disease (can be left alone)		2.5	5.6	11.6
Cannot be left alone		11.1	11.2	27.8
Demographic characteristics and family structure				
Age, mean	62.1	56.9	58.4	59.5
Married	77.5	82.5	81.1	75.0
Has sister	72.0	75.9	72.8	66.5
Education, %				
<High school	16.4	14.7	9.7	9.1
High school	36.3	34.8	37.6	36.3
Some college	47.2	50.5	52.7	54.6
Years of work experience, mean	28.3	26.0	28.2	27.7

ADL=activity of daily living.

of a semiprivate bed in a nursing home was \$85,775 in 2017—a 2-year cost of nursing home care of \$171,550.¹⁵ Our results suggest that the costs of informal care to a daughter's well-being are similar to those of full-time institutional care. The cost comparability suggests that further work is needed in assessing the benefits of these 2 different types of care. The BrightFocus Foundation's recent recommendations include making home the nexus of dementia care but recognize the need to put in place numerous community-based interventions to maximize quality of life.¹⁶

This work highlights that there is heterogeneity in the costs of informal care to the daughter's well-being based on the health of the mother. There are a variety of plausible

mechanisms that could explain the nonlinear relationship between the direct utility effects of caregiving and the mother's health. The direct utility effects reflect utility gains from care provision, which may be derived from reciprocity, responsibility norms, or altruism, as well as the utility losses from care provision, which may stem from caregiving being stressful and burdensome. Providing care may lead to larger net benefits to the caregiver as the care recipient gets sicker, but when health impairments become severe, caregiving may become more burdensome. Providing intensive care to someone with memory problems provides lower direct utility to the caregiver than providing care to someone with ADL limitations. This difference could be driven by a clearer understanding by the caregiver and other

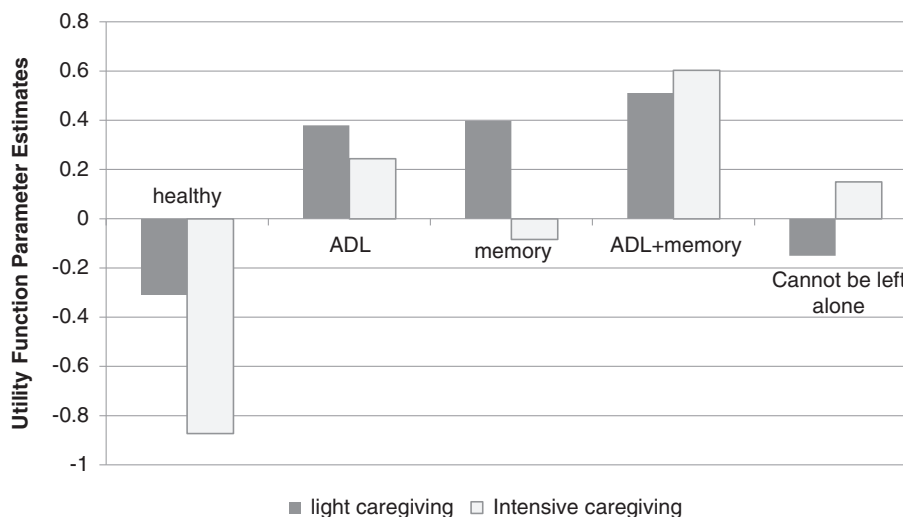


Figure 1. Direct utility effect of caregiving on well-being, according to health of mother. Light caregiving = < 1,000 hours of care over 2 years. Intensive caregiving = ≥1,000 hours of care over 2 years. ADL = activity of daily living.

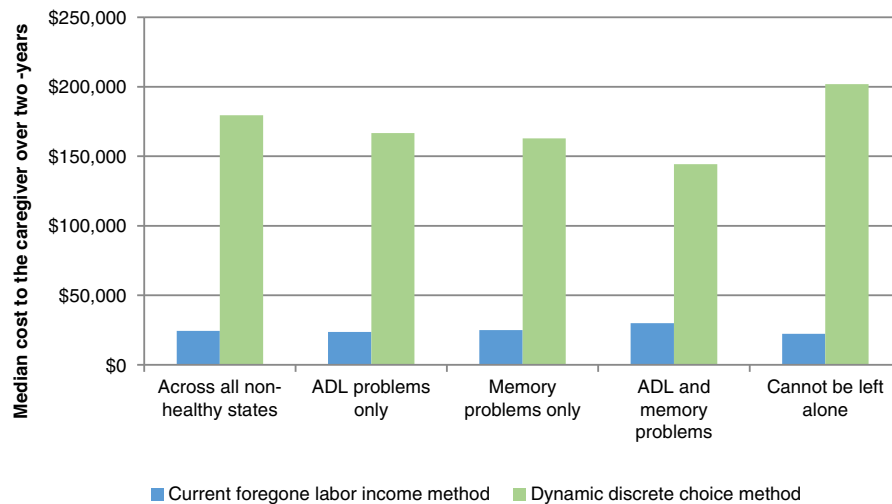


Figure 2. Cost estimates of informal care over 2 years. ADL = activity of daily living.

support systems of what is needed to provide care for someone with an ADL limitation as opposed to a memory problem. Although caring for someone with memory problems seems to have the same implications for well-being as caring for someone with only ADL limitations, combining the 2 types of health problems makes a big difference in terms of cost.

To gauge the economic importance of caregiving, we made a quick calculation. There were an estimated 14.7 million family and unpaid caregivers in 2011, approximately half of whom were children providing care to parents, and approximately half of the care recipients had dementia.¹⁷ Using the most conservative estimates of the median costs to the daughter's well-being related to memory-related disease and assuming they were a lower bound for other caregiving dyads, the cost of informal care was at least \$277 billion in 2011, 20% greater than the current estimate of \$230.1 billion.³

Our study has limitations. Structural models in general, of which dynamic discrete choice models are one, require a detailed specification of the decision-making problem. We must specify the constraints, preferences, and determinants of well-being and the choices people face. Although we tested many assumptions and conducted numerous sensitivity analyses to ensure the robustness of our estimates, they may be biased if we misspecified the model. For example, we missed small adjustments in hours worked because of the discrete nature of the choices. We limited our analysis to mother–daughter dyads, the most common intergenerational caregiving relationship observed. Our estimates may not be generalizable to other intergenerational caregiving pairs. Finally, we are limited in our definition of the health of the care recipient because of the survey data; these are self-reported health measures by the daughter and not clinical assessments. Furthermore, we could not separate conditions distinctly or identify the presence or severity of behavioral problems which are likely to have complicated the caregiving relationship.

CONCLUSION

As the long-term care service and supports policy continues to discuss “rebalancing,”¹⁸ or reducing the bias toward

institutionalization in insurance coverage, the costs to caregivers' well-being must be kept in mind. Moving someone from full-time institutional care to home, even with the support of formal home health care or community-based care, as the BrightFocus Foundation recommends,¹⁶ inevitably requires additional support from the family.¹⁹ When considering only forgone earnings because of caregiving, these policy changes may seem to be cost reducing on a societal level, but accounting for the cost to the well-being of the caregiver may alter the calculation.

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SUPPORTING INFORMATION

Additional Supporting Information may be found in the online version of this article.

Appendix S1. Dynamic Discrete Choice Model

Table S1. Structural Parameter Estimates

Table S2. Estimated Offer Probabilities