

Statement of Peter Arno

Introduction

Good morning, Mr. Chairman and members of the Committee. My name is Peter Arno and I am a health economist and Professor in the Department of Epidemiology and Social Medicine at Montefiore Medical Center and Albert Einstein College of Medicine in the Bronx. It is a privilege to be here today.

The work that I will present this morning has been done in collaboration with Carol Levine, who is the Director of the Families and Health Care Project at the United Hospital Fund of New York.

I am sure that most people here are aware of the fact that more than a year ago we surpassed the \$1 trillion dollar mark in health care spending in the United States. Because of the vast scope of health care and its political, as well as personal, importance, more intense scrutiny has probably been devoted to this sector of the economy than any other.

Yet a vital dimension of this far-reaching enterprise has never been calculated in economic terms. And this is the contribution made by unpaid family members and friends to the care of ill or disabled persons, especially in cases of chronic or terminal illness or serious disability. To fill that gap, we have engaged in a study which I will describe, which estimates the economic value of informal, unpaid caregiving. But before I do let me just say a few words about why we did this study.

Firstly, informal caregiving is generally not acknowledged to be of economic value in part because the burden is borne mainly by family members and friends outside the market economy. Personal bonds and familial obligations lead people to become and remain caregivers, despite the sacrifices they may have to make. The costs - and the value provided - thus remain socially invisible. Imputing a value to the extraordinary level of caregiving described in this study may be novel, but it provides a tangible and crucial measure of the massive and vulnerable base on which America's chronic health care system rests.

In the current economic environment, government programs, private insurers, managed care organizations, and other payers are trying to reduce formal, paid services. Cost cutting is in many instances really just cost shifting, adding to the responsibilities of individuals and families. Fewer hospital admissions, shorter lengths of stay and high-tech medical procedures done at home are only the most obvious manifestation of this trend.

Clearly, some aspects of families' contributions to patient care are impossible to measure such as the comfort of the patient cared for by intimates rather than strangers or the value of care provided at home rather than in a hospital or nursing home. However, other aspects of caregiving can be expressed quantitatively, which I will now describe.

Methodology

The major question that we posed is what is the annual dollar value of the unpaid caregiving provided by family members to relatives who are chronically or terminally ill or seriously disabled? In other words, what would this care cost if it were treated as employment paid for by health and social service programs?

In order to answer this question reliably, two key questions were analyzed with information available in large-scale national data sets.

- 1) What is the national prevalence of informal caregiving?
- 2) What is a reasonable market wage that would have to be paid to replace informal caregiving?

What is the national prevalence of informal caregiving? We probably spent the most time trying to answer this question. We reviewed a number of different datasets looking for the answer to this question. Perhaps the most well-known source of data and published studies on the prevalence of disability and homecare in the U.S. comes from National Long Term Care Survey. Unfortunately, this survey is confined to the elderly Medicare-enrolled (>65) population. Due to its focus on the chronically disabled elderly, we chose to use more general samples of the U.S. population found in the Survey of Income and Program Participation (SIPP), conducted by Census Bureau and the National Survey of Families and Households (NSFH) for this analysis.

Figure 1: Estimated Number of Care Recipients and Informal Caregivers, U.S., 1996 Here we see two sets of estimates of the number of caregivers and care recipients. On the left, we have recent estimates on the number of persons with serious disabilities who are the recipients of caregiving - 9.5 million persons as measured by the STPP and 9.2 million based on the Health Interview Survey. On the right hand side of Figure 1 we have three separate estimates of the number of caregivers ranging from 23.6 million to 27.4 million caregivers. Thus, the mid-range estimate would be 25.5 million caregivers in 1996. Because our estimate of caregiving prevalence is crucial for this study, I would like to show you how we derived these figures.

Figure 2: Projected Number of Caregivers (Based on SIPP)

In Figure 2 we have illustrated one approach to estimating the current number of caregivers. The SIPP survey asked about both care recipients and caregiving only in 1986. The more recent survey asked only about the number of persons who needed personal assistance, defined as needing assistance with

1ADL or IADL over an extended period of time. If you make the reasonable assumption that the ratio of caregivers to care recipients was the same in 1996 as in 1986 then the number of caregivers in 1996 is easily derived. As illustrated here the number for 1996 is 24.1 million.

Figure 3: Projected Number of Informal Caregivers (Based on the National Survey of Families and Households)

In Figure 3 we used an entirely different data source, the National Survey of Families and Households, which was also a national probability sample of the US population. This survey was conducted in 1987-88 and asked specifically about the number of persons who were caregivers. By making the assumption that the proportion of caregiving in the population by gender was the same in 1996 as it was 1987-88, we can again derive reasonable estimates for the number of caregivers, in 1996. This gave us our upward bound estimate of 27.4 million caregivers for 1996.

Thus, we felt satisfied that with entirely different datasets and conservative assumptions we produced estimates of caregiving prevalence that fell within a fairly narrow range - from 23.6 million to 27.4 million caregivers in 1996.

Our second task was to determine the number of hours of weekly care provided by informal caregivers. Here again we looked at a number of different studies, but these were mostly small studies of specific diseases such as Alzheimer's or Parkinson's Disease. The best overall estimate was found in the 1996 National Family Caregiving Survey conducted by the National Alliance for Caregiving and the

American Association of Retired Persons. This survey found that on average, caregivers provided 17.9 hours of caregiving per week.

Figure 4: Distribution of Caregiving Hours Per Week

In Figure 4 you can see the distribution of hours per week in this study. In part we chose the average figure of 17.9 hours per week, because it was based on a nationally representative sample and to be conservative, it was lower than almost every other study we examined. Applying this weekly figure to our mid-range estimate of the number of estimated caregivers yields approximately 24 billion hours of caregiving per year, nationwide.

Figure 5: Economic Value of Informal Caregiving, US 1996

Our final task was to determine what is the appropriate wage rate that would have to be paid to replace informal caregiving. Again, to be as conservative as possible we used the lowest legal wage rate, the minimum wage, which is currently \$5.15 /hour. For our upper bound estimate we used the national wage rate for home health aides which is \$11.20 /hour according to the Bureau of Labor Statistics. And averaging these rates together, our mid-range estimate is \$8.18 per hour. In this figure we applied these three different wage rates to our lower, middle and upper estimates for the number of caregivers, holding the number of hours of caregiving constant at 17.9 hours per week. This yields a range of economic value of informal caregiving from \$113 billion to \$286 billion dollars per year, with our best, mid-range value at \$194 billion dollars per year. From another perspective, these figures suggest that the average care recipient receives informal caregiving services worth approximately \$21,000 per year.

Figure 6: Paid Home Care, Nursing Home Care, Informal Caregiving and National Health Expenditures

In Figure 6 we have tried to put our best, mid-range estimate of the economic value of caregiving into some perspective. The \$194 billion for caregiving dwarfs the \$30 billion in paid home care and is about 2 ; times as large as the \$79 billion that what we spend on nursing home care. In fact, our estimate of \$194 billion for caregiving is equivalent to approximately 1970 of total national health care expenditures. Informal caregiving is not counted as part of national health care expenditures, but if it were, the trillion-dollar figure would rise by nearly \$200 billion.

Conclusion

Families have been undervalued as contributors to the health care economy for many reasons. They do not see themselves primarily as caregivers but as parents, spouses, partners, or daughters or sons. They do not expect to be paid for their work, which they provide out of love, duty, obligation, or lack of alternatives. If they find their tasks rewarding it is because they develop new strengths and skills or deepen their relationship to the care recipient. There are serious costs in terms of physical and emotional strain on caregivers, in addition to financial costs.

Focusing on the economic value of caregiving, especially in a market-driven health care system, we hope will help raise professional and policy makers' awareness of the importance of family caregiving to the smooth functioning of the system, especially as more care moves from hospitals and institutions to homes and communities. Political pressures are mounting to curb the growth of formal (paid) home health care expenditures which have grown dramatically in recent years. Between 1990 and 1996 total homecare expenditures rose more than three times faster than for hospital or physician services, for example. However, efforts to constrain homecare expenditures can only exacerbate the burden already

felt among informal caregivers. We should be seeking ways to support and strengthen informal caregivers rather than adding new and overwhelming responsibilities to the burdens they have already assumed.

Finally, I would like to commend this Committee for its willingness to open up the public discourse on this vulnerable and neglected pillar of our nation's chronic health care system. By taking leadership on this issue the Committee can help to reframe the issue of family caregiving, which has generally been understood only at 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 and meaningful ways to support and sustain the family caregivers of our country.

Thank you.