DIAGNOSTIC ASSESSMENT & PROGNOSIS

Diagnosed prevalence of Alzheimer's disease and related dementias in Medicare Advantage plans

Eric Jutkowitz[1,2] | Julie P.W. Bynum[3] | Susan L. Mitchell[4,5] | Noelle M. Cocoros[6] | Oren Shapira[6] | Kevin Haynes[7] | Vinit P. Nair[8] | Cheryl N. McMahill-Walraven[9] | Richard Platt[6] | Ellen P. McCarthy[4,5]

[1] Department of Health Services, Policy & Practice, Brown University School of Public Health, Providence, Rhode Island 02912, USA

[2] Providence Veterans Affairs (VA) Medical Center, Center of Innovation in Long Term Services and Supports, Providence, Rhode Island 02908, USA

[3] Department of Internal Medicine, University of Michigan, Ann Arbor, Michigan, USA

[4] Hebrew Senior Life, Hinda and Arthur Marcus Institute for Aging Research, Boston, Massachusetts, USA

[5] Department of Medicine, Beth Israel Deaconess Medical Center, Harvard Medical School, Boston, Massachusetts, USA

[6] Department of Population Medicine, Harvard Pilgrim Health Care Institute, Boston, Massachusetts, USA

[7] Department of Scientific Affairs, Health Core, Inc., Wilmington, Delaware, USA

[8] Humana Healthcare Research, Humana Inc., Louisville, Kentucky, USA

[9] Healthagen LLC, part of the CVS Health family of companies, Blue Bell, Pennsylvania, USA

Correspondence
Eric Jutkowitz, Brown University School of Public Health, Box G-S121-6, 121 S. Main Street, 6th Floor, Providence, RI 02912, USA.
Email: Eric_Jutkowitz@Brown.edu

Abstract

Introduction: One-third of Medicare beneficiaries are enrolled in Medicare Advantage (MA). Yet, little is known about MA beneficiaries diagnosed with Alzheimer's disease (AD) and AD-related dementias (AD/ADRD).

Methods: We calculated the prevalence of AD/ADRD diagnoses in 2014 and 2016 in three MA plans. We determined the demographic characteristics of beneficiaries diagnosed with AD/ADRD, and whether they disenrolled from the MA plan for any reason within 364 days from the index date.

Results: In 2014 and 2016, the overall prevalence of AD/ADRD diagnoses was 5.6% and 6.5%, respectively. In 2016, AD/ADRD beneficiaries were on average 82.4 (SD = 7.4) years of age, 61.8% female, and had multiple comorbidities. By 364 days post-index date, 32% of beneficiaries with AD/ADRD had disenrolled from their plan. The demographic characteristics of 2014 beneficiaries with diagnosed AD/ADRD were similar to their 2016 counterparts.

Discussion: The prevalence of AD/ADRD diagnosis in MA is lower than rates reported in Medicare fee-for-service.

KEYWORDS
Medicare, Medicare Advantage, dementia, Alzheimer's disease, mild cognitive impairment

1 | INTRODUCTION

More than 5 million Americans currently live with Alzheimer's disease (AD) and AD-related dementias (AD/ADRD), and this number is expected to increase substantially in the coming decades.[1] These high-need, high-cost patients are vulnerable to receiving low quality, poorly coordinated care that leads to adverse health outcomes, poor quality of life, and misuse of resources.[2-4] Maximizing the value of care provided to this growing population is a critical health policy challenge.[5]

Much of our understanding about the characteristics of people with AD/ADRD diagnoses who are receiving health care is based on data from Medicare fee-for-service and nationally representative surveys. These studies estimate the prevalence of diagnosed AD/ADRD in the United States to be 7% to 14%.[6-11] Yet, one-third of Medicare beneficiaries are enrolled in MA plans.[12] Little is known about AD/ADRD for the population enrolled in MA.

As MA grows in popularity, it is vital to understand the characteristics of the plans' most vulnerable beneficiaries including people living with AD/ADRD. MA plans have unique features that may impact the type of beneficiaries who enroll and disenroll from plans and provider documentation of AD/ADRD. Compared to traditional Medicare, MA plans are paid on a risk-adjusted capitated basis (Centers for Medicare & Medicaid Service's Hierarchical Condition Category [CMS-HCC] risk adjustment model), which incentivizes plans to minimize unnecessary utilization by providing care management or other innovative services or care options. Using data from three large MA insurers,[13] we evaluated the diagnosed prevalence of AD/ADRD in 2014 (ICD-9-CM era) and 2016 (ICD-10-CM era).

2 | STUDY DATA AND METHODS

We calculated the annual prevalence of AD/ADRD diagnoses in 2014 (ICD-9-CM) and 2016 (ICD-10-CM) in three health insurance MA plan providers (Data Partners) that participate in the National Institutes of Health (NIH) Health Care Systems Research Collaboratory Distributed Research Network (DRN). These Data Partners comprise approximately 30% of the MA market. The Data Partners transform their MA enrollment and claims to the DRN Common Data Model, which includes demographic information (age and sex), dates of coverage, type of coverage (medical, pharmacy), diagnosis codes, and procedure codes.

We identified all beneficiaries enrolled in an MA plan in 2014 and 2016 who were ≥65 years of age and continuously enrolled in plans with medical and drug coverage for at least 183 days, which allowed for coverage gaps of up to 45 days. Among eligible beneficiaries, we identified individuals with AD/ADRD using ICD-9 (2014) and ICD-10 (2016) diagnosis codes included in the Medicare Chronic Conditions Warehouse algorithms for AD/ADRD (Table S1).[14] The first date of an AD/ADRD diagnosis code in any care setting defined cohort entry and served as the index date.

For beneficiaries with AD/ADRD diagnoses, we determined age and sex on the index date of cohort entry. To assess comorbidity, we used a

---

RESEARCH IN CONTEXT

1. Systematic review: Medicare Advantage (MA) is becoming increasingly popular; however, little is known about MA beneficiaries diagnosed with Alzheimer's disease (AD) and AD-related dementias (AD/ADRD).
2. Interpretation: MA beneficiaries with AD/ADRD are predominately female and have multimorbidity. The age and sex stratified prevalence of AD/ADRD diagnoses in MA is lower than rates reported in traditional Medicare and nationally representative surveys.
3. Future directions: Future research should investigate the reasons MA beneficiaries with AD/ADRD disenroll from MA plans. Research is also needed to investigate the effects of two key recent MA policy changes on AD/ADRD diagnosis rates. Specifically, MA plans are now permitted to offer long-term care services and supports as a benefit, and starting in 2020 AD/ADRD is included in the Centers for Medicare & Medicaid Service's Hierarchical Condition Category (CMS-HCC) risk adjustment model that is used to determine payments to MA plans.

---

window of 183 days before and up to 183 days after cohort entry. We calculated the combined comorbidity score as described by Gagne.[15] We determined cumulative all-cause disenrollment from the enrolled MA plan up to 364 days from the index date. Reasons for disenrollment are unknown in DRN data and may include death, enrollment in a different MA plan, enrollment in Medicare fee-for-service, or discontinuation of a plan. Finally, we calculated rates of having a prevalent AD/ADRD diagnosis in 2014 and 2016 overall and stratified by age and sex. We calculated prevalence rates by determining the number of beneficiaries with an AD/ADRD diagnosis divided by the total number of MA beneficiaries enrolled in the plans without an AD/ADRD diagnosis.

3 | RESULTS

In 2016, among 3,178,703 total eligible members, 207,539 (6.5%) beneficiaries had an AD/ADRD diagnosis. On average, AD/ADRD beneficiaries were 82.4 (SD = 7.4) years of age, 61.8% female, and had a mean combined comorbidity score of 5.8 (SD = 3.5) (Table 1). Overall, 11.4% of beneficiaries with prevalent AD/ADRD disenrolled from their plan within 90 days of their index date. By 364 days post-index date, 32% of beneficiaries with prevalent AD/ADRD had disenrolled from their plan. In 2014, among 2,884,334 total eligible members, 163,499 (5.6%) beneficiaries had an AD/ADRD diagnosis code. The demographic characteristics of 2014 beneficiaries with AD/ADRD were similar to their 2016 counterparts.

As expected, the prevalence of AD/ADRD diagnoses increased with age and was generally greater for female compared to male patients (Table 2). For example, in 2016 for both 65- to 69-year-old women

TABLE 1 Characteristics of Medicare Advantage beneficiaries with Alzheimer's disease and related dementias in 2014 and 2016.[a]

	2014	2016
Eligible MA population	2,884,334	3,178,703
	2014 (ICD-9-CM)	2016 (ICD-10-CM)
	Alzheimer's Disease and Related Dementias	Alzheimer's Disease and Related Dementias
	n = 164,195	n = 207,539
Diagnosed prevalence, (Raw)	5.6%	6.5%
Mean age, (SD)	82.6 (7.2)	82.4 (7.4)
Female sex, n (%)	102,741 (62.6)	128,309 (61.8)
Mean Gagne Comorbidity Score, (SD)	4.4 (3.3)	5.8 (3.5)
Congestive heart failure, n (%)	52,403 (31.9)	72,255 (34.4)
Depression, n (%)	48,459 (29.5)	73,236 (35.3)
Diabetes, n (%)	59,212 (36.1)	77,943 (37.6)
Hypertension, n (%)	138,752 (84.5)	180,738 (87.1)
Renal failure, n (%)	48,507 (29.5)	68,579 (33.0)
Cumulative all-cause disenrollment[b], n (%)		
90 days	18,839 (11.5)	23,825 (11.5)
180 days	33,854 (20.6)	39,398 (18.9)
270 days	44,217 (26.9)	52,357 (25.2)
364 days	56,768 (34.6)	66,882 (32.2)

[a]Comorbidity history was assessed in the 183 days before through 183 days after the index code/cohort entry date; one diagnosis code of interest was required to be counted as having the comorbidity.

[b]Includes disenrollment due to death, enrollment in a new MA plan, enrollment in Medicare fee-for-service, or discontinuation of a plan.

and men, the prevalence of AD/ADRD was ~1.4%. However, among patients 85+, the prevalence of AD/ADRD for women and men was 23.6% and 18.8%, respectively. The 2014 overall and age- and sex-stratified diagnosed prevalence rates of AD/ADRD were similar to 2016.

4 | DISCUSSION

Our study is the first to report the prevalence of having an AD/ADRD diagnosis among MA beneficiaries immediately prior to and following the transition from ICD-9 (2014) to ICD-10 (2016). Congruent with studies using Medicare fee-for-service data and nationally representative surveys, the prevalence of diagnosed patients with AD/ADRD increased with age and those with AD/ADRD were more likely to be female, and have high rates of congestive heart failure and multimorbidity.[7,16] However, age- and sex-stratified prevalence of AD/ADRD among MA beneficiaries was lower than rates reported in Medicare fee-for-service data and nationally representa-

tive surveys.[7,8,11] For example, in 2016, the Medicare CMS Chronic Condition Data Warehouse, which uses a 3-year look-over period, reported that the overall diagnosed prevalence of AD/ADRD in Medicare fee-for-service was 9.9% for men and 13.6% for women.[11] In contrast, in our study, which uses a 1-year look-over period, the prevalence of diagnosed AD/ADRD in MA among men and women was 5.5% and 7.3%, respectively. We used a 1-year look-over period, which may be more useful/pragmatic for identifying people living with AD/ADRD in health care systems due to the high mortality rate of the disease.

We observed a modest increase in the prevalence of AD/ADRD diagnoses in 2016 compared to 2014. However, comparisons across years should be made with caution. First, differences in rates may be due to differences in ICD-9 (2014) and ICD-10 (2016). Second, from 2014 to 2016 providers may have become more adapt at diagnosing patients with AD/ADRD and documenting such diagnoses. Third, from year to year, health insurance companies offer different benefits (eg, free gym membership) in their MA plans, or change their marketing, so the markets in which they operate may have a different prevalence of AD/ADRD and the characteristics (eg, level of impairment) of dementia patients they enroll may not be comparable.

The all-cause disenrollment rates observed in our study are higher than ~17% disenrollment rates (excluding mortality) observed in studies of other high-need, high-cost MA beneficiaries.[17,18] This is an important methodologic consideration for AD/ADRD research among MA beneficiaries. Multiple factors may contribute to disenrollment and we cannot disentangle those who died. Previous research suggests that aspects of the MA plan's feature may be particularly challenging for beneficiaries with AD/ADRD and their caregivers (eg, need for prior authorizations or narrow provider networks).[19] Providers may also end their contracts with MA plans, resulting in higher patient costs or requiring patients to find a different provider or a plan that includes the patient's preferred provider.

Several important policy changes in MA have occurred, which may impact AD/ADRD diagnostic rates in the coming years. Starting in 2019, MA plans were permitted to offer long-term care services and supports. This may positively affect MA beneficiaries with cognitive impairment, increase MA plan retention, and subsequently increase the prevalence of AD/ADRD diagnoses in MA. Prior to 2020, the CMS-HCC risk adjustment model, an algorithm that is used to determine payments to MA, did not include AD/ADRD. With the inclusion of AD/ADRD in the CMS-HCC risk adjustment model it will be important to evaluate trends in the use of AD/ADRD diagnostic codes among MA providers.

Our study has important limitations. First, we measure only AD/ADRD that has been submitted on a medical claim by a clinician, not true disease prevalence. Second, we obtained data from three MA plans and these plans may not be representative of the broader MA market. Third, we observed only all-cause disenrollment and cannot distinguish reasons for disenrollment including death, enrollment in a different MA plan, or enrollment in Medicare fee-for-service. We also do not know whether these disenrollment rates are comparable to those of the general population of MA beneficiaries enrolled in these plans.

TABLE 2   Prevalence of Alzheimer's disease and related dementias in Medicare Advantage in 2014 and 2016

	Female		Male	
	Total number of members	Number and prevalence (%) of members with Alzheimer's disease and related dementias	Total number of members	Number and prevalence (%) of members with Alzheimer's disease and related dementias
	2014			
Overall	1,599,163	102,741 (6.4)	1,285,171	61,454 (4.8)
65–69 years	369,120	3,758 (1.0)	312,890	2,958 (1.0)
70–74 years	457,447	11,753 (2.6)	394,244	9,323 (2.3)
75–79 years	336,246	18,803 (5.6)	282,021	13,558 (4.8)
80–84 years	233,263	24,813 (10.7)	176,379	15,551 (8.8)
85+ years	203,087	43,614 (21.5)	119,637	20,064 (16.8)
	2016			
Overall	1,749,224	128,309 (7.3)	1,429,479	79,230 (5.5)
65–69 years	396,917	5,688 (1.4)	345,342	4,593 (1.3)
70–74 years	487,432	14,950 (3.1)	423,147	11,779 (2.7)
75–79 years	385,689	24,134 (6.3)	326,753	17,707 (5.4)
80–84 years	254,264	30,303 (11.9)	197,460	19,420 (9.8)
85+ years	224,922	53,234 (23.6)	136,750	25,731 (18.8)

In conclusion, the overall (5.6% in 2014 and 6.5% in 2016) and age- and sex-stratified prevalence of AD/ADRD diagnosis are lower than prevalence rates reported in Medicare fee-for-service and nationally representative surveys. MA beneficiaries with AD/ADRD are predominately female, have multimorbidity, and at 1 year 30% are no longer enrolled in their MA plan.

REFERENCES
1. Alzheimer's Association. 2018 Alzheimer's disease facts and figures. *Alzheimers Dement*. 2018;14(3):367-429.
2. Jutkowitz E, Kane RL, Gaugler JE, MacLehose RF, Dowd B, Kuntz KM. Societal and family lifetime cost of dementia: implications for policy. *J Am Geriatr Soc*. 2017;65(10):2169-2175.
3. Mitchell SL, Teno JM, Kiely DK, et al. The clinical course of advanced dementia. *N Engl J Med*. 2009;361(16):1529-1538.
4. Mitchell SL, Mor V, Gozalo PL, Servadio JL, Teno JM. Tube feeding in US nursing home residents with advanced dementia, 2000-2014. *JAMA*. 2016;316(7):769-770.
5. Blumenthal D, Abrams MK. Tailoring complex care management for high-need, high-cost patients. *JAMA*. 2016;316(16):1657-1658.
6. Taylor DH Jr, Fillenbaum GG, Ezell ME. The accuracy of medicare claims data in identifying Alzheimer's disease. *J Clin Epidemiol*. 2002;55(9):929-937.
7. Goodman RA, Lochner KA, Thambisetty M, Wingo TS, Posner SF, Ling SM. Prevalence of dementia subtypes in United States Medicare fee-for-service beneficiaries, 2011-2013. *Alzheimers Dement*. 2017;13(1):28-37.
8. Plassman BL, Langa KM, Fisher GG, et al. Prevalence of dementia in the United States: the aging, demographics, and memory study. *Neuroepidemiology*. 2007;29(1-2):125-132.
9. Plassman BL, Langa KM, Fisher GG, et al. Prevalence of cognitive impairment without dementia in the United States. *Ann Intern Med*. 2008;148(6):427-434.
10. Chen Y, Tysinger B, Crimmins E, Zissimopoulos JM. Analysis of dementia in the US population using Medicare claims: insights from linked survey and administrative claims data. *Alzheimers Dement (N Y)*. 2019;5:197-207.

11. Centers for Medicare & Medicaid Services. Chronic Conditions. 2019 [cited 2019 Nov 01]. Available at: https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/Chronic-Conditions/CC_Main.html

12. Livingston S. Medicare Advantage industry sees slower growth for 2019. 2019 Jan 16 [cited 2019 Oct 30]. Available at: https://www.modernhealthcare.com/article/20190116/NEWS/190119927/medicare-advantage-industry-sees-slower-growth-for-2019

13. Brown JS, Holmes JH, Shah K, Hall K, Lazarus R, Platt R. Distributed health data networks: a practical and preferred approach to multi-institutional evaluations of comparative effectiveness, safety, and quality of care. *Med Care.* 2010;48(6 Suppl):S45-S51.

14. Centers for Medicare & Medicaid Services (CMS). Chronic Conditions Data Warehouse. 2019 [cited 2019 Oct 28]. Available at: https://www2.ccwdata.org/web/guest/condition-categories

15. Gagne JJ, Glynn RJ, Avorn J, Levin R, Schneeweiss S. A combined comorbidity score predicted mortality in elderly patients better than existing scores. *J Clin Epidemiol.* 2011;64(7):749-759.

16. Langa KM, Larson EB, Crimmins EM, et al. A comparison of the prevalence of dementia in the United States in 2000 and 2012. *JAMA Intern Med.* 2017;177(1):51-58.

17. Meyers DJ, Belanger E, Joyce N, McHugh J, Rahman M, Mor V. Analysis of drivers of disenrollment and plan switching among Medicare Advantage beneficiaries. *JAMA Intern Med.* 2019;179(4):524-532.

18. Rahman M, Keohane L, Trivedi AN, Mor V. High-cost patients had substantial rates of leaving Medicare Advantage and joining traditional Medicare. *Health Aff (Millwood).* 2015;34(10):1675-1681

19. DuGoff E, Chao S. What's driving high disenrollment in Medicare Advantage?. *Inquiry.* 2019;56:46958019841506.

SUPPORTING INFORMATION

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