Primary care expenditures before the onset of Alzheimer's disease

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Abstract—*Objective:* To investigate primary care expenditures in the period before diagnosis of AD. *Methods:* In a population-based sample of Medicare enrollees in New York City, person-level 1996 Medicare claims, summed over primary care encounters, were examined for people who developed AD in 1997 to 1998 and those who did not. *Results:* People who developed AD were more likely to use Medicare outpatient and ambulatory care 1 to 2 years before diagnosis. Compared with respondents who did not develop AD, the excess cost for men was $1,167 (85% higher) and for women $239 (26% higher). Among elderly people ≥75 years in the United States, the prodromal period of AD was associated with an excess Medicare-based primary care cost of $128.5 to $194.7 million. *Conclusion:* In addition to huge costs associated with AD after diagnosis, prediagnosis costs are an unrecognized source of expenditures related to the disease.

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It is unclear if people with declining cognitive abilities use primary care medical services to a greater extent than elderly people without cognitive deficits. Studies of medical care costs for older adults with early AD have been inconsistent, with some studies reporting increased utilization and others no difference. One study used the Mayo Clinic (Rochester, MN) database to examine an incident cohort of patients with AD 1 year before diagnosis and 4 years after diagnosis.[1] This study found no differences in inpatient or outpatient care between AD cases and matched control subjects in either the pre- or the postdiagnosis period. By contrast, studies of the cost of AD in Medicare managed care have reached the opposite conclusion.[2,3]

Differences in study designs make it hard to reconcile these findings. Because of the high use of nursing home care in the Mayo Clinic study, it is possible that AD cases received primary care in this setting. Ambulatory and outpatient care costs associated with AD in regions or medical systems with less nursing home use may therefore be higher. By contrast, the managed care studies may have overestimated costs associated with AD. Because these studies did not have clinical diagnoses for ascertaining AD cases independently of medical claims, they may have introduced an "observation bias," in which only cases with the highest expenditures were identified.[4]

Additional material related to this article can be found on the *Neurology* Web site. Go to www.neurology.org and scroll down the Table of Contents for the August 27 issue to find the link for this article.

Although it is clear that AD is associated with excess nursing home and in-home assisted living expenditures,[5-9] primarily captured in Medicaid-reimbursed expenses, no such consensus exists for primary care in the earliest period of the disease.[8,10-14] To investigate this issue, we examined primary care expenditures for older adults 1 to 2 years before they received a diagnosis of AD and compared their experience with that of elderly people from the same cohort who never received a diagnosis. For comparison purposes, we also include costs for prevalent AD cases in 1996.

Methods. *Derivation of study sample.* The Washington Heights–Inwood Columbia Aging Project (WHICAP) is a longitudinal population-based cohort, in which clinical and epidemiologic data are collected at regular intervals and vital status is continually updated. This stratified random sample was drawn from Medicare enrollment files (n = 2,126) in northern Manhattan, NY, in 1992 to 1993. Sampling strata for this survey included age (65 to 74, ≥75 years) and race–ethnicity (Hispanic, non-Hispanic black, and non-Hispanic white). Thirty-seven systematic replicate subsamples were drawn using random starts, such that each subsample contained age and race–ethnicity groups of equal size. The response rate for the entire sample at baseline was 62%.[15,16] Analyses comparing WHICAP participants and nonparticipants did not reveal differences in sex or race–ethnicity.[17] The Columbia University/New York Presbyterian Institutional Review Board reviewed and approved the WHICAP protocol.

The derivation of subjects included in analyses is shown in figure 1. By the end of 1996, 319 (15%) subjects were

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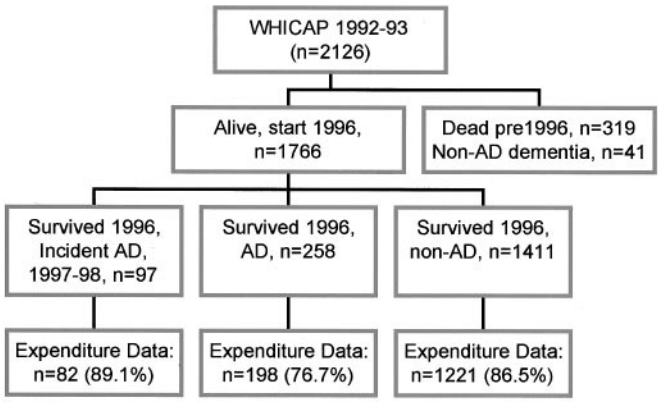

Figure 1. Expenditure study sample: Washington Heights–Inwood Columbia Aging Project (WHICAP).

known to have died. These people were excluded because we matched subjects to medical claims data beginning in January 1996 and restricted the sample to those who could have claims throughout the whole year. We also excluded 41 subjects with other forms of dementia (stroke-related dementia or dementia from focal effects of stroke; dementia secondary to metabolic, toxic, or traumatic causes; hydrocephalus; or dementia with unknown cause), though we recognize that some may be considered cases of "possible AD." We used Alzheimer's Disease and Related Disorders Association–National Institute of Neurological Disorders and Stroke criteria to identify people with probable AD, AD with stroke, AD with parkinsonian features, or AD with other concomitant disease.

Excluding subjects who died before follow-up or who had non–AD-related dementia left a sample of 1,766 who survived 1996. Of these subjects, 258 were diagnosed with AD in 1996 or earlier and were considered prevalent cases. One thousand four hundred eleven never met criteria for AD at any point throughout 1996 to 1998, and 97 met criteria for AD for the first time in either 1997 or 1998. As incident cases were ascertained in 1997 to 1998 and we examined medical claims in 1996, our analyses investigate medical care costs associated with cognitive impairment 1 to 2 years before an AD diagnosis. While an additional small number of respondents (n = 23) received an AD diagnosis in 1999, we did not consider them prodromal cases for this analysis. Thus, our estimates apply only to costs 1 to 2 years before diagnosis and can be considered conservative for this reason.

Identification of older adults who developed AD. Every WHICAP subject completes neuropsychological testing at each assessment interval. Respondents who met criteria for AD were classified as either "prevalent" (subjects who met criteria for AD at their initial assessment) or "incident" (subjects who did not meet criteria for AD at their first visit but did so at a later visit). Although subjects were diagnosed by the research team at different times throughout 1997 to 1998, all subjects were assessed for medical care costs in 1996, the same 1-year period.

Medical expenditure data. We examined Medicare outpatient and ambulatory care [Part B] standard analytical files for 1996, obtained from the Health Care Financing Administration (HCFA), because these cover the domain of primary care. The ambulatory care file (also known as the "physician/supplier" file) covers all costs associated with physicians, other providers, clinical lab services provided in a physician's office, durable medical equipment, and related costs. The outpatient file covers all costs related to clinic services.[18] We obtained utilization and expenditure data for all Medicare enrollees in the three zipcodes that make up the WHICAP catchment area. We then matched WHICAP respondents to HCFA files by social security number and birth date and manually checked each match.

With use of Medicare data, 66.3% of the cohort had at least one claim in either ambulatory care, outpatient, or inpatient files. The Medicare match rate was similar within cognitive status groups (nondemented, 65.7%; prevalent AD, 63.6%; prodromal AD, 75.3%; $p > 0.05$ by χ^2). If we consider Medicaid in addition to Medicare claims, the match rate was higher: 86.5% (1,221/1,411) of the non-AD group, 76.7% (198/258) of the prevalent AD group, and 89.1% (82/97) of the prodromal group ($p < 0.01$). Respondents in the prodromal group were significantly more likely to have claims using the combined Medicare and Medicaid data.

Respondents in Washington Heights–Inwood are likely to receive primary care in both hospital outpatient and ambulatory care settings. Hence, we computed a "primary care" composite, which was simply the sum over all encounters in these two files for each subject.

Medical conditions. Research physicians and trained research assistants elicited medical conditions (heart disease, hypertension, pulmonary disease, diabetes, arthritis, PD, depression, or other disorders) from respondents or proxies. The number of conditions was summed to create a modified Charlson index.[19] We established three groups (0, 1, or 2+ conditions), each representing about a third of the sample.

Analyses. Respondent-level utilization and expenditure indicators were derived by summing over Medicare encounters. For subjects who had a claim in one file (e.g., ambulatory care) but lacked claims in another (e.g., outpatient), we assigned the subject a zero value for the latter type of medical encounter. These subjects were clearly in the Medicare system, and absence of a claim in such cases can reasonably be construed as absence of a medical encounter. We also assigned a zero value to subjects without claims in any of the Medicare standard analytic files and who did not have Medicaid claims. This approach is reasonable because all subjects in the cohort were originally ascertained from Medicare enrollment files. We conducted analyses without the latter imputation, but as results were similar, we report only the imputed analysis.

For ambulatory and outpatient care in the cognitive status groups, we examined any use and mean and median expenditures in 1996, adapting the two-part model suggested by Duan et al.[20] Because of skew in cost distributions, we used nonparametric tests (Mann–Whitney *U*, Kruskal–Wallis) to test whether median costs in groups defined by cognitive status were significantly different.

Finally, we used expenditure data from New York City (NYC) to estimate the aggregate US primary care cost of cognitive impairment in the period before AD diagnosis. To convert WHICAP expenditures into national figures, we reweighted mean costs by race–ethnicity group to match those of the NYC metropolitan area as a whole. We then converted these regional costs to national estimates using the adjusted average per capita cost (provided by HCFA),

Table 1 *Characteristics of WHICAP subjects with claims data, by dementia status, 1996*

Characteristic	Nondemented, n = 1,221	Demented, AD, n = 198	Prodromal AD, n = 82
Age in 1996, y*	77.3 ± 5.9	83.1 ± 6.9	82.4 ± 6.7
Education, y*	8.7 ± 4.6	5.9 ± 4.4	7.6 ± 4.6
Female, %†	69.8	79.8	66.0
Race–ethnicity, %*			
White	91.8	4.6	3.5
Black	77.8	15.8	6.4
Hispanic	75.9	18.4	5.6
Co-morbid conditions, %			
0	21.5	16.2	19.5
1	32.1	28.4	26.8
2+	46.5	55.3	53.7

Subjects were recruited in 1992 and survived through 1996. Subjects with "other" self-reported race (n = 7) were excluded from Race–ethnicity presentation. Counts of conditions were based on a modified Charlson index.

* $p < 0.001$, † $p < 0.01$, by χ^2 or one-way analysis of variance.

WHICAP = Washington Heights–Inwood Columbia Aging Project.

Table 2 *Ambulatory and outpatient Medicare expenditures, WHICAP 1996, by cognitive status*

Sample	Nondemented	Prodromal AD	Prevalent AD
Full sample, n	1,221	82	198
Any primary care, %*	71.7	82.9	79.8
Primary care, median $‡	587	1,480	943
Males, n	382	30	42
Any primary care, %†	63.9	86.7	78.6
Primary care, median $‡	336	1,738	1,206
Females, n	839	52	156
Any primary care, %	75.2	80.1	80.1
Primary care, median $*	662	1,389	891
Age <75 y, n	521	7	23
Any primary care, %	68.3	75.0	82.6
Primary care, median $	561	1,783	1,023
Age ≥75 y, n	700	75	175
Any primary care, %	74.2	84.0	79.4
Primary care, median $‡	595	1,462	938
White, non-Hispanic, n	321	13	14
Any primary care, %	60.8	76.9	35.7
Primary care, median $	287	1,498	0
Black, n	399	30	63
Any primary care, %	68.7	76.7	76.2
Primary care, median $*	498	1,353	902
Hispanic, n	501	39	121
Any primary care, %	81.1	89.7	86.8
Primary care, median $	840	1,502	1,103

Primary care includes costs in outpatient and ambulatory (Part B) files.

* $p < 0.05$, † $p < 0.01$, ‡ $p < 0.001$ by χ^2 (any primary care) or Mann–Whitney test (median $) for comparison of non-AD and prodromal AD groups.

WHICAP = Washington Heights–Inwood Columbia Aging Project.

with appropriate age- and sex-rescaling weights. Specifically, NYC costs were multiplied by the ratio of the retrospective US per capita cost to the NYC cost (Part B Aged rates: http://www.hcfa.gov/stats/hmorates/aapccflt.htm). We obtained the proportion of elderly people in the United States ≥75 years old from the US Census 2000[21] and used a range of AD prevalence and incidence established in recent meta-analyses.[22,23] Because so few elderly people younger than 75 years became incident cases, no cost estimate is provided for this group. With these assumptions, we estimated the aggregate excess primary care cost (in 1996 dollars) associated with prodromal AD projected for the US population.

Results. *Sociodemographic and vital status of WHICAP expenditure cohort.* Table 1 presents features of the cognitive status groups in 1996. The groups differed significantly in age and education; prevalent AD cases were older and less educated. Prevalent AD cases were also more likely to be minority. The groups did not significantly differ in total number of medical conditions. The proportion of respondents with particular medical conditions in each of the cognitive status groups is also shown (additional material can be found on the *Neurology* Web site; go to www.neurology.org).

Medicare expenditures in 1996. The cognitive status groups did not significantly differ in the proportion of subjects with hospitalizations in 1996 (nondemented, 14.3%; prevalent AD, 17.2%; incident AD, 22.0%). The groups did differ in primary care expenditures, as shown in table 2. One to 2 years before diagnosis, people who went on to develop AD were more likely to have an outpatient or ambulatory care visit (82.9 vs 71.7% in nondemented and 79.8% in prevalent AD; $p = 0.01$ by χ^2). Respondents who later received AD diagnoses were also likely to have higher primary care costs. Median costs in 1996 were $587 for nondemented, $943 for prevalent AD, and $1,480 for prodromal AD ($p = 0.001$ by Kruskal–Wallis test for all three groups, $p = 0.001$ by Mann–Whitney U test for nondemented vs prodromal AD).

Sex and expenditures. Separating total costs by sex shows that the greater cost in the prodromal AD group holds for both men and women but is considerably larger among men (see table 2). Comparing nondemented and prodromal AD groups, median costs were $336 and $1,738 for men ($p < 0.001$) and $662 and $1,389 for women ($p < 0.05$).

Age and expenditures. Primary care costs were higher in the prodromal group compared with people who remained dementia-free, but this difference did not achieve significance in the young–old, defined here as people younger than 75 years (see table 2). Among elderly people

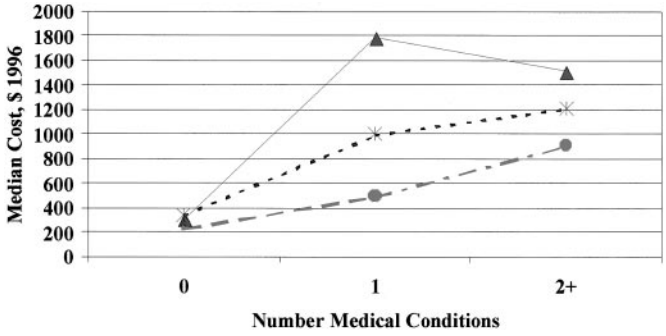

Figure 2. Median cost, 1996: AD status by number of comorbid conditions. Triangles = prodromal AD; stars = prevalent AD; circles = no AD.

≥75 years old, the median primary care cost in the prodromal AD group was $1,462 compared with $595 in the group that remained free of dementia ($p < 0.001$).

Race–ethnicity and expenditures. In all three race–ethnicity groups, prodromal AD was associated with increased primary care costs relative to respondents who never met criteria for AD (see table 2). Median costs for nondemented and prodromal AD groups were $287 and $1,498 among whites, $498 and $1,353 among blacks, and $840 and $1,502 among Hispanics. The small number of whites with prevalent AD (n = 14) were largely in nursing homes and accordingly had few Medicare charges for primary care (hence the $0 median primary care charge).

Comorbid medical conditions and expenditures. Figure 2 plots primary care costs in the cognitive status groups by number of medical conditions. Prodromal AD was associated with increased median primary care costs for respondents who had one ($p = 0.005$) or two or more ($p = 0.04$) conditions. Within groups defined by the presence or absence of particular medical conditions, the prodromal AD group had higher primary care costs than the non-AD group (additional material can be found on the *Neurology* Web site; go to www.neurology.org). For example, for respondents with pulmonary disease, mean primary care costs were $2,198 for the prodromal AD group and $1,969 for the non-AD group.

Aggregate US costs of prodromal AD, elders ≥75 years old. We developed estimates for the aggregate cost of prodromal AD in the period before diagnosis but restricted these estimates to people ≥75 years old because, as noted earlier, few older adults younger than 75 years developed AD. Results are shown in table 3. The mean primary care cost (US equivalent) for men with prodromal AD in 1996 was $2,532, an excess of $1,167 (or 85%) over men who did not develop AD. For women, the cost was $1,142, an excess of $239 (or 26%) over women who did not develop AD.

The US Census 2000 reported 6.1 million men and 10.5 million women ≥75 years old and 1.2 million men and 3.0 million women were ≥85 years old.[18] To estimate the total cost of primary care for prodomal AD, we assumed a prevalence rate of 6% in the 75 to 84 age group and 20% in people ≥85 years old.[22] We assumed an annual AD incidence of 1.1 to 1.8% for people aged 75 to 84 and 3 to 4% in people ≥85 years old.[22,23] With these assumptions, approximately 230,000 to 345,000 people ≥75 years old develop AD each year and can be considered to have prodromal disease. Using the lower-end incidence estimate, total primary care costs for men with prodromal disease (estimated at $2,532 per case from table 3) were $128.3 million (age 75 to 84) and $72.9 million (age ≥85). If these men did not have prodromal AD, total primary care costs (estimated at $1,365 per case) would have been $69.2 and $39.3 million. The excess primary care expense attributable to prodromal AD is the difference, or $92.7 million. Repeating this analysis for women, the excess primary care cost attributable to prodromal AD is $35.8 million. The total increase in primary care cost associated with prodromal AD is $128.5 million. With use of the higher incidence estimates, the increase in primary care costs associated with prodromal AD is $194.7 million.

Discussion. Respondents identified as having AD for the first time in 1997 to 1998 were likely to have high primary care expenditures already in 1996, 1 to 2 years before their diagnosis. This finding is

Table 3 *Medicare-based primary care costs of AD, aged ≥ 75 years: Washington Heights (n = 955), New York City (NYC), and national cost estimates, 1996*

Sex	Cognitive status	Medicare primary care cost, WHICAP, $ (n)	Medicare primary care cost, NYC, $*	AAPCC/USPCC US equivalent cost, $†	Excess cost of incident AD case in year prior to diagnosis, $‡
Male	Prevalent AD	2,967 (35)	1,972	1,309	—
	Prodromal AD	2,826 (28)	3,815	2,532	1,167
	No AD	1,790 (203)	2,056	1,365	—
Female	Prevalent AD	1,902 (140)	987	655	—
	Prodromal AD	1,854 (47)	1,720	1,142	239
	No AD	1,652 (502)	1,361	903	—

* The Washington Heights–Inwood Columbia Aging Project (WHICAP) sample is skewed toward blacks (33%) and Hispanics (43%) compared with whites (24%). Cost estimates were reweighted to reflect race–ethnicity among elders aged 75+ in the NYC metropolitan area as a whole, as derived from the Current Population Survey, March 2000 (blacks, 10%; Hispanics, 10%; whites, 80%).

† AAPCC = adjusted average per capita cost using age- and gender-rescaling weights. NYC costs were multiplied by (retrospective US per capita cost [USPCC] estimates/NYC estimate) using figures for Part B Aged. Available at: http://www.hcfa.gov/stats/hmorates/aapccflt.htm.

‡ Cost of prodromal case − cost of respondent without AD.

strengthened by a number of features of our study design. First, expenditure data and diagnoses were obtained separately; thus, we were able to avoid the observation bias that has been identified for claims-based studies.[4] Second, our results were derived from a population-based study and hence avoid threats to generalizability associated with samples drawn from clinics or managed care organizations. Finally, through use of a neuropsychological test battery and medical and neurologic examination, we were able to separate AD from other forms of dementia.

Why should respondents have increased primary care expenditures in the period before an AD diagnosis? The increased cost does not appear to be a result of a greater number of comorbid conditions, at least when expressed as a simple count. When matched for number of comorbid conditions, people who went on to develop AD had higher primary care expenditures than people who never met criteria for AD. A limitation of this approach is that it treats each disease equally when clearly some diseases lead to more encounters. More research on the co-occurrence of AD and other medical conditions will be required to clarify this issue. Increased expenditures in the absence of at least gross differences in medical status suggest that prodromal AD may itself increase the need for medical care. Also, increased median costs were evident across groups defined by race, age, and sex.

These high expenditures may be related to the diagnostic process; that is, families utilize medical services (primary care physician, neurologist, memory disorder clinic) as they attempt to determine what is wrong with an elder. It is also possible that high primary care expenditures are related to poorer post-treatment medical outcomes in people with early evidence of cognitive deficit who do not yet meet criteria for AD. People who go on to receive AD diagnoses may be less able to adhere to treatment and medication regimens and may also fail to recognize medical symptoms early. The result may be more expensive primary care.

Additional research is required to clarify this question. Whereas the increased risk for mortality associated with AD is well established,[24-26] people who die with AD do not appear to die of different causes than other people. The most frequent causes of death, established from death certificates or through multiple data sources (as in the National Mortality Followback Survey), do not distinguish people with and without AD.[27] Increased primary care expenditures associated with prodromal AD, then, may not be due to a particular medical profile, such as pneumonia or falls, but may instead reflect the general medical needs of people with increasing disability. In NYC, for example, physician evaluation is required for Medicaid approval of personal assistance care.

One potential limitation in this research is the match rate we obtained for Medicare data. The match rate in the WHICAP sample was 66.3%, which is lower than that reported for older adults in other studies, such as the National Long-Term Care Survey.[28] The WHICAP match rate should be considered in light of the predominantly minority (and immigrant) status of the cohort and its high Medicaid profile.

An unexpected result in this research was the lower use of Medicare-reimbursed primary care among women who ultimately developed AD. This result requires further investigation. It supports recent research showing disparities between older men and women in receipt of home care[29] and suggests that women may be better advocates for a spouse's health than men.

Finally, our results suggest that primary care for people with prodromal AD is expensive. The aggregate excess annual Medicare-reimbursed primary care cost for this group, projected to the US population ≥75 years old, is $128.9 to $195.5 million. Cost estimates used for this projection were drawn from a particular sample within one region of the United States. For this reason, we applied adjustments to make the sample representative of the racial–ethnic (and hence socioeconomic) distribution of the NYC metropolitan area as a whole and adjusted for this regional effect. The estimate must be considered approximate, as estimates of annual AD incidence and prevalence vary considerably. Still, the large excess primary care cost suggests that therapies able to delay the incidence of AD would have immediate economic importance. It is also likely that many other diseases are associated with excess primary care costs in the prodromal period. These costs need to be captured if we are to understand the total economic impact of disease.

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