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FEATURED ARTICLE

Cognitive measures lacking in EHR prior to dementia or Alzheimer's disease diagnosis

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Abstract

Introduction: The extent that cognitive measures are documented in electronic health records (EHR) is important for quality care and addressing disparities in timely diagnosis of dementia or Alzheimer's disease (AD).

Methods: Analysis of U.S. EHR data to describe the frequency and factors associated with cognitive measures prior to diagnosis of dementia (N = 111,125) or AD (N = 30,203).

Results: Only 11% of dementia patients and 24% of AD patients had a cognitive measure documented in the 5 years prior to diagnosis. Black race, older age, non-commercial health insurance, lower mean neighborhood income, greater in-patient stays, and fewer out-patient visits were associated with lacking cognitive measures.

Discussion: Extensive missing cognitive data and differences in the availability of cognitive measures by race, age, and socioeconomic factors hinder patient care and limit utility of EHR for dementia research. Structured fields and prompts for cognitive data inputs at the point of care may help address these gaps.

KEYWORDS
Alzheimer's disease, dementia, electronic health records, electronic medical records, healthcare disparities, mild cognitive impairment, Mini-Mental State Examination, neurocognitive tests

1 | INTRODUCTION

Globally, approximately 50 million people suffer from dementia, with Alzheimer's disease (AD) the suspected pathology in an estimated 60% to 80% of cases.[1–3] Symptoms of cognitive impairment begin years before overt dementia is evident.[4] Timely detection and diagnosis provide a foundation for high-quality care.[5,6] For example, recognition of cognitive impairment better equips health-care providers to manage comorbidities, medications, and communication with patients and families,[4,5] and assist in advance care planning.[7] Indeed, numerous countries include a timely diagnosis as a fundamental goal of their dementia strategies.[8–10] However, cognitive impairment may be subtle and difficult to detect during routine patient visits, and many patients with dementia remain undiagnosed even years after dementia onset.[11–13]

To help achieve earlier diagnosis, important first steps are to detect and track cognitive decline by measuring and documenting cognitive function during medical visits.[5,14–16] Despite insufficient evidence to recommend broad screening of the general older adult population,[4] recommendations to assess cognitive status, especially when symptoms or concerns are present, are promoted by numerous organizations and reimbursement agencies.[5,6,14,15,17] Recommendations for the assessment process in routine clinical care include observing and asking about cognitive problems, and if a brief cognitive assessment is used, recording the name of the test and the result into the electronic health record (EHR).[5,14,15,18] By documenting in EHR, the patient's cognitive status is available to all his/her health-care providers, even with transitions in care. Furthermore, monitoring change is facilitated. The extent to which providers adhere to recommendations for documenting cognitive measures among symptomatic or concerned patients is

important to identify and address gaps in care. In a 2019 survey of 1954 U.S. adults aged 65 years and older, 47% reported ever having a conversation regarding thinking or memory abilities with their providers, and only 16% reported having regular brief cognitive assessments.[16] This low frequency may have reflected that respondents were from a general survey panel sample, and not necessarily experiencing cognitive symptoms or concerns at the time of a clinic visit. For patients experiencing symptoms of incipient AD or dementia, documentation of cognitive assessments is a particularly valuable part of the diagnostic and care pathway.[16]

The objective of this analysis was to describe the frequency and factors associated with documented cognitive measures among patients prior to the diagnosis of AD or dementia in a large U.S. EHR database. By focusing on patients prior to their coded diagnosis for dementia, we focus on the time period when patients were most likely experiencing cognitive impairment[11] and documented measures would have been useful for monitoring change, informing various providers of cognitive status, and aiding in earlier detection. We further examined whether the likelihood of having a documented cognitive measure differed by patient age, sex, race, comorbidities, and health-care use. These results are also informative of the quality and missingness in EHR data, which is increasingly used to develop algorithms to predict incidence of dementia and conduct embedded pragmatic clinical trials.[19–22]

HIGHLIGHTS

- Analysis of a large geographically diverse U.S. electronic health records (EHR) database.
- Only 11% of dementia patients had cognitive measures recorded prior to diagnosis.
- Race, age, sex, and socioeconomic disparities exist in cognitive electronic records.
- Improvements in EHR systems such as structured cognitive data fields are needed.

RESEARCH IN CONTEXT

1. **Systematic review**: A PubMed search retrieved no prior studies that described cognitive measures in electronic health records (EHR) among dementia or Alzheimer's disease patients.
2. **Interpretation**: Recommendations to document cognitive function are largely unimplemented, with only 11% of dementia patients having documented cognitive measures prior to diagnosis. Heightened gaps for patients who were Black, male, older, or without commercial insurance indicate that systematic differences affect the care pathway for patients with recognizable cognitive impairment.
3. **Future directions**: To best address gaps, future research should explore reasons for missing cognitive data, such as: no test conducted, test conducted but not entered into patient's record, and EHR data extraction issues. In the meantime, EHR systems should increase structured data fields that prompt cognitive data and facilitate entry of cognitive tests and results. Better documentation of cognitive measures will improve quality of EHR, improve monitoring of cognitive decline, and help achieve more timely diagnosis.

2 | METHODS

We conducted a retrospective cohort study and a nested case-control analysis using data from the Optum® de-identified EHR database. The database license provided access to data on 5.3 million patients from January 2007 through March 2016 from across the United States. Patients fulfilling at least one of three criteria were included in the licensed database: (1) International Classification of Diseases (ICD)-9 or ICD-10 code for dementia or AD; (2) memory, cognition, or AD mention in provider note; or (3) Mini-Mental State Examination (MMSE) with result. The database contains longitudinal health information including diagnosis codes and provider notes data for patients from diverse ages, socioeconomic backgrounds, and geographical regions across the United States. Clinical data and claims data are obtained from both in-patient and ambulatory EHRs, practice management systems, and numerous other internal systems, and are processed, normalized, and standardized across the continuum of care from both acute in-patient stays and out-patient visits. No identifiable protected health information was extracted or accessed; thus, institutional review board approval or waiver of authorization was not required.

To evaluate the scenario for which documented cognitive measures would be valuable for earlier detection, the observation period for this analysis focused on the 5-year period prior to the first dementia diagnosis code among patients with a dementia diagnosis code. Thus, the cohort is comprised of patients appropriate for a cognitive measurement, considering that signs and symptoms of cognitive impairment are reported to appear an average of approximately 2 to 5 years prior to dementia onset or diagnosis.[11,23] Within the retrospective cohort sample, we then conducted a case-control analysis to examine whether certain patient characteristics such as age, sex, race, and socioeconomic status indicators were associated with having a documented cognitive measure prior to diagnosis.

Inclusion and exclusion criteria for the statistical analysis were designed to maximize sensitivity and specificity of the case definition while minimizing missing data. Inclusion criteria were: (1) at least one ICD-9 or ICD-10 code for dementia, (2) age $\geq$ 50 years at time of first dementia code, (3) at least 5 years' data available prior to the first dementia ICD code, (4) at least one out-patient visit in the first year of the observation period, (5) part of an integrated delivery network (IDN,

defined as a formal system of providers and sites of care providing both health-care services and health insurance plans to patients, thereby producing a comprehensive EHR; 82% of Optum data are sourced from IDNs), and (6) provider notes present. A total 119,668 patients met these inclusion criteria. Because the study was conducted to evaluate adherence to recommendations for cognitive measures during routine clinical care, we then excluded patients who had only in-patient cognitive measures (n = 5673, 4.7%) or had an in-patient measure before out-patient measure (n = 726, 0.6%) to avoid bias to the likelihood of a subsequent out-patient measure during routine case. We also excluded patients missing data to link the cognitive measure to a medical encounter type and date (n = 2144, 1.8%). This primary analysis included N = 111,125 dementia patients.

In secondary analysis, we examined a cohort of patients with at least one AD ICD-9 or ICD-10 code. AD codes have higher specificity but lower sensitivity than general dementia codes.[24,25] Applying the remaining inclusion criteria as in the main analysis, N = 30,203 patients with AD were included in this secondary analysis.

2.1 | Measures

Cognitive measurement data were extracted from clinical notes and structured fields by the Optum natural language processing (NLP) system.[26] NLP measures were sourced from clinical notes appearing anywhere in the patient EHR, from any provider type or specialty. An artificial intelligence algorithm built on standardized vocabulary from the Unified Medical Language System was used to tag, curate, and report the NLP-derived measures. In the development and validation of the NLP programming, Optum conducted manual reviews of samples of narrative texts to identify appropriate targets for the NLP process and to confirm the correct output. At the time of this analysis, the Optum NLP-derived measurement file included more than 56,600 different measurement terms, of which 16 were cognitive measures and used in this analysis.

Patient age was determined by birth year, with maximum truncated at 89 years per data privacy requirements. Patient sex, race, and ethnicity were self-reported. The Optum database classified race as African American [Black], Asian, Caucasian [White], or Other/Unknown, and ethnicity as Hispanic or non-Hispanic. Mean household income in the patient's residential 3-digit zip code geographic area was a measure of neighborhood income and analyzed in quartiles. Education data were unavailable. Insurance type refers to the most common insurance provider(s) during the observation period. A modified version of the Elixhauser comorbidity index, which considers the presence of 31 conditions, was calculated for the first year of the observation period.[27–29] Medication data were obtained from all prescriptions and categorized as number of prescription medications during the first year of the observation period.

2.2 | Statistical analysis

For the descriptive analysis of documentation of cognitive measures, the index date was defined as the first diagnosis code for dementia, and the observation windows spanned from 5 years prior to index date through 3 months post-index date. We calculated the frequency (N,%) of documented measures ever in the 5 years prior to index date, with subgroups of 2 to 5 years prior, 3 months to 2 years prior, and <3 months prior, and furthermore on the index date and in the 3 months post-index date considering that the diagnostic process may extend beyond one visit.[30,31] To test the statistical significance of age or racial/ethnic differences in health-care use characteristics, we use the Cochran-Mantel-Haenszel chi-square test for categorical variables and the analysis of variance F-test for continuous variables.

To examine whether patient or health-care use characteristics decrease or increase the likelihood of having a documented cognitive measure, we conducted a case-control analysis within the retrospective cohort sample. Cases were the dementia patients with a documented cognitive measure ever in the 5 years prior to index date; noncases were dementia patients with no such measure in this observation period. We used logistic regression to calculate odds ratios (OR) and 95% confidence intervals (CI) for the associations between baseline values of potential predictors and the dependent variable of having a documented cognitive measure. Baseline was defined as the first year of the 5-year observation period. The final multivariable models included potential predictors that were associated with the outcome at $P < 0.2$ in the age-adjusted models and were statistically significant at $P < 0.05$ upon adjustment for other predictors. All analyses were repeated in patients with a coded AD diagnosis, using the first AD diagnosis code as the index date. Analyses were conducted using SAS v9.4.

3 | RESULTS

3.1 | Cohort description

Among the 111,125 dementia patients, the mean age at the first coded dementia diagnosis was 78 ± 9 years, and 11.1% were under age 65 years (Table 1). Among the 30,203 patients with coded AD, mean age at first AD code was 81 ± 7 years, and 3.4% under age 65 years. Approximately 60% of dementia or AD patients were female, 91% were non-Hispanic White, 5% were Black, and 2% were Hispanic (Table 1). Overall, African American dementia patients had fewer primary care provider (PCP) visits (median one visit, vs median two visits among Hispanic or White patients, $P < 0.001$) and more likely to have emergency visits (23.6% vs 15.8% of non-Hispanic Whites; 21.3% of Hispanics, $P < 0.001$) during the first 12 months of their analysis period, and Hispanics had a higher mean comorbidity index compared to non-Hispanic White patients (2.1 ± 2.6 vs 1.6 ± 2.2, $P < 0.001$).

During the 5-year period prior to the coded dementia diagnosis, patients frequently interacted with health-care providers (median 60 encounters; interquartile range [IQR] 28–112). PCP visits were common, with median 27 (IQR 11–58) PCP visits on different dates over the 5 years. Emergency physician visits occurred for 68.8% and neurologist visits occurred for 31.3% of dementia patients (median 3 visits [IQR 1–6] each) in the 5 years prior. Neurologist or psychiatrist visits during the first year of the analysis period were more common among younger

TABLE 1 Patient sex, race/ethnicity, and age at first coded diagnosis of Alzheimer's disease or dementia

	Dementia (any type) N = 111,125		Alzheimer's disease N = 30,203	
Age, years at diagnosis date				
Mean (SD) years	78	(9)	81	(7)
Median (Q1, Q3) years	81	(73, 85)	83	(78, 86)
Age, categorical year:	*N*	*%*	*N*	*%*
50–54	2656	2.4	141	0.5
55–60	5051	4.6	381	1.3
61–64	4597	4.2	495	1.6
65–70	9997	9.0	1586	5.3
71–74	10,197	9.2	2309	7.6
75–80	21,393	19.2	6146	20.3
81–84	20,996	18.9	6771	22.4
85+	36,238	32.5	12,374	41.0
Sex	*N*	*%*	*N*	*%*
Male	44,391	39.9	10,788	35.7
Female	66,715	60.0	19,409	64.3
Race/ethnicity	*N*	*%*	*N*	*%*
Black	5513	5.0	1593	5.3
Asian	716	0.6	160	0.5
Hispanic	2222	2.0	602	2.0
Non-Hispanic white	100,337	90.3	27,125	89.8
Other or unknown	2337	2.1	723	2.4

*Data on sex were missing for n = 6 AD and n = 19 dementia patients.

patients (for ages < 65, 65–80, 81+ respectively: neurologist, 12.2%, 7.8%, 5.9%; psychiatrist, 8.4%, 3.1%, 1.9%; $P < 0.001$). Younger dementia patients were more commonly male or non-White (male: 44.9%, 40.9%, 34.0%; non-White: 12.0%, 7.0%, 5.6%; $P < 0.001$). Medicaid use was more common among Hispanic (19.5%) and Blacks (14.6%), compared to non-Hispanic White (3.0%) or Asian (9.4%) dementia patients ($P < 0.001$).

3.2 | Cognitive measures in EHR

During the 5 years prior to diagnosis, only 11.0% (n = 12,174) of dementia patients and 23.6% (n = 7127) with coded AD had a cognitive assessment with test name and result noted (Table 2). Thus, 89% of dementia patients and 76% with coded AD had no cognitive assessment documented prior to the date of the coded diagnosis.

Among dementia patients who had a prior cognitive measure noted, the median time between the first cognitive measure and the dementia diagnosis code was 12.9 months (IQR 3.1–29.4; mean 17.9 ± 16.8 months). The percentage of patients with a cognitive measure increased as time to index date neared (Table 2). MMSE was the most common cognitive measure recorded (57% of dementia patients with a cognitive measure prior to diagnosis), followed by a Recall Test (37%), Clock Drawing (11%), Montreal Cognitive Assessment (MoCA, 10%), Mini-Cog (7%), and Saint Louis University Mental Status (SLUMS; 7%), with other tests comprising < 5% of all tests noted (Figure 1).

PCPs were often the first provider type to note a cognitive measure prior to diagnosis: 48.9% of all first cognitive measures for dementia patients were noted during a PCP visit, whereas 19.0% were with a neurologist and 9.7% with a mid-level provider (Figure 2).

3.3 | Results of logistic regression models for disparities in having a prior cognitive measure noted

Patient and health-care characteristics associated with a cognitive measure noted in the 5 years prior to the dementia diagnosis are displayed in Table 3. Table S1 in supporting information shows prevalence percentages by these characteristics, and Figure S1 in supporting information shows predicted probabilities by age, race/ethnicity, and insurance type. All variables—with the exception of emergency visits—were significant in the univariate analyses, and most associations remained robust in the multivariable model. The average age at the start of this period was 73 ± 9 years, and age was a strong predictor of cognitive measurement. Dementia patients aged > 80 years (vs 60–80 years), male (vs female), or Black (vs non-Hispanic White) were

TABLE 2 Percent of dementia (n = 111,125) or AD patients (n = 30,203) with a cognitive measure noted, by time window in relation to the date of the first coded diagnosis of dementia or AD

	% of dementia patients (N = 111,125)						% of AD patients (N = 30,203)					
		Prior: Time windows within 0–5 years:						Prior: Time windows within 0–5 years:				
	Prior: Ever 0–5 years	2–5 years	3 months–2 years	<3 months	On date of 1st dementia diagnosis code	After: 0.1–3 months	Prior: Ever 0–5 years	2–5 years	3 months–2 years	<3 months	On date of 1st AD diagnosis code	After: 0.1–3 months
Cognitive measure noted, any of the below	11.0	3.6	6.0	3.6	6.4	14.8	23.6	9.8	14.7	6.6	8.8	15.9
MMSE	6.2	1.9	3.4	1.9	2.9	5.8	15.1	6.3	8.9	3.5	4.3	7.4
Recall Test	4.1	1.4	2.0	1.2	2.3	7.0	9.9	3.7	5.4	2.5	2.9	6.2
-Immediate or short-term	0.5	0.1	0.2	0.1	0.4	1.3	1.8	0.5	0.9	0.5	0.4	1.0
-Delayed	0.6	0.1	0.3	0.2	0.6	1.7	2.5	0.7	1.3	0.6	0.7	1.2
Clock Drawing	1.2	0.3	0.6	0.3	0.6	1.6	3.2	1.1	1.7	0.7	1.1	1.7
MoCA	1.1	0.2	0.5	0.5	0.9	2.0	3.0	0.8	1.8	0.9	1.4	2.1
SLUMS	0.7	0.2	0.4	0.3	0.7	1.9	1.9	0.6	1.2	0.6	1.0	2.0
Mini-Cog	0.8	0.3	0.4	0.1	0.1	0.2	1.0	0.5	0.5	0.1	0.1	0.2
RBANS	0.2	0.1	0.1	0.1	0.2	0.4	0.7	0.3	0.3	0.3	0.2	0.4
IQ test	0.3	0.1	0.1	0.1	0.2	0.8	1.5	0.5	0.5	0.5	0.2	0.6
Boston Naming Test	0.1	<0.1	<0.1	<0.1	<0.1	0.2	0.3	0.1	0.2	0.1	0.1	0.1
Cognistat	<0.1	<0.1	<0.1	<0.1	<0.1	<0.1	0.1	0.1	<0.1	<0.1	<0.1	0.0
Cognitive Linguistic Quick Test	<0.1	<0.1	<0.1	<0.1	<0.1	<0.1	<0.1	<0.1	<0.1	<0.1	0	0.0
Trail-Making Test	0.1	<0.1	<0.1	<0.1	<0.1	0.1	0.3	0.1	0.1	<0.1	<0.1	0.1
Wisconsin Card Sorting Test	<0.1	<0.1	<0.1	<0.1	<0.1	0.1	0.1	<0.1	0.1	<0.1	<0.1	0.1
Brief Cognitive Rating	0	0	0	0	0	<0.1	<0.1	0	<0.1	0	0	.

Abbreviation: AD, Alzheimer's disease; MMSE, Mini-Mental State Examination; MoCA: Montreal Cognitive Assessment; RBANS, Repeatable Battery for the Assessment of Neuropsychological Status; SLUMS, Saint Louis University Mental Status.

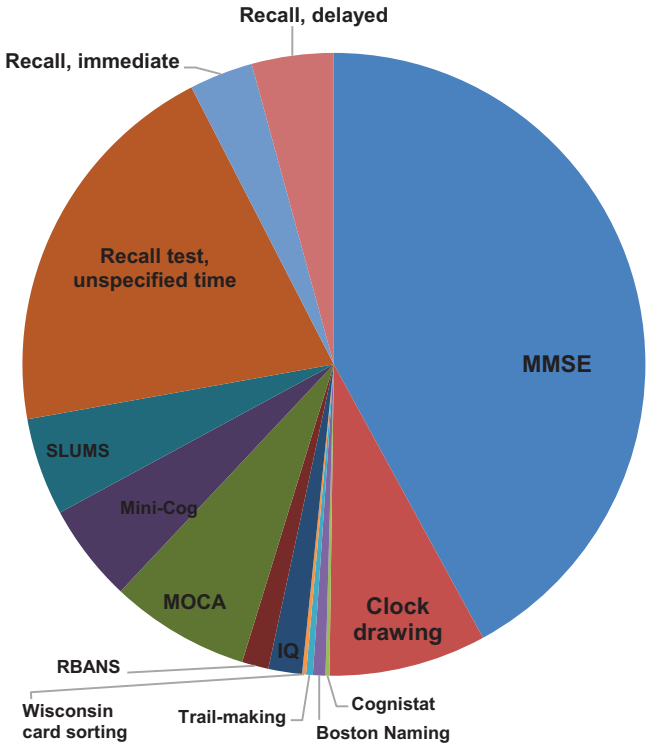

FIGURE 1 Cognitive measures noted from 16,387 measures among 12,174 dementia patients with cognitive measures in the 5 years prior to the first coded dementia diagnosis.
* * Proportion shown is of all cognitive measures recorded in 0 to 5 years prior (N = 16,387 measures); patients who had more than one measure recorded in the 5 years prior were counted for each in the figure. Tests that were recorded for < 0.1% of dementia patients are not depicted; these were the Cognitive Linguistic Quick Test (N = 9 dementia patients), Brief Cognitive Rating (N = 0 dementia patients). Overall in the 5 years prior, the percentage of patients (N = 12,174) with a Mini-Mental State Examination (MMSE) was 57%; Recall Test 37%; Clock Drawing 11%; Montreal Cognitive Assessment (MoCA) 10%; Mini-Cog 7%; and Saint Louis University Mental Status (SLUMS) 7%. Results were similar in the Alzheimer's disease patient sample (data not shown).

less likely to have a cognitive measure noted compared to their counterparts ($P < 0.001$). Medicare, Medicaid, or other non-commercially insured patients (vs those with commercial insurance), and patients from neighborhoods with household income lower than the 75% percentile (vs the highest 25th percent) were less likely to have a cognitive measure noted ($P < 0.001$). The number of prescriptions and PCP visits, as well as visits with specialists in neurology, geriatrics, or psychiatry, was positively associated with cognitive measurement. In contrast, a longer duration or higher frequency of in-patient stays was associated with a lower likelihood of cognitive measures.

While a higher comorbidity burden was predictive of having a cognitive measure in the age-adjusted model, this association was not statistically significant in the multivariable model, particularly with adjustment for in-patient stays. Given that the Elixhauser index was designed to indicate risk of in-hospital events and duration of stay, we conducted an additional exploratory multivariable model that removed adjustment for in-patient stays and observed that patients with higher comorbidity burden were less likely to have a cognitive test noted in the multivariable model (OR = 0.99, 95% CI:0.98–1.00, $P = .01$). The finding that cognitive measures were less likely noted for patients with longer or more frequent in-patient stays, and for patients with higher comorbidity index once adjusting for prescriptions and other out-patient health-care use indicators, supports that patients with critical health conditions were less likely to have cognitive tests noted during routine care.

Among patients with coded AD, the multivariable model results also showed that patients were less likely to have a cognitive measure if they were over age 80 years, Black, non-commercially insured, and from lower neighborhood household incomes (Table 4; Table S2 in supporting information). Furthermore, health-care use as measured by prescription medications and visits to PCPs or specialists was associated with a higher likelihood of having a cognitive measure, while in-patient stays were associated with a lower likelihood of a cognitive measure, consistent with the analysis in all dementia patients. However, the association between male sex and lower likelihood of a cognitive measure was not observed among patients subsequently coded as having AD (OR = 0.99, 95% CI:0.94–1.05, $P = 0.74$).

4 | DISCUSSION

In this analysis of 111,125 dementia patients from a large U.S. EHR database, cognitive measures were lacking in 89% of medical records prior to a coded dementia diagnosis, indicating a major gap in the utility of EHR for dementia diagnosis, care, and research.[5,14,15,18] Numerous patient and health-care use factors were associated with lacking a cognitive measure, including Black race, older age, male sex, and markers of lower socioeconomic status such as non-commercial health insurance and lower mean neighborhood income. Patients with more out-patient visits and prescriptions were more likely to have a cognitive assessment noted, whereas those with in-patient stays were less likely to have such a measure noted. When cognitive assessments were noted, it was most commonly by PCPs, on average 1.5 years prior to the coded dementia diagnosis, and use of the MMSE or a Recall Test. Results were similar among patients with coded AD. These novel data identify gaps in provider practices regarding recommendations to document cognitive assessments to help achieve a timely diagnosis of dementia.[5,14,15] In addition, these results highlight current limitations in EHR for dementia research aiming to develop predictive models, clinical support tools, or conduct embedded pragmatic clinical trials, as there was extensive missing cognitive data and differences in the availability of cognitive measures by race, age, and socioeconomic factors.

While this study is among the first to examine cognitive measures noted in EHR of dementia patients, our results are consistent with studies that have examined a related issue, of undiagnosed dementia, and observed differences by age, sex, race, and socioeconomic status.[12,13] For example, among 307 participants with dementia from the U.S. Aging, Demographics and Memory Study, those with undiagnosed dementia were more likely to be older, male, unmarried, have

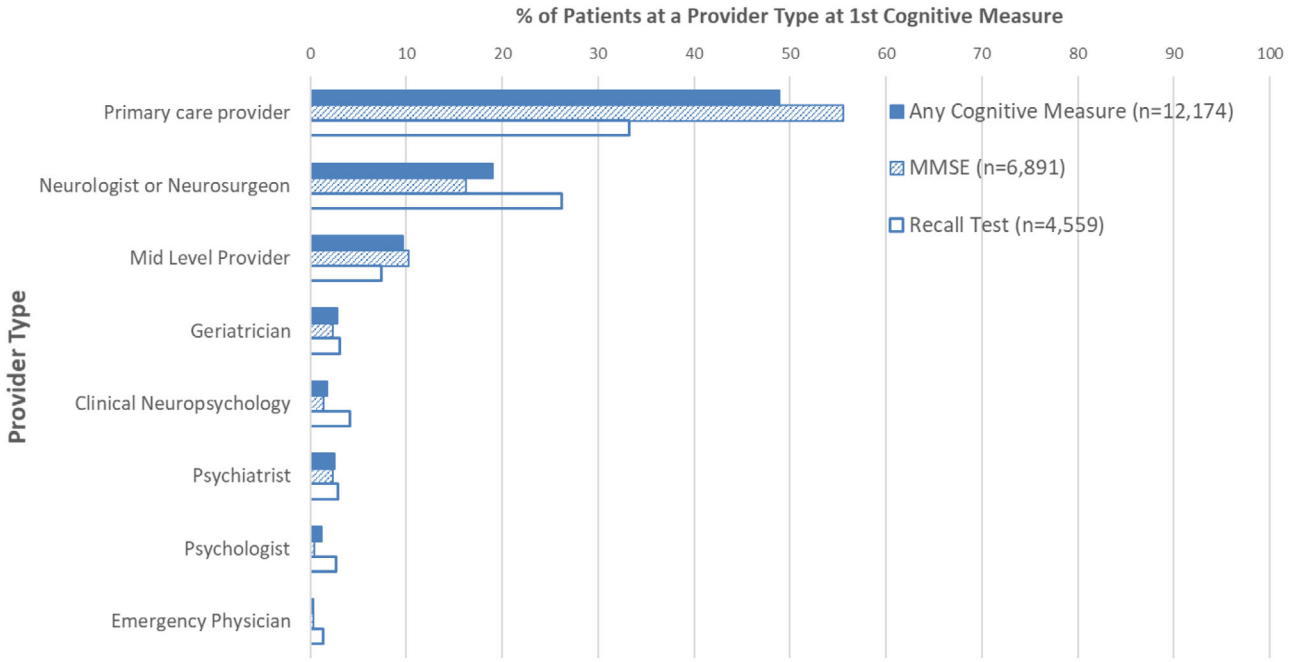

FIGURE 2 First provider type to record a cognitive measure, among patients prior to dementia diagnosis.
* *Among patients who had an out-patient cognitive measure in the 5 years prior to receiving a coded dementia diagnosis. Solid bar represents the percentage of patients with any of the cognitive measures listed in Table 2. Checked bar represents patients at first Mini-Mental State Examination (MMSE). Clear bar represents patients at first Recall Test. Primary care provider includes "family practice," "internal medicine," and "general practice" classifications. Psychiatrist includes "psychiatry and neurology" classification. When more than one provider type was associated with the note, the primary specialty of the attending physician (rather than the admitting physician or secondary specialty) was selected as provider type. Other provider types that each accounted for <1% of provider types at the first noted cognitive measure are not depicted in the figure. Data on provider type on the date of the first noted cognitive measure was missing for 12.0% of dementia patients.

fewer years in education, and have less severe dementia than those whose dementia had been diagnosed.[12] Similarly, a study of 585 participants of the National Health and Aging Trends Study showed that undiagnosed individuals were more likely to be non-White, have lower educational attainment, and less functional impairment compared to diagnosed individuals.[13] Non-White race and lower educational attainment were also associated with undiagnosed dementia in Medicare claims in the national Health and Retirement Study.[32] Overall, findings on the role of age and sex have varied, whereas disparities related to socioeconomic status and race have been consistently observed.

With a longstanding link between race and health in the United States, it is apparent that racial disparities occur throughout the AD patient journey; Blacks are more likely to have a delayed diagnosis and greater severity at diagnosis, and the prevalence and incidence of AD is higher among Blacks compared to non-Hispanic Whites.[33–36] In our analysis, Black dementia patients were approximately 20% less likely to have a cognitive measure noted prior to diagnosis compared to non-Hispanic Whites, even after adjusting for other factors such as age, socioeconomic indicators, and health-care use. This finding points to a specific gap that can be addressed to help improve racial disparities in dementia diagnosis, ie, concerted efforts to conduct and document cognitive assessments among Black patients. Also at issue is that racial disparities exist for cognitive test performance: on average, cross-sectional test performance tends to be worse among Blacks compared to non-Hispanic Whites.[33] Even with attempts to adjust for testing differences, relying on cognitive assessments at a single time point could lead to overcounting of dementia in Blacks.[32,33] Tracking and comparing cognitive measures over time within an individual would alleviate these challenges and improve accuracy of dementia diagnosis.[33] Thus, the importance of a prior cognitive measure recorded in the EHR may be heightened for Black patients as a resource in the ascertainment of cognitive decline.

In addition to racial and socioeconomic factors, the likelihood of having a cognitive measure differed by health insurance type and the frequency and nature of patients' interactions with the health-care system. More frequent primary care visits and relevant specialist visits increased the likelihood of a cognitive measure, whereas in-patient stays or a greater comorbidity index decreased this likelihood in multivariable models. One possible explanation is that for patients with critical conditions or events that require hospitalization, cognitive health is relatively lower priority. Otherwise, it is reasonable that patients with more frequent out-patient visits have increased opportunities for providers to recognize symptoms that trigger cognitive testing. Differences by insurance type may reflect a host of health-care delivery and patient factors, such as available time spent with patients or for entering results into EHR, and residual socioeconomic differences in health.

Reasons cognitive data are lacking in EHR may be a lack of cognitive testing, a lack of entering testing results into the EHR, or a lack

TABLE 3 Associations between baseline patient characteristics or health-care use and presence of a cognitive measure noted in the 5 years prior to dementia diagnosis (n = 111,125)[a]

			Age-adjusted				Multivariable model			
			OR	95% CI		*P*-value	OR	95% CI		*P*-value
Age, years:	*N*	*%*								
45–49	*2656*	*2.4*	0.99	0.86	1.13	0.87	0.95	0.82	1.10	0.47
50–54	*5051*	*4.5*	0.92	0.82	1.04	0.18	0.90	0.80	1.02	0.09
55–60	*4597*	*4.1*	1.08	0.99	1.17	0.10	1.03	0.93	1.13	0.59
61–64	*9997*	*9.0*	1.17	1.07	1.27	0.0005	1.16	1.06	1.27	0.002
65–70	*10,197*	*9.2*	1.34	1.26	1.43	<.0001	1.40	1.31	1.49	<.0001
71–74	*21,393*	*19.3*	1.39	1.30	1.48	<.0001	1.46	1.37	1.56	<.0001
75–80	*20,996*	*18.9*	1.18	1.12	1.24	<.0001	1.31	1.25	1.39	<.0001
81–84	*36,238*	*32.6*	ref				ref			
Sex										
Male	*44,391*	*39.9*	0.90	0.87	0.94	<.0001	0.89	0.85	0.93	<.0001
Female	*66,715*	*60.0*	ref				ref			
Race/ethnicity										
Black	*5513*	*5.0*	0.73	0.66	0.81	<.0001	0.81	0.73	0.89	<.0001
Asian	*716*	*0.6*	0.98	0.77	1.24	0.86	0.87	0.69	1.11	0.27
Hispanic	*2222*	*2.0*	0.98	0.86	1.12	0.81	1.14	1.00	1.31	0.06
Non-Hispanic White	*100,337*	*90.3*	ref				ref			
Other/Unknown	*2337*	*2.1*	0.54	0.45	0.63	<.0001	0.72	0.61	0.85	0.0002
Mean household income of 3-digit zip code area, quartiles										
Q1 (< $34,855)	*27,540*	*24.8*	0.64	0.61	0.68	<.0001	0.65	0.61	0.68	<.0001
Q2 ($34,855– $39,816)	*27,252*	*24.5*	0.67	0.64	0.71	<.0001	0.73	0.69	0.77	<.0001
Q3 ($39,816–45,537)	*26,222*	*23.6*	0.50	0.48	0.53	<.0001	0.49	0.46	0.52	<.0001
Q4 (≥ $45,537)	*26,768*	*24.1*	ref				ref			
Insurance type										
Commercial	*19,022*	*17.1*	ref				ref			
Medicare	*73,192*	*65.9*	0.74	0.71	0.78	<.0001	0.81	0.77	0.85	<.0001
Medicare and Medicaid	*2623*	*2.4*	0.42	0.36	0.49	<.0001	0.49	0.42	0.58	<.0001
Medicaid	*1861*	*1.7*	0.56	0.48	0.67	<.0001	0.79	0.66	0.93	0.007
Other	*1048*	*0.9*	0.44	0.34	0.56	<.0001	0.50	0.39	0.64	<.0001
Uninsured	*6703*	*6*	0.16	0.13	0.18	<.0001	0.26	0.22	0.30	<.0001
Number of prescription medications	*N*	*%*								
0	*56,861*	*51.2*	ref				ref			
1 to 4	*22,804*	*20.5*	2.17	2.06	2.28	<.0001	1.75	1.66	1.84	<.0001
5 to 9	*18,910*	*17.0*	2.65	2.52	2.79	<.0001	1.94	1.84	2.05	<.0001
10+	*12,550*	*11.3*	2.72	2.57	2.88	<.0001	1.91	1.80	2.04	<.0001
Primary care provider visits	*median 2*	*(0, 5)*								
0	*33,028*	*29.7*	ref				ref			
1	*17,796*	*16.0*	1.31	1.23	1.41	<.0001	1.21	1.13	1.30	<.0001
2	*11,860*	*10.7*	1.53	1.42	1.64	<.0001	1.33	1.23	1.43	<.0001
3+	*48,441*	*43.6*	2.43	2.31	2.55	<.0001	1.81	1.72	1.91	<.0001

(Continues)

TABLE 3 (Continued)

			Age-adjusted				Multivariable model			
			OR	95% CI		*P*-value	OR	95% CI		*P*-value
Neurologist or neurosurgeon encounter										
No	*102,115*	*91.9*	ref				ref			
Yes	*9010*	*8.1*	1.64	1.55	1.74	<.0001	1.37	1.28	1.46	<.0001
Psychiatrist or psychologist encounter										
No	*106,943*	*96.2*	ref				ref			
Yes	*4182*	*3.8*	1.59	1.46	1.73	<.0001	1.31	1.20	1.43	<.0001
Geriatrician encounter										
No	*107,287*	*96.5*	ref				ref			
Yes	*3838*	*3.5*	1.71	1.56	1.86	<.0001	1.30	1.19	1.42	<.0001
Duration (# nights) of in-patient hospitalizations										
0	*93,769*	*84.4*	ref				ref			
1	*1283*	*1.2*	0.65	0.53	0.80	<.0001	0.66	0.54	0.82	0.0001
2	*2186*	*2.0*	0.87	0.76	1.01	0.06	0.77	0.67	0.89	0.0004
3+	*13,887*	*12.5*	0.82	0.78	0.88	<.0001	0.71	0.66	0.75	<.0001
Episodes of in-patient hospitalizations										
0	*93,769*	*84.4*	ref				ns	.	.	.
1	*12,098*	*10.9*	0.87	0.81	0.92	<.0001	.	.	.	.
2	*3153*	*2.8*	0.72	0.64	0.82	<.0001	.	.	.	.
3+	*2105*	*1.9*	0.68	0.58	0.80	<.0001	.	.	.	.
Emergency visits										
0	*93,102*	*83.8*	ref				ns	.	.	.
1	*12,256*	*11.0*	1.01	0.95	1.07	0.76	.	.	.	.
2	*3472*	*3.1*	0.96	0.86	1.07	0.42	.	.	.	.
3+	*2295*	*2.1*	0.93	0.81	1.06	0.29	.	.	.	.
Elixhauser comorbidity score										
Mean (sd)	*mean 1.6*	*sd 2.2*	1.10	1.09	1.11	<.0001	ns	.	.	.

[a]Baseline refers to the first 12 months of the observational period for time-varying possible predictors. Data on sex was missing for n = 19 (<0.1%), mean household income in 3-digit zip code area was missing for 3.0% (n = 3343), data on insurance type was missing for 6.0% (n = 6676). Medicare insurance includes patients who may have had secondary commercial insurance. ns = not statistically significant so dropped from the multivariable model. Frequency values (N, %) and descriptive statistics appear in italic font.

Abbreviations: CI, confidence interval; OR, odds ratio.

of EHR processing systems extracting a result. Because the precise reason that a cognitive measure was not recorded remains unknown, the most effective points of intervention remain uncertain. For example, while it is possible that some providers missed symptoms or dismissed concerns expressed by patients, it is also possible that some patients declined testing that was offered.[7] Further, we did not have data to examine how many of the dementia patients had actually undergone a cognitive assessment that was not entered. For instance, scanned paper-based assessments would not appear in the database unless the result were entered into the notes or a structured data field. To gain some insight on this possibility, we conducted an additional analysis among patients with procedure codes (typically used for billing) for cognitive or neuropsychological testing. The generalizability of this exploratory analysis is uncertain, as only 1.6% (n = 1725) of the dementia patients had a procedure code prior to diagnosis; of these, half (n = 870, 50.4%) had a cognitive measure noted, thereby moving the percentage from 11.0% (considering only cognitive measures) to 11.8% with a measure noted or coded in dementia patients, and from 23.6% to 27.1% in AD patients prior to index date. That only 20% to 25% of patients had a cognitive measure recorded on or within 3 months after the index date is also lower than expected. Thus, the percentage of patients that actually had a cognitive assessment is likely somewhat higher than the percentage with the cognitive measure. However, even if underestimating the number of patients who underwent a cognitive evaluation, that only 11% of dementia patients had a cognitive measure entered prior to diagnosis indicates that recommendations to document cognitive measures are largely unimplemented.

TABLE 4 Associations between baseline patient characteristics or health-care use and presence of a cognitive measure noted in the 5 years prior to Alzheimer's disease diagnosis (N = 30,203)

			Age-adjusted				Multivariable model			
			OR	95% CI		*P*-value	OR	95% CI		*P*-value
Age, years:	*N*	*%*								
45–49	*141*	*0.5*	1.13	0.75	1.70	0.56	1.15	0.74	1.76	0.54
50–54	*381*	*1.3*	1.23	0.93	1.63	0.15	1.35	0.99	1.82	0.05
55–60	*495*	*1.6*	1.29	1.09	1.54	0.004	1.29	1.07	1.56	0.01
61–64	*1586*	*5.3*	1.51	1.30	1.75	<.0001	1.75	1.50	2.05	<.0001
65–70	*2309*	*7.6*	1.58	1.44	1.73	<.0001	1.80	1.63	1.98	<.0001
71–74	*6146*	*20.3*	1.57	1.44	1.71	<.0001	1.78	1.63	1.95	<.0001
75–80	*6771*	*22.4*	1.26	1.18	1.35	<.0001	1.48	1.38	1.59	<.0001
81–84	*12,374*	*41.0*	ref				ref			
Sex										
Male	*10,788*	*35.7*	0.99	0.94	1.05	0.74	ns	.	.	.
Female	*19,409*	*64.3*	ref							
Race/ethnicity										
Black	*1593*	*5.3*	0.69	0.60	0.78	<.0001	0.77	0.67	0.88	0.0001
Asian	*160*	*0.5*	0.88	0.60	1.27	0.49	0.73	0.50	1.09	0.12
Hispanic	*602*	*2.0*	0.74	0.60	0.90	0.003	0.91	0.74	1.13	0.41
Non-Hispanic White	*27,125*	*89.8*	ref				ref			
Other/Unknown	*723*	*2.4*	0.54	0.44	0.66	<.0001	0.71	0.57	0.88	0.002
Mean household income of 3-digit zip code area, quartiles										
Q1 (< $34,855)	*7536*	*25.0*	0.78	0.72	0.83	<.0001	0.76	0.70	0.82	<.0001
Q2 ($34,855–$39,816)	*7055*	*23.4*	0.79	0.73	0.85	<.0001	0.85	0.78	0.92	<.0001
Q3 ($39,816–45,537)	*6551*	*21.7*	0.53	0.49	0.57	<.0001	0.50	0.46	0.54	<.0001
Q4 (≥ $45,537)	*7876*	*26.1*	ref				ref			
Insurance type										
Commercial	*4242*	*14.0*	ref				ref			
Medicare	*20,909*	*69.2*	0.43	0.30	0.61	<.0001	0.54	0.37	0.78	0.001
Medicare and Medicaid	*711*	*2.4*	0.58	0.54	0.62	<.0001	0.69	0.64	0.75	<.0001
Medicaid	*211*	*0.7*	0.17	0.13	0.22	<.0001	0.21	0.16	0.28	<.0001
Other	*133*	*0.4*	0.16	0.09	0.31	<.0001	0.16	0.08	0.29	<.0001
Uninsured	*1818*	*6.0*	0.08	0.07	0.11	<.0001	0.16	0.13	0.21	<.0001
Number of prescription medications	*N*	*%*								
0	*15,810*	*52.3*	ref				ref			
1 to 4	*6307*	*20.9*	2.70	2.52	2.90	<.0001	2.26	2.10	2.44	<.0001
5 to 9	*5149*	*17.0*	3.24	3.01	3.48	<.0001	2.47	2.28	2.68	<.0001
10+	*2937*	*9.7*	3.60	3.30	3.93	<.0001	2.57	2.33	2.83	<.0001
Primary care provider visits										
Median (Q1, Q3)	*median 2*	*(0, 6)*								
0	*8075*	*26.7*	ref				ref			
1	*4925*	*16.3*	1.29	1.17	1.41	<.0001	1.17	1.07	1.29	0.001
2	*3356*	*11.1*	1.50	1.35	1.66	<.0001	1.21	1.09	1.35	0.0004
3+	*13,847*	*45.8*	2.51	2.34	2.69	<.0001	1.62	1.50	1.75	<.0001

(Continues)

TABLE 4 (Continued)

			Age-adjusted				Multivariable model			
			OR	95% CI		*P*-value	OR	95% CI		*P*-value
Neurologist or neurosurgeon encounter										
No	*27,670*	*91.6*	ref				ref			
Yes	*2533*	*8.4*	1.80	1.65	1.96	<.0001	1.49	1.36	1.64	<.0001
Psychiatrist or psychologist encounter										
No	*29,010*	*96.1*	ref				ref			
Yes	*1193*	*3.9*	1.59	1.40	1.80	<.0001	1.20	1.05	1.37	0.01
Geriatrician encounter										
No	*28,826*	*95.4*	ref				ref			
Yes	*1377*	*4.6*	1.75	1.56	1.96	<.0001	1.39	1.23	1.58	<.0001
Duration (# nights) of in-patient hospitalizations										
0	*25,503*	*84.4*	ref				ref			
1	*187*	*0.6*	1.38	1.01	1.89	0.05	1.30	0.93	1.81	0.12
2	*514*	*1.7*	1.11	0.90	1.35	0.33	0.92	0.74	1.13	0.43
3+	*3999*	*13.2*	0.88	0.81	0.96	0.002	0.72	0.66	0.79	<.0001
Episodes of in-patient hospitalizations										
0	*25,503*	*84.4*	ref				ns	.	.	.
1	*3300*	*10.9*	0.96	0.88	1.05	0.39	.	.	.	.
2	*855*	*2.8*	0.83	0.70	0.99	0.03	.	.	.	.
3+	*545*	*1.8*	0.83	0.68	1.03	0.09	.	.	.	.
Emergency visits										
0	*25,024*	*82.9*	ref				ns	.	.	.
1	*3531*	*11.7*	1.08	1.00	1.18	0.06	.	.	.	.
2	*1011*	*3.3*	1.14	0.99	1.32	0.08	.	.	.	.
3+	*637*	*2.1*	1.03	0.86	1.24	0.72	.	.	.	.
Elixhauser comorbidity index score										
Mean (SD)	*mean 1.7*	*SD 2.2*	1.13	1.12	1.14	<.0001	ns	.	.	.

*Baseline refers to the first 12 months of the observational period for time-varying possible predictors. Data on sex was missing for n = 6 (< 0.1%), mean household income in 3-digit zip code area was missing for 3.9% (n = 1,185), data on insurance type was missing for 7.2% (n = 2,179). Medicare insurance includes patients who may have had secondary commercial insurance. ns = not statistically significant so dropped from the multivariable model.
Abbreviations: CI, confidence interval; OR, odds ratio; SD, standard deviation.

Missing cognitive data, particularly when heightened among demographic subsets, affects not only quality of patient care, but also quality of EHR databases increasingly used for research and clinical decision-making algorithms. Researchers have developed models to identify patients with high risk of AD using various EHR data including the presence of cognitive symptoms in EHR.[19–21,37] Suboptimal data inputs reduce the accuracy and generalizability of EHR-based models. Large-scale initiatives to facilitate EHR embedded pragmatic clinical trials face challenges in obtaining valid dementia outcome measures.[22] Furthermore, our results support that disparities related to race and socioeconomic status are present in EHR databases, reflecting structural racism, interpersonal racism, and differences in communication and trust.[38,39] Unfortunately, algorithms based on the available EHR databases will propagate bias and disparities in care, potentially worsening delayed diagnosis, delayed treatment, and decreased participation in clinical trials, among certain demographics. A solution lies in changing the data that we feed into algorithms, at the point-of-care scenarios at which demographic subgroups are underassessed.[38,39] As a specific step to help address this gap, EHR systems should increase structured data fields that prompt cognitive assessments when appropriate and/or facilitate accurate entry of cognitive tests and results.

In addition to lacking insight on the precise reasons for missing cognitive data, other limitations of this analysis include the reliance on ICD codes to ascertain dementia and AD. As dementia and AD are undercoded, some patients with dementia were likely missed, but the specificity that we included patients with dementia is likely high, given validation studies showing high positive predictive values for ICD-coded dementia.[13,40] Biomarker data to confirm AD pathology, severity of dementia, and the presence of subjective cognitive concerns at the time of the coded diagnosis were lacking. However, numerous prior studies provide evidence to support the assumption that during the 5 years prior to first coded diagnosis, it would be appropriate for patients to undergo cognitive assessments owing to recognizable symptoms of their impending dementia diagnosis.[11–13,23] For example, the Cognitive Function and Ageing Study-II showed a median of 3 years between the onset of dementia and the first record of dementia in EHR.[11] Thus, by the time patients receive the first diagnosis code for dementia or AD, most were experiencing cognitive impairment for years. Also, cognitive or functional impairment has been found to be more severe among patients with diagnosed dementia, compared to undiagnosed dementia.[12,13] Accordingly, in the years prior to the first coded diagnosis, these patients likely had signs and symptoms that should have triggered cognitive evaluations as part of appropriate care.[4,14,15] To explore timing of diagnosis, future EHR-based studies could examine the cognitive test scores, though with such a small percentage of patients having a recorded measure, the generalizability of results would be questionable. We restricted the analysis to patients receiving care in IDNs to obtain comprehensive patient EHRs; this design feature increased validity but possibly affected generalizability by excluding a minority (18%) of Optum data sources that were not part of integrated networks. While we explored numerous potential predictors of cognitive measures, the analysis was limited in its ability to examine other possible factors, such as family history of dementia, educational level, and lifestyle and social–cultural factors, as well as patient preference to decline cognitive testing. Future research may also consider examining other dementia types in addition to AD, such as frontotemporal dementia or Parkinson's disease dementia.

Our analysis focused on patients with dementia, but these results may have relevance to discussions on general population screening and general improvements needed in documentation of cognitive function. To date, there is no definitive recommendation on dementia screening in the general adult population. The U.S. Preventative Services Task Force concluded that current evidence is insufficient to assess the balance of benefits versus harms of screening for cognitive impairment in older adults.[4] However, Medicare requires assessment of cognitive function for reimbursement of the Annual Wellness Visit. The American Academy of Neurology recommends cognitive testing for this visit or when there are concerns, and other organizations including the Alzheimer's Association and Gerontological Society of America support cognitive evaluations for a timely diagnosis.[5,14,15] Our finding that primary care providers commonly were the first to note cognitive function supports recent reports from the Alzheimer's Association on the importance of improving PCPs' ability and resources to detect and care for dementia.[1,16] In a recent report on a community-based dementia screening program, no adverse events of screening were detected, but less than half of PCPs acted on the results or recommendations of the dementia screening that was completed for them.[7] Missed opportunities to be informed of patients' cognitive status and engage with patients on cognitive health matters affect not only management of dementia, comorbidities, medications, and financial or life planning, but also patients' ability to participate in clinical research, which increasingly focuses on patients with early AD and continues to have underrepresentation of underserved populations.

Overall, these real-world data indicate gaps in the assessment and documentation of cognitive function in dementia and AD, which should be addressed to improve timely detection and diagnosis. Heightened gaps for patients who were Black, male, older age, or without commercial insurance indicate that systematic and structural forces affect the care pathway for patients with recognizable cognitive impairment. By improving EHR systems at the point of care and data entry, disparities in delayed diagnosis may be improved. Furthermore, research using EHR will also be improved, thereby allowing more robust and accurate predictive algorithms, embedded pragmatic clinical trials, and sources of real-world evidence. The importance of cognitive assessments will increase as new disease-modifying therapies for some of the neurodegenerative diseases that contribute to cognitive impairment become developed and approved for use.[6] Ultimately, improvements in documentation of cognitive measures will provide better quality data sources and help achieve more timely diagnosis and improved monitoring for patients and care partners.[16]

CONFLICTS OF INTEREST

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SUPPORTING INFORMATION

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

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