

## Health services research: Cost of care and implications for intervention

## Dementia diagnosis disparities by race and ethnicity

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## Abstract

**Background:** Dementia is often underdiagnosed, and self-reported data suggest that this problem may be more common among racial and ethnic minority groups. This study examined racial and ethnic disparities in the timeliness in which individuals receive a formal dementia diagnosis.

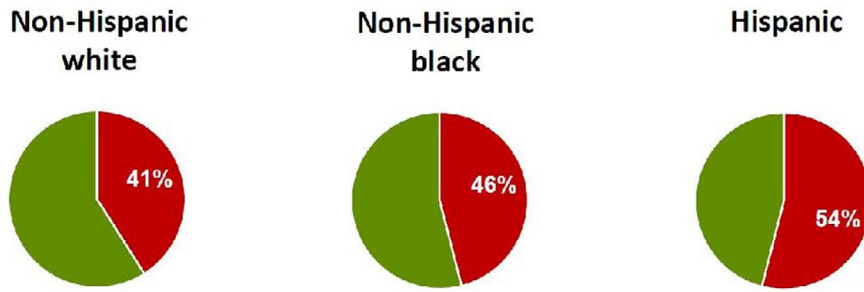
**Method:** This analysis used eight waves of US national surveys from 2000-2014 Health and Retirement Study, linked with Medicare and Medicaid claims. We identified study participants age  $\geq 70$  with dementia using a well-validated statistical model based on individual's age, gender, education, cognition, and functional limitations. We assessed the proportion of patients not receiving a coded diagnosis of dementia in their claims by the time the prediction model classified them as having dementia. We used logistic regression models to compare the likelihood of missed or delayed dementia diagnoses in claims by race and ethnicity, adjusting for patient characteristics. We analyzed dementia severity, measured by cognition (TICS scores for self-respondents; IQCODE scores for proxy-respondents) and functional limitations, at the time of a dementia diagnosis documented in claims, by race/ethnicity. All analyses adjusted for sampling weights.

**Result:** Our sample included 3,966 older adults with dementia. Forty-two percent had a missed or delayed dementia diagnosis in their claims. This proportion was higher among non-Hispanic blacks and Hispanics than among non-Hispanic whites (46% and 54% vs. 41%,  $p < 0.001$ ). Logistic regression model indicated more frequent missed/delayed dementia diagnoses among non-Hispanic blacks (OR=1.27; 95% CI: 1.05-1.53) and Hispanics (OR=1.83; 95% CI: 1.43-2.35), compared to non-Hispanic whites. Over the study period, 76% had a dementia diagnosis documented in their claims. At the time of diagnosis, non-Hispanic blacks and Hispanics had poorer cognitive function and more functional impairments, compared to non-Hispanic whites.

**Conclusion:** Non-Hispanic blacks and Hispanics may experience missed or delayed diagnoses of dementia more often than non-Hispanic whites. When they are diagnosed, non-Hispanic blacks and Hispanics may have more advanced dementia compared to non-Hispanic whites. Public health efforts such as the Brain Health Initiative should tailor campaigns to different ethnoracial groups when promoting early

diagnosis of dementia. The medical community should implement provider training on culturally competent dementia care and improve documentation of dementia diagnostic findings in health insurance claims.

**Figure 1. Proportion of missed or delayed diagnoses of dementia in claims data (shown in red), by race and ethnicity**



**FIGURE 1**

TABLE 1

Table 1. Sample characteristics

	Participants with dementia and with linked claims data (n= 3,966)	No missed or delayed diagnosis of dementia (n= 2,270) 57.7%	Missed or delayed diagnosis of dementia (n= 1,696) 42.4%	P value
<b>Race</b>				<0.001
White NH	80.8%	59.2%	40.8%	
Black NH	11.9%	54.5%	45.5%	
Hispanic	7.3%	45.8%	54.2%	
<b>Mean age (SD)</b>	84.42 (0.11)	84.16 (0.14)	84.77 (0.16)	0.004
<b>Gender</b>				<0.001
Male	33.2%	53.2%	46.8%	
Female	66.8%	59.9%	40.2%	
<b>Proxy Status</b>				<0.001
Self-reported	61.0%	52.4%	47.6%	
Proxy	39.0%	65.9%	34.1%	
<b>Mean TICS score (SD)<sup>1</sup></b>	9.84 (0.08)	9.37 (0.11)	10.36 (0.10)	<0.001
<b>Mean IQCODES score (SD)<sup>2</sup></b>	3.48 (0.03)	3.63 (0.04)	3.20 (0.05)	<0.001
<b>Mean number of ADL limitations (SD)<sup>3</sup></b>	1.68 (0.03)	1.94 (0.05)	1.33 (0.05)	<0.001
<b>Mean number of IADL limitations (SD)<sup>4</sup></b>	2.01 (0.03)	2.36 (0.04)	1.53 (0.04)	<0.001
<b>Nursing Home status</b>				<0.001
Not in nursing home	77.5%	51.6%	48.4%	
Nursing home	22.5%	78.5%	21.5%	
<b>Mean number of comorbidities (SD)</b>	2.90 (0.03)	3.00 (0.03)	2.77 (0.04)	<0.001
<b>Education</b>				<0.001
Less than high school	42.6%	52.8%	47.3%	
High school	44.2%	59.8%	40.2%	
More than high school	13.2%	66.3%	33.8%	
<b>Mean Income (SD)</b>	\$27,844 (954)	\$30,129 (1,514)	\$24,734 (905)	0.002
<b>Medicare-Medicaid dual eligibility</b>				0.029
Not dual eligible	75.9%	56.6%	43.4%	
Dual eligible	24.1%	60.9%	39.1%	

1. Only for participants who did not have a proxy respondent (self-reported). Scale from 0-33; Higher scores indicate higher cognitive function.

2. Only for participants who had a proxy respondent. Scale from 0-5; Lower scores indicate higher cognitive function.

3. ADL: Activities of Daily Living. Numbers are the reported number of activities (6 total) participants have difficulty performing; Lower scores indicate higher functional ability.

4. IADL: Instrumental Activities of Daily Living. Numbers are the reported number of activities (5 total) participants have difficulty performing; Lower scores indicate higher functional ability.

TABLE 2

Table 2. Odds ratios of missed or delayed diagnoses of dementia in claims data

	Model 1			Model 2		
	OR	95% CI	p	OR	95% CI	p
<b>Race</b>						
NH White	ref	-	-	ref	-	-
NH Black	1.27	(1.05, 1.53)	0.014	1.23	(1.01, 1.50)	0.043
Hispanic	1.83	(1.43, 2.35)	<0.001	1.84	(1.41, 2.40)	<0.001
<b>Sex</b>						
Male	ref	-	-	ref	-	-
Female	0.72	(0.62, 0.84)	<0.001	0.76	(0.65, 0.89)	0.001
<b>Age</b>						
70-74	0.72	(0.55, 0.95)	0.018	1.09	(0.81, 1.46)	0.571
75-79	0.66	(0.53, 0.82)	<0.001	0.88	(0.70, 1.11)	0.278
80-84	0.81	(0.69, 0.96)	0.015	0.89	(0.75, 1.07)	0.224
85+	ref	-	-	ref	-	-
<b>HRS Wave</b>	0.93	(0.90, 0.96)	<0.001	0.87	(0.84, 0.90)	<0.001
<b>Cognitive Impairment<sup>1</sup></b>				0.82	(0.78, 0.86)	<0.001
<b>Number of ADL Limitations<sup>2</sup></b>				0.99	(0.95, 1.04)	0.834
<b>Number of IADL Limitations<sup>3</sup></b>				0.80	(0.76, 0.85)	<0.001
<b>Other Comorbidities</b>				1.00	(0.95, 1.05)	0.948
<b>Living in a nursing home</b>				0.38	(0.31, 0.47)	<0.001
<b>Dual Eligible</b>				0.81	(0.67, 0.97)	0.019

1. Cognitive impairment is on a 0-10 scale by using normalized TICS scores and IQCODES scores scaled to 10. IQCODES are for HRS participants who had a proxy respondent. 0: No impairment; 10: High impairment.

2. Activities of Daily Living. Numbers are the reported number of activities (6 total) participants have difficulty performing; Lower scores indicate higher functional ability.

3. Instrumental Activities of Daily Living. Numbers are the reported number of activities (5 total) participants have difficulty performing; Lower scores indicate higher functional ability.

TABLE 3

**Table 3. Dementia severity at the time of dementia diagnoses in claims data, by race and ethnicity**

	Mean scores (SD)							
	TICS <sup>1</sup> (n= 2,010)	P value	IQCODES <sup>2</sup> (n= 1,001)	P value	ADL <sup>3</sup> (n= 3,011)	P value	IADL <sup>4</sup> (n= 3,011)	P value
<b>Race</b>		<0.001		0.079		0.002		0.021
Non-Hispanic White	13.04 (0.15)		3.52 (0.05)		1.36 (0.04)		1.64 (0.04)	
Non-Hispanic Black	10.16 (0.31)		3.41 (0.11)		1.50 (0.09)		1.82 (0.09)	
Hispanic	11.45 (0.41)		3.31 (0.11)		1.79 (0.14)		1.87 (0.13)	

1. Only for self respondents. Scale from 0-33; higher scores indicate higher cognitive function.

2. Only for participants who had a proxy respondent. Scale from 0-5; Lower scores indicate higher cognitive function.

3. ADL: Activities of Daily Living. Numbers are the reported number of activities (6 total) participants have difficulty performing; lower scores indicate higher functional ability.

4. IADL: Instrumental Activities of Daily Living. Numbers are the reported number of activities (5 total) participants have difficulty performing; lower scores indicate higher functional ability.