

The Monetary Costs of Dementia in the United States

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Before the Committee on Appropriations
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
United States Senate

February 26, 2014

Chairman Harkin, Ranking Member Moran, and Members of the Subcommittee, thank you for the opportunity to testify before you today about the monetary costs of dementia in the United States. My testimony will be based upon research performed at the RAND Corporation and the University of Michigan by me, and Professors Paco Martorell, Adeline Delavande, Kathleen Mullen, and Kenneth Langa. It was published in April, 2013 in the *New England Journal of Medicine* last year.

Introduction: Dementia and Its Costs

Dementia, a chronic disease of aging characterized by progressive cognitive decline that interferes with independent functioning, affects a large and growing number of older adults. The National Alzheimer's Project Act seeks to improve the ability of the federal government to track monetary costs incurred by individuals and public programs, such as Medicare and Medicaid, that result from dementia. We believe that our research will contribute to that effort.

Our goal in this research was to estimate the monetary costs due to dementia, not the monetary costs of people with dementia. Accurately identifying the costs attributable to dementia is challenging for many reasons but two stand out: First, persons with dementia are likely to have co-existing health problems: insulating the costs attributable to dementia requires that they be separated from other concurrent health care costs. Second, informal caregiving, the unpaid care provided by family and friends for assistance with activities of daily living, is an important component of the support required by persons with dementia, yet it is unclear how to attribute a monetary cost to an informal caregiver's time.

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² This testimony is available for free download at <http://www.rand.org/pubs/testimonies/CT406.html>.

Data Available for Estimation

The complexities of the research made it difficult to find valid and reliable data that were adequate for our needs. Fortunately the National Institute on Aging, under the leadership of Dr. Richard Hodes and Dr. Richard Suzman, had the foresight many years ago to invest in a data infrastructure, the Health and Retirement Study (HRS), without which this research could not have been accomplished. The HRS is a longitudinal survey; that is, it interviews repeatedly the same individuals over time, about 20,000 persons over the age of 50 every two years in the case of the HRS. The HRS was first fielded in 1992 and since then has become the pre-eminent data source for population-representative studies of aging. Funded by the National Institute on Aging and the Social Security Administration, it provides a wide variety of longitudinal data on persons, including cognitive assessments and data on the need for assistance in activities of daily living as well as on health-care and other costs. However, the HRS does not have a direct measure of dementia, but such a measure is available through the Aging, Demographics, and Memory Study, or ADAMS. The ADAMS is study of a nationally-representative sub-sample of 856 HRS respondents who underwent a detailed in-home clinical assessment for dementia. Using the diagnoses of the ADAMS subjects, we constructed a statistical model to identify the probability that some 6,000 HRS respondents over the age of 70 had dementia.

We assessed several categories of health-care spending: out-of-pocket spending, spending by Medicare, net nursing-home spending, and formal and informal health-care spending. Out-of-pocket spending includes any out-of-pocket health-care expenses for nursing-home or hospital stays, medical visits, outpatient surgery, home health care, special services such as outpatient rehabilitation, prescription drugs, and dental services. Medicare spending is available for HRS respondents who agreed to the linkage of their Medicare records and who were enrolled in fee-for-service plans, or approximately 70 percent of persons in our study population. Net nursing-home spending distinguished between rates paid by Medicaid and those paid by third parties. Formal health care includes paid care in home. Informal care includes unpaid care in home, most often provided by family members.

Individual Prevalence and Costs of Dementia

Overall, we found 14.7 percent of the population 71 years of age or older had dementia in 2010. Nonwhite, female, single, less-educated, and lower-income persons have an elevated probability of dementia, as do persons with a history of stroke, heart disease, or psychiatric conditions. Those who did not graduate from high school were more than twice as likely as those who graduated from college to have dementia, and those with household income of less than \$15,000

were more than four times likely to have dementia as those with household income more than \$75,000.

We distinguish between costs that flow through the marketplace such as spending for hospital stays, doctor visits, nursing homes, hired caregiving at home and so forth, and implicit additional costs that are due to informal care and result from caregivers withdrawing from the labor market. We found that persons with dementia had \$33,329 more in annual health-care costs that flow through the marketplace than persons without dementia. Adjusting for coexisting conditions and demographic characteristics reduced this estimate to \$28,501. This is the average annual market cost attributable to dementia. Of the \$28,501 in costs attributable to dementia, \$13,900 is for nursing-home care, \$6,200 is for out-of-pocket expenditure, \$5,700 is for formal home care; Medicare spent \$2,700 of the total.

We were not able to distinguish costs due to Alzheimer's disease from costs due to other types of dementia, but we know from other research that Alzheimer's disease is responsible for a large majority of dementia cases.

Adding the cost of informal care to the cost of market-based care increases the total annual costs due to dementia to \$41,685 per person with dementia when based on the value of foregone wages. These costs would be \$56,290 per person with dementia when based on the valuation of replacement cost for the informal care. Put another way, the value of informal home care represents 31 percent to 49 percent of the costs attributable to dementia, depending on how such care is valued.

Population-wide Costs and Projections

To estimate the total cost of dementia to the U.S. economy now and in the future, we combined the adjusted cost per person with dementia with prevalence rates from the ADAMS and population estimates and projections from the U.S. Census. Multiplying the per-person costs for dementia by the estimated number of persons with dementia who were 71 years of age or older in 2010 indicates an annual population cost of \$109 billion for care purchased in the market. Including the estimated value of informal home care boosts this estimate to a range of \$159 billion to \$215 billion. The cost for care purchased in the market place (\$109 billion) places dementia as the most costly disease in terms of actual spending in the United States: according to tables based on the Medical Expenditure Panel Survey published by the Agency for Healthcare Research and Quality, heart disease cost \$102 billion in 2010 (adjusted from \$96 billion in 2008) and cancer cost \$77 billion in 2010 (adjusted from \$72 billion in 2008). Because neither heart

disease nor cancer is likely to require the large amount of informal care that is required by dementia, accounting for informal care would increase the cost difference between dementia and those diseases even further.

Because of the aging of the population, the fraction of the population at advanced old age where the risk of dementia is greatest will increase. By 2040, assuming that prevalence rates of dementia at each age remain the same, our estimates suggest that the costs for care purchased in the market place will more than double from \$109 billion to \$259 billion in real terms. Adding in the cost of informal care places the cost in 2040 from \$379 billion to \$511 billion, depending on the method for valuing informal care.

Differences from Other Estimates and possible bias

A critical assumption in our estimates was that real costs per case will remain constant. This may be likely for care-giving, because wages of workers likely to provide care have remained stable or even decreased in real terms. It is less likely, however, for health-care spending such as that for hospital costs or medication costs. To the extent such costs continue to rise we may be underestimating future costs of dementia. However, the amount of bias may be relatively small because between 75 percent and 84 percent of attributable costs are for care-giving, which has not been subject to the large increases in prices of health care services.

Our cost estimates are considerably lower than those reported by the Alzheimer's Association, which estimated that annual monetary costs alone were \$172 billion in 2010, compared with our estimate of \$109 billion. There are several reasons for this difference. The Alzheimer's Association estimate of cost per case was higher than ours, but it was based on a more severely-impaired population. Its estimated prevalence of dementia, which was higher than ours, was derived from a different population than the population that produced the cost per case. Prevalence came from a study of three Chicago neighborhoods. In that study the diagnostic criteria for dementia did not require the presence of a limitation in activities of daily living, as the ADAMS does, likely explaining why prevalence was higher. Finally, its cost estimate was not adjusted for coexisting conditions, as ours was.

Future Research

Considerable future research remains to be done on this topic. We did not address the distribution of costs, that is, who is likely to pay the costs of dementia, particularly at the household level. Most households will not incur large costs for dementia care: many patients will

have their care covered by Medicaid or private long-term care insurance. Their nursing-home or hospitalization stays may be short and relatively affordable, or households will avoid serious hardship for some other reason. However, other households may face great costs because of nursing-home stays of five years or more. In new, ongoing research we found that when out-of-pocket spending for nursing homes is aggregated over time, the distribution of costs is highly skewed because of those very long nursing home stays. Thus, a minority of families may face financially-devastating costs. Research is needed to quantify the distribution of costs so that families will have a better understanding of the risks.

Such research will also clarify the role of long-term-care insurance. This situation in which many families incur minor costs but a few incur very large costs ought to call for an insurance solution, one in which the costs of long-term care could be spread across the entire population rather than being concentrated on the unlucky few. At the moment the long-term-care insurance products that are available apparently do not meet the needs of the older population as evidenced by the very low take-up rates, about 13 percent in the population age 55 or older. Better designed products to reduce the risk of very large out-of-pocket spending for long-term-care would help reduce a significant cause for concern of the older population.

Because a large majority of costs due to dementia are for long-term care, supported by a grant from a private donor, RAND is developing a report to be released this year that aims to help providers, payers and policy makers efficiently improve dementia long-term care.

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