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Kali S. Thomas
Brown University

Wenhan Zhang
US department of Veterans Affairs

Portia Cornell
Brown University

Lindsey Smith
Portland State University

Brian Kaskie
University of Iowa

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Authors

Kali S. Thomas, Wenhan Zhang, Portia Cornell, Lindsey Smith, Brian Kaskie, and Paula C. Carder



State Variability in the Prevalence and Healthcare Utilization of Assisted Living Residents with Dementia

Kali S. Thomas, PhD,*  Wenhan Zhang, MPH,[†] Portia Y. Cornell, PhD,* Lindsey Smith, MPP,[‡] Brian Kaskie, PhD,[§] and Paula C. Carder, PhD[‡]

OBJECTIVES: Almost 1 million older and disabled adults who require long-term care reside in assisted living (AL), approximately 40% of whom have a diagnosis of Alzheimer's disease and related dementias (ADRD). States vary in their regulations specific to dementia care that may influence the presence of residents with ADRD in AL and their outcomes. The objectives of this study were to describe the state variability in the prevalence of ADRD among Medicare beneficiaries residing in larger (25+ bed) ALs and their healthcare utilization.

DESIGN: Retrospective observational national study.

PARTICIPANTS: National cohort of 293,336 Medicare fee-for-service enrollees residing in larger (25+ bed) ALs in 2016 and 2017 including 88,867 (30.3%) residents with ADRD. We compared this cohort's characteristics and healthcare utilization with that of individuals with ADRD who resided in nursing homes (NHs; n = 602,521) and the community (n = 2,074,420).

METHODS: Medicare enrollment data, claims, and the NH Minimum Data Set were used to describe differences among ADRD patients in AL, NHs, and the community. We present rates of NH admission and hospitalization, by state, adjusting for age, sex, race, dual eligibility, and chronic conditions.

RESULTS: The prevalence of ADRD among AL residents varied by state, ranging from 24% to 47%. In 2017, AL residents with ADRD had higher rates of NH admission than their community-dwelling counterparts (adjusted national average = 24%, ranging from 14% to 35% among states).

AL residents with ADRD had higher rates of hospitalization (38%) than populations in either NHs (29%) or the community (34%), and ranged from 29% to 45% of residents among states.

CONCLUSION: These findings have implications for states as they regulate AL and for healthcare professionals whose patients reside in AL. Future work is needed to understand specific elements of states' regulatory environments and local markets that may impact access and outcomes for this vulnerable population of residents with ADRD. *J Am Geriatr Soc* 68:1504-1511, 2020.

Keywords: assisted living; Alzheimer's disease and related dementias; long-term care

From the *Brown University School of Public Health, U.S. Department of Veterans Affairs Medical Center, Providence, Rhode Island; [†]Center for Gerontology and Healthcare Research, Brown University School of Public Health, Providence, Rhode Island; [‡]Institute on Aging, Portland State University, Portland, Oregon; and the [§]Department of Health Management and Policy, University of Iowa, Iowa City, Iowa.

Address correspondence to Kali S. Thomas, PhD, Box G-S121(6), 121 S. Main Street, Providence, RI 02912. E-mail: kali_thomas@brown.edu. Twitter: @kalit23

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Over the past 2 decades, assisted living (AL) has rapidly emerged as a preferred residence for many older and disabled adults who require long-term care. Each day in 2016, approximately 29,000 AL residences were home to more than 800,000 people.¹ Studies vary on their prevalence estimates of cognitive impairment or an Alzheimer's disease and related dementias (ADRD) diagnosis among AL residents, and range anywhere from 40% to 72%.¹⁻⁷ Estimates derived from the National Survey of Residential Care Facilities suggest that in 2010, 7 of 10 AL residents had some form of cognitive impairment, with 19% exhibiting severe cognitive impairment.³ Persons with ADRD residing in AL represent a population with an increased risk of poor outcomes. For example, persons with ADRD often have co-occurring chronic illnesses, putting them at risk for higher healthcare utilization.⁸ Further, individuals with ADRD are not always able to advocate for themselves, making them potentially vulnerable to abuse.⁹ Given the current size of the AL industry and the large population of residents with ADRD, more information is needed about the care provided to individuals with dementia residing in AL.

The development and growth of the AL industry has occurred largely without the influence of federal regulation. The lack of federal regulation is mainly a result of the funding structure of AL: in 2016, 84% of residents paid privately for their care.¹ With minimal federal oversight, state regulations dictate requirements for licensure and monitoring of AL. Previous work suggests that states vary widely in their regulations specific to the care of AL residents with ADRD¹⁰⁻¹⁴ and their enforcement practices.¹⁵ Regulation has also increased and diversified over time: in 2000, 28 states had at least one regulatory requirement for providing care to residents with ADRD in AL,¹⁶ and by 2014, that number had increased to 49 states.¹⁰ Given the differences across states in what is considered AL and the regulations related to caring for residents with ADRD (eg, staffing requirements, level of care permitted), it is important to examine state variation in the presence of AL residents with ADRD and their care experiences because regulations likely shape providers' behaviors and ultimately residents' outcomes.

The objectives of this study are to describe the state variability in the prevalence of ADRD among AL residents and their healthcare utilization. We use national Medicare claims data to characterize the sociodemographic and health characteristics of a cohort of Medicare beneficiaries with ADRD who reside in larger (25+ bed) AL settings and compare them with Medicare beneficiaries with ADRD living in the community and nursing homes (NHs). In addition, we present cross-sectional state variability in the prevalence of ADRD among a cohort of AL residents and their rates of NH admission and acute care hospitalization, and compare these rates with the population of community-dwelling Medicare beneficiaries with ADRD.

METHODS

Data

Information on AL communities comes from a national census we compiled from individual state licensing agencies. We reviewed state websites and contacted state agents for information on licensed AL/residential care settings in each state. Licensing agencies provided information, at a minimum, on the license type, address, and capacity. Following past work, we only include AL residences licensed to serve a population of older adults and with capacities for 25+ residents.^{1,17-20} Although larger AL communities (25+ beds) made up approximately 39.2% of AL communities in 2016, they comprised 84.1% of all licensed beds nationally.¹ Therefore, residential care settings with fewer than 25 beds, which represent more than 60% of licensed care settings but only 15.9% of residents, were not included in our analyses.

The Medicare Master Beneficiary Summary File (MBSF) was used to obtain beneficiaries' age, race, sex, reason for Medicare entitlement, Medicaid eligibility, and date of death. The Chronic Conditions Warehouse (CCW) segment of the MBSF was used to identify beneficiaries' chronic conditions including ADRD (see Supplementary Material for additional details). The MBSF was linked to a ZIP Code History File to obtain beneficiaries' residential ZIP Codes.

To identify Medicare beneficiaries in AL, we updated a previously published methodology relying on the 9-digit

ZIP Code reported in the MBSF¹ (see Supplemental Material for additional details) and created a finder file of 52,493 validated 9-digit ZIP Codes associated with 11,916 ALs (many large AL campuses have more than one 9-digit ZIP Code). Using this finder file, we searched beneficiaries' residential ZIP Codes to identify Medicare beneficiaries residing in large AL settings with a validated 9-digit ZIP Code pertaining to an AL on December 31, 2016.

To identify our cohorts of community-dwelling and NH residents, we combined Medicare claims with the Minimum Data Set and Home Health Outcome and Assessment Information Set assessments to form a Residential History File (RHF) that identifies a person's location of care and healthcare utilization on each day within a calendar year.²¹

Sample

We identified 439,272 Medicare beneficiaries with a ZIP Code pertaining to an AL in the 48 contiguous states who were not in any other healthcare setting on December 31, 2016. Because utilization and claims data are not available for Medicare Advantage (MA) beneficiaries, we excluded AL residents with any MA coverage during calendar years 2016 and 2017, resulting in 293,336 beneficiaries enrolled in traditional Medicare residing in AL on December 31, 2016. We used the CCW segment of the MBSF to identify residents with ADRD. This resulted in a sample of 88,867 (30.3%) beneficiaries enrolled in traditional Medicare with an ADRD diagnosis residing in AL on December 31, 2016.

To compare our sample of AL residents with ADRD with other populations, we identified the population of Medicare beneficiaries with an ADRD diagnosis residing in the community (ie, were not in AL, an inpatient setting, or an NH) on December 31, 2016, and without any MA enrollment during 2016 and 2017 ($n = 2,074,420$). We also identified the population of beneficiaries enrolled in traditional Medicare in 2016 and 2017 with an ADRD diagnosis who were in an NH on December 31, 2016 ($n = 602,521$).

Measures

The RHF was used to create the following outcomes for each of the study cohorts: any NH admission (both post-acute and long-stay) and any inpatient acute hospitalization during 2017. Inpatient acute hospitalization was specified for NH residents as an inpatient admission while an NH resident. For AL and community residents, inpatient admissions were included if they occurred while in AL or the community (ie, hospitalizations from an NH were not included).

Analyses

We conducted descriptive analyses documenting the differences in demographic and health characteristics among Medicare beneficiaries with an ADRD diagnosis who resided in AL with those residing in the community or an NH. We then calculated the percentage of AL residents with ADRD in each of the 48 states. Next, we estimated separate logistic regression models for each outcome measure (ie, NH admission and hospitalization) for AL and community-dwelling residents with ADRD. The models adjusted for age group (≤ 64 , 65-74, 75-84, 85-94, and ≥ 95

y), sex, race,²² dual eligibility (ie, Medicare and Medicaid) status in December 2016, and the presence and number (<2, 2-3, 4-5, and ≥6) of the following chronic conditions: anemia, atrial fibrillation, cancer, chronic kidney disease, chronic obstructive pulmonary disease, depression, diabetes, heart failure, hyperlipidemia, hypertension, ischemic heart disease, and stroke.

We calculated the risk-adjusted rates of each outcome, by state, as the ratio of observed events over expected events in each state, multiplied by the national rate. The risk-adjusted data were plotted to compare the rates of the outcomes in AL vs the community. The bootstrap resampling method was performed to estimate the 95% confidence intervals (CIs) of adjusted rates, and two-sample

t tests were used to compare adjusted group means. All analyses were approved by the Brown University institutional review board and conducted with SAS v.9.4 (SAS Institute, Cary, NC) and Stata v.15.1 (StataCorp 2017, College Station, TX). Additional information about the data and methods used for these analyses can be found in the Brown University Digital Repository (<https://repository.library.brown.edu/studio/item/bdr:1078482/>).

RESULTS

A total of 88,867 (30.3%) beneficiaries enrolled in traditional Medicare residing in AL had a diagnosis of ADRD, compared with 6.1% in the community and 72.7% in NHs (Table 1).

Table 1. Demographic and Health Characteristics of Assisted Living Residents with a Diagnosis of Alzheimer's Disease and Related Dementias Compared with Community-Dwelling and Nursing Home Residents

	Assisted living N = 88,867 (30.3%)	Community N = 2,074,420 (6.1%)	Nursing home N = 602,521 (72.7%)
Age groups,^a y, n (%)			
<65	2,925 (3.3)	130,588 (6.3)	34,138 (5.7)
65-74	7,587 (8.5)	362,158 (17.5)	83,208 (13.8)
75-84	19,604 (22.1)	727,822 (35.1)	169,192 (28.1)
85-94	45,869 (51.6)	726,491 (35)	243,909 (40.5)
95+	12,882 (14.5)	127,360 (6.1)	72,074 (12)
Sex, n (%)			
Male	27,107 (30.5)	797,248 (38.4)	187,800 (31.2)
Female	61,760 (69.5)	1,277,171 (61.6)	414,721 (68.8)
Race, n (%)			
White	81,624 (91.9)	1,642,568 (79.2)	478,472 (79.4)
Black	3,668 (4.1)	199,346 (9.6)	74,269 (12.3)
Hispanic	1,913 (2.2)	137,109 (6.6)	31,667 (5.3)
Other	1,662 (1.9)	95,396 (4.6)	18,113 (3)
Dual eligible,^a n (%)	18,503 (20.8)	487,601 (23.5)	451,920 (75)
Chronic conditions,^a n (%)			
Anemia	39,457 (44.4)	791,298 (38.2)	342,002 (56.8)
Atrial fibrillation	16,474 (18.5)	300,995 (14.5)	106,911 (17.7)
Cancer	8,833 (9.9)	205,119 (9.9)	47,194 (7.8)
Chronic kidney disease	34,101 (38.4)	774,811 (37.4)	274,375 (45.5)
Chronic obstructive pulmonary disease	17,909 (20.2)	384,770 (18.6)	149,652 (24.8)
Depression	38,697 (43.5)	698,182 (33.7)	339,951 (56.4)
Diabetes	27,588 (31.0)	733,149 (35.3)	256,216 (42.5)
Heart failure	29,525 (33.2)	569,210 (27.4)	250,358 (41.6)
Hyperlipidemia	46,799 (52.7)	1,134,061 (54.7)	295,509 (49.1)
Hypertension	71,137 (80.1)	1,555,130 (75)	508,506 (84.4)
Ischemic heart disease	40,351 (45.4)	897,237 (43.3)	289,819 (48.1)
Stroke	8,718 (9.8)	208,144 (10)	95,772 (15.9)
2+ chronic conditions,^a n (%)	77,354 (87)	1,708,310 (82.4)	559,050 (92.8)
4+ chronic conditions,^a n (%)	53,118 (59.8)	1,128,755 (54.4)	421,013 (69.9)
6+ chronic conditions,^a n (%)¹	27,277 (30.7)	567,905 (27.4)	240,041 (39.8)
Healthcare utilization,^b n (%)			
Any nursing admission ^c	21,151 (23.8)	342,190 (16.5)	N/A
Any hospitalization ^c	33,457 (37.6)	697,968 (33.6)	174,323 (28.9)
No. of hospitalizations, ^d mean (standard deviation)	1.48 (.92)	1.58 (1.11)	1.55 (1.02)
Mortality rate,^b n (%)	17,491 (19.7)	303,891 (14.7)	187,350 (31.1)

^aAs of December 31, 2016.

^bDuring 2017.

^cNursing home admission and/or hospitalization occurred while in that setting.

^dNumber of hospitalizations that occurred while in that setting, among those with any hospitalization during the year. Data come from the 2016 and 2017 Medicare Master Beneficiary Summary File, chronic conditions, and Residential History File.

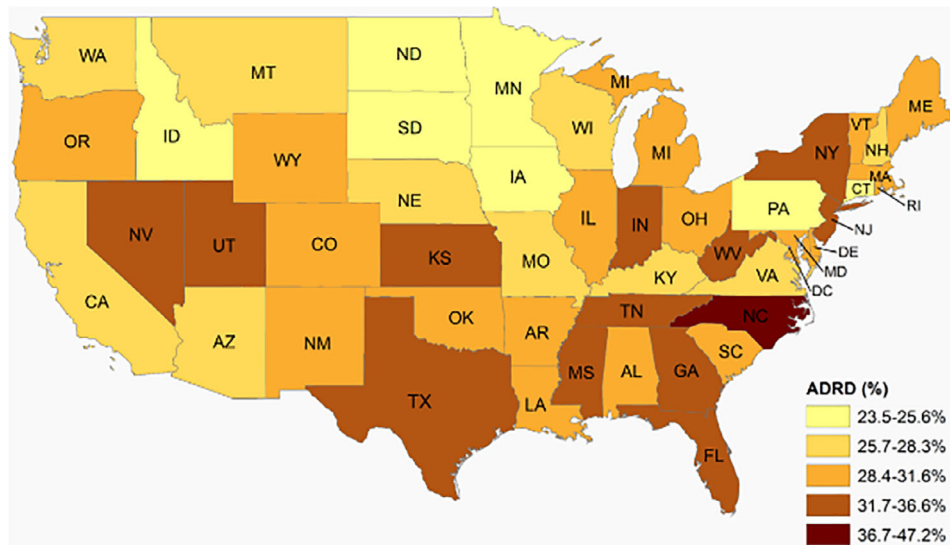


Figure 1. Geographic variability in the share of beneficiaries enrolled in traditional Medicare residing in assisted living with a diagnosis of Alzheimer’s disease and related dementias (ADRD) (2016). Data come from the 2016 Medicare Master Beneficiary Summary File and chronic conditions segment.

Our national cohort of beneficiaries with ADRD residing in AL were more likely to be older, female, and white than Medicare beneficiaries with a diagnosis of ADRD living in the community or NH. AL residents had more diagnosed chronic conditions than the community-dwelling population with ADRD but fewer than NH residents with ADRD. In addition, AL residents with ADRD had rates of hospitalization higher than community-dwelling and NH residents with ADRD (37.6% vs 33.6% and 28.9%, respectively).

Among our cohort of AL residents, states varied in their unadjusted percentage of residents with an ADRD diagnosis, from 23.6% in Minnesota to 47.2% in North Carolina (Figure 1 and Supplementary Table S1). In 2017, a total of

21,151 (23.8%) AL residents with an ADRD diagnosis were admitted to an NH during the year compared with 16.5% of community-dwelling beneficiaries with ADRD. The adjusted percentage of AL residents with an NH admission varied by state, ranging from 13.7% (95% CI = 9.7-18.7) in New Mexico to 34.9% (95% CI = 29-40.5) in North Dakota. Figure 2 shows that the rate of NH admission among AL residents is higher than in the community, but that state-level rates are strongly correlated ($r = .74$). With few exceptions, states whose community rates of NH admission were above/below the median also had higher/lower NH admission among AL residents. Delaware, North Dakota, and Connecticut had the greatest absolute difference in the rate of NH admission

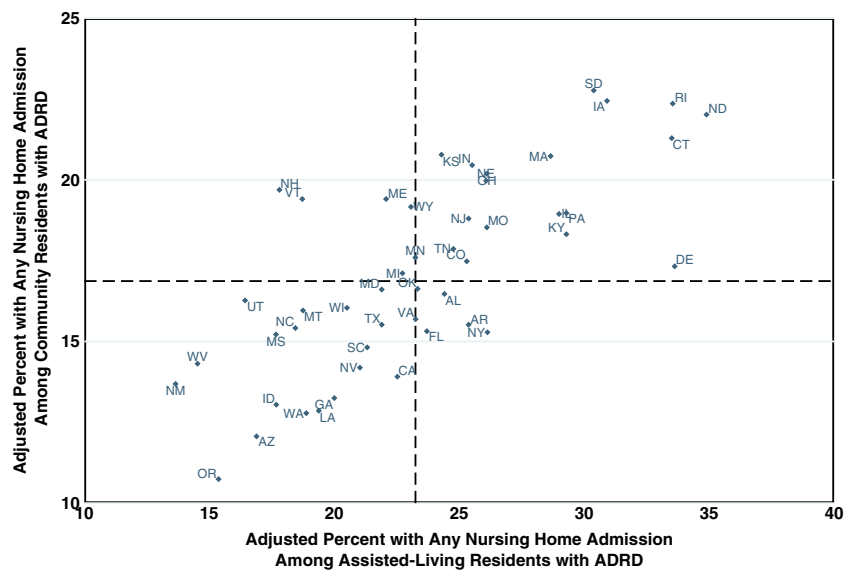


Figure 2. Adjusted* percentage of Medicare beneficiaries with Alzheimer’s disease and related dementias (ADRD) with a nursing home admission in 2017. *Percentage adjusted for age, race, sex, dual eligibility, chronic conditions, and the number of chronic conditions. Data come from the 2016 and 2017 Medicare Master Beneficiary Summary File and the Residential History File. Dashed lines indicate median values. [Color figure can be viewed at wileyonlinelibrary.com]

We also observed significant state variation in the rates of using NH care among AL residents with ADRD. Two types of factors may contribute to variation in NH admission rates: those that affect both community and AL residents, and those specific to AL. The mechanisms driving the differences in NH admission in both settings, therefore leading to strong correlation between community and AL rates, are likely related to potential factors contributing to differential access, as listed earlier (eg, market factors). For example, the number of NH beds per capita vary across the country, as does post-acute skilled nursing facility utilization.^{29,30} It may be the case that in states with less robust Medicaid support for home- and community-based services, individuals with ADRD living in the community may be left with few care alternatives to NHs.

The variation in NH placement among AL residents across states may also reflect differences in Medicaid policies: states without Medicaid waivers or state plans allowing for services to be provided in AL may result in residents spending down their assets, requiring relocation to an NH or other setting that accepts Medicaid reimbursement. State regulations related to retention or move-out requirements may affect the case mix within AL,³¹ thereby potentially driving the differences in NH admission across states.

In North Dakota, the state with the highest NH admission rate, AL settings may not retain residents who require more than intermittent nursing care unless the resident requires and elects to receive end-of-life care from a Medicare-certified hospice agency and the AL is licensed to provide end-of-life care (NDAC 33-03-24.1).³² This policy might result in transfers of residents with ADRD who have nursing care needs that are not deemed as life limiting.

State-specific dementia care rules might also influence the number of individuals with ADRD who are able to maintain residence in AL as their disease progresses. For example, Vermont, a state with a higher NH admission rate in the community than AL, has a policy that residents “will be permitted to age in place” (CVR 13-110-007.6.5)³³ provided that their mobility, ambulation, and transfer needs can be met by one staff person, cognitive impairment is at a moderate or lesser degree of severity, and behavioral symptoms consistently respond to appropriate intervention.

Other regulatory requirements, such as staffing, admission criteria, care processes, and tolerance for aging in place, might also explain the differences in NH admission observed among states. Our findings set the stage for future work examining the relative contribution of these market, financing, and regulatory factors on the state variations observed in this study.

Nationally, our cohort of AL residents with ADRD had higher rates of hospitalization than community-dwelling and NH residents, and the differences between AL and community rates varied by state. These rates might reflect differences in quality of care provided in AL, state requirements for level of care to be provided, or underlying patient need. It is impossible to draw conclusions about the quality of care provided in AL because systematic unmeasured aspects of health, such as the level of functional and cognitive impairment, could contribute to AL residents’ differences in hospitalization rates. Additional work examining hospitalizations conditioned on underlying patient need is important and required to better understand the

quality of care provided to residents with ADRD in AL compared with the community and NHs.

As it relates to state regulations for dementia care requirements, of the four states with the greatest differences in AL and community rates of hospitalization, three (Arkansas, Rhode Island, and Nevada) require dementia care units to be licensed. However, of the seven states with lower rates of hospitalization in AL, only Connecticut requires dementia care units to be licensed.¹¹ It is possible that states with more stringent rules for dementia care settings have provisions that result in differential rates of hospitalization or that they admit residents with differing levels of need. However, documentation of state variation in dementia care requirements for AL is limited.

One regulatory review found that only seven states specify minimum staffing levels or ratios in dementia care units; 13 states specified administrator training requirements, with the total hours of training ranging from 7 to 120 hours in the first year, and 14 states required a preadmission assessment of dementia care needs.¹¹ Given the previous link between nurse staffing levels, staffing mix, and AL residents’ outcomes,^{34,35} it is possible that state staffing requirements may also be associated with differences in rates of hospitalization. Future research is needed to assess systematically whether and how differences in states’ requirements for dementia care, particularly staffing levels and mix, affect hospitalization of AL residents with ADRD.

Differences among states in healthcare utilization of their AL residents may be a function not only of states’ regulations but also how those regulations are monitored and enforced. Although the relationship between enforcement of regulations and resident outcomes has not been explored in the context of AL, the link between oversight and quality of care in NHs has been well documented. For example, implementation of the Nursing Home Reform Act care standards and surveillance system was tied to reductions in chemical restraints and improved resident quality of care.³⁶ Following the nationwide implementation of the National Partnership to Improve Dementia Care in Nursing Homes, one study³⁷ found state agencies supporting frequent facility monitoring had reduced rates of inappropriate antipsychotic prescribing. Additional work to understand the relationship between how states enforce regulations and residents’ outcomes is an area of important study.

Limitations

This analysis has limitations. First, we present a cross section of data and report on the resident composition and healthcare utilization in 2017; therefore, we are unable to draw any causal conclusions. As such, we do not formally measure the impact of market factors, regulations, or enforcement that may be attributable to the geographic variation observed.

Second, our ascertainment of ADRD relies on a diagnosis in Medicare claims. Therefore, we may be underestimating the prevalence of residents with ADRD⁴ and are unable to identify the prevalence of ADRD among MA enrollees. Given the varying diagnosing patterns^{23,24} and MA penetration rate across states,³⁸ this may bias our estimates of ADRD prevalence in these settings. However, it does not appear that AL prevalence rates across

states track those among community-dwelling older adults (Supplementary Table S1).

Third, our methodology depends on identifying residents in larger AL settings (25+ beds), limiting its generalizability to smaller settings. Data from the National Study of Long-Term Care Providers (NSLTCP) suggests that the percentage of residents with ADRD decreases with increasing AL size, from 51% of residents in AL settings with 4 to 25 beds, to 44% with 26 to 50 beds, to 39% in the largest AL settings (50+ beds). Understandably, our study had lower rates of ADRD than previously published findings from the 2016 NSLTCP.³⁹ In addition, relying on 9-digit ZIP Codes to identify AL residents means that we are only able to identify residents who changed their addresses, and we may be including independent living residents on the same campus.

Finally, this study was designed and carried out using the state as the primary unit of analysis. However, most states provide two or more types of licensed care that falls under the umbrella of AL, and requirements for licensed settings within a state can vary. Additional investigation is needed to better understand the within-state variability that is likely to exist in resident characteristics and outcomes. Despite these limitations, our study presents the first insight into the state variability in the prevalence of ADRD and residents' healthcare utilization.

In conclusion, for several decades, AL has been preferred by older adults who need assistance with personal care and health-related needs. As this and other recent studies have indicated,¹⁻⁷ AL serves significant numbers of older adults with ADRD. The state variation in the percentage of residents with ADRD diagnoses, and the variation in their health service utilization, suggest unequal access to AL, differences in care processes, as well as possible underlying variability in the population of beneficiaries with ADRD residing in AL. The reasons for such differences are as yet unknown, although market forces, regulatory requirements, and enforcement may play important roles. Our findings suggest that clinicians caring for residents in these settings likely practice under varying constraints. These findings also point to the importance of clinicians' familiarity with state and specific AL communities' requirements for care. Ultimately, these findings call for further work to better understand the factors that might be driving the variations observed in this study.

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SUPPORTING INFORMATION

Additional Supporting Information may be found in the online version of this article.

Supplementary Table S1: Unadjusted rate of Alzheimer's disease and related dementias (ADRD) by state.

Supplementary Table S2: Adjusted rates of moving into a nursing home among residents with an Alzheimer's disease and related dementias (ADRD) diagnosis in assisted living and community.

Supplementary Table S3: Adjusted rates of hospitalization before moving to a nursing home among residents with an Alzheimer's disease and related dementias (ADRD) diagnosis in assisted living and community.