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Racial/Ethnic Disparities in Misidentification of Dementia in Medicare Claims: Results from the Washington Heights-Inwood Columbia Aging Project

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Abstract.
Background: Misidentification of dementia in Medicare claims is quite common.
Objective: We examined potential race/ethnic disparities in misidentification of dementia in Medicare claims in a diverse cohort of older adults who underwent careful clinical assessment.
Methods: Participants were enrolled in the Washington Heights-Inwood Columbia Aging Project (WHICAP), a multiethnic, population-based, prospective study of cognitive aging in which dementia status was assessed using a rigorous clinical protocol. ICD-9-CM and ICD-10-CM diagnosis codes in all available Medicare claims (1999–2019) were compared to clinical dementia diagnosis and categorized into three mutually exclusive groups: 1) congruent-, 2) over-, and 3) under- identification during the study period. Multinomial logistic regression model was used to examine the relationship between race (White, African American/Black, other) and ethnicity (Hispanic/Latinx, non-Hispanic/Latinx) and congruency of dementia identification after controlling for clinical (cognition, function, comorbidities) and demographic characteristics (age, sex, education), and inpatient and outpatient utilization.
Results: Across all person-years, 88.4% had congruent identification of dementia compared to clinical diagnosis, in 4.1% of the times participants were over-identified with dementia, and 7.5% of the times the participants were under-identified. Rates of misidentification was higher in minority participants than in White, non-Hispanic participants. Multivariable estimation results showed that the probability of over-identification with dementia was 2.2% higher for African American/Black than White ($p = 0.05$) and 2.7% higher for Hispanic participants than non-Hispanics ($p = 0.03$) participants. Differences in under-identification by race/ethnicity were not statistically significant.
Conclusions: African American/Black and Hispanic participants were more likely over-identified with dementia in Medicare claims.

Keywords: Alzheimer's disease, clinical diagnosis, disparities, Medicare claims

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INTRODUCTION

As the number of people with Alzheimer's disease and related dementias (ADRD) continues to grow, administrative data generated from routine delivery of care, such as Medicare claims, are increasingly being used for case identifications. Accurate identification of dementia is important when defining and evaluating patient populations and has implications for disease management, healthcare systems budgeting, and achieving health equity [1–3].

There has been much research on under-identification of dementia [4–9]. There is strong evidence that under-diagnosis and delayed-diagnosis of dementia are more common in racial/ethnically under-represented populations [10–19]. Across all patient populations, 40–50% of the dementia patients are unaware of their diagnosis [6, 20]. This rate is even higher in racial/ethnically under-represented populations [14, 21–23]. Under-diagnosis of dementia delays timely disease management and treatment, patient and caregiver support and planning, and access to clinical trials, which tend to be more impactful during early stages of the disease [24].

Compared to under-identification of dementia, over-identification of dementia, that is, misidentification of individuals who do not have dementia as having the disease is less prevalent and has received much less attention in research [15, 16, 25–27]. Over-identification of dementia exposes patients and their families to costly diagnosis and may result in inappropriate disease management and undue burden. Some studies have shown higher stress and lower quality of life in patients who are informed of their diagnosis of cognitive impairment and dementia [8]. These poorer outcomes have been reported to be stronger among minority groups [4, 10, 24, 28].

Systematic, persistent disparities in under- or over-identification of dementia across racial/ethnic groups may have important implications for perpetuating or exacerbating racial/ethnic disparities in dementia care [8, 10, 29–31]. The extent to which the degree of under- or over-identification of dementia differs across racial/ethnic groups in the US, and whether this has changed over time, however, remains unclear. Only one study examined disparities in dementia prevalence across racial/ethnic groups over time and showed that disparities may not be narrowing over time [32].

In this study, we aim to examine the relationship between misidentification of dementia in a largely minority, ethnically diverse cohort for whom comprehensive cognitive and functional assessments were systematically and frequently carried out [33, 34]. The Washington Heights-Inwood catchment area from which the cohort is drawn is one of the most vulnerable communities with limited income, poor health, low health literacy, and low insurance coverage [25]. While it is not a representative sample of the general Medicare population, the WHICAP participants were representative of older adults living in the community [35]. Our analysis adds to the literature by including a large group of Hispanic/Latino cohort, a population segment that is the fastest growing of the US population but often under-represented in research. Our study adds to the handful of studies that have been able to overcome major challenges in conducting population-based studies of dementia in minority communities [36–40]. It also has the advantage of having careful diagnosis of dementia against which accuracy of dementia identification in Medicare claims would be compared.

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 age 65 or older residing in northern Manhattan. Lists of all Medicare or Medicaid recipients living in the area were provided by Centers for Medicare and Medicaid Services (CMS) at the beginning of study enrollment in 1992. An additional cohort was formed in 1999 using similar methods based on an updated beneficiaries list. Each original list was divided into six strata based on age (65–74, $\geq$75 years) and ethnicity (Hispanic, non-Hispanic black, non-Hispanic white) groups. These strata were further divided into subsamples so that the distributions by age and ethnicity within each subsample were similar. This provided a means to ensure equal representation of the community during participants' initial assessment. Specifically, excluding those who died, the proportion of individuals in each age stratum who did not wish to participate for any reason, including refusal, did not differ by ethnic group. The proportion of individuals within each age stratum and ethnic group who participated in the study did not differ significantly from the source population. Detailed descriptions of study methodology have been reported previously [41].

At the time of study entry and at approximately 18-month follow-up intervals, 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. Evaluations were conducted in English or Spanish, based on participant's primary language or preference. All participants were able to provide written informed consent at the initial visit, which included consent for follow up. Recruitment, informed consent, and study procedures were approved by the Institutional Review Boards of Columbia Presbyterian Medical Center and Columbia University Health Sciences, New York State Psychiatric Institute, and CMS Privacy Board.

Individuals were matched to Medicare Beneficiary Summary File (MBSF, 1999–2019) using social security number, name, and Medicare beneficiary ID. We followed CMS Chronic Condition Warehouse (CCW) guidelines and excluded observations from subjects who were not covered by Medicare fee-for-service (FFS) providers for 10 or more months during a calendar year (or had more than 1 month not covered by FFS during the year of death if the participant died) to ensure Medicare claims were complete [42]. 5,156 unique individuals in WHICAP were matched to Medicare claims.

Claims-identified dementia

Individuals with any ICD-9-CM or ICD-10-CM diagnosis codes for Alzheimer's Disease and Related Dementias as defined by CCW in all available Medicare claims during a calendar year were categorized as claims-identified dementia in that year [42]. The list of diagnosis codes is in the Supplementary Materials (Supplementary Table 1).

Clinical diagnosis of dementia

At each WHICAP visit, diagnostic conferences were held by a group of neurologists, psychiatrists, and neuropsychologists using results from the neuropsychological battery and evidence of impairment in social or occupational functions [43, 44]. A diagnosis of dementia was determined based on DSM IV criteria [45]. Diagnosis of probable or possible AD was made based on National Institute of Neurological and Communicative Disorders and Stroke and the Alzheimer's Disease and Related Disorders Association (now Alzheimer's Association, NINCD/ADRDA) criteria [43]. Because of the epidemiologic nature of the study, neither participants nor their primary care providers were notified of a study diagnosis of dementia, reducing the likelihood of contamination in Medicare claims-identified dementia.

Accuracy of claims-identified dementia compared to clinical diagnosis of dementia

We compared individual's WHICAP clinical dementia status to claims-identified dementia status each year and categorized participants into four mutually exclusive groups: 1) congruent identification-no dementia (clinically diagnosed no dementia, claims-identified no dementia), 2) congruent identification-dementia (clinically diagnosed dementia, claims-identified dementia), 3) under-identification (clinically diagnosed dementia, claims identified non-demented), and 4) over-identification (clinically diagnosed non-demented, claims-identified dementia). Because our focus was neurodegenerative dementias, we excluded from the analysis sample 32 individuals who were clinically diagnosed with dementia at some point during the study and reverted to being cognitively normal at later visits. Records where accuracy of claims-identified dementia were unable to be categorized were excluded from the analysis. For example, records from Medicare claim years after the last clinical assessment in which the participant was diagnosed as cognitively normal and records from Medicare claim years before the first clinical assessment in which the participant was diagnosed with dementia were dropped. The analysis sample includes 4,268 individuals for which we were able to categorize accuracy of claims-identified dementia using their clinical dementia status.

The first year in which Medicare claims were observed was considered the index year. Cognitive and functional status of the participants in the WHICAP clinical assessment closest to the index year was selected to describe the participant's index year clinical profile. Years between WHICAP clinical assessment and Medicare index year was recorded.

Participant characteristics

Our main independent variables were self-reported race (White, African American/Black, American Indian/Eskimo/Alaskan, Asian/Pacific

Islander, Other) and ethnicity (Hispanic/Latinx, non-Hispanic/Latinx). The race variable was combined into White, African American/Black, and others because of the small sample sizes of the other groups. Demographic characteristics included participant's age, sex, and education. Participants' clinical profiles included cognition, function, and comorbidities. Cognitive status was measured by a global cognitive z-score, comprising multiple domains of cognition including memory, abstract reasoning, language, visuospatial, and executive/speed processing [46]. Higher score indicates better cognition. Functional status was measured using the Blessed Dementia Rating Scale (BDRS, range = 0–13, higher score indicates worse functioning) [47]. Comorbidities were measured using a modified Elixhauser comorbidities index by summing all individual indicators, excluding dementia [48]. (Detailed codes for identifying each condition are in Quan et al. (2005) report [49].) Inpatient and outpatient utilization during the year were used to control for exposures to Medicare claims.

Statistical analysis

Participant characteristics at index year were compared by race/ethnic group using Kruskall-Wallis tests for continuous variables and chi-square tests for categorical variables. Unadjusted rates of congruency of identification of dementia by race and ethnic groups were compared by chi-square tests.

We used random effects multinomial logistic regression models to examine the relationship between race/ethnicity and congruency of dementia identification over time. The outcome of interest was congruency of claims identification of dementia each year. We combined the two congruent identification groups to facilitate analysis, so the outcome has three levels: congruent, under-identified, and over-identified. Our main independent variables were race (White, Black, other), ethnicity (Hispanic, non-Hispanic), and interaction between race and ethnicity. Participant characteristics included clinical (cognition, function, comorbidities) and demographic characteristics (age, sex, education), and inpatient and outpatient utilization. A linear and squared term for time (year) were included to estimate temporal trends. Random effects specific to each outcome level were included to account for time-invariant subject-specific characteristics.

Because estimated coefficients in the multinomial logistic regression models are difficult to interpret, we reported relative-risk ratios (exponentiated coefficients), which provide estimates of change in an outcome level from a unit change in an explanatory variable on a multiplicative scale. We also reported estimated average marginal effects, which provide estimates of change in the probability of an outcome level for a unit change in an explanatory variable on an additive scale.

In addition to examining accuracy of claims-identified dementia status annually, we also assessed overall accuracy of Medicare claims identification by aggregating all years of data. A participant was defined as being over-identified with dementia if the individual was never clinically diagnosed with dementia but was identified with dementia in the claims. A participant was defined as being under-identified if the individual was clinically diagnosed with dementia but was never identified with dementia in the claims. Similar to longitudinal analyses, multinomial logit models were used. Results are provided in the Supplementary Material (Supplementary Table 2). All analyses were performed in SAS 9.4 and Stata 17. Statistical significance was set *a priori* at $p = 0.05$.

RESULTS

The analysis sample included 1,178 individuals who were diagnosed with dementia and 3,048 individuals who were never diagnosed with dementia during the study, with 1,520 White, 1,333 African American/Black, and 1,373 participants of other races; 985 participants self-identified as Hispanic, 2,241 non-Hispanic (Table 1). 69% of the participants were female, with average age of 75.3 ± 8.1 years at index year, 9.9 ± 5.1 years of schooling, and 2.7 ± 2.0 comorbid conditions. In terms of Medicare utilization, participants had on average fewer than one inpatient stay and 4 outpatient visits during the index year.

Across all person-years, 88.4% had congruent identification of dementia compared to clinical diagnosis, in 4.1% of the times participants were over-identified with dementia, and 7.5% of the times the participants were under-identified (Table 2). These distributions differed significantly by race and ethnic groups (both $p < 0.001$). Specifically, congruency rates were lower in Black (88.8%) and other races (85.7%) compared to White participants (90.6%), and lower in Hispanic (85.1%) compared to non-Hispanic (91.9%) participants. Rates of under-identification

Table 1
Participant characteristics at index year

Variable	All	Race group			Ethnic group	
		White	Black	Other	Non-Hispanic	Hispanic
	4,226	1,520	1,333	1,373	2,241	1,985
Race (%)						
White	36.0	–	–	–	45.6	25.1
Black	31.5	–	–	–	51.7	8.8
Other	32.5	–	–	–	2.7	66.1
Hispanic (%)	47.0	32.8	13.1	95.6	0.0	100.0
Age, mean y (SD)	75.3	75.4	76.3	74.2	75.9	74.6
	(8.1)	(7.7)	(8.6)	(8.0)	(8.2)	(8.0)
Female (%)	68.8	63.9	72.2	70.8	67.9	69.7
Years of education, mean (SD)	9.9	11.9	10.9	6.7	12.7	6.7
	(5.1)	(5.0)	(4.2)	(4.5)	(3.9)	(4.3)
Cognition	0.4	0.3	0.3	0.5	0.3	0.5
	(1.2)	(1.0)	(1.1)	(1.4)	(1.0)	(1.3)
Function	4.5	3.7	4.3	5.6	3.4	5.7
	(8.1)	(7.2)	(7.8)	(9.0)	(6.9)	(9.1)
Number of comorbidities, mean (SD)	2.7	2.3	2.8	2.9	2.4	2.9
	(2.0)	(1.9)	(1.9)	(2.1)	(1.9)	(2.1)
Number of inpatient stays, mean (SD)	0.4	0.3	0.5	0.3	0.4	0.3
	(0.8)	(0.7)	(0.9)	(0.8)	(0.9)	(0.7)
Number of outpatient visits, mean (SD)	3.9	3.2	3.9	4.6	3.3	4.5
	(5.8)	(4.9)	(6.1)	(6.2)	(5.3)	(6.2)
Index year, mean (SD)	2002.6	2002.3	2003.3	2002.1	2003.1	2001.9
	(5.4)	(5.3)	(5.8)	(5.0)	(5.7)	(4.9)
Years of follow up, mean (SD)	7.3	7.4	6.1	8.3	6.3	8.4
	(5.8)	(5.7)	(5.3)	(6.1)	(5.3)	(6.1)

Cognition measured by a global cognitive z-score comprising multiple domains of cognition including memory, abstract reasoning, language, visuospatial, and executive/speed processing; Function measured by Blessed Dementia Rating Scale (BDRS); Comorbidities measured by a modified Elixhauser comorbidities [48].

were higher in Black (7.8%) and other races (9.8%) compared to White participants (5.1%), and higher in Hispanic (10.0%) compared to non-Hispanic (4.8%) participants. Rates of over-identification were higher in Hispanic (5.0%) compared to non-Hispanic (3.3%) participants.

Table 3 shows estimated effects on differences in dementia identification by race/ethnicity after controlling for participant characteristics. Results show that the relative risk of being over-identified with dementia for Hispanic versus non-Hispanic participants is 1.75 times as large as the relative risk in the case of congruent identification. Because the model included an interaction term between race and ethnicity, results show that in non-Hispanic participants, the relative risk of being under-identified with dementia for Black versus White participants is 3.87 times higher than their relative risks in the case of congruent identification. In White participants, the relative risk of being under-identified with dementia for Hispanic participants is 3.56 times higher than the relative risk in the case of congruent identification.

Looking at other covariates, older age was associated with both under- and over-identification of dementia. Being female, having lower education was associated with higher likelihood of under-identification. Higher number of inpatient stays was associated with both under- and over-identification of dementia. Results suggest that over time, risk of over-identification increased and risk of under-identification decreased. Estimates suggest slowing rate of change over time, but the magnitude of change was miniscule.

To facilitate interpretation of results, we computed predicted probabilities of congruent, over-, and under-identification of dementia by race/ethnic groups and associated average marginal effects (Table 4). Except for a 1.4% lower rate of over-identification in Black compared to White participants, differences in accuracy of dementia identification by race groups largely disappeared. The predicted probability in Hispanic participants of being over-identified with dementia (4.7%) and the probability of being under-identified without dementia (7.7%) were both significantly higher compared to non-Hispanic participants (3.4% and 5.8%, respectively). That is, compared to non-Hispanic participants, the probability of being over-identified with

Table 2
Congruency of dementia identification in Medicare claims

	All	Race group			Ethnic group	
		White	Black	Other	Non-Hispanic	Hispanic
Number of person-years	31,174	11,774	8,385	11,015	15,056	16,118
Congruent identification						
n	27,549	10,664	7,443	9,442	13,839	13,710
%	88.4	90.6	88.8	85.7	91.9	85.1
Over-identification						
n	1,288	509	285	494	489	799
%	4.1	4.3	3.4	4.5	3.3	4.9
Under-identification						
n	2,337	601	657	1,079	728	1,609
%	7.5	5.1	7.8	9.8	4.8	10.0

Chi-squared tests of distributions of accuracy of dementia identification by race and ethnic groups statistically significant at $p < 0.001$.

Table 3
Random effect multinomial logistic regression estimates of relationship between race/ethnicity on congruency of identification of dementia over time (base outcome = Congruent identification)

	Over-identification			Under-identification		
Variables	RRR	SE	p	RRR	SE	*p*
Race (reference = White)						
Black	0.924	0.153	0.631	3.865	1.038	<0.001
Other	0.642	0.354	0.421	1.968	1.627	0.413
Hispanic (reference = non-Hispanic)	1.754	0.352	0.005	3.564	1.116	<0.001
Interaction Race × Hispanic						
Black	0.528	0.184	0.067	0.238	0.110	0.002
Other	1.226	0.703	0.722	0.607	0.518	0.559
Age	1.058	0.007	<0.001	1.222	0.013	<0.001
Female	1.064	0.128	0.607	0.518	0.085	<0.001
Years of education	1.001	0.014	0.953	0.833	0.017	<0.001
Cognition	1.014	0.060	0.815	1.023	0.065	0.723
Function	0.994	0.008	0.494	1.050	0.010	<0.001
Number of Comorbidities	1.048	0.029	0.090	1.008	0.040	0.834
Number of Inpatient stays	1.065	0.011	<0.001	1.124	0.016	<0.001
Number of Outpatient visits	1.001	0.001	0.398	0.992	0.001	<0.001
Year	1.166	0.027	<0.001	0.842	0.019	<0.001
Year × year	0.994	0.001	<0.001	1.003	0.001	0.004

RRR, relative risk ratio; SE, standard error; Cognition measured by a global cognitive z-score comprising multiple domains of cognition including memory, abstract reasoning, language, visuospatial, and executive/speed processing; Function measured by Blessed Dementia Rating Scale (BDRS); Comorbidities measured by a modified Elixhauser comorbidities [48].

dementia was higher by about 1.3 percentage points for Hispanic participants. The probability of being under-identified with dementia also was higher by about 1.9 percentage points for Hispanic participants.

DISCUSSION

In this study we examined racial/ethnic disparities in misidentification of dementia over time in an ethnically diverse cohort of older adults who have been prospectively followed with clinical evaluations of dementia. We found higher congruency rates in White non-Hispanic participants than non-White, Hispanic participants.

Specifically, our results showed significantly higher risks of under-identification of dementia in Black compared to White older adults. These results are consistent with results from several recent studies using the Health and Retirement Study (HRS) comparing algorithmic determination of dementia status to Medicare claims identification of dementia that showed non-Hispanic blacks with higher risks of being under-diagnosed with dementia than non-Hispanic Whites [16, 21]. Our finding that showed no significant differences in the risk of over-identification in Black older adults was consistent with one other study that examined over-identification of dementia using the HRS [16].

Table 4
Predicted probability on congruency of identification by race/ethnicity

Outcome		Predicted Probability	SE	Average Marginal Effect	SE	*p*
By Race group						
Congruent identification	White	0.890	0.005	(reference)		
	Black	0.891	0.008	0.00115	0.00935	0.902
	Other	0.890	0.010	–0.00003	0.01119	0.998
Over-identification	White	0.048	0.003	(reference)		
	Black	0.034	0.004	–0.01397	0.00538	0.009
	Other	0.038	0.006	–0.01060	0.00666	0.111
Under-identification	White	0.062	0.004	(reference)		
	Black	0.075	0.007	0.01282	0.00825	0.120
	Other	0.073	0.009	0.01063	0.00958	0.267
By ethnicity						
Congruent identification	Non-Hispanic	0.909	0.010	(reference)		
	Hispanic	0.876	0.005	–0.03264	0.01174	0.005
Over-identification	Non-Hispanic	0.034	0.005	(reference)		
	Hispanic	0.047	0.003	0.01348	0.00594	0.023
Under-identification	Non-Hispanic	0.058	0.010			
	Hispanic	0.077	0.004	0.01917	0.01067	0.072

Hispanic older adults are often under-represented in research studies. Our study adds to the handful of studies that have been able to overcome major challenges in conducting population-based studies of dementia that includes a large group of Hispanic older adults [36–40]. Our results showed that compared to non-Hispanics, Hispanic participants had higher risks for both over- and under-identification of dementia. These results are in line with the few existing studies examining under- and over- diagnosis of dementia in Hispanic participants. A cross-sectional analysis of data from the National Health and Aging Trends Study (NHATS) found higher risk of under-diagnosis in Hispanics [14]. Results using data from the HRS are more mixed. One study reported more frequent missed/delayed dementia diagnoses Hispanics [21]. Another showed higher risk of over-identification of dementia in Hispanics compared to non-Hispanics but no significant differences in the risk of under-diagnosis [16].

Our study adds to the few studies that examined over-identification of dementia in the literature [8, 16, 27]. We found higher rates of under-identification than over-identification across all groups as reported [8] but our results did not show significant changes in the rates of over-identification over time. Only one study has examined trends over time in over-diagnosis of dementia that showed increasing rates of over-diagnosis between 2000–2010 [16].

Results from our study should be considered in the context of the current literature on misidentification of dementia. Ideally, analysis of misidentification of dementia would best be done on large, nationally representative samples of older adults who have had clinical assessment of dementia according to standard research criteria. In practice, there is always a tradeoff between these considerations. Most of the existing studies have used nationally representative samples such as the HRS or NHATS and relied on algorithmic dementia classification [16, 22] or self-reported dementia status [14] as the benchmark. Although algorithmic dementia classifications have been improving over time, the models' predictive performance vary for different groups. Usage of these measures may limit the accuracy of study results. Our data, while not representative of the general population, has the advantage of having careful diagnosis of dementia, which remains the gold standard of diagnostic assessment, against which accuracy of dementia identification in Medicare claims was compared. Our results therefore complement existing studies that used large national databases.

In conclusion, this study highlights the continued racial/ethnic disparities in misidentification of dementia. Black and particularly Hispanic older adults are more likely than their White counterparts to be both under- and over-identified with dementia. These minoritized groups may particularly

benefit from careful dementia assessment and guard against misidentification of dementia. Efforts to better understand and reducing disparities in dementia identification are warranted.

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CONFLICT OF INTEREST

Y. Stern provides consulting for Eisai, Lilly, and Arcadia.

All other authors have no conflict of interest to report.

DATA AVAILABILITY

The data supporting the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

SUPPLEMENTARY MATERIAL

The supplementary material is available in the electronic version of this article: https://dx.doi.org/10.3233/JAD-230584.

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