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BRIEF REPORT

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Healthcare contact days among older adults living with dementia

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Abstract

Background: For older adults with dementia and their care partners, accessing health care outside the home involves substantial time, direct and indirect costs, and other burdens. While prior studies have estimated days spent by these individuals in or out of hospitals and nursing homes, ambulatory care burdens are likely substantial yet poorly understand. Therefore, we characterized "health care contact days"—days spent receiving ambulatory or institutional care—in this population.

Methods: We used 2019 Medicare Current Beneficiary Survey data linked to claims for community-dwelling, ≥65-year-old adults with dementia in Traditional Medicare. We measured contact days including ambulatory days (with an office visit, test, imaging, procedure, or treatment) and institutional days (spent in an emergency department, hospital, skilled nursing facility, or hospice facility). We described variation and patterns in contact days. Using multivariable Poisson regression, we identified sociodemographic and clinical factors associated with contact days.

Results: In weighted analyses, 887 older adults with dementia (weighted: 2.9 million) had mean (SD) 31.1 (33.7) total contact days/year, of which 21.7 (20.6) were ambulatory. Ten percent had ≥68 contact days in the year. One-third (34%) of ambulatory contact days involved multiple services. In multivariable models, receipt of more ambulatory contact days was associated with younger age (65–74 reference vs. −32.3% [95% CI: −42.2%, −20.7%] for 85+), higher income (>200% Federal Poverty Level [FPL] reference versus −16.6% [95% CI: −26.7%, −5.0%] for ≤200% FPL), and lack of functional impairment (reference versus −14.6% [95% CI: −23.7%, −4.4%]). Each additional chronic condition was associated with 8.2% (95% CI: 6.7%, 9.8%) more ambulatory contact days.

Conclusions: Older adults with dementia spent 31 days a year accessing care which was mostly ambulatory. These days varied widely by both clinical and sociodemographic factors. These results highlight the need to reduce patient burden through strategies such as reducing unneeded care, coordinating care, and shifting care to home settings through telemedicine and home care.

KEYWORDS
ambulatory care, dementia, healthcare contact days

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INTRODUCTION

Older adults with dementia face health challenges leading to substantial healthcare utilization, including preventable and nonpreventable hospitalizations[1] and invasive end-of-life interventions.[2] This care can be necessary and it can also present burdens. While prior research has focused on burdens of institutional care, ambulatory care can require considerable time, effort, transportation costs, and lost wages for older adults and their care partners.[3] These challenges may be particularly acute for the estimated 40% of older adults with dementia who are homebound,[4–6] and the estimated 75% whose care partners accompany them to visits.[7] Yet, there is little understood about the use and potential burdens of ambulatory care.

"Healthcare contact days," defined as days spent on institutional care as well as ambulatory care (e.g., office visits, tests, and procedures), can capture the full spectrum of healthcare and its potential burdens in older adults with dementia. This concept builds on existing measures of "home days," or days spent outside of institutional settings such as hospitals or skilled nursing facilties.[8–10] Home days have strong face validity and are associated with patient-centered outcomes[8,11] but are limited by low variability in institutional care use, even among patients with serious illnesses including dementia.[11,12] Despite the enormous potential of healthcare contact days to build on home days,[12,13] this measure has been studied in limited contexts[14,15] and never assessed in older adults with dementia.

Understanding how older adults with dementia use healthcare contact days can inform efforts to optimize health care delivery through strategies such as reducing unnecessary care,[16] improving care coordination,[17] and bringing care to the home through telemedicine[18] and home-based care.[19] Therefore, we defined and operationalized a claims-based measure of contact days to characterize use of, and variation and patterns in, these days among community-dwelling older adults with dementia. We then investigated the association between ambulatory contact days and patient characteristics such as age, function, and multimorbidity.

Key points

- On average, community-dwelling older adults with dementia spend a full month per year receiving care outside the home.
- Younger age, higher income, and lack of functional impairment were associated with having more ambulatory contact days.
- With each additional chronic condition, older adults' contact days increased by 8%.

Why does this paper matter?

This study applies a novel measure of care use and finds substantial time burden of institutional and ambulatory health care for older adults with dementia. Policymakers and clinical leaders should consider strategies to improve efficiency of care such as reducing low-value care, improving coordination and use of co-located services, and bringing care to the home via telemedicine and home health.

METHODS

Data

We used 2019 data from the Medicare Current Beneficiary Survey (MCBS), a rotating panel survey that covers an annual statistical sample of Medicare beneficiaries in the continental US, linked to Fee-For-Service (FFS) Medicare claims data (physician, outpatient, inpatient, skilled nursing facility [SNF], and hospice files).

Cohort definition

We included adults who were ≥65 years old on January 1, 2019, were continuously enrolled in Fee-For-Service Medicare for the full year or until death, and who completed the fall MCBS survey component. We restricted the analysis to community-dwelling adults for whom contact days may be particularly burdensome without facility support. We excluded beneficiaries with end-stage renal disease because Medicare's prospective payment system for these patients obscures dates of service.

We defined adults with dementia as those who met the Chronic Conditions Warehouse's (CCW) claims-based definition for Alzheimer's disease or non-Alzheimer's dementia (Supplemental Methods) OR self-reported that a doctor had told them they had Alzheimer's disease or any dementia. We used the most expansive definition possible with our data due to known underdiagnosis of these conditions.[20]

Study measures

Outcomes

For each older adult, we used relevant Medicare claims files and dates of service to identify institutional contact days (i.e., days spent in the inpatient setting, an emergency department, a skilled nursing facility [SNF], or an

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inpatient hospice facility) and ambulatory contact days (days with one or more primary care or specialty care visit, test, imaging study, procedure, or treatment, grouped based on 2021 Restructured Betos Classification System [RBCS] Taxonomy) (see Table S1 for details). We excluded virtual and home-based care to focus on care outside of the home. In defining contact days, we applied the following hierarchy: inpatient > ED > SNF > inpatient hospice > ambulatory care. For example, if a patient had any ambulatory service on the same day as an ED visit, we did not count the ambulatory service. For patients who died in 2019, we pro-rated contact days by days alive.

Patient characteristics

Sociodemographic variables were age, sex, rural-urban residence (administrative), self-reported race and ethnicity, and total income. Clinical and functional variables included number of chronic conditions (out of 35) from the CCW diagnosed before 2019, self-reported health, and functional impairment (defined as reporting needing help with ≥1 out of 6 activities of daily living). We captured self-reported care-seeking behaviors: worry more about health than the average person their age, go to the doctor as soon as they felt bad, and do anything to avoid going to the doctor. We also examined reported trouble getting places like the doctor's office,[4] report of a regular helper for activities of daily living, and report of regular accompaniment to the doctor's office.

Statistical analysis

We performed descriptive statistics of institutional, ambulatory, and total contact days and their individual components. To explore care patterns relevant to care coordination, we also described percentage of ambulatory days that had two or more services (≥2 visits or ≥2 services in distinct ambulatory service categories, for example, a visit and an imaging study or an imaging study and a procedure). We measured contact days in relevant subgroups (e.g., those reporting trouble getting places like the doctor's office).

To identify factors associated with receipt of ambulatory contact days, we built univariable and multivariable Poisson regression models with an offset for days alive, HRR random effects, and adjustment for overdispersion. The Poisson models assessed factors that could plausibly contribute to differences in health care utilization, including the aforementioned sociodemographic factors, clinical and functional factors, and care-seeking behaviors. We used indicator variables to handle small amounts of covariate missingness.

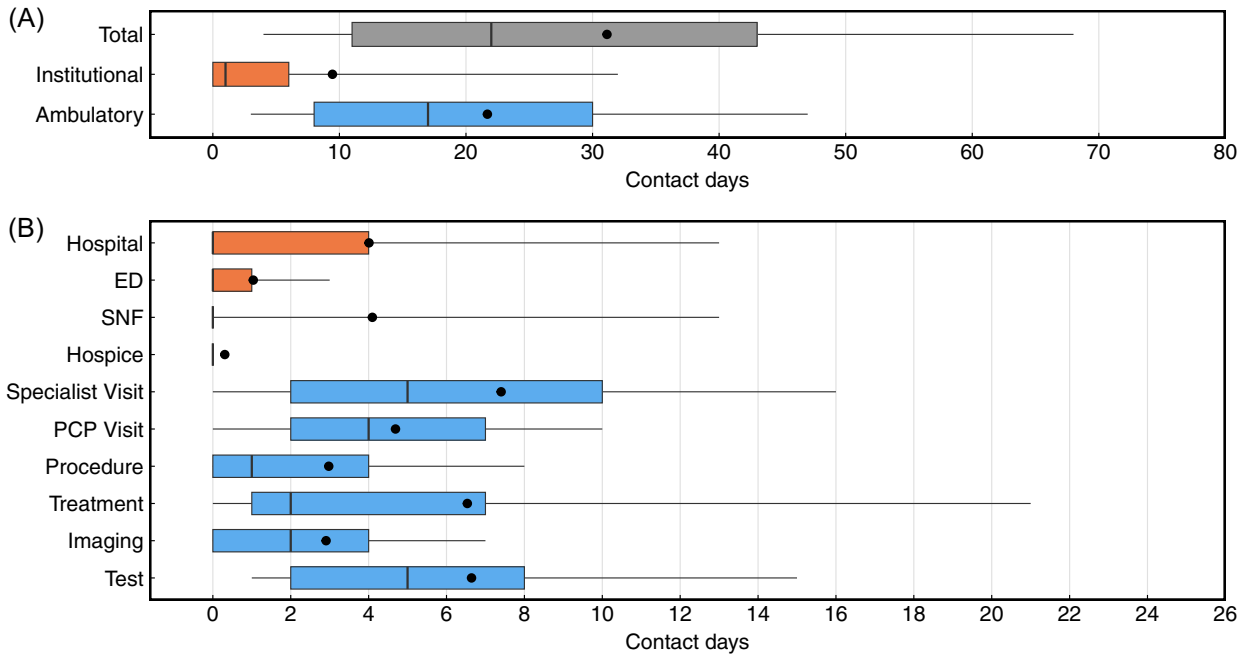

FIGURE 1 Distribution of contact days and their components. Box and whisker plot of (A) composite outcomes and (B) individual services. Dots indicate mean contact days for each outcome, horizontal line indicates median, box covers 25th and 75th percentiles, and whiskers cover the 10th and 90th percentiles. ED, emergency department; SNF, skilled nursing facility; PCP, primary care provider.

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To assess the sensitivity of our results to defining the cohort by claims and self-report, we repeated measurement of contact days among older adults with dementia defined by the claims definition alone.

We used MCBS cross-sectional survey weights in all analyses and applied balanced repeated replication weights for variance estimation. We used SASv9.4 (SAS Institute) and Rv4.2.3. The study followed Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) reporting guidelines. The Mass General Brigham institutional review board waived review.

RESULTS

Full cohort analysis

We identified 887 older adults with dementia, representing 2.9 million Medicare beneficiaries. Overall, they had mean (SD) age 80.7 (9.3) years; 59.7% were female and 83.7% were white, and 47.5% had household incomes ≤200% of the federal poverty level (FPL). More than half (54.5%) reported functional impairment, and 40.3% reported trouble getting places like the doctor's office. Most (60.2%) had someone who regularly helped with activities of daily living and 63.6% were regularly accompanied to the doctor's office (Table S2).

In 2019, older adults with dementia had mean (SD) 31.1 (33.7) total contact days, most of which (21.7 (20.6)) were ambulatory (Figure 1). The main source of ambulatory days was office visits (11.9 (12.5), including 7.4 (10.6) specialty care visit days and 4.7 (5.1) primary care visit days) followed by test days (6.6 (8.2)). They had 6.5 (13.5) treatment days, 2.9 (3.2) imaging days, and 3.0 (5.6) procedure days. These counts varied widely across individuals. One-third (33.7%) of ambulatory contact days involved multiple services.

Subgroup analyses

Patients who reported trouble getting places like the doctor's office had more mean institutional contact days than the full cohort and similar ambulatory contact days (14.5 (30.4) institutional, 21.9 (21.8) ambulatory) (Figure 2), with a similar proportion of ambulatory days involving multiple services (33.5%). Similarly, patients who had a regular helper with activities of daily living had 11.9 (29.4) institutional contact days and 21.7 (21.9) ambulatory contact days; 33.2% of their ambulatory days involved multiple services.

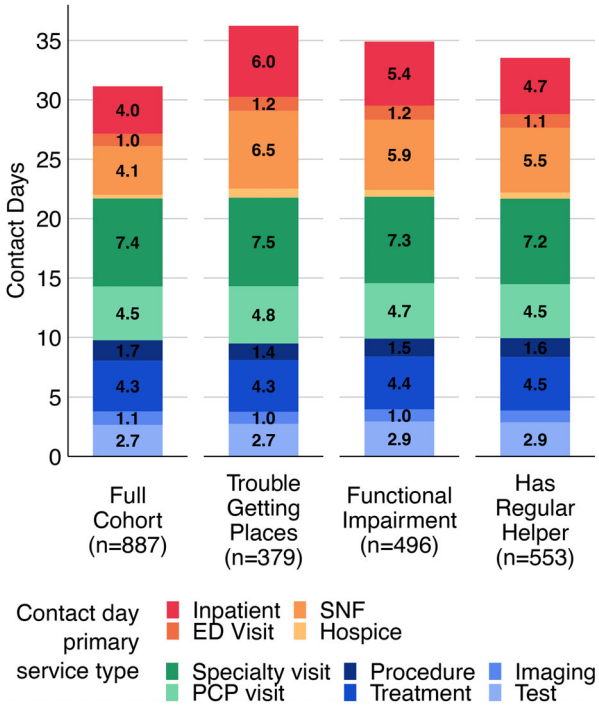

FIGURE 2 Components of healthcare contact days among those with reported trouble getting places, functional impairment, and report of a regular helper. For these stacked bar graphs, if a patient had multiple healthcare contact types on the same day, the day was assigned to a category based on the following hierarchy: Inpatient (highest priority) > ED visit > SNF > Hospice > Specialty visit > PCP visit > Procedure > Treatment > Imaging > Test. As such, bar heights represent total mean contact days for a given population. Components with ≥1 day are labeled with counts of days to aid comparison between groups. Each n refers to the unweighted sample size.

Unadjusted and adjusted Poisson model results

In unadjusted Poisson models of potential drivers of ambulatory contact days, lower income and number of chronic conditions was associated with more ambulatory contact days (Table S3). After adjustment, more ambulatory contact days were associated with younger age (65–74 reference vs. −32.3 [95% CI: −42.2%, −20.7%] for 85+), higher income (>200% Federal Poverty Level [FPL] reference vs. −16.6% [95% CI: −26.7%, −5.0%] for ≤200% FPL), and lack of functional impairment (reference vs. −14.6% [95% CI: −23.7%, −4.4%]. Figure 3). Each additional chronic condition was associated with 8.2% (95% CI: 6.7%, 9.8%) more contact days.

Sensitivity analysis

A total of 818 (92%) of adults in the cohort met the CCW claims definition for dementia (Table S4). We estimated

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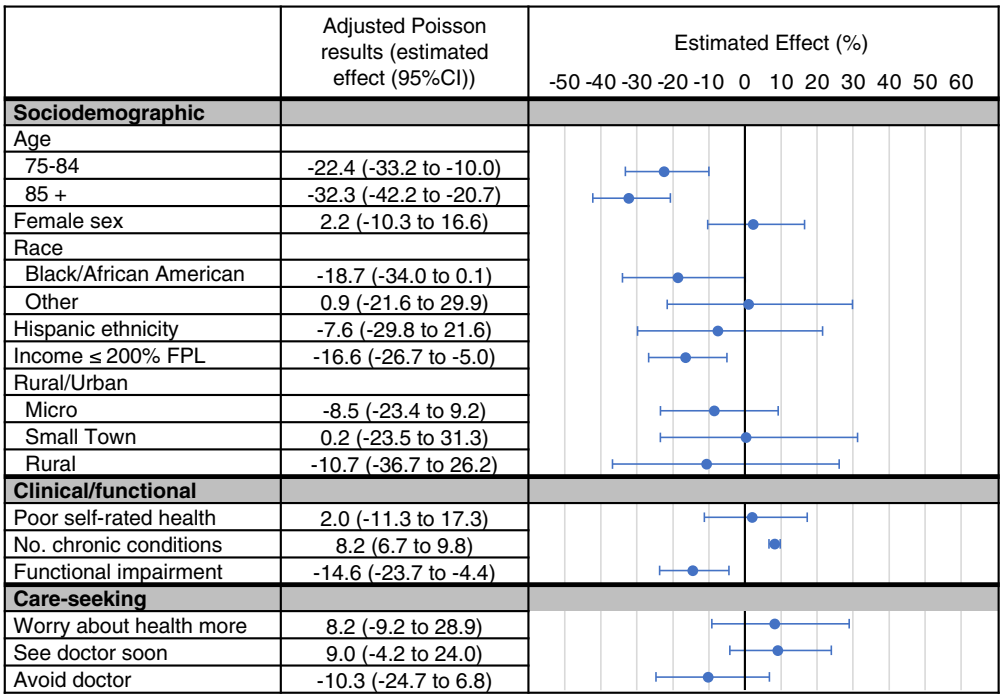

FIGURE 3 Association of sociodemographic, clinical and functional characteristics, and care-seeking behaviors with ambulatory contact days. Results of adjusted Poisson model. Reference categories for categorical variables were as follows: Age: 65–74 years, Race: White, Ethnicity: non-Hispanic, Income: >200% FPL, Rural/Urban: Metro area; Self-rated health: not poor; Functional impairment: not impaired; Worry about health: does not worry more about health; See doctor soon: does not see doctor as soon as there is a problem; Avoid doctor: does not avoid doctor. Number of chronic conditions was included as a continuous variable. FPL Federal Poverty Limit, ADL Activities of Daily Living.

mean (SD) 32.2 (33.1) contact days for this group, of which 22.3 (21.1) were ambulatory (Table S5).

DISCUSSION

In this nationally representative Fee-For-Service Medicare analysis, older adults with dementia spent 31 days receiving health care outside of the home, 22 of which were spent on ambulatory care, with wide variation across adults. Many of these adults relied on care partners and reported trouble getting places like the doctor's office, suggesting that these contact days can confer substantial burdens on patients and their care partners.

We found that older adults with dementia who also reported trouble getting to places like the doctor's office, had functional impairment, or relied on regular helpers had more institutional contact days but a similar number of ambulatory contact days to the full cohort, consistent with the possibility that barriers to accessing ambulatory care may contribute to higher acuity care needs.[21] We would expect a complicated relationship between functional status and healthcare contact days, as underlying health conditions that require more care may also pose a barrier to accessing that care in traditional office settings, as suggested by high rates of unmet physical and mental health needs among homebound older adults.[22,23]

We also found that younger age, higher income, lack of functional impairment, and more chronic conditions were significantly associated with more ambulatory contact days. The inverse association with age may partly reflect a survivor effect (in kind, chronic conditions are less predictive of mortality for older adults than younger adults[24,25]), decreased perceived benefits of preventive health care with increasing age,[26] challenges accessing care, and increased use of home-based care.[27] For those with lower income, the cost of transportation itself may serve as a barrier to ambulatory care. Similarly, for those with functional impairment, accessing health care outside the home may be prohibitively challenging. Multimorbidity was strongly associated with more contact days, reflecting both the complexity of managing multiple chronic conditions as well as increasing medical sub-specialization contributing to fragmented care for these patients with multiple discordant conditions.[28]

Our results highlight the need to decrease the time burden of accessing care while ensuring patients with dementia receive needed care, for example, through

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reducing low-value care, coordinating care, and shifting care provision to the home.[27] While we do not adjudicate the value of care received in a given day in this study, prior research demonstrates that older adults with dementia frequently receive services that offer little to no benefit and potential for harm.[2,16] In addition, we found that only one third of ambulatory contact days had multiple types of service, such as two office visits or a visit and a test, suggesting potentially missed opportunities to co-locate services or coordinate scheduling.[29] Expanding the home health workforce to keep pace with expanding need would also serve this population.[19] Finally, shortly after this study period, the COVID-19 pandemic motivated telemedicine use to increase dramatically and persistently.[18] While there are potential trade-offs to telemedicine, particularly for those with lower digital literacy, it may improve care access and satisfaction.[30]

Limitations

Underdiagnosis of dementia[20] may limit generalizability of our study beyond FFS Medicare beneficiaries with access to care. To mitigate this, we defined our cohort using both self-report and claims data; notably, our results were similar when using the claims definition alone. Null results may reflect insufficient power. Finally, it will be important to understand how older adults with dementia have experienced contact days in more recent years.

Conclusion

Healthcare contact days represent an intuitive, person-centered, claims-based measure of the potential burdens of institutional and ambulatory health care on patients' lives. We find that older adults with dementia have frequent contact days that are largely ambulatory and vary widely by individual. Policymakers and clinical leaders can consider contact days when designing strategies to reduce healthcare burdens.

AUTHOR CONTRIBUTIONS

Study concept and design: Emma D. Chant and Ishani Ganguli. Data analysis and interpretation: All authors. Initial preparation of manuscript: Emma D. Chant and Ishani Ganguli. All authors involved in critical revision of manuscript for important intellectual content.

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CONFLICT OF INTEREST STATEMENT

Ishani Ganguli received consultant fees from F-Prime unrelated to this work.

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The funder had no role in the design, methods, data collections, analysis, and preparation of the paper.

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SUPPORTING INFORMATION

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

Supplementary Text. Supplementary methods.
Supplementary Table S1. Contact days measures.
Supplementary Table S2. Characteristics of study population.
Supplementary Table S3. Patient sociodemographic, clinical, and care-seeking behavior characteristics associated with ambulatory healthcare contact days, unadjusted analyses.
Supplementary Table S4. Distribution of beneficiaries identified by claims and survey responses.
Supplementary Table S5. Sensitivity analysis using claims definition of dementia alone to define cohort.

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