

Misidentification of Dementia in Medicare Claims and Related Costs

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OBJECTIVES: To examine how misidentification of dementia affects estimation of Medicare costs in a largely minority cohort of participants for whom accurate in-person diagnoses are available.

DESIGN: Prospective cohort study.

SETTING: Washington Heights-Inwood Columbia Aging Project, a multiethnic, population-based, prospective study of cognitive aging of Medicare beneficiaries aged 65 and older.

PARTICIPANTS: Individuals clinically diagnosed with dementia (n=495) and individuals clinically diagnosed without dementia (n=1,701).

MEASUREMENTS: Medicare claims-identified dementia was defined according to the presence of any *International Classification of Diseases, Ninth Revision, Clinical Modification* diagnosis codes for Alzheimer's disease and related dementias in all available claims during the study period. Participant characteristics associated with claims misidentification of dementia were estimated using logistic regression. Effects of dementia misidentification on Medicare expenditures were estimated using generalized linear models.

RESULTS: Medicare claims correctly identified 250 of the 495 (51%) dementia cases and 1,565 of the 1,701 (92%) nondementia cases. Sensitivity of claims-identified dementia was 0.51, and specificity was 0.92. Average annual Medicare expenditures were \$14,721 for a beneficiary with a clinical diagnosis of dementia, and \$18,208 for a

beneficiary with claim-identified dementia, suggesting an overestimation of \$3,487 per person per year when Medicare claims were used to identify dementia. Total annual expenditures for all beneficiaries with claims-identified dementia were \$258,707 lower than that for all those who were clinically diagnosed, suggesting an overall underestimation of total Medicare expenditures if Medicare claims were used to identify dementia. Different types of misidentification have different effects on dementia-related cost estimates. Average annual expenditures per person were highest for false positives.

CONCLUSION: Misidentification of dementia in Medicare claims is common. Using claims to identify dementia may result in significantly biased estimates of the cost of dementia. *J Am Geriatr Soc* 00:1–8, 2018.

Key words: dementia; Medicare claims; clinical diagnosis; cost

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The number of people with Alzheimer's disease (AD) and other dementias continues to grow and exert tremendous socioeconomic burden on healthcare systems. Despite increased awareness, evidence suggests that dementia is often underdiagnosed and poorly documented, particularly in the early stages. For individuals living in the community, only approximately half of those who meet diagnostic criteria for AD and other dementias are estimated to have been diagnosed by a physician.^{1–6} Accurate identification of dementia is critical to disease management, is important when defining and evaluating populations, and has profound implications for cost of care and healthcare systems budgeting.⁷

A recent review comparing the validity of dementia identification in administrative datasets with that of expert-led reference standards such as a clinical diagnosis reported tremendous heterogeneity in sensitivity estimates, ranging from 21% to 86%.⁸ The majority of studies reported

moderate sensitivity (40–50%) in detecting dementia,^{5,9–11} but several reported sensitivity estimates below 30%^{10,12,13} or as high as 80%.^{14,15} Direct comparisons of these studies are difficult because they varied widely in terms of country of study, sample characteristics, data sources and types, coding systems and versions, codes used for case selection, and reference standards. Two of the studies that reported the highest sensitivity of dementia detection used Medicare claims.^{14,15} However, diagnoses recorded in Medicare claims often fail to capture milder cases^{14–19} and sometimes misidentify individuals who do not have the disease as having dementia.^{14,15} It is likely that the combined effects of both types of incorrect identification result in biased estimation of dementia-associated costs.^{15,16,20}

We aimed to examine the relationship between misidentification of dementia and costs in a largely minority, ethnically diverse cohort for whom comprehensive cognitive and functional assessments were systematically and frequently performed, yielding accurate in-person diagnoses of dementia and for whom Medicare claims data are available.^{21,22} Because of the epidemiological nature of the study, neither subjects nor their primary care providers were notified of a diagnosis of dementia, reducing the likelihood of contamination in Medicare claims. We asked which participants were more likely to be misidentified in their dementia status in Medicare claims and what are the implications of dementia misidentification for the accuracy of dementia-related cost estimates. By including individuals clinically diagnosed with and without dementia, underestimation (through false negatives) and overestimation (through false positives) can be identified, and their effects on Medicare expenditures can be estimated separately.

METHODS

Participants

Participants were drawn from the Washington Heights-Inwood Columbia Aging Project (WHICAP), a multiethnic, population-based, prospective study of cognitive aging of Medicare beneficiaries aged 65 and older residing in northern Manhattan. The Centers for Medicare and Medicaid Services (CMS) provided lists of all Medicare and Medicaid beneficiaries living in the area at the beginning of study enrollment in 1992. An additional cohort was formed in 1999 using similar methods based on an updated beneficiary list. The original list of names was divided into 6 strata based on age (65–74, ≥75) and ethnicity (Hispanic, non-Hispanic black, non-Hispanic white). These strata were further divided into subsamples so that the distributions within each subsample were similar according to age and ethnicity. This provided a means to ensure equal representation of the community during participants' initial assessment. Detailed descriptions of study methodology have been reported previously.^{23,24}

At the time of study entry, each participant underwent an in-person interview on general health and functional ability, followed by a standardized assessment including medical history, physical and neurological examination, and a neuropsychological battery. Participants were then followed at approximately 18-month intervals with similar assessments. Evaluations were conducted in English or

Spanish, based on participants' primary language or preference. The institutional review boards of Columbia Presbyterian Medical Center and Columbia University Health Sciences, New York State Psychiatric Institute, and CMS Privacy Board approved recruitment, informed consent, and study procedures. Written informed consent was obtained from all participants.

Individuals were matched to the Medicare Beneficiary Summary file using social security number and Medicare beneficiary identification number. The study period for the current analysis was defined to begin with an individual's first WHICAP visit or beginning of Medicare data availability (January 1, 1999), whichever was later, and to end with an individual's last WHICAP visit, end of Medicare data availability (December 31, 2010 at the time of data acquisition), or death, whichever was earlier, to ensure data overlap between WHICAP study visits and Medicare claims. Because Medicare claims from individuals who were covered under managed care plans are incomplete, we followed CMS Chronic Condition Warehouse guidelines and excluded observations from subjects who were not covered by Medicare fee-for-service providers for 10 or more months during a calendar year (or had no more than 1 month not covered by fee-for-service during the year of death if the participant died).²⁵

Clinical Diagnosis of Dementia and Medicare Claims-Identified Dementia

At each WHICAP visit, a group of neurologists, psychiatrists, and neuropsychologists held diagnostic conferences using results from the neuropsychological battery and evidence of impairment in social or occupational functions.^{23,26} A diagnosis of dementia was determined based on *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* criteria. Diagnosis of probable or possible AD was made based on National Institute of Neurological and Communicative Disorders and Stroke and Alzheimer's Disease and Related Disorders Association criteria. Because of the epidemiological nature of the study, neither participants nor their primary care providers were notified of a diagnosis of dementia. The current study included participants clinically diagnosed with dementia at their first WHICAP visit and those who were never clinically diagnosed with dementia throughout the study period.

Medicare claims-identified dementia was defined according to the presence of any *International Classification of Diseases, Ninth Revision, Clinical Modification* (ICD-9-CM) diagnosis codes for AD and related dementias as defined by Chronic Condition Warehouse (331.0, 331.11, 331.19, 331.2, 331.7, 290.0, 290.10, 290.11, 290.12, 290.13, 290.20, 290.21, 290.3, 290.40, 290.41, 290.42, 290.43, 294.0, 294.10, 294.11, 294.20, 294.21, 294.8, 797) in all available Medicare claims during the study period.²⁵

Participants clinically diagnosed with dementia included true positives (TP, clinically diagnosed dementia, claims-identified dementia) and false negatives (FN, clinically diagnosed dementia, claims identified no dementia). Participants clinically diagnosed as not having dementia included true negatives (TN, clinically diagnosed without dementia, claims identified no dementia), and false positives

(FP, clinically diagnosed without dementia, claims-identified dementia). Dementia misidentification therefore included FP and FN.

Medicare Expenditures

Medicare expenditures data were obtained from Medicare Standard Analytical Files and included all covered services. Total expenditures were computed by summing all payments to each beneficiary during the study period. Because participants were followed for varying lengths of time for the study, we computed an average annual Medicare expenditure for each individual by dividing total expenditures during the study by years of follow-up. Expenditures were adjusted to 2015 dollars using the medical care component of the Consumer Price Index.²⁷

Other Clinical and Sociodemographic Characteristics

Participants' medical histories were obtained using WHI-CAP surveys to construct a modified version of the Charlson Comorbidity Index.^{22,28} Comorbidities included myocardial infarction, congestive heart failure, peripheral vascular disease, hypertension, chronic obstructive pulmonary disease, arthritis, gastrointestinal diseases, liver disease, diabetes, chronic renal disease, and systemic malignancy. A modified Elixhauser comorbidities index throughout the study period also was constructed using all ICD-9-CM diagnosis codes in all Medicare Standard Analytical Files.^{29,30}

Functional status was measured using the Blessed Dementia Rating Scale (BDRS, range 0–13, higher scores indicate worse functioning).³¹ Cognitive status was measured according to a global cognitive z-score, comprising multiple domains of cognition including memory, abstract reasoning, language, visuospatial, and executive/speed processing.³² Higher scores indicate better cognition.

Sociodemographic characteristics were included a priori in multivariate analyses based on known associations with healthcare spending: age, sex, race, ethnicity, years of education, marital status, and Medicaid eligibility. Because individuals with more Medicare encounters have a greater probability of having a dementia diagnosis (or any diagnosis) recorded, we included number of hospital admissions, skilled nursing facility (SNF) admissions, and outpatient claims as covariates.

Analysis

We computed sensitivity, specificity, and positive and negative predictive values of Medicare claims-identified dementia over the entire study period. Agreement of claims-identified and clinically diagnosed dementia was computed using kappa statistic.³³

We then compared characteristics of participants who were correctly identified and those who were misidentified in Medicare claims using t-tests for continuous variables and chi-square tests for discrete variables. We estimated independent effects of participant characteristics on the likelihood of misidentification of dementia using logistic regression. The following control variables were included: age, sex, race, ethnicity, marital status, education, length of

Medicaid eligibility, number of comorbidities, and functional and cognitive status. Number of follow-up years was highly correlated with number of outpatient visits ($\rho = 0.56$, $p < .001$) but not with number of hospital ($\rho = 0.24$, $p < .001$) or SNF admissions ($\rho = 0.011$, $p = .80$). Estimation models were therefore further controlled for years of follow-up and number of hospital or SNF admissions. We explored models using cognitive composite score versus domain scores and Charlson versus Elixhauser comorbidity indices. Akaike Information Criterion³⁴ was used to select model specification for cognitive composite and Charlson Comorbidity Index. Extrapyramidal signs were not significantly associated with misidentification in any exploratory models and were subsequently excluded. Participants with and without a clinical diagnosis of dementia were analyzed separately.

To examine the effects of misidentification of dementia on Medicare expenditures, we first compared unadjusted costs of those who were correctly identified and those misidentified in Medicare claims using the nonparametric Wilcoxon rank-sum test. We then estimated independent effects of misidentification of dementia on Medicare expenditures using generalized linear models with a log link and gamma family distribution. The main independent variable was category of claims-identification of dementia (FN, FP, and TP vs TN as the reference group). Because the dependent variable was average annual Medicare expenditures, years of follow-up and numbers of hospital and SNF admissions were not included in the models. Marginal effects were reported for ease of interpretation. Statistical significance was set a priori at $p < .05$. All analyses were performed using Stata version 13.0 (Stata Corp., College Station, TX).

RESULTS

Clinical Diagnosis Versus Claims Identification of Dementia

Figure 1 summarizes the study's sample selection process. Four hundred ninety-five participants were clinically diagnosed with dementia, and 1,701 were clinically diagnosed as not having dementia throughout the study. Medicare claims correctly identified 250 of the 495 (51%) individuals with dementia and 1,565 of the 1,701 (92%) without (agreement rate = 82.7%; kappa = 0.46). Sensitivity of claims-identified dementia was 0.51, specificity 0.92, PPV 0.65, and NPV 0.86.

Sample Characteristics

Of participants who were clinically diagnosed with dementia, those who were misidentified as not having dementia (FN) were significantly younger (83.6 vs 85.3), were less likely to be female (67% vs 76%), and had slightly more comorbidities (3.1 vs 2.8) than those correctly identified with dementia (TP) (Table 1). They also had lower BDRS (2.2 vs 3.7) and higher cognitive scores, indicating better function and cognition. Follow-up years, number of hospital and SNF admissions, and number of outpatient visits were all lower in FN than TP. There were no statistically significant differences in race, ethnicity, marital status, education, or Medicaid eligibility between FN and TP.

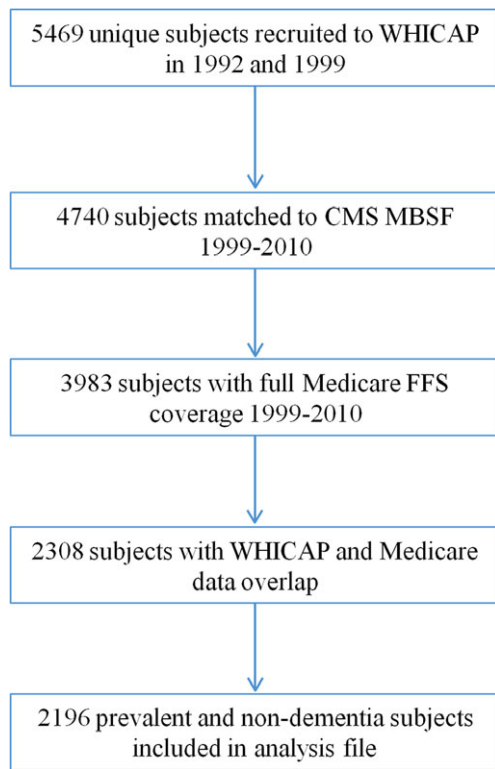


Figure 1. Sample selection. CMS = Centers for Medicare and Medicaid Services; MBSF = Medicare Beneficiary Summary file; FFS=fee for service.

Of participants without a clinical diagnosis of dementia, those who were misidentified as having dementia in the claims (FP) were significantly older (80.2 vs 77.2), less likely to be married (15.4% vs 30.4%), and more likely to be Medicaid eligible (41.9% vs 33.2%) than those correctly identified as not having dementia (TN). They also had higher BDRS (0.9 vs 0.4) and lower cognitive scores, indicating worse function and cognition. Follow-up years, number of hospital and SNF admissions, and number of outpatient visits were all higher in FP than TN. There were no statistical differences in sex, race, ethnicity, education, or number of comorbidities between FP and TN.

Characteristics Associated with Misidentification of Dementia in Medicare Claims

Table 2 reports logistic regression results estimating participant characteristics associated with claims misidentification of dementia, stratified according to clinical diagnosis of dementia. In participants with a clinical diagnosis of dementia, being FN was associated with younger age, more comorbidities, better functional and cognitive status, and fewer hospitalizations. Being black or Hispanic was also marginally associated with greater likelihood of being FN.

In participants who had no clinical diagnosis of dementia, being FP was associated with older age, longer Medicaid eligibility, worse functional and cognitive status, and more SNF admissions. Not being married was also marginally associated with greater likelihood of being FP.

Medicare Expenditures

Annual (unadjusted) Medicare expenditures for individuals with claims-identified dementia were more than twice the expenditures for individuals identified according to claims as not having dementia (\$18,208 vs \$8,742) (Table 3), although a comparison of differences in annual Medicare expenditures of individuals with and without clinically diagnosed dementia revealed a more modest contrast (\$14,721 vs \$9,149). In participants clinically diagnosed with dementia, annual Medicare expenditures were substantially lower in FN than TP (\$11,327 vs \$18,048). In participants without a clinical diagnosis of dementia, annual Medicare expenditures were substantially higher in FP than TN (\$18,503 vs \$8,337).

After controlling for other covariates, adjusted annual Medicare expenditures were \$7,316 higher in FP than TN (Table 4) and \$3,183 higher in TP than TN. Differences in expenditures between FN and TN were not statistically significant. Other characteristics that are associated with higher Medicare expenditures included being male, black, and unmarried and having more comorbidities and worse functional and cognitive status. Longer lengths of Medicaid eligibility were significantly associated with lower Medicare expenditures, but the effects were small.

DISCUSSION

We assessed the accuracy of Medicare claims records in identifying dementia in an ethnically diverse cohort of older adults who had been prospectively followed with clinical evaluations of dementia. By including individuals clinically diagnosed with and without dementia, effects on Medicare expenditures from FP and FN were differentiated. Results showed that misidentification of dementia in Medicare claims is common. Of the 495 participants with a clinical diagnosis of dementia, 245 (49%) were misidentified as not having dementia in Medicare claims. Of the 1,701 participants clinically diagnosed as not having dementia, 136 (8%) were misidentified in Medicare claims as having dementia. These results are consistent with the wide range of results reported.⁸

This study should be considered in the context of 2 earlier reports that also used Medicare claims, both reporting the most robust sensitivity (>80%) of detecting dementia of existing studies.^{14,15} Some significant differences between these cohorts provide possible reasons for differences in our results. The Consortium to Establish a Registry for Alzheimer's Disease study included individuals with a clinical diagnosis of AD in more-severe disease stages seen at major AD centers.¹⁴ Individuals with other forms of dementia were excluded. Unlike our study, individuals and their healthcare providers were informed of the dementia diagnosis, and the presence of an informant was required. It is likely that all of these factors led to greater awareness of dementia and more accurate identification of dementia in Medicare claims. The Aging, Demographics, and Memory Study (ADAMS) cohort was drawn from respondents from the Health and Retirement Study.¹⁵ The WHICAP cohort was 35% non-Hispanic white, 40% younger than 80, 46% with a high school education, whereas the ADAMS cohort was 87% non-Hispanic white, 60% younger than 80, and

Table 1. Participant Characteristics at Baseline Year According to Clinical Diagnosis and Medicare Claims-Identified Dementia

Variable	Clinical Diagnosis of Dementia			Clinical Diagnosis of No Dementia		
	Claims Identification of No Dementia (False Negative), n=245	Claims Identification of Dementia (True Positive), n=250	P-Value	Claims Identification of No Dementia (True Negative), n=1,565	Claims Identification of Dementia (False Positive), n=136	P-Value
Sociodemographic characteristics						
Age, mean±SD	83.6±6.8	85.3±6.6	.004	77.2±6.5	80.2±6.3	<.001
Female, %	67.8	76.0	.04	66.7	71.3	.27
Race and ethnicity, %						
White	16.3	16.0	.74	36.9	33.1	.66
Black	25.7	28.8		24.9	25.7	
Hispanic	58.0	55.2		38.1	41.2	
Marital status, %			.47			.002
Married	18.0	14.8		30.4	15.4	
Widowed	35.5	40.4		30.9	41.2	
Never married	10.6	8.0		11.4	14.0	
Divorced, separated	14.3	12.8		17.1	16.9	
Education, years, mean±SD	6.8±4.6	7.2±4.4	.42	10.6±4.7	10.2±4.7	.30
Months Medicaid eligible, mean±SD	12.1±14.1	12.3±14.5	.94	7.6±13.3	12.2±17.6	<.01
Clinical characteristics						
Number of comorbidities, mean±SD	3.1±1.9	2.8±1.9	.03	2.6±2.0	2.8±2.1	.305
Blessed Dementia Rating Scale score, mean±SD	2.2±2.9	3.7±3.9	<.001	0.4±1.0	0.9±1.5	<.001
Cognitive composite, mean±SD	-1.17±0.52	-1.29±0.58	.02	0.07±0.64	-0.12±0.60	<.001
Memory	-1.56±0.49	-1.71±0.55	<.001	0.04±0.83	-0.32±0.75	<.001
Abstract reasoning	-0.90±0.80	-1.08±0.94	.03	0.11±0.81	-0.06±0.79	.03
Visuospatial	-1.18±0.96	-1.07±0.96	.26	0.07±0.82	-0.02±0.86	.23
Language	-1.10±0.97	-1.29±1.16	.07	0.06±0.72	-0.06±0.80	.08
Executive function	-1.10±0.51	-1.28±0.54	<.001	0.10±0.88	-0.09±0.97	.02
Medicare use						
Follow-up, years, mean±SD	2.4±2.3	2.8±2.4	.04	3.6±3.1	4.4±3.1	.005
Number of hospitalizations	0.6±1.2	1.3±1.6	.001	0.6±1.3	1.5±2.1	.001
Number of skilled nursing facilities admissions	0.1±0.3	0.2±0.6	.001	0.1±0.3	0.4±0.7	.001
Number of outpatient visits	37.1±37.8	49.8±41.2	.001	51.8±49.0	83.8±69.1	.001

SD = standard deviation.

67% with at least a high school education. Although Medicaid eligibility was not reported in the ADAMS study, 37% of the WHICAP cohort was Medicaid eligible, compared with a national average of 11% of older adults. It is likely that obstacles to dementia identification, including lack of disease recognition, social resistance, suboptimal coding, and suboptimal care, are exacerbated in this more vulnerable WHICAP cohort, resulting in higher rates of misidentification of dementia in Medicare claims.

Similar to the ADAMS study, underestimation (through FN) and overestimation (through FP) were identified in the current study.¹⁴ Consistent with earlier results, we found a greater likelihood of underestimation of dementia for participants with better function and cognition, suggesting that milder dementia is more likely to be missed in Medicare claims. We also found greater likelihood of overestimation of dementia in participants with worse function and cognition. FP was also more likely in unmarried, older

Table 2. Logistic Regression Estimates of Effects of Participant Characteristics on Misidentification of Dementia in Medicare Claims

Variable	Clinical Diagnosis of Dementia			Clinical Diagnosis of No Dementia		
	OR (95% CI)	SE	P-Value	OR (95% CI)	SE	P-Value
Age	0.964 (0.931–0.998)	0.017	.04	1.047 (1.014–1.081)	0.017	.005
Female	0.625 (0.351–1.112)	0.184	.11	0.894 (0.569–1.403)	0.206	.63
Black	0.444 (0.185–1.068)	0.199	.07	1.094 (0.646–1.853)	0.294	.74
Hispanic	0.422 (0.169–1.053)	0.197	.06	1.269 (0.688–2.340)	0.396	.45
Married	0.617 (0.315–1.210)	0.212	.16	0.601 (0.346–1.042)	0.169	.07
Education	0.959 (0.897–1.026)	0.033	.22	1.022 (0.962–1.085)	0.032	.48
Number of months Medicaid insured	1.009 [0.985, 1.033]	0.012	.48	1.016 [1.001–1.031]	0.008	.04
Number of comorbidities	1.175 (1.028–1.343)	0.080	.02	0.982 (0.891–1.083)	0.049	.72
Blessed Dementia Rating Scale	0.819 (0.743–0.902)	0.041	<.01	1.166 (1.037–1.310)	0.069	.01
Cognitive status	1.607 (0.998–2.596)	0.393	.05	0.566 (0.386–0.831)	0.111	.004
Follow-up years	0.95 (0.831–1.087)	0.065	.46	1.029 (0.955–1.109)	0.039	.45
Number of hospitalizations	0.769 (0.624–0.948)	0.082	.01	1.092 (0.961–1.242)	0.072	.18
Number of skilled nursing facility admissions	0.698 (0.370–1.316)	0.226	.27	2.464 (1.593–3.811)	0.548	<.01

OR=odds ratio; CI=confidence interval; SE=standard error.

Table 3. Unadjusted Annual Medicare Expenditures According to Clinical Diagnosis and Medicare Claims-Identified Dementia

Unadjusted Annual Medicare Expenditure	Clinical Diagnosis of Dementia	Clinical Diagnosis of No Dementia	Total
Claims identification of dementia,			
n	250 ¹	136 ²	386
Expenditures, \$, mean±SD	\$18,048±26,625	\$18,503±20,862	\$18,208±24,720
Claims identification of no dementia			
n	245 ³	1,565 ⁴	1,810
Expenditures, \$, mean±SD	\$11,327±19,195	\$8,337±14,152	\$8,742±14,962
Total			
n	495	1,701	
Expenditures, \$, mean±SD	\$14,721±23,464	\$9,149±15,047	

¹True positive.

²False positive.

³False negative.

⁴True negative.

SD=standard deviation.

participants and those who were eligible for Medicaid longer, suggesting greater risk of receiving inappropriate care in these vulnerable groups.

Misidentification of dementia in individuals without dementia (FP) has received less attention in the literature. Our data indicate that FP may be more medically complex than TN, as evidenced by their poorer functional and cognitive status and greater number of comorbidities than TN. In contrast, FN had cognition similar to that of TP but less functional impairment and fewer comorbidities. Given the characteristics of individuals apt to be misidentified, results from studies that use Medicare claims only may be problematic, because severity of cognitive and functional deficits can strongly influence whether dementia was identified in the claims data.

Our results suggest that using Medicare claims to identify dementia may bias estimates of cost of dementia. Average annual Medicare expenditures for an individual with dementia, identified using clinical diagnosis, was \$14,721, whereas for those identified using Medicare claims, it was \$18,208. This suggests an overall overestimation of \$3,487

per person per year if Medicare claims were used to identify individuals with dementia, although total annual expenditures for all individuals with dementia identified by claims (FP + TP) were \$258,707 lower than for all individuals clinically diagnosed with dementia (FN + TP), suggesting an underestimation of total Medicare expenditures if Medicare claims were used to identify dementia. Results from this study also show that different types of misidentification have different effects on dementia-related cost estimates. Average annual expenditures per person were highest for FP—\$7,316 higher than for TN—but expenditures for FN and TN were similar. Expenditures on TP were \$3,183 higher than for TN, reflecting a more modest “true” excess cost of dementia per person.

Because individuals with more Medicare encounters have a greater probability of having a dementia diagnosis (or any diagnosis) recorded, we controlled for the number of follow-up years as a covariate in the analysis, but our results showed that it was not associated with misidentification in the claims data. An earlier report¹⁴ suggested that 3 years appears to be the optimal duration of time for

Table 4. Costs Associated with Misdiagnosis of Dementia

Variable	b (Standard Error)	P-Value	Marginal Effects (2015\$)
Claims misidentification (reference true negative ¹)			
False negative ²	−0.088 (0.140)	.53	−732 (1,129)
False positive ³	0.632 (0.152)	<.001	7,316 (2,321)
True positive ⁴	0.321 (0.171)	.06	3,183 (1,944)
Age	−0.003 (0.006)	.60	−26 (50)
Female	−0.202 (0.087)	.02	−1,814 (810)
Black	0.166 (0.100)	.10	1,491 (939)
Hispanic	0.010 (0.116)	.93	89 (1,000)
Married	−0.305 (0.093)	.001	−2,457 (707)
Education	0.016 (0.011)	.17	136 (99)
Medicaid insured	−0.009 (0.003)	.003	−79 (27)
Number of comorbidities	0.143 (0.019)	<.001	1,234 (169)
Blessed Dementia Rating Scale	0.100 (0.026)	<.001	867 (224)
Cognitive composite	−0.227 (0.078)	.004	−1,957 (677)

¹Clinical diagnosis of no dementia and identified as not having dementia in claims.

²Clinical diagnosis of dementia but identified as not having dementia in claims.

³Clinical diagnosis of no dementia but identified with dementia in claims.

⁴Clinical diagnosis of dementia and identified with dementia in claims.

which to screen Medicare claims to identify persons with AD. Fewer years resulted in a larger undercount, but more than 3 years of data did not increase the sensitivity of Medicare claims identification of dementia substantially. Participants in our sample were followed for an average of more than 3 years (slightly more in the sample without dementia than in those with dementia), suggesting that our estimates of rates of misidentification could be an upper bound for this sample. Future studies are needed to examine optimal length of follow-up in claims data.

Several limitations of the study should be noted. First, our sample included participants whose clinical assessment overlapped with Medicare data availability. It is possible that some participants may have been identified with dementia in Medicare claims before but not during the study period and therefore have been incorrectly identified as FN. Second, it is possible that changes in dementia awareness and diagnosis over time may affect the way in which individuals are identified in Medicare claims. During the 10 years before our study period (1991–99), age-adjusted rates of Medicare identification of AD rose for all demographic groups.³⁵ It is unclear whether these changes had continued. An exploratory analysis of the current cohort showed stable identification rates during our study period. In addition, results from our sample, almost two-thirds of whom were minorities, may not be generalizable to the general population.

In conclusion, claims-based diagnoses resulted in substantial misidentification of dementia status. As the population of older adults becomes more ethnically diverse,²⁷ the importance of examining racially and ethnically diverse, vulnerable populations cannot be overemphasized. Accurate identification of dementia is critical to management and coordination of care and is important when defining and evaluating populations. Furthermore, such misidentification bias has profound implications for cost analyses. Determining how certain subpopulations may be more likely to be misidentified is critical to understanding how we can more accurately use claims-based assessments in cost research.

This is especially critical as we increasingly use Medicare claims and “big data” in population health services research.

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