Received: 22 June 2022 | Revised: 9 September 2022 | Accepted: 9 October 2022

DOI: 10.1111/jgs.18115

CLINICAL INVESTIGATION

Journal of the American Geriatrics Society

Use of long-term services and supports among dual-eligible beneficiaries with Alzheimer's disease and related dementias

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Funding information
National Institute on Aging, Grant/Award Number: 1RF1AG069782-01

Abstract

Background: To respect people's preference for aging in place and control costs, many state Medicaid programs have enacted policies to expand home and community-based services as an alternative to nursing facility care. However, little is known about the use of Medicaid long-term services and supports (LTSS) at a national level, particularly among dual-eligible beneficiaries with Alzheimer's disease and related dementias (ADRD).

Methods: Using Medicare and Medicaid claims of 30 states from 2016, we focused on dual-eligible beneficiaries 65 years or older with ADRD and described their use of any form of LTSS and sub-types of LTSS (home-based, community-based, and nursing facility services) across states.

Results: We found that 80.5% of dual-eligible beneficiaries with ADRD received some form of Medicaid LTSS in 2016. The most common LTSS setting was nursing facility (46.7%), followed by home (31.5%) and community (12.2%). There was sizeable state variation in the percentage of dual-eligible beneficiaries with ADRD who used any form of LTSS (ranging from 61% in Maine to 96% in Montana). The type of LTSS used also varied widely across states. For example, home-based service use ranged from 9% in Maine, Arizona, and South Dakota to 62% in Oregon. Nursing facility services were the most common type of LTSS in most states. However, home-based service use exceeded nursing facility use in Oregon, Alaska, and California.

Conclusions: Our findings suggest substantially different use of LTSS across states among dual-eligible beneficiaries with ADRD. Given the importance of LTSS for this population and their families, a deeper understanding of state LTSS policies and other factors that contribute to wide state variation in LTSS use will be necessary to improve access to LTSS across states.

KEYWORDS

dual-eligible beneficiaries, long-term services and supports, people with Alzheimer's disease and related dementias

INTRODUCTION

People with Alzheimer's disease and related dementias (ADRD) typically experience declines in cognition and physical functioning and may struggle with self-care and other daily activities, eventually necessitating long-term services and supports (LTSS). LTSS includes a variety of services for people who need assistance with daily activities due to aging, illness, or disability. While many people with ADRD live at home and rely on unpaid friends or family members to provide informal care, some people with ADRD also receive some kind of formal, paid care.[1,2] One study reported that 50% and 44% of community-dwelling adults with dementia receive informal and formal help, respectively.[3] Most people with ADRD have Medicare, but Medicare covers home health and skilled nursing facility services primarily for post-acute care. Medicaid, however, provides expansive coverage of LTSS for beneficiaries who meet financial and functional eligibility criteria. About 25% of people with ADRD are "dually eligible," receiving coverage from both Medicaid and Medicare.[4]

Historically, many Medicaid beneficiaries with ADRD received LTSS in nursing facilities. However, to respect people's preference for aging in place and control costs, many state Medicaid programs have enacted policies to expand their home and community-based service (HCBS) programs as an alternative to nursing facility care. These efforts are often referred to as "LTSS rebalancing." Despite LTSS rebalancing efforts in recent decades, little is known about the percentage of people with ADRD who used Medicaid LTSS at a national level or across states. Some studies have used Medicaid Analytic eXtract data to describe the percentage of people with ADRD who used LTSS and HCBS nationwide. However, the most recent year for which these data included all states was 2012.[1,5] The Centers for Medicare and Medicaid Services (CMS) publishes reports on annual Medicaid LTSS beneficiaries and expenditures. However, these data are not specific to people with ADRD.

Linking Medicare claims with a newly available nationwide Medicaid claims database, this study provides a more recent picture of Medicaid LTSS use among dual-eligible beneficiaries with ADRD. Specifically, we described LTSS use across states. We focused on state-level differences in LTSS use because state Medicaid programs have considerable flexibility in shaping the structure and delivery of LTSS, particularly HCBS.

We classified LTSS into home-based, community-based, and nursing facility services based on the location of services received and then examined the use of these sub-types of LTSS separately. Here, we defined community-based services as LTSS provided in a licensed, community-based setting, including assisted living facilities, group homes, hospice facilities, or adult day care.[6] Of note, Medicaid does not cover room and board

Key points

- The majority (80.5%) of dual-eligible beneficiaries with Alzheimer's disease and related dementias (ADRD) received some form of Medicaid long-term services and supports (LTSS) in 2016. The most common type of LTSS setting was nursing facility (46.7%), followed by home (31.5%) and community (12.2%).
- There was sizeable state variation in the proportion of dual-eligible beneficiaries with ADRD who used any form of LTSS (ranging from 61% in Maine to 96% in Montana) and different types of LTSS.

Why does this paper matter?

Our research findings matter for the following reasons. First, we examined the use of sub-types of LTSS (home-based, community-based, and nursing facility services) separately. Most previous studies have not distinguished home-based services from community-based services, yet the distinction is essential for people with ADRD. Home-based and community-based services may impact the care experience and family caregiving burden differently. For example, compared to community-based services, home-based services may be better suited to address an individual's needs but may still require intense family involvement, leading to more caregiving stress. In addition, community-based services provide people with an opportunity for social interaction, which may contribute to higher life satisfaction. Furthermore, on average, community-based services for people with ADRD cost more than home-based services. Second, understanding the percentage of dual-eligible beneficiaries with ADRD who used Medicaid LTSS (including specific sub-types of LTSS) across states is a critical first step toward improving access to LTSS. Access to Medicaid LTSS can reduce the financial burden and improve the quality of life for dual-eligible beneficiaries with ADRD and their families.

fees for assisted living facility residents. However, most states do pay for personal care services provided by assisted living facilities.[7] Therefore, we classified assisted living facility residents who received Medicaid-covered personal care services as community-based service users.

Most previous studies have not distinguished home-based services from community-based services.[1,8] However, the distinction is essential for people with ADRD because these two types of LTSS may impact people's care experience and family caregiving burden differently. For example, compared to community-based services, home-based services may be better suited to address an individual's needs but may still require intense family involvement, leading to more caregiving stress.[9,10] In addition, community-based services provide people an opportunity for social interaction, which may contribute to higher life satisfaction.[11] Furthermore, on average, community-based services for people with ADRD cost more than home-based services. For example, assisted living facility for people with ADRD cost about $6900 per month while homemaker services cost $3200 (assuming 80 hours service received per month) in Portland Oregon, in 2021.[12,13] As a result, some state Medicaid agencies distinguish between home-based and community-based services when reporting LTSS enrollment and analyzing the effect of state policy on LTSS use.[6,14]

Understanding the percentage of dual-eligible beneficiaries with ADRD who used Medicaid LTSS, including specific sub-types of LTSS, across states is a critical first step toward improving access to LTSS. The use of Medicaid LTSS can reduce financial burdens and improve the quality of life for this population and their families.

METHODS

Data sources

We conducted a cross-sectional study with 2016 national Medicare and Medicaid data linked at the individual level. We used the Medicare Master Beneficiary Summary File to identify dual-eligible beneficiaries with ADRD who were at least 65 years of age and their demographic and health characteristics. We then used the Transformed Medicaid Statistical Information System Analytic File (TAF) Other Services and Long-Term Care files to identify each dual-eligible beneficiary's LTSS use. We accessed county-level data on LTSS supply from the Area Health Resource Files[15] and the US Bureau of Labor Statistics Occupational Employment and Wage Statistics Survey (Table S1).[16]

Study sample

We identified 759,386 people with ADRD who were at least 65 years of age and had both Medicare coverage (through a fee-for-service plan) and full Medicaid coverage (through either a fee-for-service or managed care plan) each month they were alive in 2016. Our sample included individuals who died during 2016 and were thus not enrolled in Medicare and Medicaid for the entire year. We used the Chronic Conditions Data Warehouse (CCW) Chronic Condition Segment file to identify people with ADRD. The CCW uses an algorithm with a three-year lookback to identify at least one claim with an ICD-9 or ICD-10 code for an ADRD diagnosis.[17]

Of the 759,386 beneficiaries identified, we excluded those who had no Medicaid record ($n = 2989$; 0.40%), moved states ($n = 5477$; 0.72%), lived in a US territory where HCBS is either not provided or records were unavailable ($n = 105$; 0.01%), and had a conflicting state of residence in their Medicare and Medicaid record ($n = 21{,}994$; 2.90%). We further excluded beneficiaries from 21 states with poor data quality ($n = 242{,}158$; additional detail provided in Data S1). Finally, we excluded beneficiaries in the remaining states who used any HCBS but for whom we were unable to classify their service use as home- or community-based ($n = 14{,}646$; 1.77%). Our final sample included 472,017 beneficiaries in 30 states (Figure S1).

LTSS utilization

We used Medicaid professional and facility claims to identify LTSS use provided under both fee-for-service and managed care plans.[18] We used a combination of type of service, place of service, procedure, revenue center, HCBS taxonomy, and billing/service provider taxonomy claim codes to define the five following binary measures of LTSS utilization (specific codes are presented in Tables S2 and S3). We defined 1) *Any Nursing Facility Service* use as any stay in a nursing facility lasting more than 90 consecutive days. A total of 6576 beneficiaries (1.4% of the total sample) had nursing facility stays that began after October 3, 2016, and lasted through December 31, 2016. Without access to 2017 data, we could not confirm if these stays were at least 90 days in length, and therefore we did not include these individuals as nursing facility users in our analysis. We defined 2) *Any HCBS* use as having at least one claim for an HCBS service (defined according to the prior convention as home health, personal care, hospice, etc.).[19,20] We further classified any HCBS use as 3) *Any Home-based Service* use, defined as having at least one claim for an HCBS

TABLE 1 Characteristics of dual-eligible beneficiaries with Alzheimer's disease and related dementias (ADRD) in 30 states across different long-term services and supports (LTSS) settings ($n = 472{,}017$).

		Any LTSS use		
	No LTSS use	**Home**	**Community**	**Nursing facility**
n (% of sample)	91,983 (19.5%)	148,585 (31.5%)	57,391 (12.2%)	220,842 (46.7%)
Demographics				
Age, years				
[65, 70)	10,387 (11.3%)	14,651 (9.9%)	5030 (8.8%)	17,696 (8%)
[70, 75)	13,754 (15%)	19,467 (13.1%)	7018 (12.2%)	24,459 (11.1%)
[75, 80)	16,150 (17.6%)	26,856 (18.1%)	9404 (16.4%)	31,616 (14.3%)
[80, 85)	17,263 (18.8%)	30,933 (20.8%)	11,197 (19.5%)	40,623 (18.4%)
[85, 90)	17,123 (18.6%)	30,164 (20.3%)	11,902 (20.7%)	48,365 (21.9%)
[90, 115]	17,306 (18.8%)	26,514 (17.8%)	12,840 (22.4%)	58,083 (26.3%)
Missing	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Sex: Female	63,839 (69.4%)	108,225 (72.8%)	41,372 (72.1%)	160,808 (72.8%)
Race/ethnicity				
American Indian/Alaskan Native	916 (1%)	987 (0.7%)	730 (1.3%)	1400 (0.6%)
Asian/Pacific Islander	8087 (8.8%)	20,248 (13.6%)	4505 (7.8%)	5861 (2.7%)
Black	14,116 (15.3%)	24,105 (16.2%)	7235 (12.6%)	35,581 (16.1%)
Hispanic	19,572 (21.3%)	27,730 (18.7%)	7141 (12.4%)	14,185 (6.4%)
Other	984 (1.1%)	2527 (1.7%)	540 (0.9%)	1180 (0.5%)
White non-Hispanic	47,590 (51.7%)	71,007 (47.8%)	36,680 (63.9%)	162,130 (73.4%)
Missing	718 (0.8%)	1981 (1.3%)	560 (1%)	505 (0.2%)
Health insurance				
Reason for Medicaid eligibility				
Supplemental security income	46,268 (50.3%)	88,428 (59.5%)	24,401 (42.5%)	33,820 (15.3%)
Expanded FPL eligibility[a]	5947 (6.5%)	12,459 (8.4%)	4543 (7.9%)	16,600 (7.5%)
Medically needy	10,046 (10.9%)	10,870 (7.3%)	7935 (13.8%)	56,609 (25.6%)
Expanded access for LTSS[b]	10,647 (11.6%)	7089 (4.8%)	5814 (10.1%)	67,105 (30.4%)
Other	17,106 (18.6%)	26,913 (18.1%)	12,573 (21.9%)	40,780 (18.5%)
Missing	1969 (2.1%)	2826 (1.9%)	2125 (3.7%)	5928 (2.7%)
Years in Medicare, mean (sd)	17.6 (9.5)	17.7 (9.1)	19.7 (9.9)	21.2 (9.1)
Health characteristics				
Years since ADRD diagnosis, mean (sd)[c]	4.2 (3.8)	4.6 (4.0)	5.0 (4.0)	5.3 (4.1)
No. of chronic conditions, mean (sd)	8.2 (4.5)	8.7 (4.4)	8.8 (4.3)	9.3 (4.0)
Cancer	7142 (7.8%)	11,957 (8%)	4342 (7.6%)	14,091 (6.4%)
Chronic kidney disease	33,853 (36.8%)	59,389 (40%)	21,219 (37%)	85,963 (38.9%)
COPD	21,264 (23.1%)	38,003 (25.6%)	13,969 (24.3%)	53,795 (24.4%)
Depression	37,089 (40.3%)	58,306 (39.2%)	27,724 (48.3%)	122,937 (55.7%)
Diabetes	42,648 (46.4%)	80,101 (53.9%)	26,435 (46.1%)	99,553 (45.1%)
Hypertension	74,814 (81.3%)	126,607 (85.2%)	47,350 (82.5%)	186,803 (84.6%)
Heart disease[d]	53,081 (57.7%)	93,818 (63.1%)	33,930 (59.1%)	137,252 (62.1%)
Stroke	10,571 (11.5%)	17,093 (11.5%)	6137 (10.7%)	34,445 (15.6%)
Died in 2016	23,903 (26%)	15,422 (10.4%)	15,352 (26.7%)	41,524 (18.8%)

TABLE 1 (Continued)

		Any LTSS use		
	No LTSS use	**Home**	**Community**	**Nursing facility**
Neighborhood characteristics				
Rural/urban status				
Isolated	2408 (2.6%)	3524 (2.4%)	1613 (2.8%)	8726 (4%)
Large rural	5898 (6.4%)	10,182 (6.9%)	5339 (9.3%)	25,853 (11.7%)
Small rural	3338 (3.6%)	5442 (3.7%)	2458 (4.3%)	13,710 (6.2%)
Urban	80,302 (87.3%)	129,416 (87.1%)	47,963 (83.6%)	172,525 (78.1%)
Missing	37 (0%)	21 (0%)	18 (0%)	28 (0%)
Social deprivation index, mean (sd)	60.7 (28.6)	65.4 (26.7)	56.5 (28.6)	54.5 (28.0)
LTSS supply: Per 1000 residents 65+, mean (sd)				
Personal care workers	24.8 (14.4)	27.7 (13.3)	22.9 (13.8)	23.4 (14.9)
Home health agencies	0.2 (0.3)	0.2 (0.2)	0.2 (0.2)	0.2 (0.2)
SNF + NF beds	32.4 (15.2)	32.4 (14.2)	33.7 (16.3)	38.1 (18.3)

Source: Authors' analysis of national Medicare/Medicaid data, 2016.

Note: Any LTSS use is not mutually exclusive, beneficiaries who used more than one type of LTSS were included in each applicable column. States that were excluded from this table include AR, CO, DE, HI, IA, ID, IL, KS, MN, MO, MS, ND, NE, NM, PA, TN, TX, VA, WA, WI, and WY.

[a]Expanded eligibility up to 100% FPL.

[b]Expanded access for LTSS through the Special Income Rule or Qualified Income Trusts.

[c]Heart disease includes congestive heart failure and ischemic heart disease.

[d]Chronic Condition Data Warehouse chronic conditions file was created using Medicare fee-for-service claims, not Medicare advantage encounter records. If dual-eligible individuals were enrolled in Medicare Advantage plan prior to 2016, the date of the first diagnosis of ADRD in chronic condition file may be incorrect.

received in the beneficiary's home, and 4) *Any Community-based Service* use, defined as at least one claim for an adult day care service or any HCBS received in an assisted living, group home, custodial care, or hospice facility.[21] Finally, we defined 5) *Any LTSS* use as any nursing facility service or any HCBS use. LTSS utilization measures were not mutually exclusive. Beneficiaries who used more than one type of service were included in each relevant measure.

Additional variables

Additional variables included each dual-eligible beneficiary's age, sex, race/ethnicity, and Medicaid eligibility pathway. We used condition flags created by the Chronic Conditions Data Warehouse (CCW) to calculate the number of years since a beneficiary first met claims criteria for ADRD,[22,23] as well as whether they had any of the following conditions at the end of 2015: cancer (breast, lung, colorectal, prostate, or endometrial), chronic kidney disease, chronic obstructive pulmonary disease, depression, diabetes, hypertension, heart disease (congestive heart failure or ischemic heart disease), and stroke. We linked each beneficiary's zip code to a 2010 rural–urban commuting area designation[24] and a 2015 Social Deprivation Index score.[25,26] We also linked each beneficiary's county of residence to the number of personal care aides,[16] home health agencies,[15] and available nursing facility/skilled nursing facility beds[15] per 1000 county residents at least 65 years of age in 2016 (Table S4).

Analyses

Our primary analysis was descriptive. We used logistic regression to estimate the adjusted proportion of dual-eligible beneficiaries with ADRD in each of 30 states who used any LTSS, any home-based service, any community-based service, and/or any nursing facility service.[27] We created a separate model for each of these four LTSS utilization measures and regressed the LTSS utilization measure on state of residence, adjusting for age (continuous), sex, number of chronic health conditions (continuous), and number of years since first documented ADRD diagnosis (continuous). We used output from the logistic regression to predict the adjusted probability of LTSS use in each state,[28] a method comparable to direct standardization.[27]

To assess the sensitivity of our results to missing data, we conducted two additional analyses. First, we compared the characteristics of dual-eligible beneficiaries

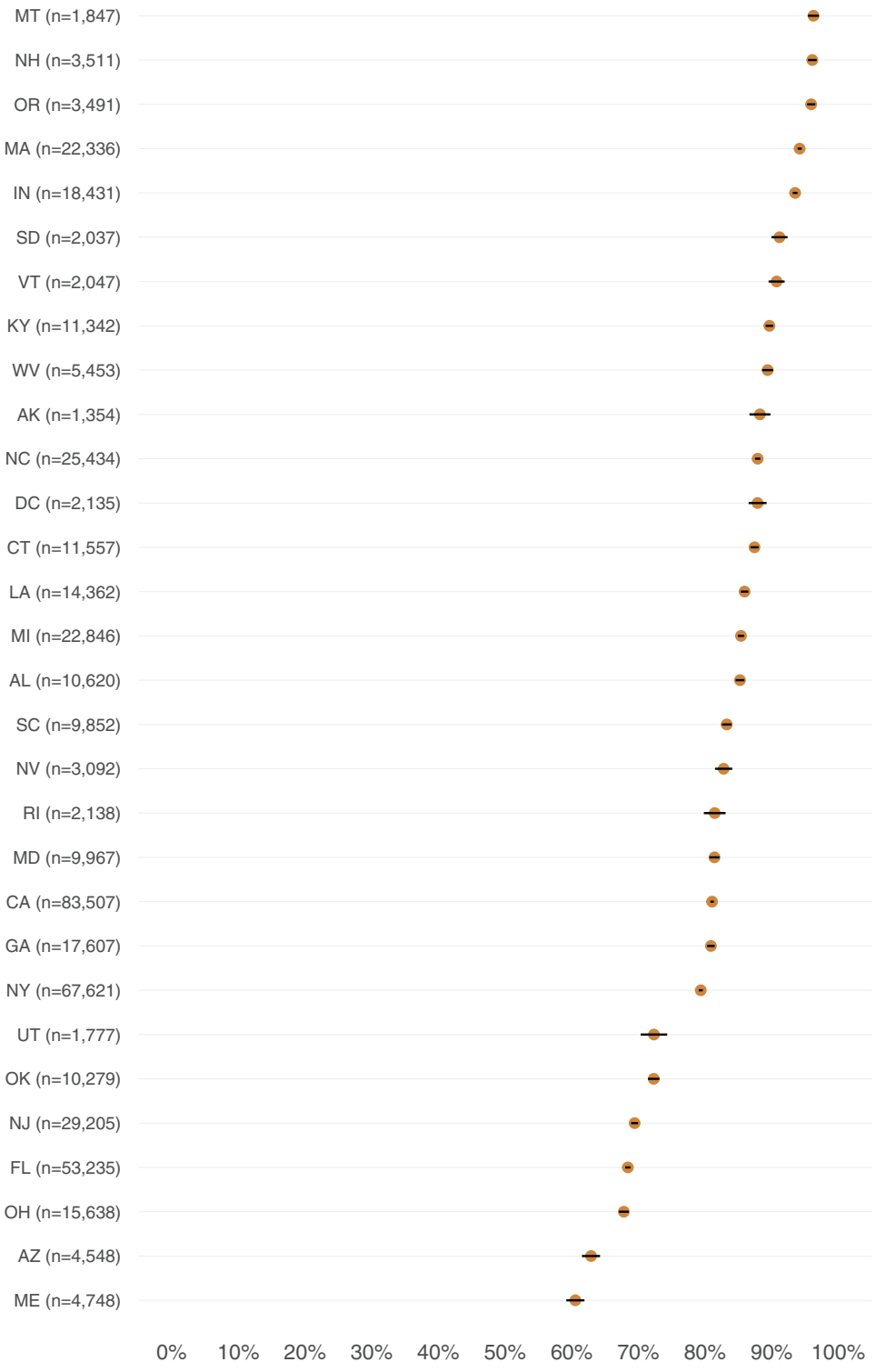

FIGURE 1 Percentage of dual−eligible beneficiaries at least 65 years of age with Alzheimer's disease and related dementias (ADRD) who used any long−term services and supports (LTSS) in 2016. *Source*: Authors' analysis of national Medicare/Medicaid data, 2016. *Note*: Percentages are adjusted for age, sex, number of chronic health conditions, and years since first documented ADRD. Black horizontal bars represent 95% confidence intervals.

with ADRD in the 30 states included in the main analysis to those from the 21 states excluded from the main analysis. Second, we retained 142,803 dual-eligible beneficiaries with ADRD who used HCBS but were excluded from the main analysis (i.e., those for whom we could not identify a service setting and those who lived in one of 11 states where >10% of beneficiaries were unclassified HCBS users; Figure S1). This allowed us to describe LTSS use in 11 states that would have otherwise been excluded from this work. Using this larger sample (614,822 beneficiaries in 41 states), we described the adjusted proportion of dual-eligible beneficiaries with ADRD who used 1) any LTSS, 2) any HCBS, and/or 3) any nursing facility service.

RESULTS

Among the study sample, 80.5% of dual-eligible beneficiaries with ADRD used some form of LTSS in 2016: 31.5%, 12.2%, and 46.7% used home-based services, community-based services, and long-term nursing facility services, respectively (Table 1).

Demographic and health characteristics across users of different types of LTSS

Home-based and community-based service users were more likely to be Asian/Pacific Islander and Hispanic compared to nursing facility service users (Table 1). They were also more likely to qualify for Medicaid through the Supplemental Security Income eligibility pathway compared to nursing facility users, who were more likely to become eligible through the medically needy or expanded LTSS financial eligibility pathway. Community-based service users were more likely to have died compared to home-based and nursing facility users. We attribute this finding to the fact that hospice services provided in a hospice facility were included as a community-based service. Community-based service users were also older, more likely to be white, diagnosed with ADRD earlier, and lived in a county with a lower social deprivation index (less disadvantaged county) compared to home-based service users. Eighteen percent of the study sample died during 2016, and of those who died, 72.2% used some form of LTSS in 2016 (data not shown in Table 1).

LTSS use across states

After adjusting for age, sex, number of chronic conditions, and years since the first documented ADRD diagnosis, the percentage of dual-eligible beneficiaries with ADRD who used any form of LTSS varied across states, from 61% in Maine to 96% in Montana (Figure 1). The type of LTSS used also varied widely across states (Figure 2). For example, 9% of beneficiaries used home-based services in Maine, Arizona, and South Dakota, compared to 62% of beneficiaries in Oregon. Community-based service use ranged from 0% in Alabama to 56% in Oregon, and nursing facility service use ranged from 18% in Alaska to 79% in New Hampshire. In most states, nursing facility services were the most common type of LTSS used. However, home-based service use exceeded nursing facility use in Oregon, Alaska, and California.

Sensitivity analysis

We compared the characteristics of dual-eligible beneficiaries with ADRD in the 30 states included in the main analysis to those from the 21 states excluded from the main analysis (Table S5). Beneficiaries from excluded states were more likely to be non-Hispanic white; to qualify for Medicaid through Supplemental Security Income or expanded LTSS financial eligibility pathway; and to reside in areas with a higher per-capita supply of personal care workers and skilled nursing facility beds, compared to beneficiaries in included states.

As expected, the inclusion of HCBS users who could not be classified as home-based or community-based increased the percentage of dual-eligible beneficiaries with ADRD who used any LTSS in our primary study sample. However, increases were small and ranged from 0.04% to 3.9% across states. The overall pattern of LTSS use remained consistent across states (Figure S2). Among this expanded sample (41 states instead of 30 states), any HCBS use exceeded any nursing facility service use in nine states, including NC, CA, TX, CO, MN, NM, WA, AK, and OR (Figure S3).

DISCUSSION

Our analysis yielded two key findings. First, 80.5% of dual-eligible beneficiaries with ADRD received some form of Medicaid LTSS in 2016. The most common LTSS setting was nursing facility (46.7%), followed by home (31.5%) and community (12.2%). Second, there was sizeable state variation in the proportion of dual-eligible beneficiaries with ADRD who used any form of LTSS and different types of LTSS.

Nursing facility care was the most common type of LTSS for dual-eligible beneficiaries with ADRD, potentially reflecting the fact that people with advanced dementia require intensive care more easily delivered in nursing facilities. Some evidence suggests that the nursing facility may be a safer LTSS setting for people with ADRD. For example, among people with ADRD, the probability of being hospitalized in a given year is ten-percentage-point lower for individuals in a nursing facility compared to those receiving HCBS.[29] Nevertheless, many people with ADRD wish to remain in their own home,[30] and living at home is associated with a higher quality of life.[31] These tradeoffs require a nuanced consideration of each individual's preference to age at home while balancing the potential risk of adverse health outcomes when selecting an LTSS setting for people with ADRD.

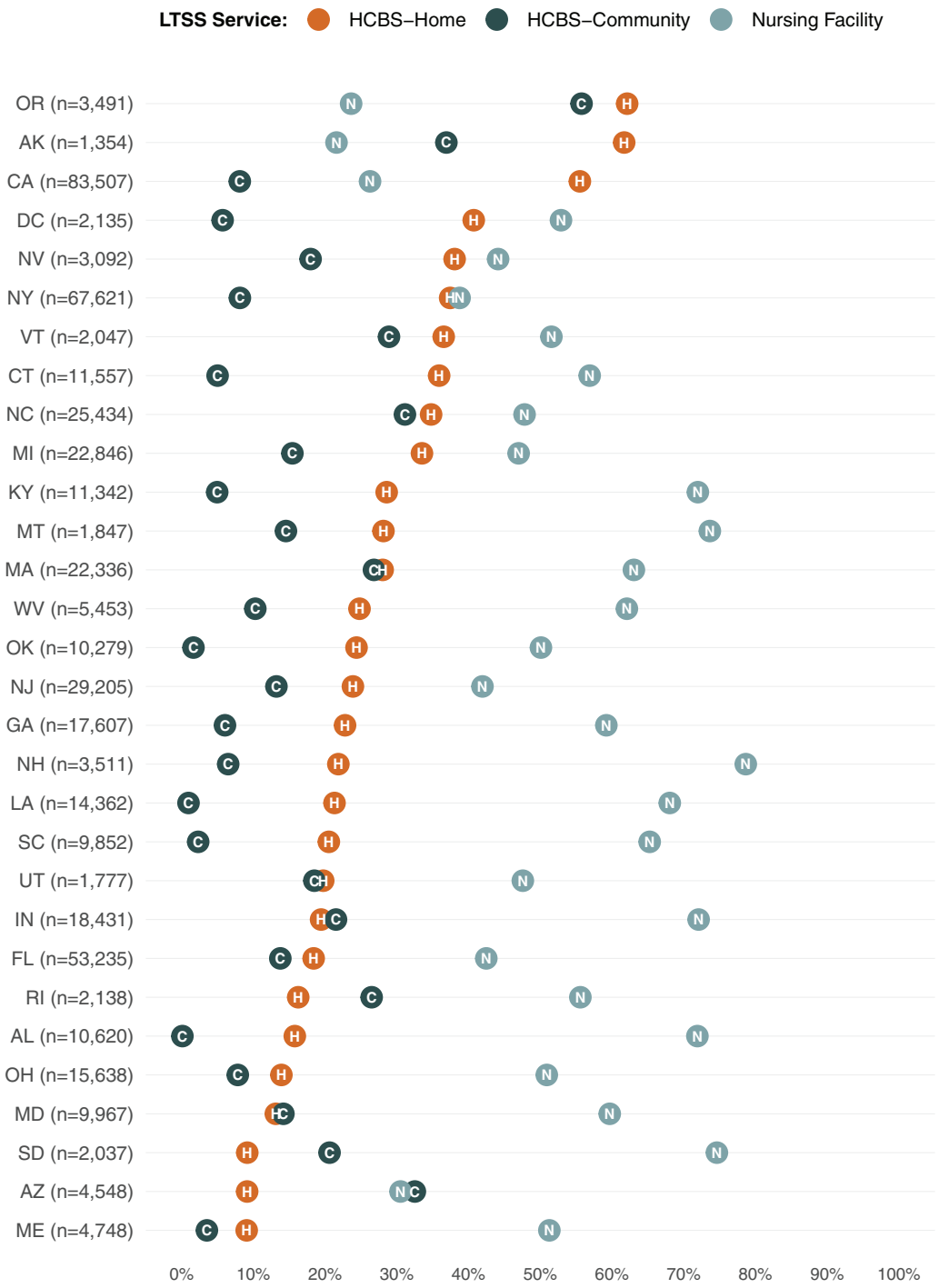

FIGURE 2 Percentage of dual-eligible beneficiaries at least 65 years of age with Alzheimer's disease and related dementias (ADRD) who used any home-based services (H), community–based services (C), and/or long–term nursing facility services (N) in 2016. *Source*: Authors' analysis of national Medicare/Medicaid data, 2016. *Note*: Service use is not mutually exclusive, beneficiaries who used more than one type of service were included in each applicable category. Percentages are adjusted for age, sex, number of chronic health conditions, and years since first documented ADRD.

We observed wide variation in the types of LTSS used across states, even after adjusting for age, sex, health conditions, and years from ADRD diagnosis. Variation in state Medicaid policies or each state's specific LTSS environment may reflect state-level variation in the types of LTSS used. For example, home-based service use exceeded nursing facility use in three out of 30 states, including Oregon, California, and Alaska. In 2016, Oregon used a 1915(k) state plan (also as known as Community First Choice Plan) to expand home-based services

that were previously mostly provided under a 1915 (c) waiver. 1915(k) offers 6% enhanced federal matching funds for personal care services and prohibits the state Medicaid program from limiting the number of HCBS users.[32] In the same year, in addition to using a 1915 (k) state plan, California sought to increase HCBS use through managed care arrangements that provided LTSS on either a mandatory or voluntary basis.[19,33] In contrast, Alaska Medicaid did not use 1915(k) or managed care plans to provide LTSS in 2016. The rates of home-based service use in Alaska may reflect its unique LTSS environment. The state only had 19 nursing facilities,[34] with the cost of nursing facilities the highest in the nation, nearly five times the national average.[35]

In addition to state Medicaid policies or specific LTSS environment, multiple factors may have contributed to wide variation in LTSS use across states. For example, dual-eligible beneficiaries with ADRD in different states may have had different preferences for informal caregivers or/and home, community, and nursing facility-based services. Quality of care may have differed by home-, community, and nursing facility-based services across states, influencing people's choice of LTSS. In addition, dual-eligible beneficiaries with ADRD in different states may have had different types of complex healthcare needs that were not observed in our administrative data, again influencing their choice of LTSS type.

Although community-based services have emerged as a preferred option over nursing facilities among the general older adult population,[36] we found that community-based service use was generally low among dual-eligible beneficiaries with ADRD. Less than 10% of these beneficiaries in 13 states used community-based services. Multiple factors may explain this relatively low use. A small number of state Medicaid programs do not cover personal care services provided in an assisted living facility.[37] Even when Medicaid pays for personal care services provided in an assisted living facility, Medicaid does not generally cover room and board, making assisted living a costly option for some and inaccessible to others. Community-based service providers may also be less willing to serve dual-eligible beneficiaries because Medicaid reimbursement rates for LTSS are lower than private pay rates.[7,38]

We further classified HCBS into home- and community-based services, considering that home-based and community-based services may impact people's care experience, family caregiving burden, and cost differently. Our study suggests that disaggregating home- and community-based services may be informative. Dual-eligible beneficiaries with ADRD who used home-based versus community-based services differed in demographic and health characteristics. Community-based service users were older on average, more likely to be white, diagnosed with ADRD earlier, and reside in a less disadvantaged county than home-based service users. Furthermore, the use of home- or community-based services was quite different across states with similar levels of total HCBS use. For example, while the proportion of dual-eligible beneficiaries with ADRD who received HCBS was similar in Montana (34%) and Arizona (34%), enrollees in Montana were much more likely to receive care in a home setting than in Arizona (28% vs. 9%).

We used the newly available Medicaid claims Transformed Medicaid Statistical Information System (T-MSIS) Analytic Files (TAF) for this analysis. National beneficiary-level Medicaid claims have been available for research purposes since 1995,[39] yet concerns about errors, missingness, and inconsistent coding across states have limited the use of these data. T-MSIS was created in part to improve Medicaid claims data collection and quality, and TAF are available for all states and the District of Columbia since 2016.[40] Some data quality issues persist, however, particularly for earlier years of TAF.[41] Data quality varies across topics, variables, and states. Therefore, researchers must carefully explore the quality of data relevant to their research question of interest. We excluded 21 states from our analysis because of data quality concerns. While this limited our ability to describe the use of LTSS among dual-eligible beneficiaries with ADRD in those 21 states, the exclusion reduced misclassification bias and strengthened our confidence in the data for the remaining 30 states.

Our study has additional limitations. First, our study design was descriptive, and we did not examine factors contributing to the substantial state-level variation in LTSS use. Second, our sample did not include dual-eligible beneficiaries with Medicare Advantage plans because Chronic Conditions Data Warehouse's ADRD indicator was not available for people with Medicare Advantage. Third, we measured LTSS use at the state level, but access to LTSS/HCBS is often dictated by waiver eligibility and service availability at the county level. Fourth, we could not confirm the length of nursing facility stay for a small number of beneficiaries. Additionally, we included beneficiaries who died in 2016. As a result, we may have underestimated LTSS use in our sample. Fifth, we used the Chronic Conditions Data Warehouse variables to identify people with Alzheimer's disease or another related dementia. People with mild cognitive impairment are less likely to have a dementia diagnosis code in Medicare claims. Thus, our approach may have excluded people with less advanced disease.[42] Finally, our analyses could not account for ADRD acuity because claims do not provide such information.

Despite the benefits of LTSS for people with ADRD and their families, the percentage of dual-eligible

beneficiaries with ADRD using any form of LTSS and different types of LTSS varied significantly across states. A deeper understanding of state LTSS policies and other factors that contribute to wide state variation in LTSS use will be necessary to improve access to LTSS across states.

AUTHOR CONTRIBUTIONS

Study concept and design: all authors. *Acquisition of data*: Hyunjee Kim, Angela Senders, Erika Simeon, Cesar Juarez. *Analysis and interpretation of data*: all authors. *Preparation of manuscript*: all authors.

CONFLICT OF INTEREST

The authors have no conflicts.

SPONSOR'S ROLE

This study was funded by grant 1RF1AG069782-01 from National Institute on Aging. The funder had no role in the design and conduct of the study; collection, management, analysis, and interpretation of the data; preparation, review, or approval of the manuscript; or the decision to submit the manuscript for publication.

FINANCIAL DISCLOSURE

This study was funded by grant 1RF1AG069782-01 from National Institute on Aging.

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SUPPORTING INFORMATION

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

Data S1: The Supplemental Material includes Tables S1–S5, Figures S1–S3, and details on study sample selection.

How to cite this article: Kim H, Senders A, Simeon E, et al. Use of long-term services and supports among dual-eligible beneficiaries with Alzheimer's disease and related dementias. *J Am Geriatr Soc*. 2022;1-11. doi:10.1111/jgs.18115