

## Original Report

# Does Adult Day Service Use Improve Well-Being of Black Caregivers of People Living With Dementia?

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## Abstract

**Background and Objectives:** Despite adult day services (ADS) being the most racially diverse home- and community-based service (HCBS), there is a paucity of research that has examined the impact of ADS on well-being measures among Black caregivers of people living with dementia. To address this gap, this study examined the association between the use of ADS and depressive symptoms among Black dementia caregivers.

**Research Design and Methods:** Using baseline data from 2 behavioral intervention trials, Advancing Caregiver Training ( $n = 72$ ) and Care of Persons with Dementia in their Environments ( $n = 63$ ), we conducted ordinary least squares regression to examine the association between ADS use in the past 6 months and depressive symptoms ( $n = 135$ ). The dependent variable, depressive symptoms, was assessed by the 10-item Center for Epidemiologic Studies—Depression (CES-D) scale. The independent variable was assessed by self-report of ADS use in the past 6 months.

**Results:** Nearly 36% of the sample used ADS in the past 6 months. After controlling for caregiver characteristics associated with depression (burden, social support, self-rated health, caregiving relationship status, years caregiving, religious/spiritual coping, and demographic characteristics), caregivers who utilized ADS had a lowered CES-D score ( $B = -1.97$ ,  $p = .03$ ) compared to those who did not use ADS.

**Discussion and Implications:** Black dementia caregivers who utilized ADS had lower depressive symptoms compared to those who did not utilize ADS. ADS may be a critical HCBS that can provide relief to Black caregivers. Research is needed to examine additional benefits of ADS use among Black caregivers and the policy and programming needed to enhance access to ADS.

**Translational Significance:** This study examined the association of adult day service utilization on depressive symptoms among a community-based sample of Black caregivers of people living with dementia. The study found that among Black caregivers, those who used adult day services within the past 6 months had fewer depressive symptoms compared to those who did not use adult day services. The results highlight the benefit of using adult day services among Black caregivers and suggest the need to make this service widely available to this underserved group.

**Keywords:** Alzheimer's disease, Caregivers, Community-based long-term care, Minority aging

The rate of Alzheimer's disease and related dementias (ADRD) is nearly twice as high among Black Americans when compared with Whites (Alzheimer's Association, 2019). Black Americans are more likely than others to age with ADRD in the community (Schulz & Sherwood, 2008) and rely heavily on family members or other informal sources for support (Friedman et al., 2015). In addition to caring for immediate relatives, Black American caregivers often care for siblings, other relatives, or fictive kin at rates higher than other racial/ethnic groups (National Alliance for Caregiving, 2015). Studies consistently show that more than one half of Black American caregivers provide care-related assistance for more than one individual, and 25% report spending an average of 21 h/week providing care (Alzheimer's Association, 2019; National Alliance for Caregiving, 2015). Unfortunately, Black caregivers are underrepresented in nonpharmacological studies and have limited access to evidence-based services like adult day services (ADS) that can provide opportunities for respite and assist with care needs (Gitlin et al., 2015; Hodgson & Gitlin, 2021).

ADS for persons living with ADRD is a critical community-based component of long-term care that offers out-of-home, supervised support to clients. Compared to other home- and community-based services, ADS is the most racial/ethnic diverse service and half of all ADS programs predominately served racial/ethnic clients (Harris-Kojetin et al., 2016; Lendon et al., 2021). ADS also provide respite opportunities for family caregivers to remain in the workforce or perform other activities while relinquishing daytime care responsibilities (Fields et al., 2014). Previous research has shown the importance of ADS for addressing caregiver burden and supporting caregiver well-being (Gitlin et al., 2006; Parker et al., 2019). Whereas ADS has been reported to reduce stress and depression among White caregivers (Parker et al., 2019; Zarit et al., 2011), it is unclear if these benefits extend to Black American caregivers and this group has not been represented in most studies of ADS. ADS may offer an important resource to address caregiving-related stressors among Black American caregivers. Understanding if the benefits of ADS extend to Black caregivers, an underserved population, has important policy and practice implications.

Studies comparing well-being between Black and White caregivers have consistently demonstrated that Black caregivers report lower levels of depressive symptoms (Clay et al., 2008; Roth et al., 2001). Despite the reported positive aspects of providing care-related tasks, Black caregivers report a greater need for daytime respite, skills training, and caregiving support (Burgio et al., 2003; Desin et al., 2016; Roth et al., 2015). Stress process frameworks used to explain relationships between social role (i.e., caregiving) and mental health outcomes suggest that greater exposure to stressors and less access to coping resources are associated with poorer health outcomes (Pearlin, 1989; Pearlin et al., 1990). Black dementia caregivers, compared to their White counterparts,

spend more time providing care (Alzheimer's Association, 2019; Fabius et al., 2020) and perform more physically demanding care-related tasks (e.g., bathing and lifting; Miles et al., 2001), yet have limited access to community-based services that can provide disease education, support, hands-on skills, or respite. As such, it appears paradoxical that Black caregivers compared to other race/ethnic groups tend to report lower depressive symptoms. However, this may, in part, be explained by the limited studies that have examined within-group differences in depressive symptoms among Black dementia caregivers as well as lack of measurement of aspects of well-being that matter to this population.

Accordingly, the purpose of this study was to examine the association between the use of ADS and depressive symptoms among a sample of Black American dementia caregivers who were enrolled in a randomized clinical trial testing a nonpharmacological intervention. We examine ADS use and depressive symptoms prior to randomization and treatment. We hypothesized that Black caregivers who reported using ADS would report fewer depressive symptoms compared to Black caregivers who reported that they did not utilize ADS services.

## Method

The sample consisted of 135 Philadelphia-area Black caregivers of community-living persons living with moderate-stage dementia, pooled from two behavioral intervention trials: Advancing Caregiver Training (ACT,  $n = 72$ ) and Care of Persons with Dementia in their Environments (COPE,  $n = 63$ ). 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 distressing behavioral symptoms among persons with dementia exhibiting behavioral symptoms (Gitlin et al., 2007). COPE was a randomized intervention to test a behavioral approach to support physical functioning and quality of life of people living with dementia and caregiver well-being (Gitlin et al., 2010). 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 4 h of daily care. Institutional Review Board (IRB) 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.

## Measures

### Depressive symptoms

Depressive symptoms were measured similarly in each trial using the 10-item Center for Epidemiologic Studies—Depression (CES-D) scale (Andresen et al., 1994).

Respondents were asked whether they experienced the following symptoms rarely or most of the time in the past week: (a) felt that everything was an effort, (b) sleep was restless, (c) felt depressed, (d) was happy, (e) felt lonely, (f) people were unfriendly, (g) enjoyed life, (h) felt sad, (i) felt that people disliked them, and (j) could not get going. Positive items were reverse-coded, and the summed score ranged from 0 to 30. A cutoff score of 8 identifies individuals at risk of clinical depression (Andresen et al., 1994). The Cronbach's alpha for the Black respondents was 0.79 for this study sample.

### ADS use

Similar to previous research (Brown et al., 2014; Parker et al., 2019), caregivers indicated whether the person living with dementia used ADS or not in the past 6 months (0 = no, 1 = yes).

### Covariates

An a priori decision was made to control for factors that could be associated with depressive symptoms or use of ADS. The covariates include caregiver burden, social support, self-rated health, and religious/spiritual coping. Caregiver burden was assessed with the 12-item Zarit Burden Interview Short Form (continuous; Bédard et al., 2001). For each item, caregivers responded on a 4-point scale (0 = never, 1 = rarely, 2 = sometimes, 3 = quite frequently, and 4 = nearly always). A total mean score was derived by summing item responses with higher scores representing more burden (range = 0–48). Social support was assessed by participants' responses to the frequency in the past month as to how often someone was physically with them in a stressful situation (0 = never, 1 = once in a while, or 2 = often). A total mean score was derived with higher scores representing more social support. Self-rated health was assessed by participants' self-report of their health (0 = poor/fair, 1 = good/very good, 2 = excellent). Religious/spiritual coping was assessed using the six-item Brief RCOPE Scale (e.g., "I think about how my life is part of a larger spiritual force"; continuous; Fetzer, 2003). Participants were asked to indicate the extent to which they agree with each of the items using a 4-point scale (1 = not at all to 4 = a great deal). A total score was derived by taking the mean of the mean with higher values indicated more religious/spiritual coping (range = 1–4).

Demographic characteristics included age (continuous), education (0 = ≥high school, 1 = some college/associates, and 2 = college degree/post graduate degree), sex (0 = female, 1 = male), caregiving relational status (0 = nonspouse, 1 = spouse), being employed (0 = not employed, 1 = employed), financial strain (0 = no financial strain, 1 = financial strain), and number of years caregiving (continuous).

### Data Analysis

Sample characteristics were summarized with descriptive statistics. Chi-square and Student's *t*-tests were used

to compare those who used ADS in the past 6 months to study enrollment compared to those who did not (Table 1). In Table 2, we present the results from the ordinary least squares (OLS) regression analyses depicting the association between depressive symptoms and ADS use controlling for caregiver burden, social support, self-rated health, religious/spiritual coping, and demographic characteristics. *p* values of less than .05 were considered statistically significant. All analyses were completed using Stata 15.

## Results

### Sample Characteristics

The mean age of all caregivers was 60 (standard deviation [*SD*] = 10.7), with 79.1% (*n* = 103) having some college or a college graduate and most being female (90.0%, *n* = 117). Most provided care for a nonspouse (54.6%, *n* = 71) with a mean of 3.3 years (*SD* = 2.7) caregiving. The mean caregiver burden score was 19.9 (*SD* = 9.4). Almost half of the caregivers (48.0%, *n* = 62) reported having social support, and 70.7% (*n* = 92) rated their own health as good to excellent. The mean religious/spiritual coping score was 2.6 (*SD* = 1.1). There were no observed differences in ADS by any of the covariates or demographic variables (Table 1). Of note is that there were no large or statistically significant differences between ADS users and nonusers with regard to employment status and financial strain.

### ADS Use and Depressive Symptoms

About 36% (*n* = 47) of the sample used ADS in the past 6 months. The mean CES-D score for the sample was 9.6 (*SD* = 5.5, range 0–24), indicating that most caregivers were above the cutoff score of 8 for clinical depressive symptoms. The mean CES-D score for caregivers who reported ADS use in the past 6 months was 8.3 (5.2), and the mean score for those who did not report ADS use was 10.3 (5.6) representing a statistically significant difference such that those reporting use of ADS also reported on average lower CES-D scores (Table 1).

As given in Table 2, findings from the OLS regression determined that use of ADS ( $B = -1.97, p < .05$ ), older age ( $B = -0.10, p < .05$ ), good/very good ( $B = -2.68, p < .01$ ), and excellent ( $B = -4.73, p < .01$ ) self-rated health were each associated with a decrease in depressive symptoms. Independent of ADS use, caregivers reporting higher burden ( $B = 0.20, p < .001$ ) had more depressive symptoms.

## Discussion

This cross-sectional study examined the association between ADS use and depressive symptoms among Black caregivers for persons living with dementia. Among this sample derived from two trials, 36% of caregivers reported using ADS for their family member living with dementia. Caregivers who used ADS within the past 6 months of being

**Table 1.** Distribution of Characteristics of Black Caregivers of Persons Living With Dementia ( $n = 130$ ): The Full Sample and by Adult Day Service Use in the Past 6 Months

Characteristics	Total ( $N = 130$ )	Adult day service use	
		Yes ( $n = 47$ )	No ( $n = 83$ )
Adult day service use, $n$ (%)		47 (36.1)	83 (63.8)
<i>Background characteristics</i>			
Age, mean ( $SD$ )	60.0 (10.7)	59.3 (10.1)	61.2 (10.9)
Education, $n$ (%)			
$\leq$ High school graduate	27 (20.7)	10 (21.2)	17 (20.4)
Some college	40 (30.7)	11 (23.4)	29 (34.9)
College/postcollege	63 (48.4)	26 (55.3)	37 (44.5)
Sex, $n$ (%)			
Female	117 (90.0)	43 (91.4)	74 (89.1)
Male	13 (10.0)	4 (8.5)	9 (10.8)
Years caregiving, mean ( $SD$ )	3.3 (2.7)	3.2 (2.4)	3.4 (2.8)
Employed, $n$ (%)	48 (36.9)	17 (36.1)	31 (37.3)
Financial strain, $n$ (%)	78 (60.0)	29 (61.7)	49 (59.0)
<i>Caregiver well-being</i>			
Caregiver burden, mean ( $SD$ )	19.9 (9.4)	19.0 (9.5)	20.4 (9.4)
CES-D, mean ( $SD$ )	9.6 (5.5)	8.3 (5.2)	10.3 (5.6)*
Religious/spiritual coping, mean ( $SD$ )	2.6 (1.1)	2.7 (1.0)	2.6 (0.9)
<i>Caregiver health</i>			
Self-rated health, $n$ (%)			
Poor/fair	38 (29.2)	13 (27.5)	25 (30.1)
Good/very good	81 (62.3)	30 (63.8)	51 (61.4)
Excellent	11 (8.4)	4 (8.5)	7 (8.4)
<i>Caregiver support</i>			
Social support, $n$ (%)			
Never	28 (21.7)	11 (23.4)	17 (20.7)
Once in a while	39 (30.2)	14 (29.7)	25 (30.4)
Often	62 (48.0)	22 (46.8)	40 (48.7)
Caregiver relational status, $n$ (%)			
Nonspouse	71 (54.6)	26 (55.3)	45 (54.2)
Spouse	59 (45.3)	21 (44.6)	38 (45.7)

Note: CES-D = Center for Epidemiologic Studies—Depression scale.

\* $p < .05$ .

interviewed at baseline for one or the other trial reported a score of 8.3 on the CES-D scale, which is 2.0 points less than their counterparts who reported not using ADS (10.3). Age, caregiver burden, and self-rated health were also associated with depressive symptoms independent of ADS use. Specifically, older age and good to excellent self-rated health were associated with fewer depressive symptoms. As expected, more reports of caregiver burden were associated with depressive symptoms.

Our findings demonstrate that Black caregivers who used ADS had lower depressive symptoms compared to those who did not report ADS use within the past 6 months. This finding extends previous research that demonstrates the positive benefits of ADS for caregivers who utilize such services for their family member with dementia by examining this association for Black caregivers (Zarit et al., 1998). The findings on the association between ADS use and depressive symptoms are also consistent with social

stress frameworks such as the Stress Process Theory, which suggests that resources for respite might reduce mental health outcomes related to the caregiving role (Pearlin et al., 1990). The findings of this study are important because they confirm that the benefits of ADS extend beyond its predominately White constituents and are conferred to Black caregivers as well. Furthermore, the findings are novel as no previous studies have explicitly examined this relationship among Black caregivers.

However, it is unclear why some caregivers utilize ADS and others do not. ADS is the most utilized home- and community-based resource by diverse racial/ethnic groups (Harris-Kojetin et al., 2016). A recent study demonstrated that predominately Black ADS centers reside in counties with a high proportion of Black Americans (Lendon et al., 2021). Such centers are often located in metropolitan areas, and clients are not likely to self-pay for services (Lendon et al., 2021). While our results are good news for Black

**Table 2.** Results From OLS Regression Analysis Depicting the Association Between CES-D and Adult Day Service Use Among Black Caregivers of Persons Living With Dementia Caregivers (*n* = 130)

Characteristics	<i>B</i>	<i>SE</i>	<i>p</i>
Adult day service use	-1.97	0.87	*
<i>Background characteristics</i>			
Age	-0.10	0.04	*
<i>Education</i>			
Some college	-0.19	1.24	
College/postcollege	-0.33	1.12	
Sex	-2.29	1.41	
Years caregiving	-0.14	0.15	
<i>Caregiver well-being</i>			
Caregiver burden	0.20	0.04	***
Religious/spiritual coping	0.14	0.50	
<i>Caregiver health</i>			
<i>Self-rated health</i>			
Good/very good	-2.68	0.96	**
Excellent	-4.73	1.63	**
<i>Caregiver support</i>			
<i>Social support</i>			
Once in a while	-1.66	1.21	
Often	-1.48	1.09	
Spouse	0.92	0.95	

Note: CES-D = Center for Epidemiologic Studies—Depression scale; OLS = ordinary least squares.

\**p* ≤ .05, \*\**p* ≤ .01, \*\*\**p* ≤ .001.

caregivers who utilize ADS, this group as a whole is less likely to utilize respite services (Parker & Fabius, 2020). It may be that support services like ADS are costly, and out-of-pocket expenses for ADS may limit its use. It is important to identify barriers to the use of ADS so that policy and programming can be addressed to meet the care needs of Black caregivers and people living with dementia.

The mean score of depressive symptoms among the Black dementia caregivers in the study was 9.6 (*SD* = 5.5, range 0–25). This score is above the cutoff of 8.0, indicative of clinical depressive symptoms (Andresen et al., 1994), and 63.8% of the sample was above this score. Given that Black caregivers spend more time providing care and have unmet needs for respite services, it is not surprising that Black caregivers may be at risk for depressive symptoms. While previous studies consistently show that Black caregivers on average report fewer depressive symptoms than White caregivers, these studies have not examined within-group differences, which is an important contribution of our study. It is critical to assure the inclusion of Black caregivers in nonpharmacological trials in order to identify the within-group disparities. We may be overlooking important health and psychosocial experiences that are masked when only Black and White analytic comparisons are made, and hence, drawing inaccurate conclusions as to unmet needs for supportive services.

It is suggested that coping strategies like the use of religious/spiritual support and unique cultural factors such as a strong sense of familial obligation may buffer the stressors of caregiving on self-reported health outcomes for Black caregivers (Dilworth-Anderson, 2011; Nkimbeng & Parker, 2021). Some research has suggested that when confronted with care-related stressors, Black American caregivers utilize more emotion-focused coping, including distancing, accepting responsibility, and escapism, than White caregivers (Knight et al., 2000). Religiosity/spirituality is an example of such a coping resource. Interestingly, in this study, religious/spiritual coping was not a significant factor associated with depressive symptoms and the average scale score was quite low. As expected, caregiver burden and self-reported health were both factors associated with depressive symptoms.

Our findings have important research, policy, and practice implications. As to research, in this study, we were not able to assess how specific cultural values or norms regarding caregiving affect Black caregivers' depressive symptoms or their decision to use or not ADS. More studies are needed to identify if there are unique cultural caregiving experiences among Black caregivers that influence care preferences and their emotional consequences and to understand how these experiences relate to the decision to use ADS. Furthermore, a better understanding of the multiple factors that influence decision making to use ADS is critical. For example, individual factors such as care preferences, employment status, financial status, knowledge of ADS and its benefits along with structural factors including geographic proximity, access to, and ADS capacity may all be relevant to utilization. While in our study we did not find differences between users and nonusers of ADS by their employment status or level of financial strain, these factors require further exploration.

There are also numerous policy implications. ADS need more adequate funding to support the communities they serve and there need to be more ADS available to families, particularly in remote and underserved communities. Our study is consistent with previous research demonstrating the positive outcomes of ADS use, indicating that greater federal and state financial support should be directed to this effective community-based service.

With regard to practice, most caregivers are unaware of ADS and its benefits or learn about this community-based service late in the disease process. Health providers do not routinely provide information about ADS or refer families to this and other community-based services that could support quality of life. A referral to ADS, for example, could be part of the Medicare Wellness visit that supports care coordination activities. Also, health providers need a better understanding that although there are currently no disease-modifying treatments, nonpharmacological strategies and community-based support programs, such as ADS, can support quality of life and are important.

Several study limitations should be noted. Data for this study were derived from caregivers living in an urban

setting where access to community services may be more available compared to those in more rural or suburban settings. However, it is not known whether ADS sites were accessible to the Black American caregivers in this study. Another limitation to the study is that we are unable to determine the causal pathway of ADS usage and depressive symptoms or how the duration of ADS use (i.e., length of time during the day and over time) may affect depressive symptoms of family caregivers. Additional research is needed to determine whether contextual factors such as cost of ADS use and mistrust of the health care system are related to the use of ADS among Black caregivers, and how such factors may affect mental and physical health outcomes. Despite the limitations, the strength of our study is that we demonstrate the positive benefits of ADS use among Black dementia caregivers. This finding not only extends the evidence for ADS but supports developing strategies to assure that Black caregivers become aware of ADS, understand, and receive help with financial aspects of using ADS, and that culturally relevant messaging and approaches be developed and implemented that promote ADS use among Black families. We also show that within this group, there is variation in community-based service use and mental health experiences that need to be better understood. Yet another consideration may be that the sample size appears to be small and geographically limited. Given the history of low engagement and participation in community-based research and formal dementia support services by Black American caregivers, the sample size of 130 is a start in understanding within-group differences and hence, we do not consider our sample size a limitation. Our findings may be more relevant to urban environments in which there may be greater opportunity for caregivers to participate in ADS, and thus, these findings need to be replicated elsewhere.

In conclusion, consistent with previous research on the mental health benefits of ADS use, Black dementia caregivers who utilize ADS experience fewer depressive symptoms compared to those who do not use ADS. Due to the burden of providing care to a person living with dementia, and that Black caregivers provide many more hours of care than their White counterparts and to individuals who tend to have limited resources, Black caregivers may be at risk for depression. ADS may be a critical home- and community-based resource that can provide relief to caregivers, above and beyond religious/spiritual coping strategies and social support. Future research is needed to examine why some Black caregivers utilize ADS and others do not, the additional benefits of ADS use among Black caregivers to support their care experiences, and the financial structure, policy, and programming needed to enhance access to ADS.

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## Conflict of Interest

None declared.

## Author Contributions

L. J. 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. L. N. 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.

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