

HHS Public Access

Author manuscript *J Alzheimers Dis*. Author manuscript; available in PMC 2020 April 17.

Published in final edited form as:

JAlzheimers Dis. 2019; 67(2): 769–778. doi:10.3233/JAD-181005.

Evaluation of Medicare claims data as a tool to identify dementia

Eunjung Lee^a, Margaret Gatz^b, Chiuchen Tseng^a, Lon S. Schneider^{c,d,e}, Sonia Pawluczyk^e, Anna H. Wu^a, Dennis Deapen^a

^aDepartment of Preventive Medicine, Keck School of Medicine, University of Southern California, Los Angeles, CA

^bUSC Dornsife Center for Economic and Social Research, University of Southern California, Los Angeles, CA

°USC Davis School of Gerontology, Los Angeles, CA

^dDepartment of Neurology, Keck School of Medicine of USC, Los Angeles, CA

^eDepartment of Psychiatry and the Behavioral Sciences, Keck School of Medicine of USC, Los Angeles, CA

Abstract

Background: Medicare claims record linkage has been used to identify diagnosed dementia cases in order to estimate dementia prevalence and cost of care. Claims records in the 1990s and early 2000s have been found to provide 85%-~90% sensitivity and specificity. Considering that dementia awareness has improved over time, we sought to examine sensitivity and specificity of more recent Medicare claims records against a standard criterion, clinical diagnosis of dementia.

Methods: For a sample of patients evaluated at the University of Southern California Alzheimer Disease Research Center (ADRC), we performed database linkage with Medicare claims files for a six-year period, 2007-2012. We used clinical diagnosis at the ADRC as the criterion diagnosis in order to calculate sensitivity and specificity.

Results: Medicare claims correctly identified 85% of dementia patients and 77% of individuals with normal cognition. About half of patients clinically diagnosed with mild cognitive impairment had dementia diagnoses in Medicare claims. Misclassified dementia patients (i.e. missed diagnosis by Medicare claims) had more favorable Mini-Mental State Examination and Clinical Dementia Rating scores and were less likely to present behavioral symptoms than correctly-classified dementia patients.

Conclusions: Database linkage to Medicare claims records is an efficient and reasonably accurate tool to identify dementia cases in a population-based cohort. However, possibilities of obtaining biased results due to misclassification of dementia status need to be carefully considered to use Medicare claims diagnosis for etiologic research studies. Additional confirmation of dementia diagnosis may also be considered. A larger study is warranted to confirm our findings.

Corresponding author: Eunjung Lee, Department of Preventive Medicine, Keck School of Medicine, University of Southern California/Norris Comprehensive Cancer Center, Room 4449A, 1441 Eastlake Avenue, Los Angeles, CA 90089. Phone: 323 865 0827, Fax: 323-865-0827, leee@usc.edu.

Conflict of Interest/Disclosure Statement: The authors have no conflict of interest to report.

Keywords

Medicare; data linkage; dementia; sensitivity and specificity

Introduction

About 5.5 million Americans in 2017 were estimated to have Alzheimer's disease, which comprises 60-80% of all dementia, and this number is likely to increase nearly three fold by 2050 (1). Given the lack of effective treatment, identifying preventive factors is crucial. However, accurate assessment of dementia diagnosis in large-scale population-based cohort studies is difficult and has been a major barrier to advancing prevention research (2).

Most epidemiological studies of dementia use a two-step strategy to identify dementia patients (3-8): screening of the study population followed by clinical assessments of those with cognitive problems at screening stage. Utilizing various databases and record systems to ascertain dementia outcome has been explored as a low cost alternative method (9). The sensitivity, or the proportion of dementia patients correctly ascertained by those database(s) or record system(s), was lower when using hospital admissions records and/or death records alone (20%-65%) compared to results when also including outpatient records (see review(9) of studies conducted in countries including Canada, Spain, Sweden, United Kingdom, Finland, and the United States). For example, in a study utilizing two population-based disease registries in Sweden, namely the Inpatient Discharge Registry and the Cause of Death Registry, the sensitivity was 63% for prevalent cases, indicating that addition of outpatient and other records is essential to improve sensitivity (3, 10). Additional use of the Drug Reimbursement Register improved the sensitivity of the Hospital Discharge Register in Finland from <20% to 65% (11). In the United States, a sensitivity close to 70% was reported in two studies using medical records systems of the Rochester Epidemiology Project (Olmsted County, Minnesota) and the Group Health, a managed care health plan (Group Health, Seattle, Washington); these databases include outpatient records and other records such as prescription data (12). However, these medical record systems and medication databases are rarely available for a population-based study. Several studies used Medicare claims for the purpose of estimating prevalence and cost of care (13) (14–18) and reported a wide range of sensitivity and specificity (18–20). In one study utilizing Medicare claims records in the early 1990's, sensitivity for Alzheimer's disease using ICD-9 code 331.0 only (Alzheimer's disease) was 20% (18). Two other studies based on Medicare claims records in the early 1990's (19) and in the 1990's through early 2000's (20) used a broader list of dementia diagnosis codes and reported 85%-87% sensitivity (19, 20) and 89% specificity (20). Ascertainment of dementia through medical claims has improved over time, consistent with increased recognition of dementia in primary care practice (12, 13). Thus, we decided to examine the validity of dementia ascertainment using multi-year Medicare claims records in 2007-2012 for a convenience sample of University of Southern California (USC) Alzheimer Disease Research Center (ADRC) participants whose dementia status was comprehensively evaluated. We also compare the cognitive and other personal characteristics of individuals correctly-classified versus incorrectly-classified.

Materials and Methods

Subjects

The study subjects were 250 participants of the USC ADRC, ages 65 or older as of 2007, who were included in the National Alzheimer's Coordinating Center (NACC) Uniform Data Set between September 1, 2005 and December 31, 2010, and for whom the information necessary for Medicare data linkage was available to the study team at study initiation. The USC ADRC patients were enrolled by clinician referral, self-referral, and recruitment by USC ADRC, and encouraged to be re-evaluated annually by ADRC staff. During their USC ADRC visits, patients or informants provided information on demographics, family history of dementia, anthropometric measurements, and medical history, and were evaluated for cognition, function, and behavior using Clinical Dementia Rating (CDR), Functional Assessment Questionnaire, Neuropsychiatric Inventory, Geriatric Depression Scale, and UDS neuropsychologic test battery, which includes Mini-Mental State Examination (MMSE), Logical Memory A Immediate and Delayed, Trail Making Test Part A and Part B, Category Fluency Animals, Category Fluency Vegetables, Digit Span Forward, Digit Span Backwards, WAIS Digit Symbol, and Boston Naming (21). Clinical diagnosis of cognitive status and dementia was made at the USC ADRC and recorded following the National Alzheimer's Coordinating Center Uniform Data Set Coding Guidebook (22). Geriatric Depression Scale was assessed at each visit; scores of 5 or higher are considered to suggest mild or more severe depression (23, 24). Clinician evaluation of behavioral symptoms such as apathy/withdrawal, depression, visual hallucination, auditory hallucination, delusional beliefs, disinhibition, irritation, agitation, personality change, and REM sleep disorder, as well as age of onset of cognitive symptoms was recorded during each visit.

The 250 study subjects were linked to the 2007-2012 Master Beneficiary Summary File of the Medicare data; 227 individuals were linked successfully. Considering that Medicare claims data are available only from individuals who received care under fee-for-service plan and that we are interested in both inpatient (Part A) and outpatient (Part B) records, we limited the analyses to 147 (65%) individuals who were enrolled in both Part A and Part B fee-for-service plan for at least 1 month during this time period. This figure is similar to the proportion of Part A and Part B fee-for-service enrollees (63%) reported in a large population-based cohort in California and Hawaii (25). Because the chance of having Medicare claims is lower for short-term enrollees, we repeated the analyses restricting the study to individuals enrolled in both Part A and Part B fee-for-service plan for a longer time period, by increasing the requirement of minimum duration of fee-for-service enrollment to at least 1 year, at least 2 years, at least 3 years, at least 4 years, or at least 5 years.

This study was approved by the USC institutional review board (IRB). All participants provided written informed consent when participating in the ADRC. A waiver of separate informed consent for Medicare data linkage was granted by the IRB consistent with the waiver criteria of the Common Rule.

Definition of dementia in ADRC database and in Medicare claims

When using the ADRC diagnosis, we first classified subjects into dementia and nondementia patients at each ADRC visit. We then subdivided non-dementia patients into two groups: those with normal cognition and those with mild cognitive impairment (MCI). This was done because we were interested in evaluating whether non-dementia patients with MCI were more likely than those with normal cognition to be misclassified as having dementia according to Medicare claims. The dementia group included individuals with various types of dementia; however, the primary etiology of dementia for the majority of dementia patients (85%) was probable or possible Alzheimer's disease. Other types of dementia among the study subjects included: vascular dementia, dementia with Lewy bodies and frontotemporal dementia.

Medicare-defined dementia diagnoses were identified from the Chronic Conditions segment of the Master Beneficiary Summary File, which includes the date of first occurrence of dementia since 1999 for each individual. Dementia in the Centers for Medicare and Medicaid Services (CMS) dataset was defined as "Alzheimer's disease and related disorders or senile dementia" by the presence of any of the 24 ICD-9-CM codes (Supplementary Table 1) in any of the inpatient, skilled nursing facility, home health agency, hospital outpatient, and carrier claim files, as one of the primary or secondary diagnosis codes (26) . These ICD-9-CM codes were originally developed based on the work by Taylor et al. (19) and are essentially identical to the list used in previous investigations except that a few diagnostic sub-codes and recently added codes were also included in the CMS algorithm (19, 20) (see Supplementary Table 1 for comparison). Our Medicare linkage did not include Medicare Part D prescription records.

We considered diagnosis of dementia a permanent event and generated an outcome variable 'ever diagnosed with dementia' based on clinical diagnosis at time of last ADRC visit up to December 31, 2012. The majority (84%) of patients with dementia were diagnosed at their initial ADRC visit. None of the patients with dementia later reverted to normal or MCI during the follow up to December 31, 2012. We also generated an outcome variable 'ever diagnosed with dementia' based on Medicare claims at the end of the follow up by using the CMS variable 'the first calendar year quarter in which the beneficiary met the dementia algorithm criteria'. The end of follow up was defined as the last date a participant was enrolled in a Medicare fee-for-service plan up to December 31, 2012. This means that if a patient was first diagnosed with dementia at ADRC after the patient discontinued fee-for-service enrollment, we considered this patient had normal cognition during the time period enrolled in fee-for-service.

Statistical analyses

We compared the Medicare-defined dementia with the clinical diagnosis of dementia assessed at the ADRC and calculated sensitivity and specificity for dementia identified by Medicare claims. Sensitivity indicates the proportion of ADRC dementia patients who were identified to have dementia in Medicare claims. Specificity indicates the proportion of ADRC patients without dementia who were not identified to have dementia in Medicare claims. We assumed that the proportion of individuals with MCI will be higher among

clinical samples such as the current study population than in the general population because people with memory problems tend to get referred or refer themselves to memory clinics and the ADRC made special efforts to recruit individuals with MCI. Thus, when calculating specificity, we separately examined individuals who had normal cognition and those who had MCI. We then estimated overall specificity in a hypothetical population if the proportion of individuals with MCI in that population was 5%, 10%, 15%, or 20%.

To better understand the characteristics and potential reasons of misclassification of dementia based on Medicare claims, we compared characteristics of individuals whose dementia diagnoses were correctly identified and those who were misclassified (true positives vs. false negatives; false positives vs. true negatives) with respect to demographics, duration of fee-for-service enrollment, and cognitive test scores. We used z-scores adjusted for age, sex, and education for all cognitive test scores except MMSE scores (27). We also compared the total number of behavioral symptoms for dementia patients (comparing true positives and false negatives); cognitively normal individuals rarely had these behavioral symptoms noted by the clinicians. Unless specified otherwise, we compared these characteristics at time of the last follow up (i.e. their last visit to the ADRC while enrolled in a fee-for-service plan). If any information was missing, such as a missing MMSE measurement at a given ADRC visit, we chose an MMSE score at the closest previous ADRC visit. All P-values reported are two sided and based on Pearson's Chi-square test, Fisher's exact test, Mantel-Haenszel Chi-square test, or analysis of variance. All analyses were conducted using SAS 9.4 (SAS Institute, Inc., Cary, NC).

Results

Of the 250 ADRC participants, the 147 individuals included in the analysis were slightly younger (mean age 78) than the 103 individuals excluded from the analysis (mean age 81). Otherwise, these two groups were similar with regards to demographic and cognitive characteristics (Table 1). Among the 147 study participants, 54% were diagnosed with dementia, another 15% were assessed to have MCI, and the rest (31%) were assessed to have normal cognition. The mean number of ADRC visits was 2.9 overall (3.4, 3.0, and 2.7 for normal, MCI, and dementia, respectively). Mean duration of fee-for-service enrollment was 4.9 years, with 55% of the 147 participants enrolled during the entire 6 year period between 2007 and 2012.

Sensitivity and specificity of Medicare claims in identifying dementia diagnosis:

Using the UDS clinical diagnosis of dementia as the gold-standard, Medicare claims to identify dementia from non-dementia including both normal cognition and MCI showed 85% sensitivity (68/80) and 67% specificity (45/67) (Table 2). The specificity was higher (76%; 34/45) when excluding MCI cases from the non-dementia, and simply comparing individuals with dementia to individuals with normal cognition. For distinguishing dementia from MCI, the specificity was only 50% (11/22). In other words, 50% of MCI patients had a dementia diagnosis in Medicare claims. In an otherwise similar hypothetical population, if the proportion of individuals with MCI was 5%, 10%, 15%, or 20%, the overall specificity among all individuals without dementia in that hypothetical population would be 75%, 73%,

Page 6

72%, and 71%, respectively. When we repeated the analysis limited to individuals enrolled for longer time periods (i.e. increasing the requirement of duration of fee-for-service enrollment to at least 1 year, at least 2 years, at least 3 years, at least 4 years, or at least 5 years), sensitivity measures were similar but slightly higher and specificity measures were similar but slightly lower.

Characteristics of missed dementia patients and incorrectly diagnosed normal individuals:

Age and education levels were similar between true positives and false negatives or between false positives and true negatives (Table 3). Other demographics such as sex, race, and primary language as well as family history of dementia were also similar between true positives and false negatives or between false positives and true negatives (data not shown). Duration of enrollment in Medicare fee-for-service between 2007 and 2012 was shorter for false negatives (3.5 ± 2.7 years) than true positives (4.7 ± 1.6 years) (Table 3).

True positive patients generally appeared to have more advanced disease than false negative patients as indicated by unfavorable scores for CDR global score and MMSE. Although the scores for Trail Making test Part A were similar between true positives and false negatives, ~30% of the true positive patients did not complete this test due to cognitive problems whereas all false negative patients completed the test, indicating that the scores for true positives are likely to be much lower than false negatives. Scores for Trail Making test Part B showed a similar pattern in that a lower proportion of true positives compared to false negatives completed the tests (data for false negatives are not presented according to the CMS policy). Scores for other UDS neuropsychological test battery items and the Geriatric Depression Scale were similar between true positives and false negatives. The true positive group tended to have a higher number of behavioral symptoms, although this difference was not statistically significant (Table 3).

Among cognitively normal individuals, false positives and true negatives were not significantly different in most aspects except that false positives had slightly lower scores for Trail Making test Part B and were more likely to have higher scores for Geriatric Depression Scale. Individuals with normal cognition rarely displayed any of the behavioral symptoms (data not shown).

Discussion

In this study of a convenience sample of USC ADRC participants whose dementia and cognitive status were comprehensively evaluated, Medicare claims records correctly identified 85% of dementia patients and 67% of individuals without dementia. Our findings, although based on small sample sizes, also show that the misclassified dementia patients (i.e. missed diagnosis by Medicare claims; false negatives) had more favorable MMSE and CDR scores and were less likely to present behavioral symptoms than correctly-classified dementia patients (true positives). To our knowledge, this is the first study to comprehensively examine the cognitive and behavioral characteristics associated with incorrect dementia classification when using Medicare claims records.

The sensitivity of 85% observed in this study is much higher than that reported in the Swedish study using inpatient registry data only (47% for prevalent cases) (10). This is consistent with a previous report that use of Medicare claims records from outpatient setting provided substantially higher sensitivity than use of the records from hospital files only (87% vs. 35%) (19), and indicates that use of outpatient data is critical especially in the US to improve sensitivity. When comparing our results with other studies using Medicare claims records, the sensitivity was similar to the sensitivity results of 87% (19) and 85% (20) from two earlier studies, which used 5-year (1991-1995) (19) or 13-year (1993-2005) (20) Medicare claims records. The undercounting or 'missingness' of cases when using Medicare claims records has been attributed to several factors including lack of disease recognition, social resistance, suboptimal coding system and reimbursement (28). While disease recognition and public awareness improved in recent decades, there remains a wide variation in physician practice patterns with regard to dementia diagnosis (29–31). In our study using more recent Medicare claims records, the undercounting of dementia cases stayed at a level similar to the earlier studies using Medicare claims in 1990's and early 2000's (19, 20). This means that the sensitivity of Medicare claims records in identifying dementia has improved little over the past decades. One of these earlier studies was conducted among a subset of the Consortium to Establish a Registry for Alzheimer's Disease, a consortium of the memory disorders clinics at tertiary care medical centers (19), as is in our study; and the other was conducted among a subset of participants of the Aging, Demographics, and Memory Study (ADAMS), a study of a nationally representative sample of elderly population (20). The undercounting may also be attributed to a small number of fee-for-service enrollees who never had any claims. However, nearly all of our study participants had one or more records of being diagnosed with one of the 27 chronic conditions according to the Medicare records, indicating that the issue of individuals with 'no-claims' would have been minimal, and unlikely to impact our sensitivity measures. Our observation of a very similar sensitivity measure when excluding individuals with a short-term fee-for-service enrollment, which happened to exclude those without any chronic conditions records in Medicare data, additionally supports that effects related to no-claims are minimal in our study. Consistent with an earlier report that mild dementia patients are more likely to be missed or not receive a dementia code in Medicare records (14, 28), false negative cases in this study had less severe disease with more favorable CDR scores and MMSE than true positive cases, and a higher proportion of false negative cases than true positive cases were able to complete Trail Making Test Part A and B. In addition, false negative cases appeared to be less likely to have prominent behavioral symptoms than true positive cases, although this comparison was not statistically significant. These results indicate that dementia patients at an earlier stage or with a more favorable cognitive and behavioral status are less likely to be given dementia codes in the Medicare claims records or are actually not recognized as demented or not diagnosed by the clinical practitioner in the community.

The specificity in this study was lower than the measures from the Swedish study (98% when using both inpatient and death registries) and the one study that used Medicare records and included normal individuals (89%) (3, 20); the other study did not include normal individuals (19). The overdiagnosis of dementia in Medicare has not been as well described as the undercounting problem. The improved recognition of dementia over time may have

led to the increase in overdiagnosis of normal or mildly impaired individuals. However, our results need to be interpreted with caution considering the referral pattern of the study subjects. Unlike the earlier study based on ADAMS study participants (20), this study is based on patients who were referred to or had voluntarily consulted a federally-funded ADRC located in a metropolitan city (Los Angeles). Therefore, the cognitively 'normal' individuals in our study sample may not represent other 'normal' individuals in the general population, and some may have had experienced memory or other cognitive problems that led them to be concerned about dementia although these symptoms ultimately did not meet criteria for either dementia or MCI. It has been well recognized that primary care physicians face with many challenges in making accurate dementia diagnosis (29, 32-34). Although there is a separate diagnosis code for MCI (ICD-9-CM 331.83), 50% of the MCI patients in this study had dementia codes in Medicare claims. The low specificity among individuals with MCI also indicate that dementia diagnosis for patients presenting minor to moderate cognitive problems can be difficult in general clinical practice. In addition, patients with depression may also display cognitive impairment, making the differential diagnosis of depression and dementia difficult (35, 36). Our observation of higher Geriatric Depression Scale scores for false positives than true negatives also suggests that the over-diagnosis may be more frequent among individuals with depression. Thus, when using Medicare claims records to identify dementia patients, the over-diagnosis issue also needs to be carefully considered.

The education level of the current study participants without dementia was much higher than the non-dementia participants of the ADAMS study: >83% in this study vs. <40% in the ADAMS studies received education above high school (4, 20). It is plausible that patients and families with higher education may be more sensitive to minor cognitive problems and complain when consulting physicians, although education was not a significant predictor of dementia coding in Medicare claims among dementia patients according to our own data (Table 3) and others (19).

The strengths of this study include that we presented sensitivity and specificity of dementia diagnosis based on Medicare claims when compared with gold-standard diagnosis based on the ADRC clinical research diagnoses. Availability of neuropsychological test results obtained from comprehensive evaluations at the USC ADRC is unique and enabled us to examine the characteristics of missed cases (false negatives) and incorrectly-diagnosed normal individuals (false positives) in relation to not only demographic characteristics but also important cognitive and behavioral functioning. Medicare claims linkage of the entire NACC dataset would be ideal and likely to significantly improve the accuracy and precision of the results. To do so, coordinated efforts from the NACC participating centers to collect personally identifying information for the linkage and to obtain patient consent and/or approval from ethics committee would be necessary.

The limitations include the small sample size and the fact that the study participants were sampled from patients at an ADRC and thus do not represent the general population. A future study with a larger number of participants sampled from the general population may find improved sensitivity and specificity measures. Nevertheless, the sensitivity measures observed in this study, particularly the low specificity among those with MCI, suggest that

Medicare records should be used with caution especially when there is a need to distinguish MCI and dementia diagnosis. Additional limitations include that Medicare Part D prescription records were not available for this study. Because prescriptions are required for FDA-approved drugs for Alzheimer's disease (37), we speculate that the claims from pharmacies will likely have matching claims from physicians with corresponding ICD-9 diagnosis codes. However, an earlier study reported little overlap between Alzheimer's disease diagnosis identified from 1999-2004 Part A/Part B Medicare claims data with ICD-9 290.0 and 331.0 codes and the prescription drug use identified from the survey responses in the 1994-2004 Medicare Current Beneficiary Survey (14). Given that many dementia patients including Alzheimer's disease patients are identified using diagnostic codes other than these two codes (290.0 and 331.0) (19, 20), the overlap may have been larger if an extended list was used. It needs to be determined whether and how much Medicare Part D prescription records would improve the sensitivity. It is also possible that the patients themselves or their family members informed their healthcare providers of their dementia evaluation results at USC ADRC, thus increasing the chance of correctly carrying a diagnosis of dementia in the claims for true dementia patients as well as the chance of correctly not carrying a diagnosis of dementia in the claims for individuals without dementia. Therefore, we cannot rule out that the sensitivity and specificity of Medicare claims in identifying dementia in the general population might be even lower than these observed results. In addition, due to the limited sample size, we were unable to conduct multivariable analyses to examine the characteristics appropriately adjusting for potential confounders. Thus, our results on the characteristics associated with false positives and false negatives are descriptive in nature and need to be interpreted with caution. A larger study is warranted to confirm our findings.

In conclusion, our observations show that database linkage to Medicare claims records is an efficient and reasonably accurate tool to identify potential dementia patients in large population-based cohort studies. However, possibilities of obtaining biased results due to misclassification of dementia status need to be carefully considered to use Medicare claims diagnosis for etiologic research studies. Additional confirmation of dementia diagnosis may also be considered. For example, use of Medicare record linkage will provide reasonably accurate information about dementia diagnosis in a cohort as a cost efficient first-step screening; then a nested case-control study may be designed where additional efforts are made to confirm the disease diagnosis. A population-based dementia registry, such as the population-based cancer registry (e.g. Surveillance, Epidemiology, and End Results (38)) would provide an ideal platform for future research. SveDem, the Swedish Dementia Registry (39) covers ~30% of incident cases, and the dementia registry in Denmark (40) covers ~30% of the population.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgements:

Research reported in this publication was supported by the USC Alzheimer Disease Center grant 15-10291 from the State of California Department of Health Services, the USC Alzheimer Disease Research Center from the National

Institutes of Health, grant P50 AG05142, the Zumberge Fund Individual Grant program and the Office of the Provost at the University of Southern California, and the Southern California Clinical and Translational Science Institute (NIH/NCATS) through Grant UL1TR000130. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the NIH.

References

- 1. Hebert LE, Weuve J, Scherr PA, Evans DA. Alzheimer disease in the United States (2010-2050) estimated using the 2010 census. Neurology. 2013;80(19):1778–83. [PubMed: 23390181]
- Daviglus ML, Bell CC, Berrettini W, Bowen PE, Connolly ES Jr., Cox NJ, et al. National Institutes of Health State-of-the-Science Conference statement: preventing alzheimer disease and cognitive decline. Ann Intern Med. 2010;153(3):176–81. [PubMed: 20547888]
- Jin YP, Gatz M, Johansson B, Pedersen NL. Sensitivity and specificity of dementia coding in two Swedish disease registries. Neurology. 2004;63(4):739–41. [PubMed: 15326258]
- Plassman BL, Langa KM, Fisher GG, Heeringa SG, Weir DR, Ofstedal MB, et al. Prevalence of dementia in the United States: the aging, demographics, and memory study. Neuroepidemiology. 2007;29(1-2):125–32. [PubMed: 17975326]
- Seshadri S, Beiser A, Au R, Wolf PA, Evans DA, Wilson RS, et al. Operationalizing diagnostic criteria for Alzheimer's disease and other age-related cognitive impairment-Part 2. Alzheimers Dement. 2011;7(1):35–52. [PubMed: 21255742]
- Ganguli M, Dodge HH, Chen P, Belle S, DeKosky ST. Ten-year incidence of dementia in a rural elderly US community population: the MoVIES Project. Neurology. 2000;54(5):1109–16. [PubMed: 10720283]
- Geerlings MI, Schmand B, Jonker C, Lindeboom J, Bouter LM. Education and incident Alzheimer's disease: a biased association due to selective attrition and use of a two-step diagnostic procedure? Int J Epidemiol. 1999;28(3):492–7. [PubMed: 10405854]
- Hendrie HC, Ogunniyi A, Hall KS, Baiyewu O, Unverzagt FW, Gureje O, et al. Incidence of dementia and Alzheimer disease in 2 communities: Yoruba residing in Ibadan, Nigeria, and African Americans residing in Indianapolis, Indiana. JAMA. 2001;285(6):739–47. [PubMed: 11176911]
- Wilkinson T, Ly A, Schnier C, Rannikmae K, Bush K, Brayne C, et al. Identifying dementia cases with routinely collected health data: A systematic review. Alzheimers Dement. 2018 14, 1038–1051 [PubMed: 29621480]
- Rizzuto D, Feldman AL, Karlsson IK, Dahl Aslan AK, Gatz M, Pedersen NL. Detection of Dementia Cases in Two Swedish Health Registers: A Validation Study. J Alzheimers Dis. 2018;61(4):1301–10. [PubMed: 29376854]
- Solomon A, Ngandu T, Soininen H, Hallikainen MM, Kivipelto M, Laatikainen T. Validity of dementia and Alzheimer's disease diagnoses in Finnish national registers. Alzheimers Dement. 2014;10(3):303–9. [PubMed: 23849592]
- Knopman DS, Petersen RC, Rocca WA, Larson EB, Ganguli M. Passive case-finding for Alzheimer's disease and dementia in two U.S. communities. Alzheimers Dement. 2011;7(1):53– 60. [PubMed: 21255743]
- Taylor DH Jr., Sloan FA, Doraiswamy PM. Marked increase in Alzheimer's disease identified in medicare claims records between 1991 and 1999. The journals of gerontology Series A, Biological sciences and medical sciences. 2004;59(7):762–6.
- Lin PJ, Kaufer DI, Maciejewski ML, Ganguly R, Paul JE, Biddle AK. An examination of Alzheimer's disease case definitions using Medicare claims and survey data. Alzheimers Dement. 2010;6(4):334–41. [PubMed: 20434960]
- Weiner M, Powe NR, Weller WE, Shaffer TJ, Anderson GF. Alzheimer's disease under managed care: implications from Medicare utilization and expenditure patterns. J Am Geriatr Soc. 1998;46(6):762–70. [PubMed: 9625195]
- Taylor DH Jr., Sloan FA. How much do persons with Alzheimer's disease cost Medicare? J Am Geriatr Soc. 2000;48(6):639–46. [PubMed: 10855599]
- Pressley JC, Trott C, Tang M, Durkin M, Stern Y. Dementia in community-dwelling elderly patients: A comparison of survey data, medicare claims, cognitive screening, reported symptoms, and activity limitations. J Clin Epidemiol. 2003;56(9):896–905. [PubMed: 14505776]

- Newcomer R, Clay T, Luxenberg JS, Miller RH. Misclassification and selection bias when identifying Alzheimer's disease solely from Medicare claims records. J Am Geriatr Soc. 1999;47(2):215–9. [PubMed: 9988293]
- Taylor DH Jr., Fillenbaum GG, Ezell ME. The accuracy of medicare claims data in identifying Alzheimer's disease. J Clin Epidemiol. 2002;55(9):929–37. [PubMed: 12393082]
- Taylor DH Jr., Ostbye T, Langa KM, Weir D, Plassman BL. The accuracy of Medicare claims as an epidemiological tool: the case of dementia revisited. J Alzheimers Dis. 2009;17(4):807–15. [PubMed: 19542620]
- Weintraub S, Salmon D, Mercaldo N, Ferris S, Graff-Radford NR, Chui H, et al. The Alzheimer's Disease Centers' Uniform Data Set (UDS): the neuropsychologic test battery. Alzheimer Dis Assoc Disord. 2009;23(2):91–101. [PubMed: 19474567]
- 22. ADC Clinical Task Force and the National Alzheimer's Coordinating Center. NACC Uniform Data Set Coding Guidebook 2006 [updated January 14, 2014 Available from: https:// www.alz.washington.edu/NONMEMBER/UDS/DOCS/VER2/ivpguide.pdf.
- Yesavage JA, Sheikh JI. 9/Geriatric Depression Scale (GDS). Clinical Gerontologist. 1986;5(1-2):165–73.
- 24. Yesavage JA. Geriatric Depression Scale [Available from: http://web.stanford.edu/~yesavage/ GDS.html.
- Setiawan VW, Virnig BA, Porcel J, Henderson BE, Le Marchand L, Wilkens LR, et al. Linking data from the Multiethnic Cohort Study to Medicare data: linkage results and application to chronic disease research. Am J Epidemiol. 2015;181(11):917–9. [PubMed: 25841869]
- 26. CCW Chronic Conditions Algorithms, Chronic Conditions Data Warehouse [updated September 2015 Available from: https://www.ccwdata.org/web/guest/condition-categories.
- 27. Shirk SD, Mitchell MB, Shaughnessy LW, Sherman JC, Locascio JJ, Weintraub S, et al. A webbased normative calculator for the uniform data set (UDS) neuropsychological test battery. Alzheimers Res Ther. 2011;3(6):32. [PubMed: 22078663]
- Fillit H, Geldmacher DS, Welter RT, Maslow K, Fraser M. Optimizing coding and reimbursement to improve management of Alzheimer's disease and related dementias. J Am Geriatr Soc. 2002;50(11):1871–8. [PubMed: 12410910]
- Sivananthan SN, Puyat JH, McGrail KM. Variations in self-reported practice of physicians providing clinical care to individuals with dementia: a systematic review. J Am Geriatr Soc. 2013;61(8):1277–85. [PubMed: 23889524]
- Aminzadeh F, Molnar FJ, Dalziel WB, Ayotte D. A review of barriers and enablers to diagnosis and management of persons with dementia in primary care. Can Geriatr J. 2012;15(3):85–94. [PubMed: 23259021]
- Baloch S, Moss SB, Nair R, Tingle L. Practice patterns in the evaluation and management of dementia by primary care residents, primary care physicians, and geriatricians. Proc (Bayl Univ Med Cent). 2010;23(2):121–5. [PubMed: 20396419]
- Galvin JE, Meuser TM, Morris JC. Improving physician awareness of Alzheimer disease and enhancing recruitment: the Clinician Partners Program. Alzheimer Dis Assoc Disord. 2012;26(1):61–7. [PubMed: 21399484]
- Dwolatzky T, Clarfield AM. Assessment of dementia in the primary care setting. Expert review of neurotherapeutics. 2004;4(2):317–25. [PubMed: 15853573]
- Valcour VG, Masaki KH, Curb JD, Blanchette PL. The detection of dementia in the primary care setting. Archives of internal medicine. 2000;160(19):2964–8. [PubMed: 11041904]
- 35. Swainson R, Hodges JR, Galton CJ, Semple J, Michael A, Dunn BD, et al. Early detection and differential diagnosis of Alzheimer's disease and depression with neuropsychological tasks. Dement Geriatr Cogn Disord. 2001;12(4):265–80. [PubMed: 11351138]
- Zakzanis KK, Leach L, Kaplan E. On the nature and pattern of neurocognitive function in major depressive disorder. Neuropsychiatry Neuropsychol Behav Neurol. 1998;11(3):111–9. [PubMed: 9742509]
- Alzheimer's Association. FDA-approved treatments for Alzheimer's [updated March 2017 Available from: https://www.alz.org/media/Documents/fda-approved-treatments-alzheimers-ts.pdf.

- 38. Howlader N, Noone AM, Krapcho M, Garshell J, Miller D, Altekruse SF, et al. SEER Cancer Statistics Review, 1975-2013, National Cancer Institute Bethesda, MD, http://seer.cancer.gov/csr/ 1975_2013/, based on November 2015 SEER data submission, posted to the SEER web site, April 2016. 2016 [
- 39. Religa D, Fereshtehnejad SM, Cermakova P, Edlund AK, Garcia-Ptacek S, Granqvist N, et al. SveDem, the Swedish Dementia Registry - a tool for improving the quality of diagnostics, treatment and care of dementia patients in clinical practice. PLoS One. 2015;10(2):e0116538. [PubMed: 25695768]
- 40. Johannsen P, Jorgensen K, Korner A, Elmo EG, Lauesen LB, Utzon J. Development of a dementia assessment quality database. Aging Ment Health. 2011;15(1):40–6. [PubMed: 21271390]

Table 1.

Characteristics of USC ADRC participants by Medicare fee-for-service plan enrollment (i.e. eligible for analysis).

| Characteristics, N (%) | Included in analysis (n=147) | Excluded from analysis (n=103) |
|--|------------------------------|--------------------------------|
| Age at initial visit (mean ± SD; range) | $78 \pm 6.9; 71-85$ | $81 \pm 7.4; 74-89$ |
| Sex | | |
| Male | 58 (39%) | 36 (35%) |
| Female | 89 (61%) | 67 (65%) |
| Race/ethnicity | | |
| Non-Hispanic whites | 98 (67%) | 69 (67%) |
| Hispanics | 23 (16%) | 20 (19%) |
| Other (African Americans/Asians/Other) | 26 (18%) | 14 (14%) |
| Primary language | | |
| English | 119 (81%) | 88 (85%) |
| Other (Spanish/Russian/Japanese/Other) | 28 (19%) | 15 (15%) |
| Education (yr) | | |
| 12 | 47 (32%) | 36 (35%) |
| 13-14 | 26 (18%) | 23 (22%) |
| 15-16 | 34 (23%) | 21 (20%) |
| 17+ | 40 (27%) | 23 (22%) |
| Dementia/cognition status | | |
| Normal | 45 (31%) | 33 (32%) |
| Mild cognitive impairment | 22 (15%) | 22 (21%) |
| Dementia | 80 (54%) | 48 (47%) |
| Diagnosed at initial ADRC visit (prevalent dementia) | 67 (84%) | - |
| Diagnosed after initial ADRC visit (incident dementia) | 13 (16%) | - |
| Family history of dementia (in parents or siblings) | | |
| None | 72 (49%) | 57 (55%) |
| One | 54 (37%) | 30 (29%) |
| Two or more | 21 (14%) | 16 (16%) |
| Reasons for exclusion | | |
| Medicare not enrolled | - | 23 (22%) |
| Medicare enrolled, but not on fee-for-service plan | - | 80 (78%) |

_

_

Table 2.

Comparison of number of individuals diagnosed with dementia between USC ADRC clinical diagnosis (gold standard) and Medicare diagnosis.

| | Dementia (| vs. no-d | ementia) |
|--|------------|----------|----------|
| Medicare dementia diagnosis | Dementia | No d | ementia |
| | | MCI | Normal |
| Total (n=147) | 80 | 22 | 45 |
| Yes (n=90) | 68 | 11 | 11 |
| No (n=57) | 12 | 11 | 34 |
| Sensitivity: | 68/80=85% | | |
| Specificity: | | 45/6 | 67=67% |
| Specificity among individuals with normal cognition (without dementia or MCI): | | 34/4 | 5=76% |
| Specificity among individuals with MCI (no dementia): | | 11/2 | 22=50% |

Abbreviations: MCI, mild cognitive impairment

Table 3.

Demographic characteristics and cognitive and behavioral functioning of individuals with dementia and individuals with normal cognition, excluding those with mild cognitive impairment, correctly and incorrectly classified by Medicare claims records.

| | Dementia | Dementia by ADRC assessment | ent | No-dementi | No-dementia by ADRC assessment | nent |
|--|----------------------|-----------------------------|---------|------------------------|--------------------------------|---------|
| N (%) or mean \pmSD | True Positives | False Negatives | P-value | False Positives | True Negatives | P-value |
| Total | 68 | 12 | | 22 | 45 | |
| Age (mean \pm SD) | | | | | | |
| At initial visit | 78.2 ± 6.1 | 78.0 ± 8.0 | 0.91 | 78.6 ± 7.2 | 78.2 ± 7.9 | 0.84 |
| At last visit | 80.4 ± 6.5 | 79.8 ± 8.7 | 0.81 | 81.9 ± 6.8 | 82.2 ± 7.8 | 0.89 |
| Education, N of years of schooling (mean \pm SD; range) | 13.1 ± 3.7 | 11.3 ± 4.5 | 0.14 | 16.1 ± 2.6 | 16.3 ± 3.3 | 0.83 |
| N of total fee-for-service years during 2007-2012 $(mean \pm SD)$ | 4.7 ± 1.6 | 3.5 ± 2.6 | 0.030 | 5.1 ± 1.5 | 4.9 ± 1.8 | 0.67 |
| Clinical Dementia Rating global score $\hat{\boldsymbol{\$}}(mean\pm SD)$ | 1.9 ± 0.9 | 1.1 ± 0.8 | 0.003 | 1 | | |
| $\mathbf{MMSE}^{\mathscr{S}}(Mean\pmSD)$ | 15.7 ± 6.9 | 21.7 ± 4.2 | 0.001 | 27.7 ± 2.3 | 28.4 ± 1.7 | >0.99 |
| Selected ADRC neuropsychological test battery \dot{f},\dot{S} (z-score, mean \pm SD) | | | | | | |
| Logical Memory Immediate Recall | -2.2 ± 0.9 | -1.7 ± 1.3 | 0.58 | -0.5 ± 1.4 | -0.2 ± 1.0 | >0.99 |
| Logical Memory Delayed Recall | -2.1 ± 0.7 | -1.6 ± 1.1 | 0.78 | -0.4 ± 1.2 | -0.1 ± 1.0 | 0.99 |
| Digit Span Forward, length | -1.0 ± 1.2 | -0.9 ± 1.0 | >0.99 | -0.6 ± 1.0 | -0.3 ± 0.9 | >0.99 |
| Digit Span Backward, total number of trials correct | -1.4 ± 1.3 | -0.7 ± 1.0 | 0.37 | -0.1 ± 0.9 | -0.2 ± 0.9 | >0.99 |
| Trail Making Test Part A (sec) | -3.8 ± 3.2 MJ | -3.4 ± 3.3 | >0.99 | -0.8 ± 1.3 | -0.3 ± 1.4 | >0.99 |
| Trail Making Test Part B (sec) | $-3.6\pm1.5\text{M}$ | - 88 | >0.99 | -1.7 ± 1.8 | -0.3 ± 1.1 | 0.001 |
| Category Fluency Animals | -2.0 ± 1.1 | -1.6 ± 0.7 | >0.99 | -0.5 ± 1.2 | -0.3 ± 0.9 | >0.99 |
| Category Fluency Vegetables | -1.2 ± 1.1 | -0.5 ± 1.1 | 0.37 | 0.3 ± 1.6 | 0.7 ± 1.2 | 0.95 |
| WAIS-R Digit Symbol score | -1.8 ± 1.6 | -1.7 ± 0.9 | >0.99 | -0.4 ± 0.8 | 0.1 ± 1.1 | 0.56 |
| Boston Naming Test score | -3.9 ± 2.9 | -3.2 ± 2.8 | >0.99 | -0.3 ± 0.8 | -0.3 ± 1.4 | >0.99 |
| Geriatric Depression Scale ${}^{\hat{\mathcal{S}}}$ | | | | | | |
| Mean (SD) | 2.5 ± 2.7 | 3.8 ± 3.7 | 0.15 | 3.0 ± 2.6 | 1.6 ± 2.4 | 0.038 |
| Behavioral symptoms in any ADRC visit $^{\$}$ | | | | | | |
| Number of behavioral symptoms displayed (Mean \pm SD) | 4.5 ± 2.6 | 3.0 ± 2.1 | 0.067 | 0.77 ± 1.34 | 0.36 ± 1.02 | 0.16 |

Author Manuscript

| | Dementia | Dementia by ADRC assessment | ent | No-dementi | Vo-dementia by ADRC assessmen | ment |
|------------------------|----------------|-----------------------------|---------|-----------------|--------------------------------|---------|
| N (%) or mean \pm SD | True Positives | False Negatives | P-value | False Positives | False Positives True Negatives | P-value |
| | | | | | | |

* Prevalent means dementia present at initial ADRC assessment; incident means dementia developed after initial assessment.

 f_{Y} rear starting to show cognitive changes based on clinician's assessment

 ${\mathscr S}_{
m At\ last\ visit}$

 $\stackrel{f}{\tau} Adjusted for age, sex, and education.$

Trail Making test Part A score was available for 47 true positive participants (i.e. n=21 true positive patients had missing values); Trail Making test Part B score was available for 31 true positive participants (i.e. n=37 true positive patients had missing values).

 $\delta \delta$ Data not presented according to CMS policy (<11 individuals completing the test).