Racial and Ethnic Differences in Dementia Diagnosis Following Cognitive Decline: Insights from Linked Survey and Health Care Claims Data

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Abstract

INTRODUCTION: Medicare claims data may be a rich data source for tracking population dementia rates. Insufficient understanding of completeness of diagnosis across racial/ethnic groups limits their use.

METHODS: We analyzed agreement in prevalent and incident dementia based on cognitive assessment from the Health and Retirement Study for persons with linked Medicare claims including diagnosed dementia from 2000 to 2008 (N= 10,450 persons, 31,186 person-waves). Multinomial logistic regression identified factors associated with disagreement.

RESULTS: Cognitive tests and coded diagnosis yielded identical prevalence estimates (14%) yet only half of identified cases overlapped. Eighty-five percent of respondents with incident dementia based on cognitive assessment in survey received a diagnosis. Blacks and Hispanics had lower odds of receiving medical diagnosis than whites with similar cognitive decline.

DISCUSSIONS: Time-lag in dementia diagnosis for racial and ethnic minorities reduced over time. Claims data are valuable for tracking dementia in the US population.

Keywords: prevalence; incidence; diagnosis; cognition; race/ethnicity; disparities

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1. Introduction

Accurate estimates of the prevalence and incidence of dementia and how they are changing over time are essential for quantifying disease burden and for preparing health and long-term care systems for the inevitable increase in cases. In the absence of dementia tracking through a national screening program, the main sources for estimating dementia in the US are nationally representative surveys and health care claims.

Medicare claims are an important data source for identifying and tracking rates of diagnosed disease over time in the older US population because the program provides health insurance for about 97% of older Americans from the age of 65 years until death. The number of diagnosed cases in the Medicare records however, may underestimate the actual burden of disease if individuals do not seek treatment for symptoms or request cognitive assessments, providers do not recognize symptoms and/or undertake assessment, or choose not to report it because of a lack of treatments that can change the course of the disease [1-3]. Nationally representative surveys are another key source for estimating population dementia prevalence. The Health and Retirement Study (HRS) has repeatedly used cognitive tests to measure dementia prevalence as well as onset [4-6]. The National Health and Aging Trends Study (NHATS) also has followed a nationally representative cohort of persons ages 65 and older since 2011. Cognitive tests for dementia ascertainment from surveys have been criticized for focusing heavily on language and memory [7], being sensitive to education level [8] and for their limited ability to differentiate mild cognitive impairment from dementia [9].

Medicare claims have been validated against in-person clinical assessment, the gold standard for dementia. Taylor et al. [10] compared dementia diagnoses in Medicare claims to clinical examinations from the 2001-2003 Aging Demographic and Memory Study (ADAMS) cohort of the HRS and reported a high sensitivity of 85 percent and a specificity of 89 percent. Although nationally representative, ADMAS with limited sample size of racial/ethnic minorities may provide less precise estimate for non-whites than whites. Other validation studies [11-14] using regional samples also reported co-existence of false positive and negative diagnoses in claims data, as observed in medical records when validated against clinical assessment [15]; yet their findings are not generalizable to all Americans. Insufficient understanding of

completeness of diagnosis across various populations limits the use of Medicare claims for dementia research.

Comparing coded diagnoses with cognitive abilities in a wide population provides unique insights into the performance of Medicare claims in ascertaining dementia prevalence and incidence. Two prior studies reported higher dementia ascertainment in Medicare claims data compared to a single survey interview-based ascertainment [16, 17]. Using data from the 2011 NHATS, Amjad and colleagues [18] reported that 60 percent of respondents with 'probable' dementia had formal diagnosis in three-year Medicare claims. None of these studies required continued low cognition as a verification of dementia, as two recent studies did [6, 19]. Nor did they verify dementia in claims data to 'rule-out' diagnosis of reversible dementia symptoms (e.g. visual or auditory problems, vitamin B_{12} deficiency, thyroid disturbance).

Prior studies found that the level of agreement across data sources varied with the characteristics of the individual, including gender, age, doctor visit, and dementia severity [10, 12, 13, 15, 17, 18, 20]. We hypothesized racial disparities in the concordance between diagnoses in Medicare claims and cognitive tests in survey, and thus the accuracy of estimating dementia rates using Medicare claims may differ by race/ethnicity. On the one hand, racial/ethnic minorities are disproportionately affected by environmental, sociocultural, and behavioral barriers to health care utilization, likely leading to more missed or delayed diagnoses [21-23]. On the other hand, individuals with low educational attainment score lower in cognitive test [24]. Minorities who generally obtain lower level of education than whites may be more likely to be incorrectly identified as having dementia in survey data [25, 26].

The goal of this study is to improve understanding of misclassified dementia in Medicare claims, by analyzing individual-level concordance in dementia status utilizing longitudinal data from HRS respondents linked with their Medicare claims records from 2000-2008. In doing so we improve upon the methods used in prior studies by requiring verification of dementia in both survey and claims based data sources to reduce measurement error. We add to prior literature an analysis of how (dis)agreement in dementia prevalence is changing over time, and for the first time, quantify concordance in incidence of dementia and the timing of diagnosis after substantial cognitive decline. We identify racial/ethnic differences in this timing, which may lead to disparities in patient outcomes, considering medical benefits of a

timely diagnosis [27]. For researchers, our findings illuminate values and caveats of using Medicare claims for studying dementia, including risk of dementia, care for person with dementia and costs of dementia. This is particularly important given the absence of clinical assessments in nationally representative, large, and longitudinal samples. Since diagnosis in Medicare claims also reflects clinical practice, the study informs policies to reduce disparities in dementia diagnosis and resulting health outcomes.

2. Methods

2.1 Study Population

We use data from the HRS linked to respondents' Medicare claims from the beginning of 2000 to the end of 2008. HRS is a nationally representative longitudinal study that has surveyed Americans over 50 years of age and their spouses since 1992. Respondents are interviewed biennially, on topics of health, health care usage, employment, economic, and family. A key feature of the HRS study design is oversampling of African Americans and Hispanics and weights may be used for providing a nationally representative sample. Minority response rates at baseline and in longitudinal follow-ups have been equal to or better than that of majority whites [28]. Eighty-eight percent of HRS respondents consented to the linkage of their survey responses to their Medicare claims records [29]. Our sample is restricted to HRS respondents age 67 and older, with linked claims data and at least two years of continuous fee-for-service (FFS) enrollment yielding 10,450 unique persons and 31,186 person-waves. The mean follow-up was 2.98 HRS interview waves.

2.2 Dementia Measures and Outcomes

In HRS, individuals were classified as having dementia based on having a low score (0-6 out of 27) on test items that evaluate memory and concentration and executive function: immediate and delayed word recall, counting back from 100 by 7's, and counting back from 20 [4, 5, 30]. Tests were administered at each wave to respondents using an adapted version of the Telephone Interview for Cognitive Status (TICS). When missing for self-respondents, the measures were imputed by HRS as described by Fisher et al. [31]. Around 6.2 percent of self-respondents in our study sample had at least one imputed scores for cognitive tests. When a respondent does not, or cannot perform the cognitive assessment, dementia is determined using

information provided by a proxy respondent, typically a spouse or other family member and the interviewer [28]. Among respondents with a proxy, dementia is assigned for sum scores between 6-11 for the following: number of instrumental activities of daily living with limitation (IADLs) (0-5), interviewer impairment rating (0 = no cognitive limitations, 1 = some limitations, 2 = cognitive limitations), and proxy informant's rating of the respondent's memory (from 0 [excellent] to 4 [poor]). The classification of dementia is based on the concordance of HRS cognitive functioning scores and consensus diagnosis of dementia in a subset of HRS respondents who had extensive neuropsychological assessment in ADAMS [4, 30]. To reduce measurement error in dementia ascertainment based on cognitive scores, we required one wave with dementia and evidence of continued cognitive impairment in the next consecutive wave [6, 19]. If the respondent with one wave of dementia died before the next wave, he or she was assumed to have dementia before dying. Once we identified a respondent as having 'verified' dementia, we assumed dementia in all subsequent waves.

In Medicare claims, we ascertained dementia based on the Chronic Conditions Data Warehouse (CCW) algorithm for Alzheimer's disease or related disorders or senile dementia using the following ICD-9 diagnosis codes: 331.0, 331.11, 331.19, 331.2, 331.7, 290.0, 290.10, 290.11, 290.12, 290.13, 290.20, 290.21, 290.3, 290.40, 290.41, 290.42, 290.43, 294.0, 294.10, 294.11, 294.20, 294.21, 294.8, and 797. Additional diagnostic codes were also included, to account for dementia with Lewy bodies, cerebral degeneration, senile psychosis, and dementia classified elsewhere: 331.82, 331.89, 331.9, 290.8, 290.9, 294.9. CCW algorithm requires at least one inpatient, facility, home health or outpatient claim with one of the above diagnosis codes during a three-year lookback period. Similar to the verified measure in HRS, we additionally required a second diagnosis claim over the study period to rule out reversible dementia symptoms.

The main outcome of interest is the (dis)agreement between the two measures of dementia. Agreement at a point in time (prevalent dementia) was defined as having the same dementia status across the data sources during the years between two consecutive HRS waves, which was approximately two years. We assessed agreement in incident dementia by examining the timing of diagnosis, the earliest date provided on a claim with a verified dementia diagnosis, relative to the date of 'verified' incident dementia as measured by HRS assessment (the survey date when a

respondent is classified with incident dementia, verified by subsequent low cognitive state and conditional on no dementia in previous waves).

2.3 Explanatory Variables

Also included in the analysis are: age, gender, and race (black, Hispanic, non-Hispanic white), highest level of education (less than high school, high school, college and above), marital status (married or not), the presence of chronic conditions and diseases (stroke, heart disease, diabetes, and hypertension), health care utilization (binary indicator for a physician visit during the past two years), and survival (indicator for whether died between survey waves).

2.4 Statistical Analysis

When analyzing concordance in dementia prevalence across the two measures of dementia, we applied HRS sampling weights to describe the concordance pattern in a representative national sample, by race, and over time. Pooling data from 2000 to 2008, we used multinomial logistic regression to quantify demographic and socioeconomic factors associated with concordance in dementia prevalence, also adjusting for survival into the next wave, physician visit, and a linear time trend. An interaction term between race and time was tested separately to see whether there were differential time trends by race.

We reported the incidence rate per 100,000 person-years based on both measures by race and over time. When calculating at-risk person-years, we assumed that new respondents entered the sample at the beginning of a period, contributing 2 years of dementia-free time if they had no onset of dementia over the period, and that dementia onset, mortality, or loss to follow-up occurred at the midpoint of the interval, contributing 1 year of dementia-free time.

We selected a subsample who were ascertained as having dementia based on HRS survey for the first time between 2000 and 2004[1] (N=1,161), and analyzed whether and when a dementia diagnosis occurred. We assumed the ascertained cognitive decline in HRS (i.e. meeting the threshold of "dementia" in HRS classification for the first time) as indicative of dementia, considering the HRS measure has been validated against clinical assessment in ADAMS [30]. Based on the

[1] Since 12/31/2008 is the end of our linked Medicare claims, respondents with incident dementia after 2004 were excluded to allow for longer follow-up periods.

comparison between their dementia incidence in HRS and in Medicare claims, we divided this subsample and described it with HRS sampling weights. A multinomial logistic regression was utilized to understand socioeconomic and demographic factors associated with the outcomes.

For sensitivity checks, we modified definition of dementia by: 1) requiring any subsequent verification of dementia in HRS, as opposed to that at the next consecutive wave; 2) requiring no verification for diagnosis in claims; or 3) using an augmented list of diagnostic codes including dementia symptoms (ICD-9 codes: 780.93, 784.3, 784.69, and 331.83). When defining agreement, we also allowed for a longer period for diagnosis or HRS dementia (extending by approaximately 2 years). Additional multivariate analyses controlling for household wealth (using wave-specific quartiles) were performed.

3. Results

3.1 Sample characteristics

Table 1 reports the cross-sectional characteristics of the respondents in years 2000 and 2008. Characteristics in this linked sample were compared to that in the full HRS sample aged 67 and above. Our sample was comparable to the full HRS sample in terms of gender, education, marital status, and cardiovascular profiles. Whereas racial/ethnical minorities and younger respondents were underrepresented in our sample, relative to the full HRS. In general, the difference was more pronounced at the 2008 wave as compared to the 2000 wave.

3.2 Concordance in prevalent dementia

We report concordance in prevalent dementia for persons according to four categories of (dis)agreement: (a) person does not have dementia, both measures, (b) has dementia, both measures, (c) has dementia based on cognitive tests only, and (d) has dementia based on coded diagnosis only, during years between two consecutive HRS survey waves. The first two categories were considered as agreement. There was concordance in prevalent dementia for 86.1 percent of the respondents based on the two measures (Table 2). Dementia prevalences ascertained by survey-based cognitive tests and coded diagnosis were similar; however only half of dementia cases identified by one source had dementia ascertained by the other measure. Agreement among respondents who died between HRS survey waves (approximately a two-year

time span) was lower than for those who survived (73.3 percent v. 87.8 percent) and was equally distributed across measures (13.0% survey-based cognitive tests, 13.7% physican diagnosis). Whites had higher concordance than blacks and Hispanics ($concordance_W$ = 88.1 percent, 95% CI: 87.6%-88.4%; $concordance_B$ = 74.9 percent, 95% CI: 73.5%-76.2%; $concordance_H$ = 70.8 percent, 95% CI: 68.6%-72.9%). The dominant disagreement type among whites was 'dementia by coded diagnosis only', while that among blacks and Hispanics was 'dementia by cognitive tests only'. Such pattern held when concordance in prevalent dementia was described over time and separetly for racial and ethnic groups (see Supplementary Figure).

Table 3 shows results of agreement across data sources using multinomial logistic regressions for the four categories of (dis)agreement with category (b) has 'dementia, both measures' as the reference group. After adjusting for age, gender, education, marital status, survival into the next HRS wave, physician visit during the past two years, and year, relative to 'dementia, both measures,' blacks and Hispanics were more likely to have dementia according to the cognitive test measure and no diagnosis than whites (OR_B=1.735, 95% CI: 1.413-2.131; OR_H=1.949, 95% CI: 1.420-2.676). Over time, the likelihood of having dementia based on cognitive tests only relative to dementia according to both measures declined (OR=0.933, 95% CI: 0.890-0.977). Compared to whites, blacks and Hispanics were less likely to have 'no dementia, both measures' relative to 'dementia, both measures' (OR_B= .386, 95% CI: .317-.469; OR_H= .574, 95% CI: .424-.778). Blacks also had lower odds of 'dementia by coded diagnosis only' relative to whites (OR_B= .405, 95% CI: .309-.531) while there were no statistical differences between whites and Hispanics (OR_H= 1.118, 95% CI: .774-1.616). We found no differential time trends by race.

Higher education compared to less than high school education was associated with increased odds of 'dementia by coded diagnosis only' relative to having dementia according to both sources ($OR_{high\ school}$=2.389, 95% CI: 1.915-2.979; $OR_{college}$=2.957, 95% CI: 2.370-3.689) and lower odds of 'dementia by cognitive tests only' ($OR_{high\ school}$= .656, 95% CI: .525-.820; $OR_{college}$= .362, 95% CI: .280-.469). Other characteristics associated with lower odds of disagreement relative to dementia in both data sources include being female, advanced age, and no doctor visit in the last two years. All results were robust to varying definitions of dementia and of agreement, and to adding wealth to models.

3.3 Concordance in incident dementia

Figure 1 shows the dementia incidence rate per 100,000 person-years by race and over the course of 2002-2008, with each data point representing the annual incidence rate in the past two years. Blacks had significantly higher incidence rate than whites during each period and across both measures with the exception at 2008 based on cognitive tests (P value=.066) and at 2004 (P value=.099) based on coded diagnosis. Hispanics had significantly higher incidence rate based on coded diagnosis than whites only at 2002 (P $value_{2004}$=.318; P $value_{2006}$=.900; P $value_{2008}$=.240), and always had significantly higher incidence rate based on cognitive tests than whites. Over the study period, there was no statistical difference in dementia incidence across time for either dementia measure by race.

We divided a subsample of respondents with incident dementia based on cognitive tests between years 2000 and 2004 into seven mutually exclusive groups: (1) diagnosed preceding the prior HRS wave (or two years if not present in the prior wave), (2) diagnosed between the prior and this wave, (3) diagnosed between this and the next wave, (4) diagnosed after the next wave and before 12/31/2008, (5) died before the next wave without a diagnosis, (6) died after the next wave and before 12/31/2008 without a diagnosis, and (7) survived to 12/31/2008 without a diagnosis. About 85 percent were either diagnosed with dementia or died during the study period (Table 4). The remaining 15.3 percent of this sample were on average followed for 5.9 years without receiving a diagnosis. Forty-eight percent of this group is under age 74, half of this group was black or Hispanic, and 79 percent had less than a high school education. Twenty-three percent of the incident sample had a dementia diagnosis before incident dementia as measured using HRS cognitive scores. Respondents classified in this group, on average, had cognitive scores in the 'normal' range for another two waves of HRS cognitive tests (4.7 years) after being diagnosed.

We examined the cognitive test scores of the 177 persons who survived and did not receive a diagnosis compared to those who received a diagnosis (n=984) and by type of respondent, self or proxy and results are reported in the Supplementary Table. Self-respondents without diagnosis had a change in cognitive score that was not statistically different than those with a diagnosis (-5.01 and -5.48 respectively). Proxy respondents who did not receive a diagnosis had a score indicating higher cognition than proxy respondents who received a diagnosis. Among individuals who changed respondent types (self or proxy) the scores in the wave prior to incident

dementia and at incident dementia were not statistically different between individuals with and without a diagnosis.

Using multinominal logistic regression we quantified socio-demographic factors associated with agreement and time to agreement. We combined the groups (2) and (3) in Table 4 where the time difference between incident dementia and diagnosis is two years or less, and used this as the reference group. We combined the groups of persons who died without a coded diagnosis (groups 5, 6) due to lack of statistical power. Table 5 reports odds ratios for the four outcomes relative to the reference group. None of the covariates were statistically different for 'diagnosis preceding the prior wave' relative to the reference group. Blacks relative to whites were twice as likely to receive 'diagnosis after one wave but before the end of 2008' compared to the reference group (OR=1.985, 95%CI: 1.225-3.217). Hispanics were marginally more likely to enter this group (OR=2.092, 95%CI: 0.998-4.387). Blacks and Hispanics relative to whites had higher odds of 'survival to the end of 2008 without a diagnosis' compared to the reference group (OR_B=2.737, 95%CI: 1.762-4.253; OR_H=3.458, 95%CI: 1.786-6.695). Respondents with college education were less likely to have no diagnosis by 2008 (OR=0.242, 95% CI: 0.113-0.516) or to receive diagnosis later (OR=0.378, 95% CI: 0.183-0.782), compared to those without a high school diploma. Advanced age was associated with lower odds of dying before a diagnosis or surviving to the end of study period and not receiving a diagnosis. Linear time trend revealed lower likelihood of receiving a delayed diagnosis (OR=0.550, 95%CI: 0.420-0.719) over time.[2] Results were not qualitatively different when definition of dementia was modified and when wealth was adjusted for.

4. Discussion

Utilizing a nationally representative longitudinal dataset that linked health care claims-based diagnosis with a survey measure of dementia based on cognitive scores, we found that at a point in time, cognitive tests and coded diagnosis ascertained similar prevalence estimates at the population level. However, only half of dementia cases based on one of the measures also had dementia based on the other measure. The low agreement at the individual level was consistent with previous literature [16-

[2] The statistically significant OR for linear time trend in the 'survived to 12/31/2008 without diagnosis' (OR=1.511, 95% CI: 1.190-1.920) cannot rule out censoring effects, thus not interpreted here.

18].

To our knowledge, this is the first study to examine concordance in incident dementia. Following incident dementia between the years 2000-2004, as defined by HRS cognitive assessment, 85 percent of these respondents were diagnosed or died by 2008. We did not find strong evidence of differential cognitive loss between the undiagnosed group and the diagnosed, and we observed robust disparities in the likelihood of receiving dementia diagnosis associated with race/ethnicity and educational attainment. Race/ethnicity and education may be associated with access to and utilization of medical care, specifically cognitive screening, through mechanisms including but not limited to health behaviors and cultural beliefs and thus lead to under- or delayed diagnosis[21-23].

This also points to the open question of whether racial/ethnic minorities face higher risks of dementia, independent of education and baseline cognition, and how well both measures reflect the racial/ethnic difference. Studies using in-depth clinical examinations for dementia ascertainment reported mixed evidence on elevated risk of dementia for blacks, in geographically restricted samples [32-35]. Using the nationally represented ADAMS, Plassman and colleagues [36] found no black-white difference in dementia risk, yet the estimation may be biased by the small sample size of minorities. In this study, we observed generally higher dementia incidence for racial minorities based on HRS cognitive tests, but not based on diagnosis in claims, especially for Hispanics. Combined with racial disparities in the likelihood of being diagnosed, our results may suggest claims data during the study period under-diagnosed some dementia cases for non-whites, with caveat of the limitations of using cognitive tests as dementia indicators.

As for education-related disparities, higher-educated individuals were more likely assessed as having ‘normal’ cognition while at the same time receiving a dementia diagnosis compared to low-educated individuals; and after cognitive decline, they had a lower odds of delayed diagnosis or no diagnosis. These results are consistent with a cognitive reserve hypothesis [37, 38], contending that education would mitigate the symptoms of dementia, such as impaired cognition, until dementia is at a more advanced stage. At the same time, trained physicians and patients’ reports of changes in memory may lead to a diagnosis. Furthermore, highly educated individuals may be more likely to be diagnosed than low educated individuals as a result of better access to and utilization of health care services. If the cognitive

batteries in the HRS are less sensitive to cognitive decline among highly educated individuals, these individuals would have a lower likelihood of being in our subsample analysis of incident diagnosis after cognitive decline and thus less likely to be at risk of 'no/later diagnosis'. Several studies have called for an adjustment of cognitive batteries for education [8, 39]. However, trade-offs between standardization of test and precision of estimation require further investigations.

Over time, we observed potential improvement in diagnostic practice between 2000 and 2008, as shown by the shrinking likelihood of 'dementia by cognitive tests only' in prevalent dementia and 'later diagnosis' in incident dementia. With doctor visit being a significant predictor for 'dementia by cognitive tests only', continued efforts are needed to alleviate barriers to diagnosis, including increased access to care, or improvements in physicians' knowledge about dementia and willingness to diagnose [3]. A timely diagnosis not only confers benefits to patients and families afflicted with dementia [27, 40, 41], but also reduces long-term care spending to the health care system [42, 43].

There exist several limitations in this study. Although broadly representative, this sample does not include individuals in Medicare HMOs who are more likely to be racial/ethnic minorities and at younger ages [44], and respondents consenting for linkage to Medicare claims tend to be younger, non-white, and wealthier [45, 46]. The study sample was comparable to the nationally representative HRS sample in terms of gender, education, marital status, and cardiovascular profiles, yet being older and with less Hispanics. Over time, comparability and thus sample representativeness reduced, in part due to a steady increase in HMO population since 2002 [44]. Measurement error in dementia status is reduced by requiring a second dementia ascertainment, and by examining cognitive loss, rather than cross-sectional variations in cognition. If non-whites are more likely than whites to be categorized incorrectly with cognitive decline, then the disparities may be over-stated. Finally, statistical power is limited due to small sample size of our incident sample. Future studies may incorporate more waves of HRS-Medicare linked data. Another promising direction is to examine concordance across data sources by dementia subtype, to see whether different types of dementia impair cognitive domains differentially.

In conclusion, Medicare claims data are a key data resource for researchers studying dementia and this study found value in its use for assessing prevelance and incidence of dementia in the US population and how it is changing over time. More

misclassification of dementia among blacks and Hispanics compared to whites remains a concern with both survey-based cognitive test measures and coded diagnosis from claims data. Methodological advances for identifying dementia in surveys using cognitive assessments that is sensitive to different racial/ethnic populations is also warranted. Policy change that increases dementia diagnosis rate, such as the reimbursement for cognitive assessment under the new Medicare Annual Wellness Visit, may greatly improve recognition of dementia in clinical practice and across diverse populations. Screening programs is of particular value for racial/ethnic minorities, who are at an elevated risk of missed diagnosis under current practice.

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Table 1. Sample Characteristics in Years 2000 and 2008

	HRS-Claims Linked Sample		HRS 67+ Sample		P Values	
	2000	2008	2000	2008	2000	2008
N	6,142	5,706	9,404	10,285		
Age					0.169	0.000
67 to 74	42.6%	39.3%	46.7%	45.0%		
75 to 84	42.8%	41.1%	40.4%	38.4%		
85 and above	14.6%	19.6%	12.9%	16.6%		
Mean (SD), years	76.8 (6.80)	77.6 (7.17)	76.2 (6.78)	76.6 (7.16)	0.049	0.000
Female	59.8%	60.0%	59.2%	58.1%	0.369	0.149
Race					0.010	0.000
White	86.8%	87.5%	86.4%	84.6%		
Black	9.0%	8.0%	8.5%	8.4%		
Hispanic	4.1%	4.5%	5.1%	7.0%		
Education					0.893	0.761
Less than high school	35.5%	25.9%	35.3%	28.3%		
High school & equivalent	32.1%	34.1%	31.5%	33.2%		
College and above	32.4%	40.0%	33.2%	38.4%		
Not Married/Partnered	47.5%	47.2%	46.9%	45.1%	0.474	0.041
Cardiovascular risk factors						
Stroke	12.8%	13.4%	12.1%	12.8%	0.653	0.041
Heart disease	32.0%	34.7%	30.3%	32.7%	0.222	0.001
Diabetes	15.0%	21.5%	15.4%	22.1%	0.493	0.919
Hypertension	52.8%	64.8%	52.0%	64.6%	0.672	0.279
Died between this and next wave	12.2%	11.3%	11.9%	12.4%	0.021	0.028

Notes: HRS 67+ sample requires 1) age>=67 years, and 2) responded to HRS interview. HRS-claims linked sample additionally requires continuous FFS enrollment for at least 2 years. The reported percentages are weighted, using wave-specific HRS sampling weights to adjust for survey design. P values indicate level of statistical difference in characteristics between HRS 67+ sample and HRS-claims linked sample.

Table 2. Concordance in Prevalence by Survival into Next HRS Wave and by Race 2000-2008

	All	Survived into Next HRS Wave	Died before Next HRS Wave	Whites	Blacks	Hispanics
No dementia, both measure	78.90%	83.20%	45.90%	6.70%	12.20%	9.40%
Dementia, both measure	7.20%	4.60%	27.40%	81.40%	62.70%	61.40%
Dementia, cognitive test only	6.90%	6.10%	13.00%	4.80%	20.80%	21.10%
Dementia, diagnosis only	7.00%	6.10%	13.70%	7.20%	4.30%	8.10%
Concordance in prevalent dementia	86.10%	87.80%	73.30%	88.10%	74.90%	70.80%
N	31,186	27,494	3,692	25,504	3,953	1,728

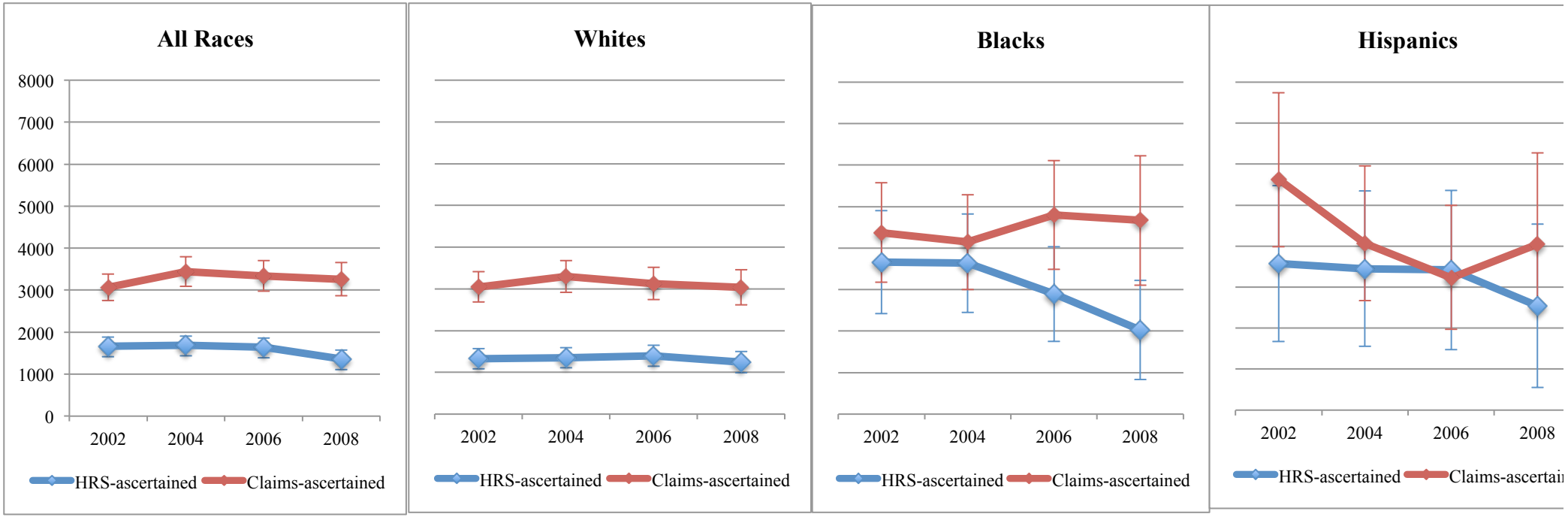
Notes: Agreement is based on the same dementia status during the years between two consecutive HRS waves. Next wave is approximately two years after prior wave.

Table 3: Odds Ratios for Concordance in Prevalence, Relative to 'Dementia, Both Measures (N=31,186)

OR [95%CI]	No Dementia, both measures	Dementia only in HRS	Dementia only in Medicare claims
Female	0.709***	0.585***	0.683***
	[0.597 - 0.842]	[0.480 - 0.714]	[0.558 - 0.837]
Age			
Aged 75 to 84	0.221***	0.377***	0.672**
	[0.182 - 0.269]	[0.301 - 0.471]	[0.529 - 0.854]
Aged 85 +	0.063***	0.311***	0.411***
	[0.051 - 0.079]	[0.243 - 0.397]	[0.315 - 0.537]
Race			
Black	0.386***	1.735***	0.405***
	[0.317 - 0.469]	[1.413 - 2.131]	[0.309 - 0.531]
Hispanic	0.574***	1.949***	1.118
	[0.424 - 0.778]	[1.420 - 2.676]	[0.774 - 1.616]
Education			
High school	2.657***	0.656***	2.389***
	[2.211 - 3.192]	[0.525 - 0.820]	[1.915 - 2.979]
College and above	3.238***	0.362***	2.957***
	[2.684 - 3.905]	[0.280 - 0.469]	[2.370 - 3.689]
Single	0.749***	0.844	0.945
	[0.634 - 0.885]	[0.692 - 1.028]	[0.771 - 1.157]
Died before the next wave	0.137***	0.400***	0.397***
	[0.122 - 0.152]	[0.350 - 0.458]	[0.346 - 0.455]
Visited doctors during past two years	0.551***	0.459***	1.424
	[0.409 - 0.744]	[0.331 - 0.636]	[0.922 - 2.201]
Linear time trend	0.976	0.933**	0.995
	[0.940 - 1.014]	[0.890 - 0.977]	[0.949 - 1.043]
Constant	135.5***	18.13***	1.384
	[87.48 - 209.8]	[11.04 - 29.76]	[0.767 - 2.497]
Observations		31,117	

Notes: Variables are measured at the specific HRS wave. *** denotes P value <.001, ** P value <.01, and * P value <.05.

Figure 1. Annual Incidence Rate of Dementia (per 100,000 person-years) under Different Measures



Notes: Blue line denotes the incidence rate per 100,000 person-years ascertained by HRS measure during the past two years, and red line denotes that by Medicare claims. Error bar indicates 95% confidence interval. Incidence rate at year 2002, for instance, refers to that during 2000-2002. Incidence during 1998-2000 is excluded, since cognition was measured differently among proxy respondents in HRS-1998. When calculating at-risk person-time (i.e. the denominator), we assumed that new respondents entered the sample at the beginning of a period, contributing 2 years of dementia-free time if they had no onset of dementia over the period, and that dementia onset, mortality, or lost to follow-up occurred at the halfway, contributing 1 year of dementia-free time.

Table 4. Characteristics of Sample at the Time of Incident Dementia Ascertained by HRS (N=1,161)

	Diagnosed within study period				Never diagnosed within study period		
	1. DX preceding prior wave	2. DX between prior and this wave	3. DX between this and next wave	4. DX after next wave and before 12/31/08	5. Died before next wave w/o seeing DX	6. Died between next wave &12/31/08 w/o DX	7. Survived to 12/31/08 w/o DX
n (% of N)	22.3	22.4	13.9	10.5	7.8	8.0	15.3
Age (%)							
67-74	12.0	12.1	15.9	23.3	28.9	34.7	48.3
75-84	44.0	49.6	46.3	50.9	32.7	30.9	39.5
85+	44.0	38.3	37.8	25.8	38.3	34.4	12.3
Mean Years (SD)	82.9(7.11)	82.6(7.00)	82.5(7.54)	80.1(7.37)	80.7(8.22)	79.3(8.76)	75.8(7.12)
Male (%)	33.1	28.3	37.8	38.6	48.9	54.7	39.0
Race (%)							
White	83.8	87.2	78.5	63.6	79.5	72.7	51.2
Black	12.5	10.2	16.1	27.8	15.6	20.7	34.3
Hispanic	3.7	2.6	5.4	8.6	4.9	6.6	14.5
Education (%)							
Less than high school	47.5	46.1	53.8	70.9	42.3	72.0	79.1
High school	23.3	28.8	29.1	20.5	37.7	20.4	15.3
College and above	29.2	25.1	17.1	8.6	20.0	7.6	5.6
Doctor Visit during the past 2 years	96.7	96.8	96.7	93.6	97.3	84.9	93.7
Disease Prevalence							
Stroke (%)	37.8	33.3	26.5	21.1	35.5	26.1	12.9
Heart disease (%)	41.8	49.0	48.7	42.3	64.9	43.2	32.1
Diabetes (%)	15.6	20.6	31.0	17.5	32.0	35.1	24.9
Hypertension (%)	58.7	59.2	64.4	62.5	66.2	54.8	60.8
Nursing Home Residency at Incident Wave	35.1	43.6	18.2	3.6	27.4	15.8	1.9
Mean Time Difference (years)	-4.64	-1.05	0.85	4.00	0.81	3.70	5.88

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Notes: DX= diagnosis coded in Medicare claims. This subsample is limited to respondents who were ascertained as dementia by HRS measure for the first time during HRS 2000, 2002, or 2004 waves. From the left to the right, outcome groups are: (1) being diagnosed preceding the prior wave (or two years if not present in the prior wave), (2) being diagnosed between the prior and this wave, (3) being diagnosed between this and the next wave, (4) being diagnosed after the next wave and before 12/31/2008, (5) died before the next wave without seeing a diagnosis, (6) died after the next wave and before 12/31/2008 without seeing a diagnosis, and (7) survived to 12/31/2008 without seeing a diagnosis. Mean time difference is calculated as the date of diagnosis minus the date of HRS-ascertained dementia onset. The former is based on the date provided in a claim with a diagnosis of incident dementia. The latter is based on the corresponding HRS survey date when dementia was ascertained by HRS for the first time.

Table 5. Odds Ratios for Concordance in Incidence, Relative to 'Time Difference Less than 2 Years' (N = 1,161)

	DX preceding prior wave	DX after one wave but before 12/31/2008	Died before 12/31/2008 w/o seeing DX	Survived to 12/31/2008 w/o seeing DX
Female	0.972	0.838	0.520***	0.934
	[0.694 - 1.362]	[0.549 - 1.279]	[0.359 - 0.753]	[0.629 - 1.386]
Race				
Black	0.952	1.985**	1.421	2.737***
	[0.615 - 1.475]	[1.225 - 3.217]	[0.905 - 2.229]	[1.762 - 4.253]
Hispanic	0.821	2.092	1.541	3.458***
	[0.390 - 1.727]	[0.998 - 4.387]	[0.738 - 3.215]	[1.786 - 6.695]
Education				
High school	0.789	0.678	1.097	0.561*
	[0.526 - 1.183]	[0.400 - 1.150]	[0.706 - 1.703]	[0.338 - 0.930]
College and above	1.225	0.378**	0.664	0.242***
	[0.819 - 1.833]	[0.183 - 0.782]	[0.388 - 1.136]	[0.113 - 0.516]
Age				
Aged 75-84	1.003	0.712	0.372***	0.266***
	[0.606 - 1.660]	[0.412 - 1.231]	[0.228 - 0.608]	[0.168 - 0.421]
Aged 85+	1.171	0.454**	0.488**	0.120***
	[0.708 - 1.936]	[0.250 - 0.823]	[0.299 - 0.795]	[0.0689 - 0.209]
Visited doctor during the past 2 years	1.007	0.448	0.272**	0.482
	[0.352 - 2.882]	[0.159 - 1.264]	[0.116 - 0.639]	[0.182 - 1.277]
Linear time trend	1.069	0.550***	0.780*	1.511***
	[0.880 - 1.297]	[0.420 - 0.719]	[0.624 - 0.976]	[1.190 - 1.920]
Constant	0.423	39.57***	18.85***	0.224
	[0.0837 - 2.139]	[5.856 - 267.3]	[3.765 - 94.41]	[0.0368 - 1.359]
Pseudo R^2		0.0931		
Observations		1,161		

Notes: DX= diagnosis coded in Medicare claims. *** denotes P value <.001, ** P value <.01, and * P value <.05.

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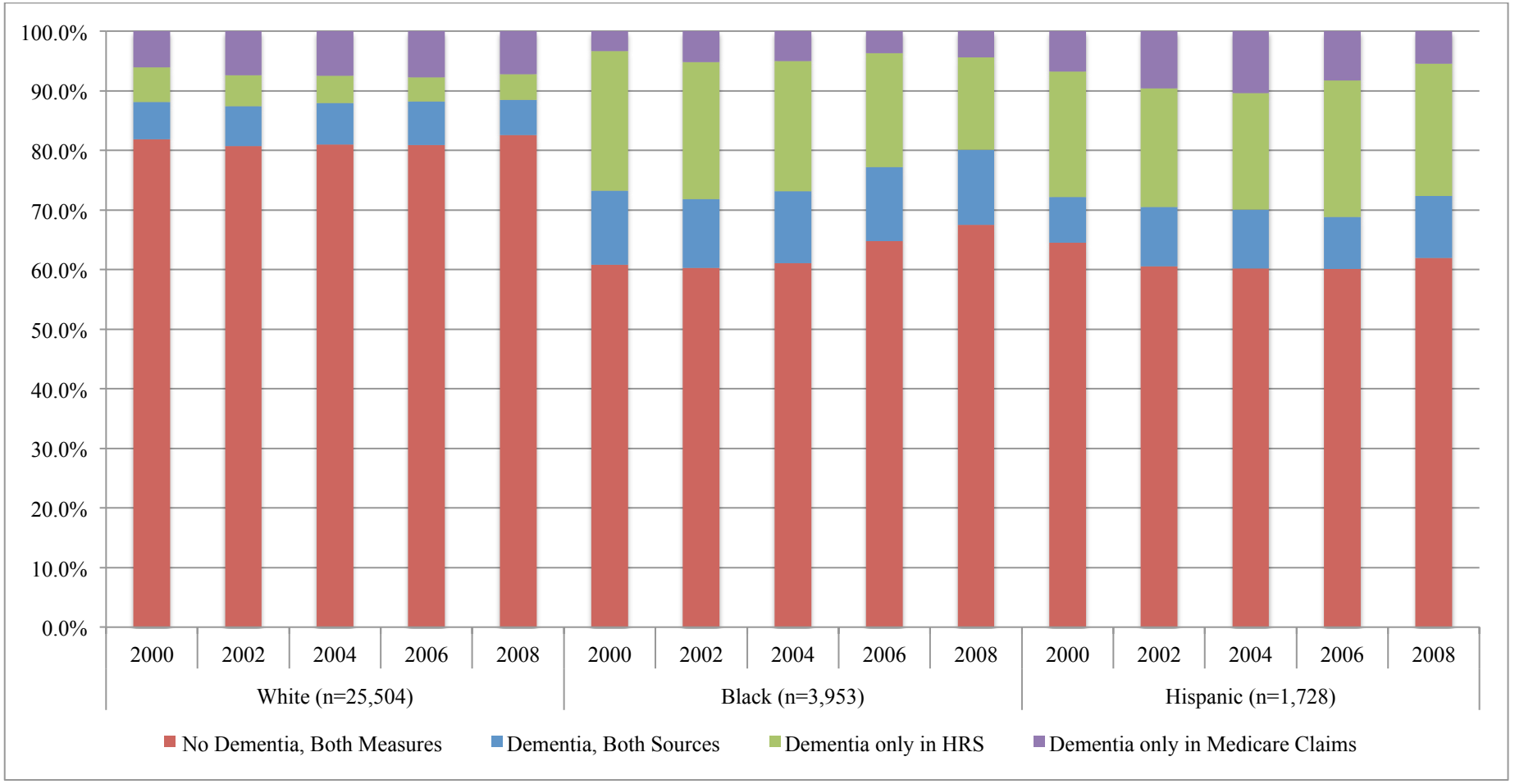
Supplementary Figure. Concordance in Prevalence by Race over 2000-2008



Supplementary Table. Changes in Cognitive Score around Incident Dementia in HRS

	Received no DX and survived			Received DX regardless of survival		
Transition in respondent type	**Wave prior to incident dementia**	**Wave of incident dementia**	**Change in score**	**Wave prior to incident dementia**	**Wave of incident dementia**	**Change in score**
Self to self	9.92 [9.38, 10.45]	5.03* [4.76, 5.30]	-5.01 [-5.60, -4.42]	10.20 [9.88, 10.51]	4.69 [4.52, 4.85]	-5.48 [-5.82, -5.14]
Self to proxy	10.55 [6.18, 14.9]	8.45 [5.51, 11.40]	N/A N/A	10.53 [10.10, 10.97]	9.02 [8.78, 9.25]	N/A N/A
Proxy to proxy	2.62 [1.58, 3.66]	6.45*** [5.91, 6.98]	3.69 [2.33, 5.05]	3.51 [3.20, 3.81]	8.47 [8.18, 8.75]	4.63 [4.17, 5.08]
Proxy to self	1.79* [0.85, 2.74]	5.39* [4.78, 6.00]	N/A N/A	3.10 [2.39, 3.82]	3.98 [3.40, 4.56]	N/A N/A

Notes: DX= diagnosis coded in Medicare claims. Cognitive score and dementia criteria for self-respondents: 0-6 "Dementia", 7-11 "CIND", 12-27 "Normal". Cognitive score and dementia criteria for proxy-respondents: 6-11 "Dementia", 3-5 "CIND", 0-2 "Normal". We divided the subsample based on cross-wave respondent type: self to self (n= 603), self to proxy (n=269), proxy to proxy (n=217), and proxy to self (n=72). Changes in cognitive score were only calculated for individuals with the same respondent type across wave. P values were calculated for the significant difference in mean score between 'received no DX and survived' and 'received DX regardless of survival'. *** denotes P value <.001, ** P value <.01, and * P value <.05.