Marked Increase in Alzheimer’s Disease Identified in Medicare Claims Records Between 1991 and 1999

Donald H. Taylor, Jr., 1,3 Frank A. Sloan, 1,3 and P. Murali Doraiswamy 2,3

1Center for Health Policy, Law and Management, Terry Sanford Institute of Public Policy, Duke University, Durham, North Carolina.
2Departments of Psychiatry, Geriatrics, and Medicine, Duke University Medical Center, Durham, North Carolina.
3Duke University Center for the Study of Aging and Human Development, Durham, North Carolina.

Background. Epidemiologic evidence suggests that African Americans have higher rates of Alzheimer’s disease (AD) than whites. Examining longitudinal trends in the number of persons who are identified as having AD in administrative databases may provide insights into this phenomenon.

Methods. We analyzed 9-year longitudinal data (1991–1999) for 29,679 Medicare beneficiaries who were screened for the National Long-Term Care Survey. Cases of AD were identified using ICD-9-CM diagnosis codes from Medicare claims files.

Results. Age-adjusted rates of Medicare beneficiaries identified as having AD rose from 1991–1999 for all groups studied, but particularly among African Americans. In 1991, African Americans made up 6.5% of the identified AD cases but comprised 11.0% of cases in 1999 ($X^2 = 6.79, p = .005$). The rate of increase in identification of AD was particularly large for women who were aged 85 years and older.

Conclusions. Reasons for increased identification of AD in Medicare claims is likely multifactorial; sharp increases among African Americans may reflect improved access.

Alzheimer’s disease (AD) is a progressive neurodegenerative disorder and is the most common cause of dementia in older adults in the United States (1,2). Contemporary diagnostic criteria for AD were published in 1987 (3), and numerous AD prevalence studies have been conducted in the United States (4–14). The true prevalence of AD is unknown, but a recent meta-analytic study based on prevalence rates from 21 studies conducted in the 1980s through the mid-1990s concluded that the discrepancy in prevalence rates of AD was due in large part to differing levels of severity of AD used to identify cases across studies (12).

Epidemiologic evidence suggests that the frequency of AD is higher among African Americans compared with whites (15–18). One difficulty in determining the true prevalence of AD, both generally and among racial groups, is the selected nature of many of the samples used to assess the incidence and prevalence of AD. The ability to identify AD in broader populations is important in order to have a clear understanding of the magnitude of the disease, and Medicare claims records are a source of data that are potentially available for the vast majority of persons aged 65 and older in the United States. The use of Medicare claims to identify cases of AD using ICD-9-CM (International Classification of Diseases, 9th Revision, Clinical Modification) diagnosis codes raises issues about the validity of identifying cases in this manner. Several studies have analyzed cases of AD identified in Medicare claims records (19–21), resulting in prevalence estimates that are well below the assumed true prevalence of AD. A recent study using the Center to Establish a Registry for Alzheimer’s Disease (CERAD) population found that Medicare claims records have sensitivity to detect known cases of AD of between 80% and 90% when using 3–5 years of claims data (22). The sensitivity of Medicare claims to identify AD may be higher in the CERAD sample compared to other databases, because all cases in CERAD had autopsy-proven AD. This means that the cases of AD in CERAD are likely more severe, on average, than would be the cases that occur in more population-based samples. There was no difference in sensitivity by race in the CERAD study (22). The specificity of Medicare claims to identify AD is unknown, and was not assessed using CERAD because of very few control cases.

Our study question is whether the age-adjusted rate of Medicare beneficiaries identified as having AD increased from 1991 to 1999, and whether such rates differed between African Americans and whites. We used Medicare claims records to track changes in the proportion of beneficiaries who were identified as having AD from 1991–1999 using ICD-9-CM diagnosis codes present in the data. Comparing longitudinal trends in the rate of identified AD among African Americans and whites in Medicare claims records provides an opportunity to determine whether racial differences in the prevalence of AD identified in past work hold true in this more population-based data source. Such analyses may also point out progress in recognition, knowledge of, or diagnosis of AD, access to care, changes in rules regarding the acceptability of AD as a diagnosis in Medicare claims, or any combination thereof.

Methods

Study Sample

Our study sample consisted of 29,679 Medicare beneficiaries; 21,918 were aged 65 years or older on January 1,
1991 and were alive on June 30, 1991, allowing a span of at least 6 months of potential Medicare claims data with which to assess AD status (discussed below). The other 7761 turned 65 after January 1, 1991 and were included in the sample as of their 65th birthday, when Medicare eligibility began.

This study sample was taken from a representative sample of age-eligible Medicare beneficiaries that was drawn in order to provide a sampling pool for the National Long-Term Care Survey (NLTCS), which was conducted in 1982, 1984, 1989, 1994, and 1999. Respondents came from 42 states across the country; details of the sampling strategy have been published elsewhere (23). We have previously used Medicare claims data from the NLTCS to investigate cost of AD to the Medicare program (19), and outcomes of acute hospitalizations in different hospital types (24). Persons included in the sample were followed continuously from January 1, 1991 or their 65th birthday, through December 31, 1999, or death.

We examined 8 types of Medicare claims records for individuals in all study years: Carrier (Physician Supplier/Part B), Outpatient, Inpatient, Skilled Nursing, Home Health Agency, Clinical Laboratory, Durable Medical Equipment, and Hospice. These claims records provide a detailed history of all medical care financed by Medicare during the study period, regardless of the reason for the care. The claims included up to 10 ICD-9-CM diagnosis codes (1 primary, up to 9 secondary reasons for the claim) for each claim. AD could be identified in Medicare claims during 3 types of health care encounters: 1) health care utilization designed to diagnosis AD; 2) treatment of diseases or conditions directly related to AD; and 3) treatment of diseases or conditions unrelated to AD in which AD was simply comorbid. For these reasons, we use the terms “identified AD” to depict the rates we present in the study as contrasted with true population prevalence or incidence rates. We used the following variables obtained from Medicare claims data and Medicare Vital Statistics files: sex, race, and age (year of birth), which were used to stratify prevalence estimates. Date of death was obtained from the Health Care Financing Administration Vital Statistics data, and was used as a censoring variable with which to adjust the denominator for calculations of rates in each study year.

How AD Was Identified

Persons were classified as having AD as of the date of their first Medicare claim noting ICD-9-CM code 331.0 in either the primary or one of the secondary diagnosis codes. AD could have been identified using diagnosis codes contained in any 1 of the 8 types of Medicare claims files mentioned above. After the initial notation of AD in Medicare claims, an individual was assumed to remain in the disease cohort, and therefore in both the numerator and denominator for identified rate calculations, for the remainder of the study (or until death). For all types of files except the Physician Supplier/Part B claims (which did not contain ICD-9-CM diagnosis codes in earlier years), we also examined claims from 1984–1990 for the individuals in our sample who turned age 65 prior to 1991. Each claim record was checked for a diagnosis of AD in the manner described above. Each individual with one or more of these diagnoses prior to 1991 was coded as having AD, in 1991, and for the remainder of the study, or until death.

We conducted sensitivity analyses to determine whether not having ICD-9-CM codes from 1984–90 in Part B Medicare claims files had a large effect on the rate of identified AD in 1991. If the 1991 rate was artificially low because of not having these codes in 1984–1990, then any increase observed between 1991 and 1999 could be due to this artifact. These analyses consisted of determining how important Part B claims are in identifying AD, and how many cases of AD were only identified through the 1984–1990 claims.

Calculation of Rates of Persons Identified as Having AD

We calculated rates of persons identified as having AD as of December 31 of each study year (1991–1999). The rate for a given year was calculated as the ratio of the number of living individuals who had been identified as having AD at the end of the year (December 31) over the total number of individuals alive on the same day, multiplied by 1000. We then recalculated rates by omitting from the denominator for a given year any individual who was enrolled in a Health Maintenance Organization (HMO) for longer than 6 months during that year. Health care utilization information for such persons was not represented in Medicare claims files for the period during which they were enrolled in a Medicare HMO. We present rates that exclude such persons, but not using this exclusion did not alter the basic findings of our paper. The proportion of the sample in an HMO ranged from 6.2% in 1991 to 17.6% in 1999 after peaking at approximately 18% in 1997. We used direct age adjustment, weighting prevalence rates in all study years by the age strata weights present in 1991 for the following strata: 65–69 years, 70–74 years, 75–84 years, and 85+ years.

Testing Changes in Rate of Identified AD

The Cuzik test, a nonparametric test for trend across years (25), was performed using STATA (26). Each of the trend tests (with p values < .01) indicated whether or not the identified rate of AD increased over time.

Testing Changes in Rate of Identified AD By Race

We used a chi-square test to ascertain whether the proportion of cases of diagnosed AD that occurred among African Americans in 1991 differed from the proportion of diagnosed cases that occurred among African Americans in 1999. We conducted a similar test for gender.

RESULTS

Women comprised 61.7% of the sample at baseline in 1991; 7.4% were African American, less than 1% had other race, with the remainder being white. The mean age of the full sample was 76.8 years (SD [standard deviation] 7.9), 77.6 years (SD 8.3) for women, and 75.5 years (SD 7.0) for men. Women were much more likely to be among persons aged 85+ years, with 2823 (21.1%) of women and 953 (11.5%) of men being in this age group. One third of the 29,679 study participants (33.5%) died during the study period (Table 1). The proportion of study participants...
excluded from calculations of rates of identified AD because of membership in a Medicare HMO varied from 1330 (6.1%) in 1991 to 3722 (18.9%) in 1999. In addition, 14.1% of study participants who were not in a Medicare HMO for 6 or more months had no Medicare-financed care in 1991, dropping to 9.6% who had no utilization in 1999. Such persons had no opportunity to be newly identified as having AD during a study year because they used no Medicare-financed health care services. Identification of AD was cumulative, with 324 persons being diagnosed in at least 1 Medicare claim as of December 31, 1991. The number of persons identified as having AD at least once prior to December 31, 1999 was 730.

The age-adjusted rate of AD identified in Medicare claims rose generally from 1991–1999 (Table 2). The age-adjusted increase in identification for each of the 8 stratifications by race and gender shown in Table 2 each represent statistically significant increases (with \( p < .01 \) in all cases). However, the increase was particularly notable among African Americans, especially African American women, where the rate increased by a factor of 4.7 compared with 2.3 for white women. Overall, whites had higher rates of identified AD in 1991 (16.5/1000 vs 13.7/1000), but African Americans had higher rates in 1999 (62.5 vs 40.9). In 1991, African Americans made up 20 of 324 (6.2%) of the diagnosed cases of AD in our sample, but comprised 80 of 730 (11.0%) of the identified cases of AD in 1999; this difference was highly significant (\( X^2 = 6.79, p = .005 \)) indicating that the rate of identified AD rose much faster among African Americans than whites. There was no difference in the rate of increase in diagnosed all-cause dementia rates by race [results not shown but available upon request; ICD-9-CM codes used to identify all-cause dementia were the same as those used in past work (22)]. There was no trend for the rate of identification of AD by gender, as women represented 74.7% of all AD claims in 1991 and 73.4% in 1999 (\( X^2 = 0.19, p = .67 \)).

Rates of identified AD increased over the period 1991 to 1999 in all age strata used for age-adjustment among both men and women (Figures 1A and B). The increase in rates of identification among women who were among the oldest-old was particularly rapid, rising from 35/1000 in 1991, to 135/1000 in 1999, roughly a fourfold increase. The rate of increase in identification among oldest-old men rose from 24/1000 to 65/1000, slightly less than a threefold increase. Rates of identification of AD were relatively stable from 1991 to 1999 for persons who were aged between 65 and 74 years. The effect of not having ICD-9-CM codes for Part B claims from 1984–1990 but using Part A claims from the same period to identify cases of AD was not large and did not change any of our main conclusions when analyses were conducted not using the earlier period. Approximately 40% of all persons identified during the 1991–1999 period as having AD had a mention of AD in a Part B claim only.

### Table 1. Sample Construction

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Notes: *The numbers in this column represent the denominators used for the calculation of the prevalence rates highlighted in the text. Numbers represent cell N. HMO = health maintenance organization.

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Figure 1. Changes in unadjusted identification rates of Alzheimer’s disease by age strata, males (A) and females (B).
However, most persons who were identified as having AD in the period 1984–1990 died prior to 1991 and were not included in the study calculations. Further, most of those who were identified as having AD prior to 1991 and who survived to be included in the study calculations were also identified as having AD during the period 1991–1999. In 1991, 16% of persons identified as having AD were only identified during 1984–1990; in 1992, the figure was 9%, and less than 1% by 1993 and beyond. The lack of ICD-9-CM codes in Part B Medicare claims from 1984–1990 most likely contributed to the undercount of persons who may have been identified in Part B claims during this period, but this effect was negligible by 1994. Excluding the claims records from the 1984–1990 period would have only resulted in a larger undercount. Only a small portion of the increase in the rate of diagnosed AD from 1991–1999 can be attributed to an artifact arising from not having ICD-9-CM codes in Part B claims, and virtually none of the increase from the period 1994–1999 can be so attributed.

**DISCUSSION**

The rate of age-adjusted identified AD increased in our study population of age-eligible Medicare beneficiaries from 1991 to 1999, with the greatest increases seen among African Americans, especially African American women. Women had higher age-adjusted identification rates than men in all study years, and the gender differential was roughly constant over time with women comprising three fourths of the cases.

Most studies have either reported finding higher prevalence of AD among African Americans compared with whites, or no difference (27–32). Our results are consistent with this general conclusion. Although it is possible that AD rates for African Americans have simply risen dramatically in the last decade, the increase we identified is more likely due to other factors: improved access to health care, increased sensitivity of the medical community and the population to AD among African Americans as not being a normal part of aging, and changes in coding rules allowing for identification of persons as having AD when they also had risk factors for vascular dementia such as prior stroke, which are more common among African Americans than whites. Coding did not allow an assignment of AD given such risk factors until the early 1990s, and this change likely took time to diffuse into practice, potentially explaining the increase in rates of identified AD. Finally, the development of pharmaceutical treatments for symptoms of AD would be expected to have the effect of increasing the likelihood of an elderly person being diagnosed as having AD, in spite of the fact that the Medicare program does not finance such prescription drugs as part of its benefit package.

The rise in identification rates over the study period was particularly steep among oldest-old women compared to men of the same age, regardless of race. It is not clear why the rate of increase should be higher among women, but one possibility is the fact that women live longer than men do, and therefore have more opportunity to be identified as having AD above age 85 years. In a similar vein, given that men have a shorter life expectancy than do women, those surviving to age 85 years and older may be considered to be healthy survivors who have a lower likelihood of being identified as having AD for reasons that are not clear.

**Study Limitations**

There are several limitations of our study. First, we measured the rate of identified AD in Medicare claims, and not the true prevalence of AD. Second, persons who are in Medicare HMOs are censored from being able to be identified as having AD while in an HMO because of unavailable data. If expansion of Medicare HMOs were to occur, it would further limit the ability to use Medicare claims data to estimate diagnosed prevalence of AD (or any other disease), but the current secular trend is toward fewer Medicare beneficiaries selecting Medicare HMOs than did so in the mid-1990s (33). Third, we were unable to estimate identification rates for Hispanics or Asians because of their small numbers in the database we used; the data use agreement under which the data were analyzed forbid the identification of any subpopulation with fewer than nine cases. Fourth, while Medicare claims identified 80%–90% of cases of AD in the CERAD population, this likely represented a high-water mark for sensitivity of Medicare claims to detect cases because of the intensive follow-up those patients received and severity of cases (22). There is no information on the specificity of Medicare claims for identifying AD. Fifth, we did not have ICD-9-CM codes for Part B claims during the period 1984–1990, but there were relatively few participants identified as having AD during the years 1991 through 1999, although data are only shown in the Table for selected years. Each of the trend tests (with small number of cases of Alzheimer’s disease occurring in Hispanics and other racial groups because cases for these subgroups were smaller than 9). The data use agreement with the Center for Medicare and Medicaid Services under which these data were analyzed does not allow identification of any cell with fewer than 9 cases. Therefore, we excluded all participants who were not white or black. **Factor increase is defined by the rate in 1999 divided by the rate in 1991 and shows how rapidly the identification of Medicare beneficiaries increased over the entire study period.**

A nonparametric test for trend (25) was performed using STATA for the total sample shown in the last row, and also for each of the 8 stratifications by race and gender shown in the Table. These tests were conducted across the years 1991 through 1999, although data are only shown in the Table for selected years. Each of the trend tests (with p values < .01) indicated that the rate of identified Alzheimer’s disease was increasing over time.
the 1984–1990 period only, so this “extra” undercount does not explain the increase we identified over the period 1991–1999. Finally, severity of dementia cannot be assessed using Medicare claims. The undercount of AD among persons with mild disease is likely greater than that among persons with more severe symptoms.

There are several notable strengths of our study design, including our ability to assess AD longitudinally and using a more nationally representative study sample than is practicable in traditional epidemiological studies. Increased understanding of how rates of identified AD in Medicare claims data compare to catchment area studies will clarify the best ways to use rates such as the type we have produced. Finally, our past work shows that being identified as having AD in Medicare claims has an effect on the amount and cost of care received, making the study of changes in rates of AD in Medicare claims has an effect on the amount and cost of care received, making the study of changes in rates of identification important from the standpoint of understanding how such a label impacts Medicare beneficiaries and the Medicare program as a whole.

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Address correspondence to Donald Taylor, PhD, Box 90253, Duke University, Durham, NC 27708. E-mail: dtaylor@hpolicy.duke.edu

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