Distribution of Adult Day Health Centers and Persons Living with Dementia Among Hospital Service Areas in Rhode Island

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ABSTRACT

INTRODUCTION: Adult day health centers (ADHCs) provide an important service to community-dwelling adults with functional dependency. This includes persons living with dementia (PLWD) and their caregivers, but we don't know how well ADHC capacity matches the distribution of PLWD.

METHODS: For this cross-sectional study, we identified community-dwelling PLWD using Medicare claims, and ADHC capacity using licensure data. We aggregated both features by Hospital Service Area. By linear regression, we determined the association between ADHC capacity and community-dwelling PLWD.

RESULTS: We identified 3836 community-dwelling Medicare beneficiaries living with dementia. We included 28 ADHCs, with licensed capacity for 2127 clients. The linear regression coefficient (95% Confidence Interval) for number of community-dwelling beneficiaries with dementia was 1.07 (0.6–1.53).

DISCUSSION: Rhode Island's ADHC capacity distribution roughly approximates the distribution of persons with dementia. Plans for the future of dementia care in Rhode Island should consider these findings.

KEYWORDS: adult day health centers; dementia; distribution

INTRODUCTION

More than 11 million Americans provide unpaid care to a person living with dementia, and most report that this causes them a high level of stress.[1] These caregivers, usually a family member of the person with dementia, often balance competing demands of paid employment with their unpaid caregiving.[2] Several high-quality studies have demonstrated that distress in dementia caregivers is associated with higher rates of institutionalization, behavioral symptoms, and abuse of the person with dementia.[3] Dementia caregivers can also suffer negative health consequences from this distress. Most dementia caregivers report feeling concerned about maintaining their own health after becoming a caregiver, and many report delaying or not doing things for their own health.[1,4] Adult day health centers are one type of program to help alleviate these caregiver challenges by providing respite where a substitute care provider provides temporary caregiving to a person with dementia.

Adult day health centers provide for social, safety, nutritional, and potentially other needs of community-dwelling adults with functional dependencies. Persons with dementia benefit from this service as well as their caregivers.[5] Adult day health centers provide service during the day, allowing their clients to continue to dwell in the community while receiving the service. The person living with dementia can spend time in a safe and supportive environment while the caregiver spends time away from caregiving. Adult day health center participation may improve quality of life in both physical and emotional domains for persons living with dementia.[6] Caregivers of adult day health center users with dementia report lower frequency of behavior problems and less time spent on behavior problems than caregivers of non-users with dementia.[7] Adult day health center participation also helps dementia caregivers complete important self-care tasks such as attending their own medical appointments.[8] Availability of adult day health centers benefits both members of the patient-caregiver dyad, and may also help health systems by delaying or substituting for more expensive forms of care such as long-term nursing home care.[5]

Adult day health centers predominantly rely on public sources of participant fees such as state Medicaid programs for financial viability. Private sources of participant fees including individual payments and health plan payments also contribute substantially.[9] Most states, including Rhode Island, require adult day health centers to undergo certification and licensing.[9–11] Rhode Island regulations require centers offering special care service for clients with Alzheimer's dementia or other dementias to offer standard disclosures.[11] These disclosures include the program philosophy, information about the processes of care, program costs, and the process of termination. However, the regulation does not clearly define a level of dementia severity at which the rule applies, leaving interpretation to the centers and to the state department of health.

Access to adult day health centers by Rhode Islanders living with dementia and their caregivers relies in part on the geographic distribution of licensed adult day center capacity within the state. Per state regulations, adult day health

centers should encourage families of participants to arrange their own transportation whenever possible.[11] Therefore, the geographic distribution of licensed adult day center capacity would ideally mirror the distribution of potential service users in the state. The Hospital Service Areas construct divides the United States into a set of clearly defined geographic areas which approximate local markets for healthcare. After reviewing abstracts and articles retrieved via relevant search terms on PubMed, we did not identify any studies comparing the geographic distribution of persons living with dementia to the geographic distribution of adult day health centers in Rhode Island. This study will compare the distribution of community- dwelling persons living with dementia by Hospital Service Area within the State of Rhode Island to the distribution of licensed adult day health center capacity.

METHODS

We completed a cross-sectional ecological study using Medicare claims and publicly available data on licensed adult day center capacity from the Rhode Island Department of Health. The use of the secondary Centers for Medicare and Medicaid Services data was reviewed and approved by the Brown University Institutional Review Board, and the Rhode Island Department of Health data was public use and exempt from IRB review. The sample of Medicare beneficiaries included 100% of beneficiaries, ages 65 and older, enrolled in Medicare parts A and B (traditional fee-for-service Medicare) or Medicare part C (Medicare Advantage) who were alive and residing in Rhode Island on January 1, 2020. We used our Residential History File[12] methodology to exclude beneficiaries who were not community dwelling as of January 1, 2020. We used the Medicare Master Beneficiary Summary File to determine the zip code of residence as of January 1, 2020. We then grouped beneficiaries by Hospital Service Area using the methodology published by The Dartmouth Atlas of Healthcare. Hospital service areas represent local health care markets.[13,14] Using the Master Beneficiary Summary File, we considered any individual who satisfied the Chronic Conditions Warehouse criteria for either Alzheimer's disease[15] or non-Alzheimer's Dementia[16] to be a person living with dementia. The updated 30-chronic condition segment algorithms use a 2-year reference period for Medicare claims identifying dementia. We used the qualifying claim period ending January 1, 2020, to reduce the impact of underutilization of routine healthcare during the Severe Acute Respiratory Syndrome Coronavirus 2019 pandemic on our results. We also used the Master Beneficiary Summary File to determine the age, race, sex, and Medicaid eligibility of beneficiaries within each Hospital Service Area.

We obtained the address and licensed capacity of each operating adult day health center in Rhode Island as of October 2022. We excluded 6 licensed centers whose original date of licensure occurred after January 1, 2020 with the aim of temporally aligning this measurement with our sample of beneficiaries with dementia. Because only 2 of the licensed centers reported special licensure for Alzheimer's Dementia and other dementias, we included all licensed centers. We used the zip codes and licensed capacities of the adult day health centers to determine the licensed capacity within each Hospital Service Area.[14]

For the primary analysis, we fit a linear regression model of licensed adult day health center capacity as a function of the number of community-dwelling Medicare beneficiaries living with dementia in each Hospital Service Area. We used R version 4.4.1 (The R Foundation for Statistical Computing, Vienna, Austria) for the regression analysis. To test the sensitivity of our result to inclusion of adult day health centers licensed after January 1st 2021, we repeated the primary analysis including all of the operating adult day health centers that were licensed as of October 2022. As an exploratory analysis, we visually assessed the distribution of adult day health centers within and between Health Service Areas by geocoding the location of each center and projecting its location on a map of the Health Service Area boundaries using ArcGIS online (Esri, Redlands, CA).

RESULTS

We identified 3836 community-dwelling Medicare beneficiaries living with dementia. In the overall sample, 2,926 (76.3%) were in the age range of 75 to 94 years old (**Table 1**). We included 28 adult day health centers, which were distributed between 5 Hospital Service Areas. (**Table 2**). The included centers had licensed capacity for a total of 2127 clients. The adult day health centers that we excluded due to initial licensure after January 1, 2020 had a total capacity of 580 and 2 of these centers were located in Hospital Service

Table 1. Sample Characteristics

Characteristic	No. (%) (n = 3836)
Age	
65–74	590 (15.4)
75–84	1435 (37.4)
85–94	1491 (38.9)
95+	320 (8.3)
Race	
White	3431 (89.4)
Black	86 (2.2)
Hispanic	210 (5.5)
Other	109 (2.8)
Male	1476 (38.5)
Eligible for Medicaid	479 (12.49)
Enrolled in Medicare A and B	3416 (89.1)

Areas without any other licensed adult day centers. Only 2 centers, both of which were licensed before 2020, were specifically licensed for Alzheimer's Dementia or Other Dementia Special Care Services. One was located in the Providence Hospital Service Area and licensed for 65 participants, and one was located in the Warwick Hospital Service Area and licensed for 80 participants.

Table 2. Comparison of beneficiaries with dementia and licensed adult day center capacity by Health Service Area.

Health Service Area	Beneficiaries No. (%) (n = 3836)	Licensed Adult Day Center Capacity No. (%) (n = 2127)
Fall River[a]	130 (3.4)	0
Newport	316 (8.2)	0
Pawtucket	194 (5.1)	110
Providence[a]	1569 (40.9)	1665
Wakefield	326 (8.5)	0
Warwick	814 (21.2)	140
Westerlya	177 (4.6)	46
Woonsocket[a]	310 (8.1)	166

[a] These Health Service Areas overlap state boundaries, and only the portion in Rhode Island is included.

In our linear regression model for the licensed adult day center capacity per Health Service Area, the coefficient (95% Confidence Interval) for the number of community dwelling beneficiaries with dementia was 1.07 (0.61–1.53). In our sensitivity analysis, the coefficient (95% Confidence Interval) for the number of community dwelling beneficiaries with dementia was 1.20 (0.70–1.71). Our map demonstrates that most of the licensed adult day health centers are centrally located in the state (**Figure 1**), and located near population centers (**Figure 2**).

DISCUSSION

We found that Hospital Service Areas had an average increase in licensed adult day center capacity of about 1 for each additional community-dwelling person with dementia. This implies that at the geographic level of Hospital Service Areas, the distribution of adult day health centers is well-matched to the distribution of community-dwelling persons

Figure 1. Distribution of adult day health centers in Rhode island, by Hospital Service Area. Black squares and circles represent adult day health centers licensed before January, 2020; with and without special Alzheimer's Dementia or Other Dementia Special Care Services, respectively. Black diamonds represent adult day health centers with initial licensure between January, 2020 and October, 2022. Color-shaded areas represent Health Services Areas, as defined by the Dartmouth Atlas of Healthcare.

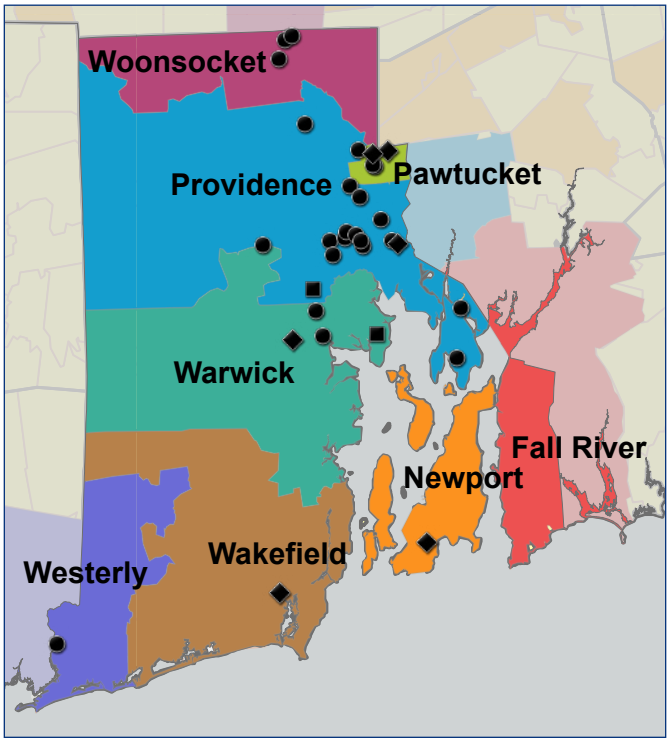
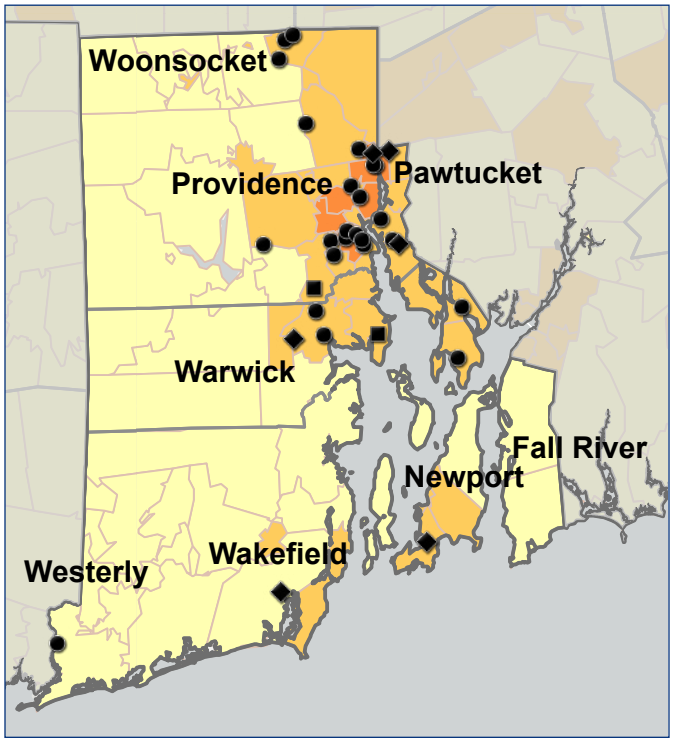


Figure 2. Distribution of adult day health centers in Rhode island, by Hospital Service Area. Black squares and circles represent adult day health centers licensed before January, 2020; with and without special Alzheimer's Dementia or Other Dementia Special Care Services, respectively. Black diamonds represent adult day health centers with initial licensure between January, 2020 and October, 2022. Background map shading represents population density based on the 2020 United States census.



living with dementia. Our sensitivity analysis examined this distribution including the adult day health centers licensed between January 2020 and October 2022, assuming that the distribution of persons living with dementia did not change. Here, we found that licensed capacity expanded in hospital service areas which did not previously contain adult day health centers. The overall distribution of centers remained well matched to the distribution of community-dwelling persons living with dementia at the Hospital Service Area geographic level. By plotting the locations of the licensed adult day health centers on a map, we found that most of their capacity was clustered in central and more populous areas of the state. This implies that persons in rural areas of the state would generally need to travel further than persons in the state's urban centers. Public and facility-provided transportation could overcome this geographic barrier. Our study did not examine the ways that existing transportation programs serve the needs of rural persons with dementia.

A study of dementia care capacity in Ireland found a much lower rate of about 17 'dementia places' per 100 persons with dementia.[17] This study used survey methods rather than licensure information to determine adult day center capacity. For estimates of dementia prevalence, the study relied on application of data from multiple international studies to the results of the 2016 Irish census, rather than healthcare claims. The study only included the 77% of responding adult day centers stating that they accepted participants with dementia. In contrast, only 2 (7%) of included Rhode Island adult day health centers had special licensure for dementia care, so we included all licensed centers. Had we restricted our sample to specially licensed centers, our overall capacity would have been much lower than that in the Irish study – about 3.7 per 100 persons with dementia. Our use of claims to estimate the prevalence of dementia is more robust than extrapolation of prevalence data from other populations. Our study is the first that we know of examining the distribution of adult day health service centers in the United States and comparing this to the distribution of community-dwelling persons living with dementia.

Limitations

Our study has several limitations. Our use of Medicare claims to identify persons with dementia would not identify those not enrolled in Medicare or Medicare beneficiaries in whom dementia was not identified in a claim. Also, our analysis does not account for the geographic distribution of other populations of people likely to benefit from adult day health centers, such as persons with developmental and intellectual disabilities. Because we made comparisons at the level of the Hospital Service Area, our quantitative analysis would not detect maldistribution of centers within Hospital Service Areas. The Hospital Service Area construct uses geographic patterns of hospital utilization to define local healthcare markets, therefore we considered this a reasonable unit of analysis for our research question. We also did not analyze other factors involved in adult day center availability such as payment considerations, availability and limitations of public or center-provided transportation, and length of waiting times for service enrollment.

CONCLUSION

Among Hospital Service Areas in Rhode Island, adult day health centers are distributed roughly according to the number of community-dwelling Medicare beneficiaries living with dementia. Within Hospital Service Areas, the same adult day health centers are clustered in population centers, a potential barrier to access for rural residents. These results may have relevance to public officials, policymakers, and health systems in the State of Rhode Island. Clearer regulations regarding the role of adult day health centers in the care of persons with mild dementia would facilitate greater precision in assessing the adequacy of the current care infrastructure. This study's approach may interest concerned parties in other jurisdictions who seek an equitable approach to licensure and financing of adult day health centers and other critical community health resources. Rhode Island's adult day health centers capacity is distributed between healthcare markets in a manner that roughly approximates the distribution of persons with dementia. Plans for the future of dementia care in Rhode Island should consider these findings.

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Acknowledgments

Christopher M. Santostefano was supported by National Institutes on Aging P01AG027296, which also provided data for this project. The authors acknowledge Vincent Mor, PhD; Kali Thomas, PhD, and James L. Rudolph, MD, SM, for their support of this project.

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