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Measuring Alzheimer's Disease and Other Dementias in Diverse Populations Using Medicare Claims Data

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Abstract

We examined how methods used for identifying dementia in administrative claims affected dementia incidence across racial/ethnic populations using a 100% sample of Medicare beneficiaries (n=23,793,452). We found levels differed by method from 3.1% annual incidence to 3.6% in 2014. Dementia incidence declined 2007 to 2014 but choice of method differentially impacted levels and trends by race/ethnicity. Methods using codes for dementia diagnosis and drugs to treat symptoms identified proportionally more Hispanics and Asians with dementia than other race/ethnicities, while codes for dementia diagnosis, drugs and symptoms identified proportionally more whites and American Indians/Alaska Natives with dementia than other race/ethnicities.

Keywords

dementia; diagnosis; incidence; Alzheimer's disease; measurement

INTRODUCTION AND BACKGROUND

Accurate estimates of the number and characteristics of Americans with dementia are essential for quantifying disease burden and preparing health and long-term care systems. Medicare claims data provide a rich resource for studying diagnosed dementia in the US and across diverse populations because of Medicare's broad coverage of nearly all Americans ages 65 and older. These data have been used to analyze multiple aspects of dementia including costs of dementia [1–3], trends in disease prevalence [4, 5], care transitions [6], the association of dementia risk and fitness [7], and dementia risk associated with common drug therapies including anti-hypertensive treatments [8] and statins [9]. Claims records

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linked to surveys with rich data on respondents' socio-economic characteristics and caregiving support, or to clinical trial data can further expand knowledge in diverse areas [7, 10–12]. In 2003, the Centers for Medicare and Medicaid Services, launched the Chronic Conditions Warehouse (CCW), a research database to facilitate researchers in identifying beneficiaries with particular conditions. The CCW algorithm links beneficiaries across the continuum of care and requires one dementia diagnosis code to detect the condition of dementia. However, other sources of information exist for identifying dementia, and methods for confirming presence of the condition, and there is a growing interest in identifying dementia in the population using claims data [13].

Sources in claims data for identifying dementia include but are not limited to diagnosis codes for services performed in outpatient, home health care, skilled nursing facilities or hospitals settings. Information also resides in drug claims and codes for dementia-related symptoms and these can be tracked over time. Understanding the implications of various definitional methods will aid future research on dementia incidence and prevalence in the US population, as well as research on dementia risk, treatment, care and cost and inform interpretation of results. In this study, we calculated dementia incidence from 2007 to 2014 using different sources of information for identifying persons with dementia, and tracking codes over time to verify diagnosis in claims data. We measured all types of dementia including but not limited to, Alzheimer's disease and Alzheimer's disease-related dementias. We quantified the effect of method used on estimates for the elderly US population and separately for populations of non-Hispanic white, black, Hispanic, Asian and American Indian/Alaska Native people.

DATA, SAMPLE AND METHODS

Medicare Sample

We used a 100% sample of Medicare beneficiaries and linked data on enrollment, demographics, vital status and claims from Part A (hospital stay), Part B (out-patient), and Part D (prescription drugs). The study sample consisted of beneficiaries aged 67 and older and enrolled in Medicare Fee-For-Service and Part D for at least 2 years from years 2007 to 2016. The final study sample of 23,793,452 beneficiaries consisted of 19,667,494 non-Hispanic white people, 1,918,931 black people, 1,419,317 Hispanic people, 694,324 Asian people, and 93,386 American Indian/Alaska Native people.

Dementia Codes in Medicare Claims

We identified codes from inpatient, outpatient, home health care, skilled nursing facility and carrier claims. We utilized the *International Classification of Diseases, Ninth and Tenth Revisions* (ICD-9-CM, ICD-10-M) diagnoses codes for dementia as defined by the Chronic Conditions Warehouse. A full list of codes is included in Supplementary Table 1. We also used Part D claim codes for drugs used to treat the symptoms of dementia, acetylcholinesterase inhibitors (donepezil, galantamine, rivastigmine) or NMDA receptor antagonists (memantine). Drug treatments prescribed to persons with dementia, but not specific to dementia, such as anti-psychotics, anti-anxiety and anti-depression medications, are not included. ICD-9-CM diagnoses codes for symptoms/conditions associated with

dementia: amnesia (780.93), aphasia (784.3), mild cognitive impairment (331.83), apraxia and agnosia (784.69) [14]. The corresponding ICD-10-CM codes for these symptoms are R41.1, R41.2, R41.3, R47.01, R48.1, R48.2, R48.8, and G318.4.

Method

To identify incident dementia cases, we required that beneficiaries had no dementia diagnosis prior to the year of interest. An initial diagnosis may be subsequently determined not to be dementia, thus we required a second diagnosis code within two years to verify the diagnosis. We analyzed three different methods to measure incidence, using combinations of dementia diagnosis, dementia symptoms, and use of drug therapy defined as one claim of at least fourteen days' supply of acetylcholinesterase inhibitors or NMDA receptor antagonists.

1. One dementia diagnosis code AND second verification dementia diagnosis within two years OR death within one year after diagnosis (diagnoses only)
2. One dementia diagnosis code AND second verification diagnosis code OR drug claim in any order within two years OR death within one year after the first claim (diagnosis and drug)
3. One dementia diagnosis code AND second verification diagnosis code OR one dementia symptom code OR drug code in any order within two years OR death within one year after the first claim (diagnosis, drug and symptom)

For all three methods, the date of the first of the two codes was considered the index dementia date. In methods 2 and 3, we allowed drug claims or dementia symptoms codes to precede or follow diagnosis. Few beneficiaries had a diagnosis first, followed by symptoms (1 percent). We consider death within one year of a diagnosis as verified incident dementia in all three methods (e.g. 10.8% of cases for method 1), and assume death after one year allows sufficient time for a 'verifying' second diagnosis, symptom or drug code. To calculate the incidence rate, we divided the number of cases of verified dementia diagnoses in a given year, as defined in each of the three methods, by the at-risk population in the same year. We quantified dementia incidence in each year from 2007 to 2014 and separately for different racial/ethnic populations and compared differences across the three methods.

RESULTS

Figure 1 shows annual dementia incidence for years 2007 to 2014 for each of the three methods of defining dementia for our entire sample of Medicare beneficiaries. In 2007, dementia incidence was 3.53% (CI 3.52% to 3.55%) for diagnosis codes only, 3.71% (CI 3.70% to 3.72%) for diagnosis and drug codes, and 3.93% (CI 3.91% to 3.94%) for diagnosis, drug and symptom codes. Between 2007 and 2014, dementia incidence declined by: 11.0% (diagnoses only), 13.7% (diagnosis and drug), and 8.5% (diagnosis, drug, symptom). In all years, the method based on two diagnoses only identified the lowest number of cases. In 2014, it identified 35,084 fewer cases than the methods utilizing drugs and symptoms to verify dementia (299,145 compared to 334,229 incident cases).

Figure 2 shows the incidence rates over time for each of the five racial/ethnic groups. Incidence was higher among blacks and Hispanics compared to Asians and whites across all

methods. Based on diagnoses only, incidence in 2014 was 3.06% for whites, 4.31% for blacks, 3.39% for Hispanics, 2.79% for Asians and 3.53% for American Indians/Alaska natives. Incidence declined between 2007 and 2014 for whites (−11.56%), blacks (−10.89%), and Hispanics (−2.97%) and increased for Asians (4.65%) and American Indians/Alaska Natives (6.46%). Verifying dementia diagnoses with drug use and dementia symptoms led to higher incidence levels across all racial/ethnic groups. In 2014, incidence was 3.51% for whites, 4.73% for blacks, 3.75% for Hispanics, 3.19% for Asians and 4.04% for American Indians/Alaska natives using diagnosis, drugs and symptoms method. The impact of method on levels varied across racial/ethnic groups. In 2014, the percent change between dementia incidence levels using diagnosis and drug use relative to diagnoses only was greater for Hispanics (2.12%) and Asians (5.23%) than blacks (0.53%), whites (1.69%) or American Indians/Alaska Natives (1.28%). Dementia identification that included dementia symptoms, compared to identification using diagnosis and drug use identified more dementia cases among whites (12.94%) and American Indians/Alaska Natives (12.99%) than blacks, Hispanics and Asians (9.25%, 8.40%, and 8.45%, respectively).

We tested the sensitivity of incidence estimates based on diagnosis codes only to the Part D sample restriction. In 2007, rates were 0.47 percentage points higher, and in 2014 0.18 percentage points higher, for the sample with Part D compared to the FFS population that includes beneficiaries without Part D (Supplementary Figure 1 and Figure 2). Higher rates reflect the higher propensity to enroll in Part D among less healthy Medicare beneficiaries [15] and the declining difference over time is due to increasing participation in Part D by all Medicare beneficiaries. [16] We also test the sensitivity of trends in incidence to changes in the age structure of the population over time (Supplementary Table 2). In 2014, age-adjusted incidence based on diagnosis only was 0.11 percentage points higher.

DISCUSSION

This study elucidated the different types of claims records and codes from billable health care services and drug therapies, how they may be used for identifying persons with dementia, and the implications for measuring the size of racially/ethnically diverse populations with dementia over time. The methods we used reduced measurement error in incidence from ‘rule-out’ diagnosis by requiring a second indicator of dementia appear on a claim after the first code indicating dementia within two years. The two-year window was based on empirical observation that 92% of subsequent diagnoses occurred within two years. Allowing for longer time periods did not change results and would have reduced the number of years available for reporting of incidence rates. Allowing death within one year to serve as a verification resulted in incidence rates that were between 0.35 and 0.54 higher, depending on the year, than without this verification.

Number of incident cases may be underestimated in studies using diagnosis codes only to identify dementia. Including dementia symptoms codes and codes for drugs used to treat symptoms of dementia, along with a diagnosis codes, identified 35,084 more cases in 2014 than diagnosis codes alone. The difference between the number of persons with dementia based on diagnosis codes only and based on diagnosis and drug codes reduced over time which may infer decreased drug use without a coded diagnosis between 2007 and 2014. In

contrast, the difference between dementia based on diagnosis codes only and based on diagnosis, drugs and symptoms increased over time inferring increased use of diagnosis codes for symptoms along with diagnosis codes for dementia over time.

The methods we utilized, and drawing from a sample of Medicare beneficiaries with Part D, result in 2014 prevalence estimates of 15.9 % to 18.0% across methods (Supplementary Table 2) that are higher than those reported in a recent study (14.4%) of Medicare FFS beneficiaries and ascertainment based on a single diagnosis. [4] The study sample that does not include Medicare Advantage beneficiaries (30% of beneficiaries in 2014) [17] and is restricted to Part D enrollees are limitations for drawing conclusions about all Medicare beneficiaries.

Regardless of method used, diagnosed dementia incidence declined between 2007 and 2014, but not for all racial/ethnic groups. The increased incidence over time among Asians and American Indians/Alaska Natives, but not whites, blacks and Hispanics, may indicate increasing detection among people in these groups. Hispanics and Asian people with dementia are more likely to be excluded from studies of dementia than other race/ethnicities if identification relies only on diagnosis codes and does not include use of drugs for dementia symptoms along with diagnosis codes to identify and verify persons with dementia. The methodological insights from this study will inform future studies using Medicare claims for the study of dementia in diverse populations.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Fig. 1.
Dementia incidence over time among Medicare beneficiaries ages 67 and older, by three different methods

Fig. 2.
Dementia incidence over time among Medicare beneficiaries ages 67 and older, by three different methods, by race/ethnicity