The Costs Associated with Alzheimer's Disease

National Institute on Aging, Division of Behavioral and Social Research

National Institutes of Health

TELECONFERENCE OCTOBER 26, 2011

Summary

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Introduction

The National Institute on Aging (NIA) Division of Behavioral and Social Research (BSR) is actively involved in the effort to fully understand and plan for the emerging costs of Alzheimer's disease (AD). These efforts include the development of better data collection methods for identifying and quantifying the costs of AD, better mining of administrative records, and the development of economic modeling tools based on new estimates and projections of disease prevalence. Colin Baker (NIA/BSR) organized this teleconference to serve as the beginning of a discussion to review recent and ongoing research on cost projections and modeling of direct formal costs (e.g., acute care, nursing home) and indirect informal costs (e.g., family caregiving and associated loss of earnings) and to identify research gaps in this area. The teleconference featured presentations by Peter Neumann and Pei-Jung Lin (Tufts Medical Center) on "Costs and Cost-Effectiveness in Alzheimer's Disease" based on modeling of Medicare claims data, and by Michael Hurd (RAND Corporation) on "The Costs of Dementia" based on data from the Health and Retirement Study (HRS) and The Aging, Demographics, and Memory Study (ADAMS), followed by general discussion. In addition to NIA staff from both the BSR and the Division of Neuroscience, participants included staff from the Alzheimer's Association, study collaborators, and other invited commentators (see Appendix 1 for list of participants).

Costs and Cost-effectiveness in Alzheimer's Disease
Peter Neumann and Pei-Jung Lin, Tufts Medical Center

Overview of Literature

There is a substantial literature on the costs of AD from various perspectives (e.g., cost-effectiveness models, ecological intervention models). It is well recognized that AD imposes substantial economic burden on patients, caregivers, and the health care system. While there is evidence that individuals with AD do incur higher health care costs relative to those without the disease, great variation exists in the magnitude of specific cost estimates. Direct medical costs for AD are driven by inpatient care. Caregiving costs are considerable, although there is variation in how informal costs are calculated. Greater disease severity and comorbidities, which are highly prevalent in AD patients, substantially increase costs. There are some studies showing that costs prior to AD diagnosis are elevated compared to those for individuals not diagnosed with AD.

Work in the late 1990s on the cost-effectiveness of donepezil drug treatment[1] is illustrative of the assumptions and misleading conclusions that can be made about cost-effectiveness of treatment. Clinical trial data on donepezil have been used to suggest that treating patients in the early stages of mild AD provides a longer time frame of benefit. Cost-effectiveness, however, depends on duration of treatment. If the effects of the drug last 2 to 3 years, cost-effectiveness is better because the treatment is cheaper per unit of health gain. It was noted

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[1] Neumann, P. J., Hermann, R. C., Kuntz, K. M., Araki, S. S., et al. (1999). Cost-effectiveness of donepezil in the treatment of mild or moderate Alzheimer's disease. *Neurology, 52*, 1138-1145.

that there is a lot of noise around these types of assumptions; the results are driven by the cost of the drug, duration of treatment effects, and the effect sizes.

Another assumption concerns the impact of drug therapy on mortality. It is actually less cost-effective for a drug therapy to increase length of life because AD patients have greater disease severity and incur greater costs later in life, thus likely reducing quality of life. There are a number of models funded by the pharmaceutical industry showing that drug therapies are cost-effective but there is reason to be skeptical about these claims. The models assume patients stay on the drugs for a long time and that their use offsets the need for nursing homes later in life; however, there is not much evidence of that.

Examples of Cost Comparisons Using Medicare Data

Drs. Neumann and Lin have used Medicare data as part of an ongoing project to examine the costs associated with AD. They estimated the Medicare expenditures among people with AD and related dementia compared to non-AD controls matched using propensity scores in the 5 percent sample claims dataset from 2007. Overall, Medicare expenditures are 50 percent higher among people diagnosed with AD, with 40 percent of expenditures for those with AD going towards inpatient care, office visits, and acute care in skilled nursing facilities. However, a study using 2004 Medicare Current Beneficiary Survey (MCBS) data linked with Medicare claims data shows that within the AD group the expenditures are not equally distributed.[2] Rather, the expenditures are concentrated in a distinct group of high-spenders. The top 10 percent of patients with AD with the highest expenditures spend 44 percent of overall health care dollars; the top 25 percent of patients account for 69 percent of spending; and the top 50 percent of patients account for almost 90 percent of overall spending. In other words, the remaining 50 percent of AD patients account for only 10 percent of the overall expenditures. Subsequent analyses revealed that there is strong expenditures persistence with the majority of these high spenders staying in these categories, especially for drug expenditures. Logistic regression was used to minimize the bias due to AD and non-AD patients having different age distributions and comorbidity burdens.

Another approach is to compare Medicare expenditures between those with and without dementia by age.[3] Data from 1997-2005 MCBS linked with Medicare claims data examined by age and dementia status show that younger patients (starting at age 65) with dementia had higher expenditures, but that end of life expenditures for dementia patients are lower than for those without dementia. It is possible this trend reflects physicians not treating dementia patients as aggressively as non-dementia patients at end of life.

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[2] Lin, P. J., Biddle, A. K., Ganguly, R., Kaufer, D. I. & Maciejewski, M. L. (2009). The concentration and persistence of health care expenditures and prescription drug expenditures in Medicare beneficiaries with Alzheimer's disease and related dementias. *Medical Care, 47*, 1174-1179.

[3] Yang et al., (in press). Medicare expenditures associated with dementia over the lifespan. *Health Services Research*.

Challenges to Using Medicare Data to Determine the Costs of AD

Medicare claims data are rich in terms of diagnosis, date of service, and other variables, but there are challenges in modeling costs using claims data. Dr. Lin and colleagues used 1999-2004 MCBS data linked with Medicare claims files to demonstrate how the multiple ways of defining mild AD may lead to cases being underdiagnosed or uncoded.[4] Three definitions used include an official AD diagnosis (2.8 percent of the sample), the use of anti-dementia drugs (2 percent), and self- or proxy report (3.5 percent). Only 0.6 percent of claimants (all aged 65 years and older) are captured by all three of these indicators. In other words, calculations of costs will vary when different definitions of AD are used because the definitions are not interchangeable.

There are other challenges in studying the costs of AD with claims data. There is little attention given to estimating the costs of the early phases of AD such as mild cognitive impairment (MCI). Another challenge is addressing cost differences based on disease severity. The ICD9 codes for AD do not distinguish between mild, moderate, or severe. There is a need to create a proxy for disease severity to enable accurate estimation of the differences in costs (e.g., comorbidities that are typically late-stage complications such as pneumonia or malnutrition). Quality of care issues also are not typically included in claims data and require linkages with other datasets. For example, Medicare Part D data are very important for looking at medication management and adherence and electronic health records could be a source of quality of care information. Finally, information about informal care delivery is not included in claims data. Ways to address these challenges should be explored (e.g., linking to another data source such as the new supplemental file from the HRS).

There are other gaps in the knowledge base about the costs of AD. First, new biomarkers and imaging techniques hold promise for early diagnosis of AD in the future. Researchers need to examine how these strategies, and their costs, are valued and how they fit into new models. Second, most cost-effectiveness models of AD to date focus on cognition and memory; newer models are incorporating measures of function and behavior. Finally, the cost-effectiveness of future AD-modifying agents and non-pharmacological management needs to be evaluated. Tracking people and modeling the implications of various types of interventions are important.

Discussion

Dr. Baker asked how preventive care impacts overall spending. He noted recent findings that delaying the onset of AD might reduce average spending per capita, but the total cost of preventive therapies must be considered. Dr. Neumann noted that studies have shown that preventive care may bring value for money spent but not necessarily save money in the long term. What is important to consider is the cost of preventive treatments on people for whom they do not work. To the extent that preventive care works, the costs from patients living longer, getting other diseases, and incurring other costs need to be considered. It is difficult to

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[4] Lin, P. J., Kaufer, D. I., Maciejewski, M. L., Ganguly, R., Paul, J. E., & Biddle, A. K. (2010). An examination of Alzheimer's case definitions using Medicare claims and survey data. *Alzheimer's and Dementia, 6*, 334-341

show the economic impact of a specific preventive intervention as it will depend on costs, effects, and long-term consequences.

Anders Wimo (Karolinska Institutet) offered information gained from his own studies of the costs of informal care. There can be different sets of assumptions even on the same dataset that impact the cost estimates (e.g., cost ratio of a factor of 10 within the same dataset). He noted that it is crucial to be transparent when discussing the costs of informal care because there may be huge variation depending on the definition used and the assumptions made.

Michael Chernew (Harvard Medical School) noted that it is important to be cognizant of the system within which the costs of AD are being measured. There are nuances in any health system that will impact costs and these features are unrelated to the disease itself. The costs of AD should be compared across more than one health care system. The incentive systems in the United States are changing rapidly and the result is that costs are being pushed from one sector to another. We need to not only understand the total costs and who is paying for formal and informal care, but also how these costs are affected by the health care financing system.

Cost of Dementia

Michael Hurd, RAND Corporation, National Bureau of Economic Research (NBER), Network for Studies on Pensions, Aging and Retirement (NETSPAR), and Mannhein Research Institute for the Economics of Aging (MEA)

Future costs per AD case may be even higher than they are now not only because health care costs in general are increasing, but also because there is an expected shift of caregiver costs from the informal to the formal sector due to a rising share of women who do not have children. This project is examining the monetary cost of dementia and the monetary value of informal care with the aim of accounting for costs in a systematic way using HRS data.[5] The ADAMS, a subsample of 856 participants aged 70 years or older taken from the greater HRS study of 22,000 participants, was used to examine cost differences by dementia status (normal, cognitively impaired not demented [CIND], and demented). It is important to note that the project includes all types of dementia, not specifically AD, and it is possible this is a less severely impacted population.

Strategy and Sample

The strategy for the project was two-fold. First, cost differences by dementia status were examined for the ADAMS subsample using out-of-pocket spending as reported in the HRS interview, Medicare data, use of nursing home services, and hours of informal care. Second, cost differences were examined for a larger HRS sample based on imputed probability of dementia. The reported data are weighted based on the stratified sample and costs are shown both unadjusted and adjusted for demographics and comorbidities.

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[5] More information about the HRS and ADAMS can be found on the HRS Website: http://hrsonline.isr.umich.edu/

Proxy interviews are an important strategy for studying this population of older individuals with cognitive deficits. In the HRS wave prior to the ADAMS, 45 percent of demented participants had a proxy interview, compared to less than 10 percent of CIND participants and 2 percent of participants with normal status. The proxy interview is critical for this population both for signaling the functional impact of the dementia and for minimizing response bias.

The average age of demented subjects in the ADAMS is 85 compared to 78 for normal subjects. Those classified as normal have a higher household income than both CIND and demented subjects. Males are underrepresented in the demented population because of differential survival rates (15 percent compared to 50 percent in normal population). There is a strong education gradient with more subjects with less than a high school education being demented. This may be partly a cohort effect (rising education over time so it is actually related to age) but higher education also may confer a protective effect. Long-term care insurance is not prevalent among any of the sample but even less so for the demented population. More in the demented population have Medicaid compared to the normal and CIND populations. Among self-reported comorbidities, there is a strong gradient effect for the dementia population with stroke and heart disease.

ADAMS Out-of-Pocket Costs by Dementia Status

The self-reported out-of-pocket costs for a number of categories (e.g., hospital, nursing home, office visit, surgery, prescriptions, home health care) were compared by status. The demented population had a higher average out-of-pocket spending (~ $7,000) than both CIND (~ $3,200) and normal (~ $1,500) populations. These figures were then adjusted for demographics, income, and comorbidities using a hedonic regression of costs on characteristics. Results of the regression of out-of-pocket costs (2002 dollars) indicated that demented status is associated with additional costs of $4,703. The adjusted mean spending for the demented population was $6,294 compared to $1,591 for the normal population.

Probability of Dementia in the HRS Sample

An ordered probit regression was used to predict dementia status (normal, CIND, dementia) for the full HRS sample. Two estimations, the self-interview and the proxy interview in the wave before the ADAMS, were used. There are different measures of cognitive status in the self- and proxy interviews. A number of specific cognitive tasks in the self-interview were associated with greater likelihood of future dementia status: instrumental activities of daily living (IADLs), dates, serial 7, immediate word recall, and delayed recall. For the sample using proxy interviews, the Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) was most strongly associated with the likelihood of future dementia.

To increase the validity, the predictive model and HRS 2006 variables were used to predict dementia status among previously normal and CIND participants who participated in a follow-up assessment that took place 3 to 5 years after the initial ADAMS assessment (n=315). The model predicted 50 percent normal and 14 percent demented. In reality, 55 percent were

normal and 15 percent demented. The prediction is a good fit and this provides confidence in the model.

Cost Estimates Using the HRS Sample and Comparisons to the ADAMS

Out-of-pocket costs were estimated for the HRS sample using regression with probability of dementia as an independent variable. The probability of dementia is associated with $6,136 out-of-pocket spending related to dementia. This estimate is reduced somewhat when demographics ($6,038) or demographics and comorbidities ($5,819) are accounted for.

ADAMS data were linked to Medicare data to assess costs incurred by the Medicare system. The adjusted difference of $2,043 in Medicare costs for demented subjects ($7,751) and normal subjects ($5,708) is not statistically significant. However, the difference is significant using the full HRS sample and the probability of dementia adjusted for demographics and comorbidities with an estimated $2,515 in Medicare costs associated with probability of dementia.

The estimated nursing home spending associated with dementia was calculated with the HRS sample and probability of dementia using information reported to the HRS on nights in nursing home and state-level average daily costs of nursing home care. Probability of dementia adjusted for demographics and comorbidities was associated with $16,555 in nursing home costs compared to $12,300 associated with dementia status (adjusted) in the ADAMS sample.

Hours per week of informal care is also reported in the HRS. There is a strong gradient by imputed dementia status: over 25 hours per week of informal care for demented subjects, just under 10 hours per week for CIND subjects, and approximately 2 hours per week for normal subjects. The adjusted probability of dementia is associated with an estimated 35 hours per week of informal care (compared to 17 hours in the ADAMS sample).

A summary of adjusted excess annual spending associated with dementia is presented for both the ADAMS sample and the HRS imputed probability of dementia (Table 1). Informal care was valued at $15 per hour annualized at $27,000; this is a rough estimate currently being used as a placeholder. The grand total of costs estimated with the HRS imputed data to be associated with dementia is roughly $55,000 annually in 2010 dollars.

Remaining Tasks and Conclusions

There are some adjustments to be made in the model: eliminating some double counting, including private insurance, and using a better valuation of informal care. Age, education, and gender from the Current Population Survey (CPS) will be used to impute foregone earnings and adjust for the probability of working using observed employment rates in order to refine the cost estimate for informal care. Other adjustments to the model may be to conservatively offset value of room and board in nursing homes and account for some in-home care that is paid by Medicare and Medicaid.

Table 1: Summary of adjusted excess yearly spending associated with dementia (versus normal)

	ADAMS	HRS imputed probability of dementia
Out-of-pocket spending	5,374	5,819
Medicare	2,043	2,515
Nursing home (reduced for some double counting)	7,503	10,099
Total 2002$	14,249	18,433
Total 2010$	21,374	27,650
Informal hours of care per week	17.4	34.6
Annualized at $15 per hour	13,572	26,988
Grand total (2010$)	34,946	54,638

Dementia is associated with substantial health care costs. Nursing home and in-home professional care dominate the formal costs. Informal care costs are substantial but non-market based. The bearer of these costs depends on public policy. Currently, a substantial amount is paid by Medicaid. Future costs are expected to grow because of the aging of the population.

Discussion

The total cost is of interest, but it is also important to understand who bears the costs. Deadweight loss results if public financing bears the majority of costs. If most of the costs are paid privately then there are distributional costs (i.e., leading to some families going bankrupt because of medical costs). Market failure in the long-term care insurance market is an example. Long-term care insurance would result in certainty about a payment stream. Without insurance, people may save too much and the foregone expenditures may be productive (e.g., preventive care).

More detailed information about the informal caregivers (e.g., were they employed prior to being caregivers) is beyond the scope of this project. It is an interesting issue and more appropriate for labor economists to examine in detail. There is some information in the HRS on the respondents' adult children but the main limitation is that the HRS participants are age 65 and older. An examination of the population age 50 and younger would need to rely on the Panel Study of Income Dynamics (PSID), but it lacks the richness of the HRS.

Richard Suzman (NIA/BSR) noted that in previous years, Mark McClellan (Engelberg Center for Health Care Reform) and others used the HRS to examine the impact of a serious health event (e.g., stroke, heart attack) on household wealth. Household wealth is a noisy variable but they found a loss of 10 to 15 percent over a period of 2 to 4 years, most of which was loss of labor income. It may be worthwhile to use this strategy to estimate loss of earnings due to costs of AD. Dr. Hurd noted that this strategy may be worth attempting and there are two aspects to consider: out-of-pocket and nursing home costs associated with dementia and loss of earnings.

It may be possible to look at data on withdrawals from the labor market over time and younger HRS participants.

Dr. Wimo noted the importance of being transparent about the representativeness of the samples being examined in terms of estimating costs, particularly for informal care. His study in Sweden found large differences in informal care between the cohort and the population indicating undiagnosed people with mild dementia have lower uses of resources. If a sample includes more serious cases (e.g., diagnoses in Medicare based on ICD9 codes), then the cost estimates may be overestimated. Dr. Hurd's project uses dementia, including mild and severe cases from the HRS, which he asserts is an improvement in representativeness for this reason; the same sample is being used for costs and prevalence.

Dr. Suzman indicated that many publicly reported estimates on the costs of AD include all Medicare costs of anyone diagnosed with AD, rather than an estimate of the excess costs attributable to AD. Robert Egge (Alzheimer's Association) agreed that it is important to be clear and transparent about what is included in cost estimates.

National Institutes of Health
National Institute on Aging
The Costs Associated with Alzheimer's Disease (AD)
October 26, 2011
11:00 a.m. to 12:30 p.m. EST

Appendix 1: List of Participants

National Institute on Aging

Dallas Anderson
Colin Baker
John Haaga
Nina Silverberg
Richard Suzman
Chandra Keller-Allen (Contractor)
Rose Li (Contractor)

Other Participants

Michael Chernew, Harvard Medical School
Michael Hurd, RAND Corporation
Ira Katz, University of Pennsylvania
Pei-Jung Lin, Tufts Medical Center
Kathleen Mullen, RAND Corporation
Peter Neumann, Tufts Medical Center
Anders Wimo, Karolinska Institutet

Alzheimer's Association

Christopher Adamec
Matthew Baumgart
Robert Egge
Niles Frantz
Hye Kim
Mary Richards
Jennifer Sheridan
Heather Snyder
Toni Williams