

Racial and Ethnic Differences in Knowledge About One's Dementia Status

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OBJECTIVES: To examine racial and ethnic differences in knowledge about one's dementia status.

DESIGN: Prospective cohort study.

SETTING: The 2000 to 2014 Health and Retirement Study.

PARTICIPANTS: Our sample included 8,686 person-wave observations representing 4,065 unique survey participants, aged 70 years or older, with dementia, as identified by a well-validated statistical prediction model based on individual demographic and clinical characteristics.

MEASUREMENTS: Primary outcome measure was knowledge of one's dementia status, as reported in the survey. Patient characteristics included race/ethnicity, age, sex, survey year, cognition, function, comorbidity, and whether living in a nursing home.

RESULTS: Among subjects identified as having dementia by the prediction model, 43.5% to 50.2%, depending on the survey year, reported that they were informed of the dementia status by their physician. This proportion was lower among Hispanics (25.9%-42.2%) and non-Hispanic blacks (31.4%-50.5%) than among non-Hispanic whites (47.7%-52.9%). Our fully adjusted regression model indicated lower dementia awareness among non-Hispanic blacks (odds ratio [OR] = 0.74; 95% confidence interval [CI] = 0.58-0.94) and Hispanics (OR = 0.60; 95% CI = 0.43-0.85), compared to non-Hispanic whites. Having more instrumental activity of daily living limitations (OR = 1.65; 95% CI = 1.56-1.75) and living in a nursing home (OR = 2.78; 95% CI = 2.32-3.32)

were associated with increased odds of subjects reporting being told about dementia by a physician.

CONCLUSION: Less than half of individuals with dementia reported being told by a physician about the condition. A higher proportion of non-Hispanic blacks and Hispanics with dementia may be unaware of their condition, despite higher dementia prevalence in these groups, compared to non-Hispanic whites. Dementia outreach programs should target diverse communities with disproportionately high disease prevalence and low awareness. *J Am Geriatr Soc* 68:1763-1770, 2020.

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The Healthy People 2020 public health goals for the United States suggest that 65% of Americans with dementia may be unaware of their diagnosis.¹ Although the reported proportion varies by study, researchers often find that more than half of those with dementia are unaware they have the condition.²⁻⁹ Compared to people with other common chronic conditions, such as cancer, people with dementia may be much less likely to be informed of their diagnosis.¹⁰ Knowing the diagnosis may have psychological benefits to patients with dementia because it may help them understand and cope with their memory problems and other symptoms.^{10,11} Some dementia patients and caregivers feel relieved once an explanation for symptoms is provided and a treatment plan is in place.¹² When patients with dementia know about their condition, they have the opportunity to seek appropriate medical care and support services, maximize benefits of available treatments, and participate in decisions about their care.^{10,11,13} Even though dementia may influence one's ability to remember a diagnosis, knowing one's dementia status in the early stages of disease also allows patients to play an active role in making legal and financial plans.^{10,11} Moreover, many observers

argue people have a right to know and understand their diagnosis, including dementia, because patient autonomy is an important principle of medical ethics.¹⁴ Respecting patient autonomy and shared decision making have been shown to improve quality of care, treatment adherence, and patient outcomes.¹⁰

According to Healthy People 2020, disease awareness among older adults with a dementia diagnosis has been similar across racial and ethnic groups (37% among blacks and Hispanics and 34% among whites in 2007-2009).¹ In contrast, an analysis of the National Health and Aging Trends Study found that, once diagnosed with dementia, a higher proportion of blacks and Hispanics know they have the condition, compared to whites.² While useful, these data may be liable to sample selection bias because they reflect disease awareness among people who have a dementia diagnosis documented in their Medicare claims files, omitting individuals without a claims-based diagnosis.

Dementia diagnosis codes may appear on a claim well after a patient has already progressed to more advanced disease stages, thus underrepresenting patients with milder dementia.¹⁵ Moreover, dementia may be undercoded in administrative claims files for several reasons, including limited access or poor quality of available care, little financial incentive for coding dementia, or patient and family resistance to a dementia diagnosis.^{9,16} Although undiagnosed dementia is a problem across all racial and ethnic groups, it may be more common among non-Hispanic blacks and Hispanics than among non-Hispanic whites.^{2,17-21} Other analyses using small or convenient samples generally underrepresent non-Hispanic black and Hispanic populations.³⁻⁸ Therefore, current data, based on selected samples, are insufficient to characterize potential differences by race and ethnicity in dementia awareness. Quantifying these differences is critical to understanding the unmet healthcare needs of underserved dementia patients and their caregivers.

This study examines trends over time in knowledge about one's dementia status reported by patients themselves or their informants. We also assess racial and ethnic differences in dementia awareness. To address limitations stemming from use of claims-based dementia diagnoses, we use a modeling approach to identify individuals with dementia. Our analysis leverages nationally representative survey data with unique measures of cognitive function, making our findings generalizable to the US population.

METHODS

Data Source

This study used eight waves of national survey data from the Health and Retirement Study (HRS) between 2000 and 2014, which was the latest wave available at the time of our analysis.²² The HRS is a longitudinal, national panel survey of US adults older than 50 years and their spouses or domestic partners. The study interviews roughly 20,000 respondents every 2 years (sample retention rate = 81%), eliciting information about demographics, income, health, cognition, healthcare utilization and costs, living arrangements, and other aspects of life. The HRS is well suited for our investigation of racial and ethnic disparities in dementia because the survey oversamples non-Hispanic blacks and Hispanics and allows the results to generalize to the US

population by applying sampling weights. Our sample included community-dwelling and nursing home residents, rather than recruitments from selected hospitals, for example, thus minimizing sample selection bias.

Identifying Dementia Cases

We identified HRS participants with dementia by using a statistical prediction model developed by Hurd and colleagues.²³ The model estimates an HRS respondent's probability of having dementia, based on the individual's demographic and clinical characteristics. We used a modeling approach because HRS lacks a direct measure of dementia status. Hurd's dementia prediction model has been well validated and described in detail elsewhere.^{23,24} Briefly, the estimation involved two steps. Step 1 used a three-category order probit model to estimate the likelihood of "dementia," "cognitive impairment no dementia (CIND)," or "normal" based on the Aging, Demographics and Memory Study (ADAMS) assessment. The initial ADAMS consisted of a stratified random subsample of 856 HRS respondents, aged 70 years or older, who underwent intensive clinical and neuropsychological assessments in their homes by a team of professionals.²⁵⁻²⁹ These assessments then classified each ADAMS respondent as having dementia, a less significant level of cognitive impairment (ie, CIND), or normal cognitive functioning, which served as the outcome variable of the order probit model. Predictors of the model include age, sex, education, imputed cognitive scores to account for missing values, changes in imputed cognitive scores between two previous HRS waves, functional limitations (including activities of daily living [ADLs] and instrumental ADLs [IADLs]), and changes in functional limitations.²³ Race or ethnicity was not used to predict dementia status.

The Hurd model predicted dementia status separately for self-respondents and proxy respondents because cognitive assessments differ for these two groups (survey participants with severe cognitive and/or physical disabilities use a proxy respondent to give an interview). For self-respondents, the model used cognitive function, measured by the Telephone Interview for Cognitive Status (TICS) scores, whereas for respondents represented by a proxy, cognitive function was measured by the Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) scores.

Step 2 used these prediction results to calculate probabilities of dementia for all respondents aged 70 years or older who participated in the 2000 to 2014 waves of HRS. Per Hurd's model, predicted dementia status referred to the time period 1 year after the HRS interview. For example, for an HRS 2000 respondent, the model would use the person's responses to the 1998 and 2000 HRS interviews and estimate whether s/he had dementia in 2001. Following Hurd's method, we categorized an HRS participant as having "dementia" if her/his predicted probability of dementia was higher than that of CIND or normal. The predicted dementia status served as the "gold standard" and determined subjects who had dementia. Our analyses assumed no backward transitions (ie, from a more severe to a less severe state), because fluctuation in the dementia prediction results may reflect short-term variation in cognitive states and measurement differences. Therefore, we excluded the few cases whose status changed from dementia to normal between two

consecutive waves ($n = 20$) and recoded a small proportion of subjects whose prediction results changed from dementia to CIND in subsequent surveys ($n = 453$). Tests for within-sample fit in ADAMS suggest that our recreated Hurd model demonstrates good predictive power to discriminate dementia cases (sensitivity = 78.0%; specificity = 86.9%); overall, the model correctly classified 83.6% of cases. These performance metrics track closely with those reported by Hurd et al.^{2,3} Details of our recreation of Hurd's dementia prediction model are available in Supplementary Material S1 (data set available from authors).

Measures

We measured knowledge of dementia based on an affirmative answer to the question, "Has a physician told you that you have Alzheimer's disease or dementia?" in the HRS. We identified race and ethnicity (categorized as non-Hispanic white, non-Hispanic black, and Hispanic) based on survey reports in the HRS. Non-Hispanic "other" respondents were excluded from the analyses due to small sample size. Other patient characteristics included age, sex, imputed cognitive scores (TICS scores for self-respondents and IQCODE scores for proxy respondents), ADL and IADL function, number of comorbidities, and place of residence (community or nursing home).

Analysis

We analyzed predicted dementia prevalence rates in years 2001 to 2015 (ie, the time period 1 year after the HRS interview) and survey-reported knowledge of dementia in 2002 to 2014 by race and ethnicity. Among individuals classified as having dementia by the prediction model, we examined racial and ethnic trends in awareness of one's dementia status (ie, whether they recalled receiving a memory problem/Alzheimer's disease/dementia diagnosis from their physician) in all waves in which they participated following the year of initial dementia prediction. For example, for a respondent classified as having dementia in 2001, who

subsequently participated in the 2002, 2006, and 2008 HRS waves, we analyzed her/his survey-reported knowledge of dementia in those years.

We also conducted longitudinal analyses to examine whether knowledge about one's dementia status differed by race and ethnicity, pooling data across eight HRS cohorts from 2000 to 2014. We used a logit-link binomial distribution generalized estimating equation, assuming an unstructured correlation. Our parsimonious model adjusted for age, sex, and HRS survey year; the expanded model further adjusted for cognition, functional limitations, comorbidities, and nursing home status, in addition to age, sex, and year. All analyses adjusted for HRS sampling weights and were conducted using SAS Enterprise Guide 7.1 or STATA 15.1. This study was approved by the Tufts Medical Center/Tufts University Health Sciences Institutional Review Board.

RESULTS

Predicted Dementia Prevalence Rates by Race and Ethnicity

Our analytic sample included 8,686 person-wave observations representing 4,065 unique individuals, aged 70 years or older, with dementia (Supplementary Figure S1), as identified by the prediction model. Predicted dementia prevalence rates in 2001 to 2015 ranged from a high of 13.9% in 2003 and in 2013 to a low of 12.8% in 2009. The model-predicted dementia prevalence was highest among non-Hispanic blacks (range during years 2001-2015 = 21.6%-24.2%), followed by Hispanics (19.0%-21.4%) and non-Hispanic whites (11.4%-12.5%) (Figure 1). Estimated dementia prevalence appeared fairly consistent over time within each racial and ethnic group.

Sample Characteristics

Study participants classified as having dementia in 2001 (the earliest cohort of our analysis) on average had two ADL limitations, two IADL limitations, and almost three

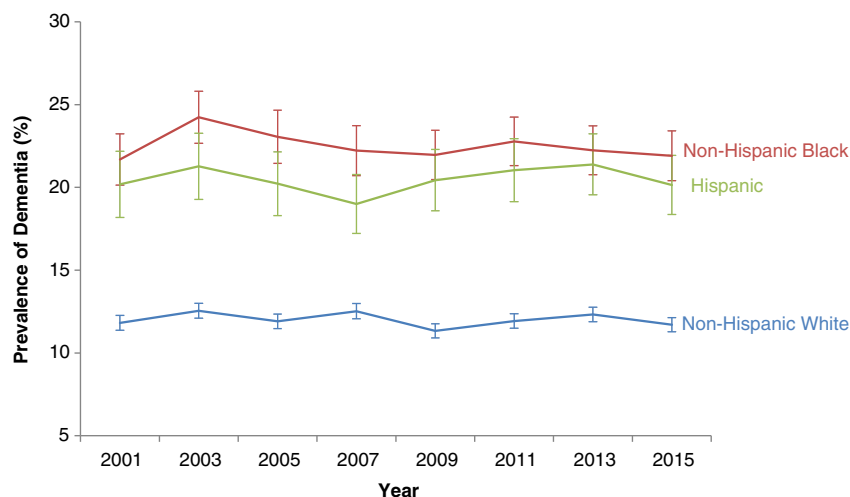


Figure 1. Trends in predicted prevalence rates of dementia by race and ethnicity ($n = 16,052$). *Note.* Sample used for this analysis is Health and Retirement Study respondents meeting criteria for inclusion in the dementia prediction model (box 2 of the consort diagram in Supplementary Figure S1).

Table 1. Characteristics of HRS Participants Classified as Having Dementia

Characteristic	HRS Participants Classified as Having Dementia in 2001			HRS Participants Classified as Having Dementia in 2015		
	Non-Hispanic White (n = 702)	Non-Hispanic Black (n = 199)	Hispanic (n = 107)	Non-Hispanic White (n = 780)	Non-Hispanic Black (n = 213)	Hispanic (n = 136)
Age, y, % ^a						
70-74	6.3	12.2	18.9	2.8	3.7	6.8
75-79	15.7	12.8	17.3	9.7	14.9	13.9
80-84	24.6	29.9	26.0	21.0	27.5	26.0
≥85	56.1	45.1	37.9	66.6	54.0	53.4
Female, % ^a	71.9	70.4	65.4	63.5	72.2	65.8
Proxy respondent, % ^a	61.0	53.7	59.7	40.1	38.9	38.1
TICS score, mean (SD) ^d	9.75 (0.22)	7.44 (0.41)	9.34 (0.44)	9.86 (0.23)	8.77 (0.41)	8.24 (0.41)
IQCODE score, mean (SD) ^e	3.73 (0.05)	3.77 (0.11)	3.64 (0.14)	3.51 (0.06)	3.24 (0.14)	3.47 (0.12)
No. of ADL limitations, mean (SD) ^f	1.96 (0.08)	1.89 (0.17)	1.81 (0.22)	2.00 (0.09)	1.97 (0.16)	2.41 (0.21)
No. of IADL limitations, mean (SD) ^{ag}	2.51 (0.07)	2.31 (0.14)	2.22 (0.19)	2.21 (0.07)	2.31 (0.14)	2.64 (0.18)
No. of comorbidities, mean (SD)	2.63 (0.06)	2.70 (0.12)	2.51 (0.16)	3.31 (0.06)	3.41 (0.14)	3.30 (0.14)
Living in a nursing home, % ^a	37.1	23.6	19.6	25.6	16.0	11.2

Abbreviations: ADL, activity of daily living; HRS, Health and Retirement Study; IADL, instrumental ADL; IQCODE, Informant Questionnaire on Cognitive Decline in the Elderly; TICS, Telephone Interview for Cognitive Status.

^aWeighted percentages/means using the HRS sample weights.

^bWeighted χ^2 test, $P < .5$.

^cWeighted analysis of variance test, $P < .5$.

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

^eOnly for participants who had a proxy respondent. Scale from 0 to 5; lower scores indicate higher cognitive function.

^fNumbers are the reported number of activities (six total) participants have difficulty performing; lower scores indicate higher functional ability.

^gNumbers are the reported number of activities (five total) participants have difficulty performing; lower scores indicate higher functional ability.

other chronic conditions (Table 1). Among self-respondents, non-Hispanic whites had slightly higher average TICS scores (ie, better cognitive function) than non-Hispanic blacks and Hispanics, whereas among those represented by proxy respondents, the three groups had similar average IQCODE scores. More non-Hispanic whites were living in a nursing home (37.1%) compared to non-Hispanic blacks (23.6%) and Hispanics (19.6%). These trends were similar among participants with dementia in 2015 (the latest cohort of our analysis).

Proportion of Subjects Reporting Being Informed of Dementia by Their Physician in the Overall HRS Sample

Of HRS participants aged 70 years or older in 2014 ($n = 7,829$), 7.7% reported that they were informed of the dementia status by their physician (Table 2). More non-Hispanic blacks reported knowing their dementia status (11.6%), compared to Hispanics (9.5%) and non-Hispanic whites (7.1%). The gaps between racial and ethnic groups in predicted dementia prevalence were wider than the gaps in survey-reported knowledge of dementia.

Awareness of One's Dementia Status Among HRS Participants With Dementia

Among subjects identified as having dementia by the prediction model ($n = 4,065$), 43.5% to 50.2% (depending on the HRS survey year) reported that they were informed of the dementia status by their physician (Figure 2). Knowledge of one's

dementia status was lower among Hispanics (25.9%-42.2%) and non-Hispanic blacks (31.4%-50.5%) than among non-Hispanic whites (47.7%-52.9%). Dementia awareness generally improved over time across all racial and ethnic groups.

In adjusted analyses (Table 3), our parsimonious model showed that non-Hispanic black and Hispanic respondents with dementia (as classified by model) were less likely than their non-Hispanic white peers to report being told by a

Table 2. Percentage of HRS Participants With Dementia, by Race and Ethnicity

Variable	Model-Predicted Dementia (2013 HRS, n = 8,144) ^a	Survey-Reported Dementia (2014 HRS, n = 7,829) ^b	κ Statistic
Overall	13.9	7.7	0.490
Non-Hispanic white	12.5	7.1	0.497
Non-Hispanic black	23.1	11.6	0.506
Hispanic	21.7	9.5	0.395

Abbreviation: HRS, Health and Retirement Study.

^aReflects predicted dementia status of respondents who participated in HRS survey years 2010 and 2012, and met the inclusion criteria for the dementia prediction model (this group belongs to box 2 of the consort diagram in Supplementary Figure S1).

^bReflects respondents who participated in the 2014 HRS survey and reported being told by a physician of having dementia.

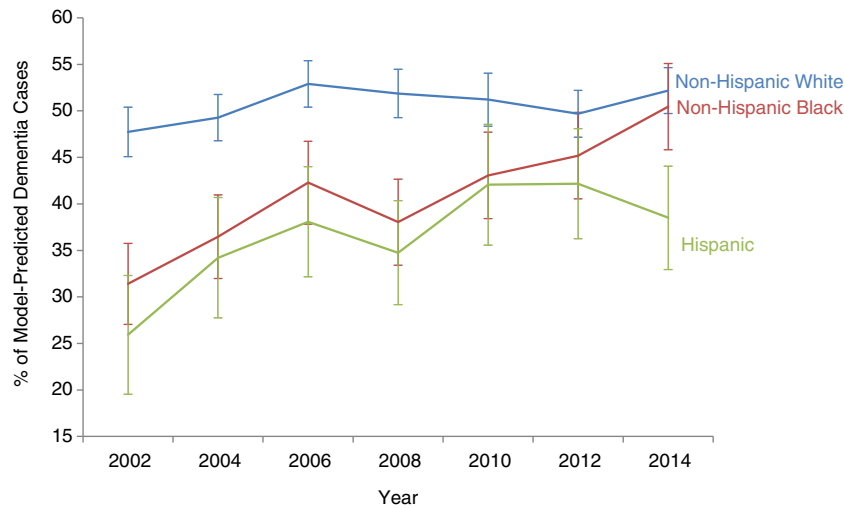


Figure 2. Trends in knowledge about dementia status by race and ethnicity among model-predicted dementia cases (n = 4,065). *Note.* Sample used for this analysis is Health and Retirement Study respondents predicted to have dementia (box 4 of the consort diagram in Supplementary Figure S1). [Color figure can be viewed at wileyonlinelibrary.com]

Table 3. Odds Ratios (95% Confidence Intervals) of Reporting Being Told of Dementia by a Physician Among Model-Predicted Dementia Cases

Variable	Model 1	Model 2
Race and ethnicity		
Non-Hispanic white	Reference	Reference
Non-Hispanic black	0.66 (0.53-0.83)	0.74 (0.58-0.93)
Hispanic	0.61 (0.46-0.80)	0.60 (0.43-0.85)
Age, y		
70-74	1.48 (1.02-2.14)	1.46 (0.89-2.38)
75-79	1.53 (1.22-1.92)	1.55 (1.17-2.06)
80-84	1.15 (0.98-1.36)	1.33 (1.10-1.60)
≥85	Reference	Reference
Female vs male	1.29 (1.06-1.57)	1.12 (0.91-1.40)
HRS survey year	1.09 (1.07-1.11)	1.05 (1.03-1.07)
Cognitive impairment ^a		1.31 (0.98-1.76)
No. of ADL limitations ^b		1.00 (0.96-1.03)
No. of IADL limitations ^c		1.65 (1.56-1.75)
No. of comorbidities		1.03 (0.97-1.09)
Living in a nursing home		2.77 (2.32-3.32)

Note: Sample used for the analyses corresponds with box 5 of the consort diagram in Supplementary Figure S1 (n = 2,367 respondents). The analyses used a weighted logit-link binomial distribution generalized estimating equation, assuming an unstructured correlation structure. We used average sample weights of each HRS respondent, following National Health and Nutrition Examination Survey guidelines on combining survey cycles. The results had little to no change when using participants' combined, first, last, or first year predicted to have dementia HRS wave-specific sample weights. Abbreviations: ADL, activity of daily living; HRS, Health and Retirement Study; IADL, instrumental ADL.

^aCognitive function combined normalized Telephone Interview for Cognitive Status scores and Informant Questionnaire on Cognitive Decline in the Elderly scores based on whether participants had a proxy respondent (0 = no impairment; 1 = high impairment).

^bNumbers are the reported number of activities (total of six) participants have difficulty performing; lower scores indicate higher functional ability.

^cNumbers are the reported number of activities (total of five) participants have difficulty performing; lower scores indicate higher functional ability.

physician that they had dementia (odds ratio [OR] = 0.66 [95% confidence interval [CI] = 0.53-0.83] and OR = 0.61 [95% CI = 0.46-0.83], respectively). Similarly, the expanded model adjusting for additional patient characteristics also indicated lower dementia awareness among non-Hispanic blacks (OR = 0.74; 95% CI = 0.58-0.94) and Hispanics (OR = 0.60; 95% CI = 0.43-0.85), compared to non-Hispanic whites. Having more IADL limitations (OR = 1.65; 95% CI = 1.56-1.75) and living in a nursing home (OR = 2.77; 95% CI = 2.32-3.32) were associated with increased odds of reporting being told about dementia by a physician. Supplementary Table S1 summarizes baseline characteristics of these respondents.

DISCUSSION

Leveraging nationally representative survey data with unique cognitive measures, our study found that less than half of those with dementia (as identified by a prediction model) reported being told by a physician about the condition. Awareness of one's dementia status improved in more recent years in all racial and ethnic groups. Our modeling results showed that dementia prevalence rates may be nearly twice as high among non-Hispanic blacks and 1.7 times as high among Hispanics, compared to non-Hispanic whites. A higher proportion of non-Hispanic black and Hispanic patients with dementia may be unaware of their condition, despite higher dementia prevalence in these groups, compared to non-Hispanic whites.

Why are there ethnorracial differences in dementia awareness? We consider two possibilities. First, levels of undiagnosed dementia may vary across populations (ie, diagnosis disparity). Although undiagnosed dementia in its early stages is a general phenomenon, it may be more common among non-Hispanic blacks and Hispanics than among non-Hispanic whites.^{2,17-21} Racial and ethnic minority groups also may experience additional barriers, such as less knowledge about dementia and inferior access to healthcare services.³⁰ Ethnorracial differences in dementia prevalence found in our model prediction were

greater than claims-based estimates reported in the literature,³¹ also suggesting more frequent undiagnosed dementia among non-Hispanic blacks and Hispanics.

Second, some groups may be less likely to be informed of their illness by their healthcare providers (ie, disclosure disparity). Although not specifically about dementia, some evidence indicates that provider bias may affect their disease disclosure or treatment decisions in certain ethnorracial groups.³²⁻³⁴ Suboptimal communication of diagnostic findings to dementia patients and their caregivers is problematic because it prevents or delays access to timely medical and supportive care. Besides diagnosis and disclosure disparities, it is possible that some people may be reluctant to report they have dementia and some may perceive memory loss as part of normal aging, thus underrecognizing the condition. However, because differences between each of these two ethnorracial groups and non-Hispanic whites observed in our study show consistent patterns, it is unlikely such differences are due to personal or cultural factors.

Our study results, whether they reflect diagnosis disparity, disclosure disparity, or both, have important implications for community education and provider training. We found that reporting about being informed of dementia has increased in recent years, suggesting that disease awareness may have generally improved in the community. Still, roughly half of dementia patients or their caregivers in our study may be unaware of the condition. Prior research comparing claims-based dementia diagnosis and survey-reported knowledge of dementia also found approximately half of Medicare beneficiaries diagnosed with dementia may not know they had the condition.⁹ These findings highlight an important unmet need in dementia care. As proposed in Healthy People 2020, increasing awareness of dementia diagnosis among individuals with the condition and their caregivers is an important policy goal.¹ Our findings call for system changes to promote early detection and assessment of dementia and better communication of the diagnosis. More important, such efforts should target diverse communities, especially those with disproportionately high dementia prevalence and low awareness. These interventions should develop culturally appropriate education, based on community and other stakeholder input,³⁵ to increase awareness and knowledge about cognitive health. Lacking knowledge about early signs of dementia among some ethnorracial minority groups, rather than culturally influenced beliefs, has been identified as a key deterrent to memory assessment in older adults.³⁶

Furthermore, provider training in making and delivering a dementia diagnosis also needs improvement. Training programs should promote culturally sensitive and competent dementia care, such as using a tailored approach to communicate dementia diagnostic information.^{17,36-38} For example, some individuals may prefer a direct disclosure, whereas others may benefit from having the physician ease them into the dementia diagnosis.³⁷ Despite concerns about causing an emotional reaction, studies of the general population and people with dementia and their caregivers all suggest the desire of knowing.^{12,17,36} Physicians should work with the person with dementia and her/his care partner(s) to understand preferences for diagnostic disclosure, as recommended by the Alzheimer's Association Clinical Practice Guidelines.³⁹

Because HRS lacks a direct measure of dementia status and because there is no uniformly accepted definition of

dementia in observational studies, we rely on a statistical model to identify subjects with dementia. Our approach has the advantage of including patients who otherwise may have been missed by using claims-based dementia diagnoses. Studies linking Medicare claims records and clinical dementia assessments have reported that Medicare claims correctly identify roughly 85% of patients with dementia, but the sensitivity by race and ethnicity is less clear due to lacking sufficient sample sizes.^{15,40} The Hurd model has been well validated and may outperform other dementia prediction algorithms, such as those cutoff-based approaches that classify dementia status based solely on summary cognitive and/or functional scores.⁴¹ Our recreated Hurd model demonstrates good predictive performance in ADAMS not only among non-Hispanic whites (sensitivity = 75.1%; specificity = 91.0%), but also among non-Hispanic blacks (sensitivity = 84.8%; specificity = 76.7%) and Hispanics (sensitivity = 91.3%; specificity = 75.4%). Newly available data from the HRS-linked Healthy Cognitive Aging Project with dementia ascertainment information could help assess model prediction results across ethnorracial subgroups in a large, nationally representative sample.

Several study limitations warrant consideration. First, some individuals, especially self-respondents with dementia, may not recall whether being told that they have the condition. However, consistent with prior research,¹⁰ our data showed that individuals who had more severe cognitive and functional limitations were more likely than those with milder impairment to report having dementia. Moreover, self-report or proxy report of dementia in survey data is an important source for case ascertainment and may identify more dementia cases than diagnosis codes in medical claims.⁹ Second, self-respondents and subjects using proxies may have different patterns for reporting knowledge of dementia status. In our data, sample members using proxy informants had poorer cognitive function, more functional impairments, and more comorbidities than self-respondents. These trends are consistent with the fact that the HRS includes interviews of proxy informants when sample members are unable to complete an interview due to physical or cognitive limitations. In our adjusted analyses, including proxy status in the expanded model did not have an impact on the relationship between dementia awareness and race/ethnicity or other patient characteristics. Although proxy interviews are not a perfect substitute, prior research has shown that excluding proxy responses may introduce more biases than including them.⁴² In fact, by integrating the use of proxies into the study design, HRS data can minimize sample composition bias on cognitive function due to attrition and nonresponse.⁴² Third, our analyses were restricted to individuals aged 70 years or older. We found that younger individuals may be more likely to report being told about having dementia, although the differences by race and ethnicity might not fully generalize to a younger population.

Using national survey data with unique cognition measures, we found that less than half of individuals with dementia may be aware of their condition, and this problem may be more pronounced among some ethnorracial minority groups. Our analyses highlight important unmet needs in diagnosing dementia and communicating the diagnosis effectively. These findings call for improvement in dementia diagnostic services to assist underserved populations and their families. Dementia outreach programs should target diverse communities with

disproportionately high disease prevalence and low awareness. Moreover, provider training should include communication skills tailored to patient and caregiver needs and preferences. Further qualitative and quantitative research is critical to understanding healthcare barriers to dementia assessment among different racial and ethnic groups.

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SUPPORTING INFORMATION

Additional Supporting Information may be found in the online version of this article.

Supplementary Material S1: Supporting Information.

Supplementary Figure S1: Consort diagram.

Supplementary Table S1: Baseline Characteristics of HRS Participants in GEE Model of Reporting Being Told About Dementia by a Physician.