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Acute care utilization risk among older adults living undiagnosed or unaware of dementia

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Abstract

Background: Dementia is associated with increased risk of hospitalization and emergency department (ED) visits. Many persons with dementia are undiagnosed or unaware of their diagnosis, however. Our objective was to determine whether undiagnosed dementia or unawareness affects risk of hospitalization or ED visits.

Methods: Retrospective longitudinal cohort study of 3537 community-living adults age ≥65 enrolled in the 2011–2017 National Health and Aging Trends Study with linked fee-for-service Medicare claims. Using self or proxy reported diagnosis, proxy dementia screening questionnaire, cognitive testing, and Medicare claims diagnosis, participants were classified as having (1) no dementia or dementia, for which they were classified as (2) undiagnosed, (3) diagnosed but unaware, or (4) diagnosed and aware. Proportional hazards models evaluated all-cause and potentially preventable hospitalization and ED visit risk by time-varying dementia status, adjusting for older adult characteristics.

Results: Most participants ($n = 2879$) had no dementia at baseline. Among participants with dementia at baseline ($n = 658$), 187 were undiagnosed, 300 diagnosed but unaware, and 171 diagnosed and aware. In multivariable adjusted proportional hazards models, persons with undiagnosed dementia had lower risk of hospitalization and ED visits compared to persons diagnosed and aware (all-cause hospitalization aHR 0.59 [0.44, 0.79] and ED visit aHR 0.63 [0.47, 0.85]) and similar risks of these outcomes compared to persons without dementia. Individuals diagnosed but unaware had greater risk compared to those without dementia: aHR 1.37 (1.18, 1.59) for all-cause hospitalization and 1.48 (1.28, 1.71) for ED visits; they experienced risk comparable to individuals diagnosed and aware.

Conclusion: Older adults with undiagnosed dementia are not at increased risk of acute care utilization after accounting for differences in other characteristics. Individuals unaware of diagnosed dementia demonstrate risk similar to

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individuals aware of the diagnosis. Increasing diagnosis alone may not affect acute care utilization. The role of awareness warrants further investigation.

KEYWORDS
dementia, diagnosis, healthcare utilization, hospitalization

INTRODUCTION

Alzheimer's disease and related dementias are common, affecting an estimated six million Americans.[1] Approximately half of persons living with dementia are undiagnosed.[2–4] Among those diagnosed, approximately one-third of patients and families do not report a formal diagnosis and are unaware of their dementia status.[4,5] Individuals with diagnosed dementia experience high rates of acute care utilization (emergency department [ED] visits and hospitalizations).[6–10] ED visits and hospitalization in dementia may lead to adverse events, iatrogenic injury, and accelerated cognitive decline;[11–17] these events also contribute to high costs of care.[7,18]

Dementia diagnosis and awareness, or lack thereof, may impact acute care utilization. Diagnosis and awareness may affect clinician, health system, and family support for the individual, management of cognitive, behavioral, and functional challenges, care for comorbid medical conditions, and goals of care. Effects of living undiagnosed or unaware of dementia on acute care utilization are not well understood; benefits of earlier detection and diagnosis of dementia remain unclear.[19,20] Studies using Medicare claims include only diagnosed individuals,[7,21] whereas studies using epidemiologic cohorts combine undiagnosed and diagnosed individuals together.[8,9,22] The few studies that consider undiagnosed dementia do not account for people unaware of their diagnosis.[23,24] Previous studies are also largely cross-sectional[25] or do not use a generalizable cohort,[23,26] highlighting the need for longitudinal studies with nationally representative samples.

Greater understanding of the relationship between dementia, formal diagnosis, awareness, and acute care utilization can help elucidate whether and how screening, earlier diagnosis, diagnosis disclosure practices, and patient/family education might impact hospitalizations and ED visits, important outcomes in a high risk population. The objective of this study was to determine whether dementia diagnosis and awareness are associated with risk of all-cause ED visits and all-cause and potentially preventable hospitalizations. Specifically, we sought to examine whether persons undiagnosed or unaware of dementia were at higher risk compared to two groups: (1) persons without dementia, who are not cognitively impaired, and (2) persons diagnosed and aware, who may have greater support and family/clinician recognition of their needs.

Key points

- Older adults with undiagnosed dementia are not at increased risk of acute care use after accounting for other characteristics.
- People unaware of diagnosed dementia have risk similar to people aware of the diagnosis.

Why does this paper matter?

Increasing dementia diagnoses may not impact acute care use; the potential impact of increasing awareness among the diagnosed warrants further research.

METHODS

Participants and study design

Participants were drawn from the National Health and Aging Trends Study (NHATS) with linked fee-for-service (FFS) Medicare claims. NHATS is an ongoing nationally representative, population-based study of Medicare beneficiaries age ≥65 in the continental United States. Started in 2011, NHATS follows 8245 older adults with annual, in-person surveys conducted with the older adult or proxy respondent, covering topics such as functional abilities, health status, medical care, and cognition.[27] Linked claims data were available for FFS Medicare beneficiaries from 2011–2017.

We used a retrospective, longitudinal study design to examine acute care utilization risk. To be included in this study, NHATS participants were required to be community-dwelling and have three previous years of FFS Medicare (for ascertainment of dementia status) and at least 1 year of subsequent FFS Medicare or continuous FFS Medicare until death (for ascertainment of outcomes) at any NHATS interview between 2011 and 2016. Year of baseline entry into the study cohort varied

depending on when participants met eligibility criteria. Eligible NHATS participants ($n = 3537$) were then followed until (1) death, (2) last NHATS interview before nursing home placement, (3) Medicare Advantage enrollment, (4) 1 year after last NHATS interview if lost to follow up, or (5) end of study follow-up (December 31, 2017). For each outcome examined, participants were censored at the time of first event. The study was approved by the Johns Hopkins Medicine Institutional Review Board.

Dementia status

Dementia status accounted for the presence of dementia, formal diagnosis of dementia, and awareness of the diagnosis. Participants were classified as belonging to one of four groups at any time: (1) no dementia, (2) undiagnosed dementia, (3) diagnosed but unaware of dementia ("unaware"), or (4) diagnosed and aware of dementia ("aware").

Presence of dementia was assessed using data from NHATS and Medicare claims. NHATS has validated an algorithm to determine whether a participant has probable dementia using reported diagnosis and objective assessments.[28] In this study, we applied objective NHATS assessment criteria to classify participants as having dementia. Participants with a proxy respondent who scored ≥2 on the validated proxy AD-8 Dementia Screening Interview[29] were classified as having dementia. Participants who scored 1.5 SDs or more below the mean for self-respondents in ≥2 cognitive domains on brief tests of memory, orientation, and executive function were also classified as having dementia. All self-respondents completed cognitive testing, and over half of participants with a proxy completed cognitive testing at baseline (all participants have either AD-8 or cognitive testing).[28] We additionally used Medicare claims to identify dementia. Consistent with Medicare Chronic Conditions Warehouse methods, we examined 3 years of Medicare claims to identify at least one ICD-9 or ICD-10 code (Table S1) for Alzheimer's disease and related disorders or dementia in inpatient, skilled nursing facility, home health, outpatient, or carrier files.[30,31] Participants with a claims diagnosis of dementia were classified as having dementia. Thus, participants who met NHATS AD-8 or cognitive testing criteria or had a claims diagnosis of dementia were classified as having dementia; remaining participants were classified as no dementia. In sensitivity analysis, at least two claims diagnoses for dementia were required.

For participants with dementia, we further classified diagnosis and awareness status. Diagnosed versus undiagnosed was based on the presence or absence of a Medicare claims diagnosis for dementia in the previous 3 years. Diagnosed participants were then classified as being unaware or aware of the diagnosis based on self or proxy response to whether a doctor has said they have dementia or Alzheimer's disease in NHATS.

Dementia status was treated as time-varying such that participant status could change over the study period. A participant without dementia at baseline could develop dementia or a participant with undiagnosed dementia could become diagnosed. Dementia status could change at each NHATS interview (with new assessments) or when a new Medicare claims diagnosis appeared. Over the study period, a new dementia claims diagnosis was found for 263 participants; their dementia status was changed at the date of that claim. Awareness was only assessed at the time of each NHATS interview. For participants with a new claims diagnosis, awareness was backfilled to the date of dementia diagnosis using awareness at the next NHATS interview. For 93 participants with a new diagnosis who were missing subsequent awareness data, we implemented imputation procedures using variables associated with awareness to predict awareness. Of note, once diagnosed or aware, participants remained in those groups.

Outcomes

We identified all-cause acute, nonobservation, short-stay hospitalizations from inpatient Medicare claims. We examined potentially preventable hospitalizations using 10 specific conditions identified by the Agency for Healthcare Research and Quality as prevention quality indicators (Table S2).[32] Potentially preventable hospitalizations represent hospitalizations that could be avoided through timely and adequate outpatient care, such as hospitalizations for dehydration, pneumonia, and urinary tract infection. We examined ED visits from outpatient claims to capture ED visits that did not lead to hospitalization.

Covariates

We considered potential confounders of the association between dementia status and hospitalization from NHATS and Medicare claims. Demographic characteristics included age, gender, and race/ethnicity reported in NHATS. Socioeconomic and behavioral factors included education and living alone from NHATS and Medicare-Medicaid dual eligibility from claims data. Functional impairment was assessed through NHATS. Activity of daily living (ADL) impairments were assessed through difficulty or help required for bathing, eating, dressing, toileting, getting around inside the home, or leaving

home. Instrumental activity of daily living (IADL) impairments were assessed through difficulty or help required in cooking, managing finances, managing medications, shopping, and doing laundry.[33] Both ADL and IADL impairment were categorized as no, moderate, or severe impairment based on the number of impairments reported (0, 1–2, ≥3, respectively). Health status and healthcare utilization factors included baseline Charlson Comorbidity Index,[34] excluding dementia, calculated using claims data. Depression and anxiety were assessed in NHATS using the Patient Health Questionnaire-2 and Generalized Anxiety Disorder-2 scales, respectively, with scores >2 considered positive.[35,36] History of seeing their regular doctor in the past year was assessed from NHATS whereas hospitalization in the year before baseline was assessed from Medicare claims. Lastly, we accounted for presence of a proxy respondent. Gender, race/ethnicity, education, baseline Charlson Comorbidity Index, and prior hospitalization were time-fixed; remaining covariates were time-varying.

Statistical analyses

We compared characteristics of participants by baseline dementia status using chi-square or ANOVA to identify differences between all four groups (no dementia + dementia groups) and between the three dementia groups. We then constructed proportional hazards models to examine predictors of each outcome. In all models, death and nursing home placement were treated as competing risks using Fine and Gray methods.[37] Our primary focus was on the risk of each outcome for undiagnosed and unaware participants; these groups were compared to two reference groups: (1) no dementia and (2) diagnosed and aware. We first examined unadjusted models of each outcome by time-varying dementia status and then evaluated multivariable adjusted proportional hazards models.

To develop multivariable models, we considered covariates associated with both dementia status and all-cause hospitalization. Demographics and proxy respondent

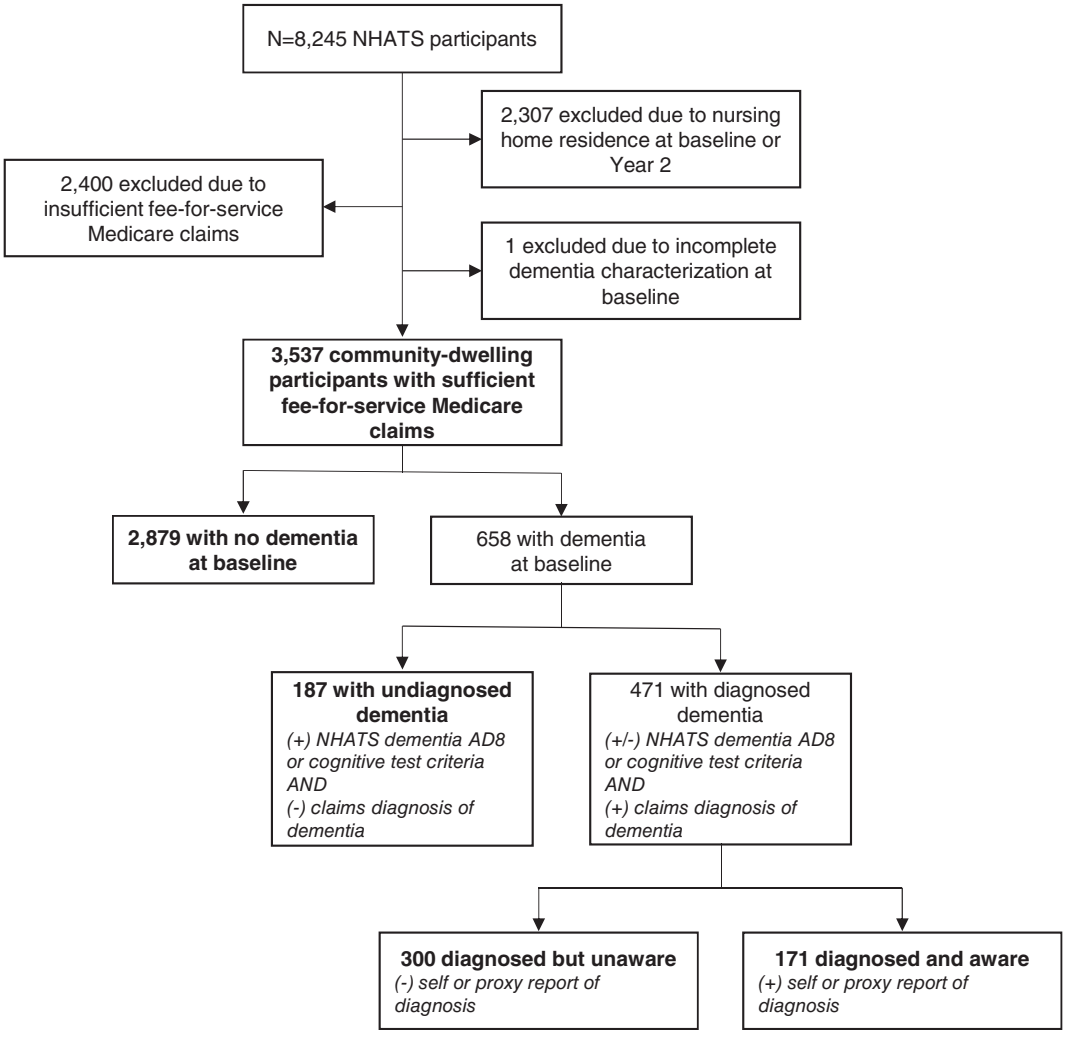

FIGURE 1 Flow diagram of National Health and Aging Trends Study (NHATS) participant eligibility and dementia status. Resulting baseline cohort is highlighted in bold

TABLE 1 Participant characteristics by baseline dementia diagnosis and awareness status[a]

Characteristic	No dementia ($n = 2879$)	Undiagnosed ($n = 187$)	Unaware of diagnosis ($n = 300$)	Aware of diagnosis ($n = 171$)	p-value[b]
Age, mean (SD)	77.2 (7.0)	83.8 (8.0)	82.6 (7.5)	83.9 (6.5)	0.1
Male	1284 (44.6)	81 (43.3)	100 (33.3)	61 (35.7)	0.08
Race/ethnicity					
White, non-Hispanic	2195 (76.4)	99 (52.9)	200 (66.7)	99 (57.9)	<0.001
Black, non-Hispanic	506 (17.6)	47 (25.1)	71 (23.7)	---	
Other	178 (6.2)	41 (21.9)	29 (9.7)	***	
Education[c]					
<High school	603 (21.1)	104 (56.5)	106 (35.8)	74 (44.3)	<0.001
≥High school, no higher degree	1371 (47.9)	59 (32.1)	137 (46.3)	60 (35.9)	
≥Associate's degree	889 (31.1)	***	53 (17.9)	33 (19.8)	
Dual eligible	343 (11.9)	68 (36.4)	72 (24.0)	44 (25.7)	0.01
Lives alone[c]	947 (33.0)	53 (28.5)	103 (34.6)	***	<0.001
IADL impairment severity					
No impairment	2045 (71.0)	54 (28.9)	116 (38.7)	***	<0.001
Moderate impairment	553 (19.2)	30 (16.0)	77 (25.7)	***	
Severe impairment	281 (9.8)	103 (55.1)	107 (35.7)	137 (80.1)	
ADL impairment severity					
No impairment	1944 (67.5)	48 (25.7)	116 (38.7)	***	<0.001
Moderate impairment	629 (21.9)	48 (25.7)	87 (29.0)	---	
Severe impairment	306 (10.6)	91 (48.7)	97 (32.3)	112 (65.5)	
Charlson index, mean (SD)[d]	1.81 (2.06)	2.35 (2.44)	2.95 (2.57)	2.41 (2.16)	0.01
Depression[e]	336 (11.7)	64 (34.2)	72 (24.0)	52 (30.4)	0.04
Anxiety[e]	271 (9.4)	53 (28.3)	63 (21.0)	39 (22.8)	0.17
History of seeing regular doctor in year prior[c]	2623 (91.2)	158 (84.5)	280 (94.3)	156 (91.2)	0.001
History of hospitalization in year before baseline	451 (15.7)	45 (24.1)	109 (36.3)	66 (38.6)	0.005
Proxy respondent	48 (1.7)	72 (38.5)	33 (11.0)	96 (56.1)	<0.001
Acute care utilization over follow up					
All-cause hospitalization	1325 (46.0)	95 (50.8)	192 (64.0)	123 (71.9)	<0.001
Potentially preventable hospitalization	313 (10.9)	31 (16.6)	65 (21.7)	50 (29.2)	0.02
ED visit	1503 (52.2)	92 (49.2)	199 (66.3)	106 (62.0)	0.001

Note: *** represent cell sizes of 25 or less and --- represent cell size >50 (>29%) for Black, non-Hispanic race/ethnicity and cell size >30 (>17%) for moderate ADL impairment among participants aware of diagnosis, exact cell size suppressed due to other categories with cell size of 25 or less, per National Institute on Aging CMS data cell size suppression policy.

Abbreviations: SD, standard deviation; IADL, instrumental activity of daily living; ADL, activity of daily living; ED, emergency department.

[a]Values represent sample unweighted n (%) unless specified.

[b]Difference in any of the 3 dementia groups. $p \leq 0.003$ when no dementia group was included for all characteristics.

[c]27 (0.8%), 15 (0.4%), and 6 (0.2%) of participants were missing data for education, living alone, and seeing regular doctor in year prior, respectively.

[d]Charlson Comorbidity Index excluded dementia.

[e]Determined by responses to PHQ-2 and GAD-2, respectively.

were planned for inclusion a priori. Additional covariates were entered into models that included time-varying dementia status and demographic characteristics (age, gender, race/ethnicity) as predictors and all-cause hospitalization as the outcome. Covariates were entered into these models in blocks examining socio-behavioral factors, functional impairment, and health status and healthcare utilization, respectively. Statistically significant covariates from these blocks were included in multivariable models (education, IADL and ADL impairment severity, baseline

Charlson score, depression, history of seeing regular doctor in year prior, and hospitalization in year before baseline).

We first examined a multivariable model that excluded covariates that might serve as surrogates for dementia severity (functional impairment and proxy respondent). We then examined a full multivariable model that included IADL and ADL impairment severity and proxy respondent to understand the effect of dementia diagnosis and awareness status after accounting for dementia severity.

Sensitivity analyses considered different methods of ascertaining dementia status. We repeated analyses requiring that a participant have two or more dementia claims to be classified in the diagnosed dementia groups (unaware or aware). We also repeated analyses with a stricter definition of dementia, including only participants meeting objective AD-8 or cognitive testing criteria for dementia among the three dementia groups. In this sensitivity analysis, participants with a claims diagnosis of dementia but no objective NHATS evidence of dementia were classified as having no dementia to account for possible misdiagnosis. Results of sensitivity analyses are available in Tables S3–S6 and are not discussed further as results mirrored the primary analyses.

Appropriateness of using proportional hazards models was assessed by examining unadjusted Kaplan–Meier survival curves that censored at death or nursing home placement. All tests were two-sided and considered $p < 0.05$ to be statistically significant. NHATS sampling weights were not applied as we were examining subsets of participants using time-varying data and focusing on associations rather than descriptive national estimates. Analyses were conducted using SAS version 9.4 (SAS Institute Inc, Cary, NC).

RESULTS

A total of 3537 NHATS participants met criteria for inclusion in our analyses (Figure 1). Most participants (81.4%) had no dementia at baseline. Among 658 (18.6%) participants with dementia at baseline, 28.4% were classified as undiagnosed, 45.5% as diagnosed but unaware, and 25.9% were diagnosed and aware. Shown in Table 1, the no dementia group differed from the three dementia groups on all characteristics. Participants with no dementia were younger and more likely to be White with higher levels of education. They were less likely to report functional impairment or history of hospitalization. They had the lowest comorbidity burden. When the three dementia groups were compared, there were no significant differences in age, gender, or anxiety. Persons undiagnosed had the lowest education and were least likely to have history of seeing their regular doctor or hospitalization. Those unaware were most likely to be White, living alone, report no functional impairment, and have history

TABLE 2 Risk of acute care utilization among different dementia diagnosis and awareness status groups compared to individuals *without dementia*

	Unadjusted model		Adjusted model without dementia severity[a]		Adjusted model with dementia severity[a]	
Outcome	**Hazard ratio (95% CI)**	***p*-value**	**Hazard ratio (95% CI)**	***p*-value**	**Hazard ratio (95% CI)**	***p*-value**
Undiagnosed dementia						
All-cause hospitalization	1.40 (1.10, 1.78)	0.006	1.05 (0.81, 1.35)	0.72	0.89 (0.68, 1.16)	0.38
Potentially preventable hospitalization	2.09 (1.39, 3.14)	<0.001	1.22 (0.78, 1.91)	0.39	0.99 (0.63, 1.55)	0.95
ED visit	1.25 (0.99, 1.57)	0.06	0.97 (0.76, 1.24)	0.81	1.00 (0.77, 1.29)	0.99
Diagnosed but unaware of dementia						
All-cause hospitalization	2.00 (1.74, 2.29)	<0.001	1.46 (1.26, 1.70)	<0.001	1.37 (1.18, 1.59)	<0.001
Potentially preventable hospitalization	2.57 (2.02, 3.27)	<0.001	1.54 (1.19, 2.01)	0.001	1.38 (1.06, 1.79)	0.02
ED visit	1.92 (1.68, 2.26)	<0.001	1.50 (1.30, 1.74)	<0.001	1.48 (1.28, 1.71)	<0.001
Diagnosed and aware of dementia						
All-cause hospitalization	2.64 (2.24, 3.12)	<0.001	1.88 (1.57, 2.26)	<0.001	1.51 (1.22, 1.87)	<0.001
Potentially preventable hospitalization	3.39 (2.55, 4.51)	<0.001	2.00 (1.45, 2.75)	<0.001	1.54 (1.09, 2.17)	0.01
ED visit	1.97 (1.65, 2.35)	<0.001	1.48 (1.22, 1.79)	<0.001	1.57 (1.26, 1.97)	<0.001

[a]Covariates in adjusted model included age, gender, race, education, baseline Charlson index score, depression, history of seeing regular doctor in year prior, history of hospitalization in year before baseline. Dementia severity covariates included IADL and ADL functional impairment severity and proxy respondent. Adjusted models excluded 163 of 10,260 total observations due to missing covariate data.

of seeing their regular doctor in the prior year; they were least likely to have a proxy and had the greatest comorbidity burden. Mean follow-up (SD) in years was 2.5 (1.9), 3.3 (2.1) years, and 2.2 (1.8) years for all-cause hospitalization, potentially preventable hospitalization, and ED visits, respectively; event frequency is shown in Table 1.

Acute care utilization compared to persons without dementia

In the unadjusted models, all dementia groups had greater risk of acute care utilization outcomes compared to no dementia (Table 2). Individuals with undiagnosed dementia had 40% greater risk of all-cause hospitalization (95% CI 10%–78%) and over twice the risk of potentially preventable hospitalization (HR 2.09, 95% CI 1.39–3.14) compared to those without dementia. After accounting for sociodemographic and health status/utilization factors, differences in undiagnosed versus no dementia attenuated and were no longer significant; no differences were observed after additionally accounting for functional impairment and having a proxy, surrogates for dementia severity (Figure 2).

As shown in Figure 2, the diagnosed but unaware had at least a 37% greater risk of all acute care utilization outcomes compared to no dementia even after adjusting for older adult characteristics (HR [95% CIs] 1.37 [1.18, 1.59], 1.38 [1.06, 1.79], and 1.48 [1.28, 1.71] for all-cause hospitalization, potentially preventable hospitalization, and ED visits, respectively). Significant results were also observed for

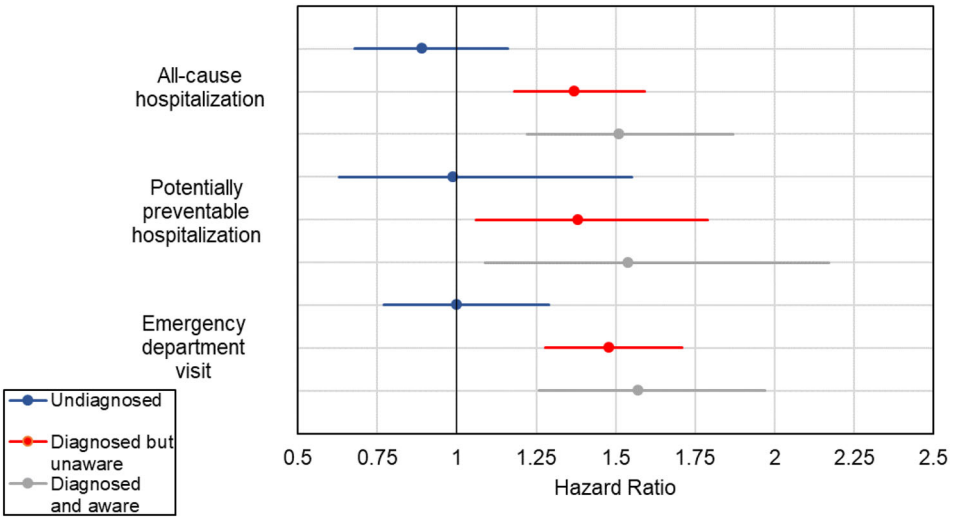

FIGURE 2 Multivariable adjusted hazard ratios for acute care utilization outcomes by dementia group compared to no dementia as the reference group (blue = undiagnosed, red = diagnosed but unaware, gray = diagnosed and aware)

TABLE 3 Risk of acute care utilization among older adults undiagnosed or unaware of dementia compared to the *diagnosed and aware*

	Unadjusted model		Adjusted model without dementia severity[a]		Adjusted model with dementia severity[a]	
Outcome	**Hazard ratio (95% CI)**	***p*-value**	**Hazard ratio (95% CI)**	***p*-value**	**Hazard ratio (95% CI)**	***p*-value**
Undiagnosed dementia						
All-cause hospitalization	0.53 (0.40, 0.70)	<0.001	0.56 (0.42, 0.74)	<0.001	0.59 (0.44, 0.79)	<0.001
Potentially preventable hospitalization	0.62 (0.39, 0.98)	0.04	0.61 (0.38, 0.99)	0.04	0.64 (0.39, 1.04)	0.07
ED visit	0.63 (0.48, 0.84)	0.001	0.66 (0.49, 0.88)	0.004	0.63 (0.47, 0.85)	0.002
Diagnosed but unaware of dementia						
All-cause hospitalization	0.75 (0.62, 0.92)	0.006	0.78 (0.63, 0.96)	0.02	0.91 (0.72, 1.15)	0.41
Potentially preventable hospitalization	0.76 (0.54, 1.06)	0.10	0.77 (0.54, 1.10)	0.15	0.89 (0.62, 1.29)	0.55
ED visit	0.98 (0.79, 1.20)	0.83	1.02 (0.82, 1.26)	0.89	0.94 (0.74, 1.20)	0.61

[a]Covariates in adjusted model included age, gender, race, education, baseline Charlson index score, depression, history of seeing regular doctor in year prior, history of hospitalization in year before baseline. Dementia severity covariates included IADL and ADL functional impairment severity and proxy respondent. Adjusted models excluded 163 of 10,260 total observations due to missing covariate data.

persons aware, who had at least a 51% greater risk of each outcome (HR [95% CIs] 1.51 [1.22, 1.87], 1.54 [1.09, 2.17], and 1.57 [1.26, 1.97] for all-cause hospitalization, potentially preventable hospitalization, and ED visits, respectively). In both of these groups, differences in sociodemographic and health status/utilization as well as dementia severity explained some, but not all, of the differences observed compared to the no dementia group (Table 2).

Acute care utilization compared to persons diagnosed and aware

Compared to persons diagnosed and aware, the undiagnosed demonstrated significantly lower risk of all outcomes even after adjusting for older adult characteristics (Table 3). In contrast, after adjusting for functional impairment and proxy respondent, the unaware demonstrated risk of hospitalization similar to persons aware. There were no differences in risk of ED visits comparing unaware to aware in unadjusted and adjusted analyses.

DISCUSSION

In this study of the association of dementia diagnosis and awareness with acute care utilization, older adults with dementia living undiagnosed or unaware of their diagnosis demonstrate increased risk of hospitalization compared to older adults without dementia. In undiagnosed dementia, differences in sociodemographic characteristics, healthcare utilization, and health status account for increased risk; after accounting for these factors, older adults with undiagnosed dementia have risk similar to those without dementia. Older adults unaware of their diagnosis have greater risk of acute care utilization compared to those without dementia even after accounting for other factors. Notably, the unaware experience risk of hospitalization and ED visits comparable to their peers aware of their diagnosis.

To our knowledge, this study is the first to longitudinally examine effects of both dementia diagnosis and awareness on acute care utilization. Greater risk of all-cause and potentially preventable hospitalization and ED visits in people with versus without dementia is well-documented,[6–9,21,22] but persons undiagnosed were not included or combined with the diagnosed. One study in an integrated healthcare system examined documented diagnosis and healthcare utilization 2 years before a study diagnosis of dementia; the undiagnosed fell between the diagnosed and no dementia groups in experiencing a hospitalization or ED visit.[23] Our unadjusted results for undiagnosed individuals align with this study. However, our adjusted results suggest that other characteristics may account for the observed differences. Baseline evaluation in a German dementia screening and intervention study also found no differences between the undiagnosed and diagnosed in inpatient treatment rates.[25] One recent study comparing people diagnosed with Alzheimer's disease to people without dementia found hospitalization and ED visits were more likely over 3 years before an Alzheimer's disease diagnosis. Although people eventually diagnosed may have fallen into our undiagnosed group, objective measures of dementia or functional impairment were not available; moreover, the study focused specifically on Alzheimer's disease diagnosis.[24]

Our findings can also be considered in the context of dementia screening studies. Screening would likely detect dementia in undiagnosed older adults in this study. An RCT comparing older adults undergoing versus not undergoing dementia screening found no difference in ED visits or hospitalizations over 12 months.[20] Given our finding of no difference in undiagnosed versus no dementia, the RCT result is not surprising. RCT participants who screened positive, were diagnosed with dementia, and received collaborative dementia care did experience less hospitalizations than participants not screened.[20] This finding suggests that diagnosis linked to awareness and dementia-centered care could impact acute care utilization. A pre- versus postscreening study also found that detection of cognitive impairment did not affect utilization.[38] One Veterans Affairs study found that individuals who screened positive for cognitive impairment had higher rates of hospitalization and ED visits compared to those who screened negative.[26]

Study results have implications for dementia screening and diagnosis. Individuals with undiagnosed dementia may not be at heightened risk of hospitalization or ED visits. Differences observed in other studies may be due to confounding factors rather than to undiagnosed dementia itself. Screening or early detection interventions may thus be unlikely to impact these utilization outcomes, though there may be subgroups of patients who would benefit. Earlier diagnosis may also benefit outcomes beyond acute care utilization, such as caregiver support, future care planning, and patient, family, or clinician decision-making.[19]

Our study also has implications for dementia disclosure and education (awareness). In people unaware, dementia has been detected by a clinician but the patient or family is unaware of the diagnosis. Awareness linked to support and dementia-centered care could potentially reduce utilization risk.[20] Given limited study of dementia awareness and patient outcomes, further research is warranted into whether awareness could impact utilization and mechanisms underlying risk. Potential mechanisms may include inadequate caregiver or social support, safety hazards such

as medication errors, difficulty self-managing chronic conditions, and poor care coordination. Greater understanding and knowledge in these areas could help dementia care interventions and clinicians more effectively address acute care utilization and quality of care in dementia, regardless of diagnosis or awareness status.

Our study has limitations. Although use of a population-based study allows for a larger, more generalizable sample, dementia assessment methods in larger studies are epidemiologic rather than clinical and use screening tools. Some individuals with no dementia or mild cognitive impairment may be misclassified as undiagnosed dementia. Others with dementia may be misclassified as no dementia: they may not be detected by brief screening or have a medical record diagnosis not included in Medicare billing claims. Sensitivity analyses suggest that effects of potential misclassification on our results are minimal. Exclusion of Medicare Advantage enrollees limits generalizability. In addition, reduced sample size due to their exclusion may have limited power to detect differences, especially in potentially preventable hospitalizations, a rarer outcome. We also did not examine recurrent utilization, examining only time to first event. Of note, we cannot infer causal relationships between dementia status and acute care utilization in this observational study. Additional research, including in samples larger or with more detailed dementia assessments, can address study limitations. Lastly, although we adjust for multiple confounders, there may be additional unmeasured confounders.

One potential confounder, dementia severity, may impact diagnosis, awareness, and acute care utilization. Functional impairment, one aspect of dementia severity, is associated with hospitalization,[8] a finding confirmed in our multivariable hospitalization models. In addition, functional impairment and use of a proxy explain some of the differences observed between groups. We included these variables to understand effects of diagnosis and awareness on utilization independent of dementia severity. Diagnosis and awareness status themselves may be indicators of severity. Diagnosis means dementia has risen to the level of clinician detection. Awareness of diagnosed dementia means the condition has risen to the level of clinician and patient/family recognition. Individuals aware and diagnosed may have more severe dementia, suggested by greater functional impairment and proxy use. Greatest dementia severity among the aware and diagnosed increases the importance of our findings in the unaware whose risk of acute care utilization is comparable despite potentially less severe dementia.

In this population-based, longitudinal study, undiagnosed dementia is not associated with increased risk of hospitalization or ED visits. Being diagnosed but unaware of dementia is associated with greater risk of acute care utilization compared to no dementia and similar risk to those diagnosed and aware. Further observational and interventional research on the impact of patient and family awareness of a dementia diagnosis on patient outcomes, including acute care utilization, is necessary to potentially impact not only patient outcomes but also quality of care, beginning with dementia disclosure and education practices.

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CONFLICT OF INTEREST

Halima Amjad, Quincy Samus, Julie Bynum, Jennifer Wolff, and David Roth have grant funding from the NIA. The authors have no other conflicts of interest to disclose.

AUTHOR CONTRIBUTIONS

Study concept and design: Halima Amjad, Quincy M. Samus, Jin Huang, Julie P. W. Bynum, Jennifer Wolff, David L. Roth. *Acquisition of subjects and/or data*: Halima Amjad, David L. Roth. *Analysis and interpretation of data*: Halima Amjad, Quincy M. Samus, Jin Huang, JPWB, Jennifer Wolff, David L. Roth. All authors: Preparation of manuscript.

SPONSOR'S ROLE

The sponsor had no role in the design, methods, subject recruitment, data collection, analysis and preparation of this paper.

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

Table S1. ICD-9 and ICD-10 codes used to identify dementia
Table S2. Prevention quality indicator conditions examined as potentially preventable hospitalizations
Table S3. Risk of acute care utilization among different dementia diagnosis and awareness status groups compared to individuals *without* dementia applying two claim requirement
Table S4. Risk of acute care utilization among older adults undiagnosed or unaware of dementia compared to the *diagnosed and aware* applying two claim requirement
Table S5. Risk of acute care utilization among different dementia diagnosis and awareness status groups compared to individuals *without* dementia based on objective NHATS criteria for dementia
Table S6. Risk of acute care utilization among older adults undiagnosed or unaware of dementia compared to the *diagnosed and aware* based on objective NHATS criteria for dementia

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