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Cognitive and Functional Status of Persons Newly Enrolled at Dementia-Specific Adult Day Centers and Burden of Their Caregivers

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Abstract

Background and Objectives: Recognizing the important role that dementia-specific adult day centers have in maintaining persons with a neurocognitive disorder in their home, this article examines three critical indicators at the time when people first enroll in such a center: cognitive and functional impairment of the enrollee, and burden reported by their family caregivers. We also considered variations in these 3 indicators by race/ethnicity and by the relationship of caregiver to the new enrollee.

Research Design and Methods: We conducted a secondary analysis of data collected by a nonprofit organization operating 11 dementia-specific adult day centers located on the east coast of Florida. Nursing staff conducted intake interviews with enrollees and their caregivers, and assessed functional status within one month of admission. Instruments included the Zarit Burden Scale and components of the Minimum Data Set: the Brief Interview for Mental Status (BIMS) and 4 measures of functional status.

Results: On average the cognitive scores of newly enrollees were well-within the range indicated for severe impairment, and these levels did not differ by race/ethnicity. Burden reported by caregivers however differed significantly, with Latinx caregivers reporting the greatest burden and African American/Black caregivers reporting the least. Further, while daughters generally reported higher levels of burden than other family caregivers, Black daughters reported the least.

Discussion and Implications: Results suggest a need for greater dissemination efforts about adult day programs to the Latinx community, as well as attention to the disparate burden placed upon differing family relationships of caregivers to enrollees.

Translational Significance: Adult day centers that specialize in the care of persons with neurocognitive disorders (NCDs) play an important role in both reducing the burden placed upon caregivers and in slowing or even removing the trajectory to institutionalized long-term care. Research on this type of specialized day center is minimal. This article provides information on the cognitive status and functional independence of new enrollees, and the burden of their caregivers at the point of enrollment. It also considers racial/ethnic differences.

Keywords: Daycare, Dementia, Minorities, Neurocognitive disorders

This article investigates the cognitive and functional status of new enrollees to adult day centers that only serve people with neurocognitive disorders (NCDs), and the burden reported by their caregivers. NCDs include Alzheimer's disease and related disorders, such as Lewy body, vascular, or frontotemporal dementia. Although their services are generally not part of specific federal programming, adult day centers do play an important role in the federal government's home and community-based service initiative (HCBS; [Centers for Medicare and Medicaid Services, n.d.](#)). The need for that initiative and its related programs is widely recognized, but to date the literature on day centers is minimal. The final report of the National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers emphasizes the need to identify and study effective comprehensive interventions for community-residing persons with NCDs and their caregivers, and also emphasizes the importance of studying persons from diverse backgrounds ([Gitlin, Maslow, & Khillan, 2018](#); [Hinton, 2017](#)).

Demographics reinforce the importance of community services. The Family Caregiver Alliance (2016; see also [Alzheimer's Association, 2018](#)) reports that as of 2007 there were 12–15 million people in the US who needed long-term care (LTC) services because of behavioral, cognitive, or activity of daily living limitations. Of these people, roughly 63% were aged 65 and older, well more than 8 million were receiving LTC on an annual basis ([Family Caregiver Alliance, 2016](#)), and over half of the latter were receiving care from home health services or from one of the approximately 4,800 adult day centers in the US ([National Center for Health Statistics, 2016](#)). In addition to age distribution, another relevant demographic is the race and ethnicity of day center enrollees. According to a national study of LTC service providers and users, adult day centers generally have higher proportions of Hispanic/Latinx (20.3%) and non-Hispanic Black (17.3%) participants than those using services provided by home health, hospice, nursing homes, and residential care communities ([Harris-Kojetin et al., 2016](#)). Little is known about how and why this heavier use by traditionally underserved populations occurs.

As an alternative to institutional care, adult day centers have existed for decades. While early research questioned their cost benefits, more recent research indicates that these centers are both cost effective and linked to delays in the trajectory toward institutionalization (e.g., [Ellen, Demaio, Lange, & Wilson, 2017](#); [Skarupski & Evans, 2008](#)). They generally serve clients with a broad range of debilitating behavioral and health problems that hinder independent living ([Dabelko-Schoeny, Anderson, & Park, 2016](#); [Szekais, 1985](#); [Weissert et al., 1989](#)). Almost a third of clients have a NCD, and from 25% to nearly 40% need assistance with one or more activities of daily living ([Lendon & Rome, 2018](#)). Given the proportion with an NCD it is not surprising that over two-thirds of adult day centers offer programs in cognitive skills ([Alzheimer's Foundation,](#)

[2018](#)). The prevalence of these programs also reflects the prevalence of NCDs in the US: 5.7–8 million are estimated to be in some stage of Alzheimer's disease; millions more having other forms of NCD ([Alzheimer's Association, 2018](#); [Brookmeyer, Abdalla, Kwas, & Corrada, 2018](#); [Hebert, Weuve, Scherr, & Evans, 2013](#); [Metlife Foundation, 2011](#); [Satizabal et al., 2016](#)).

Another consequence of the high proportion of clients with an NCD has been the growth of day centers that focus on persons with that form of disorder. The [Alzheimer's Foundation \(2018\)](#) estimates that 14% of all adult day centers now specialize in care to persons with Alzheimer's disease or other NCD. In existence since at least the 1990s their caseload of approximately 100% clients with NCDs exceeds that of the more general population of nursing homes. For example, the Alzheimer's Association (2018) reports that in 2014 roughly 50% of nursing home residents had some form of NCD, and 61% of those with NCDs were moderately or severely impaired. NCD-specific adult day centers clearly have an important role to play in community care.

Like other adult day centers, those focused on persons with NCDs typically offer a variety of activities and services. Most focus on the center enrollee but some centers also provide services for family caregivers. By addressing the needs of both enrollee and caregiver, such centers follow family-centered models that may be the most effective ([Zarit & Famia, 2008](#)). This is in contrast to the many community interventions that have focused on psychosocial interventions targeting just the caregiver, with many either failing to provide convincing evidence of efficacy or providing only mixed results. For example, [Gaugler, Reese, and Mittelman \(2018\)](#) report that in a 3-year longitudinal case-control single blind study of the well-known and generally effective New York University psychosocial intervention, no differences were found between cases and controls in degree of caregiver perceptions of social support, role conflict, or family conflict. As another example, [Farran and colleagues \(2016\)](#) found in a randomized 1-year trial with caregivers that an intervention focused on increasing physical activity reduced caregiver burden but only in the short term, while an intervention focused on enhancing caregiver skills did not lead to improvements in burden, positive affect, or depressive symptoms.

As suggested above, one reason for the mixed study findings for interventions may be their frequent focus on either caregiver or care receiver alone. Indeed, there is increasing evidence that NCD-related interventions should attend to both the caregiver and the care recipient, and that because of the great range of problems faced by caregivers and recipients, tailored interventions may be most effective ([Liew & Lee, 2018](#); [Zarit & Famia, 2008](#)). This is where NCD adult day centers come in, since the latter often offer a variety of services, including education and other assistance for the caregiver as well as psychosocial and health-oriented services for the recipient (e.g., [Anderson, Dabelko-Schoeny, Fields, & Carter, 2015](#); [Ellen et al., 2017](#)).

Despite their vital role as a bridge between totally independent living and more institutionalized settings, adult day centers that focus on persons with NCDs have received relatively little attention. In particular, little is known about the characteristics of care recipients and their caregivers at the point of center enrollment. Three questions about their initial characteristics formed the focus of the present study: (1) what are enrollee levels of cognitive and functional impairment and caregiver burden evident at admission, (2) do cognitive and functional impairment and burden differ according to the race/ethnicity and family relation of the caregivers, and (3) do demographic characteristics, levels of cognitive and functional impairment, race/ethnicity, and family relationship of caregivers predict caregiver burden?

Guiding the research was the behavioral model of health services use developed by Andersen (1995; Andersen, Davidson, & Baumeister, 2013). According to this framework, there are potentially three elements that may affect the use of health services: background or predisposing characteristics, enabling personal and community resources, and perceived and evaluated need. The predisposing characteristics include factors, such as age, race/ethnicity, and gender may create vulnerabilities. For example, the Family Care Alliance (2016) reports statistics indicating that older and/or female caregivers may be more burdened by caregiving demands.

Consistent with the model, research suggests that persons from disadvantaged groups often lack access to health care a lack of personal and community enabling resources (the second element of the Andersen model). For example, economic hardship, limited English proficiency, health beliefs, and a general lack of familiarity with services associated with health care are more common in racial/ethnic groups (Clauss-Ehlers, Chiriboga, Hunter, Roysircar-Sodowsky, & Tummala-Narra, 2019; Kim, Kim, Park, Jimenez, & Chiriboga, 2018). However, while the model would lead to a hypothesis that both African American/Black and Hispanic/Latinx caregivers would report burden than non-Hispanic White caregivers, this does not seem to be the case for community caregivers. It has been consistently reported that Black caregivers in the community are among the least burdened, while Hispanics/Latinx are the most burdened (e.g., Aranda & Knight, 1997; Knight & Seyegh, 2010). A critical disadvantage for the latter is that they are not only more likely to suffer from economic issues but also less likely to speak English fluently and utilize services (Ryan, 2013). Finally, and with respect to the third element in the Anderson model, need, there is evidence that members of the Hispanic/Latinx population are less likely to perceive the need for service utilization (Clauss-Ehlers et al., 2019; Rote, Angel, & Markides, 2015).

In general, the Andersen model suggested that the Hispanic caregivers, in particular, would show evidence of a disparity in access, including enrolling their loved one at day centers when the latter are at more advanced stages of cognitive and functional impairment and when they

themselves are experiencing greater burden. In addressing these questions in the context of the Anderson framework, this study had access to a limited but relevant set of data collected at the time of enrollment: levels of cognitive impairment, caregivers' self-assessments of burden, sociodemographic information. Information on activities of daily living, as assessed during the first month of actual participation in a center's activities, was included because not only cognition and burden but functional issues are often associated with placement in nursing homes (e.g., Fong, Mitchell, & Koh, 2015; Miller, & Weissert, 2000; Toot, Swinson, Devi, Challis, & Orrell, 2017) and therefore relevant to studies of enrollment in day centers.

Research Design and Methods

The current study involved a secondary analysis of data collected by a nonprofit organization, Alzheimer's Community Care, Inc. (ACC). In operation for over 20 years, the ACC now operates 11 of the currently-existing 42 state licensed NCD-specific adult day centers in Florida. To qualify for enrollment in an NCD-specific center, Florida Statute 429.918 (Online Sunshine, 2018) requires that potential enrollees must have a "documented diagnosis of Alzheimer's disease or a dementia-related disorder (ADRD) from a licensed physician, licensed physician assistant, or licensed advanced registered nurse practitioner." The ACC adds a requirement that enrollees must be capable of transfer (from bed to chair, etc.) with a maximum of two staff assisting. Requirements for center licensure include a staff to enrollee ratio of 1–5, individualized care plans, monthly nursing evaluations, daily therapeutic activities as defined in the Florida statute, referrals and coordination of services, and on-site presence of a registered or practical nurse for at least 75% of the time.

Expanding on these requirements each of the 11 centers offered a variety of activities and programs: case management with contacts on at least a monthly basis, falls prevention and medication management programs, referrals and support groups for caregivers, wandering/exit-seeking interventions such as an electronic locator system, education provided to senior centers and other community programs, and specialized interventions such as those for persons with an NCD who live alone and for caregivers identified as being at high risk as determined by their burden scores (Zarit, Reever, & Bach-Peterson, 1980).

Sample

All centers operated by the ACC are located in three counties on the east coast of Florida. The sample consisted of all persons enrolling in the ACC from February 2015 through December 2017. The total number of new enrollees potentially available for inclusion in the sample was 569, but the number of people for whom data were available varied from measure to measure and the number with data

available for all measures was 306. Missing data occurred for a variety of reasons. In some cases, a family dropped out before all intake assessments could be completed; in other cases a measure was not recorded by staff at the appropriate point in time, the family opted for other, less intensive services of the ACC that did not include day center use, or the enrollee did not have a caregiver and therefore was dropped from analyses. Because there was a possibility that persons with missing data might differ systematically, a series of *t*-tests were conducted that compared enrollees on study variables who either had or did not have scores on the outcome variable, the Zarit Caregiver Burden Interview (Zarit et al., 1980). No differences were found for age, gender, race, ethnicity, or relationship to caregiver. The one significant difference ($p < .000$) was that enrollees whose caregiver provided a Zarit caregiver burden score were more cognitively impaired: means (and standard deviations) for those with versus without a burden score: 5.61 (4.0) versus 8.04 (4.5).

Measures

Data on cognitive impairment and caregiver burden were collected in face to face interviews by five family nurse coordinators, four with an LPN degree and one with an RN degree; they made initial intake assessments of both the client and caregiver, either before participation in the day centers began or within 30 days of enrollment. Data on race/ethnicity, gender, age, and activities of daily living were entered at each center by nurses, all with LPN or RN degrees, on the basis of caregiver interviews or observation. Both the family nurse coordinators and center staff received initial training on use of the measures, with annual training updates.

Sociodemographic Characteristics

The family nurse coordinators collected information on the age, gender, and race/ethnicity of those with NCD. Sociodemographic information on caregivers was not consistently collected. In all cases, the latter had been identified by staff as the primary caregiver since the ACC staff was required to maintain frequent contact with this individual. Only the race/ethnicity of enrollees was recorded, and therefore when a statement about the race/ethnicity of a caregiver is made it is important to note that the race/ethnicity was inferred on the basis of enrollee information.

Brief Interview for Mental Status (BIMS)

Part of the Minimum Data Set (version 3.0) that forms part of intake and periodic assessment of nursing home residents, the Brief Interview for Mental Status (BIMS) is a 7-item scale that covers word repetition, temporal orientation, and word recall (Centers for Medicare and Medicaid Services, 2014; Saliba et al., 2012). Each item receives a score, and

the sum of all scores is calculated. The sum ranges from 0 to 15, with summary scores of 0–7 indicating severe cognitive impairment, 8–12 indicating moderate impairment, and 13–15 indicating the respondent is cognitively intact. Saliba and colleagues (2012) report a sensitivity and specificity of 0.83 and 0.91, respectively for identifying moderate impairment, and 0.83 and 0.92 for the sensitivity and specificity of identifying severe impairment.

Caregiver Burden

The primary outcome variable in the study, the 22-item Zarit Caregiver Burden Interview (Zarit et al., 1980) assesses a caregiver's self-perceptions of the burden of providing care to a family member. Sample items include "Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?" and "Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?" Each of these items is scored from 0 (*never*) to 4 (*nearly always*), with summated scores ranging from 0 (*no burden reported*) to 88 (*burden reported as nearly always for all items*). Scores from 0 to 20 indicate little or no burden, 21–40 indicate mild to moderate burden, 41–60 indicate moderate to severe burden, and more than 61 indicate severe burden.

Activities of Daily Living

Activities of daily living (ADL) information was obtained for the first month in which the client participated in a day center. Like the BIMS, the ADL measures used for this article were drawn from the Centers for Medicare and Medicaid Services (2014) Minimum Data Set. Four of the 10 MDS ADL items were included: eating, toileting, transfers, and locomotion. Each activity was rated by a nursing staff member of the specific day center attended by the enrollee. Ratings were made on an 8-point scale: "0" (*complete independence in the activity*), "1" (*supervision only*), "2" (*limited assistance from one person in guiding limbs or other nonweight-bearing help*), "3" (*limited assistance from two staff required*), "4" (*extensive assistance from one staff member, but client performs part of activity*), "5" (*extensive assistance from two staff members*), "6" (*total dependence; resident unable to perform task and requires full assistance of one staff member in order to perform the activity*), and "7" (*total dependence; requires full assistance of two staff members*). In addition to individual scores, a summary score of the four ADL items was created, where higher scores indicated greater dependence.

Data analysis

After initial descriptive statistics one-way ANOVAs and a posteriori tests were calculated that contrasted distributions on BIMS and the Zarit Caregiver Burden Interview by both race/ethnicity and caregiver relationship. Hierarchical

regression analyses were then conducted to assess the relationships between caregiver burden and the other independent variables.

Results

On average new enrollees were approximately 80 years old, although in fact 6% were under age 65 due to cognitive impairments arising from early onset Alzheimer’s disease, brain trauma, or other NCDs (Table 1). Possibly reflecting the disease-specific focus of the centers, the proportion aged 85 and older, at approximately 37%, was well above the 16% average for day centers reported in the National Study of Long-Term Care Providers (Harris-Kojetin et al., 2016). There were no racial/ethnic differences in age.

More than 61% were women and the majority of the new enrollees, at 62%, were non-Hispanic White. The proportions of Black (21.6%) and Latinx (16.7%) enrollees were slightly below national averages for persons attending in all types of day centers (Alzheimer Association, 2018). It is noteworthy however that national statistics suggest that both Blacks and Latinx are more likely to participate in adult day centers than they are to any other LTC program, and in fact do so in excess of their proportion of the older population.

Well over a third of enrollees were independent on all four measures of ADL functioning. Nearly 90% were able to eat by themselves and more than 40% were independent

in toileting. Racial/ethnic differences were evident for both locomotion and transfers, with non-Hispanic White enrollees being most likely to be independent (53.4% and 58.2%, respectively). African American/Black enrollees were least likely to be independent in locomotion (36%) and transfers (40.9%).

Finally, the average BIMS score for the sample was 5.22, a score well within the range (summary scores of 0–7) indicating severe cognitive impairment. Indeed 75.8% of the newly enrolled had BIMS scores indicating severe levels of impairment. No differences in BIMS were found across the three racial/ethnic groups.

Turning to the caregivers, their average age, at 66.6, was considerably less than that of the new enrollees, with non-Hispanic White caregivers being the oldest (Table 1). More than 50% were children of the enrollee: daughters were the most common caregiver (42.3%), followed by wives (23.8%), husbands (12.1%), sons (11.4%), and a mixed category of other relationships (10.4%). Significant differences by race/ethnicity were found for the proportion who were wives, daughters, and other family members. Non-Hispanic caregivers were the most likely of any group to be wives (29.6%), Hispanic/Latinx caregivers were most likely of any racial/ethnic group to be daughters (65.4%), and African American/Black caregivers were most likely to be other family members (18.2%). The “other” category included two parents of enrollees, grandchildren, friends and other relatives; keeping in line with results for close family

Table 1. Characteristics of New Enrollees and Their Caregivers

Measures	Total sample (N = 306)	Non-Hispanic White (n = 189)	African American/Black (n = 66)	Hispanic/Latinx (n = 51)
<i>Characteristics of enrollees</i>				
Mean age (SD)	79.64 (10.8)	80.50 (9.7)	77.35 (13.1)	79.41 (11.2)
% 85 and above	36.6	38.6	27.3	41.2
% female	61.4	58.7	66.7	64.7
% Independent				
Toileting	41.2	43.9	39.4	33.3
Locomotion*	48.0	53.4	36.0	45.1
Transfers*	52.9	58.2	40.9	49.0
Eating	89.2	90.5	89.4	84.3
Summated	34.6	38.1	31.8	25.5
Average BIMS (SD)	5.22 (3.9)	5.46 (4.2)	4.86 (3.6)	4.82 (3.3)
% BIMS (severe impairment)	75.8	73.0	78.8	82.4
<i>Characteristics of caregivers</i>				
Average age (SD)**	66.6 (12.8)	69.7 (11.0) ^{2,3}	62.7(15.5) ¹	57.8 (11.1) ¹
% Husband	12.1	15.9	4.5	7.7
% Wife	23.8***	29.6	16.7	11.5
% Son	11.4	13.8	6.1	9.6
% Daughter***	42.3	31.7	54.5	65.4
% Other*	10.4	9.0	18.2	5.8
Average caregiver burden (SD)***	37.43 (17.5)	37.46 (17.3) ^{2,3}	31.41 (14.03) ^{1,3}	45.14 (19.6) ^{1,2}
% moderate to severe burden***	41.2	41.8	27.3	56.9

Note: A posteriori test difference between a group with specified other racial/ethnic groups (numbered 1–3), significant at $p < .05$. * $p < .05$. ** $p < .01$. *** $p < .001$ (ANOVA/chi-square).

caregivers, two thirds of those in the “other” category were female.

While there were no race/ethnicity differences among the enrollees in levels of cognitive impairment, caregivers from the three groups differed significantly from each other in burden (Table 1). Black caregivers reported the least burden ($M = 31.41, SD = 14.03$), Whites were intermediate ($M = 37.46, SD = 17.3$), and Hispanic/Latinx caregivers reported the highest levels ($M = 43.14, SD = 19.6$). The Hispanic/Latinx caregivers were the only group whose average score fell within the moderate to severe burden range; the other two groups score averages were well-within the mild to moderate range (21–40). Nearly 60% of Hispanic/Latinx caregivers, in contrast, were at least moderately burdened, as compared to 41.8% non-Hispanic White and 27.3% African American/Black caregivers.

The family relationship of caregivers was also significantly associated with the outcome variables of interest (Table 2). With regard to cognitive impairment, husbands enrolled their wives when the latter were at significantly greater levels of cognitive impairment ($M = 3.84, SD = 3.6$) than was the case for husbands enrolled by wives ($M = 5.63, SD = 4.5$), and parents enrolled by daughters ($M = 5.35, SD = 3.7$). Sons enrolled parents when the latter were intermediate in terms of the level of cognitive impairment ($M = 5.11, SD = 3.8$).

Somewhat paradoxically, given that they were enrolling spouses at the highest levels of impairment, husbands reported significantly less burden ($M = 29.54, SD = 13.1$) than did wives and daughters. Wives reported the greatest burden at the point of enrollment ($M = 42.07, SD = 18.7$), followed by daughters ($M = 39.00, SD = 17.0$); both wives and daughters reported more burden than husbands, and wives reported more burden than sons ($M = 33.08, SD = 16.5$). Those in the miscellaneous “other” group were in the middle in terms of burden scores but did score significantly lower than wives.

Hierarchical regression analyses provided a multivariate consideration of the results presented above. As a means of checking on the presence of multicollinearity, VIF values were computed. With exception of VIF for interactive terms, the values ranged from 1.01 to 2.2, all being well below 4, a suggested threshold for multicollinearity (Cohen, Cohen, West, & Aiken, 2003); VIF for interactions were necessarily high since measures used to compute interactions are correlated with their products.

For the hierarchical analyses on caregiver burden, the first predictive set included just two variables, client gender and age (Table 3). Gender made a significant contribution: caregivers of men reported significantly more burden than did caregivers of women. In set two, neither functional levels nor cognitive status contributed significantly, but when race and ethnicity were entered as a third set, Latinx caregivers were found to be significantly more burdened when compared with other caregivers. Black caregivers were significantly less burdened when compared with others.

Entry of the family relationship of caregivers to enrollees contributed significantly when entered as the fourth set. Wife and daughter caregivers were significantly more burdened than the referent category of other family caregivers. The fifth and final set examined interactions based on the four indicators that made contributions in sets 3 and 4: being Latinx, Black, a wife or a daughter. Of the four interaction terms, only the one for being Black and a daughter contributed significantly ($p < .05$). As shown in Figure 1, caregivers who were not Black but were daughters scored highest in burden. In contrast, Black caregiver daughters were the least burdened of the four groups.

Discussion

This investigation addressed preliminary findings from 11 NCD-specific adult day centers. Such centers, and indeed adult day centers of all types, are important components of community-based continuum of care programs designed to reduce institutionalization. Most existing studies of adult day centers have examined either costs associated with such services compared with the cost of nursing homes, or have examined the efficacy of adult day centers in delaying the trajectory toward institutionalization. The present study represented a beginning look at the characteristics of the new enrollees and caregivers at the point of enrollment into adult day centers that focus on clients with NCDs.

The research was guided by elements of the Andersen (1995) model of behavioral health services use, which suggests that people from differing sociodemographic and racial/ethnic groups might follow differing pathways toward adult day center enrollment. There were several findings of interest. First, the new enrollees were relatively independent in the performance of ADLs. Second, at 76% the proportion of new enrollees with evidence of severe

Table 2. Caregiver Relationship and Initial BIMS Scores

Measures	Husbands ($n = 37$)	Wives ($n = 73$)	Sons ($n = 35$)	Daughters ($n = 129$)	Other ($n = 32$)
BIMS score**	3.84 (3.6) ^{2,4}	5.63 (4.5) ¹	5.11 (3.8)	5.35 (3.7) ¹	5.5 (4.0)
Burden score***	29.54 (13.1) ^{2,4}	42.07 (18.7) ^{1,3,5}	34.77 (16.6) ²	39.00 (17.0) ¹	32.56 (18.4) ²

Note: A posteriori test difference between a group with specified other family relationship groups (numbered 1–5), significant at $p < .05$.

* $p < .05$. ** $p < .01$. *** $p < .001$ (ANOVA).

Table 3. Standardized Beta Coefficients and Change in Variance Accounted for, Hierarchical Set Regression of the Zarit Burden Score on Selected Client and Caregiver Indicators (*n* = 306)

	Set 1	Set 2	Set 3	Set 4	Set 5
Set statistics	R ² = .03*	R ² change = .00	R ² change = .05***	R ² change = .12*	R ² change = .16*
Client					
Female	-.17**	-.17**	-.16**	-.07	-.07
Age	.02	-.02	-.03	-.06	-.06
ADL total		-.00	.01	.00	.01
BIMS		-.03	-.03	-.06	-.05
Latinx ^a			.14*	.12*	.07
Black ^a			-.13*	-.15*	.02
Caregiver					
Husband ^b				-.09	-.06
Wife ^b				.16*	.69*
Daughter ^b				.17*	.42
Son ^b				-.03	.00
Latinx × Wife interaction ^c					-.14
Latinx × Daughter interaction ^c					.20
Black × Wife interaction ^c					-.37
Black × Daughter interaction ^c					-.46*

p* < .05. *p* < .01.

^aReference group = non-Hispanic White.

^bReference group = other family or friend.

^cReference group = all other family caregiver relationships.

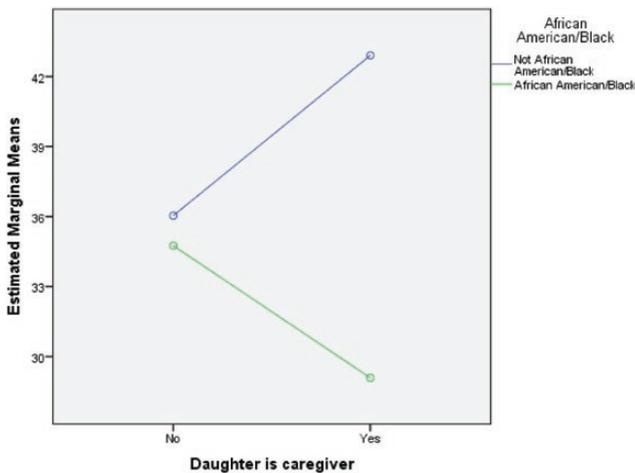


Figure 1. Estimated means of initial Zarit Burden by whether caregiver is a daughter and Black or not.

cognitive impairment exceeded the proportions reported by nursing homes both overall and for residents reported to have a NCD. Third, despite the fact that their wives were being enrolled at significantly higher levels of cognitive impairment than evident among enrolled husbands, and the parents of caregiver daughters, husbands reported significantly lower levels of burden. Fourth, consistent with our expectations based on the literature and the Andersen model, Latinx caregivers were more burdened. However, contrary to the Anderson model Black caregivers reported significantly lower levels than did either non-Hispanic

Whites or Latinx. Fifth, while daughters were generally highest in reported burden, on average Black daughters reported the lowest levels.

With respect to ADLs, there were no significant differences by race/ethnicity. The new enrollees were relatively independent at the point of enrollment, being least independent in locomotion (41%) and most independent in eating (nearly 90%). However only slightly more than one third were independent in all four ADLs studied. To put these findings into perspective, ADL levels were intermediate between, on the one hand, those reported for the general older population or those in all adult day centers, and on the other hand, those reported for the general nursing home population. For example, the functional independence of the new ACC enrollees was lower than those reported in a national study of Medicare beneficiaries in the general population, where among those aged 65–84, 76% reported no difficulties in locomotion, 88% in transfers, 96% in toileting, and 97% in eating (Parker & Guerino, 2014). The functional independence of new enrollees was also lower than reported in a national survey of persons attending all types of adult day centers: Harris-Kojetin and colleagues (2016) reported that approximately 66% were independent in locomotion, 70% in transfers, 64% in toileting, and 76% in eating.

On the other hand, enrollee levels of functional independence were substantially higher than reported for residents of nursing homes. For example, in an early study of over 175,000 nursing home residents, Morris, Fries, and Morris (1999) found that approximately 37% were

independent in eating, 25% in transfers, 32% in locomotion, and only 20% in toileting. More recently, [Harris-Kojetin and colleagues \(2016; see also Parker & Guerino, 2014\)](#) found that among nursing home residents only 9.3% were independent in locomotion, 14.8% in transfers, 12.1% in toileting, and 42% in eating. This intermediate functional status of the new ACC enrollees, between regular adult day centers and nursing homes, may reflect the debilitating nature of neurocognitive disorders. It reinforces the idea that NCD-specific adult day centers serve populations with generally greater service needs.

With respect to cognitive status at enrollment, it was not surprising that the proportion with severe impairment in a NCD-specific community program would exceed that of nursing homes residents as a whole, since nursing homes nationally have approximately 37% with no-to-mild signs of cognitive impairment ([US Department of Health and Human Service, 2015](#)). The high levels of severe cognitive impairment did not vary significantly by the race and ethnicity of the enrollee; combined with the functional dependencies of enrollees, this underscores both the challenges faced by this type of adult day center, and the important role they play in the care of persons with NCDs. Why the 76% of new day center enrollees who scored in the severely impaired range of the BIMS were able to remain living in the community is an open question, one that could not be addressed in this study due to dataset limitations.

Differences in burden scores by race and ethnicity also were of interest. The Andersen model (1995; [Andersen, Davidson, & Laumeister, 2013](#)), with its emphasis on predisposing individual and contextual factors such as economic and education disadvantages, would suggest that in general both Black and Latinx caregivers should be delayed in utilizing services such as adult day centers, and therefore might be expected to report greater burden. This however was not the case in the present sample, where Black caregivers, whose loved ones were no different in cognitive impairment than the other groups, reported significantly less burden than either non-Hispanic or Hispanic caregivers. No information was available in the data that would suggest reasons for the relatively low burden of Black caregivers at the point of enrollment. However, as noted in the introduction, several studies have reported that Black caregivers generally report less burden than other racial/ethnic groups in a variety of caregiving situations (e.g., [Aranda & Knight, 1997; Kang, Brannan, & Heflinger, 2005; Navaie-Waliser et al., 2001](#)). As is the case in the present study, the literature does not identify reasons for the differences.

In contrast to findings for Black caregivers, Hispanic caregivers reported significantly more burden than either of the other two groups at the point when they enrolled their loved one. This finding parallels the substantial literature suggesting potential barriers exit for Hispanic/Latinx caregivers utilizing adult day centers, including a general lack of familiarity with the health care system,

the importance of family solidarity, the prevalence of limited English proficiency, and economic disadvantages (e.g., [Aranda & Knight, 1997; Rote et al., 2015; Ryan, 2013](#)).

Why the results for Hispanic caregivers do conform to expectations based on the Andersen model, while results for Black caregivers did not, cannot be determined from the existing data. As noted previously there is, however, substantial evidence in the literature that the Hispanic population is generally more likely to be economically disadvantaged, less acculturated, and less likely to access health services (e.g., [Dominguez et al., 2015; Velasco-Mondragon, Jimenez, Palladino-Davis, Davis, & Escamilla-Cejudo, 2016](#)). With respect to services, Hispanic/Latinx are known to encounter relatively greater obstacles to program access due to language barriers, cultural factors such as health beliefs, and due to family solidarity that could result in caregivers being reluctant to enroll loved ones in programs such as adult day centers ([Aranda & Knight, 1997; Bengtson & Oyama, 2007; Clauss-Ehlers et al., 2019](#)). There is also some evidence in the literature that Hispanic caregivers to older adults are generally more burdened than caregivers from other racial/ethnic groups ([Aranda & Knight, 1997; Clay, Roth, Wadley, & Haley, 2008; Pinquart, & Sörenson, 2005](#)). Keeping in mind that there were no racial/ethnic differences in the cognitive impairment levels of new enrollees, these results strongly suggest the need for more effective dissemination of information to the Hispanic community about home- and community-based programs like adult day centers. Not knowing the availability of community resources may increase the stress on Hispanic caregivers, as well as limit their options for help seeking. Hence, more attention to community outreach and education may be an important activity for services such as adult day centers in order to attract those most in need and perhaps reduce health care disparities.

Interactions between race/ethnicity and the family relationship of caregivers were also found to play a role in reported burden. Even though in general daughters were likely to report the highest levels of burden, Black daughters were least burdened, followed by all other Black caregivers. In contrast, non-Black daughters reported the highest levels of caregiver burden when their loved one was admitted. Such variations in racial/ethnic family burden have rarely been studied ([Schulz & Eden, 2016](#)), a fact that again underscore the need for further research.

While these results are suggestive of the characteristics of families that decide to enroll a loved one in a NCD-specific day centers, there were a number of methodological hurdles encountered in the study. As a secondary analysis of medical records collected for nonresearch purposes, there were problems encountered in the dataset that led a number of enrollees to be dropped from the multivariate analyses. Chief among these problems was missing data. Our analysis of systematic bias in persons with missing data suggested that there was only one significant difference: those with missing data were less impaired cognitively. It is unclear

why those with missing data differed on cognitive status but not on functional status, age, and other attributes. One possibility is that family members whose loved one was less impaired only partially completed the intake process for center enrollment and instead opted for other programs offered by the nonprofit organization, such as wandering or education programs. Another limitation of concern was that the medical records used in the study were extremely limited with respect to family information. It would have been helpful, for example, to have information on how and why caregivers and care recipients arrived at the decision to enroll.

Despite these limitations, the characteristics of new enrollees and their caregivers provide clues about the pathways to NCD-specific day centers. Results for example suggest the importance of future studies on how men and women from diverse backgrounds make decisions about enrolling their loved one in an adult day center, as well as studying how best to communicate the availability of such centers. Some individuals with severe cognitive impairment but moderate functional impairment may be maintained in the community by using adult day centers. Delineating the specific characteristics of such individuals and their primary caregivers may pave the way for more tailored effective programs that reduce premature institutionalization and perhaps lower health care costs. In conclusion, use of such centers is an increasingly valuable component of the continuum of care for persons with NCD, and therefore it becomes important to understand barriers and facilitators of this usage in order to maintain older adults in the community.

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Conflict of Interest

None reported.

References

- Alzheimer's Association. (2018). 2018 Alzheimer's disease facts and figures. *Alzheimers Dementia*, 14(3), 367–429. Retrieved from <https://www.alz.org/media/HomeOffice/Facts%20and%20Figures/facts-and-figures.pdf>
- Andersen, R. M. (1995). Revisiting the behavioral model and access to medical care: Does it matter? *Journal of Health and Social Behavior*, 36, 1–10. doi:10.2307/2137284
- Anderson, K. A., Dabelko-Schoeny, H. I., Fields, N. L., & Carter, J. R. (2015). Beyond respite: The role of adult day services in supporting dementia caregivers. *Home Health Care Services Quarterly*, 34, 101–112. doi:10.1080/01621424.2015.1040939
- Andersen, R. M., Davidson, P. L. & Baumeister, S. E. (2013). Improving access to care. In G. F. Kominaki (Ed.), *Changing the U.S. health care system: Key issues in health services policy and management* (pp. 33–69). New York: John Wiley and Sons.
- Aranda, M. P., & Knight, B. G. (1997). The influence of ethnicity and culture on the caregiver stress and coping process: A sociocultural review and analysis. *The Gerontologist*, 37, 342–354. doi:10.1093/geront/37.3.342
- Bengtson, V. L., & Oyama, P. S. (2007). Intergenerational solidarity: Strengthening economic and social ties (Background paper). Department of Economic and Social Affairs Division for Social Policy and Development, United Nations. Retrieved from https://www.un.org/esa/socdev/unyin/documents/egm_unhq_oct07_bengtson.pdf
- Brookmeyer, R., Abdalla, N., Kawas, C. H., & Corrada, M. M. (2018). Forecasting the prevalence of preclinical and clinical Alzheimer's disease in the United States. *Alzheimer's & Dementia: the Journal of the Alzheimer's Association*, 14, 121–129. doi:10.1016/j.jalz.2017.10.009
- Centers for Medicare and Medicaid Services. (n.d.). Home & community based services final regulation. Retrieved from <https://www.medicare.gov/medicaid/hcbs/guidance/hcbs-final-regulation/index.html>
- Centers for Medicare & Medicaid Services. (2014). *Long-term care facility resident assessment instrument user's manual, Version 3.0 (October, 2014)*. Centers for Medicare & Medicaid Services. Retrieved from <https://downloads.cms.gov/files/1-MDS-30-RAI-Manual-v1-16-October-1-2018.pdf>
- Clauss-Ehlers, C. S., Chiriboga, D. A., Hunter, S. J., Roysircar, G., & Tummala-Narra, P. (2019). APA multicultural guidelines executive summary: Ecological approach to context, identity, and intersectionality. *The American Psychologist*, 74, 232–244. doi:10.1037/amp0000382
- Clay, O. J., Roth, D. L., Wadley, V. G., & Haley, W. E. (2008). Changes in social support and their impact on psychosocial outcome over a 5-year period for African American and white dementia caregivers. *International Journal of Geriatric Psychiatry*, 23, 857–862. doi:10.1002/gps.1996
- Cohen, J., Cohen, P., West, S. G., & Aiken, L. S. (2003). *Applied multiple regression/correlation analysis for the behavioral sciences* (3rd ed.). Mahwah, NJ: Lawrence Erlbaum.
- Dabelko-Schoeny, H., Anderson, K. A., & Park, J. H. (2016). Adult day services. In G. D. Rowles & P. B. Teaster (Eds.), *Long-term care in an aging society: Theory and practice* (pp. 181–201). New York: Springer Publishing Co.
- Dominguez, K., Penman-Aguilar, A., Chang, M. H., Moonesinghe, R., Castellanos, T., Rodriguez-Lainz, A.,...Schieber, R.; Centers for Disease Control and Prevention (CDC). (2015). Vital signs: Leading causes of death, prevalence of diseases and risk factors, and use of health services among Hispanics in the United States—2009–2013. *MMWR. Morbidity and Mortality Weekly Report*, 64, 469–478.
- Ellen, M. E., Demaio, P., Lange, A., & Wilson, M. G. (2017). Adult day center programs and their associated outcomes on clients, caregivers, and the health system: A scoping review. *The Gerontologist*, 57, e85–e94. doi:10.1093/geront/gnw165
- Family Caregiver Alliance. (2015). Selected long-term care statistics. Retrieved from <https://www.caregiver.org/print/23216>

- Family Caregiver Alliance. (2016). Caregiver statistics: Demographics. Retrieved from <https://www.caregiver.org/caregiver-statistics-demographics>
- Farran, C. J., Paun, O., Cothran, F., Etkin, C. D., Rajan, K. B., Eisenstein, A., & Navaie, M. (2016). Impact of an individualized physical activity intervention on improving mental health outcomes in family caregivers of persons with dementia: A randomized controlled trial. *AIMS Medical Science*, 3, 15–31. doi:10.3934/medsci.2016.1.15
- Fong, J. H., Mitchell, O. S., & Koh, B. S. (2015). Disaggregating activities of daily living limitations for predicting nursing home admission. *Health Services Research*, 50, 560–578. doi:10.1111/1475-6773.12235
- Gaugler, J. E., Reese, M., & Mittelman, M. S. (2018). The effects of a comprehensive psychosocial intervention on secondary stressors and social support for adult child caregivers of persons with dementia. *Innovation in Aging*, 2, 1–10. doi:10.1093/geroni/igy015
- Gitlin, L. N., Maslow, K., & Khillan, R. (2018). National research summit on care, services, and supports for persons with dementia and their caregivers. Report to the National Advisory Council on Alzheimer's Research, Care, and Services. Retrieved from <https://aspe.hhs.gov/system/files/pdf/259156/FinalReport.pdf>
- Harris-Kojetin, L., Sengupta, M., Park-Lee, E., Valverde, R., Caffrey, C., Rome, V., & Lendon, J. (2016). Long-term care providers and services users in the United States: Data from the National Study of Long-Term Care Providers, 2013–2014. National Center for Health Statistics. *Vital and Health Statistics*, 3(38). Retrieved from https://www.cdc.gov/nchs/data/series/sr_03/sr03_038.pdf
- Hebert, L. E., Weuve, J., Scherr, P. A., & Evans, D. A. (2013). Alzheimer disease in the United States (2010–2050) estimated using the 2010 census. *Neurology*, 80, 1778–1783. doi:10.1212/WNL.0b013e31828726f5
- Hinton, L. (2017). Diversity recommendations. Research summit on dementia care. Retrieved from <https://aspe.hhs.gov/system/files/pdf/259151/DiversityRecom.pdf>
- Knight, B. G., & Sayegh, P. (2010). Cultural values and caregiving: The updated Sociocultural Stress and Coping Model. *The Journals of Gerontology: Psychological Sciences*, 65B, 5–13. doi:10.1093/geronb/gbp096
- Kang, E., Brannan, A. M., & Heflinger, C. A. (2005). Racial differences in responses to the Caregiver Strain Questionnaire. *Journal of Child and Family Studies*, 14, 43–56. doi:10.1007/s10826-005-1112-1
- Kim, G., Kim, M., Park, S., Jimenez, D. E., & Chiriboga, D. A. (2018). Limited English proficiency and trajectories of depressive symptoms among Mexican American elders. *The Gerontologist*, 00, 1–9. doi:10.1093/geront/gny032
- Liew, T. M., & Lee, C. S. (2018). Reappraising the efficacy and acceptability of multicomponent interventions for caregiver depression in dementia: The utility of network meta-analysis. *The Gerontologist*, 00, 1–13. doi:10.1093/geront/gny061
- Lendon, J. P., & Rome, V. (2018). Variation in adult day services center attendee characteristics, by center ownership: United States, 2016 (NCHS Data Brief No. 296). Retrieved from <https://www.cdc.gov/nchs/products/databriefs/db296.htm>
- MetLife Foundation. (2011). What America thinks: MetLife Foundation Alzheimer's Survey. Retrieved from <https://www.metlife.com/content/dam/microsites/about/corporate-profile/alzheimers-2011.pdf>
- Miller, E. A., & Weissert, W. G. (2000). Predicting elderly people's risk for nursing home placement, hospitalization, functional impairment, and mortality: A synthesis. *Medical Care Research and Review*, 57, 259–297. doi:10.1177/107755870005700301
- Morris, J. N., Fries, B. E., & Morris, S. A. (1999). Scaling adls within the MDS. *The Journals of Gerontology, Series A: Biological Sciences and Medical Sciences*, 54, M546–M553. doi:10.1093/gerona/54.11.m546
- Navaie-Waliser, M., Feldman, P. H., Gould, D. A., Levine, C., Kuerbis, A. N., & Donelan, K. (2001). The experiences and challenges of informal caregivers: Common themes and differences among Whites, Blacks, and Hispanics. *The Gerontologist*, 41, 733–741. doi:10.1093/geront/41.6.733
- National Center for Health Statistics. (2016). Adult day services centers. Retrieved from <https://www.cdc.gov/nchs/fastats/adsc.htm>
- Online Sunshine. (2018). The 2018 Florida Statutes. Retrieved from http://www.leg.state.fl.us/Statutes/index.cfm?App_mode=Display_Statute&Search_String=&URL=0400-0499/0429/Sections/0429.918.html
- Parker, J., & Guerino, P. (2014). Centers for Medicare and Medicaid Services Releases 2012 MCBS access to care research files: Are Medicare beneficiaries getting the help they need with home-based care? (Medicare Current Beneficiary Survey, Data Brief 002). Retrieved from https://www.cms.gov/Research-Statistics-Data-and-Systems/Research/MCBS/Downloads/Access2012_DataBrief002.pdf
- Pinquant, M., & Sörenson, S. (2005). Ethnic differences in stressors, resources and psychological outcomes of family caregiving: A meta-analysis. *The Gerontologist*, 45(1), 90–106. doi:10.1093/geront/45.1.90
- Rote, S., Angel, J. L., & Markides, K. (2015). Health of elderly Mexican American adults and family caregiver distress. *Research on Aging*, 37(3), 306–331. doi:10.1177/0164027514531028
- Ryan, C. (2013). *Language use in the United States: 2011* (ACS 22). American Community Survey. Retrieved from http://curry.virginia.edu/uploads/resourceLibrary/American_Community_Survey_Language_Report.pdf
- Saliba, D., Buchanan, J., Edelen, M. O., Streim, J., Ouslander, J., Berlowitz, D., & Chodosh, J. (2012). MDS 3.0: Brief interview for mental status. *Journal of the American Medical Directors Association*, 13, 611–617. doi:10.1016/j.jamda.2012.06.004
- Satizabal, C. L., Beiser, A. S., Chouraki, V., Chêne, G., Dufouil, C., & Seshadri, S. (2016). Incidence of dementia over three decades in the Framingham Heart Study. *New England Journal of Medicine*, 374, 523–532. doi:10.1056/NEJMoa1504327
- Schulz, R., & Eden, J. (Eds.). (2016). *Families caring for an aging America*. Washington, DC: National Academies Press. doi:10.17226/23606
- Skarupski, K. A., McCann, J. J., Bienias, J. L., Wolinsky, F. D., Aggarwal, N. T., & Evans, D. A. (2008). Use of home-based formal services by adult day care clients with Alzheimer's disease. *Home Health Care Services Quarterly*, 27, 217–239. doi:10.1080/01621420802320009
- Szekais, B. (1985). Adult day centers: Geriatric day health services in the community. *The Journal of Family Practice*, 20, 157–161.

- Toot, S., Swinson, T., Devine, M., Challis, D., & Orrell, M. (2017). Causes of nursing home placement for older people with dementia: A systematic review and meta-analysis. *International Psychogeriatrics*, *29*, 195–208. doi:10.1017/S1041610216001654
- US Department of Health and Human Services. (2015). *Nursing Home Data Compendium 2015 Edition*. Baltimore, MD: Centers for Medicare & Medicaid Services. Retrieved from https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/CertificationandCompliance/Downloads/nursinghomedatacompendium_508-2015.pdf
- Velasco-Mondragon, E., Jimenez, A., Palladino-Davis, A. G., Davis, D., & Escamilla-Cejudo, J. A. (2016). Hispanic health in the USA: A scoping review of the literature. *Public Health Reviews*, *37*, 31. doi:10.1186/s40985-016-0043-2
- Weissert, W. G., Elston, J. M., Bolda, E. J., Cready, C. M., Zelman, W. N., Sloane, P. D.,...Koch, G. G. (1989). Models of adult day care: Findings from a national survey. *Gerontologist*, *29*, 640–649. doi:10.1093/geront/29.5.640
- Zarit, S., & Famia, E. (2008). Behavioral and psychosocial interventions for family caregivers. *The American Journal of Nursing*, *108*, 47–53. doi:10.1097/01.NAJ.0000336415.60495.34
- Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. *The Gerontologist*, *20*, 649–655. doi:10.1093/geront/20.6.649