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RESEARCH ARTICLE

Dementia severity at incident diagnosis in a population representative sample of older Americans

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Abstract

INTRODUCTION: We provide the first analysis of distribution of dementia severity at incident diagnosis for a population representative sample of older Americans.

METHODS: Using data from the Aging, Demographics, and Memory Study (ADAMS), the Health Retirement Study (HRS), and traditional Medicare claims, we estimated the Clinical Dementia Rating Scale for ADAMS respondents and applied parameter estimates to predict dementia severity for HRS respondents with claims-based incident dementia diagnosis.

RESULTS: Seventy percent of older adults received a dementia diagnosis of mild cognitive impairment or mild dementia (early stages). Fewer individuals were diagnosed at early stages in years 2000 to 2008 (65%) compared to years 2009 to 2016 (76%). About 72% of non-Hispanic white persons were diagnosed at early stages, compared to 63% non-Hispanic black and 59% Hispanic persons. More males than females were diagnosed at early stages (75% vs 67%).

DISCUSSION: These data linkages allow population surveillance of early and equitable dementia detection in the older US population to assess clinical and policy levers to improve detection.

KEYWORDS
health disparities, dementia severity, racial/ethnic minorities, timely dementia diagnosis

Highlights

- For the US population 70 and older, 30% were diagnosed with dementia at a moderate or severe stage.
- Fewer were diagnosed at early stages in years 2000 to 2008 compared to 2009 to 2016 (65% vs 76%).
- A total of 72% of white persons were diagnosed at early stages, compared to 63% black and 59% Hispanic persons.
- More males than females were diagnosed at early stages (75% vs 67%).
- High wealth and education level were associated with diagnosis at early stages disease.

1 | BACKGROUND

Dementia has a substantial impact on the quality of life and financial resources of the 6.7 million persons in the US living with dementia and their families.[1] The average annual total cost for a person living with dementia was over $70,000 in 2010, including medical care costs and the value of the time provided by unpaid caregivers and care partners, and this number is projected to double by 2050.[2] Diagnosis at more advanced dementia stages is associated with higher health care utilization and costs and creates additional economic strain on families and the health system due to increased preventable hospitalizations, emergency department visits, and frequent transitions of care.[3–11] Early diagnosis, before symptoms impair cognitive and physical processes, facilitates connecting to social services, and planning for future financial, health care, and long-term care needs.[12,13] Early diagnosis also supports opportunities for clinical trial participation and eligibility for new treatments.[14] Despite the importance for early detection, knowledge of the stage at which dementia is diagnosed in the older US population is limited.

Multiple population studies have documented undetected or delayed diagnoses of dementia in the older US population and reported higher rates among black and Hispanic older adults.[15–17] For example, one study comparing dementia based on cognitive tests in survey data and dementia diagnosis codes in Medicare claims found that black and Hispanic persons were 3.8 times and 2.9 times, respectively, as likely as white persons to have dementia based on cognitive tests but no dementia diagnosis.[15] Using a similar approach, another study reported that 46% black and 54% Hispanic older adults qualified for a missed or delayed dementia diagnosis compared to 41% white older adults.[16] Despite documented disparities in timely dementia diagnoses, there is a gap in measures of the population distribution of stage or severity of dementia at the time of diagnosis and for different racial and ethnic groups.

Dementia severity is often measured in clinical and research settings using the Washington University Clinical Dementia Rating (CDR) scale. The CDR is a clinician-rated dementia staging instrument designed to clinically quantify dementia severity based on the participant's performance in multiple domains.[18] Despite being validated and widely used in clinical and research settings, the CDR is not available in large, longitudinal nationally representative data sources widely used for dementia research such as the Health and Retirement Study (HRS). The Aging, Demographics, and Memory Study (ADAMS), a subsample of HRS respondents aged 70 and older, evaluates the CDR by a clinical professional. However, the ADAMS is limited by small sample sizes that preclude estimates for different racial/ethnic groups and the lack of follow-up over time precludes measuring changes over time.

In this study, we bring together rich population survey data from the HRS and ADAMS, and traditional Medicare (TM) claims administrative data to estimate the distribution of dementia severity at time of diagnosis for the older US population and separately for non-Hispanic black, Hispanic, and non-Hispanic white persons. We characterize the associated social, economic, and health factors and compare changes in the distribution of severity at diagnosis over time. Results from the

RESEARCH IN CONTEXT

1. **Systematic review**: The authors reviewed the literature on the timing and disparities in dementia diagnosis using traditional sources (eg, PubMed, Google Scholar). While disparities in dementia diagnoses are relatively well studied, there is a gap in measures of the population distribution of stage or severity of dementia at incident diagnosis. The relevant citations are appropriately cited.

2. **Interpretation**: Our findings contribute to the understanding of the distribution of dementia severity at diagnosis for the older US population and for different racial and ethnic groups. The dementia severity measure, made available to the research community, is useful for studying drivers of heterogeneity in care and spending after a dementia diagnosis.

3. **Future directions**: Future work may use ongoing data collection and Medicare claims data releases for surveillance of changes in population dementia severity at diagnosis over time and use severity measure to quantify its association with variation in health care and social costs.

study provide first estimates of the population distribution of dementia severity at diagnosis. This information is increasingly important for assessing the potential of new treatments targeting early-stage disease to impact the population burden of dementia, and associated factors pointing to barriers and opportunities to improve early and equitable dementia detection. This study supports continued quantification of population time trends in early and equitable dementia detection in the older US population to assess and identify clinical and policy levers to improve detection. Dementia severity at diagnosis may be one mechanism contributing to disparities in mortality, health, and financial outcomes, and health care use that in prior population studies were not accounted for due to data and measurement limitations. Therefore, estimates of dementia severity at diagnosis from this study may also inform future research on the heterogeneity in outcomes for persons living with dementia. Thus, we provide, as Supplementary material, detailed Technical Documentation and code for replicating the severity measure for use by the research community.

2 | METHODS

2.1 | Data and study population

We used data from the HRS linked to TM claims and the ADAMS. The HRS is a nationally representative longitudinal study that has surveyed US adults aged 50 years and older and their spouses biennially since 1992.[19] We used data from the HRS on respondents who consented to have their data linked to TM claims records for years 2000

TABLE 1 Sample selection criteria for the study population.

Sample selection criteria	N
HRS respondents with linked TM claims data in 2000–2016	23,856
Three-year continuous TM enrollment and incident dementia	4435
Aged 70 years and older	4074
HRS interview up to 12 months before or up to 6 months after incident dementia	2021
Complete data on cognitive or functional limitations	2015

Abbreviations: HRS, Health and Retirement Study; TM, traditional Medicare.

to 2016. Eighty-eight percent of HRS respondents agreed to have their survey responses linked to their Medicare claims.[20] Medicare administrative data are an important resource for studying dementia diagnosis in the older US population as the program provides insurance coverage for almost all adults older than 65. Because the HRS and the Medicare claims do not include a clinically evaluated measure of dementia status, we also used the ADAMS, a subsample of HRS respondents who were 70 and older from the 2000 and 2002 HRS waves.[21] In the ADAMS, a consensus dementia diagnosis was determined based on a 3- to 4-h at-home structured assessment by a clinical professional and a panel review. During the assessment, a CDR score was assigned to the respondent to stage the severity of dementia based on cognitive and functional performance.[21,22]

We used 856 ADAMS Wave A participants to model CDR based on demographics, cognitive status, functional limitations, and behavioral symptom measures—predictors that were also available for all HRS respondents. We excluded four ADAMS respondents with missing data on cognitive and functional limitations. Our main study population was drawn from HRS respondents with linked TM claims data in 2000 to 2016 who had an incident dementia diagnosis on a claim that was verified over time by a second diagnosis on a claim, and who were aged 70 years and older (to match those in the ADAMS). We required HRS respondents to have had an interview within 12 months leading up to a dementia diagnosis or within 6 months after the dementia diagnosis. The sample selection criteria are detailed in Table 1. The final sample of 2015 unique persons consisted of 1577 non-Hispanic white (78.3%), 285 non-Hispanic black (14.1%), 119 Hispanic (5.9%), and 34 other race (1.7%) persons.

2.2 | Incident dementia diagnosis

Incident dementia diagnosis is a measure of the first diagnosis of dementia adjusting for the possibility of a rule-out diagnosis utilizing longitudinal diagnosis measures. We identify a dementia diagnosis in TM claims using International Classification of Diseases, Ninth and Tenth revisions (ICD-9 and ICD-10) codes listed in Table S1 and employing a rigorous algorithm for measuring diagnosed dementia in claims that is described in detail in a prior publication and publicly available.[23] Briefly, dementia cases were ascertained using a combi-

nation of dementia diagnosis codes and dementia symptom codes. To ensure that we capture incident dementia diagnoses, we required a two-year "wash-out" period with no dementia diagnosis prior to the year of incident dementia diagnosis. To exclude potential rule-out diagnoses, we required a dementia diagnosis to be followed by a second diagnosis or symptom code within two years or death within one year. Dementia diagnosis and symptom codes are identified in the inpatient, outpatient, skilled nursing facility, home health care, and carrier settings. Dementia symptom codes are used only in combination with dementia diagnosis codes and at a different time point for verification. This algorithm was found to improve the identification of diagnosed dementia among minority populations in claims data.[23]

2.3 | Dementia severity measure

The CDR in ADAMS is a dementia staging scale that quantifies the severity of dementia in six areas: memory, orientation, judgment and problem-solving, community affairs, home and hobbies, and personal care.[18] In the ADAMS, the CDR score is determined by a trained clinical professional during a structured interview with both study participants and informants.[21] The ADAMS CDR score is distinct from the 5-point scale version, as it is a 7-point scale and ranges from 0 to 5: 0 (No dementia); 0.5 (Mild cognitive impairment or questionable/very mild dementia); 1 (Mild dementia); 2 (Moderate dementia); 3 (Severe dementia); 4 (Profound dementia); and 5 (Terminal dementia). We examined characteristics of respondents across CDR scores in the ADAMS. Based on this, and to address small subgroup size and to facilitate distinguishing no/mild dementia from later stages of dementia, we combined CDR scores 2 and 3 and scores 4 and 5. Our recategorized CDR score ranges from 0 to 4 as follows: 0 (CDR = 0); 1 (CDR = 0.5); 2 (CDR = 1); 3 (CDR = 2 or CDR = 3); and 4 (CDR = 4 or CDR = 5).

2.4 | Model of dementia severity

We modeled and estimated the recategorized CDR score in the ADAMS sample using regressions with the following key predictor variables of CDR: age, sex, race, education level, cognitive function, activities of daily living (ADLs), instrumental activities of daily living (IADLs), depression status, and whether a proxy responded for the participant. We tested multiple models, including Ordinary Least Squares, Poisson, Negative Binomial, Zero-inflated Negative Binomial, Logistic, and Ordered Probit regressions. There were no large differences across models and we selected the Poisson regression model based on overall prediction accuracy in the ADAMS sample. Functional limitations are measured by five ADLs (bathing, eating, dressing, walking across a room, and getting in or out of bed) and five IADLs (using a telephone, taking medication, handling money, shopping, and preparing meals).[19] We operationalized ADLs and IADLs as follows: no difficulty, 1–2 difficulties, and 3–5 difficulties. We measured cognitive function following a validated method.[24] Using either self-reported cognitive tests or proxy-reported memory and functions
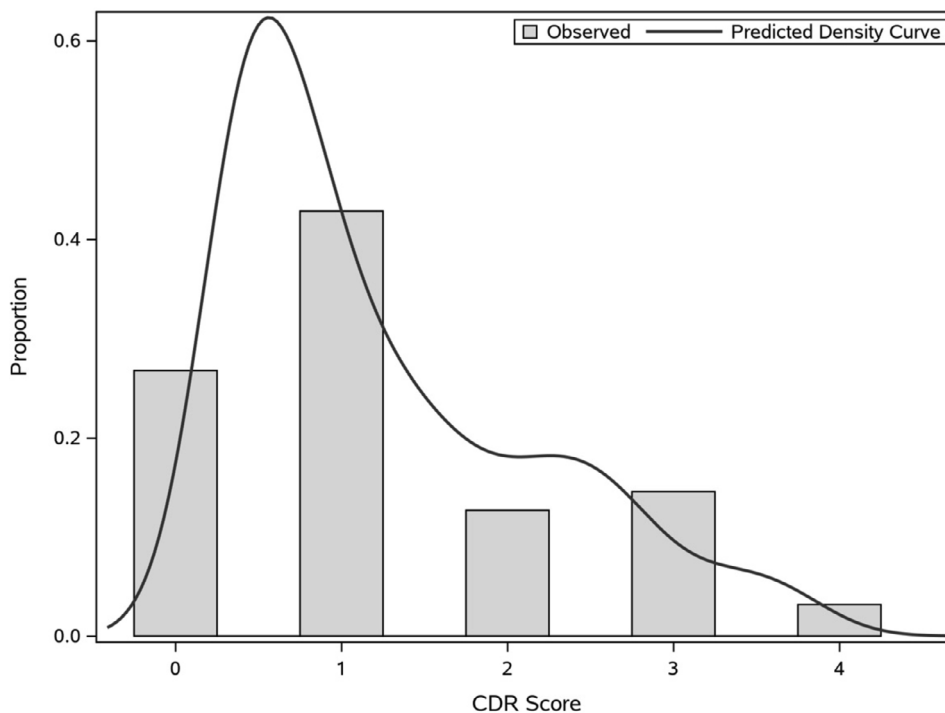
FIGURE 1 Observed and predicted CDR score in the ADAMS Sample. The sample comprises 852 respondents in the ADAMS Wave A. ADAMS, Aging, Demographics, and Memory Study; CDR, clinical dementia rating.

in the HRS, this method classifies individuals into three categories of cognitive status: dementia, cognitive impairment but no dementia (CIND), and normal. Depression symptoms are measured using the eight-item Center for Epidemiologic Studies Depression (CESD) scale in the HRS (or the self-reported Composite International Diagnostic Interview-Short Form [CIDI-SF] in the ADAMS). We operationalized depression status as follows: depression (CESD score of ≥3 or CIDI-SF score of ≥5), no depression, and missing depression scores. Information on age (continuous), sex (whether female), race (non-Hispanic white, non-Hispanic black, Hispanic, non-Hispanic other), education level (<12 years, 12 to 15 years, and ≥16 years), and whether a proxy responded for the participant was also retrieved. Table S2 reports the distribution of characteristics listed above by CDR category in the ADAMS and Table S3 provides estimates from the Poisson regression.

Figure 1 shows the density curve of the full distribution of the predicted CDR scores as compared to the observed CDR scores in the ADAMS. In Table S4, we include additional assessment of the within-sample model fit (eg, overall accuracy rate, Kappa estimates) by comparing the distribution of predicted CDR categories (predicted CDR scores are rounded to the 0.25 place and binned) with the distribution of observed CDR categories in ADAMS. Table S5 shows the pseudo R-squared test statistic for models that include only cognitive status and compares to the full model with additional covariates that are associated with severity of dementia. Additional Technical Documentation in the Supporting Information provides details for recreating the dementia severity measure including how the variables were operationalized and recoded, and how missing observations were

handled and results from tests of sensitivity of the predicted estimates to the Poisson model.

2.5 | Predicted dementia severity

We applied the model parameters from the Poisson regression estimated in ADAMS to all HRS respondents 70 years of age and older with incident dementia diagnosis identified in TM claims data. We predicted the CDR for each HRS respondent based on the model. We categorized the predicted severity score into the following groups: mild cognitive impairment (CDR < 0.5); mild dementia (0.5 ≤ CDR < 1.5); moderate dementia (1.5 ≤ CDR < 2.5); and severe dementia (CDR ≥ 2.5).

2.6 | Analysis

We reported the distribution of dementia severity based on the predicted score and reported the percent distribution across dementia severity categories by time, for years 2000 to 2008 compared to years 2009 to 2016, and by race/ethnicity and sex. We described individual level demographic (age, sex, marital status), socioeconomic (highest education level, wealth, nursing home status), and diagnosed comorbid health conditions at the time of dementia diagnosis associated with different categories of dementia severity at diagnosis. We used TM claims diagnosis codes and Chronic Conditions Data Warehouse (CCW) algorithms to identify respondents with comorbid health conditions of stroke, diabetes, hypertension, hyperlipidemia, acute
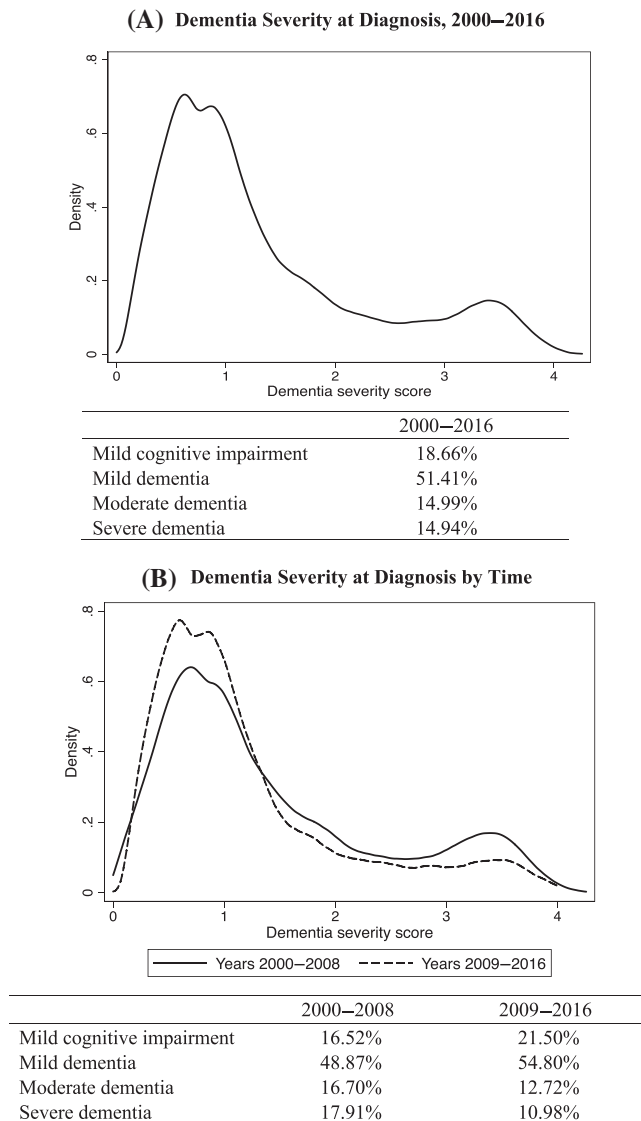
(A) Dementia Severity at Diagnosis, 2000–2016

	2000–2016
Mild cognitive impairment	18.66%
Mild dementia	51.41%
Moderate dementia	14.99%
Severe dementia	14.94%

(B) Dementia Severity at Diagnosis by Time

Years 2000–2008 - - - - - Years 2009–2016

	2000–2008	2009–2016
Mild cognitive impairment	16.52%	21.50%
Mild dementia	48.87%	54.80%
Moderate dementia	16.70%	12.72%
Severe dementia	17.91%	10.98%

FIGURE 2 Distribution of predicted dementia severity score and percent distribution across dementia severity categories at incident dementia diagnosis, for a sample of HRS respondents aged 70 and older with diagnosed dementia. (A) Overall distribution for the years 2000 to 2016 (n = 2015). (B) Distribution stratified by time, for years 2000 to 2008 (n = 1150) compared to years 2009 to 2016 (n = 865). HRS, Health and Retirement Study.

myocardial infarction, atrial fibrillation, congestive heart failure (CHF), and ischemic heart disease at the time of dementia diagnosis.

3 | RESULTS

### 3.1 | Distribution of dementia severity at diagnosis

Figure 2A shows the distribution of predicted dementia severity score at the time of incident dementia diagnosis among all HRS respondents 70 years of age and older. The predicted severity score ranged from

0.29 to 4.26. Seventy percent of individuals were diagnosed at MCI or mild stages of disease. The average severity score at incident dementia was 1.32 (SD = 0.95), which was equivalent to mild dementia. The median severity score at diagnosis was 0.99. Fifteen percent of individuals had a severity score between 1.5 and 2.5, equivalent to moderate dementia. Fifteen percent scored higher than 2.5 at the time of incident dementia, equivalent to severe dementia.
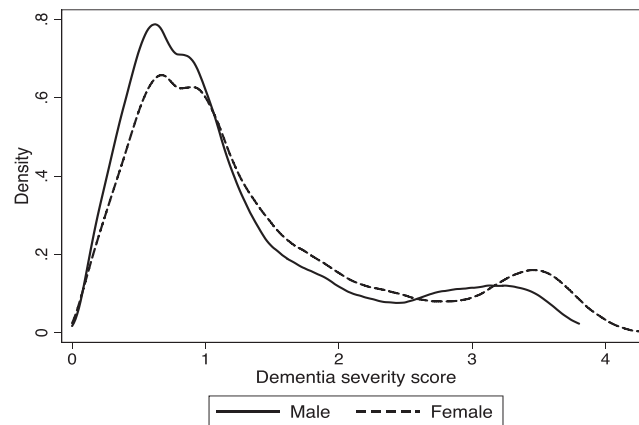
Figure 2B shows the distribution of predicted dementia severity scores at diagnosis by time, for years 2000 to 2008 compared to years 2009 to 2016. In years 2000 to 2008, the average and median severity score at incident dementia were 1.42 and 1.06, respectively (SD = 0.99). In contrast, the average and median severity scores at diagnosis for years 2009 to 2016 were 1.20 and 0.90, respectively (SD = 0.87). The distribution of the predicted dementia severity score in 2009 to 2016 was statistically different from 2000 to 2008 (Table S6). In particular, more people were diagnosed at MCI and mild stages of the disease in 2009 to 2016 compared to 2000 to 2008 (76% vs 65%).

Figure 3A compares the distribution of predicted dementia severity scores at diagnosis by race/ethnicity. At the time of incident diagnosis, non-Hispanic white persons had the lowest dementia severity score on average (1.27) and at the median (0.93). Hispanic persons had the highest mean and median severity score (1.54 and 1.36, respectively), followed by non-Hispanic black persons (1.52 and 1.18, respectively). About 72% of non-Hispanic white persons were diagnosed at MCI or mild stages of dementia. Fewer, 63% non-Hispanic black persons and 59% Hispanic persons, were diagnosed at MCI or mild stages of the disease. The distribution of the predicted dementia severity score at diagnosis among non-Hispanic black and Hispanic persons was statistically different from non-Hispanic white persons (Table S7). Table 3 compares the distribution of predicted dementia severity categories at diagnosis by race/ethnicity over time, in years 2000 to 2008 compared to years 2009 to 2016. In years 2000 to 2008, 58% non-Hispanic black and 56% Hispanic older adults were diagnosed at MCI or mild stages of dementia, compared to 68% non-Hispanic white older adults. Racial/ethnic differences in dementia severity at diagnosis remained in years 2009 to 2016: 70% non-Hispanic black and 66% Hispanic persons were diagnosed at MCI or mild stages of the disease, compared to 78% non-Hispanic white persons.

Figure 3B compares the distribution of predicted dementia severity scores at diagnosis by sex. At the time of incident dementia diagnosis, the average and median severity scores among males were 1.21 and 0.90, respectively (SD = 0.87). In contrast, the average and median severity scores at diagnosis among females were 1.39 and 1.04 (SD = 0.98). The distribution of the predicted dementia severity score at diagnosis was statistically different by sex (Table S8). More males were diagnosed at MCI and mild stages of dementia compared to females (75% vs 67%). Table 3 compares the distribution of predicted dementia severity categories at diagnosis by sex over time. In years 2000 to 2008, 70% of males and 63% females were diagnosed at MCI and mild stages of dementia. The sex difference remained in years 2009 to 2016: 80% male and 74% female older adults were diagnosed at MCI and mild stages of dementia.

(A) Dementia Severity at Diagnosis by Race/Ethnicity, 2000—2016
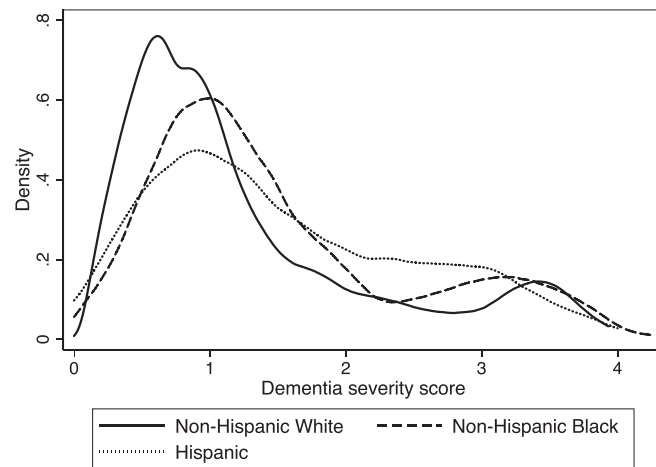
	Non-Hispanic White	Non-Hispanic Black	Hispanic
Mild cognitive impairment	21.12%	9.12%	10.08%
Mild dementia	51.24%	53.68%	48.74%
Moderate dementia	14.08%	18.25%	19.33%
Severe dementia	13.57%	18.95%	21.85%

(B) Dementia Severity at Diagnosis by Sex, 2000—2016

	Male	Female
Mild cognitive impairment	21.66%	16.94%
Mild dementia	53.13%	50.43%
Moderate dementia	12.40%	16.47%
Severe dementia	12.81%	16.16%

FIGURE 3 Distribution of predicted dementia severity score and percent distribution across dementia severity categories at incident dementia diagnosis, stratified by race/ethnicity and sex, for a sample of HRS respondents aged 70 and older with diagnosed dementia. (A) Distribution among non-Hispanic white ($n = 1577$), non-Hispanic black ($n = 285$), and Hispanic persons ($n = 119$). (B) Distribution among males ($n = 734$) and females ($n = 1281$). HRS, Health and Retirement Study.

3.2 | Characteristics of respondents by dementia severity at diagnosis

Table 2 reports characteristics by dementia severity categories at incident diagnosis. Mean age at incident dementia diagnosis was 83.54 years. On average individuals diagnosed at moderate and severe dementia stages were older (86.82 and 86.08 years, respectively) than those diagnosed at MCI and mild dementia stages (80.24 and 83.04

years, respectively). Individuals diagnosed at MCI were the most educated, with 28.72% of them having a bachelor's degree or higher. Only 8.28% and 9.63% of those diagnosed at moderate and severe stages of the disease completed college. Persons diagnosed at moderate and severe stages were more likely to be without a spouse or partner (69.21% and 73.09%) than persons diagnosed at MCI and mild stage disease (46.54% and 57.05%). Wealth was also associated with diagnosis at early stages of dementia. Median wealth was $288,731 and

TABLE 2 Sample characteristics by dementia severity at incident diagnosis.

	All	MCI (CDR < 0.5)	Mild (0.5 ≤ CDR < 1.5)	Moderate (1.5 ≤ CDR < 2.5)	Severe (CDR ≥ 2.5)
N	2015	376	1036	302	301
Mean age (SD), years	83.54 (6.94)	80.24 (5.93)	83.04 (6.61)	86.82 (7.05)	86.08 (6.86)
Female, %	63.57	57.71	62.36	69.87	68.77
Education, %					
Less than high school	34.14	13.30	32.92	48.68	49.83
High school/some college	50.77	57.98	53.38	43.05	40.53
College and above	15.09	28.72	13.71	8.28	9.63
Single, %	59.31	46.54	57.05	69.21	73.09
Total wealth quartile, %					
1st quartile	28.64	14.89	26.64	36.42	44.85
2nd quartile	25.91	20.21	27.22	32.45	21.93
3rd quartile	23.42	30.85	23.84	19.21	16.94
4th quartile	22.03	34.04	22.30	11.92	16.28
Median total wealth, 2016$	129,769	288,731	135,818	61,474	56,852
Comorbidity, %					
AMI	10.57	9.57	10.42	10.60	12.29
ATF	26.55	23.67	26.74	31.46	24.58
Stroke	32.80	26.33	31.56	40.40	37.54
Diabetes	39.06	37.23	39.58	42.72	35.88
Hypertension	89.63	87.50	89.86	94.70	86.38
Hyperlipidemia	70.97	78.72	73.17	68.21	56.48
CHF	50.52	43.35	48.36	62.25	55.15
IHD	69.63	66.76	69.79	74.17	68.11
Live in nursing home, %	13.35	*	7.43	17.55	43.52

Note: Sample comprises HRS respondents aged 70 and older with diagnosed dementia in years 2000–2016.
Abbreviations: AMI, acute myocardial infarction; ATF, atrial fibrillation; CDR, Clinical Dementia Rating; CHF, congestive heart failure; IHD, ischemic heart disease; MCI, mild cognitive impairment.
[a]Total wealth quartiles are relative to the position in this sample.
[b]Values with * are censored (n < 25).

TABLE 3 Distribution of dementia severity at diagnosis over time by race/ethnicity and by sex.

	Non-Hispanic white		Non-Hispanic black		Hispanic	
	2000–2008	2009–2016	2000–2008	2009–2016	2000–2008	2009–2016
MCI	19.21%	23.58%	5.65%	14.81%	9.52%	10.71%
Mild dementia	48.54%	54.73%	52.54%	55.56%	46.03%	54.79%
Moderate dementia	16.29%	11.21%	18.64%	17.59%	17.46%	21.43%
Severe dementia	15.96%	10.48%	23.16%	12.04%	26.98%	16.07%
	Male		Female			
	2000–2008	2009–2016	2000–2008	2009–2016		
MCI	20.74%	22.80%	14.23%	20.71%		
Mild dementia	49.63%	57.45%	48.46%	53.17%		
Moderate dementia	13.83%	10.64%	18.26%	13.99%		
Severe dementia	15.80%	9.12%	19.06%	12.13%		

Note: Sample comprises HRS respondents aged 70 and older with diagnosed dementia in years 2000 to 2016. .
Abbreviation: MCI, mild cognitive impairment.

$135,818 among persons with MCI and mild disease at diagnosis. This compares to $61,474 and $56,852 among those with moderate and severe disease at diagnosis, respectively. Among individuals diagnosed at severe stage disease, 43.52% were living in nursing homes, compared to 7.43% at mild stage and 17.55% at moderate stage. Persons diagnosed at later stages of dementia had higher rates of stroke and CHF compared to persons diagnosed at MCI and mild stages. Among persons diagnosed at severe stage dementia, 37.54% had a diagnosis of stroke, 55.15% had a diagnosis of CHF, and 12.29% had a diagnosis of acute myocardial infarction. Table S9 provides the statistical difference in distribution of sample characteristics among persons diagnosed at mild, moderate, and severe dementia relative to persons diagnosed at MCI.

4 | DISCUSSION

A measure of dementia severity is currently unavailable in large, nationally representative longitudinal studies. Using the ADAMS and the HRS-linked TM claims data, this study is the first to examine the distribution of dementia severity at the time of incident dementia diagnosis for a broadly representative sample of older US adults. Administrative data are an important data source for measuring incident and prevalent rates of diagnosed dementia in the population and for examining time trends. However, data are limited for assessing whether the diagnosis is "timely." We developed and utilized a dementia severity measure which approximates the validated CDR to measure dementia severity at the time of first diagnosis among a sample of HRS respondents aged 70 years and older who are enrolled in TM. Quantifying the population distribution of dementia severity at diagnosis provides increasingly important information for assessing the potential of new treatments targeted at early-stage disease to impact population burden of dementia. Indeed, without early diagnosis, many eligible persons may not have opportunities to uptake new treatments, or participate in programs, trials, and care models to improve their quality of life over the course of the disease. Dementia severity at diagnosis may also be one mechanism contributing to disparities in health and health care outcomes. Several previous studies have shown large variations in length of life after a dementia diagnosis across racial/ethnic groups[25,26]; however, these studies do not account for the difference in dementia severity at diagnosis due to the lack of such measure at the population level. Our dementia severity measure, made available to the research community, is useful for researchers who are studying drivers of heterogeneity in outcomes among persons living with dementia, including type and amount of medical care and informal care received, financial outcomes, and longevity among others.

We find that among older adults with a diagnosis of dementia, 19% are diagnosed at the MCI stage. This is similar to the estimate of 22% (95% confidence interval [CI], 20% to 24%) prevalence of MCI reported based on the Harmonized Cognitive Assessment Protocol (HCAP).[27] Seventy percent are receiving a diagnosis at MCI or mild dementia (early) stages of the disease (CDR < 1.5). Currently, this is the tar-

get population for current disease-modifying therapies. Although 30% are being diagnosed at moderate or severe stages, time trends suggest improvements over time. More individuals are diagnosed at early stages of the disease in more recent years compared to earlier years (76% vs 65%). About 72% of non-Hispanic white persons are diagnosed at MCI or mild stages of dementia. However, among non-Hispanic black persons only 63% are diagnosed at MCI or mild stages of the disease and only 59% among Hispanic persons. Research has identified multiple factors that may contribute to racial/ethnic disparities in timely dementia diagnosis, including lack of awareness and knowledge of dementia, differences in perceptions about normal aging, lack of access to health care, stigma, and cultural bias of cognitive assessment tools.[28–31] Additionally, we find that fewer females were diagnosed at MCI or mild stages of dementia relative to males (67% vs 75%). The observed racial/ethnic and sex disparities in dementia severity at diagnosis persisted over time.

A recent study comparing prevalence of diagnosed dementia among all Medicare beneficiaries and dementia among HRS respondents based on the HCAP estimated the number of persons aged 65 and older in the US with undetected dementia to be about 20% of the population.[32] While this is lower than prior estimates, when combined with this study's finding of 30% detected at late stages, it suggests that there is a large portion of the population to target for improved detection and diagnosis, and opportunities for better quality of life for themselves and their families over the course of the disease.

We reported large socioeconomic differences between persons diagnosed at MCI and mild disease and those at moderate or severe disease. Only 8% of persons diagnosed at moderate dementia and 10% of those diagnosed at severe dementia had a college degree compared to 29% among those diagnosed at MCI. This finding is consistent but distinct from prior literature that found higher prevalence of undiagnosed dementia among those with low education.[15,17] Likewise, there were large differences in wealth. The median wealth of those diagnosed at MCI was five times as high as that of those diagnosed at moderate or severe dementia. Given the descriptive goals of this paper, the interaction between social, demographic, and economic factors in severity of dementia at diagnosis is not disentangled and left for future research. Health care system factors may also play a role and are not addressed here.

Our study has limitations. Our analysis is based on a predicted dementia severity measure. We tested multiple models, including Ordinary Least Squares, Poisson, Negative Binomial, Zero-inflated Negative Binomial, Logistic, and Ordered Probit regressions. There were no large differences across models and we selected the Poisson model based on overall prediction accuracy. Model fit based on the pseudo R-squared is 0.56 for the full model. To assess the within-sample fit of our model, we compared the distribution of our predicted dementia severity score with the distribution of observed CDR in ADAMS (Figure 1 and Table S4).

Second, our dementia severity model was based on the ADAMS sample which includes those 70 years and older only thus our dementia severity model and subsequent conclusions about the distribution of dementia severity at diagnosis only apply to this age group in the

population. It also relies on both self-reports and proxy respondents and we account for the difference in reporting by an indicator variable in the model. Third, differential survival and/or survey attrition by race/ethnicity may bias results. In particular, Hispanic persons live longer on average than non-Hispanic white or black persons[25] with unmeasured consequences to the distribution of dementia severity at diagnosis by race/ethnicity. Additionally, our sample was drawn from beneficiaries enrolled in TM. The different benefit design, care organization, and financial incentives to diagnose health conditions in Medicare Advantage may elicit different dementia diagnosis patterns. Non-white persons are more likely to be undiagnosed in claims compared to white persons.[15] We used a combination of dementia diagnosis codes and dementia symptom codes that, based on prior study, identifies more black and Hispanic persons than the use of diagnosis codes alone.[23] Cognitive status and functional limitations were assessed at the closest HRS interview that was no more 12 months before or 6 months after the diagnosis. We test sensitivity to this sample restriction using a less restrictive time window and average and median severity score at incident dementia was slightly higher (1.38 [SD = 0.98] and 1.03 respectively) but not statistically different from the reported scores (Figure S1). The Technical Documentation in the Supporting Information provides details for recreating the dementia severity measure including how the variables were operationalized and recoded, and how missing observations were handled and results from tests of sensitivity of the predicted estimates to the Poisson model.

The study provides new insight into the distribution of dementia severity at diagnosis for the older US population and for different racial and ethnic groups. Future research may benefit from using the dementia severity measure for surveillance of changes over time and for population-representative studies that quantify health care costs associated with different levels of dementia severity at diagnosis as well as the magnitude of cost savings had a diagnosis been given at an earlier stage.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest. Author disclosures are available in the Supporting Information.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.