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Alzheimer's disease and related dementias among Medicare beneficiaries aged ≥ 65 years in rural America, by Census region and select demographic characteristics: 2020

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Abstract

Purpose: Alzheimer's disease and related dementias (ADRD) are a significant public health concern characterized by memory decline that, over time, leads to loss of independence. This study reports ADRD diagnosis rates among Medicare beneficiaries aged ≥ 65 years in rural America.

Methods: We conducted a descriptive analysis of Medicare Fee-for-Service (FFS) and Medicare Advantage enrollees using administrative Medicare data from 2020. Combining data from Medicare FFS and Medicare Advantage produces a more complete and representative sample of older adults than previous studies that used FFS data alone. Nonmetropolitan counties were used to define rural. Rural ADRD diagnosis rates, stratified by age, sex, race/ethnicity, and Census region, were adjusted using the 2000 Census population standard.

Findings: The study population consisted of 54 million Medicare data Fee-for-Service (FFS) and Medicare Advantage enrollees aged ≥ 65 ; 5.3 million beneficiaries were diagnosed with ADRD, and 16.2% ($n = 861,337$) of beneficiaries diagnosed with ADRD resided in rural America. The age-adjusted ADRD diagnosis rate was slightly lower in rural America (9.6 per 100 beneficiaries) than in the United States (10.0 per 100 beneficiaries). The South Census region had the highest rural ADRD diagnosis rates.

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CONFLICT OF INTEREST STATEMENT

The findings and conclusions of this report are those of the author(s) and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

Conclusion: These findings underscore the need for targeted interventions and support mechanisms to address the growing burden of ADRD in rural communities.

Keywords

aging; Alzheimer's disease; dementia; disparity; Medicare; rural

INTRODUCTION

Alzheimer's disease and related dementias (ADRD) are a significant public health concern characterized by memory decline that, over time, leads to loss of independence. Alzheimer's disease is the most common form of dementia and is the fifth leading cause of death for people aged ≥ 65 years in the United States. Current estimates suggest that nearly 5.8 million adults aged ≥ 65 years had ADRD in 2020, which will triple to 14 million and be seven times higher for minority populations by 2060.¹

However, there are currently no estimates of the prevalence of ADRD diagnosis in rural America, an important population to study because ADRD is an age-related disease, and 17.5% of the rural population was aged ≥ 65 years in 2016.² Rural populations are also getting older due to increased numbers of people aging in place, retirement migration to rural areas, and the outmigration of younger individuals from rural to urban areas.³ Furthermore, ADRD mortality rates are significantly higher in rural America (65.1 per 100,000 persons) compared to the United States (53.6 per 100,000 persons).⁴ On average, people live 4–8 years after their ADRD diagnosis, with the level of care they need increasing as their disease progresses.⁵

There is a shortage of health care workers to care for older adults, especially those in rural areas because the rural health care infrastructure cannot keep up with the current and increasing demand for taking care of older rural adults, including those with ADRD.⁶ The health care workforce in rural areas is even more inadequate to meet the needs of the rural populations, leading to limited access to primary prevention, early detection, and long-term care for older rural residents.⁷

In this study, we calculated the observed prevalence of ADRD diagnosis among all Medicare Fee-for-Service (FFS) and Medicare Advantage enrollees aged ≥ 65 years in rural areas in 2020 by select demographic characteristics. The results from this report will be critical to planning for the impact of dementia on rural communities as the rapidly growing population of people with dementia coincides with a rapidly declining availability of formal and unpaid caregivers.

METHODS

Medicare is a federal health insurance program operated by the Centers for Medicare and Medicaid Services (CMS) for individuals aged ≥ 65 years, younger people with disabilities, or those with certain conditions such as end-stage renal disease. The health services utilization data collected by CMS are derived from reimbursement information or bill payments. Claims data are clinically valid and include various key attributes related to

care, such as admission and discharge dates, diagnoses and procedure codes, source of care, date of death, and demographic data (e.g., age, race and ethnicity, place of residence).

The study population consisted of Medicare beneficiaries aged ≥ 65 years who resided in the 50 states and the District of Columbia and had at least 1 month of continuous enrollment in a traditional Medicare FFS or participated in a Medicare Advantage program in 2020. We obtained data about the Medicare beneficiaries from the Chronic Conditions Data Warehouse (CCW) database,⁸ which contains enrollment, demographic, diagnostic, and claims data for each Medicare beneficiary. Beneficiaries with ADRD were identified if they had ≥ 1 inpatient, skilled nursing facility, home health agency, hospital outpatient, or carrier (physician) claim with an International Classification of Diseases 10th Revision Clinical Modification (ICD-10-CM) diagnosis code for ADRD in a 3-year reference period (2018–2020). However, we modified the set of ICD-10-CM codes selected (Table 1) to reduce the false-positive cases identified using the CCW algorithm for ADRD,⁸ including noncognitive codes and codes for cognitive impairment with reversible etiologies.⁹ We also included the dementias that are related to Alzheimer's disease because of potential diagnostic misclassification and complications in reporting mixed-state dementias.^{10–12} Furthermore, the impact of clinical symptoms on people with dementia, their families, and communities is similar despite potential etiologic differences associated with dementia subtypes.^{13,14}

Population subgroups were defined by age (65–74, 75–84, 85+), sex (men, women), race/ethnicity (Hispanic, Non-Hispanic [NH] White, NH Black, NH Asian and Pacific Islander, NH American Indian and Alaska Native, NH Two or More Races [Census], Other or Unknown [CMS]), and Census region (Northeast, South, Midwest, West). In this study, we view race as a marker rather than a cause of inequality, as race is a social construct and not a biological factor driving disparities. We classified the rural status of each Medicare beneficiary based on their residential county using the 2013 National Center for Health Statistics Urban-Rural Classification Scheme for Counties; counties were identified and matched to the classification scheme using FIPS codes.¹⁵ Rural counties were derived by combining codes 5 and 6 (micropolitan and noncore), and urban counties were derived by combining codes 1–4 (large central metropolitan, large fringe metropolitan, medium metropolitan, and small metropolitan).

We report rural ADRD burden in two ways. The difference is the choice of denominator. We calculated the proportion of rural ADRD diagnoses using the number of rural diagnoses in the numerator and the number of diagnoses in the United States in the denominator. The second way we estimated the rural ADRD burden was by using the Medicare beneficiaries as the denominator. We also calculated age-adjusted ADRD prevalence by rural-urban status. For each population group, we calculated the prevalence of ADRD diagnosis among Medicare beneficiaries aged ≥ 65 years by dividing the number of beneficiaries with an ADRD diagnosis by the total number of beneficiaries. The prevalence of ADRD diagnosis was adjusted using the 2000 US Population Standard population to ensure comparability across datasets, periods, and geographies. Maps were classified using equal intervals using ArcMap 8.2 (ESRI, Redlands, CA). The prevalence of ADRD diagnosis in rural areas is reported along with the national ADRD prevalence for context, not comparison. A two-

sample proportion z-test showed significant differences in rural prevalence rates compared to the United States, with all differences being statistically significant due to a large sample size ($n = 54.9$ million beneficiaries). This study was reviewed by the Centers for Disease Control (CDC) Human Subjects Research Office and deemed not research. It was conducted consistent with applicable federal law and CDC policy (see 45 C.F.R. part 46, 21 C.F.R. part 56; 42 U.S.C. §241(d); 5 U.S.C. §552a; 44 U.S.C. §3501 et seq.).

RESULTS

In 2020, there were 54.9 million Medicare beneficiaries aged ≥ 65 years. Nearly 5.3 million were diagnosed with ADRD, and 16.2% of them ($n = 861,377$) resided in rural America (Table 2). The age-adjusted rate of ADRD diagnosis among rural beneficiaries aged ≥ 65 years (9.6 per 100 beneficiaries) was lower than the ADRD rate of the entire United States (10.0 per 100 beneficiaries). Only rural NH-Black beneficiaries (14.1 per 100) and rural beneficiaries in the South Census region (11.4 per 100) had higher ADRD diagnosis rates than their counterparts in the entire United States. Rural ADRD diagnosis rates among beneficiaries were higher in the states located in the South Census region and lower in the West Census region (Figure 1).

Rural ADRD diagnosis rates were higher for women (10.4 per 100) than men (8.5 per 100). Rural ADRD diagnosis rates were highest among individuals aged over 85 (30.5 per 100), followed by those aged 75 to 84 (11.9 per 100) and 65 to 74 (3.2 per 100). Rural ADRD diagnosis rates were highest among Non-Hispanic (NH) Black beneficiaries (14.1 per 100), followed by Hispanic beneficiaries (11.1 per 100), NH American Indian and Alaska Native beneficiaries (10.4 per 100), NH White beneficiaries (9.3 per 100), and NH Asian and Pacific Islander beneficiaries (8.2 per 100). The South Census region had the highest rural ADRD diagnosis rates (11.4 per 100), followed by the Northeast (9.6 per 100), Midwest (8.6 per 100), and the West (7.9 per 100). Except for non-Hispanic Black beneficiaries and beneficiaries living in the South Census Region, rural ADRD diagnosis rates were lower than the rates in the United States. Figure 2 focuses on rural age-adjusted ADRD diagnosis rates, stratified by race, sex, and Census region. The highest ADRD diagnosis rate for rural women was among Hispanic beneficiaries in the South Census region (14.8 per 100 beneficiaries), and the lowest was among NH-American Indians and Alaska Natives in the Northeast Census region (7.3 per 100).

DISCUSSION

In 2020, about 5.3 million Medicare beneficiaries aged ≥ 65 years had an Alzheimer's disease and related dementias (ADRD) diagnosis, and 861,337 resided in rural America. Rural America had a slightly lower age-adjusted ADRD diagnosis rate (9.6 per 100 beneficiaries) than the United States (10.0 per 100 beneficiaries). Differences in ADRD rates were larger when stratified by race/ethnicity, rural-urban status, and region. The highest rural ADRD diagnosis rates were in the South Census region (Figure 1), which coincides with areas of the United States called the diabetes belt^{16,17} and the stroke belt.^{18,19} Both diabetes and stroke are known risk factors for ADRD, and addressing the fundamental causes of these chronic conditions among rural populations may also have the collateral effect of decreasing

rates of ADRD. It is unclear whether geographic differences in age-adjusted prevalence of ADRD diagnosis are related to true ADRD risk or access to an ADRD diagnosis.

Because rural populations are getting older due to increased numbers of people aging in place, retirement migration to rural areas, and the outmigration of younger individuals from rural to urban areas, we expected rural areas to have higher ADRD diagnosis rates compared to the United States, but we found that rural rates were lower. Alternatively, rural people with advanced dementia may move to urban areas for dementia care, which would reduce the number of people with an ADRD diagnosis. This unexpected finding highlights the need for further research to discern whether differences in diagnosis reflect ADRD risk or barriers that limit access to health care providers in general and specifically to providers trained to recognize, diagnose, and manage dementia among rural populations.

The methods used in this paper can help create a more accurate and representative snapshot of ADRD prevalence by combining administrative data from the two programs that beneficiaries can enroll in, namely, the traditional Medicare Fee-for-Service and Medicare Advantage plans. This was not possible until 2018 when data about beneficiaries enrolled in Medicare Advantage programs first became available. Estimates of ADRD published before 2018 relied solely on beneficiaries enrolled in FFS programs^{11,20,21} excluded a significant portion of the Medicare-eligible population; approximately 42% of the Medicare beneficiaries in 2020 enrolled in Medicare Advantage plans.²² Excluding such a large number of beneficiaries may produce a biased estimate because it is unclear whether the assumption that ADRD risk among Medicare Advantage enrollees is similar to the risk among FFS enrollees.

The methods used in this analysis can be used to address some elements of the Healthy Brain Initiative's (HBI) State and Local Road Map for Public Health, 2023–2027.²³ The Medicare administrative claims data for this analysis can be used to supplement existing health systems data, identify resource needs, and develop programs and policies for populations affected by dementia (Element M-2). The method can also be replicated to help identify rural areas needing quality support services for caregivers (Element P-3) and assess shortages of dementia care workers in rural areas (Element M-5). These results highlight the need to continue providing evidence-informed training and informational resources for primary health care providers to facilitate culturally sensitive conversations about brain health with patients and caregivers across the life course (Element W-1). The results can also support efforts detailed in the Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act of 2018, the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act of 2022, and the National Plan to Address Alzheimer's Disease: 2023 Update.²⁴

The ADRD statistics reported in this study are generally lower than those reported in previous studies.^{11,20,21} There are several reasons for this difference. First, rather than creating ADRD estimates using solely FFS enrollees, the statistics reported here are based on the observed number of diagnoses among Medicare FFS and Medicare Advantage enrollees, which accounts for nearly all Medicare beneficiaries aged ≥ 65 years. Without the Medicare Advantage data, ADRD prevalence estimates from other studies may have

been biased because the prevalence among FFS beneficiaries may differ from that among Medicare Advantage enrollees, which may not have been representative of all beneficiaries. Second, our definition of ADRD differed from that of previous studies; our study used ICD-10-CM codes, which replaced the ICD-9-CM codes starting in 2015. Third, our definition of ADRD used a narrower, more conservative set of ICD-10-CM codes because a recent study showed that the Chronic Condition Warehouse (CCW) algorithm included noncognitive codes and codes for cognitive impairment with reversible etiologies resulting in many false-positive ADRD diagnoses.⁹

This study has several weaknesses. First, the reported number of ADRD diagnoses is likely an underestimate of ADRD prevalence. An ADRD diagnosis is only included in Medicare claims data if a medical provider examines and diagnoses the patient, so people who do not visit a provider or cannot do so are not counted. Likewise, the provider must submit the correct diagnosis codes for billing, but there may be some variability in their ability to identify symptoms of dementia and diagnose it. Second, the results are limited to data from 2020 (with a 3-year lookback), which prevented us from analyzing the impact of seasonal migration by older adults to warmer climates. Another weakness of this study is that it does not address the impact of the COVID-19 pandemic, which occurred during the study period. Particularly relevant potential impacts of the pandemic are higher COVID-19 mortality rates among ADRD patients compared to other Medicare beneficiaries²⁵ and that rural rates of COVID-19 incidence were higher in rural America for most of 2020.²⁶

Despite these limitations, our study provides a more accurate estimate of the public health burden of ADRD in rural America because it uses a much more complete sample of older adults than previous studies. The findings highlight the importance of expanding programs and public health interventions that mitigate the risk of dementia, enable early diagnosis, ensure prompt and convenient care for people with dementia, and offer caregiver support in rural areas. Making decision-makers more aware of the importance of considering the needs of rural America may assist them when preparing for the impact of dementia on communities, health care and public health systems, and economies. This approach could lead to more effective and targeted interventions, providing reassurance and confidence in our ability to address the impact of dementia in rural areas.

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DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the Centers for Medicare and Medicaid Services. Restrictions apply to the availability of these data, which were used under license for this study. Data are available from the authors with the permission of the Centers for Medicare and Medicaid Services.

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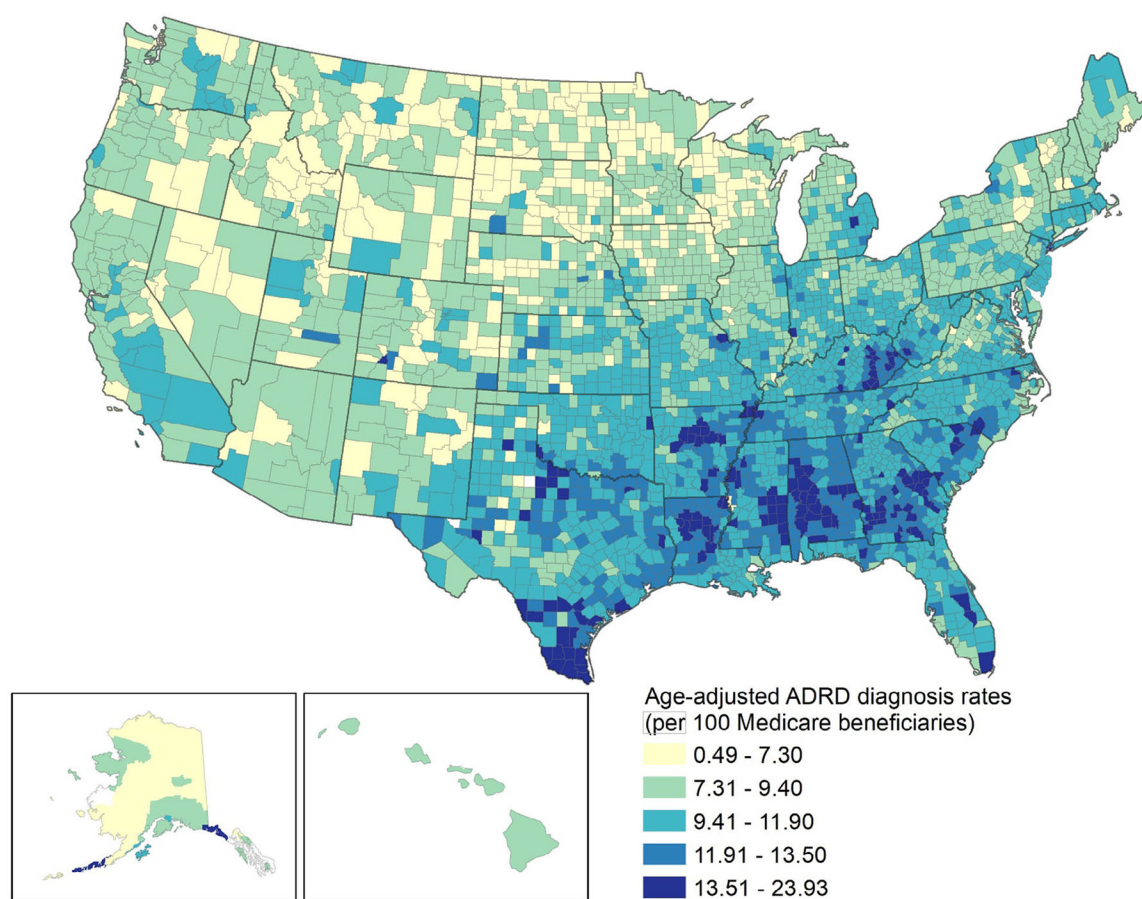
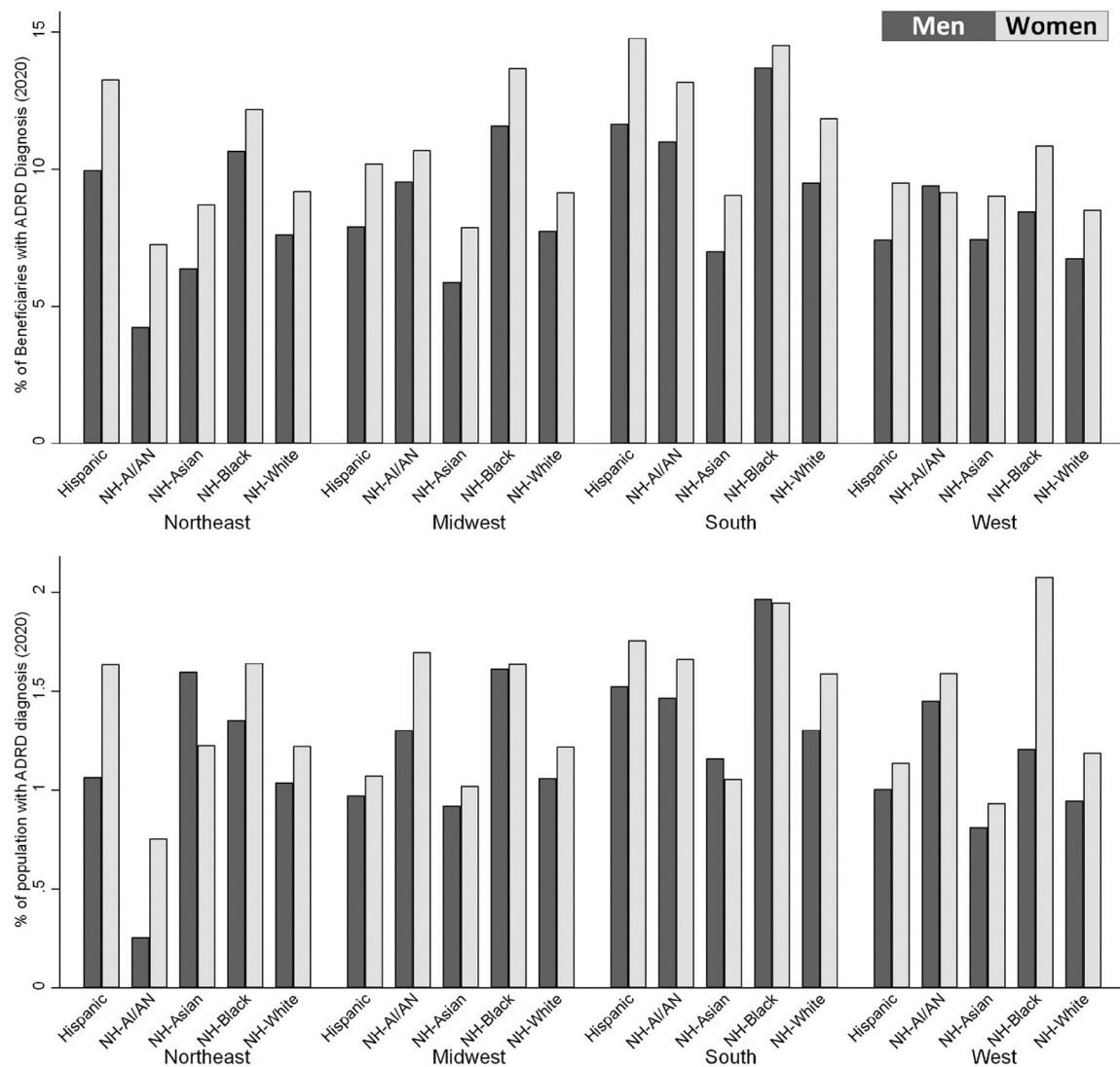


FIGURE 1.

Age-adjusted Alzheimer's disease and related dementias (ADRD) diagnosis rates among Medicare beneficiaries aged ≥ 65 years, by county (2020). *Note:* Age-adjusted to 2000 Census population standard.

**FIGURE 2.**

Percent of Medicare beneficiaries¹ aged ≥ 65 years residing in rural² America with an ADRD diagnosis, by race/ethnicity, Census region, and sex, 2020. NH, Non-Hispanic; Asian, Asian and Pacific Islander; AI/AN, American Indian and Alaska Native. ¹Rates reflect observed ADRD diagnoses among Medicare beneficiaries enrolled in Fee-for-Service or Medicare Advantage plans. Rates are presented per 100 people of all ages, interpretable as a population percentage, and are age-adjusted to the 2000 US population standard.

²National Center for Health Statistics 2013 Urban-Rural Classification Scheme for Counties codes 5 and 6 (micropolitan and noncore) serve as a proxy for rural.

TABLE 1

International Classification of Disease—10th Revision—Clinical Modification (ICD-10-CM) Codes used to identify Alzheimer's disease and related dementias (ADRD).^a

ICD-10-CM	Descriptor
F01.50	Vascular dementia, unspecified severity, without behavioral disturbance, psychotic disturbance, mood disturbance, and anxiety
F01.51	Vascular dementia, unspecified severity, with behavioral disturbance
F02.80	Dementia in other diseases classified elsewhere, unspecified severity, without behavioral disturbance, psychotic disturbance, mood disturbance, and anxiety
F02.81	Dementia in other diseases classified elsewhere, unspecified severity, with behavioral disturbance
F03.90	Unspecified dementia, unspecified severity, without behavioral disturbance, psychotic disturbance, mood disturbance, and anxiety
F03.91	Unspecified dementia, unspecified severity, with behavioral disturbance
G13.8	Systemic atrophy primarily affects central nervous system in other diseases classified elsewhere.
G30.0	Alzheimer's disease with early onset
G30.1	Alzheimer's disease with late onset
G30.8	Other Alzheimer's disease
G30.9	Alzheimer's disease, unspecified
G31.1	Senile degeneration of the brain, not elsewhere classified
G31.01	Pick's disease
G31.09	Other frontotemporal neurocognitive disorder
G94	Other disorders of the brain in diseases classified elsewhere

^a Algorithms for defining Alzheimer's disease and related dementias developed and published by Centers for Medicare and Medicaid Services (CMS) research data via the Chronic Conditions Warehouse

TABLE 2

Prevalence of Alzheimer's disease and related dementias (ADRD) diagnosis among Medicare beneficiaries aged ≥ 65 years^a in rural America,^b by select characteristics: United States, 2020.

Group	Medicare beneficiaries			Medicare beneficiaries with an ADRD diagnosis ^a			Age-adjusted rate ^c of ADRD diagnoses per 100 beneficiaries	
	US	Rural		US	Rural		US	Rural
	N	N	% of Medicare beneficiaries	N	N	% of ADRD diagnoses		
Total	54,876,348	9,405,455	17.1	5,316,124	861,377	16.2	10.0	9.6
Sex								
Male	24,506,832	4,335,489	17.7	2,004,394	328,293	16.4	9.1	8.5
Female	30,369,514	5,069,966	16.7	3,311,730	533,084	16.1	10.7	10.4
Age group								
< 65 years	-	-		-	-		-	-
65–74 years	31,409,394	5,392,642	17.2	1,049,961	174,006	16.6	3.3	3.2
75–84 years	16,511,161	2,877,192	17.4	2,020,472	341,409	16.9	12.2	11.9
>85 years	6,955,791	1,135,621	16.3	2,245,691	345,962	15.4	32.3	30.5
Race/ethnicity								
Hispanic	4,513,534	282,168	6.3	503,166	26,874	5.3	12.4	11.1
NH-White	42,366,928	8,382,401	19.8	3,941,287	750,803	19.0	9.4	9.3
NH-Black	5,168,079	541,046	10.5	619,418	66,579	10.7	13.7	14.1
NH-Asian and Pacific Islander	2,125,844	57,319	2.7	190,113	4257	2.2	9.7	8.2
NH-American Indian/Alaska Native	201,017	98,953	49.2	20,192	9464	46.9	10.9	10.4
Other	500,942	43,568	8.7	41,948	3400	8.1	8.4	7.8
Census region								
Midwest	11,850,330	3,109,079	26.2	1,103,567	265,851	24.1	9.5	8.6
Northeast	9,882,839	987,703	10.0	998,843	82,455	8.3	10.0	9.6
South	20,716,204	3,903,192	18.8	2,143,569	414,626	19.3	11.0	11.4
West	12,426,975	1,405,481	11.3	1,070,145	98,445	9.2	9.1	7.9

^a Observed count of ADRD among Medicare beneficiaries enrolled in either Fee-for-Service or Medicare Advantage plans in 2020.

^b Rural was defined using the National Center for Health Statistics 2013 Urban-Rural Classification Scheme for Counties codes 5 and 6 (micropolitan and noncore)

^c Rates are age-adjusted to the 2000 US population standard; rates are statistically different due to large sample sizes.