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Research Article

Race Differences in Characteristics and Experiences of Black and White Caregivers of Older Americans

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Abstract

Background and Objectives: Racial disparities in health and socioeconomic characteristics of older adults have implications for the experiences of their family and unpaid caregivers, but knowledge to date has primarily drawn from convenience samples. Using a population-based sample, we examine associations between caregiver race and caregiving-related effects.

Research Design and Methods: Study participants include white (n = 992) and black (n = 556) respondents to the 2015 National Study of Caregiving who assisted community-dwelling older adults with disabilities who participated in the National Health and Aging Trends Study. Guided by Pearlin's Stress Process Model, hierarchical logistic regression models were constructed to examine race differences in caregiving-related effects after adjusting for caregiving context, stressors, and resources.

Results: Relative to white caregivers, blacks more often provided in excess of 40 hr of care per week (54.3% vs 38.6%) and more often cared for an older adult with dementia (27.1% vs 20.7%) who was living below the federal poverty line (31.7% vs 11.9%) or was Medicaid-eligible (42.2% vs 11.8%). Black caregivers more often used supportive services (32.9% vs 24.8%). In fully adjusted regression models, black caregivers were more likely to report gains and less likely to report emotional difficulty than whites. Service utilization did not attenuate caregiving-related emotional difficulty or participation restrictions, regardless of race.

Discussion and Implications: Findings highlight caregiving disparities and counterintuitive differences in experiences and indicate the importance of identifying supports such as paid family leave and faith and community-based programming to better support community-dwelling low-income older adults and their family and unpaid caregivers.

Keywords: Health disparities, Long-term services and supports, Minorities, Racial disparities.

There are an estimated 18 million family and unpaid caregivers of older adults in the United States (The National Academies of Sciences Engineering and Medicine, 2016; Wolff, Spillman, Freedman, & Kasper, 2016). These caregivers provide the majority of long-term services and supports (LTSS) to older adults requiring assistance with daily activities because of health-related challenges (Freedman & Spillman, 2014; Roth, Fredman, & Haley, 2015). There is a general consensus of the value that is derived by family and unpaid caregivers' efforts through enhancing older adults' quality of care and delaying or averting nursing home entry (Chari, Engberg, Ray, & Mehrotra, 2015; National Academies of Sciences Engineering and Medicine, 2016). Caregiving-related benefits and challenges are well established (Bauer & Sousa-Poza, 2015; Robison, Fortinsky, Kleppinger, Shugrue, & Porter, 2009), although the context and experiences may vary by race (Dilworth-Anderson, Williams, & Gibson, 2002).

Black older adults are affected by disparities that extend beyond race differences to such factors as financial resources, Medicare–Medicaid eligibility (dual-eligible), health and functional status, and ability to access needed health care (Fields, Cubanski, Boccuti, & Neuman, 2016; Hebert, Sisk, & Howell, 2008). These disparities may contribute to differentially higher demands for family and unpaid caregivers. Prior studies have found that relative to white caregivers, black caregivers report heavier caregiving demands, and assist older adults with greater functional impairment (Badana, Marino, & Haley, 2019; Dilworth-Anderson et al., 2002; Reinhard et al., 2019). Black caregivers report worse physical health and greater unmet needs for supportive services compared with white caregivers (Badana et al., 2017; Black et al., 2013; Sörensen & Pinquart, 2005), perhaps due to greater caregiving demands and constrained financial resources (Rosenthal Gelman, Sokoloff, Graziani, Arias, & Peralta, 2014). Despite these disparities, some analyses of caregivers find that black caregivers report a more positive appraisal of caregiving than their white counterparts (Haley et al., 2004; Roff et al., 2004; Roth, Dilworth-Anderson, Huang, Gross, & Gitlin, 2015). Less is understood about participation restrictions: some studies have found blacks to report more restrictions than whites (Miyawaki, 2015), while others suggest the opposite (Cudjoe et al., 2018). Still, with few exceptions (Wolff et al., 2016), most evidence regarding racial differences in participation has been limited to the general population of aging adults. Less is known about participation restrictions among family and unpaid caregivers, who often share similar risk factors as older adults, but have the added demand of providing care.

Several initiatives have been recently introduced to better support caregivers. Paid family leave policies have been promulgated by employers as well as state and federal policymakers seeking to ease the conflicting demands experienced by employees who also provide care for a family member (Feinberg, 2019). The RAISE Family Caregivers Council was recently established to provide recommendations to the Secretary of Health and Human Services on strategies to better support family caregivers and coordinate related efforts across federal government programs (Administration for Community Living, 2019). The National Family Caregiver Support Program, enacted in 1982, provides grants to states to fund services for caregivers of older adults (Administration for Community Living, 2019). Little is known about race-based differences in caregivers' use of available services, and whether utilization of services is associated with caregiving experiences.

Knowledge of race differences in caregiving experiences has largely been developed from convenience samples (Pinquart & Sörensen, 2005; Roth, Fredman, et al., 2015) and is not generalizable to the broad population of caregivers. Therefore, population-based analyses confer advantages with respect to informing policy and practice aimed at supporting family and unpaid caregivers. Using Pearlin's Stress Process Model (Pearlin, Mullan, Semple, & Skaff, 1990), the present study extends prior work by investigating race differences in caregiving experiences in a nationally representative sample of caregivers. Pearlin's model has been used to examine caregiver health and well-being and posits that the effects of caregiving (e.g., perceived gains and difficulties) result from a multidimensional process that comprises interrelated conditions that often vary by race. For example, the caregiving context (e.g., income, caregiver relationship to care recipient) reflects personal and social resources available to caregivers that may protect them from or expose them to stressors (Pearlin et al., 1990). Stressors (e.g., care recipient dementia status) may be mitigated by the caregiver's ability to cope under challenging circumstances, which is often influenced by cultural appraisals of caregiving (Dilworth-Anderson et al., 2005). Finally, resources (e.g., supportive services) may influence the impact of race and other stressors on caregiving-related effects as a result of challenges with access or availability (Alliance, 2006; Pearlin et al., 1990). Guided by Pearlin's model and prior literature, we hypothesize the following:

1. Black caregivers will be more likely to report positive aspects and less likely to report negative aspects and emotional difficulty with caregiving.
2. Due to race differences in older adults' health and socioeconomic context, we expect that the physical and financial difficulties and participation restrictions of caregiving will be greater for blacks than whites.
3. Caregivers who use supportive services, regardless of race, will be less likely to report negative effects of caregiving.

This study addresses contemporary concerns about equity and support among older adults who are aging with disability. To inform the development of services and supports to better address the needs of vulnerable older adults and their family and unpaid caregivers, we assess race-based differences in caregiving, drawing on a recent population-based sample with comprehensive information on older adult and family caregiver socioeconomic characteristics, health status, and caregiving circumstances.

Design and Methods

Data

Data are from the 2015 National Health and Aging Trends Study (NHATS) and National Study of Caregiving (NSOC), two linked, nationally representative studies of Medicare beneficiaries aged 65 and older and their family and unpaid caregivers. NHATS participants are sampled from the Medicare enrollment file, with persons in older age groups and of black non-Hispanic race and ethnicity oversampled (DeMatteis, Freedman, & Kasper, 2016; Montaquila, Freedman, & Kasper, 2014). The survey was first fielded in

2011 with annual follow-up interviews. In 2015, the sample was replenished (Freedman & Kasper, 2019). In-person interviews are conducted with study participants or proxy respondents if the participant is unable to respond.

Caregivers of NHATS respondents living in the community and in residential care (nonnursing home) facilities who were receiving assistance with mobility, self-care, or household activities for a health reason were eligible for the NSOC. NHATS respondents provided names of helpers who were contacted for participation in the NSOC and interviewed by phone. Up to five caregivers for each eligible older adult were interviewed. Analytic weights provide nationally representative estimates and account for differential probabilities of selection and nonresponse. Details of the NSOC sample design, including eligibility criteria, and response rates are provided in Freedman, Skehan, Wolff, and Kasper (2019).

For the present study, of the 2,414 NHATS respondents who reported having a caregiver, individuals were excluded if they lived in residential care settings or nursing homes (*n* = 428), or self-identified as a race other than non-Hispanic black or white (*n* = 253). We excluded older adults who only received help with outdoor mobility (getting around outside of the house; *n* = 52). This process yielded a sample of 1,681 older adults for which we describe characteristics by race. Black and white caregivers of individuals from this sample who completed the NSOC were included to examine the characteristics and effects of caregiving. This sample consisted of 1,548 white (*n* = 992) and black (*n* = 556) caregivers.

Measures

Care Recipient Characteristics

We examined older adults' age (65–74; 75–84; 85 and older), level of assistance, probable dementia diagnosis, federal poverty level, and Medicaid status. We measured the level of assistance using a hierarchical measure of types of assistance (self-care, mobility, household for health, or functioning reasons) for which help is provided, described in prior work (Freedman & Spillman, 2014). Activities were categorized as assistance with household activities only, one or two self-care or mobility activities, or three or more self-care or mobility activities. Dementia refers to probable dementia, either by self-report of dementia diagnoses, a score indicating dementia on the AD8 Dementia Screening Interview, and performance on cognitive tests of memory, orientation, and executive function (Kasper, Freedman, & Spillman, 2013). Three income levels (below 100% of the poverty line, between 100% and less than 200% of the poverty line, and 200% of the poverty line or greater) relative to poverty were created based on published federal poverty guidelines for persons 65 and older in 2015 (U.S. Department of Health and Human Services, 2015).

Caregiver Characteristics

Non-Hispanic black or white race, based on self-reported "primary race," was our central measure of interest. We examined caregiver relationship to the care recipient (spouse, child, other family, nonrelative), gender, age (younger than 65, 65–74, 75 and older), and whether the caregiver worked for pay (in the past week). Caregiving intensity was measured by hours of care provided in the prior week. The number of hours was missing for 7% of caregivers. For caregivers who reported providing care on a regular schedule, we recoded missing values to the mean based on the number of days of assistance per week. For those who reported that they provided care on a varying schedule, we recoded missing hours to the mean based on the relationship of the caregiver to the care recipient. Caregiver self-rated health was dichotomized as excellent, very good, or good versus fair or poor. We constructed a dichotomous measure of whether caregivers reported receiving help with daily activities, errands or chores around the house, or helping to care for the care recipient from family members or friends. A second dichotomous measure was constructed, indicating whether caregivers used any supportive services in the past year, reflecting use of support groups, respite care, caregiver training, or financial assistance.

Perceived Gains and Negative Aspects of Caregiving

Perceived gains were measured by asking caregivers whether caring for the care recipient made them (a) feel more confident about their abilities, (b) taught them to deal with difficult situations, (c) brought them closer to him/her, and (d) gave them satisfaction that their loved one is cared for. For each item, response options were *very much* (coded 2), *somewhat* (1), and *not so much* (0). We constructed a scale from 0 to 8, with substantial perceived gains of caregiving defined as 6–8 on a scale of 8, as in Spillman, Wolff, Freedman, and Kasper (2014). The same method was used for measuring negative aspects of caregiving with questions asking caregivers whether caring for the care recipient made them: (a) feel exhausted when they went to bed at night, (b) had more things to do than they could handle, (c) did not have time for themselves, or (d) were unable to maintain a routine due to caring for their loved one.

Difficulties Related to Caregiving

Caregivers indicated whether helping was financially difficult for them. If yes, respondents provided a rating between 1 (*a little difficult*) and 5 (*very difficult*), with a score of 4–5 indicating substantial financial difficulty, as in Wolff and colleagues (2016). The same approach was used to ask about emotional and physical difficulty related to caregiving.

Participation Restrictions

Participation restrictions are defined as not being able to participate in valued activities in the past month because of caregiving. Caregivers were asked to report the importance of the following activities: visiting friends and family, attending religious services, attending club meetings or group activities, and going out for enjoyment. Response options included very important, somewhat important, and not so important. Caregivers were characterized as having a participation restriction if the activity was somewhat or very important, and they were unable to participate because of providing care, similar to the method used in Wolff and colleagues (2016). One dichotomous variable was created to indicate at least one versus no restriction in participation.

Analysis

We first present characteristics of community-dwelling older adults receiving self-care, mobility, or household assistance for a health reason, stratified by race. Next, we compare black and white caregiver characteristics, use of assistance from others or supportive services, and caregiving appraisals and difficulties associated with caregiving. We then construct hierarchical logistic regression models to explore the main effects of race on caregiving effects for which race-based differences were observed in bivariate analyses. These analyses are organized by elements of Pearlin's Stress Process Model. We first report the associations between race and caregiver effects, adjusted for measures of caregiving context (relationship to care recipient, gender, caregiver and care recipient age, education, self-rated health, and employment status). Next, we extend the model to include measures relating to caregiver stressors, including care recipient level of assistance, dementia, dual-eligibility, and federal poverty level, and caregiving hours. In the final step, we examine whether race differences in caregiving effects remain after adjusting for sources of support. All analyses were conducted using weighted data and variables that account for the complex sample design (Freedman, DeMatteis, & Kasper, 2019; Freedman, Skehan, et al., 2019) with Stata, version 15 (StataCorp, 2017).

Results

Comparisons of characteristics of white and black community-dwelling older adults receiving help for health and functioning reasons are presented in Table 1. Compared with white older adults, black older adults were more likely to have probable dementia (27.1% vs 20.7; $p = .02$), were more often living on incomes below 100% of the federal poverty line (31.7% vs 11.9%; $p < .001$), and were more than three times likely to be dual eligible (42.2% vs 11.8%; $p < .001$).

Table 1. Characteristics of Older Adults Receiving Assistance With Routine Daily Activities by Race

	White	Black	
Older adult characteristics	86%	14%	p Value
Older adults receiving help with daily activities (in thousands)	5,783	968	
Age			.74
65–74	39.4	40.6	
75–84	36.6	37.2	
85+	24.0	22.3	
Level of assistance needed			.42
Household activities only	34.3	34.9	
1–2 self-care/mobility activities	42.0	38.7	
3+ self-care/mobility activities	23.7	26.4	
Probable dementia	20.7	27.1	.02
Federal poverty level status			<.001
<100% federal poverty level	11.9	31.7	
100–<200% federal poverty level	30.1	39.0	
200% federal poverty level and above	58.1	29.2	
Medicaid-eligible	11.8	42.2	<.001

Note: Data are survey-weight adjusted; National Health and Aging Trends Study 2015; 1,681 persons 65 and older identifying as white (n = 1,135) or black (n = 546), living in community settings (excluding those in nursing home and residential care facilities) and reporting receiving assistance with self-care, mobility, or household tasks (for a health reason) and eligible for National Study of Caregiving.

Comparisons of characteristics of black and white caregivers are presented in Table 2. Compared with white caregivers, black caregivers were more often a child or other family member (52.4% vs 48.4% and 24.7% vs 14.3%; $p < .001$) and less likely to be a spouse (13.3% vs 28.2%). Black caregivers were less likely to have completed college compared with white caregivers (26.1% vs 36.3%; $p = .01$) and were more likely to be younger than 65 (72% vs 57%; $p < .001$). Additionally, black caregivers were more likely than white caregivers to provide 40 or more hours of care per week (54.3% vs 38.6%; $p < .001$) and to likely to receive help with caregiving from family or friends (82.9% vs 75.5%; $p = .02$).

Overall, the use of supportive services was low regardless of race (Table 3). However, relative to white caregivers, black caregivers were twice as likely to receive caregiver training (13.1% vs 5.5%; $p < .001$) and find financial help for the care recipient (18.7% vs 8.7%; $p < .001$). Black caregivers also were more likely to report having used any services in the past year (32.9% vs 24.8%; $p < .01$) and were twice as likely to use two or more services (10.7% vs 5.4%; $p < .001$) compared with white caregivers. Among those who used services, black caregivers were more likely to receive assistance from government or community agencies (50.5% vs 37.5%; $p = .02$), medical care providers or social workers (69.1% vs 57.5%; $p = .01$), churches or synagogues (21.2% vs 11.7%; $p = .04$), and employers (11.6% vs 5.5%; $p = .02$).

Regarding positive and negative aspects of caregiving (Table 4), black caregivers were more likely to report perceived gains (83.4% vs 62.7%; $p < .01$) and financial difficulties (15.9% vs 10.1%; $p = .05$) from caregiving but were less likely to report emotional difficulty (17.9% vs 28.2%; $p < .01$) compared with

Table 2. Characteristics of Family and Unpaid Caregivers to Older Adults Receiving Assistance in Community Settings by Caregiver Race

Caregiver characteristics	White 83%	Black 17%	*p* Value
Family caregivers to older adults living in the community (in thousands)	10,569	2,241	
Caregiver relationship to care recipient			<.001
Spouse	28.2	13.3	
Child	48.4	52.4	
Other family	14.3	24.7	
Nonrelative	9.1	9.6	
Caregiver is female[a]	63.9	61.9	.51
Education[a]			.01
<High school	45.4	55.2	
Some college	18.2	18.6	
>College degree	36.3	26.1	
Caregiver age			<.001
<65	57.1	72.3	
65–74	24.1	15.1	
75+	18.7	12.5	
Fair/poor self-rated health[a]	21.9	25.1	.32
Caregiver works for pay[b]	39.7	40.6	.81
Hours of care in the past week			<.001
20 hours or fewer	38.7	24.2	
21–39 hours	22.8	21.5	
40 or more hours	38.6	54.3	
Receives help with caregiving from family or friends	75.5	82.9	.02

Note: Data are survey-weight adjusted. National Study of Caregiving 2015; 1,548 white (*n* = 992) and black (*n* = 556) caregivers of white and black community-dwelling (excluding those in residential care facilities) older adults.

[a] Cases with missing data are excluded: *n* = 9 for gender, *n* = 16 for education, *n* = 8 for self-rated health.

[b] Working for pay or doing any unpaid work in a family business or farm in the past week.

Table 3. Use of Supportive Services by Family or Unpaid Caregivers, Stratified by Caregiver Race

Caregiver supportive service use	White 83%	Black 17%	*p* Value
Family caregivers to older adults living in the community (in thousands)	10,569	2,241	
Supportive services			
Support group	3.1	3.7	.58
Respite services	14.1	12.6	.59
Training	5.5	13.1	<.001
Found financial help for recipient	8.7	18.7	<.001
Any use of supports in the last year	24.8	32.9	<.01
Number of supportive services used			<.001
None	75.2	67.0	
One	19.4	22.3	
Two or more	5.4	10.7	
	Using Supportive Services		
Caregiver supportive service use	**25%**	**33%**	***p*-value**
Caregivers using any services (in thousands)	2,623	373	
Source of information about services[a]			
Government or community agency	37.5	50.5	.02
Medical care provider or social worker	57.5	69.1	<.01
Church or synagogue	11.7	21.2	.04
Employer	5.5	11.6	.02
On your own or from a friend	58.3	54.6	.49
Some other source	21.9	22.2	.40

Note: Data are survey-weight adjusted. National Study of Caregiving 2015; 1,548 white (*n* = 992) and black (*n* = 556) caregivers of black and white community-dwelling (excluding those in residential care facilities) older adults.

[a] Percentages for each source among caregivers who used any supportive services in the past year.

white caregivers. Black caregivers were less likely to experience caregiving-related participation restrictions compared with white caregivers (13.9% vs 18.7%; p = .02): this difference was most notable with respect to reduced visiting of friends and family (7.9% vs 11.9%; p = .01).

Multivariate Analysis

Race differences in caregiving experiences were observed in models that adjust for measures of caregiver context (Model 1; Table 5). Relative to white caregivers, black caregivers had higher odds of reporting substantial perceived gains (odds ratio [OR] = 2.88; $p < .001$) and substantial financial difficulty (OR = 1.73; $p < .05$), while conversely, having lower odds of reporting emotional difficulty (OR = 0.54; $p < .01$). No race differences were observed in participation challenges.

The effect of caregiver race on perceived gains and emotional difficulty remained in models that adjusted for caregiving context and stressors (OR = 2.26; $p < .001$ and OR = 0.51; $p < .01$, respectively; Model 2) but was attenuated for financial difficulty. Although the association between caregiver race and participation restrictions was not statistically significant in the model that adjusted for contextual factors only (Model 1), this relationship was stronger and statistically significant after adjusting for caregiver stressors (Model 2)—black caregivers having nearly 40% lower odds of reporting caregiving-related participation restrictions (OR = 0.62; $p < .05$).

Race differences in perceived gains and emotional difficulty remained in models that adjust for sources of support (Model 3): black caregivers were twice as likely to report perceived gains and half as likely to report emotional difficulty (OR = 2.33; $p < .001$ and OR = 0.53; $p < .01$). No significant race differences in financial difficulty or participation restrictions were observed. In fully adjusted models, caregivers who reported using supportive services were more likely to report substantial emotional difficulty

Table 4. Gains, Negative Aspects, and Difficulties Associated With Caregiving, by Caregiver Race

	White	Black	
Caregiver appraisals and difficulties	83%	175	*p* Value
Family caregivers to older adults living in the community (in thousands)	10,569	2,241	
Perceived gains and negative aspects of caregiving[a]			
Substantial perceived gains from caregiving	62.7	83.4	<.01
Substantial negative aspects of caregiving	9.2	7.4	.33
Percent with substantial difficulties related to caregiving[b]			
Financial	10.1	15.9	.05
Emotional	28.2	17.9	<.01
Physical	12.7	10.1	.23
Percent with caregiving-related participation restrictions			
Caregiving restricts participation in 1 or more valued activities	18.7	13.9	.02
Visiting friends and family	11.9	7.9	.01
Attending religious services	7.1	7.2	.93
Attending club meetings or group activities	5.9	5.6	.84
Going out for enjoyment	10.4	7.6	.12

Note: Data are survey-weight adjusted. National Study of Caregiving 2015; 1,548 white (*n* = 992) and black (*n* = 556) caregivers of black and white community-dwelling (excluding those in residential care facilities) older adults.

[a] Substantial positive or negative aspects of caregiving is defined as 6–8 on a scale of 8.

[b] Substantial difficulty is defined as values of 4–5 on the 5-point scale.

[c] Participation restrictions defined as not being able to participate in at least one valued activity because of caregiving activities.

(OR = 1.44; $p < .05$) as well as participation restrictions (OR = 2.36; $p < .001$).

Discussion and Implications

Projected growth in the diversity of older Americans (Colby & Ortman, 2015) alongside evidence that black Americans are at greater risk for dementia and other age-related impairments (Babulal et al., 2019; Fields et al., 2016) heightens the importance of understanding and addressing disparities relating to care needs and caregiving. This population-based study provides insight regarding the magnitude and nature of race differences in caregiving-related effects. While black caregivers were more likely than white caregivers to be providing more care to older adults with greater impairment under circumstances involving greater financial strain, they were paradoxically more likely to experience gains and less likely to report emotional difficulty related to caregiving compared with white caregivers. Contrary to our hypothesis, we did not find evidence of disparities in substantial negative aspects of caregiving or physical difficulty due to providing care. In fully adjusted models, disparities in caregiving-related financial difficulty and participation restrictions were not observed.

Our study reinforces the paradox of race-based disparities among older adults with disabilities: despite the provision of higher intensity care with limited financial resources, black caregivers perceived their situation more favorably. The finding that black caregivers were more likely than white caregivers to report caregiving-related gains and less likely to report substantial emotional difficulty is supported by prior work (Beach, Kinnee, & Schulz, 2019; Roth, Dilworth-Anderson, et al., 2015). For example, a recent systematic review demonstrates that black dementia caregivers report better emotional and psychological well-being than white caregivers (Liu et al., in press). These differences may be explained by cultural appraisals of caregiving and religiosity—black caregivers report stronger cultural reasons for providing care than whites, such as religious or spiritual beliefs, or familial and generational expectations for caregiving (Dilworth-Anderson et al., 2005). The more favorable perceptions of caregiving reported by black caregivers may also be in part due to their greater connection to help with caregiving from family or friends and supportive services. These findings provide the basis for actionable steps for increasing caregiving-related gains, including providing greater attention to strengthening faith-based and community efforts to support the black and white family and unpaid caregivers, which have been shown to be effective. For example, in Chicago, IL, Caring Together, Living Better, a partnership of nonprofit and faith-based organizations, developed a culturally appropriate network of caregiving services and expanded caregiver networks that improved caregiver quality of life (Iris, Berman, & Stein, 2014). Additional supports might include the integration and adoption of technologies (e.g., telehealth) to deliver education or social support to caregivers, which have been found to enhance psychological health, improve caregiving knowledge, skills, coping, and problem solving, and increase communication with providers (Chi & Demiris, 2015).

The positive experiences of caregivers of black older adults may result in "John Henryism," a cultural phenomenon which suggests that individuals perceive that they can meet the demands of their environments through hard work and determination (Bennett et al., 2007; James, 1994). For black caregivers, despite reporting difficulties less often than their white counterparts, research has demonstrated that even with strong coping styles, those with limited access to social and economic resources may have an increased risk for mental illness and chronic disease (Merritt, McCallum, & Fritsch, 2012). To this end, the RAISE Family Caregiving Council (ACL Administration for Community Living, n.d.) and related efforts to support caregiving families should explicitly consider racial differences and disparities in the reporting of caregiving-related stress when making recommendations. Our findings indicate that black caregivers more often use supportive

Table 5. Stage Models of Caregiving-Related Gains, Difficulties, and Participation Restrictions by Caregiver Race Adjusted for Caregiving Context, Stressors, and Support

	Caregiver effects (OR)											
	Substantial perceived gains[b]			Substantial financial difficulty[c]			Substantial emotional difficulty[c]			Participation restrictions[d]		
Multivariate models	1	2	3	1	2	3	1	2	3	1	2	3
Caregiver race[a]												
Race												
White	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Black	2.88***	2.26***	2.33***	1.73*	1.11	1.14	0.54**	0.51**	0.53**	0.84	0.62*	0.65
Caregiving stressors												
Care recipient factors												
Level of assistance												
Household chores only		Ref	Ref		Ref	Ref		Ref	Ref		Ref	Ref
1–2 self-care/mobility needs		0.99	1.00		1.05	1.07		0.72	0.74		1.08	1.13
3+ self-care/mobility needs		0.98	1.01		1.00	0.97		1.34	1.29		2.11**	1.93*
Probable dementia		1.19	1.22		1.23	1.22		2.00*	1.99*		1.17	1.12
Medicaid		1.58	1.61		1.44	1.34		0.47**	0.43**		1.20	0.98
Federal poverty level status												
<100% federal poverty level		Ref	Ref		Ref	Ref		Ref	Ref		Ref	Ref
100–<200% federal poverty level		0.68	0.67		1.52	1.54		0.82	0.82		1.33	1.42
200% federal poverty level and above		0.75	0.75		0.61	0.60		0.61	0.60		1.31	1.31
Caregiver factors												
Hours of care provided in the past week												
20 or fewer		Ref	Ref		Ref	Ref		Ref	Ref		Ref	Ref
21–39		1.83*	1.86*		0.79	0.76		1.24	1.21		2.46**	2.30*
40 or more		2.05***	2.14***		2.25**	2.15*		1.62*	1.56		6.02***	5.58***
Sources of support												
Family and friends			.86			.80			.76			.71
Use of supportive services			.81			1.38			1.44*			2.36***

Notes: OR = odds ratio. Data are survey-weight adjusted; National Study of Caregiving 2015.

[a] Adjusted for caregiving context: relationship to care recipient, gender, caregiver and care recipient age, education, self-rated health, and employment status.

[b] Substantial positive aspects of caregiving defined as 6–8 on a scale of 8.

[c] Substantial difficulty defined as values of 4–5 on the 5-point scale.

[d] Participation restrictions defined as not being able to participate in at least one valued activity because of caregiving activities.

$^{*}p < .05$. $^{**}p < .01$. $^{***}p < .001$.

services compared with whites, as a result of reporting less stress related to caregiving, so some may be less often referred to services. This is particularly relevant for people who are not connected to community-based agencies or who do not interact regularly with a medical care provider or social worker, where most service users in our study received information about services.

Although black caregivers reported using services more often than their white counterparts, disparities in LTSS are notable. For example, while assisted living is increasingly becoming an option for many older adults, it is primarily a private-pay industry, and facilities are often located in counties with lower proportions of minorities (Fabius & Thomas, 2019; Stevenson & Grabowski, 2010). Black older adults are underrepresented in assisted living and have higher rates of hospitalizations and skilled nursing facility utilization compared with whites (Fabius & Thomas, 2019). Additionally, blacks less often use personal care services that help with bathing and dressing and more often receive nonskilled services such as housekeeping within the context of Medicaid Home and Community-Based Services (HCBS; Fabius, Thomas, Zhang, Ogarek, & Shireman, 2018). Black HCBS users are also more likely to be hospitalized and incur lower Medicaid spending than whites (Gorges, Sanghavi, & Konetzka, 2019). It is unclear whether the lower utilization of paid help for personal care is a result of preference or access. If the issue is access, it is important to determine whether the higher number of hours being provided by black caregivers, or greater use of caregiver services is compensating for reduced access to services. These differences likely have implications for black family and unpaid caregivers. For instance, among a cohort of black and white dementia caregivers whose care recipients were utilizing adult day services, black caregivers were more likely to miss a doctor's appointment compared with whites (Parker, Gaugler, Samus, & Gitlin, 2019). The experiences of family and unpaid caregivers should be considered as efforts are made to strengthen LTSSs, using methods such as caregiver assessments to document and address caregiver needs (Kelly, Wolfe, Gibson, & Feinberg, 2013).

Caregivers using supportive services were more likely to report emotional difficulty and participation restrictions than those who did not use supportive services. This may be due to a lack of care coordination between LTSS and medical providers, which often results in family and unpaid caregivers managing multiple systems of care for older adults (Levine, Halper, Peist, & Gould, 2010). Furthermore, caregivers may have difficulty coordinating family or paid providers to help in their absence while they engage in services. It should be noted that we are unable to determine causality, and individuals who are stressed and unable to engage in social activities may also seek services. Longitudinal analyses are needed to examine whether emotional difficulty and participation restrictions are reduced overtime for those using services. Still, adequate care coordination is needed to help families balance the multiple providers and programs that are oftentimes used by caregivers and care recipients.

We recognize several limitations. Our results cannot be interpreted as causal, although we do adjust for several factors that may reflect earlier adulthood (e.g., care recipient dual-eligibility status and federal poverty level status; caregiver education). We are also unable to capture nuances that might better inform our findings, such as cultural expectations for caregiving. We are unable to include geographic location, which might better illustrate the policy environment care recipients and caregivers are living in. For example, one study found that living in states with a higher expenditure on Medicaid HCBS is associated with reduced caregiver stress regardless of whether or not older adults use services (Hong & Casado, 2015). Other work has demonstrated that caregivers living in disadvantaged neighborhoods are less likely to be depressed and report more positive aspects of caregiving (Beach et al., 2019). As our study is limited to family and unpaid caregivers, we are unable to comparatively examine noncaregivers or speak to how our study relates to prevalent disparities in the general population. However, these differences are difficult to disentangle, particularly because family and unpaid caregivers report more psychological strain and poorer quality of life relative to noncaregivers (Roth, Perkins, Wadley, Temple, & Haley, 2009). Despite these limitations, the present study yields important findings for better understanding the experiences of black and white caregivers.

In conclusion, this nationally representative study of family and unpaid caregivers not only finds race differences in the intensity and circumstances surrounding caregiving and supportive services use, but in caregiving-related gains and emotional difficulty. Results indicate a need for greater efforts to increase equity and strengthen the methods of assessing the unique needs of racially diverse caregivers and improving services to support them. Study findings further emphasize the understanding that caregiving is a life course issue that is influenced by differential access to education, workplace supports, and medical care. While recent efforts to increase supports through initiatives such as paid family leave and addressing social determinants of health, greater attention should be devoted to eliminating disparities and addressing equity in aging across the continuum of LTSSs—for both older adults, and their family caregivers.

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Conflict of Interest

None reported.

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