RESEARCH ARTICLE

Diagnosis, Assessment & Disease Monitoring

Hospitalization outcomes among older adults living undiagnosed or unaware of dementia

Halima Amjad[1,2] | Vishaldeep K. Sekhon[2] | Jennifer L. Wolff[3] | Quincy M. Samus[4] | David L. Roth[1,2]

[1]Division of Geriatric Medicine and Gerontology, MFL Center Tower, Johns Hopkins University School of Medicine, Baltimore, Maryland, USA

[2]Center on Aging and Health, Johns Hopkins University, Baltimore, Maryland, USA

[3]Department of Health Policy and Management, Johns Hopkins Bloomberg School of Public Health, Baltimore, Maryland, USA

[4]Johns Hopkins University School of Nursing, Baltimore, Maryland, USA

Correspondence
Halima Amjad, Division of Geriatric Medicine and Gerontology, MFL Center Tower, Johns Hopkins University School of Medicine, 5200 Eastern Avenue, MFL Center Tower, Room 709, Baltimore, MD 21224, USA.
Email: hamjad1@jh.edu

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Abstract

INTRODUCTION: Many persons with dementia are undiagnosed or unaware of dementia, which may affect hospitalization outcomes.

METHODS: We evaluated differences in length of stay, days not at home, discharge destination, and 30-day readmissions over 1 year in 6296 older adults in the National Health and Aging Trends Study with linked Medicare claims. Multivariable-adjusted models compared outcomes across no dementia, undiagnosed dementia, unaware but diagnosed with dementia, and aware and diagnosed with dementia.

RESULTS: Persons with undiagnosed dementia had longer length of stay and were more likely to be discharged to a facility (44.8% vs. 19.3%) compared to no dementia; differences persisted in multivariable models. Persons undiagnosed or unaware experienced outcomes similar to persons aware and diagnosed except for more 30-day readmissions in the undiagnosed (adjusted odds ratio [95% confidence interval] 2.05 [1.01, 4.16]).

DISCUSSION: Persons undiagnosed or unaware of dementia experience worse hospitalization outcomes, suggesting potential clinically significant implications of unrecognized dementia.

KEYWORDS
dementia awareness, dementia detection, health services use, hospitalization outcomes, undiagnosed dementia

Highlights

- Persons with undiagnosed versus no dementia have worse hospitalization outcomes.
- Persons with undiagnosed dementia have more 30-day readmissions compared to persons diagnosed.
- Lack of clinician or family recognition of dementia may adversely affect hospitalization outcomes.

1 | BACKGROUND

Nearly 7 million Americans are living with Alzheimer's disease and related dementias.[1] Due to multifactorial barriers to diagnosis, awareness, and education, $\approx$ 50% of persons living with dementia (PLWD) are undiagnosed.[2–4] Among those who are diagnosed, $\approx$ 33% of PLWD or their families are unaware of this diagnosis.[4,5] PLWD who are undiagnosed or unaware of diagnosed dementia have cognitive, functional, and behavioral impairment that is undetected or unrecognized by clinicians, the health-care system, and/or their families. This lack of recognition may lead to adverse outcomes, such as safety risks and financial harm.[6–8] Undiagnosed or unaware PLWD may also experience adverse outcomes of hospitalization.

Dementia is a recognized risk factor for hospitalization; PLWD, regardless of whether they are diagnosed or aware of their condition, are more likely to be hospitalized than persons of the same age without dementia.[9–12] Persons with undiagnosed dementia have higher risk of hospitalization compared to those without dementia,[12–15] though differences may be driven by factors other than dementia.[12] Hospitalization increases risk of adverse events such as other geriatric syndromes (e.g., falls, delirium), accelerated cognitive and functional decline, and high costs of care in PLWD.[9,16–19] Beyond the hospitalization event itself, prior studies have demonstrated longer hospital length of stay and higher rates of readmissions in PLWD.[20–27] These outcomes may elevate risk of downstream adverse outcomes related to hospitalization in PLWD, including mortality and earlier transition to long-term care.[28] Few studies have examined whether undiagnosed dementia impacts hospitalization-related outcomes.[26,27]

Understanding the impact that a lack of diagnosis or awareness of dementia has on hospitalization-related outcomes may provide evidence of whether prior clinician or family recognition of dementia carries potential benefit for PLWD, families, health systems, and insurers, particularly Medicare. The objective of this study was to evaluate differences in number of hospitalizations, length of stay, days not at home, discharge destination, and 30-day readmissions over 1 year by dementia diagnosis and awareness status. We specifically examined differences among older adults with undiagnosed dementia or unaware of diagnosed dementia compared to older adults with no dementia, who do not have significant cognitive impairment, and to older adults aware of diagnosed dementia, who may have greater support and dementia-centered medical care.

2 | METHODS

2.1 | Participants and study design

We used the National Health and Aging Trends Study (NHATS) with linked fee-for-service (FFS) Medicare claims data. NHATS is an ongoing nationally representative, population-based longitudinal cohort of Medicare beneficiaries age $\geq$ 65 living in the continental United States. NHATS enrolled 8245 older adults in 2011 with replenishment of the sample in 2015, with addition of 4182 older adults. NHATS participants

RESEARCH IN CONTEXT

1. **Systematic review**: The authors reviewed published literature using PubMed and Google Scholar. Previous studies have examined hospitalization outcomes in persons living with dementia generally. Few studies have examined outcomes in persons with undiagnosed or previously undetected dementia, and these studies are cited.
2. **Interpretation**: Our results suggest that persons living undiagnosed or unaware of diagnosed dementia experience worse hospitalization outcomes (longer length of stay, more days not at home, greater likelihood of discharge to a facility) compared to similar persons without dementia. Persons with undiagnosed dementia have higher rates of 30-day readmission compared to persons aware and diagnosed with dementia.
3. **Future directions**: Additional research that confirms our findings and that considers mechanisms of hospitalization outcomes in persons undiagnosed or unaware of dementia will help better understand potential implications of dementia that is unrecognized by clinicians, the health system, or families.

or a proxy respondent complete annual in-person surveys addressing topics including sociodemographics, health conditions and events, cognition, and function.[29]

We used a retrospective, longitudinal design to examine hospitalization-related outcomes over 1 year. NHATS participants were included at their time of enrollment, 2011 or 2015, if they were community dwelling and had 3 years of prior FFS Medicare claims (for determination of dementia diagnosis) and one subsequent year of FFS claims without death or nursing home placement. From 12,427 unique participants, 869 were excluded due to nursing home residence. Another 5262 were excluded due to insufficient FFS Medicare claims or death or nursing home placement in the year. The final analytic sample included 6296 unique NHATS participants (4585 from 2011 and 1711 from 2015).

2.2 | Dementia status

Participants were assigned dementia status at baseline, accounting for presence of dementia, formal diagnosis, and awareness of dementia diagnosis.[4,12] Each participant was assigned to one of four groups based upon NHATS and Medicare claims data: (1) no dementia, (2) undiagnosed dementia, (3) unaware but diagnosed with dementia, and (4) aware and diagnosed with dementia.

To assess whether a participant had dementia, we used NHATS objective dementia criteria and Medicare claims diagnoses. Following the NHATS algorithm validated for determining probable dementia,[30]

we classified participants who scored ≥ 2 on the proxy Eight-item Informant Interview to Differentiate Aging and Dementia (AD8) Dementia Screening Interview as having dementia.[31,32] Three cognitive domains—memory, orientation, and executive function—are assessed via brief cognitive tests in NHATS. We classified participants who scored 1.5 standard deviations below the mean for self-respondents in at least two cognitive domains as having dementia.[30] Given limitations of NHATS dementia measures (87% specificity but only 66% sensitivity compared to clinical assessments and medical records used by a research consensus panel),[30] we also used Medicare claims to identify dementia. We followed the Bynum-standard algorithm for identifying International Classification of Diseases (ICD)-9 or ICD-10 codes for dementia in Medicare inpatient, skilled nursing facility, home health, hospice, and outpatient hospital or provider claims, with outpatient claims requiring at least two claims at least 7 days apart in the past 3 years.[33,34] The Bynum-standard algorithm demonstrates 79% sensitivity and 88% specificity for dementia compared to rigorous clinical assessments in research cohorts.[33] Any participant meeting AD8 criteria, cognitive testing criteria, or with a claims diagnosis of dementia was classified as having dementia. All other participants were classified as having no dementia.

Participants with dementia were classified as being undiagnosed if they did not have a claims diagnosis in the past 3 years following the Bynum algorithm.[33,34] Participants with diagnosed dementia were classified as being unaware or aware of dementia based upon self or proxy response to whether a doctor has said they have dementia or Alzheimer's disease in NHATS.

2.3 | Outcomes

Hospitalization included all acute, non-observation short-stay hospitalizations identified from inpatient Medicare claims. Length of stay was determined in days for each hospitalization. Days not at home for each participant was operationalized as the sum of the following over the course of 1 year from baseline NHATS interview: hospital inpatient days, hospital observation days, skilled nursing facility days, outpatient emergency department visit days, inpatient psychiatry days, inpatient rehabilitation days, and long-term hospital days.[35] We used days not at home, rather than days at home, for ease of interpretability alongside the other outcomes of interest. For each hospitalization, discharge destination was classified as home, home with home care or hospice (including facility-based hospice care), or non-hospital facility care (skilled nursing facility, inpatient rehabilitation, intermediate care, or long-term hospital), and occurrence of readmission within 30 days was assessed.

2.4 | Covariates

We considered participant characteristics that might affect dementia status and the outcomes of interest. Sociodemographic factors included age, sex, education, Medicare–Medicaid dual eligibility, and race/ethnicity. Social support factors included living alone, marital status (married or living with a partner vs. other categories), and number of living children. Health-care use included seeing a regular doctor and hospitalization in the prior year. Several items reflect dementia severity and disability, including instrumental activity of daily living (IADL) and basic activity of daily living (ADL) impairment severity and having a proxy respondent. IADL impairments included difficulty or needing help in meal preparation, finances, medications, shopping, and laundry. ADL impairments included difficulty or help needed in bathing, eating, dressing, toileting, getting around inside the home, or leaving home. IADL and ADL impairment severity were categorized as no, moderate, or severe by the number of impairments reported (0, 1–2, ≥ 3, respectively).[36] Comorbidity burden was measured using the Charlson Comorbidity Index, excluding dementia, based upon 3 years of Medicare claims data prior to NHATS enrollment.[37]

2.5 | Statistical analysis

We first examined participant characteristics by dementia status, comparing all four groups (no dementia and each of the three dementia groups) and just the three dementia groups (undiagnosed; unaware but diagnosed; aware and diagnosed), using chi-square or analysis of variance. We then examined unadjusted regression models for all outcomes. Negative binomial regression models were used for outcomes with observed counts and included all participants: number of hospitalizations, length of stay, and days not at home. The resulting coefficients were exponentiated to reflect incident rate ratios (IRR) for ease of interpretation. Mixed effects logistic regression models were used for binary outcomes and included only participants who experienced hospitalization in the year: discharge destination and 30-day readmission; hospitalization, rather than the participant, was the unit of analysis as participants could contribute more than one event to these analyses. Mixed effects models accounted for within-person clustering. For discharge destination, home and home with home care or hospice were combined to create a binary outcome of discharge to home/hospice versus non-hospital facility care.

We refined characteristics to include multivariable-adjusted models with methods used previously to minimize over-adjustment and collinearity among potentially relevant covariates.[4,12] First, we identified variables or constructs to include a priori: age, sex, Charlson Comorbidity Index score, and social support represented by living alone. We then ran regression models for two representative outcomes, length of stay and discharge destination, including a priori covariates and other variables of interest in blocks. Thus, we examined models that included a priori covariates with sociodemographic characteristics, social support, and health-care use, respectively. Our final set of covariates for inclusion in multivariable models demonstrated $p < 0.1$ in at least one of the models. Race/ethnicity and Medicare–Medicaid dual eligibility were included along with age, sex, Charlson Comorbidity Index score, and marital status. We ultimately included marital status rather than living alone in multivariable models due to marital status being consistently statistically significant ($p < 0.05$)

TABLE 1 Participant characteristics by dementia diagnosis and awareness status.

Characteristic[a]	No dementia (n = 5166)	Undiagnosed (n = 317)	Unaware but diagnosed (n = 531)	Aware and diagnosed (n = 282)	Dementia groups p value[b]
Age, mean (SD)	76.9 (7.3)	83.5 (8.1)	82.8 (7.6)	83.5 (6.6)	<0.001
Female	2951 (57.1)	188 (59.3)	334 (62.9)	194 (68.8)	<0.001
Education					
< High school	1044 (20.2)	167 (52.7)	166 (31.3)	104 (36.9)	<0.001
≥ High school, no additional degree	2568 (49.7)	97 (30.6)	242 (45.6)	110 (39.0)	
≥ Associate degree	1486 (28.8)	37 (11.7)	108 (20.3)	50 (17.7)	
Race/ethnicity					
White, non-Hispanic	3815 (73.8)	158 (49.8)	364 (68.5)	162 (57.4)	<0.001
Black, non-Hispanic	924 (17.9)	88 (27.8)	113 (21.3)	86 (30.5)	
Hispanic and other	427 (8.3)	71 (22.4)	54 (10.2)	34 (12.1)	
Dual eligible	678 (13.1)	129 (40.7)	120 (22.6)	78 (27.7)	<0.001
Living alone	1766 (34.2)	114 (36.0)	222 (41.8)	69 (24.5)	<0.001
Married	2733 (52.9)	104 (32.8)	187 (35.2)	105 (37.2)	<0.001
Children, mean (SD)	2.9 (2.0)	3.2 (2.6)	2.8 (2.0)	3.1 (2.2)	0.026
Charlson index,[c] mean (SD)	1.3 (1.8)	1.6 (2.0)	2.1 (2.4)	1.6 (1.9)	<0.001
Saw regular doctor in past year	4667 (90.3)	278 (87.7)	478 (90.0)	264 (93.6)	0.15
Hospitalized in the past year	778 (15.1)	64 (20.2)	188 (35.4)	95 (33.7)	<0.001
IADL impairment severity					
None	3617 (70.0)	99 (31.2)	209 (39.4)	26 (9.2)	<0.001
Moderate	1070 (20.7)	83 (26.2)	153 (28.8)	59 (20.9)	
Severe	479 (9.3)	135 (42.6)	169 (31.8)	197 (69.9)	
ADL impairment severity					
None	3442 (66.6)	97 (30.6)	206 (38.8)	45 (16.0)	<0.001
Moderate	1150 (22.3)	82 (25.9)	151 (28.4)	60 (21.3)	
Severe	574 (11.1)	138 (43.5)	174 (32.8)	177 (62.8)	
Proxy respondent	84 (1.6)	116 (36.6)	56 (10.5)	162 (57.4)	<0.001

Abbreviations: ADL, activities of daily living; IADL, instrumental activities of daily living; SD, standard deviation.

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

[b]Difference in any of the three dementia groups. p value when no dementia group was included was < 0.001 for all characteristics except for seeing the regular doctor in the past 12 months, for which p = 0.14.

[c]Charlson Comorbidity Index score excluded dementia.

when both characteristics were included in the same model. Characteristics representative of dementia severity (IADL and ADL functional impairment severity and proxy respondent) were not included in primary models as they are potential mediators. Hospitalization in the prior year was not included in primary models to avoid overadjustment. These characteristics were examined in sensitivity analyses to understand their potential effect on outcomes. Models accounting for hospitalization in the prior year did not change results and are not presented further.

All tests of statistical significance were two sided and $p < 0.05$ was used to assess the significance of model results. All analyses were conducted using SAS version 9.4 (SAS Institute Inc). The study was approved by the Johns Hopkins Medicine Institutional Review Board.

3 | RESULTS

3.1 | Participants

Participant characteristics (n = 6296) are included in Table 1. Most of the sample (82.1%) had no dementia (n = 5166); 317 participants had undiagnosed dementia while 813 were diagnosed, of which 531 were unaware of the diagnosis. The mean age was 78 years (standard deviation 7.7) with 58% females; 17.9% (n = 1125) were hospitalized in the past year. Participants with dementia were statistically significantly different from those without dementia across all characteristics, except for seeing their regular doctor in the past year. Comparing the three dementia groups, there were similar differences in all characteristics except for seeing their regular doctor in the past year. Participants with

TABLE 2   Unadjusted outcomes by dementia diagnosis and awareness status.

Outcome	No dementia (n = 5166)	Undiagnosed (n = 317)	Unaware but diagnosed (n = 531)	Aware and diagnosed (n = 282)	Dementia groups p value[a]
Hospitalizations, mean (SD)	0.25 (0.92)	0.39 (0.98)	0.53 (0.96)	0.54 (0.92)	<0.001
Length of stay, mean (SD)	1.01 (2.68)	1.97 (4.14)	2.02 (3.52)	2.27 (3.55)	<0.001
Days not at home, mean (SD)	2.38 (10.87)	9.14 (29.42)	8.39 (22.87)	10.02 (29.15)	<0.001
Hospitalization subsample	**No dementia (n = 1305)**	**Undiagnosed (n = 125)**	**Unaware but diagnosed (n = 280)**	**Aware and diagnosed (n = 153)**	
Discharge destination, n (%)					
°Home	733 (56.2)	41 (32.8)	110 (39.3)	56 (36.6)	<0.001
°Home with home care or hospice	293 (22.4)	28 (22.4)	64 (22.9)	40 (26.1)	
°Non-hospital facility care	252 (19.3)	56 (44.8)	103 (36.8)	56 (36.6)	
30-day readmission, n (%)	270 (20.7)	30 (24.0)	54 (19.3)	18 (11.8)	0.042

Abbreviation: SD, standard deviation.

[a]Difference in any of the three dementia groups. p value when no dementia group was included was < 0.001 for all characteristics except for readmissions, for which p = 0.047.

undiagnosed dementia had lower levels of education, greater dual eligibility, and were least likely to be married compared to those diagnosed. Unaware but diagnosed dementia participants had higher levels of education, were more likely to be non-Hispanic White, had higher Charlson Comorbidity Index scores, and were more likely to be hospitalized in the past year compared to the other dementia groups.

3.2 | Unadjusted hospitalization and hospitalization-related outcomes

A total of 1167 participants, 18.5% of the sample, experienced at least one hospitalization over a year, with 1863 hospitalization events. Hospitalizations and unadjusted hospitalization-related outcomes are shown in Table 2. Participants with diagnosed dementia had the highest mean number of hospitalizations over 1 year with no differences by awareness status. Those aware and diagnosed had a longer mean length of stay and more days not at home compared to all other groups. Across hospitalizations, participants with undiagnosed dementia were most likely to be discharged to a facility (45% vs. 37% in the diagnosed groups and 19% in those without dementia). They were also most likely to experience 30-day readmission, with a 24% rate of readmission across hospitalizations compared to 21% in no dementia; participants aware and diagnosed had the lowest 30-day readmission rate (12%).

3.3 | Adjusted hospitalization-related outcomes

Multivariable adjusted outcomes comparing the three dementia groups to no dementia are shown in Table 3. The risk of hospitalization over the year was greater in all dementia groups prior to adjustment. After multivariable adjustment, the risk of hospitalization in persons with undiagnosed dementia was similar to no dementia. It remained greater for the unaware but diagnosed group. Hospital length of stay

was statistically significantly longer for the undiagnosed and unaware groups even after adjusting for markers of dementia severity. Days not at home were also significantly longer for all dementia groups.

All dementia groups were less likely to be discharged home compared to individuals without dementia (Table 4). Persons with undiagnosed dementia had 64% lower odds of discharge home compared to no dementia; persons unaware but diagnosed had 49% lower odds. In regard to 30-day readmission, persons aware and diagnosed had a lower risk compared to persons without dementia while the undiagnosed demonstrated readmission risk similar to persons without dementia.

Table 5 shows direct comparisons of the undiagnosed and unaware groups to the aware and diagnosed dementia group. In adjusted models not accounting for dementia severity, there were no significant differences in length of stay, days not at home, or odds of discharge home. Persons undiagnosed were more likely to experience 30-day readmission, however, compared to aware and diagnosed (odds ratio 2.05, 95% confidence interval 1.05–4.04). All results comparing dementia groups were largely unchanged after adjusting for dementia severity.

4 | DISCUSSION

In a nationally representative cohort of older Americans, this study finds that individuals living with undiagnosed dementia experience worse hospitalization-related outcomes compared to individuals without dementia. Undiagnosed PLWD had an overall hospitalization risk similar to individuals without dementia after accounting for older adult factors including age, comorbidity burden, and functional impairment. Once hospitalized, however, they experienced longer length of stay, lower likelihood of discharge home, and more days not at home over 1 year. Undiagnosed PLWD demonstrated hospitalization-related outcomes similar to aware and diagnosed PLWD with one notable exception: undiagnosed PLWD experienced twice the odds of 30-day

TABLE 3 Incidence rate ratios for hospitalization and related outcomes among all participants comparing dementia groups by diagnosis and awareness status to persons without dementia.

Outcome	Unadjusted model		Adjusted model without dementia severity[a]		Adjusted model with dementia severity[a]	
	IRR (95% CI)	p value	IRR (95% CI)	p value	IRR (95% CI)	p value
Undiagnosed dementia (ref = no dementia)						
Hospitalization	1.56 (1.19, 2.05)	0.001	1.11 (0.84, 1.42)	0.54	1.02 (0.77, 1.36)	0.88
Length of stay	1.94 (1.46, 2.58)	<0.001	1.42 (1.06, 1.88)	0.02	1.38 (1.03, 1.85)	0.03
Days not at home	3.83 (2.31, 6.36)	<0.001	2.55 (1.53, 4.22)	<0.001	2.37 (1.41, 3.96)	0.001
Unaware but diagnosed dementia (ref = no dementia)						
Hospitalization	2.09 (1.70, 2.56)	<0.001	1.55 (1.27, 1.91)	<0.001	1.35 (1.10, 1.66)	0.004
Length of stay	2.00 (1.60, 2.49)	<0.001	1.57 (1.27, 1.97)	<0.001	1.36 (1.09, 1.69)	0.006
Days not at home	3.52 (2.36, 5.23)	<0.001	2.55 (1.72, 3.80)	<0.001	2.07 (1.40, 3.08)	<0.001
Aware and diagnosed dementia (ref = no dementia)						
Hospitalization	2.15 (1.64, 2.81)	<0.001	1.50 (1.14, 1.95)	0.003	1.31 (0.96, 1.77)	0.08
Length of stay	2.25 (1.67, 3.01)	<0.001	1.79 (1.33, 2.39)	<0.001	1.33 (0.96, 1.85)	0.08
Days not at home	4.20 (2.46, 7.17)	<0.001	3.50 (2.05, 5.93)	<0.001	1.89 (1.03, 3.48)	0.04

Abbreviations: ADL, activities of daily living; CI, confidence interval; IADL, instrumental activities of daily living; IRR, incident rate ratio.

[a]Covariates in the adjusted model included age, sex, race, education, Charlson Comorbidity Index score excluding dementia, Medicare–Medicaid dual eligibility, and marital status. Dementia severity covariates included IADL and ADL functional impairment severity and proxy respondent.

TABLE 4 Discharge destination and readmission risk among hospitalized participants comparing dementia groups by diagnosis and awareness status to persons without dementia.

Outcome	Unadjusted model		Adjusted model without dementia severity[a]		Adjusted model with dementia severity[a]	
	Odds ratio (95% CI)	p value	Odds ratio (95% CI)	p value	Odds ratio (95% CI)	p value
Undiagnosed dementia (ref = no dementia)						
Discharge home[b]	0.32 (0.20, 0.51)	<0.001	0.37 (0.23, 0.60)	<0.001	0.36 (0.22, 0.60)	<0.001
30-day readmission	1.21 (0.75, 1.94)	0.44	1.03 (0.63, 1.68)	0.91	1.02 (0.61, 1.70)	0.95
Unaware but diagnosed dementia (ref = no dementia)						
Discharge home[b]	0.42 (0.30, 0.58)	<0.001	0.48 (0.34, 0.68)	<0.001	0.51 (0.36, 0.73)	<0.001
30-day readmission	0.95 (0.67, 1.35)	0.77	0.85 (0.59, 1.22)	0.37	0.83 (0.57, 1.20)	0.32
Aware and diagnosed dementia (ref = no dementia)						
Discharge home[b]	0.45 (0.29, 0.69)	<0.001	0.53 (0.34, 0.82)	0.004	0.59 (0.35, 0.98)	0.04
30-day readmission	0.54 (0.32, 0.93)	0.02	0.49 (0.28, 0.84)	0.01	0.47 (0.26, 0.86)	0.02

Abbreviations: ADL, activities of daily living; CI, confidence interval; IADL, instrumental activities of daily living.

[a]Covariates in the adjusted model without dementia severity included age, sex, race, education, Charlson Comorbidity Index score excluding dementia, Medicare–Medicaid dual eligibility, and marital status. Dementia severity covariates included IADL and ADL functional impairment severity and proxy respondent.

[b]Reference = discharge to facility.

readmission. PLWD who were unaware but diagnosed had a similar pattern of results as undiagnosed PLWD (longer length of stay, lower likelihood of discharge home, and more days not at home compared to individuals without dementia), but they had greater hospitalization risk over 1 year.

Most prior research focuses on hospitalization in undiagnosed dementia or pre- and post-diagnosis rather than outcomes of hospitalization.[12–15,38,39] A study of dementia detection in primary care among older patients found that individuals who screened positive for cognitive impairment had longer lengths of stay compared to screen-negative patients,[40] suggesting the impact of undiagnosed cognitive impairment on this outcome. With regard to discharge destination, a study of patients admitted to post-acute rehabilitation found that dementia was present in ≈ 25% of older patients but diagnosed in < 30% of those patients before admission; most diagnoses were made during the post-acute stay.[41] A series of

TABLE 5 Hospitalization and related outcomes comparing undiagnosed and unaware dementia groups to aware and diagnosed with dementia group.

Outcome	Unadjusted model IRR or OR (95% CI)	p value	Adjusted model without dementia severity[a] IRR or OR (95% CI)	p value	Adjusted model with dementia severity[a] IRR or OR (95% CI)	p value
Undiagnosed dementia (ref = aware and diagnosed with dementia)						
Hospitalization	0.73 (0.53, 0.99)	0.048	0.70 (0.51, 0.97)	0.03	0.75 (0.69, 1.27)	0.08
Length of stay	0.86 (0.64, 1.17)	0.35	0.77 (0.57, 1.06)	0.11	0.84 (0.61, 1.17)	0.30
Days not at home	0.91 (0.51, 1.63)	0.76	0.86 (0.47, 1.60)	0.64	1.05 (0.54, 2.04)	0.88
Discharge home[b]	0.71 (0.40, 1.27)	0.25	0.72 (0.39, 1.31)	0.27	0.66 (0.35, 1.25)	0.20
30-day readmission	2.30 (1.19, 4.45)	0.01	2.05 (1.05, 4.04)	0.04	2.05 (1.01, 4.16)	0.048
Unaware but diagnosed dementia (ref = aware and diagnosed with dementia)						
Hospitalization	0.97 (0.74, 1.28)	0.84	0.92 (0.70, 1.21)	0.54	0.93 (0.69, 1.27)	0.65
Length of stay	0.89 (0.68, 1.17)	0.40	0.85 (0.65, 1.12)	0.24	0.89 (0.66, 1.20)	0.45
Days not at home	0.84 (0.49, 1.41)	0.51	0.77 (0.45, 1.32)	0.33	0.89 (0.48, 1.65)	0.71
Discharge home[b]	0.94 (0.58, 1.52)	0.79	0.95 (0.57, 1.56)	0.83	0.96 (0.55, 1.68)	0.87
30-day readmission	1.78 (0.99, 3.20)	0.06	1.63 (0.90, 2.96)	0.11	1.57 (0.81, 3.01)	0.18

ADL, activities of daily living; CI, confidence interval; IADL, instrumental activities of daily living; IRR, incident rate ratio; OR, odds ratio.
[a]Covariates in the adjusted model included age, sex, race, education, Charlson Comorbidity Index score excluding dementia, Medicare–Medicaid dual eligibility, and marital status. Dementia severity covariates included IADL and ADL functional impairment severity and proxy respondent.
[b]Reference = discharge to facility.

retrospective studies in England examined hospitalization outcomes in admitted older patients who had cognitive screening by clinical staff, comparing groups with diagnosed dementia, cognitive impairment without a dementia diagnosis (delirium or undiagnosed dementia), and no cognitive impairment.[26,27] Similar to this study, they found that patients with undiagnosed cognitive impairment had equally suboptimal hospitalization outcomes compared to patients with diagnosed dementia in terms of length of stay and discharge to a facility.[26] A subsequent study found longer length of stay and greater risk of readmission in persons with undiagnosed versus diagnosed cognitive impairment.[27] Our findings are similar with regard to readmissions and facility discharge but not length of stay. A difference between our studies is the detection of cognitive impairment at the time of hospitalization and thus the inclusion of delirium, which is associated with longer length of stay, in the hospital-based studies;[42] detection of cognitive impairment in this study occurred prior to hospitalization and is more likely to be measuring chronic rather than acute cognitive impairment.

Our results suggest that once hospitalization occurs, undiagnosed PLWD experience outcomes similar to diagnosed PLWD and are more likely to experience readmission. Undiagnosed dementia may affect hospitalization outcomes in several ways. It may impact timely diagnosis, evaluation, and management of symptoms or medical conditions due to factors such as PLWD difficulty communicating symptoms or medical history, lack of clinician recognition of cognitive impairment and its effect on accurate medical information, and inadequate family engagement in hospital evaluation or care. Undiagnosed dementia may also increase the risk of adverse events during hospitalization,

such as falls and delirium, compared to both persons without dementia who are at lower risk of these events and to diagnosed PLWD for whom these risks may be proactively identified and prevented. Adverse hospitalization events may increase the length of stay and risk of discharge to a facility. The longer length of stay may itself contribute to functional and cognitive decline that increases the risk of discharge to a facility. Discharge to a facility is an important outcome for PLWD as they also have longer lengths of rehabilitation stays and a higher risk of institutionalization after post-acute facility care compared to persons without dementia.[43,44] Hospital length of stay, discharge to a facility, and institutionalization after post-acute care, when it occurs, contribute to more days not at home.

Results for 30-day readmissions are notable, particularly given this outcome is used as a quality metric for value-based payment models.[45] Aware and diagnosed PLWD had lower odds of readmission compared to persons without dementia. It is reassuring if clinicians' and families' recognition of dementia is associated with reduced readmission risk; these individuals may receive the appropriate medical and supportive care during and after hospitalization to reduce risk. Undiagnosed PLWD had odds of readmission similar to persons without dementia and approximately twice the odds of readmission compared to the aware and diagnosed. Lack of dementia recognition by the medical system may contribute to inadequate medical and supportive care during and after hospitalization. Being unaware of diagnosed dementia had a similar trend, such that family recognition and understanding of dementia may also be relevant to reducing readmissions. Formal diagnosis is an important first step for families to understand the PLWD's condition and related support needs.

This study has several limitations. First, dementia assessment in a population-based, epidemiologic study is expected to have some degree of misclassification compared to clinical assessments. NHATS and claims-based measures of dementia have been validated against studies with in-depth dementia evaluations with acceptable but imperfect (<90%) sensitivity and specificity.[4,30,33] Among individuals classified as undiagnosed dementia, 65% met the criteria by cognitive testing only. This group may have lower cognitive abilities or test performance rather than true dementia; indeed, they had lower education and socioeconomic status (represented by higher rates of dual eligibility). Results are still notable even with this potential misclassification: it would indicate that lower cognitive abilities or performance, regardless of the cause, may impact hospitalization outcomes and suggest health disparities. Studies with clinical assessments of dementia would best distinguish undiagnosed dementia from lower cognitive abilities or performance. We also treated dementia status, including diagnosis and awareness, as time fixed. We did not account for status changes such that results reflect an association of baseline dementia status with hospitalization-related outcomes over 1 year. Our sample includes only older adults with fee-for-service Medicare; results thus do not apply to PLWD with Medicare Advantage or under age 65. Analyses restricted to the hospitalized subsample may have had limited power to detect differences in the smaller undiagnosed and unaware groups. We also used data from 2011 to 2015 based on NHATS initial and replenishment samples with available linked claims data and little change in dementia diagnosis patterns until this year. Future research in larger and more recent samples is important to both confirm our findings and to examine potential mechanisms underlying observed outcomes including differences in reasons for hospitalization. Due to our study design, we cannot infer causal relationships. While we did adjust for multiple potential confounding factors, there may be additional confounding factors for which we did not account.

This population-based study on hospitalization-related outcomes contributes to a small but growing body of literature considering implications of living undiagnosed or unaware of dementia.[4,6–8,46,47] PLWD who are undiagnosed or unaware of their diagnosis experience longer hospital length of stay, greater likelihood of discharge to a facility, and more days not at home over 1 year compared to persons without dementia and may have higher risk of 30-day readmission compared to PLWD aware and diagnosed. Given hospitalization is a common, significant event for PLWD, further quantitative and qualitative research is needed to better understand the effect of dementia diagnosis and awareness on hospitalization outcomes. Diagnosis, awareness of a diagnosis, and the hospital setting are all potential targets for intervention to ensure PLWD receive the care and support they need before, during, and after hospitalization. In this context, Centers for Medicare & Medicaid Services initiatives including the Annual Wellness Visit, cognitive assessment and care planning services (99483 billing code), and the new Guiding an Improved Dementia Experience (GUIDE) care model may support earlier diagnosis of dementia linked to awareness and appropriate care.[48–50] Diagnosis, awareness, and care within the hospital setting may be supported by Age-Friendly Health Systems and hospital policies that support caregivers (e.g., less restrictive visitation policies). Implementing, studying, and optimizing such initiatives will be essential to improving hospitalization-related outcomes among PLWD as the landscape of dementia diagnosis and care evolves.

CONFLICT OF INTEREST STATEMENT

Quincy M. Samus reports no conflicts with respect to the current work. Dr. Samus received royalties for the MIND at Home dementia care management program through Johns Hopkins Technology Ventures. The other authors declare no conflicts of interest. Author disclosures are available in the supporting information.

CONSENT STATEMENT

All human subjects participating in the National Health and Aging Trends Study (NHATS) provided written informed consent. A separate consent was, therefore, not necessary for this study. NHATS was approved by the Johns Hopkins Bloomberg School of Public Health Institutional Review Board (IRB) and these analyses were approved by the Johns Hopkins Medicine IRB.

ORCID

Halima Amjad https://orcid.org/0000-0002-0642-6956

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SUPPORTING INFORMATION

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

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