



Published in final edited form as:

J Am Geriatr Soc. 2019 July ; 67(7): 1467–1471. doi:10.1111/jgs.15995.

Adult Day Service Use Decreases Likelihood of Missed Doctor's Appointment among Dementia Caregivers

Lauren J. Parker, PhD, MPH¹, Joseph E. Gaugler, PhD², Quincy Samus, PhD³, and Laura N. Gitlin, PhD, FGSA, FAAN⁴

¹Johns Hopkins Bloomberg School of Public Health, Baltimore, MD

²School of Public Health, University of Minnesota, Minneapolis, MN

³Johns Hopkins School of Medicine, Baltimore, MD

⁴College of Nursing and Health Professions, Drexel University, Philadelphia, PA

Abstract

Background/Objective—Adult day services (ADS) that provide community-based supervised support for persons with dementia (PWD) may also function as a respite for familial caregivers to attend to self-care needs. Guided by a revised version of the Andersen Healthcare Utilization Model, the objective of this study was to identify the association between use of ADS and missed doctor's appointment among family caregivers for community-dwelling familial PWDs. A secondary objective was to identify other predisposing, enabling, and need factors associated with missed doctor's appointment.

Design—Secondary analysis of baseline, cross-sectional data from two randomized controlled trials (Advancing Caregiver Training, ACT n= 272 and Care of Persons with Dementia in their Environments, COPE (n= 237).

Setting—Community

Participants—Community-dwelling caregivers for PWD (n= 509).

Measurements—Missed doctor's appointment was measured using the caregivers' self-report of one or more missed doctor's appointment (yes/no) in the past 6 months. Adult day service use was measured using the caregivers self-report of use (yes/no).

Corresponding Author: Lauren J. Parker, PhD, MPH, Department of Health, Behavior, and Society, Johns Hopkins Bloomberg School of Public Health, 624 N. Broadway, Ste 904B, Baltimore, MD 21205-1999, (410)-955-2215, lparke27@jhmi.edu, Twitter: @dr_ljparker.

Author contribution:

Dr. Parker's role included substantial contributions to the conception and design of this research, analysis and interpretation of the data, drafting and revising this article for important intellectual content, and final approval of the version for publication.

Dr. Gaugler's role included substantial contributions to the conception and design of this research, revising this article for important intellectual content, and final approval of the version for publication.

Dr. Samus' role included substantial contributions to the conception and design of this research, revising this article for important intellectual content, and final approval of the version for publication.

Dr. Gitlin's role included substantial contributions to the conception and design of this research, acquisition of data, revising this article for important intellectual content, and final approval of the version for publication.

Conflicts of Interest:

The authors have no conflicts

Results—Over a third of the caregivers utilized ADS for their PWD. Caregivers who utilized ADS for their familial PWD were 49% less likely (95% Confidence interval: 0.32–0.81) to miss a doctor’s appointment in the past 6 months. More Black compared to white caregivers missed appointments regardless of ADS use. Caregivers with increased chronic health conditions were more likely to miss a doctor’s appointment compared to those with fewer conditions.

Conclusion—Adult day services’ provision of respite enables caregivers the time to address self-care needs by decreasing the likelihood that caregivers miss a doctor’s appointment. Findings suggest that ADS may promote positive health behaviors for caregivers and should be expanded as part of comprehensive dementia care for families. Factors associated with missed doctor appointments need further examination and intervention to support Black caregivers.

Keywords

dementia; community-residing; informal caregivers; health service use

INTRODUCTION

About 5.7 million Americans are living with Alzheimer’s disease and related disorders (AD/ADR), and this number is projected to rise to 14 million by 2050.¹ Nursing home usage among persons with ADRD may decrease, in part due to the “rebalancing” of U.S. states’ long-term care expenditures away from traditional nursing homes towards community-based long-term care services.^{2,3} Thus, use of community-based long-term services and supports that address dementia-specific care needs for both persons living with dementia and their family caregivers will be critical now and into the future.⁴ Throughout the disease trajectory, most persons with dementia rely heavily on familial support to assist with providing care.^{1,2} Most are middle-to-older aged daughters and/or spouses, who are also managing their own chronic health condition.^{1,2}

Although positive effects for caregiving exists,⁵ familial caregiving can be stressful and result in negative health consequences including psychological distress, poor health, and compromised physiological functioning.^{6,7} Many caregivers have unmet needs for care, services, and support.^{8,9} Stress and burden related to caregiving responsibilities might serve as an additional barrier to family caregivers managing their own chronic health conditions.^{10,11} Compared to non-dementia caregivers, dementia family caregivers are more likely to miss a medical appointment.¹² Further, being non-white, less educated, and increased depressive symptomology are factors associated with unmet need among familial caregivers for dementia-related support and health care.⁸ Thus, identification of facilitators to promote self-care behaviors among dementia-caregivers is critical as their care offsets costly health expenditures that would otherwise be placed on US taxpayers.¹

Adult day services (ADS) for persons living with AD/ADR (PWD) is a critical community-based component of long-term care that offers out-of-home, supervised support to clients. Adult day services also provide respite opportunities for family caregivers to remain in the workforce or perform other activities while relinquishing daytime care responsibilities.¹³ Compared to other long-term care services, ADS use is the most racially diverse sector of community-based or residential care services with 17% of Black persons

and 44% of White persons utilizing such programs.¹⁴ Consistent use of ADS has been associated with lower depressive symptoms and psychosocial distress as well as reductions in physiological stress in controlled evaluations.^{15,16} Respite provided to the caregiver through ADS may provide time for them to attend to their health needs.¹⁷

Guided by a revised version of the Andersen Healthcare Utilization Model,¹⁸ the aim of the study was to examine factors associated with having a missed doctor's appointment among dementia caregivers. The original Andersen behavioral model, designed to explain the use of formal personal health services, suggests that service utilization is a function of predisposition of service use (demographic factors), enabling factors (familial or community resource), and need for care (presence of health condition). The revised version proposed by Bradely,¹⁹ suggests that psychosocial factors (family burden, caregiving expectations) may influence service use. Our primary hypothesis was that ADS provides time for caregivers to attend to their own self-care, thus resulting in fewer missed health appointments. In addition to ADS, the study aimed to identify other predisposing, enabling, need and psychosocial factors associated with having a missed doctor's appointment among familial dementia caregivers.

METHODS

The sample consisted of 509 familial caregivers for community-living persons with moderate-stage dementia, pooled from two behavioral intervention trials: Advancing Caregiver Training (ACT, n= 272), and COPE (n= 237). The combined data used in this study were collected at the initial (baseline) interview, prior to randomization and implementation of their respective interventions. ACT was a randomized controlled efficacy trial of family caregivers that tested a home-based intervention to manage or reduce distressful behavioral symptoms among person with dementia exhibiting behavioral symptoms.²⁰ Care of Persons with Dementia was a randomized intervention to test a behavioral approach to support physical functioning and quality of life of persons with dementia and caregiver well-being.²¹ Both trials had the same eligibility criteria: caregivers had to be English-speaking, at least 21 years of age, living with the person with dementia, and providing at least four hours of daily care. Institutional Review Board approval for each trial was originally approved at the study's home institution (Thomas Jefferson University), and this secondary data analysis was approved by the Johns Hopkins Bloomberg School of Public Health IRB.

Study measures

Missed doctor appointments.—Missed doctor appointments was the primary outcome for this study. Following previous research,²² missed doctor appointments was assessed through self-report by family caregivers who indicated whether they had missed one or more doctor's appointment in the past 6 months (yes/no).

Predisposing factors included race (White vs. Black), education (High school education or lower, some college, and college education or more), age (continuous), and caregiving relational status (non-spouse vs spouse).

Enabling factors included adult day service use, social support, and employment status. Similar to previous research,²³ caregivers indicated whether the care recipient used ADS or not in the past 6 months (yes or no). Social support was assessed by participants' responses to the frequency in which friends, neighbors, or family members provided transportation or pitched in to help with household chores, yardwork, or shopping. Responses were coded into three categories never, once in a while, or often. Employment status was assessed as employed or not-employed.

Need factors were assessed by chronic health conditions. Number of chronic health conditions of caregivers was derived from the self-report of physician-diagnosed diseases using the National Health Interview Survey-13-item (continuous).²⁴

Psychosocial factors were assessed by caregiver burden. Caregiver burden was assessed with the 12-item Zarit Burden Interview Short Form (continuous).²⁵

Data Analysis

Sample characteristics were summarized with descriptive statistics. Chi-Square and Student's T-tests were used to compare those who did miss a doctor's appointment in the past 6 months compared to those who did not (Table 1). In Table 2, we present the results from the multivariate logistic regression analyses identifying those predisposing, enabling, and need factors associated with missed doctor's appointment in the past 6 months. We additionally adjusted this model by an interaction term between race (Black, White) and ADS use in order to examine if racial differences in ADS use was associated with missed doctor's appointment. P values < 0.05 were considered statistically significant. All analyses were completed using STATA 13.

RESULTS

Almost 28% (n= 138) of the sample missed a doctor's appointment in the past 6 months. About 73% (n = 362) of the sample was White and 27% (n = 135) were Black. The mean age was 65 (Standard deviation (SD): 12.5) and over half of the sample were at least college graduates (52.7%, n=268). The mean caregiver burden score was 22.4 (SD: 0.7) (mild to moderate caregiver burden), and the average number of caregiver chronic health conditions was four (SD: 2.4). Most caregivers were spouses (57%, n=219), about a third were employed (35.7%, n = 181) and reported often receiving social support (36.9%, n = 188). Over a third (37%, n=188) of the sample used adult day services.

As shown in Table 1, a larger proportion of Black caregivers, those who were younger, those who did not utilize adult day services for persons with dementia, and those with more chronic health conditions reported that they had missed a doctor's appointment in the past 6 months. There were no observed differences in missed doctor appointments by education, relationship status, being employed, or level of social support, or caregiver burden.

Based on multivariate logistic regression, Black caregivers had increased odds (Odds Ratio (OR): 1.68, Confidence interval (CI): 1.02–2.75) of missing a doctor's appointment compared to Whites, and older age was associated with decreased odds (OR: 0.97, CI: 0.95–

0.99) of missing a doctor's appointment compared to younger ages. Caregivers with an increased number of chronic health conditions were more likely (OR: 1.24, CI: 1.13–1.36) to miss a doctor's appointment, compared to those who had fewer health conditions (Table 2).

Caregivers who utilized adult day services were less likely (OR: 0.51, CI: 0.32–0.81) to miss a doctor appointment compared to those who did not attend ADS (Table 2). In an exploratory model, an interaction term for being Black and ADS use was not significantly associated with missed health appointments (OR: 1.01, $p=0.98$) (data not shown).

DISCUSSION

This cross-sectional study examines the association between ADS use, predisposing, enabling, and need factors and missed doctor appointments. Over a third of the sample ($n=188$) utilized ADS services for their family member living with dementia at baseline or at time of enrollment in the trials. Caregivers who utilized ADS for the person living with dementia were 49% less likely to miss a doctor's appointment. Further, older caregivers had a lowered likelihood of missing a doctor's appointment, whereas Black caregivers and those with an increased number of chronic health conditions were more likely to miss a doctor appointment.

We show that ADS use may offer caregivers the respite required to attend medical appointments, a key component of self-care.^{13,17} Although previous findings have demonstrated the positive health benefits of ADS to caregivers' emotional well-being and physiological regulation,^{15,16} the current study extends these benefits to include caregivers' health behavior. Collectively, the data across studies support expanding upon the number of ADS programs nationally (there are an estimated 4,800 U.S.-based centers²⁶) and that health providers could consider such programs an important potential resource for families. Future studies should examine if ADS use is associated with other health behaviors (i.e., sleep, diet). Prior research has suggested that frequency and duration of ADS use are associated with caregiver well-being, and incorporating ADS "dosage" is likely critical when examining ADS use and client/caregiver outcomes^{27,28}

Black caregivers appear particularly at risk for not attending doctor's appointment and this was the case whether ADS was used or not. It is unclear why this is the case. Other studies have demonstrated that despite Black caregivers' recognition of need for formal support services,²³ their health-service utilization may be related to the limited understanding of their cultural needs by the healthcare system.²⁹ For instance, historical experiences with mistrust of service providers, reliance on informal support networks, and lack of culturally-appropriate services have been voiced as factors related to Black caregivers' reluctance to use formal support services.³⁰ Furthermore, it is unclear if access to medical services contributes to the findings of this study. To the authors' knowledge, this is the first study to identify the risk of Black dementia familial caregivers for missing doctors' appointments. Findings suggest the need for more systematic approaches to understanding primary care use among Black caregivers, as their health behavior and self-care may be compromised due to their caregiving role. Further, findings suggest that Black caregivers will need support to attend to their own self-care over and above referral to and use of ADS.

There are several limitations of this study. First, we use a pooled convenience sample from two intervention studies that may present bias since these caregivers self-identified and volunteered for a research trial. This may imply that they are more likely to utilize ADS or similar support services. Second, we relied on self-reported attendance at ADS and also missed doctor's appointment (yes/no) in the past 6 months which may introduce recall bias. However, this is a commonly accepted practice in research trials, particularly non-pharmacological trials of dementia care. Third, generalizability may also be limited since this sample included caregivers primarily from an urban area, and the findings are not necessarily applicable to rural caregiver experiences who may have limited access to health services and ADS. Future studies should document the experiences such caregivers have in accessing health services and ADS.

Although ADS programs are designed to provide respite to family caregivers and functional help for the person with dementia, ADS programming could be expanded to encourage health-promoting behaviors among caregivers. Such programming can be useful to ensure optimal health for the caregiver, as caregivers' health and well-being are central to providing quality care for the person with dementia. Home and community-based services should thus continue to expand to allow dementia caregivers the resources to utilize support that will promote their optimal health, and as a means to enhance the quality of care provided to persons with dementia.

ACKNOWLEDGMENTS

Dr. Parker is supported by a NIH/NIA-funding (R01AG049692 - 02W1). Dr. Gitlin and Dr. Gaugler are supported in part by NIA funding (R01AG049692).

Sponsor's Role:

The sponsors had no role in the design, methods, subject recruitment, data collection, data analysis or preparation of this article.

REFERENCES

1. Alzheimer's Association. 2018 alzheimer's disease facts and figures. *Alzheimer's & Dementia*. 2018;14(3):367–429.
2. Wolff JL, Spillman BC, Freedman VA, Kasper JD. A national profile of family and unpaid caregivers who assist older adults with health care activities. *JAMA Internal Medicine*. 2016;176(3):372–379. [PubMed: 26882031]
3. Gaugler JE. Innovations in long-term care In: *Handbook of aging and the social sciences* (eighth edition). Elsevier; 2016:419–439.
4. Wolff JL, Mulcahy J, Huang J, Roth DL, Covinsky K, Kasper JD. Family caregivers of older adults, 1999–2015: Trends in characteristics, circumstances, and role-related appraisal. *Gerontologist*. 2017.
5. Roff LL, Burgio LD, Gitlin L, Nichols L, Chaplin W, Hardin JM. Positive aspects of alzheimer's caregiving: The role of race. *J Gerontol B Psychol Sci Soc Sci*. 2004;59(4):185.
6. Fonareva I, Oken BS. Physiological and functional consequences of caregiving for relatives with dementia. *International psychogeriatrics*. 2014;26(5):725–747. [PubMed: 24507463]
7. Pinquart M, Sörensen S. Correlates of physical health of informal caregivers: A meta-analysis. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*. 2007;62(2):P137.
8. Black BS, Johnston D, Rabins PV, Morrison A, Lyketsos C, Samus QM. Unmet needs of community-residing persons with dementia and their informal caregivers: Findings from the

- maximizing independence at home study. *J Am Geriatr Soc.* 2013;61(12):2087–2095. [PubMed: 24479141]
9. Waligora KJ, Bahouth MN, Han H. The self-care needs and behaviors of dementia informal caregivers: A systematic review. *Gerontologist.* 2018.
 10. Vitaliano PP, Zhang J, Scanlan JM. Is caregiving hazardous to one's physical health? A meta-analysis. *Psychol Bull.* 2003;129(6):946. [PubMed: 14599289]
 11. Pinquart M, Sörensen S. Associations of stressors and uplifts of caregiving with caregiver burden and depressive mood: A meta-analysis. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences.* 2003;58(2):P128.
 12. Wang X, Robinson KM, Hardin HK. The impact of caregiving on caregivers' medication adherence and appointment keeping. *West J Nurs Res.* 2015;37(12):1548–1562. [PubMed: 24807892]
 13. Fields NL, Anderson KA, Dabelko-Schoeny H. The effectiveness of adult day services for older adults: A review of the literature from 2000 to 2011. *Journal of Applied Gerontology.* 2014;33(2): 130–163. [PubMed: 24652952]
 14. Harris-Kojetin L, Sengupta M, Park-Lee E, et al. Long-term care providers and services users in the united states: Data from the national study of long-term care providers, 2013–2014. *Vital & health statistics.Series 3, Analytical and epidemiological studies.* 2016(38):105.
 15. Klein LC, Kim K, Almeida DM, Femia EE, Rovine MJ, Zarit SH. Anticipating an easier day: Effects of adult day services on daily cortisol and stress. *Gerontologist.* 2016;56(2):303–312. [PubMed: 24996408]
 16. Gitlin LN, Reever K, Dennis MP, Mathieu E, Hauck WW. Enhancing quality of life of families who use adult day services: Short- and long-term effects of the adult day services plus program. *Gerontologist.* 2006;46(5):630–639. [PubMed: 17050754]
 17. Oliveira D, Zarit SH, Orrell M. Health-promoting self-care in family caregivers of people with dementia: The views of multiple stakeholders. *Gerontologist.* 2019.
 18. Andersen RM. Revisiting the behavioral model and access to medical care: Does it matter? *Journal of health and social behavior.* 1995:1–10.
 19. Bradley EH, McGraw SA, Curry L, et al. Expanding the andersen model: The role of psychosocial factors in long-term care use. *Health Serv Res.* 2002;37(5):1221–1242. [PubMed: 12479494]
 20. Gitlin LN, Winter L, Dennis MP, Hauck WW. A non-pharmacological intervention to manage behavioral and psychological symptoms of dementia and reduce caregiver distress: Design and methods of project ACT3. *Clinical interventions in aging.* 2007;2(4):695. [PubMed: 18225471]
 21. Gitlin LN, Winter L, Dennis MP, Hodgson N, Hauck WW. A biobehavioral home-based intervention and the well-being of patients with dementia and their caregivers: The COPE randomized trial. *JAMA.* 2010;304(9):983–991. [PubMed: 20810376]
 22. Shimotsu S, Roehrl A, McCarty M, et al. Increased likelihood of missed appointments (“no shows”) for racial/ethnic minorities in a safety net health system. *Journal of primary care & community health.* 2016;7(1):38–40.
 23. Brown EL, Friedemann M, Mauro AC. Use of adult day care service centers in an ethnically diverse sample of older adults. *Journal of Applied Gerontology.* 2014;33(2):189–206. [PubMed: 24652954]
 24. Lucas JW, Schiller JS, Benson V. Summary health statistics for US adults; national health interview survey, 2001. . 2004.
 25. Bédard M, Molloy DW, Squire L, Dubois S, Lever JA, O'Donnell M. The zarit burden interview: A new short version and screening version. *Gerontologist.* 2001;41(5):652–657. [PubMed: 11574710]
 26. Harris-Kojetin L, Sengupta M, Park-Lee E, et al. Long-term care providers and services users in the united states: Data from the national study of long-term care providers, 2013–2014. *Vital & health statistics.Series 3, Analytical and epidemiological studies.* 2016(38):105.
 27. Zarit SH, Stephens MAP, Townsend A, Greene R. Stress reduction for family caregivers: Effects of adult day care use. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences.* 1998;53(5):S277.

28. Gaugler JE, Zarit SH. The effectiveness of adult day services for disabled older people. *J Aging Soc Policy*. 2001;12(2):23–47.
29. Bonds K, Lyons KS. Formal service use by african american individuals with dementia and their caregivers: An integrative review. *J Gerontol Nurs*. 2018;44(6):33–39.
30. Scharlach AE, Kellam R, Ong N, Baskin A, Goldstein C, Fox PJ. Cultural attitudes and caregiver service use: Lessons from focus groups with racially and ethnically diverse family caregivers. *Journal of gerontological social work*. 2006;47(1–2):133–156. [PubMed: 16901881]

Table 1:

Distribution of Characteristics of Caregivers of Persons Living with Dementia (n= 509) the Full Sample and by Missed Doctor's Appointment in the Past 6 Months

	Missed Doctor's Appointment		
	Total (n = 509)	Yes ^a (n = 138)	No ^b (n = 371)
Missed Doctors Appointments, n (%)		27.8	72.1
Predisposing Characteristics			
Race, n (%)			
White	362 (72.8)	86 (63.7)	276 (76.2)**
Black	135 (27.2)	49 (36.3)	86 (23.8)
Age, mean (SD)	65.2 (12.5)	63.4 (12.6)	65.8 (12.3)*
Education, n (%)			
High School Graduate	98 (19.3)	28 (20.3)	70 (18.9)
Some College	143 (28.1)	37 (26.8)	106 (28.6)
College/Post College	268 (52.7)	73 (52.9)	195 (52.5)
Enabling Characteristics			
Adult Day Service Use, n (%) ^c	188 (37.0)	37 (26.8)	151 (40.8)**
Relationship Status, n (%)			
Non-spouse	219 (43.0)	59 (42.8)	160 (43.1)
Spouse	290 (57.0)	79 (57.3)	211 (57.3)
Employed, n (%)	181 (35.7)	52 (37.9)	129 (34.8)
Social Support, n (%)			
Never	170 (33.5)	39 (28.3)	131 (35.5)
Once in a while	151 (28.7)	41 (29.7)	110 (29.6)
Often	188 (36.9)	58 (42.0)	130 (35.0)
Need Characteristics			
Caregiver Burden, mean (SD) ^d	22.4 (0.7)	23.7 (0.7)	21.9 (0.7)
Health Conditions, mean (SD)	4.3 (2.4)	5.1 (2.3)	4.0 (2.4)***

Notes: SE= standard error.

^a Percentages reported reflect comparisons among respondents' affirmatively reporting having missed doctor's appointment,

^b Percentages reported reflect comparisons among respondents who did not miss a doctor's appointment,

^c Adult Day Service Use measure by self-reported used,

^d Caregiver burden measure by Zarit 12-item measure

p< 0.001,

**
p<0.01,

*
p<0.05

Table 2.

Multivariate Logistic Regression Depicting the Predisposing, Enabling, and Need Factors Associated with Missed Doctor's Appointment (Yes/No) in Past 6 Months among 509 Caregivers for Persons with Dementia

	OR	95% CI	P
Predisposing Characteristics			
Race			
White	1.00		
Black	1.68	(1.02, 2.75)	0.036
Age	0.97	(0.95, 0.99)	0.020
Education			
High School Graduate	1.00		
Some College	0.69	(0.37, 1.28)	0.246
College/Post College	0.85	(0.49, 1.48)	0.585
Enabling Characteristics			
Adult Day Service Use ^b	0.51	(0.32, 0.81)	0.004
Relationship Status			
Non-spouse	1.00		
Spouse	0.93	(0.60, 1.43)	0.755
Employed	1.17	(0.72, 1.90)	0.512
Social Support			
Never	1.00		
Once in a while	1.08	(0.62, 1.86)	0.783
Often	1.44	(0.86, 2.39)	0.156
Need Characteristics			
Caregiver Burden ^c	1.01	(0.98, 1.03)	0.490
Health Conditions	1.24	(1.13, 1.36)	0.000

Note: Bold p-values indicate statistical significance.

^a Adjusted for the predisposing, enabling, and need characteristics.

^b Adult Day Service Use (yes/no) measure by self-reported used,

^c Caregiver burden measure by Zarit 12-item measure.

OR= odds ratio, CI=confidence interval.