

UCLA

UCLA Previously Published Works

Title

Self-efficacy change among diverse family caregivers in dementia care

Permalink

<https://escholarship.org/uc/item/56g6m86x>

Journal

The Journals of Gerontology Series B, 81(2)

ISSN

1079-5014

Authors

Oyeyemi, Deborah M

Greene, Erich J

Xu, Yunshan

et al.

Publication Date

2026-01-12

DOI

10.1093/geronb/gbaf233

Copyright Information

This work is made available under the terms of a Creative Commons Attribution License, available at <https://creativecommons.org/licenses/by/4.0/>

Peer reviewed

Self-efficacy change among diverse family caregivers in dementia care

Deborah M. Oyeyemi, MD, MS^{1,2,*}, Erich J. Greene, PhD³, Yunshan Xu, MS³, David R. Lee, MD, PhD, MBA¹, Rafael Samper-Ternent, MD, PhD^{4,5}, Maya L. Lichtenstein, MD, MHSc⁶, Alan Stevens, PhD⁷, Jeff D. Williamson, MD⁸, Arun S. Karlamangla, MD, PhD¹, Debra Saliba, MD, MPH^{9,10}, David B. Reuben, MD¹

¹Division of Geriatric Medicine, UCLA David Geffen School of Medicine, Los Angeles, California, United States

²National Clinician Scholars Program, UCLA David Geffen School of Medicine, Los Angeles, California, United States

³Department of Biostatistics, Yale School of Public Health, New Haven, Connecticut, United States

⁴Department of Management, Policy, and Community Health, UTHealth Houston, Houston, Texas, United States

⁵Institute on Aging, UTHealth Houston, Houston, Texas, United States

⁶Department of Neurology, Geisinger Health, Pennsylvania, United States,

⁷Center for Applied Health Research, Baylor Scott & White Health & Texas A&M Health Sciences Center, Temple, Texas, United States

⁸Section on Gerontology and Geriatric Medicine, Department of Internal Medicine, Wake Forest School of Medicine, Winston-Salem, North Carolina, United States

⁹Geriatrics Research, Education and Clinical Center (GRECC), U.S. Department of Veterans Affairs Greater Los Angeles Healthcare System (VAGLAS), Los Angeles, California, United States

¹⁰Anna and Harry Borun Center for Gerontological Research, UCLA David Geffen School of Medicine, Los Angeles, California, United States

*Address correspondence to: Deborah M. Oyeyemi, MD, MS. E-mail: doeyemi@g.ucla.edu

Decision Editor: Elizabeth Muñoz, PhD, FGSA (Psychological Sciences Section)

Abstract

Objectives: To determine whether changes in caregiver self-efficacy (beliefs about one's ability to manage dementia-related problems and access help) differed by caregiver race and ethnicity across all participants enrolled in a large pragmatic trial of comprehensive dementia care.

Methods: In the Dementia Care Study (D-CARE), community-dwelling older adults with dementia and their unpaid family caregivers were randomized to receive usual care, community-based, or health system-based comprehensive dementia care. Caregiver self-efficacy was assessed at baseline, 6 months, and 18 months using a 4-item scale (range 4–20, higher scores indicate greater self-efficacy). Among all caregivers, we compared least squares means for overall change in self-efficacy from baseline across racial and ethnic groups (Latino, non-Latino Black, and non-Latino White).

Results: Among 2,126 dementia caregivers, 205 self-identified as Latino, 247 as non-Latino Black, and 1,674 as non-Latino White. Mean baseline caregiver self-efficacy scores were between 13.1 and 13.6 for all racial and ethnic groups. The least squares mean for self-efficacy change was between +1.53 and +1.66 from the baseline for all racial and ethnic groups. Caregiver self-efficacy change did not differ significantly by caregiver race and ethnicity.

Discussion: Black, Latino, and White dementia caregivers reported similar improvements in caregiver self-efficacy after participating in a comprehensive dementia care trial. Personalized aspects of comprehensive dementia care appear to address the needs of diverse caregiver populations.

Clinical Trials Registration: NCT03786471.

Keywords: Care models, Caregiving, Diverse populations

Dementia is a leading cause of death and disability in the United States (Alzheimer's Association, 2024). Family caregivers provide most dementia care, often at the expense of their own well-being (Allen et al., 2017). Comprehensive dementia care—care that includes caregiver support, care coordination, and psychosocial support—has emerged as an evidence-based strategy to improve health outcomes for persons with dementia and their caregivers (Reuben et al., 2023). Yet literature on implementing comprehensive dementia care in diverse populations is limited (Yang et al., 2024).

Recently, the Centers for Medicare & Medicaid Services (CMS) began piloting an innovative payment model—the Guiding an Improved Dementia Experience (GUIDE) model—to reimburse comprehensive dementia care (Centers for Medicare & Medicaid Services [CMS], 2024). With the GUIDE model, CMS aims to address caregiver needs and provide equitable dementia care to racially and ethnically minoritized groups (CMS, 2024). Most comprehensive dementia care models have been piloted in predominately White populations (Possin et al., 2019; Reuben et al., 2013), yet recent studies

have highlighted racial and ethnic variations among family caregivers (Dilworth-Anderson et al., 2020; Liu et al., 2021). Hispanic and Latino dementia caregivers, for example, tend to indicate greater depression on scaled measures while White caregivers tend to report greater caregiver stress, and Black caregivers worse physical health (Coon et al., 2004; Covinsky et al., 2003; Liu et al., 2021). Racial and ethnic variation in psychosocial health, physical health, and appraisals of caregiving may indicate differential needs among dementia caregivers.

Prior studies not focusing on minoritized populations have noted improvements in caregiver self-efficacy—caregivers' beliefs about their ability to manage dementia-related problems and access help—when receiving comprehensive dementia care (Jennings et al., 2015; Merrilees et al., 2020; Reuben et al., 2025). Caregiver self-efficacy, consistent with Pearlin's stress process model for family caregiving, is believed to mediate the relationship between caregiving stressors and coping strategies like social support and respite care (Jennings et al., 2015; Pearlin et al., 1990). While there is no consensus on what defines a clinically meaningful change in self-efficacy, greater caregiver self-efficacy has been associated with reduced emergency department use by persons with dementia, reduced caregiver stress, and improved caregiver quality of life (Gallagher et al., 2011; Guterman et al., 2019; Khan et al., 2021). Given the lack of diversity in dementia care studies, we sought to evaluate the trajectories of dementia caregivers from various racial and ethnic backgrounds. We specifically assessed whether self-efficacy changes among dementia caregivers differed by race and ethnicity in a large comparative effectiveness trial of usual care, community-based, and health system-based comprehensive dementia care.

In a prior study from this trial, caregivers receiving comprehensive dementia care demonstrated greater improvements in self-efficacy than those receiving usual care (Reuben et al., 2025). Building on these findings, we hypothesized that trends in caregiver self-efficacy would be positive overall but vary in magnitude for Black, Latino, and White dementia caregivers in the study, irrespective of treatment group. Based on previous literature highlighting the importance of culturally tailored dementia care interventions for minoritized individuals and their families (Dilworth-Anderson et al., 2020; Liu et al., 2021), we further hypothesized that non-Latino White dementia caregivers would experience greater improvements in self-efficacy than their Black and Latino counterparts. Differing self-efficacy trajectories might indicate the need for additional modification or adaptation for diverse dementia caregiver populations.

Methods

The Dementia Care (D-CARE) Study was a multisite pragmatic randomized trial for persons with dementia and their caregivers. The primary aim of the trial was to compare the effectiveness of 18 months of (1) a standardized dementia care intervention based in a community care organization provided by a social worker, nurse, or therapist to (2) dementia care based in a healthcare system and provided by an advanced practice provider to (3) usual dementia care, including referral to the Alzheimer's Association helpline (Reuben et al., 2025). The D-CARE study was conducted from June 2019 to August 2023 at the following clinical sites: Baylor Scott White Health, Geisinger Health, University of Texas Medical Branch, and Wake Forest University. The central Institutional Review Board

at the University of California, Los Angeles, approved the study. The trial is registered on clinicaltrials.gov (Identifier: NCT03786471).

Community-dwelling older adults with an established dementia diagnosis, who had a primary care provider willing to partner with the trial and an unpaid family or friend caregiver who spoke English or Spanish, were eligible to participate in the trial (Reuben et al., 2025; Yang et al., 2024). Individuals who resided in a nursing home or were enrolled in hospice, as well as individuals whose caregivers had cognitive impairment or were unable to provide self-reported outcomes over the study period, were excluded from the study participation (Reuben et al., 2025; Yang et al., 2024).

For this analysis, the total D-CARE trial sample of 2,176 dementia caregivers was restricted to the 2,126 caregivers who self-identified as either Latino, non-Latino Black (hereafter, Black), or non-Latino White (hereafter, White). Of the remaining 50 caregiver participants, six were American Indian or Alaskan Native, 11 were Asian, 19 identified as more than one race, 13 selected "Other," and one refused to identify in the baseline interview.

Measures

Dementia caregivers completed 4-item self-efficacy assessments at baseline, 6 months, and 18 months into participation in the D-CARE trial (Jennings et al., 2015). Caregivers were asked to rate the degree to which the following statements were accurate (ranging from "strongly agree" to "strongly disagree"):

1. I know how to get community services that will help me provide care.
2. I feel confident that I can handle problems like the patient's memory loss, wandering or behavior problems.
3. I feel confident that I can deal with the frustrations of caregiving.
4. I know where to turn to get answers to questions about problems like the patient's memory loss, wandering, or behavior problems.

Self-efficacy scores ranged from 4 to 20, with higher scores indicating greater self-efficacy (Jennings et al., 2015). Additional measures were used to characterize dementia caregivers and their care recipients at baseline. For caregivers, these measures included: general self-rated health status; the modified caregiver strain index (MCSI) for caregiver strain (Thornton & Travis, 2003); the neuropsychiatric inventory (NPI-Q) caregiver distress scale (Kaufer et al., 2000); and the Patient Health Questionnaire-8 (PHQ-8) for depressive symptoms (Kroenke et al., 2009). For care recipients with dementia, measures included: a shortened version of the Montreal Cognitive Assessment (MoCA) for cognition (Dong et al., 2016); the Functional Activities Questionnaire (FAQ) for instrumental activities of daily living (Pfeffer et al., 1982); and the NPI-Q for severity of behavioral symptoms (Kaufer et al., 2000).

Statistical analysis

The objective of this study was to determine whether caregiver self-efficacy change in the D-CARE trial differed by race and ethnicity over time, regardless of intervention exposure. The primary outcome was caregiver self-efficacy, and the primary exposure was caregiver race and ethnicity (Latino vs Black vs

White). Statistical analyses were conducted using SAS/STAT software version 15.3 (SAS Institute, Cary, NC).

Caregiver self-efficacy was analyzed using a constrained longitudinal repeated-measures model (Fitzmaurice et al., 2012). This model treated baseline scores as outcomes rather than predictors, and all participants were assigned to a common “treatment 0” at baseline before moving into their treatment groups—usual care, community-based, or health system-based comprehensive dementia care—for the follow-up assessments, enabling the treatment groups (but not racial and ethnic groups) to be equated at baseline and allowing caregivers with follow-up data but missing baselines to contribute to the model. The model also included clinical site and racial and ethnic group, and racial and ethnic group was allowed to interact with treatment group. The overall least squares (LS) mean for each racial and ethnic group was calculated as the unweighted average of the LS means for self-efficacy at 6 months and 18 months, and the LS mean change from baseline was calculated as the difference between

the overall LS mean and the baseline LS mean. We then performed a series of pairwise comparisons of LS mean changes across racial and ethnic groups—i.e., Latino vs Black; Latino vs White; and Black vs White. The Hochberg procedure was used to control the overall Type 1 error at 0.05 (two-tailed).

Results

Among 2,126 dementia caregivers, 10% ($n=205$) were Latino, 12% ($n=247$) were Black, and 79% ($n=1,674$) were White (Table 1). In this study, 36 Latino caregivers had a racially or ethnically discordant care recipient with dementia (4 Black, 31 White, 1 “Other” person with dementia), compared to 2 Black caregivers (2 White persons with dementia) and 44 White caregivers (21 Latino, 5 Black, 18 “Other” persons with dementia). Overall, most dementia caregivers were female, were married or partnered, and lived at home with their care recipient (Table 1). However, there were some demographic differences across racial

Table 1. Baseline characteristics for dementia caregivers and their care recipients with dementia by caregiver race and ethnicity.

Characteristics	Latino ($n=205$)	Non-Latino Black ($n=247$)	Non-Latino White ($n=1674$)	<i>P</i>
Caregivers				
Age at baseline, years				
Mean (SD)	61.6 (12.9)	60.9 (12.1)	66.4 (12.0)	<.001
Sex, <i>n</i> (%)				
Male	35 (17.1)	45 (18.2)	432 (25.8)	.002
Female	170 (82.9)	202 (81.8)	1,242 (74.2)	
Marital status, <i>n</i> (%)				
Married or partnered	144 (71.3)	144 (59.0)	1,371 (82.5)	<.001
Widowed	5 (2.5)	7 (2.9)	41 (2.5)	
Divorced	27 (13.4)	34 (13.9)	145 (8.7)	
Single	26 (12.9)	59 (24.2)	104 (6.3)	
Education level, <i>n</i> (%)				
< High school graduate	20 (9.8)	10 (4.0)	35 (2.1)	<.001
High school graduate or GED	55 (26.8)	38 (15.4)	259 (15.5)	
Some college or equivalent	69 (33.7)	76 (30.8)	491 (29.3)	
Graduated from college	44 (21.5)	72 (29.1)	540 (32.3)	
Graduate or professional college degree	17 (8.3)	51 (20.6)	349 (20.8)	
Relation to patient, <i>n</i> (%)				
Spouse/Partner	64 (31.2)	59 (23.9)	838 (50.1)	<.001
Son, daughter, or son-/daughter-in-law	127 (62.0)	159 (64.4)	754 (45.0)	
Other	14 (6.8)	29 (11.7)	82 (4.9)	
Length of time providing care, <i>n</i> (%)				
Less than 6 months	9 (4.4)	11 (4.5)	79 (4.7)	.12
6 months to less than 2 years	52 (25.4)	53 (21.5)	416 (24.9)	
2 years to less than 5 years	68 (33.2)	91 (36.8)	678 (40.5)	
More than 5 years	76 (37.1)	92 (37.2)	499 (29.8)	
Refused to answer/Didn't know/Missing	0 (0.0)	0 (0.0)	2 (0.1)	
General health status, <i>n</i> (%)				
Excellent	33 (16.1)	30 (12.1)	297 (17.7)	<.001
Very good	53 (25.9)	58 (23.5)	562 (33.6)	
Good	77 (37.6)	107 (43.3)	599 (35.8)	
Fair	34 (16.6)	44 (17.8)	178 (10.6)	
Poor	8 (3.9)	8 (3.2)	37 (2.2)	
Refused to answer/Didn't know/Missing	0 (0.0)	0 (0.0)	1 (0.1)	
Treatment group, <i>n</i> (%)				
Health System Intervention	95 (46.3)	119 (48.2)	776 (46.4)	.83
Community-Based Intervention	94 (45.9)	110 (44.5)	793 (47.4)	
Usual Care	16 (7.8)	18 (7.3)	105 (6.3)	

(Continued)

Table 1. (Continued)

Characteristics	Latino (<i>n</i> =205)	Non-Latino Black (<i>n</i> =247)	Non-Latino White (<i>n</i> =1674)	<i>P</i>
Assessment scores, median (IQR) [<i>n</i> with data]				
MCSI	11.0 (6.0–17.0) [203]	11.0 (6.0–17.0) [244]	10.0 (6.0–15.0) [1656]	.1
NPI-Q distress	14.0 (5.0–22.0) [200]	11.0 (3.0–21.0) [240]	11.0 (5.0–18.0) [1643]	.05
PHQ-8	3.0 (1.0–8.0) [201]	4.0 (1.0–8.0) [245]	3.0 (1.0–7.0) [1667]	.85
Care recipients with dementia				
age at baseline, years				
Mean (SD)	81.3 (8.7)	80.7 (8.7)	80.6 (8.5)	.55
Sex, <i>n</i> (%)				
Male	80 (39.0)	83 (33.6)	723 (43.2)	.012
Female	125 (61.0)	164 (66.4)	951 (56.8)	
Education, <i>n</i> (%)				
<High school graduate	96 (47.3)	63 (25.5)	175 (10.5)	<.001
High school graduate or GED	46 (22.7)	78 (31.6)	493 (29.5)	
Some college or equivalent	28 (13.8)	47 (19.0)	421 (25.2)	
Graduated from college	19 (9.4)	38 (15.4)	327 (19.6)	
Graduate or professional college degree	14 (6.9)	21 (8.5)	256 (15.3)	
Marital status, <i>n</i> (%)				
Married or partnered	93 (45.8)	77 (31.6)	975 (58.5)	<.001
Widowed	79 (38.9)	103 (42.2)	520 (31.2)	
Divorced	20 (9.9)	39 (16.0)	145 (8.7)	
Single	11 (5.4)	25 (10.2)	28 (1.7)	
Ethnicity, <i>n</i> (%)				
Latino	169 (82.8)	0 (0.0)	21 (1.3)	<.001
Non-Latino Black	4 (2.0)	245 (99.2)	5 (0.3)	
Non-Latino White	31 (15.2)	2 (0.8)	1,630 (98.4)	
Living situation, <i>n</i> (%)				
At home alone without caregiver	22 (10.7)	30 (12.1)	234 (14.0)	<.001
At home with caregiver	154 (75.1)	185 (74.9)	1,203 (71.9)	
At home with someone else	28 (13.7)	27 (10.9)	130 (7.8)	
Assisted living facility	1 (0.5)	5 (2.0)	107 (6.4)	
Assessment scores, median (IQR) [<i>n</i> with data]				
3-item MoCA	3.0 (2.0–5.0) [163]	3.0 (1.0–5.0) [179]	4.0 (2.0–6.0) [1,154]	<.001
FAQ	23.0 (16.0–28.0) [201]	24.0 (17.0–28.0) [243]	23.0 (17.0–27.0) [1,648]	.07
NPI-Q Severity	10.0 (5.0–16.0) [199]	9.0 (4.0–15.0) [241]	9.0 (5.0–14.0) [1,637]	.08

Note. FAQ = Functional Activities Questionnaire; GED = General Educational Development Test; MCSI = Modified Caregiver Strain Index; MoCA = Montreal Cognitive Assessment; NPI-Q = Neuropsychological Inventory; PHQ-8 = Patient Health Questionnaire-8.

and ethnic groups. For example, White caregivers were older than Black and Latino caregivers, and Black and Latino caregivers were more likely to be the sons or daughters of care recipients, while White caregivers were more likely to be spouses or partners. Black and Latino caregivers had care recipients with worse cognitive function; they also reported worse general health than White caregivers. There were no statistically significant differences in baseline MCSI, NPI-Q, and PHQ-8 scores.

Raw and LS means are presented in Table 2, and LS means are plotted in Figure 1. Caregivers from all three racial and ethnic groups had a positive trajectory in their caregiver self-efficacy scores, with overall LS mean changes from baseline of +1.53 (95% CI: 0.95, 2.11), +1.58 (95% CI: 1.11, 2.05), and +1.66 (95% CI: 1.46, 1.87) for Latino, Black, and White caregivers, respectively. When we evaluated differences in overall caregiver self-efficacy change across racial and ethnic groups, we observed no significant differences among Latino, Black, and White dementia caregivers: Latino vs Black (−0.05; 95% CI: −0.96, 0.87); Latino vs White (−0.13; 95% CI: −0.89,

0.62); Black vs White (−0.09; 95% CI: −0.71, 0.54) (Supplementary Figure 1). The overall interaction of treatment group with racial and ethnic group on overall caregiver self-efficacy was likewise non-significant ($p = .88$); LS means by treatment group and caregiver race and ethnicity are plotted in Supplementary Figure 2.

We conducted a retrospective power analysis to determine whether there was sufficient power to detect a meaningful difference in caregiver self-efficacy change. A total of 2,126 caregiver participants (205 Latino, 247 Black, 1,674 White) contributed data to the model. Based on our observed standard deviations of 3.25 for baseline self-efficacy and 2.58 for average follow-up self-efficacy, observed correlation of 0.50 between baseline and average follow-up self-efficacy, and a conservative alpha of $.05/3 = 0.0167$ to account for performing three comparisons between racial and ethnic groups, we had >87% power to detect a 1-point difference in changes between any pair of racial and ethnic groups on the 4-item self-efficacy scale.

Table 2. Mean caregiver self-efficacy scores by time of assessment and caregiver race and ethnicity.

Assessment	Racial and ethnic group	N (missing)	Mean (SD)	LS Mean (95% CI)
Baseline	Latino	204 (1)	13.56 (0.23)	13.57 (13.11, 14.03)
	Non-Latino Black	247 (0)	13.56 (0.22)	13.67 (13.26, 14.09)
	Non-Latino White	1,665 (9)	13.09 (0.08)	13.15 (12.98, 13.31)
6 Months	Latino	162 (43)	15.40 (0.22)	15.18 (14.60, 15.77)
	Non-Latino Black	188 (59)	15.06 (0.21)	15.15 (14.67, 15.64)
	Non-Latino White	1,332 (342)	14.90 (0.08)	14.71 (14.49, 14.93)
18 Months	Latino	112 (93)	15.27 (0.27)	15.01 (14.29, 15.74)
	Non-Latino Black	144 (103)	15.44 (0.22)	15.35 (14.81, 15.88)
	Non-Latino White	1,028 (646)	15.19 (0.09)	14.91 (14.67, 15.16)
Overall ^a	Latino	204 (1)	14.58 (0.14)	15.10 (14.54, 15.65)
	Non-Latino Black	247 (0)	14.51 (0.13)	15.25 (14.81, 15.69)
	Non-Latino White	1,671 (3)	14.22 (0.05)	14.81 (14.61, 15.01)

Note. LS = least squares; CI = confidence interval.

^aThe overall mean was calculated as the unweighted average of mean caregiver self-efficacy scores at 6 and 18 months.

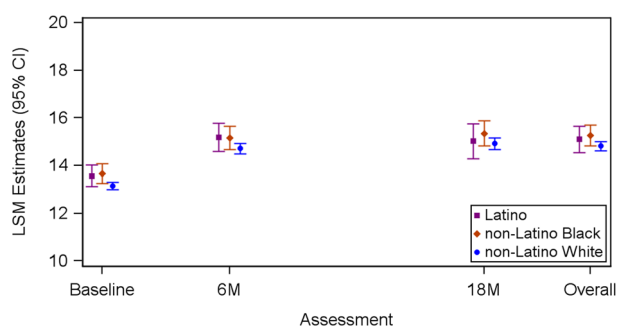


Figure 1. LS Means for caregiver self-efficacy by time of assessment, race, and ethnicity. Note. LS Mean/LSM = Least Squares Mean. The overall LS mean for each racial and ethnic group was calculated as the unweighted average of the LS means for caregiver self-efficacy at 6 and 18 months.

Discussion

This study evaluated whether self-efficacy trajectories among dementia caregivers in an 18-month comprehensive dementia care trial differed by caregiver race and ethnicity. Although there was improvement in caregiver self-efficacy across racial and ethnic groups, we found no significant difference in self-efficacy change among Black, Latino, and White dementia caregivers in the trial. Dementia caregivers, regardless of race and ethnicity, endorsed similar improvements in their ability to manage their care recipients' dementia-related problems and access help. These findings countered our initial hypothesis that caregiver self-efficacy change would be greater among White participants.

Our hypothesis had been informed by previous literature highlighting racial and ethnic differences in the dementia caregiving experience and the importance of culturally tailored dementia interventions (Coon et al., 2004; Covinsky et al., 2003; Dilworth-Anderson et al., 2020; Liu et al., 2021). Had self-efficacy trajectories differed by caregiver race and ethnicity in this study, we might have suggested that dementia care models undergo adaptation to support caregiver mastery and preparedness among diverse dementia caregivers. Instead, we found the opposite—that despite differences in some baseline characteristics, such as self-rated health and care recipient

cognitive function, changes in caregiver self-efficacy were similar across racial and ethnic groups. It is possible that dementia care services, including those provided in the D-CARE trial, are tailored enough to ensure equitable care delivery to dementia caregivers from different racial and ethnic backgrounds.

The D-CARE trial utilized advanced practice providers and community-based social workers, nurses, and therapists to provide longitudinal support to persons with dementia and caregivers randomized to the trial's intervention arms (Reuben et al., 2025). In doing so, the trial aimed to prioritize the needs of dementia caregivers and facilitate person- and family-centered dementia care. Personalized and longitudinal care for dementia caregivers, as demonstrated in this study, may attenuate, though not eliminate, the structural barriers that minoritized individuals face in receiving high-quality dementia care.

Racial and ethnic similarities in caregiver self-efficacy may have also been driven by cross-cultural similarities in our study sample. Caregiver self-efficacy may reflect universal aspects of the dementia caregiving experience that supersede cross-cultural and demographic differences that might typically be associated with variations in other caregiver outcomes like depression (Brummett et al., 2012; Skarupski et al., 2009). Caregiver self-efficacy has rarely been evaluated in subpopulations, such as in this study, so additional research is needed to determine whether the measure might serve as a more pragmatic indicator of dementia care delivery. More data and strategic guidance are also needed to ensure that dementia caregivers from different racial and ethnic backgrounds have similar access to comprehensive dementia care services (Venkataramani, 2023).

Nationally, Black and Latino older adults are more likely to develop dementia but less likely to receive a formal dementia diagnosis, be referred to a dementia specialist, or receive quality dementia care—including access to home health services, care planning services, and hospice care—than White older adults (Fashaw & Thomas, 2020; Lin et al., 2021; Lin et al., 2022). Unequal access to dementia care resources is well-documented in the literature and raises concerns that Black and Latino families may face similar challenges in accessing comprehensive dementia care services. Although we focused on dementia caregivers in this study, our findings suggest that greater emphasis should be placed on ensuring improved access to

comprehensive dementia care for persons with dementia from racially and ethnically minoritized groups and their caregivers, in line with CMS's objectives for the new GUIDE payment model (CMS, 2024).

This study had limitations. This trial identified a single 'primary' dementia caregiver, though dementia caregiving is often shared among multiple family members and friends (Yang et al., 2024). Due to sample constraints, we were also unable to adjust for differences in participant characteristics, examine dementia caregivers from other minoritized groups (e.g., Asian American and American Indian/Alaska Native), and assess contextual factors like nativity status and language in care delivery. Despite these limitations, our findings provide valuable insights into the trajectories of dementia caregivers from different racial and ethnic backgrounds participating in dementia care.

In conclusion, Black, Latino, and White dementia caregivers participating in an 18-month comprehensive dementia care trial showed similar improvements in their self-efficacy. Elements of comprehensive dementia care, such as enhanced caregiver support, care coordination, and psychosocial support, may contribute to equitable care delivery for caregivers. However, greater attention is needed to ensure that Black and Latino families, who often face additional care barriers, receive equitable access to dementia care services.

Supplementary material

Supplementary data are available at *The Journals of Gerontology, Series B: Psychological Sciences and Social Sciences* online.

Funding

The D-CARE study is funded by the Patient-Centered Outcomes Research Institute (grant number PCS-2017C1-6534), a nonprofit institution, and the National Institute on Aging (NIA) (grant number R01 AG061078). The awards include four clinical trial sites. Additional support was provided by the Yale Program on Aging/Claude D. Pepper Older Americans Independence Center (grant number P30AG021342); the National Center for Advancing Translational Science (NCATS), a component of the National Institutes of Health (NIH) (grant number UL1 TR000142); the Mexican Health and Aging Study (grant number R01AG018016); the University of Texas Medical Branch (UTMB) Claude D. Pepper Older Americans Independence Center (OAIC) (grant number P30 AG024832); the Dewey and Cynthia Robertson Fund for Wake Forest Geriatrics and the Wake Forest Alzheimer's Disease Research Center (grant number P30 AG049638). The collaborative work on this manuscript was completed by study investigators and staff who receive salaries and benefits from these funders. D.M.O. also receives support from the UCLA Division of Geriatric Medicine, the Stephen Lesser Fund, and the NIH/NIA Loan Repayment Program. D.R.L. receives support from the UCLA Division of Geriatric Medicine. R.S.-T. receives support from the UTHealth Houston Institute on Aging. J.D.W. receives additional support from the Alzheimer's Association. D.S. receives funding from NIH/NIA for other work not related to this study and is a part-time employee of the Veterans Administration. The funding sources had no role in study design, methodology, analysis and interpretation of data, and

preparation of this manuscript. The content in this paper is solely the responsibility of the authors and does not represent the official views of the Patient-Centered Outcomes Research Institute, the NIH, the Department of Veterans Affairs, or the authors' employers.

Conflict of interest

The authors have no conflicts of interest to declare.

Author contributions

Deborah M. Oyeyemi and David B. Reuben conceptualized the study. Erich J. Greene and Yunshan Xu conducted the analyses. Deborah M. Oyeyemi wrote the initial draft of the paper. All authors contributed to interpreting the data, revising the paper, and approving the final manuscript.

Data availability

The D-CARE Study was preregistered on ClinicalTrials.gov (<https://clinicaltrials.gov/study/NCT03786471>). Data requests should be directed to UCLA Central Project Management (jsummapund@mednet.ucla.edu). D-CARE data access will transition to NACDA Repository in the coming years (<https://www.icpsr.umich.edu/web/pages/NACDA/index.html>).

References

- Allen, A. P., Curran, E. A., Duggan, Á., Cryan, J. F., Chorcóráin, A. N., Dinan, T. G., Molloy, D. W., Kearney, P. M., & Clarke, G. (2017). A systematic review of the psychobiological burden of informal caregiving for patients with dementia: Focus on cognitive and biological markers of chronic stress. *Neuroscience and Biobehavioral Reviews*, 73, 123–164. <https://doi.org/10.1016/j.neubiorev.2016.12.006>
- Alzheimer's Association. (2024). Alzheimer's disease facts and figures. (2024). *Alzheimer's & Dementia*, 20, 3708–3821. <https://doi.org/10.1002/alz.13809>
- Brummett, B. H., Siegler, I. C., Williams, R. B., & Dilworth-Anderson, P. (2012). Associations of social support and 8-year follow-up depressive symptoms: Differences in African American and White caregivers. *Clinical Gerontologist*, 35, 289–302. <https://doi.org/10.1080/07317115.2012.678569>
- Centers for Medicare & Medicaid Services (2024). *Guiding an Improved Dementia Experience (GUIDE) Model*. Retrieved from <https://innovation.cms.gov/innovation-models/guide>
- Coon, D. W., Rubert, M., Solano, N., Mausbach, B., Kraemer, H., Arguëlles, T., Haley, W. E., Thompson, L. W., & Gallagher-Thompson, D. (2004). Well-being, appraisal, and coping in Latina and Caucasian female dementia caregivers: Findings from the REACH study. *Aging & Mental Health*, 8, 330–345. <https://doi.org/10.1080/13607860410001709683>
- Covinsky, K. E., Newcomer, R., Fox, P., Wood, J., Sands, L., Dane, K., & Yaffe, K. (2003). Patient and caregiver characteristics associated with depression in caregivers of patients with dementia. *Journal of General Internal Medicine*, 18, 1006–1014. <https://doi.org/10.1111/j.1525-1497.2003.30103.x>
- Dilworth-Anderson, P., Moon, H., & Aranda, M. P. (2020). Dementia caregiving research: Expanding and reframing the lens of diversity, inclusivity, and intersectionality. *The Gerontologist*, 60, 797–805. <https://doi.org/10.1093/geront/gnaa050>
- Dong, Y., Xu, J., Chan, B. P., Seet, R. C., Venketasubramanian, N., Teoh, H. L., Sharma, V. K., & Chen, C. L. (2016). The Montreal Cognitive Assessment is superior to National Institute of Neurological Disease and Stroke-Canadian Stroke Network 5-minute protocol in

- predicting vascular cognitive impairment at 1 year. *BMC Neurology*, 16, 46. <https://doi.org/10.1186/s12883-016-0570-y>
- Fashaw, S., & Thomas, K. (2020). Racial and ethnic disparities in high-quality home health use among persons with dementia. *Innovation in Aging*, 4, 666. <https://doi.org/10.1093/geroni/igaa057.2305>
- Fitzmaurice, G. M., Laird, N. M., & Ware, J. H. (2012). *Applied longitudinal analysis*. John Wiley & Sons.
- Gallagher, D., Ni Mhaolain, A., Crosby, L., Ryan, D., Lacey, L., Coen, R. F., Walsh, C., Coakley, D., Walsh, J. B., Cunningham, C., & Lawlor, B. A. (2011). Self-efficacy for managing dementia may protect against burden and depression in Alzheimer's caregivers. *Aging & Mental Health*, 15, 663–670. <https://doi.org/10.1080/13607863.2011.562179>
- Guterman, E. L., Allen, I. E., Josephson, S. A., Merrilees, J. J., Dulaney, S., Chiong, W., Lee, K., Bonasera, S. J., Miller, B. L., & Possin, K. L. (2019). Association between caregiver depression and emergency department use among patients with dementia. *JAMA Neurology*, 76, 1166–1173. <https://doi.org/10.1001/jamaneurol.2019.1820>
- Jennings, L. A., Reuben, D. B., Evertson, L. C., Serrano, K. S., Ercoli, L., Grill, J., Chodosh, J., Tan, Z., & Wenger, N. S. (2015). Unmet needs of caregivers of individuals referred to a dementia care program. *Journal of the American Geriatrics Society*, 63, 282–289. <https://doi.org/10.1111/jgs.13251>
- Kaufer, D. I., Cummings, J. L., Ketchel, P., Smith, V., MacMillan, A., Shelley, T., Lopez, O. L., & DeKosky, S. T. (2000). Validation of the NPI-Q, a brief clinical form of the Neuropsychiatric Inventory. *The Journal of Neuropsychiatry and Clinical Neurosciences*, 12, 233–239. <https://doi.org/10.1176/jnp.12.2.233>
- Khan, T. S., Hirschman, K. B., McHugh, M. D., & Naylor, M. D. (2021). Self-efficacy of family caregivers of older adults with cognitive impairment: A concept analysis. *Nursing Forum*, 56, 112–126. <https://doi.org/10.1111/nuf.12499>
- Kroenke, K., Strine, T. W., Spitzer, R. L., Williams, J. B., Berry, J. T., & Mokdad, A. H. (2009). The PHQ-8 as a measure of current depression in the general population. *Journal of Affective Disorders*, 114, 163–173. <https://doi.org/10.1016/j.jad.2008.06.026>
- Lin, P. J., Daly, A. T., Olchanski, N., Cohen, J. T., Neumann, P. J., Faul, J. D., Fillit, H. M., & Freund, K. M. (2021). Dementia diagnosis disparities by race and ethnicity. *Medical Care*, 59, 679–686. <https://doi.org/10.1097/MLR.0000000000001577>
- Lin, P. J., Zhu, Y., Olchanski, N., Cohen, J. T., Neumann, P. J., Faul, J. D., Fillit, H. M., & Freund, K. M. (2022). Racial and ethnic differences in hospice use and hospitalizations at end-of-life among medicare beneficiaries with dementia. *JAMA Network Open*, 5, e2216260. <https://doi.org/10.1001/jamanetworkopen.2022.16260>
- Liu, C., Badana, A. N. S., Burdorf, J., Fabius, C. D., Roth, D. L., & Haley, W. E. (2021). Systematic review and meta-analysis of racial and ethnic differences in dementia caregivers' well-being. *The Gerontologist*, 61, e228–e243. <https://doi.org/10.1093/geront/gnaa028>
- Merrilees, J. J., Bernstein, A., Dulaney, S., Heunis, J., Walker, R., Rah, E., Choi, J., Gawlas, K., Carroll, S., Ong, P., Feuer, J., Braley, T., Clark, A. M., Lee, K., Chiong, W., Bonasera, S. J., Miller, B. L., & Possin, K. L. (2020). The Care Ecosystem: Promoting self-efficacy among dementia family caregivers. *Dementia (London, England)*, 19, 1955–1973. <https://doi.org/10.1177/1471301218814121>
- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist*, 30, 583–594. <https://doi.org/10.1093/geront/30.5.583>
- Pfeffer, R. I., Kurosaki, T. T., Harrah, C. H., Jr, Chance, J. M., & Filos, S. (1982). Measurement of functional activities in older adults in the community. *Journal of Gerontology*, 37, 323–329. <https://doi.org/10.1093/geronj/37.3.323>
- Possin, K. L., Merrilees, J. J., Dulaney, S., Bonasera, S. J., Chiong, W., Lee, K., Hooper, S. M., Allen, I. E., Braley, T., Bernstein, A., Rosa, T. D., Harrison, K., Begert-Hellings, H., Kornak, J., Kahn, J. G., Naasan, G., Lanata, S., Clark, A. M., Chodos, A., Miller, B. L. (2019). Effect of collaborative dementia care via telephone and internet on quality of life, caregiver well-being, and health care use: The Care Ecosystem Randomized Clinical Trial. *JAMA Internal Medicine*, 179, 1658–1667. <https://doi.org/10.1001/jamainternmed.2019.4101>
- Reuben, D. B., Epstein-Lubow, G., & Super, N. (2023). The other dementia breakthrough—comprehensive dementia care. *JAMA Neurology*, 80, 770–772. <https://doi.org/10.1001/jamaneurol.2023.1252>
- Reuben, D. B., Evertson, L. C., Wenger, N. S., Serrano, K., Chodosh, J., Ercoli, L., & Tan, Z. S. (2013). The University of California at Los Angeles Alzheimer's and Dementia Care program for comprehensive, coordinated, patient-centered care: Preliminary data. *Journal of the American Geriatrics Society*, 61, 2214–2218. <https://doi.org/10.1111/jgs.12562>
- Reuben, D. B., Gill, T. M., Stevens, A., Williamson, J., Volpi, E., Lichtenstein, M., Jennings, L. A., Galloway, R., Summapund, J., Araujo, K., Bass, D., Weitzman, L., Tan, Z. S., Evertson, L., Yang, M., Currie, K., Green, A.-N. S., Godoy, S., Abraham, S., Greene, E. J., D-CARE Study. (2025). Health system, community-based, or usual dementia care for persons with dementia and caregivers: The D-CARE Randomized Clinical Trial. *JAMA*, 333, 950–961. e2425056. Advance online publication. <https://doi.org/10.1001/jama.2024.25056>
- Skarupski, K. A., McCann, J. J., Bienias, J. L., & Evans, D. A. (2009). Race differences in emotional adaptation of family caregivers. *Aging & Mental Health*, 13, 715–724. <https://doi.org/10.1080/13607860902845582>
- Thornton, M., & Travis, S. S. (2003). Analysis of the reliability of the modified caregiver strain index. *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences*, 58, S127–S132. <https://doi.org/10.1093/geronb/58.2.s127>
- Venkataramani, A. S. (2023). Moving beyond intent and realizing health equity. *JAMA Health Forum*, 4, e232525. <https://doi.org/10.1001/jamahealthforum.2023.2525>
- Yang, M., Samper-Ternent, R., Volpi, E., Green, A.-N., Lichtenstein, M., Araujo, K., Borek, P., Charpentier, P., Dziura, J., Gill, T. M., Galloway, R., Greene, E. J., Lenoir, K., Peduzzi, P., Meng, C., Reese, J., Shelton, A., Skokos, E. A., Summapund, J., Stevens, A. B. (2024). The dementia care study (D-CARE): Recruitment strategies and demographic characteristics of participants in a pragmatic randomized trial of dementia care. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*, 20, 2575–2588. <https://doi.org/10.1002/alz.13698>