SPECIAL ARTICLE

Monetary Costs of Dementia in the United States

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ABSTRACT

BACKGROUND

Dementia affects a large and growing number of older adults in the United States. The monetary costs attributable to dementia are likely to be similarly large and to continue to increase.

METHODS

In a subsample (856 persons) of the population in the Health and Retirement Study (HRS), a nationally representative longitudinal study of older adults, the diagnosis of dementia was determined with the use of a detailed in-home cognitive assessment that was 3 to 4 hours in duration and a review by an expert panel. We then imputed cognitive status to the full HRS sample (10,903 persons, 31,936 person-years) on the basis of measures of cognitive and functional status available for all HRS respondents, thereby identifying persons in the larger sample with a high probability of dementia. The market costs associated with care for persons with dementia were determined on the basis of self-reported out-of-pocket spending and the utilization of nursing home care; Medicare claims data were used to identify costs paid by Medicare. Hours of informal (unpaid) care were valued either as the cost of equivalent formal (paid) care or as the estimated wages forgone by informal caregivers.

RESULTS

The estimated prevalence of dementia among persons older than 70 years of age in the United States in 2010 was 14.7%. The yearly monetary cost per person that was attributable to dementia was either $56,290 (95% confidence interval [CI], $42,746 to $69,834) or $41,689 (95% CI, $31,017 to $52,362), depending on the method used to value informal care. These individual costs suggest that the total monetary cost of dementia in 2010 was between $157 billion and $215 billion. Medicare paid approximately $11 billion of this cost.

CONCLUSIONS

Dementia represents a substantial financial burden on society, one that is similar to the financial burden of heart disease and cancer. (Funded by the National Institute on Aging.)

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Dementia, a chronic disease of aging characterized by progressive cognitive decline that interferes with independent functioning,[1] affects a large and growing number of older adults in the United States.[2,3] Citing the growing effect of dementia on patients, families, and the health care and long-term care systems, President Barack Obama signed the National Alzheimer's Project Act into law in January 2011. One goal of the law is to improve the ability of the federal government to track the monetary costs incurred by individuals and public programs, such as Medicare and Medicaid, that result from dementia.[4]

Accurately identifying the monetary costs attributable to dementia is challenging. First, persons with dementia are likely to have more coexisting chronic health problems than those without dementia, because they tend to be older and because certain diseases (e.g., stroke and depression) are more common in persons with dementia.[5] Thus, adjusting for the presence of these coexisting conditions is important in estimating the costs due to dementia alone, as opposed to the total costs for the population with dementia. Second, informal caregiving, the unpaid care provided by family and friends, in the form of assistance with activities of daily living (ADLs), is an important component of the support required by those with dementia,[6] yet it is unclear how to attribute a monetary cost to an informal caregiver's time.[7]

Given the aging of the population and the concomitant rise in the prevalence of dementia, the current uncertainty regarding the costs associated with dementia, and the recent focus of the federal government on developing a coordinated plan to address the growing effects of dementia, we sought to determine its monetary costs in the Health and Retirement Study (HRS).

METHODS

STUDY DESIGN

The HRS is a nationally representative longitudinal survey of persons 51 years of age or older that began in 1992.[8] Because the HRS lacks a direct measure of dementia status, a subset of 856 HRS respondents underwent a detailed in-home clinical assessment for dementia, 3 to 4 hours in duration, as part of the Aging, Demographics, and Memory Study (ADAMS), a nationally representative study of dementia in the United States.[2,9]

We used data on cognition and functional limitations from the HRS survey itself to estimate a three-category, ordered probit model[10] of the probability that an ADAMS respondent had dementia, had cognitive impairment but not dementia, or was aging normally. These data on cognition and functional limitations were available for all HRS respondents, not just the ADAMS respondents. For self-respondents, the HRS assesses cognitive function using a modified version of the Telephone Interview for Cognitive Status (TICS), a validated cognitive screening instrument designed for population-based studies.[11-14] For respondents represented by a proxy in the HRS, cognitive function was assessed with the use of the Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE), a validated instrument consisting of 16 questions that address the respondent's memory and ability to function independently.[14,15] See the Supplementary Appendix, available with the full text of this article at NEJM.org, for details on these variables (Table S1 in the Supplementary Appendix) and for additional details on other data, methods, and results.

The HRS assesses whether respondents have limitations in the ability to perform six ADLs (eating, transferring [e.g., from a bed to a chair], toileting, dressing, bathing, and walking across a room) and five instrumental activities of daily living (IADLs; preparing meals, grocery shopping, making telephone calls, taking medications, and managing money).[16] We estimated the probability model over the ADAMS subsample using data from prior HRS interviews. To explain cognitive status, we used the variables of age, educational level, sex, ADL limitations, IADL limitations, and scores on TICS items (identification of the current date, backward counting from 20, subtracting by serial 7s, word naming, identification of the current U.S. president, immediate word recall, and delayed word recall) from the HRS interview immediately preceding the ADAMS assessment, and changes in ADL limitations, in IADL limitations, and in scores on TICS items from the two preceding HRS surveys. For HRS respondents represented by a proxy, a similar model was estimated with the use of the IQCODE.

To assess the within-sample fit of the model, we assigned a cognitive status of dementia if the fitted probability of dementia was greater than the fitted probability of normal aging or of cognitive impairment but not dementia. On the basis of this assignment, the within-sample fit was good: the specificity for dementia was 89.8% and the sensitivity was 77.9%. Overall, 85.7% of cases were correctly classified. We conducted a further validation by making out-of-sample predictions of dementia status for a subset of ADAMS respondents who were reassessed several years after the initial assessment. On follow-up, progression to dementia was found in 14.9% of respondents; our model predicted 13.9%. We then used this statistical model to estimate the probability of dementia for all HRS respondents older than 70 years of age in five HRS surveys (spanning the period from 2000 through 2008). See the Supplementary Appendix for further analyses of model performance.

MEASURES OF COST OF CARE

Out-of-Pocket Spending

The HRS asks respondents about health care utilization and coverage, and whether they have incurred any out-of-pocket health care expenses for the following services or items: nursing home stays, hospital stays, medical visits, outpatient surgery, home health care, special services (e.g., outpatient rehabilitation), prescription drugs, and dental services. Total annual out-of-pocket spending and spending according to type of care were computed for each year in the study period. All spending measures were converted to 2010 dollars with the use of the medical care Consumer Price Index.

Spending by Medicare

Information on Medicare spending is available for HRS respondents who have agreed to linkage of their Medicare claims records and who were enrolled in fee-for-service plans (approximately 70% percent of persons in our study population). These records have enrollment information and data on total annual payments by Medicare for durable-medical-equipment purchases, skilled nursing-facility care, hospice care, inpatient care, outpatient care, care provided by home health agencies, and care provided by noninstitutional providers of medical care.

Net Nursing Home Spending

We used the self-reported number of nights spent in a nursing home and nightly nursing home fees to estimate total nursing home spending, distinguishing fees according to state of residence and distinguishing between rates paid by Medicaid[17-23] and those paid by other third parties.[24] We reduced total nursing home spending by 8% because a portion of nursing home fees cover food and housing; such costs have to be paid whether or not someone has dementia and are therefore not attributable to dementia.

Formal and Informal Home Care

Information on the receipt of in-home assistance by persons with limitations in ADLs or IADLs was used to generate the average number of hours of care provided to persons at home. Caregiving is classified as "informal" when the caregiver is a relative or an unpaid nonrelative with no agency affiliation. All other care, whether obtained through an agency or provided by someone hired directly, is classified as "formal."[25] The methods used to calculate total hours of care have been described in earlier work[6] and are briefly summarized in the Supplementary Appendix.

To estimate the monetary value of formal care, we used 2010 average hourly rates charged by home health agencies in the respondent's state of residence.[24] We used two approaches to estimate the monetary cost of informal care. The "replacement cost" approach values care by using the cost of an equivalent service purchased in the market through a home health agency.[7] The "forgone wage" approach bases the valuation on the labor-market income forgone because of time spent on caregiving. For employed caregivers, we used the market wages reported by respondents in each HRS survey. Because most caregivers are not employed, we used average wages for persons with similar demographic characteristics (sex and, when reported, age and educational level). To account for the fact that many caregivers are elderly and out of the work force, we scaled down the imputed wages by multiplying by the rate of labor-force participation in the same demographic group, an approach that recognizes that many caregivers would not work even if they were not providing caregiving services. Our method estimates the loss of income and productive services to the market economy.

It does not measure the loss of well-being associated with alternative uses of caregiver time.

ESTIMATION OF THE COST ATTRIBUTABLE TO DEMENTIA

Persons with dementia have more coexisting conditions than those without dementia, conditions that by themselves lead to greater costs. To isolate the costs attributable to dementia, we estimated multivariate regression models that related a given cost component to the imputed probability of dementia, to coexisting conditions (stroke, diabetes, heart disease, hypertension, lung disease, cancer, psychiatric problems, and arthritis), and to demographic characteristics (age, household income, educational level, sex, and marital status). For details of these analyses, see Tables S6 through S10 in the Supplementary Appendix. We interpreted the estimated coefficient for the probability of dementia as the increase in costs associated with a change in the probability of dementia from 0 to 1.0, holding coexisting conditions and demographic characteristics constant.

We estimated two measures of the cost attributable to dementia. The first includes costs for care purchased in the market and is equal to the sum of the estimated increases in cost associated with dementia for out-of-pocket spending, Medicare spending, nursing home spending, and spending on in-home care. These estimates come from the multivariate models discussed above. The second measure adds in the monetary value of time spent by unpaid caregivers that is attributable to dementia, calculated as either the replacement cost or the cost of forgone wages.

RESULTS

PROBABILITY OF DEMENTIA

The average predicted probability of dementia, stratified according to personal and household characteristics, is shown in Table 1. Nonwhite race or ethnic group, female sex, single status, older age, lower educational level, and lower household income were associated with an increased likelihood of dementia ($P<0.001$ for all comparisons). Persons with one or more limitations in ADLs or IADLs were also more likely to have dementia, as were those who had a history of stroke or who had heart disease or a psychiatric condition ($P<0.001$ for all comparisons). However, persons who had a history of cancer were less likely to have dementia ($P<0.001$). The cost implications of these differences in demographic characteristics and coexisting conditions suggest the necessity of accounting for them in attributing costs to dementia.

ESTIMATED COST PER PERSON WITH DEMENTIA

Estimates of the yearly per-person costs attributable to dementia, both with and without adjustment for coexisting conditions and demographic characteristics, are shown in Table 2. Dementia was associated with a cost of $33,329 for care purchased in the market (95% confidence interval [CI], $24,223 to $42,434). That is, someone with a probability of dementia of 1.0 would be expected to incur $33,329 more in health care costs than someone whose probability of dementia was zero, when costs were aggregated over all payers. Adjustment for coexisting conditions and demographic characteristics reduced the cost estimate to $28,501 (95% CI, $20,881 to $36,122), a reduction of approximately 14%. The adjustments reduced attributable out-of-pocket spending and costs for formal home care and nursing home care by 3 to 18%, but the adjustments reduced attributable Medicare costs by 47%. On the basis of adjusted values, the most important attributable cost was for nursing home care (approximately $13,900), followed by out-of-pocket spending (approximately $6,200), formal home care (approximately $5,700), and Medicare (approximately $2,700).

The monetary value of informal home care attributable to dementia did not vary substantially when controlled for coexisting conditions and demographic characteristics. However, it varied by a factor of more than 2 when calculated on the basis of the replacement cost as compared with the cost of forgone wages.

After adjustment for coexisting conditions and demographic characteristics, the attributable yearly cost per person, including both the cost of care purchased in the marketplace and the cost of informal care, was $41,689 (95% CI, $31,017 to $52,362) when the valuation of forgone wages was used and $56,290 (95% CI, $42,746 to $69,834) when the valuation of replacement cost was used. Calculating the value of informal home care in terms of forgone wages yielded an estimate of the cost of unpaid caregiving that was

31% of the total cost; calculating the value of informal home care in terms of the replacement cost yielded an estimate of 49%.

ESTIMATED TOTAL COSTS

Estimates of the total cost of dementia to the U.S. economy now and in the future are shown in Table 3. To estimate these costs, we combined the adjusted cost per person with dementia shown in Table 2 with prevalence rates from ADAMS and population projections from the U.S. Census. For 2010, this estimation yielded a prevalence of 14.7% in the population older than 70 years of age and an annual population cost of $109 billion for care purchased in the market, with a cost of $159 billion to $215 billion when the estimated monetary value of informal care was included. By 2040, assuming that prevalence rates and cost per person with dementia remain the same, our estimates suggest that these costs will more than double because of the aging of the population. Although the ability to pay these costs will be ameliorated somewhat by a growing population, they are still expected to increase by 79% when calculated per adult (with adults defined as persons 18 years of age or older).

Table 1. Probability of Dementia According to the Characteristics of the Study Population.*

Characteristic	Distribution	Probability of Dementia (95% CI)	P Value for Comparison with Reference Group
	percent		
Race or ethnic group†			
White	86.7	0.097 (0.093–0.101)	Reference group
Hispanic	4.4	0.168 (0.149–0.187)	<0.001
Other	8.9	0.184 (0.170–0.199)	<0.001
Sex			
Female	60.7	0.121 (0.116–0.127)	Reference group
Male	39.3	0.088 (0.082–0.093)	<0.001
Marital status			
Married	45.9	0.065 (0.061–0.069)	Reference group
Unmarried	54.1	0.145 (0.138–0.151)	<0.001
Age			
71–74 yr	23.3	0.028 (0.026–0.031)	Reference group
75–79 yr	31.7	0.049 (0.045–0.053)	<0.001
80–84 yr	24.1	0.130 (0.123–0.137)	<0.001
85–89 yr	14.2	0.203 (0.192–0.215)	<0.001
≥90 yr	6.7	0.385 (0.365–0.406)	<0.001
Educational level			
Less than high-school graduate	32.2	0.159 (0.151–0.167)	Reference group
High-school graduate	33.1	0.103 (0.096–0.110)	<0.001
Some college or more	34.7	0.066 (0.060–0.071)	<0.001
Household income			
<$15,000	28.3	0.183 (0.174–0.191)	Reference group
$15,000–$29,999	31.8	0.104 (0.098–0.110)	<0.001
$30,000–$44,999	17.4	0.069 (0.063–0.074)	<0.001
$45,000–$59,999	8.7	0.062 (0.054–0.070)	<0.001
$60,000–$74,999	4.6	0.049 (0.041–0.058)	<0.001
≥$75,000	9.3	0.041 (0.035–0.046)	<0.001

Table 1. (Continued.)

Characteristic	Distribution	Probability of Dementia (95% CI)	P Value for Comparison with Reference Group
	percent		
Limitations in ADLs or IADLs			
No	65.1	0.042 (0.040–0.044)	Reference group
Yes	34.9	0.231 (0.222–0.240)	<0.001
Coexisting conditions			
None	6.4	0.091 (0.079–0.103)	Reference group
Stroke	13.5	0.182 (0.169–0.195)	<0.001
Diabetes	19.1	0.106 (0.099–0.114)	0.602
Heart disease	35.9	0.118 (0.112–0.124)	<0.001
Hypertension	62.3	0.106 (0.102–0.111)	0.235
Lung disease	11.8	0.104 (0.093–0.114)	0.407
Cancer	19.7	0.088 (0.081–0.096)	<0.001
Psychiatric condition	14.6	0.187 (0.174–0.201)	<0.001
Arthritis	69.6	0.107 (0.103–0.112)	0.615

* Data are based on a total of 31,936 person-years. For each characteristic, such as sex and marital status, the probability of dementia was calculated from the regression of the predicted probability of dementia on indicator variables for the categories taken by that characteristic, such as "male" and "female" in the case of sex and "unmarried" and "married" in the case of marital status. P values reflect the null hypothesis that the probability of dementia is the same as that for the reference group. CI denotes confidence interval.

† Race or ethnic group was reported by respondents in the Health and Retirement Study.

DISCUSSION

We used nationally representative data to document comprehensively the incremental increase in costs attributable to dementia that arise from market transactions for goods and services as well as the costs of unpaid caregiving. We found that dementia leads to total annual societal costs of $41,000 to $56,000 per case, with a total cost of $159 billion to $215 billion nationwide in 2010. Our calculations suggest that the aging of the U.S. population will result in an increase of nearly 80% in total societal costs per adult by 2040.

The main component of the costs attributable to dementia is the cost for institutional and home-based long-term care rather than the costs of medical services — the sum of the costs for nursing home care and formal and informal home care represent 75 to 84% of attributable costs. Our estimate places dementia among the diseases that are the most costly to society. The cost for dementia care purchased in the marketplace ($109 billion) was similar to estimates of the direct health care expenditures for heart disease ($96 billion in 2008, or $102 billion in 2010 dollars) and significantly higher than the direct health care expenditures for cancer ($72 billion in 2008, or $77 billion in 2010 dollars).[26] These costs do not include the costs of informal care, which are likely to be larger for dementia than for heart disease or cancer.

Although the costs attributable to dementia reported here are large, they are considerably smaller than those reported by the Alzheimer's Association,[27] which has estimated that in 2010 the monetary costs alone were $172 billion (2010 dollars) as compared with our estimate of $109 billion. There are several reasons for this higher estimate. It is likely that the cost per case reported by the Alzheimer's Association is higher because it was estimated on the basis of a sample from a more severely impaired population (persons identified in the Medicare Current Beneficiary Survey as having dementia). The higher cost is also based on a significantly larger estimate of the prevalence of dementia.[27] The national prevalence of dementia used by the Alzheimer's Association is derived from a study of

Table 2. Yearly Cost per Person Attributed to Dementia, in 2010 Dollars.

Variable	Yearly Cost per Person (95% CI)	
	Unadjusted	Adjusted for Demographic Characteristics and Coexisting Conditions
	dollars	
Care purchased in marketplace		
Total out-of-pocket spending	6,838 (4,854–8,821)	6,194 (4,522–7,866)
Total Medicare spending	5,226 (3,086–7,365)	2,752 (1,116–4,389)
Net formal home care	6,888 (4,775–9,000)	5,678 (3,739–7,618)
Nursing home care (excluding payments by Medicare and out-of-pocket spending)	14,377 (10,016–18,739)	13,876 (9,769–17,983)
Total	33,329 (24,223–42,434)	28,501 (20,881–36,122)
Informal home care		
Caregiving time valued according to replacement cost	30,839 (23,578–38,099)	27,789 (21,112–34,466)
Caregiving time valued according to cost of forgone wages	14,591 (10,910–18,273)	13,188 (9,636–16,740)
Grand total		
Care purchased in marketplace plus caregiving time valued according to replacement cost	64,168 (48,406–79,928)	56,290 (42,746–69,834)
Care purchased in marketplace plus caregiving time valued according to cost of forgone wages	47,920 (35,433–60,406)	41,689 (31,017–52,362)

Table 3. Projected Total and Per-Person Annual Monetary Costs of Dementia in the United States, in 2010 Dollars.*

Cost and Year	Care Purchased in Marketplace	Total Cost According to Valuation of Cost of Informal Care	
		Replacement Cost (95% CI)	Cost of Forgone Wages (95% CI)
Total cost (billions of $)			
2010	109 (86–132)	215 (171–259)	159 (126–192)
2020	129 (102–156)	255 (204–306)	189 (150–228)
2030	183 (145–221)	361 (289–434)	267 (212–322)
2040	259 (204–314)	511 (408–615)	379 (300–457)
Total per-person cost ($)			
2010	464 (416–511)	915 (825–1006)	678 (610–746)
2020	498 (445–550)	983 (882–1083)	728 (652–804)
2030	640 (569–712)	1,264 (1,128–1,400)	936 (833–1,039)
2040	831 (733–929)	1,641 (1,455–1,826)	1,215 (1,074–1,356)

* Confidence intervals, estimated with the use of bootstrapping, account for the sampling error in estimates of the effect of dementia on spending and in the prevalence of dementia but treat population projections as nonrandom. Per-person costs are total population costs divided by the number of persons 18 years of age or older.

three Chicago neighborhoods.[28] The diagnostic criteria for dementia used in that study did not require the presence of a limitation in ADLs or IADLs (a criterion that was used in ADAMS), a factor that probably led to the substantially higher estimate of the prevalence of dementia in the Chicago study.[29] Finally, the cost estimate from the Alzheimer's Association was not adjusted for the costs of coexisting conditions.[27]

Our analysis has several potential weaknesses.

First, as with all clinical assessments, the ADAMS diagnosis is subject to classification error, but a prior study that validated the ADAMS diagnostic methods with the use of neuropathological findings[30] and a meta-analysis of 27 studies of the incidence of dementia[31] suggest that the ADAMS approach achieves a diagnostic accuracy that is similar to that achieved by a reference standard for clinical evaluation. Second, we imputed dementia status to the entire HRS population rather than obtaining an actual clinical diagnosis for each respondent. Nonetheless, both the within-sample performance of the imputation model and the close correspondence between out-of-sample predictions based on our model and the follow-up assessments in ADAMS increase our confidence in the validity of our model. Furthermore, estimates of out-of-pocket spending based only on the ADAMS clinical assessments were similar to those reported here, but the ADAMS estimates had larger standard errors, reflecting its smaller sample.[32] Third, self-reported costs of care may be subject to inaccuracies. Fourth, we were not able to include attributable costs paid by Medigap policies. However, a rough estimate indicates that these costs are small and would not materially change our conclusions. Fifth, the costs of informal care are a major contributor to costs — yet attribution is difficult. For this reason, we presented a range of estimates. Sixth, regarding our cost forecasts, we assumed that the real cost per case of dementia will remain constant. Although the costs of health care services have increased faster than the rate of inflation, the majority of costs attributable to dementia are related to the informal and formal care provided to address limitations in ADLs and IADLs, and much of that care is provided by low-wage workers. Wages in the lower part of the wage distribution have been stable or have even decreased in real terms, so we believe our assumption is reasonable. Finally, we could not conduct a detailed assessment of attributable costs according to payer because we lacked a linkage to Medicaid records. From the perspective of public policy, such information would be valuable.

The views expressed are those of the authors and do not necessarily reflect the position or policy of the Department of Veterans Affairs or the U.S. government.

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