

The Economic Value Of Informal Caregiving

President Clinton's proposal to provide relief to family caregivers opens a long-overdue discussion of this "invisible" health care sector.

by Peter S. Arno, Carol Levine, and Margaret M. Memmott

ABSTRACT: This study explores the current market value of the care provided by unpaid family members and friends to ill and disabled adults. Using large, national data sets we estimate that the national economic value of informal caregiving was \$196 billion in 1997. This figure dwarfs national spending for formal home health care (\$32 billion) and nursing home care (\$83 billion). Estimates for five states also are presented. This study broadens the issue of informal caregiving from the micro level, where individual caregivers attempt to cope with the stresses and responsibilities of caregiving, to the macro level of the health care system, which must find more effective ways to support family caregivers.

182

VALUE OF
CAREGIVING

IN A MAJOR POLICY INITIATIVE the Clinton administration recently proposed a \$6 billion five-year package to begin to address the long-term care needs of persons with chronic illness or disabilities and their families.¹ By explicitly recognizing that family members are the core long-term care providers in the U.S. health care system, this initiative opens a long-overdue policy discussion.

Because "informal" caregiving lies outside the market economy and is socially and politically invisible, its economic value is not generally acknowledged. Although some aspects of families' contributions to patient care are impossible to measure (such as the comfort of being cared for at home), other aspects can be expressed quantitatively. This study addresses one such question: What is the current market value of the unpaid caregiving provided by family members and friends to adults who are chronically or terminally ill or seriously disabled? There have been some limited attempts to arrive at such a number, but no recent systematic estimates.² This study begins to fill that gap.

Peter Arno is a professor in the Department of Epidemiology and Social Medicine, Montefiore Medical Center/Albert Einstein College of Medicine, in the Bronx, New York. Carol Levine is director, Families and Health Care Project, United Hospital Fund, in New York City. Margaret Memmott is a research assistant in the Montefiore/Einstein Department of Epidemiology and Social Medicine.

Study Methods

We analyzed two key questions: (1) What is the national prevalence of informal caregiving; and (2) what is a reasonable market wage that would have to be paid to replace informal caregiving?

Prevalence and definitions. National prevalence figures were derived in two steps: (1) estimating the number of informal caregivers; and (2) determining the hours of care provided per caregiver. For the former we examined a variety of national data sets, including the Survey on Income and Program Participation (SIPP), the National Survey of Families and Households (NSFH), the National Health Interview Survey (NHIS), and the National Long-Term Care Survey (NLTCS). Because SIPP and the NSFH provide the most comprehensive data on the prevalence of caregiving in the general population, we used these surveys and their definitions of caregiving to develop our estimates. (The NLTCS includes only Medicare patients over age sixty-five.)

SIPP is a national, multipanel, longitudinal survey of adults, representative of households in the civilian, noninstitutionalized population.³ The 1986 survey wave collected information from approximately 19,100 households on whether persons age fifteen or older needed or provided personal assistance with everyday activities. A person was considered to need personal assistance only if his or her limitation was the result of a health condition that had lasted or was expected to last three months or longer. We assumed that the ratio of caregivers to the U.S. population, by age cohorts, was the same in 1997 as it was in 1986. This yielded an estimated twenty-four million caregivers in 1997.

The first wave of the NSFH included a national probability sample of 13,017 noninstitutionalized American adults in 1987 and 1988.⁴ Respondents were asked about the need for or provision of personal assistance due to a disability or chronic illness. A similar approach was used to estimate the number of caregivers as described above. The number of caregivers providing personal assistance to adults (age eighteen or older) was disaggregated by sex: 11.3 million men and 16.1 million women. Assuming that the ratio of caregivers to the general population by age and sex was the same in 1997 as it was in 1987–1988, this yielded an estimated 27.6 million caregivers in 1997.

Number of caregiving hours. The best overall source of data for estimating the number of caregiving hours in the general population was found in the National Family Caregiving Survey.⁵ Fielded in 1996, the survey was based on a nationally representative sample of 1,509 English-speaking households with telephones. This survey yielded an average of 17.9 caregiving hours per week. This figure was

used in this analysis because of the general nature and size of the sample; because of the lack of better estimates from larger, more comprehensive surveys; and because it is a conservative estimate that is lower than those found in other published studies.

Most studies reporting hours of informal caregiving targeted relatively disabled and chronically ill elderly persons or used small samples focusing on specific medical conditions. Richard Ernst and Joel Hay estimated the number of unpaid caregiver hours from nine studies of community-dwelling demented or mentally impaired patients at 52.5 hours per week.⁶ In small-sample studies of Alzheimer's disease patients, ventilator-dependent patients, and Parkinson's disease patients, investigators reported an average of 70.0, 58.8, and 22.0 hours per week, respectively.⁷

Wage rate. Two general approaches have been used in the literature to impute an economic value to the quantity of caregiving. The first entails measurement of the opportunity costs to caregivers of lost or forgone wages and benefits as a result of caregiving responsibilities.⁸ This approach is not used here because considerable caregiving is provided by retired persons. Thus, to impute their economic worth only from forgone earnings would undervalue their contribution. The second approach, which we have chosen, applies a market wage rate to caregiving activity.⁹ Because our main focus is estimating the potential cost in today's market if informal caregiving had to be replaced by paid workers, we selected a wage rate that reflects today's labor market.

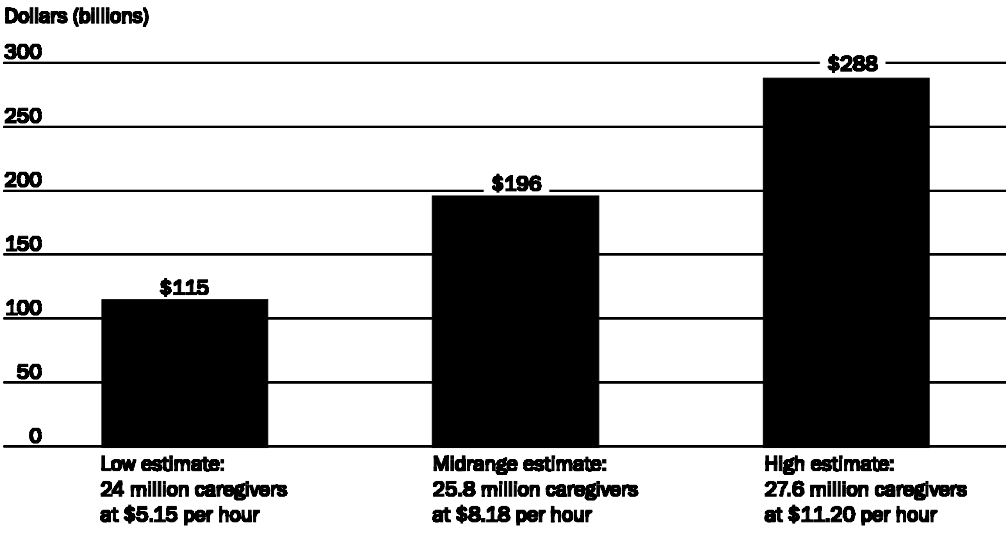
Initially, two wage rates were considered: the current minimum wage (\$5.15 per hour) and the average, national rate for home health aides (\$11.20 per hour).¹⁰ Because caregiving tasks performed by family members range from the relatively unskilled to the highly skilled, we chose \$8.18 per hour as a midrange wage rate. This figure does not include benefits or administrative overhead, which are required for formal employment.

Findings

Caregiving prevalence estimates derived from large, distinct, national data sets generated a narrow range of estimates for the number of caregivers in 1997—24.0 million to 27.6 million. The midrange estimate is 25.8 million.¹¹ Applying the average weekly figure of 17.9 hours of informal caregiving to the number of estimated caregivers yields approximately 22–26 billion hours of caregiving per year, nationwide, with a midrange estimate of 24 billion hours. Using midrange figures, the national economic value of informal caregiving in 1997 was \$196 billion (Exhibit 1).

The economic value of informal caregiving in 1997 dwarfs national

**EXHIBIT 1
Economic Value Of Informal Caregiving, 1997**



SOURCE: Authors' estimates.

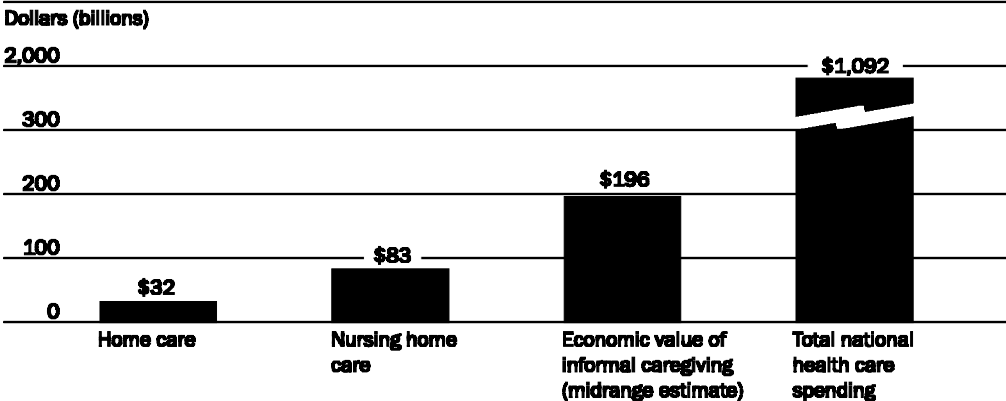
NOTE: In each of these estimates, the weekly number of hours was held constant at 17.9 hours.

spending for formal home health care (\$32 billion) and nursing home care (\$83 billion) (Exhibit 2). At the midrange estimate of \$196 billion annually, the economic value of informal caregiving is equivalent to approximately 18 percent of total national health care spending (\$1,092 billion). Informal caregiving is not counted as part of national health care spending. If it were, the trillion-dollar figure would rise by nearly \$200 billion.

DATAWATCH

185

**EXHIBIT 2
Home Care, Nursing Home Care, Informal Caregiving, And Total National Health Care Spending, 1997**



SOURCE: Expenditure data from the Health Care Financing Administration (HCFA) Office of the Actuary, National Health Statistics Group, 29 October 1998.

Using the same methods we calculated the number of caregivers and the estimated economic value for five states: California, New York, Texas, Florida, and New Jersey. California led the way, with 2.9 million caregivers at an estimated economic value of \$22.1 billion; New York followed with 1.8 million/\$13.6 billion; Texas, 1.7 million/\$12.6 billion; Florida, 1.4 million/\$10.5 billion; and New Jersey, 777,500/\$5.9 billion.¹²

Implications

Imputing an economic value to the extraordinary level of caregiving described in this study does not detract from the emotional, cultural, and societal values expressed through informal caregiving. On the contrary, it enhances their importance by providing a tangible measure of the vast but vulnerable base upon which our chronic care system rests.

Toll on individuals, families, and society. Caregiving has become a normative experience. Although it may bring personal gratification to some, it clearly takes a well-documented toll on many caregivers' physical and mental health.¹³ The costs are not only to the individual, however. Stress and exhaustion may lead to increased health care resources' being devoted to the caregiver as well as to the patient and may exacerbate family destabilization and impoverishment. These are concerns not only for individuals and families but also for the larger society. As the population ages and as chronic conditions continue to account for a high proportion of medical costs, these concerns will become even more critical.¹⁴

This study has explored only one aspect of the economic impact of family caregiving. Other studies have addressed the substantial direct costs families pay in unreimbursed health care expenses, even if they are insured.¹⁵ Other important factors are the loss of income and other benefits, such as Social Security, when a caregiver gives up a job or reduces work hours.¹⁶

Policy options. Our focus on the economic value of informal caregiving should not be interpreted as an argument to pay caregivers. Neither do we dismiss this as a policy option. Several states already have limited programs in place to pay informal caregivers.¹⁷ Paying some categories of informal caregivers under clearly defined circumstances may provide a level of flexibility and continuity that is difficult to attain in the formal system.

Beyond the tax credits and state information and referral programs outlined in the Clinton administration's proposal, other options include amending the Family and Medical Leave Act to make it more accessible to employees in small firms and its benefits better known to eligible workers. Social Security credits also might be

given to caregivers who take time off from paid employment.

Need for caregiver support. Because family caregivers are not typically part of policy discussions, the limitations on their ability to provide care and their needs for training and support are not usually considered when decisions are made about how to deliver care or save money. Informal caregivers are seldom adequately trained and almost never offered appropriate follow-up services, reevaluation of care arrangements, or referrals to community services. They are left to negotiate an increasingly complex and fragmented system and to find whatever help they can by whatever means they can.

SPENDING FOR FORMAL home health care has grown dramatically in recent years—more than three times faster than spending for hospital or physician services in 1990–1997.¹⁸ Efforts to constrain this growth by better management and monitoring are justified. However, cutting costs by cutting vitally needed services will only add to the already heavy burden on informal caregivers. They are the bedrock of our nation's chronic care system; we must find more effective ways to support and sustain them.

.....

This study was conducted as part of the Families and Health Care Project (FHCP), United Hospital Fund (UHF), New York City. The FHCP has received support from the Altman Foundation, Nathan Cummings Foundation, New York Community Trust, Prudential Foundation, JM Foundation, and William Stamps Farish Fund. The authors gratefully acknowledge the contributions of Joel Cantor, David A. Gould, and Dillan Siegler of the UHF staff; and Dorothy Rice, Clara Goldberg, Gail Gibson Hunt, Mitchell LaPlante, Nadine Marks, and Jack McNeil. The authors alone are responsible for the views expressed in this paper.

NOTES

1. R. Pear, "Clinton Seeks Aid for the Care of Those with Chronic Ills," *New York Times*, 4 January 1999, A1.
2. See, for example, K. Whetten-Goldstein et al., "The Burden of Parkinson's Disease on Society, Family, and the Individual," *Journal of the American Geriatric Society* 45, no. 7 (1997): 844–849; W. Max, P. Webber, and P. Fox, "Alzheimer's Disease: The Unpaid Burden of Caring," *Journal of Aging and Health* 7, no. 2 (1995): 179–199; H.A. Turner, J.A. Catania, and J. Gagnon, "The Prevalence of Informal Caregiving to Persons with AIDS in the United States: Caregiver Characteristics and Their Implications," *Social Science and Medicine* 38, no. 11 (1994): 1543–1552; and J. Leon, C.K. Cheng, and P.J. Neumann, "Alzheimer's Disease Care: Costs and Potential Savings," *Health Affairs* (November/December 1998): 206–216.
3. C.L. Harpine, J.M. McNeil, and E.J. Lamas, "The Need for Personal Assistance with Everyday Activities: Recipients and Caregivers," *Current Population Reports, Household Economic Studies, Series P-70*, no. 19 (1990).
4. N.F. Marks, "Caregiving across the Lifespan: National Prevalence and Predictors," *Family Relations* (January 1996): 27–36.
5. *Family Caregiving in the U.S.* (Bethesda, Md.: National Alliance for Caregiving,

and Washington: AARP, June 1997). *Caregiving* in this survey was defined broadly as “providing unpaid care to a relative or friend who is aged 50 or older to help them take care of themselves.”

6. R.L. Ernst and J.W. Hay, “The U.S. Economic and Social Costs of Alzheimer’s Disease Revisited,” *American Journal of Public Health* 84, no. 8 (1994): 1261–1264.
7. Max et al., “Alzheimer’s Disease;” M.A. Sevick et al., “Home-Based Ventilator-Dependent Patients: Measurement of the Emotional Aspects of Home Caregiving,” *Heart and Lung* 23, no. 4 (1994): 269–278; and Whetten-Goldstein et al., “The Burden of Parkinson’s Disease.”
8. See, for example, S. White-Means and D. Chollet, “Opportunity Wages and Workforce Adjustments: Understanding the Cost of In-Home Elder Care,” *Journal of Gerontology B: Psychological Sciences and Social Sciences* 51, no. 2 (1996): S82–S90; and E.R. Kingson and R. O’Grady-LeShane, “The Effects of Caregiving on Women’s Social Security Benefits,” *Gerontologist* 33, no. 2 (1993): 230–239.
9. See, for example, B.S. Harrow, S.L. Tennstedt, and J.B. McKinlay, “How Costly Is It to Care for Disabled Elders in a Community Setting?” *Gerontologist* 35, no. 6 (1995): 803–813; and Ernst and Hay, “The U.S. Economic and Social Costs of Alzheimer’s Disease Revisited.”
10. U.S. Department of Labor, Bureau of Labor Statistics, *Employment and Earnings* (Washington: BLS, June 1996).
11. Substantiating this estimate is a third calculation based on another wave of SIPP fielded in 1994–1995 (not shown). Assuming that the ratio of caregivers to those needing care was the same in 1995 as it was in 1986, an estimated 24.1 million caregivers is derived for 1995, which falls acceptably at the low end of our range of estimated number of caregivers in 1997.
12. A longer version of this paper is available on the Web at www.uhfnyc.org (April 1999).
13. See, for example, Council on Scientific Affairs, American Medical Association, “Physicians and Family Caregivers: A Model for Partnership,” *Journal of the American Medical Association* 269, no. 10 (1993): 1282–1284; P. Krach and J.A. Brooks, “Identifying the Responsibilities and Needs of Working Adults Who Are Primary Caregivers,” *Journal of Gerontological Nursing* 21, no. 10 (1995): 41–50; and B. Snyder and K. Keefe, “The Unmet Needs of Family Caregivers for Frail and Disabled Adults,” *Social Work in Health Care* 10, no. 3 (1985): 1–14.
14. C. Hoffman, D. Rice, and H.Y. Sung, “Persons with Chronic Conditions: Their Prevalence and Costs,” *Journal of the American Medical Association* 276, no. 18 (1996): 1473–1479; and S.R. Kunkel and R.A. Applebaum, “Estimating the Prevalence of Long-Term Disability for an Aging Society,” *Journal of Gerontology: Social Science* 47, no. 5 (1992): S253–S260.
15. K. Covinsky et al., “The Impact of Serious Illness on Patients’ Families,” *Journal of the American Medical Association* 272, no. 23 (1994): 1839–1844.
16. Kingson and O’Grady-LeShane, “The Effects of Caregiving on Women’s Social Security Benefits;” S.H. Sandell and H.M. Iams, “Caregiving and Women’s Social Security Benefits: A Comment on Kingson and O’Grady-LeShane,” *Gerontologist* 36, no. 6 (1996): 680–684; and R. O’Grady-LeShane and E.R. Kingson, “Caregiving and Women’s Social Security Benefits: A Response to Sandell and Iams,” *Gerontologist* 36, no. 6 (1996): 812–813.
17. N.L. Linsk et al., *Wages for Caring: Compensating Family Care for the Elderly* (New York: Praeger, 1992).
18. J.K. Iglehart, “The American Health Care System: Expenditures,” *New England Journal of Medicine* 340, no. 1 (1999): 70–76.