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Dementia Diagnosis Underreporting and Downstream Care Engagement and Planning Among US Older Adults

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Abstract

A documented diagnosis only benefits patients who know about it. Using nationally representative Health and Retirement Study data linked to Medicare claims (1998–2020), we quantify the gap between clinically documented dementia diagnoses and patients' own reports. Among self-respondents with probable dementia and a claims-based diagnosis, 67 percent do not report having been diagnosed—more than double the average underreporting rate for arthritis, hypertension, diabetes, and depression among the same population—and underreporting is highest in the early disease stage, precisely when decision-making capacity is greatest. Underreporting is more prevalent among individuals who live alone, are dually eligible, have less education, and are non-Hispanic Black, and less prevalent among Medicare Advantage enrollees and patients seen by dementia specialists, consistent with roles for stigma, social vulnerability, and provider disclosure incentives. Underreporting predicts lower post-diagnosis care engagement and a lower likelihood of establishing a will or trust, suggesting information frictions undermine the returns to early detection.

JEL classification

I11, I12, I14, J14, D83, I18

Keywords

dementia, underreporting, diagnostic disclosure, Medicare, aging, cognitive decline, end-of-life planning

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Introduction

Dementia affects more than 1 in 10 older adults and their families in the United States, imposing substantial financial, caregiving, and societal burdens.[1,2] High-quality care for people living with dementia begins with early diagnosis, which enables advance care planning,[3] time to address legal and financial needs,[4] access to support services,[1,5] and informed medical decision-making.[6,7] However, diagnostic uncertainty, inadequate clinician communication, gaps in patient and family knowledge,[8] and stigma surrounding dementia may leave individuals unaware of their condition or reluctant to accept or disclose it,[9,10] even when a diagnosis is documented in the medical record. Such unawareness or nondisclosure may disrupt care planning, endanger patient safety, and limit engagement with disease management, posing a key barrier to realizing the benefits of early detection.[11-13]

Most research on dementia diagnosis has examined how often dementia goes undiagnosed,[14-17] with limited evidence on how often patients with a documented diagnosis fail to be aware of or report their condition. The few studies documenting unawareness of a dementia diagnosis were cross-sectional and relied on small samples.[18,19] Moreover, no study has compared dementia underreporting with that of other chronic conditions among the same patients to determine whether underreporting reflects cognitive impairment versus other factors. The association of patient and care delivery factors, including health status, diagnosis timing, type of coverage, and care setting, with underreporting also remains understudied. Furthermore, whether underreporting is associated with poorer downstream care engagement and planning has not been examined. Addressing these gaps is essential to identifying populations at greatest risk of

underreporting and to guiding clinical and policy efforts to improve dementia awareness, communication, and care.

Using nationally representative longitudinal survey-linked claims data, this study assessed the extent of underreporting of dementia diagnosis relative to other conditions, its variation by timing of dementia diagnosis, associated patient and care delivery factors, and its associations with downstream care engagement and planning.

Methods

Study Data and Population

We used data from all waves of the Health and Retirement Study (HRS) from 1998 to 2020, linked with Medicare claims from 1995 to 2021. The HRS is a nationally representative biennial survey of U.S. older adults collecting detailed information on demographics, socioeconomic status, and cognitive and physical functioning. Linkage with Medicare claims enabled longitudinal tracking of respondents' clinical diagnoses alongside cognitive status. The Yale University institutional review board approved this study and waived informed consent because of minimal risk and the impracticality of obtaining consent. Data analyses were conducted between May 4, 2025, and June 24, 2026. This study followed the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) reporting guideline for cohort studies.

We included HRS respondents aged 65 years or older with linked Medicare claims who were classified as having dementia in at least one survey wave between 1998 and 2020 by the Langa-Weir classification,[20] a validated algorithm that assigns respondents to cognition categories using

the Modified Telephone Interview for Cognitive Status (TICS-M) and proxy assessments, with validation against in-person clinical examinations.[21] These individuals are hereafter referred to as persons with probable dementia (PWPD). Among PWPD, we included all person-waves from 1998 to 2020 in which a dementia diagnosis was recorded in Medicare claims. Dementia diagnoses were identified from all Medicare claim types using *International Classification of Diseases, Ninth and Tenth Revision, Clinical Modification* (ICD-9-CM and ICD-10-CM) codes (**eTable 1**).[22-25] A sample selection flowchart is provided in **eFigure 1**.

To examine underreporting of other health conditions among PWPD, we constructed separate analytic samples for depression, diabetes, arthritis, and hypertension, following the same procedure used for the dementia diagnosis sample. Each sample was restricted to PWPD per HRS and included only person-waves with the respective claims-based diagnosis (**eFigure 1)**. Diagnoses for these conditions were identified using ICD-9-CM and ICD-10-CM codes from Chronic Conditions Data Warehouse (CCW) algorithms.[26]

Study Variables

Underreporting of Diagnosis

Our main outcome was underreporting of dementia diagnosis. At each HRS interview, respondents were asked whether a doctor had ever told them they had each of several health conditions, including dementia or a memory-related disease (**eTable 2**). A PWPD was classified as underreporting dementia diagnosis at a given wave if they did not report dementia or a memory-related disease (hereafter dementia) despite having a claims-based dementia diagnosis

during the preceding two-year interview interval. Underreporting of depression, diabetes, arthritis, and hypertension among PWPD was defined analogously.

Of note, the wording of the dementia survey item changed in 2010, from a single question about "a memory-related disease" to two items asking specifically about Alzheimer's disease and dementia, senility, or serious memory impairment. Although the earlier wording was broader, dementia is a memory-related disease, and thus a respondent with a claims-based dementia diagnosis who answered "no" under either version would appropriately be classified as underreporting.

Post-Diagnosis Care Engagement and End-of-Life Planning

To assess whether underreporting was associated with post-diagnosis care engagement and end-of-life planning, we analyzed three outcomes. Care engagement was measured during the 12 months following the first claims-based dementia diagnosis within each HRS wave and included 1) any problem-based visit and 2) receipt of influenza vaccination, capturing active engagement with the health system and ongoing preventive care after diagnosis. These outcomes were identified from claims (**eTable 3**).[27-29] For end-of-life planning, we assessed whether respondents had a witnessed will or trust in each wave, based on HRS survey responses.

Covariates

Sociodemographic covariates included age, sex, race/ethnicity, education, living arrangement, and dual eligibility status from the Master Beneficiary Summary File (MBSF). Race and ethnicity were self-reported using fixed categories provided in the HRS survey instrument.

Health conditions included number of chronic conditions, activities of daily living (ADL) limitations, and years since dementia onset, defined as the first HRS wave in which a respondent met the Langa-Weir classification criteria for dementia.[20,21] We also included respondent type (self vs proxy). In the HRS, a proxy respondent is usually assigned when the participant is too ill or cognitively impaired to complete the interview independently; this assignment applies uniformly across all health questions in the HRS interview.[30]

Care delivery factors included type of coverage (Medicare Advantage vs. Medicare fee-for-service) from the MBSF; any dementia specialist visit; and setting of the first dementia diagnosis (outpatient, emergency room/urgent care, inpatient hospital, residential care, and other), ascertained using a validated algorithm based on claim type, revenue center codes, and place of service codes.[31] Dementia specialists were defined as physicians in neurology, psychiatry, neuropsychiatry, geriatrics, or geriatric psychiatry.[32]

Statistical Analysis

We conducted generalized estimating equation (GEE) regressions and calculated predictive margins to estimate the adjusted proportion of PWPD with a claims-based dementia diagnosis who did not report dementia or a memory-related condition. The GEE regressions accounted for repeated observations within individuals and were specified with a binomial family, a logit link, and an exchangeable correlation structure. Predictive margins provide standardized estimates by averaging predicted values across the covariate distribution of the study population. Adjusted underreporting proportions were estimated for the overall sample, for self-respondents, by years since dementia onset, and within subgroups stratified by patient and care delivery factors,

controlling for all covariates described above and survey year indicators. Underreporting proportions for other conditions among PWPD were estimated using the same specifications and covariates, excluding dementia-specific covariates (dementia specialist visits and dementia diagnosis settings).

We further estimated adjusted odds ratios for each patient and care delivery factor in the GEE model to examine factors associated with dementia diagnosis underreporting. This analysis was restricted to self-respondents so that patient-level factors reflected patients themselves. Cognitive score (0-27 from the HRS-adapted TICS-M) was used as a covariate in place of years since dementia onset for self-respondents.

Finally, to assess the association between dementia underreporting and post-diagnosis care engagement and end-of-life planning, we performed GEE regressions of these outcomes on underreporting status among self-respondents. Models adjusted for sociodemographic and health conditions, including age, race/ethnicity, sex, education, living arrangement, cognitive score, number of chronic conditions, number of ADL limitations, and survey year indicators.

All analyses incorporated HRS sampling weights to adjust for unequal probability of sample inclusion. Analyses were conducted using Stata version 14.1 (StataCorp). Two-sided $P < .05$ was considered statistically significant.

Sensitivity and Additional Analyses

We performed several sensitivity and additional analyses to test robustness. First, to reduce misclassification from rule-out diagnoses, we applied a more stringent approach by requiring two or more claims with a dementia diagnosis at least 7 days apart or at least one diagnosis in an inpatient, skilled nursing facility, home health, or hospice claim.[16,33,34] Second, we restricted the sample to individuals diagnosed within 6 years before HRS-defined onset, as misclassification may be greater in the earliest years. Third, we restricted the sample to respondents with non-missing self-reported status for all health conditions to avoid bias from differential missingness.

Among PWPD who underreported dementia diagnosis, we also examined whether they were equally likely to underreport other conditions with a claims-based diagnosis. If so, this could suggest an underlying cognitive etiology for underreporting. Finally, we tested whether the association between underreporting and subsequent care engagement and planning differed by respondent type (self vs proxy).

Results

A total of 6,158 person-waves (3,278 unique persons) of PWPD with a claims-based dementia diagnosis were included (**Table 1**); 50.9% were aged 65 to 84 years, 69.5% were female, and 19.1% were non-Hispanic Black, 10.0% Hispanic, and 69.1% non-Hispanic White. Of these, 3,602 (58.5%) reported having been diagnosed with dementia, whereas 2,556 (41.5%) did not. Compared with those who self-reported dementia, individuals who underreported were more likely to be younger (65-79 years; 30.5% vs 26.3%; $P = .003$) and non-White (33.2% vs 29.3%; $P = .007$), and less likely to have at least a high school education (53.1% vs 57.9%; $P < .001$).

They were also more likely to be observed in waves preceding dementia onset (28.9% vs 7.0%; $P < .001$) and had higher mean cognitive scores (7.60 vs 5.93; $P < .001$).

Figure 1 presents estimated underreporting proportions for dementia and other diagnoses. Among self-respondents, 67% (95% CI, 64%-69%) of PWPD with a claims-based dementia diagnosis did not report a dementia diagnosis. Underreporting was substantially lower for other conditions, with a mean of 31%: 17% for arthritis (95% CI, 15%-18%), 23% for hypertension (95% CI, 21%-24%), 39% for diabetes (95% CI, 37%-41%), and 46% for depression (95% CI, 43%-48%). Including proxy respondents, dementia underreporting declined to 42% (95% CI, 40%-43%) but remained high.

Beyond differences across conditions, adjusted dementia underreporting also varied substantially by years from dementia onset (as defined in HRS). Underreporting proportions were highest in the years before dementia onset, reaching 60% (95% CI, 52%-67%) among all respondents and 82% (95% CI, 76%-87%) among self-respondents 4 years prior (**Figure 2**). Proportions declined over the disease course, reaching 43% (95% CI, 41%-46%) among all respondents and 65% (95% CI, 61%-69%) among self-respondents at onset. After onset, underreporting remained at a mean of 37% among all respondents and 61% among self-respondents.

Among self-respondents, non-Hispanic Black race (OR, 1.42; 95% CI, 1.01-2.00), living alone (OR, 1.65; 95% CI, 1.27-2.13), and dual eligibility (OR, 1.35; 95% CI, 1.02-1.79) were associated with higher odds of underreporting, whereas male sex (OR, 0.79; 95% CI, 0.62-1.00) and at least a high school education (OR, 0.74; 95% CI, 0.57-0.95) were associated with lower

odds (**Figure 3**). A higher cognitive score (OR, 1.14; 95% CI, 1.11-1.18) was associated with higher odds, while more ADL limitations (OR, 0.88; 95% CI, 0.83-0.94) were associated with lower odds. For care delivery factors, MA enrollment (OR, 0.68; 95% CI, 0.52-0.89) and a specialist visit (OR, 0.64; 95% CI, 0.50-0.82) were associated with lower odds. Relative to an outpatient diagnosis, receiving a diagnosis in an inpatient hospital (OR, 1.55; 95% CI, 1.19-2.02) or in other settings (e.g., home, telehealth; OR, 1.36; 95% CI, 1.04-1.79) was associated with higher odds. Adjusted underreporting proportions across subgroups defined by these factors showed similar patterns among all respondents (**eFigure 2**).

We next examined the association of dementia underreporting with post-diagnosis care engagement and end-of-life planning. As shown in **Table 2**, respondents who underreported their dementia diagnosis at a given wave, compared with those who did not, were less likely to have a problem-based visit (OR, 0.70; 95% CI, 0.55-0.90; P=.005), to receive influenza vaccination (OR, 0.63; 95% CI, 0.51-0.77; P < .001), and to have a witnessed will or trust (OR, 0.70; 95% CI, 0.54-0.90; P=.005) in the 12 months following the first claim-based dementia diagnosis.

Sensitivity analyses applying more stringent diagnostic criteria, restricting to individuals diagnosed with dementia within 6 years before HRS-defined onset, and restricting to respondents with non-missing self-reported status across all conditions yielded results consistent with the main analyses (**eFigures 3-6**). In an analysis restricted to PWPD who underreported dementia, these individuals did not uniformly underreport other conditions for which they had a claims-based diagnosis (arthritis, 19.8%; hypertension, 24.6%; diabetes, 40.8%; depression, 48.0%) (**eTable 4**), suggesting PWPD retain the ability to report other diagnosed conditions despite not

reporting dementia. Finally, the association between underreporting and subsequent care engagement and planning did not differ significantly by respondent type, with underreporting among proxy respondents being similarly associated with lower odds of a problem-based visit (OR, 0.63; 95% CI, 0.50-0.80; P < .001) and influenza vaccination (OR, 0.65; 95% CI, 0.51-0.84; P = .001) (**eTable 5**).

Discussion

In this national longitudinal study of PWPD, two-thirds of self-respondents with a claims-based dementia diagnosis did not report having dementia or a memory-related condition, far exceeding underreporting of other diagnosed conditions, including depression, diabetes, hypertension, and arthritis. Including proxy respondents narrowed this gap, but dementia underreporting remained substantial. Although underreporting declined over the disease course, it remained persistently high even years after dementia onset, and was more pronounced among individuals with fewer social supports, lower educational attainment, and better cognitive function.

Prior literature has highlighted the role of stigma in prompting patients to conceal or deny a stigmatized condition.[35] The substantially higher underreporting of dementia compared with less stigmatized conditions, such as hypertension and arthritis, is consistent with such stigma-related denial or concealment.[36] The associations of higher underreporting with fewer ADL limitations and better cognition align with the evidence that patients in early stages of dementia face particular challenges recognizing and accepting their diagnosis.[37-42] Although depression and diabetes are also stigmatized,[43,44] and exhibited relatively high underreporting, the markedly higher underreporting of dementia among self-respondents suggests factors beyond stigma are

also likely to contribute, including clinicians' ability to effectively communicate and disclose difficult news.[39,45-47]

Our findings on care delivery factors further support this interpretation. MA enrollment and certain diagnosis settings were associated with less underreporting, which may reflect differences in clinician incentives, available time, and disclosure practices. Patients who received a diagnosis in an inpatient hospital or other settings (e.g., home, telehealth) were more likely to underreport than those diagnosed in an outpatient setting, whereas seeing a dementia specialist was associated with less underreporting. This may reflect more explicit assessment and disclosure of dementia in outpatient and specialist care.[48,49] Meanwhile, inpatient encounters may prioritize acute conditions prompting hospitalization, leaving fewer opportunities to effectively communicate a dementia diagnosis.

Early diagnosis of dementia is increasingly emphasized given emerging disease-modifying treatments and innovative care programs.[50,51] Our findings, however, point to a notable barrier to realizing the benefits of early diagnosis. Underreporting was particularly high before dementia onset as defined in HRS, when symptoms were likely still mild. In this early phase, clinicians may document a suspected or provisional diagnosis without clearly communicating it to patients and families,[47] which may partly explain this pattern. This is concerning because patients may miss the critical window when they retain the capacity to engage in care planning and make informed decisions about their future safety, health, and finances.

Indeed, underreporting was associated with lower odds of having a problem-based visit and receiving influenza vaccination following the diagnosis, and of establishing a will or trust. These associations may reflect that patients are unaware of or have not internalized their diagnosis and suggest less future planning. Absent a clinical plan and suitable counseling, patients may be less likely to recognize dementia-related risks or seek specialized care that could slow or better manage disease progression. Furthermore, whether the response was provided by the individual or their proxy, the associations did not differ. However, because HRS proxies are designated for survey completion and may not necessarily be healthcare proxies or support persons who actively manage patients' care, this finding does not suggest that the latter lack a role in care management.

Given that dementia diagnoses are frequently delayed, with referral wait times spanning months to several years,[52] ensuring that a documented diagnosis is clearly communicated to patients and families and translated into care planning is critical. The Centers for Medicare & Medicaid Services (CMS) introduced reimbursement for Cognitive Assessment and Care Plan Services in 2017,[53] which may improve diagnostic disclosure and patient-clinician communication, though uptake has remained low.[54,55] The more recent CMS Guiding an Improved Dementia Experience (GUIDE) model provides care navigation and caregiver support that may strengthen communication and patient understanding. These policies hold promise for narrowing the gap between a documented diagnosis and patient awareness, particularly in early-stage disease and among patients of lower socioeconomic status, but broader adoption is needed to realize this potential.

Limitations

We acknowledge several limitations in our study. First, although our results suggest that stigma, diagnosis recognition and acceptance, inadequate clinician disclosure, and social vulnerability may contribute to high dementia underreporting, we could not disentangle the relative contributions of each. Second, associations between underreporting and care engagement and planning suggest potential adverse consequences, but we cannot rule out the possibility of unobserved confounders, such as unmeasured health status or functional ability, and causal interpretations should be avoided. Third, the validated, widely used HRS-based measure for ascertaining dementia onset[20,56-58] may not pinpoint onset with complete accuracy; true physiological onset may have occurred earlier. Finally, self-reported diagnoses may be subject to recall bias; however, because such bias would apply across all conditions examined, it is unlikely to explain the disproportionately high underreporting observed specifically for dementia.

Conclusions

In this cohort study of PWPD, dementia diagnosis was substantially underreported relative to other diagnosed conditions. Our findings suggested that stigma, challenges in diagnosis self-recognition and acceptance, social vulnerability, and inadequate clinician communication all likely contributed to this underreporting, which was in turn associated with reduced timely care and planning. These findings may inform efforts to strengthen patient and caregiver awareness, improve diagnostic disclosure practices, and implement system-level interventions to ensure that early diagnosis translates into actionable care planning.

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Author Contributions:

Drs Qian and Chen had full access to all the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis.

Concept and design: Qian, Chen.

Acquisition, analysis, or interpretation of data: All authors.

Drafting of the manuscript: All authors.

Critical review of the manuscript for important intellectual content: All authors.

Statistical analysis: Qian.

Obtained funding: Chen.

Administrative, technical, or material support: All authors.

Supervision: Qian, Chen.

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TABLES

Table 1. Characteristics of Individuals With Dementia Who Reported vs Underreported a Dementia Diagnosis

	No. (%)			
	Self-reported as having dementia	Self-reported as not having dementia	Total	P Value
Number of person-waves	3,602 (58.5)	2,556 (41.5)	6,158	
Sociodemographic characteristics				
Age, y.o.				.003
65-69	118 (3.3)	119 (4.7)	237 (3.8)	
70-74	268 (7.4)	219 (8.6)	487 (7.9)	
75-79	563 (15.6)	440 (17.2)	1,003 (16.3)	
80-84	847 (23.5)	560 (21.9)	1,407 (22.8)	
≥85	1,806 (50.1)	1,218 (47.7)	3,024 (49.1)	
Race and ethnicity				.007
Non-Hispanic Black	663 (18.4)	513 (20.1)	1,176 (19.1)	
Hispanic	330 (9.2)	287 (11.2)	617 (10.0)	
Non-Hispanic White	2,548 (70.7)	1,708 (66.8)	4,256 (69.1)	
Non-Hispanic Other[a]	61 (1.7)	48 (1.9)	109 (1.8)	
Sex				.29
Female	2,486 (69.0)	1,796 (70.3)	4,282 (69.5)	
Male	1,116 (31.0)	760 (29.7)	1,876 (30.5)	
High school degree or above	2,086 (57.9)	1,356 (53.1)	3,442 (55.9)	<.001
Living alone	1,646 (45.7)	1,188 (46.5)	2,834 (46.0)	.54
Dual eligible[b]	1,421 (39.5)	905 (35.4)	2,326 (37.8)	.001
Health conditions				
Number of chronic conditions[c], mean (SD)	2.91 (1.61)	3.03 (1.56)	2.96 (1.59)	.004
Time relative to dementia onset[d]				<.001
Before dementia onset	252 (7.0)	738 (28.9)	990 (16.1)	
At dementia onset	1,051 (29.2)	677 (26.5)	1,728 (28.1)	
After dementia onset	2,299 (63.8)	1,141 (44.6)	3,440 (55.9)	
Cognitive score, mean (SD)[e]	5.93 (3.73)	7.60 (4.12)	7.04 (4.07)	<.001
Number of ADL difficulties, mean (SD)	3.23 (2.36)	2.01 (2.25)	2.72 (2.39)	<.001
Proxy respondent	2,691 (74.7)	729 (28.5)	3,420 (55.5)	<.001
Health care services				
MA enrollment	813 (22.6)	454 (17.8)	1,267 (20.6)	<.001
Had dementia specialist visit	1,694 (47.0)	1,141 (44.6)	2,835 (46.0)	.06
Diagnosis setting[f]				<.001

Outpatient	1,621 (45.0)	1,098 (43.0)	2,719 (44.2)
Emergency room /urgent care	238 (6.6)	155 (6.1)	393 (6.4)
Inpatient hospital	661 (18.4)	633 (24.8)	1,294 (21.0)
Residential care	601 (16.7)	290 (11.3)	891 (14.5)
Other	481 (13.4)	380 (14.9)	861 (14.0)

[a] Non-Hispanic Other includes American Indian, Alaska Native, Asian, Native Hawaiian, Pacific Islander, and other races not separately identified in the HRS data.

[b] Beneficiaries were classified as dually eligible if they received full or partial Medicaid benefits in any month during a given HRS wave.

[c] Chronic conditions data were obtained from the Chronic Condition Warehouse (CCW) linked to the Health and Retirement Study (HRS) survey year. Conditions were categorized in alignment with the HRS survey and included eight categories: high blood pressure, diabetes, cancer, lung disease, heart disease, stroke, arthritis, and psychiatric problems.

[d] Dementia onset was defined as the first HRS wave in which a respondent met the Langa-Weir classification criteria for dementia (described in *Methods*).

[e] Cognitive scores were derived from the Modified Telephone Interview for Cognitive Status (TICS-M; range, 0-27), with scores ≤6 classified as dementia by the Langa-Weir algorithm; TICS-M scores are available for self-respondents only. For proxy respondents, the Langa-Weir algorithm classified cognitive status using a separate scale combining the proxy's rating of the respondent's memory, the interviewer's assessment, and instrumental activities of daily living.

[f] Diagnosis setting was defined as the care setting in which the first dementia diagnosis was documented in each person-wave. Outpatient includes office, outpatient hospital, facility, federally qualified health center, independent clinic, public health clinic, rural health clinic, and other outpatient settings. Residential care includes skilled nursing facility, nursing facility, assisted living, custodial care facility, hospice, and other residential settings. Other includes home, specialty psychiatric care, telehealth provided other than in patient's home, community mental health center, and other places of service.

Table 2. Association of Underreporting of Dementia Diagnosis With Post-Diagnosis Care Engagement and End-of-Life Planning

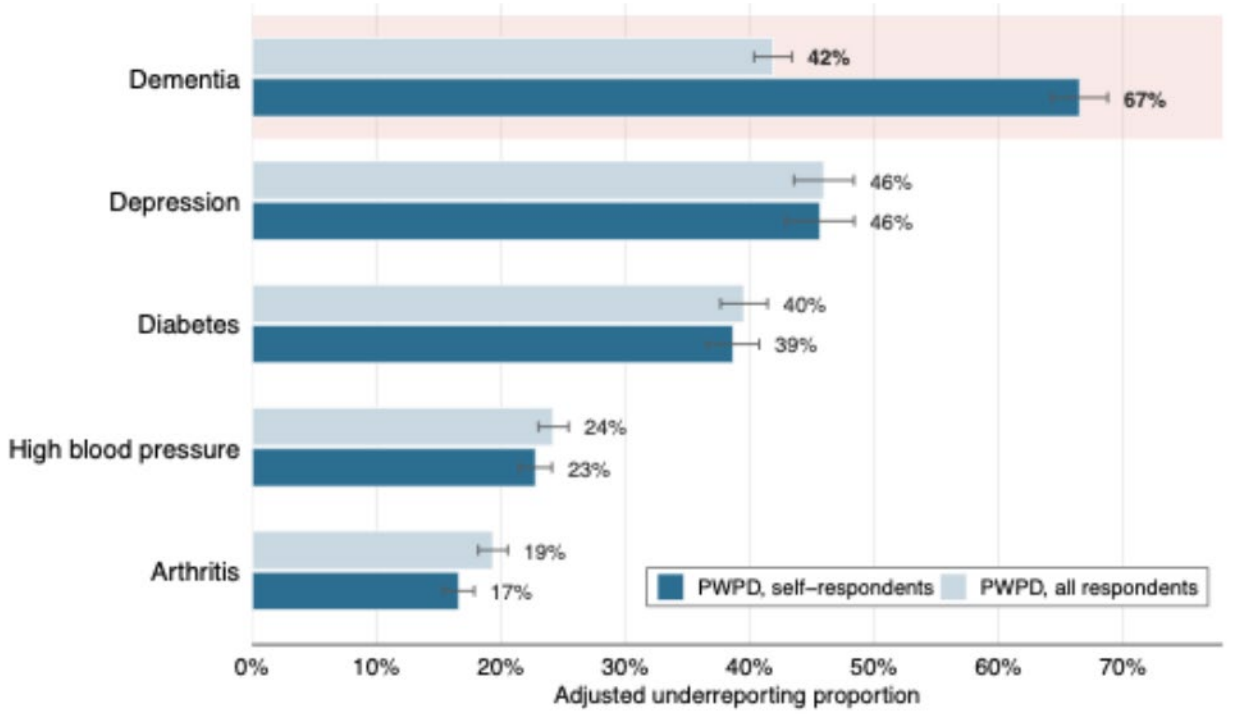
	Post-Diagnosis Care Engagement[a]		End-of-Life Planning
Variables	**Problem-based visits, OR (95% CI)[c]**	**Influenza vaccination, OR (95% CI)[c]**	**Will/trust[b], OR (95% CI)[c]**
Underreporting of diagnosis	0.700	0.626	0.697
	(0.547 - 0.896)	(0.506 - 0.774)	(0.541 - 0.898)
P value	.005	<.001	.005
Mean of dependent variable (SD)	0.74 (0.44)	0.35 (0.48)	0.59 (0.49)
No. of Observations	2,738	2,738	2,673

[a] Care engagement outcomes were measured over the 12 months following the first dementia diagnosis in each HRS wave and included 1) any problem-based visit and 2) receipt of influenza vaccination.

[b] End-of-life planning outcomes included whether patients had a witnessed will or trust in each wave, based on HRS survey responses.

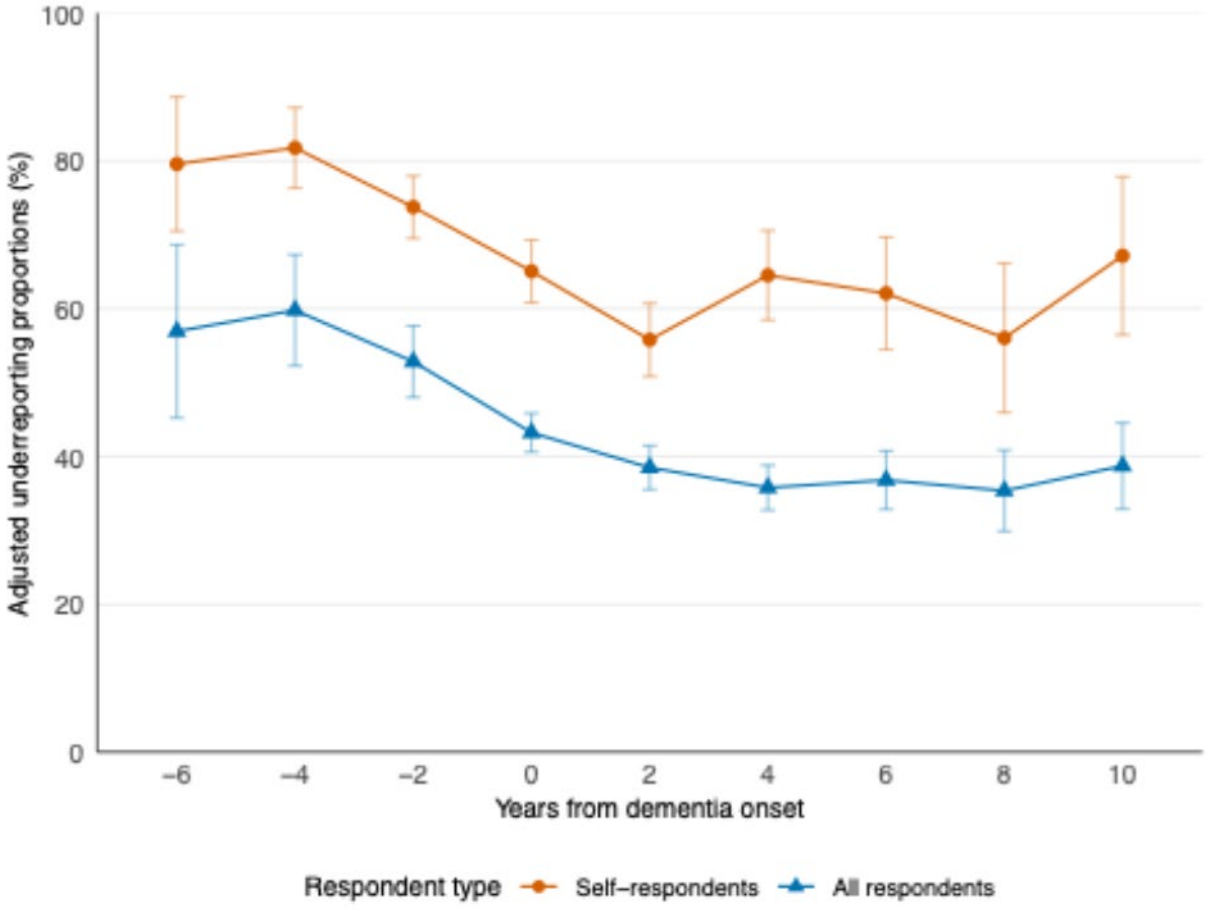
[c] Analyses were restricted to self-respondents and adjusted for sociodemographic and health characteristics, including age, race and ethnicity, sex, education, living arrangement, cognitive score, number of chronic conditions, number of activities of daily living (ADL) limitations, and survey year. Model specifications are detailed in the *Methods*.

Figure 1. Adjusted Underreporting Proportions for Dementia and Other Diagnoses Among Persons with Probable Dementia



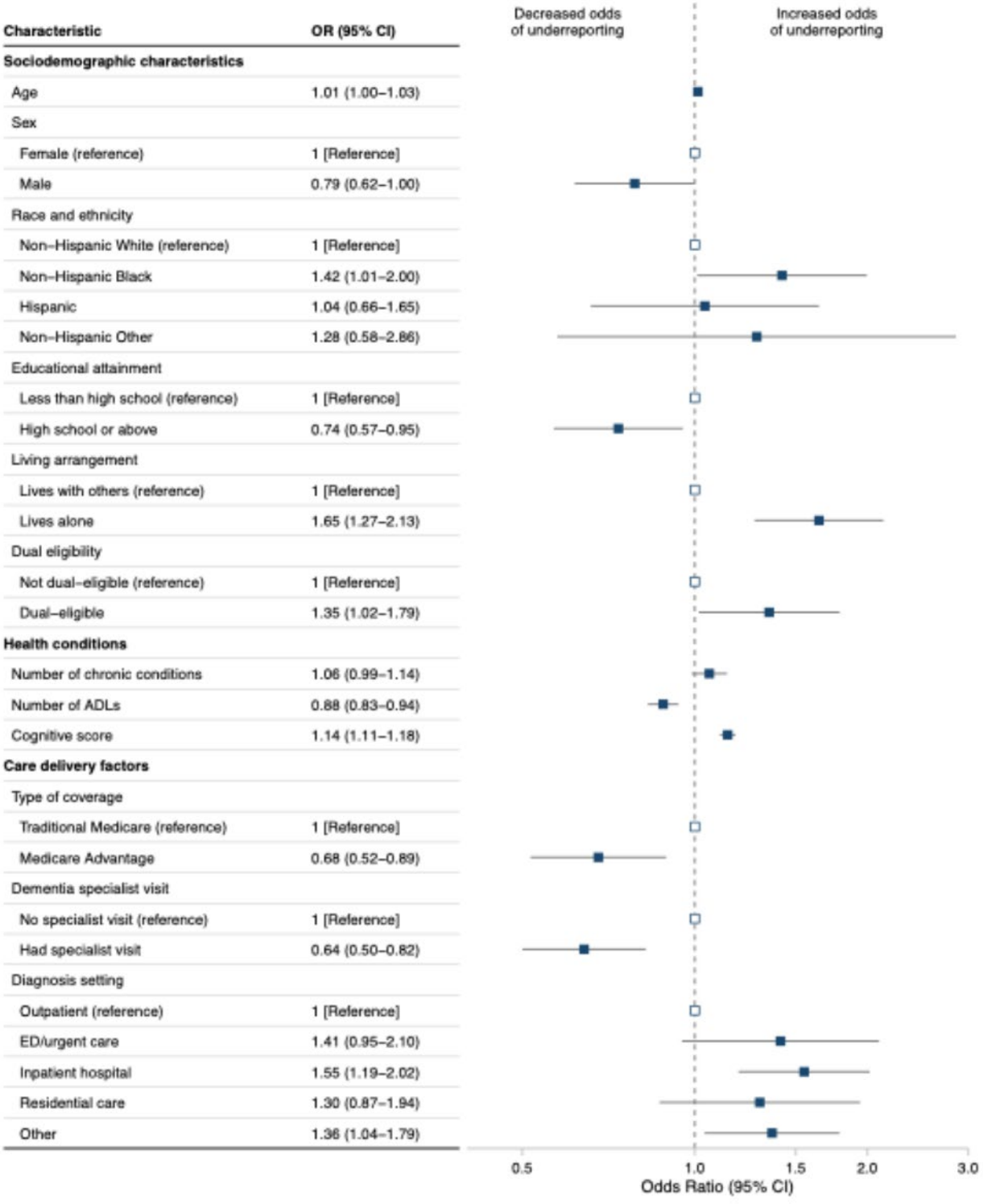
Abbreviations: PWPD, persons with probable dementia.
Notes: Underreporting proportions were estimated using generalized estimating equation (GEE) regressions to generate predictive margins, adjusted for sociodemographic characteristics, health conditions, and care delivery factors (see *Methods*). A person with probable dementia (PWPD) was classified as underreporting a given condition if they did not report the condition present in their claims-based diagnosis from the previous two years (i.e., since the last interview).

Figure 2. Adjusted Underreporting Proportions for Dementia Diagnosis by Years From Dementia Onset



Notes: The figure shows adjusted underreporting proportions for dementia diagnosis from 6 years before to 10 years after dementia onset. Underreporting proportions were estimated using generalized estimating equation (GEE) regressions to generate predictive margins. These models were adjusted for sociodemographic characteristics, health conditions, and care delivery factors. Dementia onset was defined as the first HRS wave in which a respondent met the Langa-Weir classification criteria for dementia.

Figure 3. Association of Patient and Care Delivery Factors with Underreporting of Dementia Diagnosis



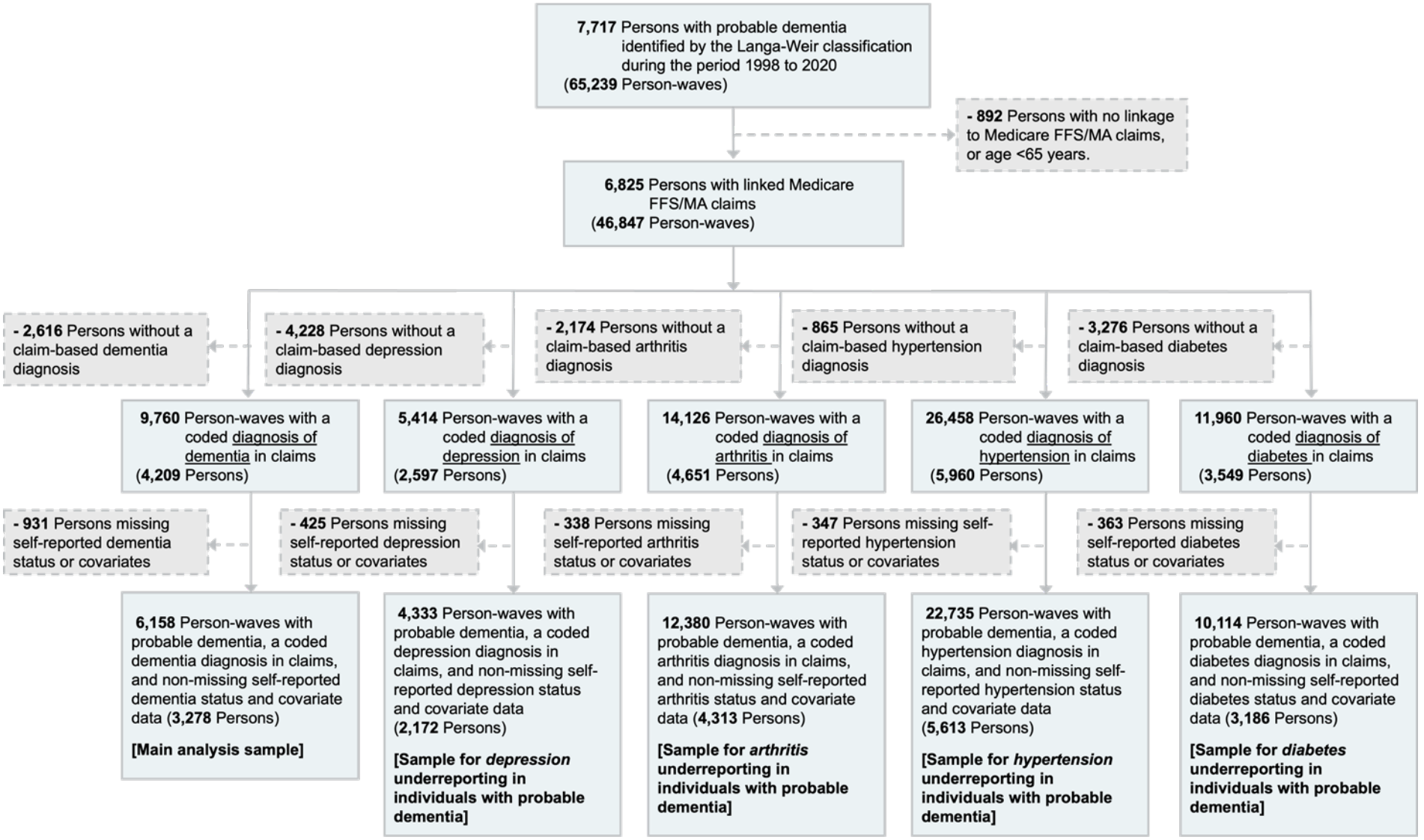
Abbreviations: ADL, activities of daily living; ED, emergency department.

Notes: The figure presents adjusted odds ratios estimated using generalized estimating equation (GEE) regressions of underreporting of dementia diagnosis as a function of all patient and care delivery factors, with additional adjustment for survey year indicators. Analyses were restricted to self-respondents. Non-Hispanic Other race and ethnicity included American Indian or Alaska Native, Asian, Native Hawaiian or Pacific Islander, and other races not separately identified in the Health and Retirement Study (HRS). Outpatient diagnosis settings included office, hospital outpatient department, facility, federally qualified health center, independent clinic, public health clinic, rural health clinic, and other outpatient settings. Residential care settings included skilled nursing facilities, nursing facilities, assisted living facilities, custodial care facilities, hospice, and other residential care settings. Other includes home, specialty psychiatric care, telehealth provided other than in patient's home, community mental health center, and other places of service.

ONLINE SUPPLEMENT

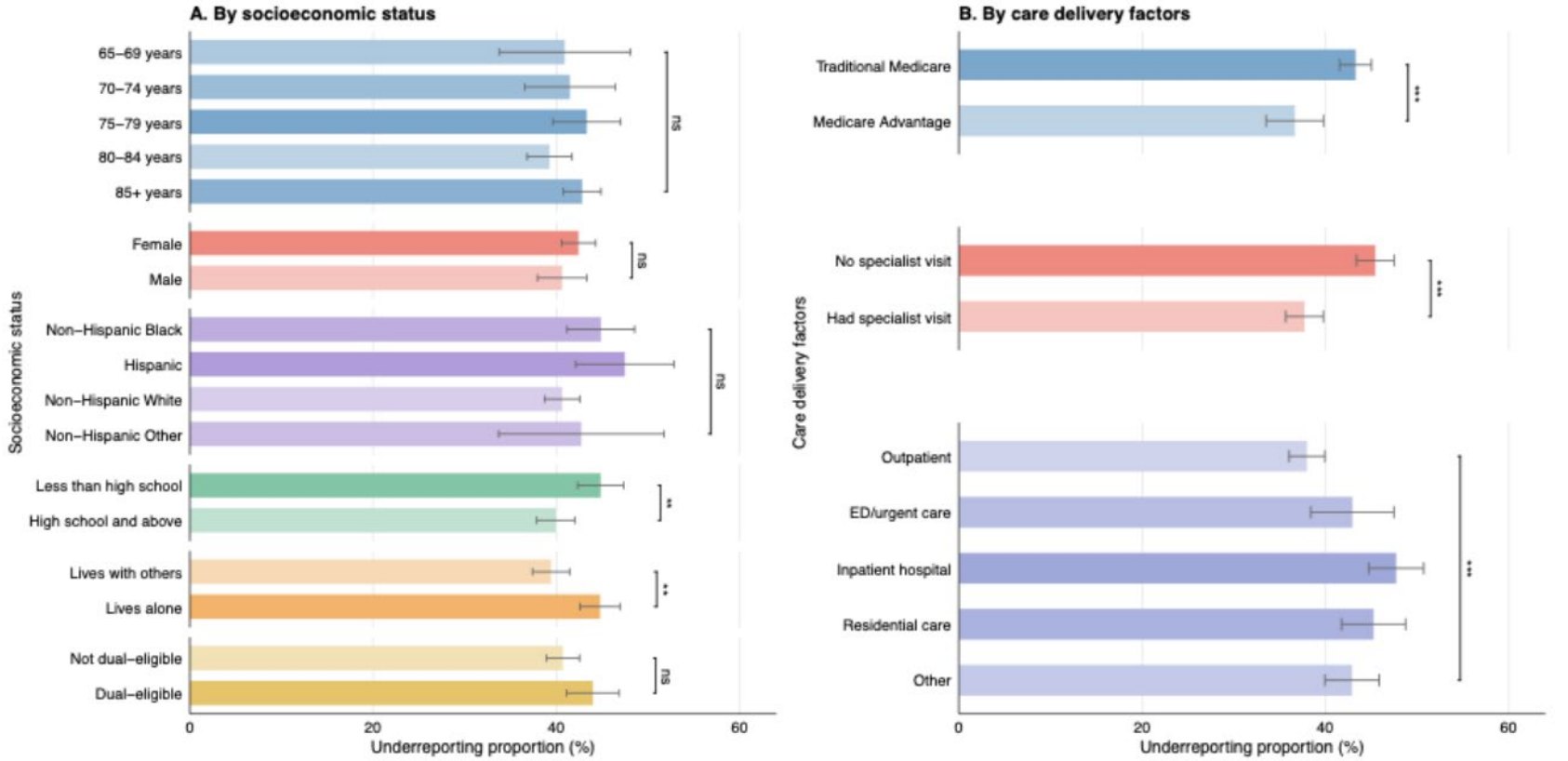
Dementia Diagnosis Underreporting and Care Engagement and Planning Among Older Adults

eFigure 1: Generation of the Analytic Sample



Notes: The figure shows the sample selection process. The sample included Health and Retirement Study (HRS) respondents aged 65 years or older with linked Medicare claims classified as having probable dementia in at least one survey wave between 1998 and 2020 using the validated Langa-Weir algorithm; these individuals are referred to as persons with probable dementia (PWPD). Among PWPD, all person-waves with a dementia diagnosis in Medicare claims were included, identified using *International Classification of Diseases, Ninth and Tenth Revision, Clinical Modification* (ICD-9-CM and ICD-10-CM) codes. Separate samples for depression, diabetes, arthritis, and hypertension were constructed using the same procedure, each restricted to PWPD with the respective claims-based diagnosis.

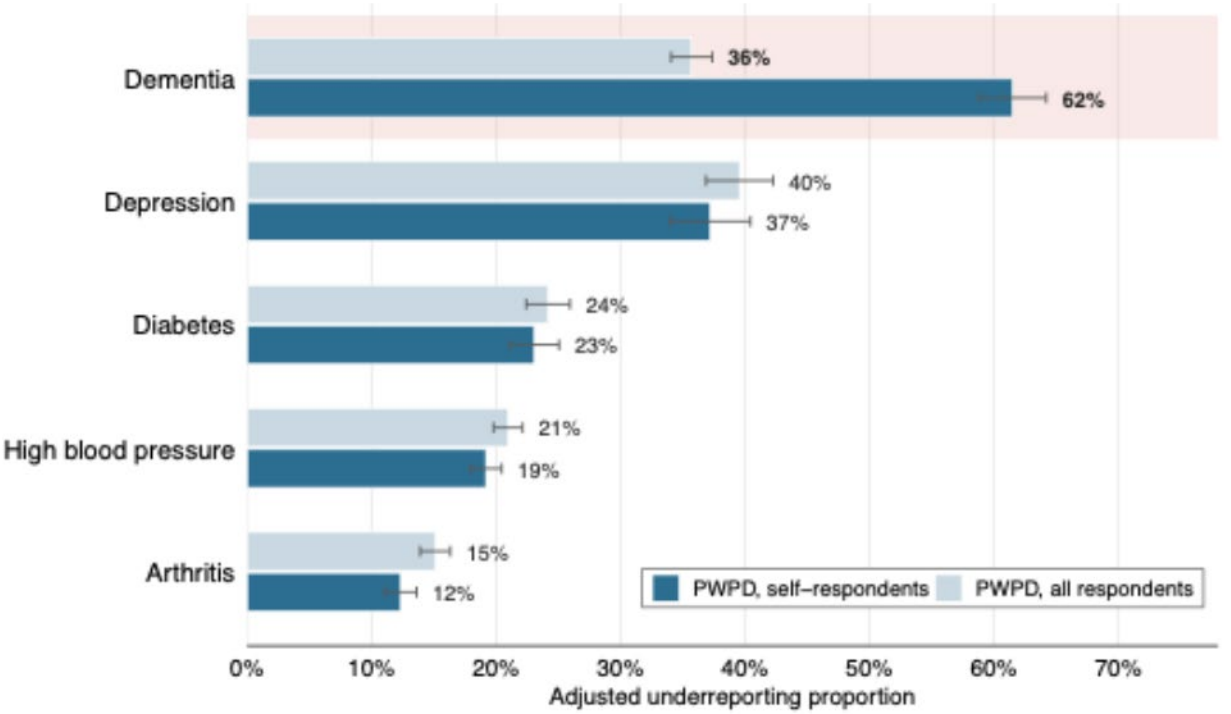
eFigure 2: Adjusted Underreporting Proportions for Dementia Diagnosis by Patient and Care Delivery Factors



Abbreviations: ns, not significant.

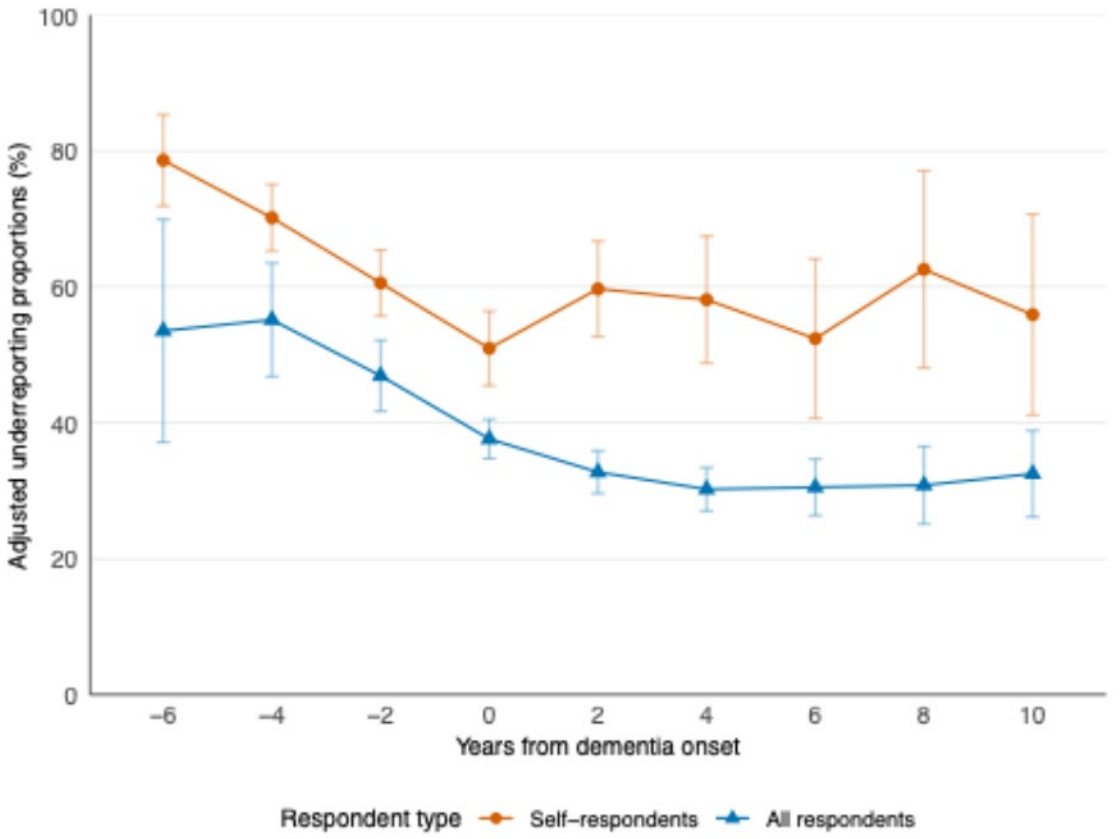
Notes: Underreporting proportions were estimated using generalized estimating equations (GEE) adjusted for all covariates listed in the *Methods* and survey year, with predictive margins calculated for each socioeconomic characteristic (Panel A) and care delivery factor (Panel B) among all respondents. Asterisks denote the significance of group differences for each factor, tested directly in the GEE models: ***P < .001, **P < .01, *P < .05. Non-Hispanic Other included American Indian or Alaska Native, Asian, Native Hawaiian or Pacific Islander, and other races not separately identified in the Health and Retirement Study (HRS). Outpatient diagnosis settings included office, hospital outpatient department, facility, federally qualified health center, independent clinic, public health clinic, rural health clinic, and other outpatient settings. Residential care settings included skilled nursing facilities, nursing facilities, assisted living facilities, custodial care facilities, hospice, and other residential care settings. Other includes home, specialty psychiatric care, telehealth provided other than in patient's home, community mental health center, and other places of service.

eFigure 3: Adjusted Underreporting Proportions for Dementia and Other Diagnoses Among Older Adults With Probable Dementia, Stringent Claims-Based Diagnosis Definition



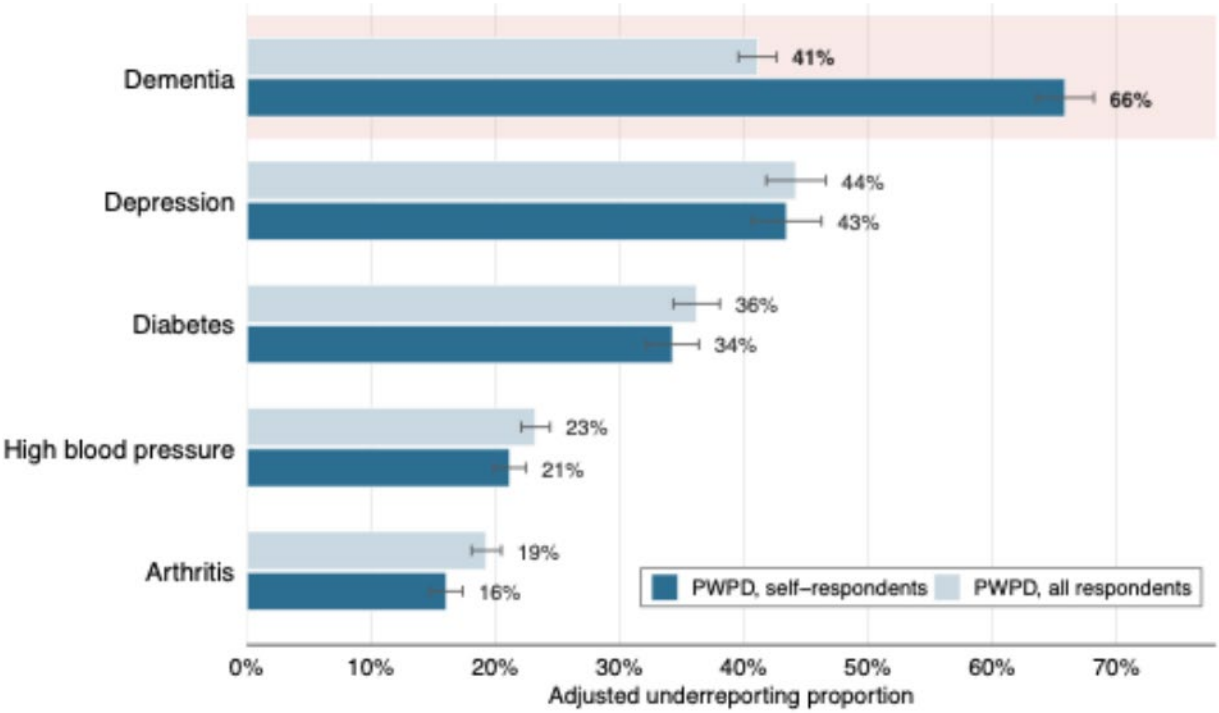
Abbreviations: PWPD, persons with probable dementia.
Notes: The figure presents sensitivity analyses estimating underreporting proportions for dementia and other diagnoses using a more stringent definition of claims-based diagnosis, defined as either ≥2 professional service claims with a diagnosis at least 7 days apart or ≥1 diagnosis in an inpatient, skilled nursing facility, home health, or hospice claim.

eFigure 4: Adjusted Underreporting Proportions for Dementia Diagnosis by Years From Dementia Onset, Stringent Claims-Based Diagnosis Definition



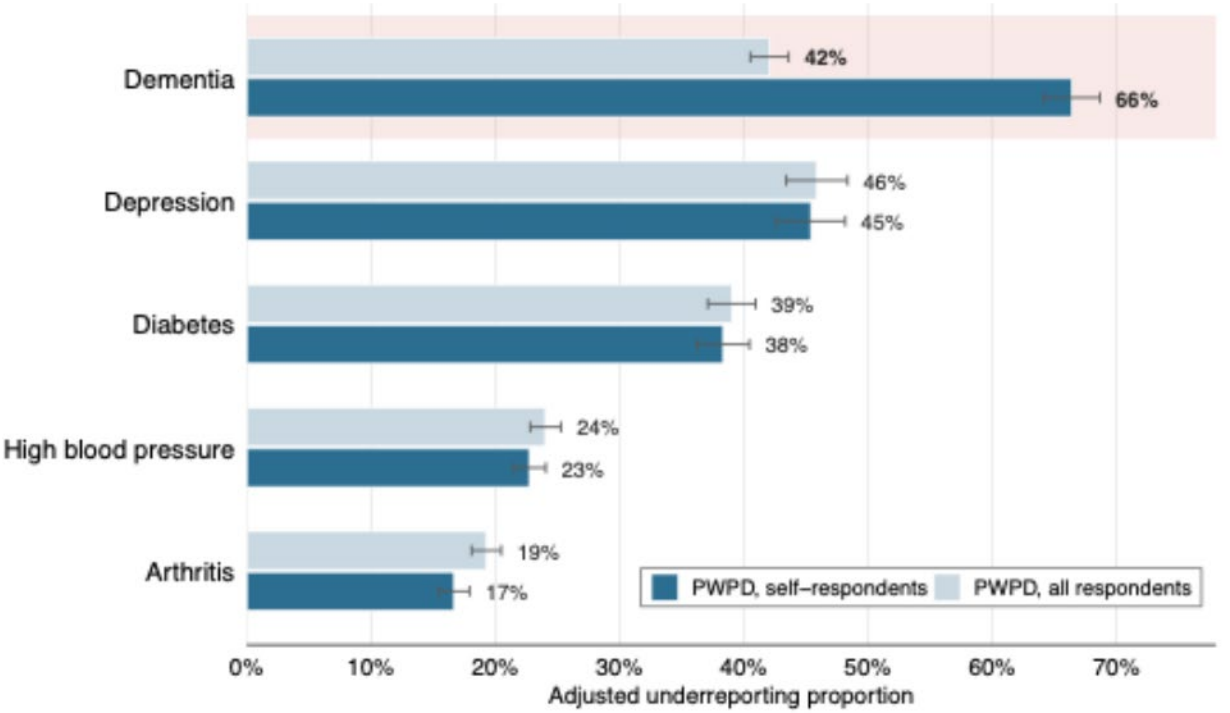
Notes: The figure presents sensitivity analyses of underreporting proportions for dementia diagnosis from 6 years before to 10 years after dementia onset, as defined in the Health and Retirement Study (HRS). A more stringent algorithm was applied to identify dementia diagnoses in claims, requiring either ≥2 professional service claims with a diagnosis at least 7 days apart or ≥1 diagnosis in an inpatient, skilled nursing facility, home health, or hospice claim.

eFigure 5: Adjusted Underreporting Proportions for Dementia and Other Diagnoses Among Older Adults With Probable Dementia, Restricted to Diagnoses Within 6 Years Before HRS-Defined Onset



Abbreviations: PWPD, persons with probable dementia.
Notes: The figure presents sensitivity analyses estimating underreporting proportions for dementia and other diagnoses, restricting the sample to person-waves with a dementia diagnosis occurring within 6 years before dementia onset as defined in the Health and Retirement Study (HRS).

eFigure 6: Adjusted Underreporting Proportions for Dementia and Other Diagnoses Among Older Adults With Probable Dementia, Restricted to Respondents With Complete Self-Reported Diagnosis Status Across All Conditions



Abbreviations: PWPD, persons with probable dementia.
Notes: The figure presents sensitivity analyses estimating underreporting proportions for dementia and other diagnoses, restricting the sample to respondents with complete (non-missing) self-reported diagnosis status across all health conditions.

eTable 1: ICD-9-CM and ICD-10-CM Codes Utilized for Identifying Dementia Diagnoses

Dementia			
ICD-9-CM Code	**Description**	**ICD-10-CM Code**	**Description**
290.0	Senile dementia, uncomplicated	F01.50	Vascular dementia without behavioral disturbance
290.1	Presenile dementia	F01.51	Vascular dementia with behavioral disturbance
290.10	Presenile dementia, uncomplicated	F02.80	Dementia in other diseases classified elsewhere without behavioral disturbance
290.11	Presenile dementia with delirium	F02.81	Dementia in other diseases classified elsewhere with behavioral disturbance
290.12	Presenile dementia with delusional features	F03.90	Unspecified dementia without behavioral disturbance
290.13	Presenile dementia with depressive features	F03.91	Unspecified dementia with behavioral disturbance
290.2	Senile dementia with delusions or depression	F10.27	Alcohol dependence with alcohol induced persisting dementia
290.20	Senile dementia with delusional features	F04	Amnestic disorder due to known physiological condition
290.21	Senile dementia with depressive features	F05	Delirium due to known physiological condition
290.3	Senile dementia with delirium	F06.1	Catatonic disorder due to known physiological condition
290.4	Vascular dementia	F06.8	Other specified mental disorders due to known physiological condition
290.40	Vascular dementia, uncomplicated	G13.8	Other systemic atrophies primarily affecting the central nervous system
290.41	Vascular dementia with delirium	G30.0	Alzheimer's disease with early onset
290.42	Vascular dementia with delusions	G30.1	Alzheimer's disease with late onset
290.43	Vascular dementia with depressed mood	G30.8	Other Alzheimer's disease
291.2	Alcohol dependence with alcohol induced persisting dementia	G30.9	Alzheimer's disease, unspecified

294.0	Amnestic disorder in conditions classified elsewhere	G31.01	Pick's disease
294.1	Dementia classified elsewhere (any specific etiology)	G31.09	Other frontotemporal dementia
294.10	Dementia in conditions classified elsewhere without behavioral disturbance	G31.83	Dementia with Lewy Body
294.11	Dementia in conditions classified elsewhere with behavioral disturbance	G31.1	Senile degeneration of the brain, not elsewhere classified
294.2	Dementia unspecified	G31.2	Degeneration of nervous system due to alcohol
294.20	Dementia, unspecified, without behavioral disturbance	G94	Other disorders of brain in diseases classified elsewhere
294.21	Dementia, unspecified, with behavioral disturbance	R54	Senility without mention of psychosis
294.8	Other persistent mental disorders due to conditions classified elsewhere		
331.0	Alzheimer’s disease		
331.11	Pick’s disease		
331.19	Other frontotemporal dementia		
331.82	Dementia with Lewy body		
331.2	Senile degeneration of brain		
331.7	Cerebral degeneration in diseases classified elsewhere		
797	Senility without mention of psychosis		

eTable 2: Health and Retirement Study Question Wording for Self- or Proxy-Reported Health Conditions

Health Conditions[a]	Survey Year	HRS Question Wording
Dementia and memory-related disease	1998 to 2008	Since we last talked with you, has a doctor told you that you have a memory-related disease?
	2010 to 2020	1. Since we last talked to you, has a doctor told you that you have Alzheimer's Disease? 2. Since we last talked to you, has a doctor told you that you have dementia, senility or any other serious memory impairment?
Depression[b]	1998 to 2008	Since we last talked to you, have you had or has a doctor told you that you have any emotional, nervous, or psychiatric problems?
	2010 to 2020	Since we last talked to you, has a doctor told you that you have had problems with depression?
Diabetes	1998 to 2020	Since we last talked with you, has a doctor told you that you have diabetes or high blood sugar?
Arthritis	1998 to 2020	Since we last talked with you, has a doctor told you that you have Arthritis or rheumatism?
Hypertension	1998 to 2020	Since we last talked with you, has a doctor told you that you have high blood pressure or hypertension?

Abbreviations: HRS, Health and Retirement Study.

[a] For each condition, if the person answering is new, this is treated as a first interview, and the question is: "Has a doctor ever told you that you have…?". In subsequent interviews, the wording depends on whether the preloaded prior-wave variable indicates a "yes". If there is no prior "yes", the question is: "Since we last talked to you, has a doctor told you that you have…?". If a prior "yes" is recorded, a statement is read: "Our records from your last interview show that you have had…". The respondent (or proxy) may dispute having had the condition, and any new response is recorded for the current wave.

[b] Because the HRS did not include a depression-specific self-report question before 2010, we used the "emotional, nervous, or psychiatric problems" item as a proxy for pre-2010 waves, given that individuals with a depression diagnosis would fall within this category.

eTable 3: Identification of Problem-Based Visits and Influenza Vaccination in Claims

Service Delivery	CPT codes	Healthcare Common Procedure Coding System codes
Problem-based visits	99201-99215, 99241-99245 (before 2010)	G0463
Influenza vaccination	90630, 90653, 90654, 90655, 90656, 90657, 90658, 90659, 90660, 90661, 90662, 90672, 90673, 90674, 90682, 90685, 90686, 90687, 90688, 90749, 90756	Q2033, Q2035, Q2036, Q2037, Q2038, Q2039

Notes: This table presents the Current Procedural Terminology (CPT) and Healthcare Common Procedure Coding System (HCPCS) codes used to construct the two care engagement measures: (1) any problem-based visit and (2) receipt of influenza vaccination.

eTable 4: Adjusted Underreporting Proportions for Other Diagnoses Among Individuals Who Underreported Dementia

	Underreporting proportions		
Self-reported diagnoses	**Estimate, 95% CI**	**Standard Error**	**No. of Observations**
Depression	0.480 (0.438, 0.521)	0.021	770
Diabetes	0.408 (0.368, 0.448)	0.020	978
Hypertension	0.246 (0.223, 0.269)	0.012	2,216
Arthritis	0.198 (0.172, 0.224)	0.013	1,387

Notes: Analyses were restricted to patients who underreported dementia diagnosis and had a claims-based diagnosis for each respective condition. Underreporting proportions were estimated using generalized estimating equation (GEE) regressions to generate predictive margins, adjusting for patient sociodemographic characteristics and health conditions described in *Methods,* as well as survey year indicators.

eTable 5: Association of Underreporting of Dementia Diagnosis With Post-Diagnosis Care Engagement and End-of-Life Planning, by Respondent Type

	Care engagement		End-of-life planning
Respondent type	**Any problem-based visit**	**Influenza vaccination**	**Witnessed will or trust**
Self-respondents	0.69 (0.55-0.88)	0.63 (0.51-0.78)	0.68 (0.53-0.87)
P value	.003	<.001	.002
No. of observations	2,738	2,738	2,673
Proxy respondents	0.63 (0.50-0.80)	0.65 (0.51-0.84)	0.80 (0.63-1.01)
P value	<.001	.001	.06
No. of observations	3,420	3,420	3,295
P value for difference	.79	.69	.64

Notes: Estimates represent the association of dementia diagnosis underreporting with the outcome indicated in each column, estimated separately for self-respondents and proxy respondents. All models were adjusted for age, race and ethnicity, sex, education, living arrangement, number of chronic conditions, number of activities of daily living (ADL) limitations, time relative to dementia onset, and survey year indicators. Time relative to dementia onset was included in place of the Modified Telephone Interview for Cognitive Status (TICS-M) cognitive score used in the main analysis, which is available only for self-respondents (proxy cognition is assessed on a different scale), to make estimates comparable across groups. The P value for difference was obtained from a pooled regression including an interaction between underreporting and respondent type and indicates whether the association differed significantly between self-respondents and proxy respondents.