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Racial Variation in the Cancer Caregiving Experience: A Multi-Site Study of Colorectal and Lung Cancer Caregivers

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Abstract

Background—Racial disparities are present in all facets of cancer care; however, little is known about the types of racial disparities that exist in the informal support provided to patients.

Objective—This study, part of a larger multi-site study of care recipients with either lung or colorectal cancer and their caregivers, examined the caregiving experiences of African American (AA) and white caregivers.

Intervention/Methods—Caregivers were identified by cancer patients in the Cancer Care Outcomes Research and Surveillance (CanCORS) consortium. Caregivers completed and returned a self-administered, mailed questionnaire that examined their characteristics and experiences. Analysis of covariance (ANCOVA) was used to compare racial groups by objective burden and caregiving resources while controlling for key covariates.

Results—Despite greater preparedness for the caregiving role (p=0.006), AA caregivers reported more weekly hours caregiving than whites (26.5 ± 3.1 vs. 18.0 ± 1.7; p = 0.01). In later phases of caregiving, AAs reported more social support (p = 0.02), more hours caregiving (31.9 ± 3.5 vs. 16.9 ± 1.9; p < .001), and performing more instrumental activities of daily living on behalf of their care recipient (p = 0.021).

Conclusions—Racial disparities in the caregiving experience exist.

Implications for Practice—Nurses play a key role in educating cancer patients and their caregivers on how to effectively cope with, and manage, cancer. Because AA caregivers appear to spend more time in the caregiving role and perform more caregiving tasks, AA caregivers may benefit from nurse interventions tailored to their specific caregiving experience.

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Introduction

Of the estimated 44 million informal caregivers in the United States, 3.5 million are thought to care for cancer survivors.[1] As cancer care shifts from the inpatient to the outpatient setting[2] and as individuals with cancer in both early and chronic stages live longer, the number of cancer caregivers will grow and their contributions will increase.

While some may assume that caregiving responsibilities are necessary only in the advanced, terminal stages of the disease, the importance of this service is evident throughout the disease process.[3,4] Similar to caregivers of individuals with other health conditions, cancer caregivers experience a range of emotional and psychological reactions as well as physical symptoms.[5–7] For those engaged in this activity, changes in appearance, physical needs, functional ability, social and employment status, and family roles and responsibilities, combined with the emotional reactions of patients to the disease, the treatment process, and the higher risk for premature death, create emotional, psychological, and physical distress.[8–10] Adding to the strain is the fact that caregivers commonly take on responsibilities for navigating the health care system, managing patient symptoms, and sharing or making treatment decisions on behalf of patients.[11–12]

Oncology nurses are well-positioned to address the needs of cancer caregivers. For them to do so, however, they should have an understanding of the multidimensional aspects of this role. In developing interventions, consideration should be given to how the experience varies with various factors, including the stages of the disease and provision of services by those with different racial and ethnic backgrounds. The cancer caregiving experience varies by race. White caregivers who care for advanced cancer patients and who report poor relationships with the patient's healthcare provider are more distressed than African American caregivers who perceive the relationships similarly.[13] In another domain, however, African American cancer caregivers fare less well. Compared to whites, African Americans report more difficulty negotiating time away from work to attend to the new responsibilities that develop from being a caregiver.[14]

An understanding of how different racial groups negotiate the caregiving experience will provide insight into why some interventions aimed at supporting caregivers have not had substantial effects, that is, the interventions may not have reflected the needs of diverse populations. Since only a few studies have explored caregiving by racially diverse populations, the present study addressed this gap in knowledge.

In this effort, we examined care given by black and white caregivers caring for lung and colorectal cancer patients. The challenges of coping with these cancers are many. Lung cancer patients report high levels of depression, fatigue, anxiety, pain, lung cancer symptoms, and poor overall well-being.[15] Among colorectal cancer survivors, compromises in quality of life include less strength, feelings of tiredness, depression and anxiety, concern about cancer recurrence, and less participation in activities that make access to toilets difficult.[16] Given the experiences of these patients, their caregivers face intense and complex situations.

While the present study was not designed to test a specific theory, we included constructs identified as important to assess when exploring the caregiving process. Pearlin's 1990 Stress Process Model[17] provides a useful framework for understanding cancer caregiving. According to this model, contextual factors (e.g., sociodemographic factors, the patient's health status), objective stressors (e.g., caregiving tasks), and resources (e.g., caregiver preparedness for their role) contribute to outcomes (e.g., perceived burden, benefit finding). We sought to determine if race has an independent effect on caregiver objective burden (i.e., number of hours spent caregiving, tasks performed) and caregiver resources (i.e., training received to perform caregiving tasks, social support, and preparedness for the role), after controlling for other contextual factors.

We hypothesized that, after adjusting for relevant factors associated with the caregiving experience, in both the early (within the first year of diagnosis) and late (1 year post diagnosis) phases of the disease, African American caregivers, compared to white caregivers, would report greater objective burdens and fewer resources.

Methods

Caregivers were identified by cancer patients who participated in the Share Thoughts on Care survey[12] conducted by the Cancer Care Outcomes Research and Surveillance (CanCORS) consortium.[18] In 2001, the National Cancer Institute established CanCORS. The Consortium which includes five large geographically based sites, five Cancer Research Network integrated health systems, and 15 Veteran hospitals was formed to identify and better understand the reasons that underlie variations in cancer treatment and cancer outcomes. The recruitment of newly diagnosed lung and colorectal cancer patients (about 4 months after diagnosis) began in 2003. Patients were identified through state cancer registries using rapid case ascertainment or identified from medical records. Minority patients were oversampled. Institutional Review Board approval from each study site was obtained and patients provided informed consent.

The CanCORS patient survey asked a consecutive sample of patients to name and provide contact information for the person who was “most likely to care for you should you need it.” Nominated caregivers were eligible to participate if the caregiver had provided care that was related to the patient’s current cancer diagnosis. Two independent samples of caregivers were drawn for the survey. One sample consisted of caregivers identified within the first year of patient diagnosis; the other sample consisted of caregivers identified after the 1st year of the patient’s diagnosis. We sent caregivers information about the study, a postage-paid return envelope, a $20 incentive, and a survey. A modified Dillman method was used to maximize response rates.[19] Of the 1430 caregivers who were identified within the first year of the patient’s diagnosis and sent questionnaires, and of the 1626 caregivers who were identified after the first year of the patient’s diagnosis we excluded those that provided information indicating that either the patient did not need care or that the identified caregiver did not provide care, those that returned incomplete questionnaires, or if the caregivers were not of Black or White race. Also excluded were those whose care recipients were not eligible for CanCORS based on information provided by the CanCORS Statistical Coordinating Center. These included care recipients who died before the caregiver completed the survey. This resulted in a final sample size of 1249 caregivers, of which 193 (15.5%) were African American and 1056 (84.5%) were white.

Measures—The study survey was developed by an interdisciplinary team across study sties. Measures assessing constructs in the study’s conceptual framework, based on Pearlin’s model, were included. A longer description of the measures appears in our previous paper.[12]

Contextual factors: Caregivers reported their gender, age, household income from all sources, educational level, marital status, current employment status and their relationship to the patient (categorized as spouse vs. other). Caregivers reported their current health status using the single self-reported health status item from the SF-12.[20]

Additional contextual factors included clinical and health status variables collected by medical record abstraction from the patient’s record. These variables included type of cancer (i.e., lung or colorectal), cancer stage at diagnosis, and a comorbidity score (none, mild, moderate, and severe according to the highest ranked single ailment of the 25 ailments in the Adult Comorbidity Evaluation-27, a comorbidity index for patients with cancer.

To assess other caregiving responsibilities and paid help *c*aregivers were asked: “Do you provide unpaid care to any other adults in addition to your care recipient (who has a lung or colorectal disease such as cancer)?” and “Do you provide unpaid care for children (yours or someone else’s)?” and asked, “Have you had any paid helpers assisting you or your Care Recipient as a result of his or her illness?”

Mastery was measured with 8 items, collectively, from the Pearlin Mastery Scale,[21] the Rosenberg Self-esteem scale,[22] and the National Survey of Families and Households, all of which loaded to a common factor. Respondents indicated agreement on a four-point scale to statements such as “On the whole, I am satisfied with myself,” and “I have little control over the things that happen to me.” A single mastery variable (Cronbach’s alpha=.79) was created that consisted of an average of responses to all 8 items.

Objective Caregiver Burden: Objective burden included standard and validated measures including number of ADLs, IADLs, and disease specific measures for CRC and lung cancer. We collected: time spent caregiving (i.e., weekly hours of care), number of clinical care tasks performed (e.g., help administering medicines to the care recipient, time spent assisting Care Recipient manage or control symptoms etc), and number of Activities of Daily Living (ADL) was based on previous work[23] (e.g., bathing the care recipient, helping the care recipient get around etc.) performed, and number of times the caregiver assisted with Instrumental Activities of Daily Living (IADL) (e.g., driving the care recipient to the doctor managing care recipient’s money etc.). For clinical care tasks, ADLs, and IADLs, caregivers responded in reference to the past 2 weeks.

Caregiver Resources: Caregivers indicated whether they received training to help their Care Recipient manage nausea, pain, fatigue, side effects/symptoms, administer medicine or change bandages. Response options were “yes,” “no,” and “not needed,” with “Yes” responses coded to one and summed to create a training score.

Caregiver preparedness/self efficacy was assessed using four items from the preparedness subscale of the Family Caregiving Inventory[24] that measures how confident the respondent feels regarding caring for the patients’ emotional needs, physical needs, finding needed services, and coping with the stress of caregiving. Response options ranged from “not at all confident” to “extremely confident” on a five-point scale. A preparedness variable was calculated by averaging the responses across the four items (Cronbach’s alpha=.83).

Perceived social support was measured with the MOS Social Support Scale.[24–27] Scale items assess the frequency of receiving specific types of support from “none of the time” to “all of the time.” Exploratory factor analysis identified three subscales of support in this sample*: emotional* (Cronbach’s alpha=.94)*, informational* (Cronbach’s alpha=.96) and *instrumental* (Cronbach’s alpha=.93). The global social support scale also showed good internal consistency (Cronbach’s alpha=.97).

Statistical Analyses—SAS software (version 9.1.3; SAS Institute, Inc., Cary, NC) was used to perform all statistical analyses. Descriptive statistics were used to summarize study variables. Differences in caregiver demographics, health status, objective burden (ADLs, clinical tasks, number of hours per week), other caregiving responsibilities and paid help, resources available to care for the patient (training received to perform clinical tasks, global, informational, instrumental, and emotional support, caregiver preparedness and mastery), and care recipient health status (including cancer type, cancer stage, and ACE 27 comorbidity score) by race (African Americans and whites) were calculated using the usual two-group test, or the two-group t-test for unequal variances when needed, for continuous variables, and the two-group chi-square test, or Fisher's exact test when needed, for categorical variables. Comparisons were performed separately for each phase of caregiving. However, these comparisons were not performed separately for care recipient cancer type. The two cancer types were combined in order to increase the sample sizes of caregivers in these analyses, particularly for the African American caregivers (where the sample sizes were very small when stratified by cancer type for some of the demographic and clinical characteristics). Cancer type was considered as one of the clinical characteristics in the univariate analyses, and as one of the key covariates in the multivariate analyses (described below).

Analysis of covariance (ANCOVA) was used to compare racial groups by objective burden and caregiving resources while controlling for key covariates (caregiver educational level, income, employment status, SF-12 mental and physical summary scores, relationship to the care recipient, and care recipient cancer type, cancer stage, and ACE 27 comorbidity score). Because African Americans tend to be diagnosed at a later stage of disease and have higher mortality, we controlled for cancer stage and the patient's comorbidity score when examining racial disparities in the caregiving experience. Since caregiving preparedness might be influenced by the caregiver's general levels of mastery, mastery was included in the caregiver preparedness model. P-values obtained from the ANCOVAs were based on the Type III sum of squares. A separate model was examined for each outcome of interest. For each model, an overall P-value and a P-value for the race effect is reported. All statistical tests were two-sided and were performed using a 5% significance level (alpha = 0.05).

Results

African American caregivers returned a lower proportion of mailed surveys than did white caregivers (60.8% vs. 69.2%, p = 0.025) for the earlier, and (51.9% vs. 63.4%, p = 0.004) for the later phase of caregiving. Overall, the majority of caregivers were female, had at least some college education, worked for pay, and had SF-12 scores that indicated that their health status was slightly below population norms (Table 1).

There were notable racial differences in caregiver characteristics (Table 1). In both the early and later phases of caregiving, African American caregivers were less likely to be the spouse of the care recipient (46.6% vs. 60.2%, p = 0.01 and 50.6% vs. 65.4%, p = 0.008), less likely to be 65 years and older (18.4% vs. 36.9%, p < 0.001; 26.4% vs. 38.1%, p = 0.037), less likely to be male (13.5% vs. 23.8%, p = 0.020; 18.2% vs 29.1%, p = 0.035), and less likely to be married (59.6% vs. 83.1%, p < 0.001; 62.9% vs 82.3%, p < 0.001). In the early phase, African American caregivers were less likely to be unemployed (p = 0.006), and their care recipient less likely to have severe comorbidities than whites (p = 0.026). In the later phase, African Americans were less likely to have incomes of $80,000 or more (8% vs. 30.2%, p = 0.002).

African American caregivers reported greater objective burden. African Americans reported more hours per week caregiving for both the early and the later phase of caregiving (p = 0.018 and p= 0.009, respectively). No significant race differences on other indicators of objective burden were found.

For the early cancer caregiving phase, African Americans were more likely to have child care responsibilities (23.8% vs 14.3%, p = 0.017), a finding that approached significance for caregivers in the later phase (22.5% vs. 15.1%, p = 0.081). African Americans reported greater informational social support in both phases of later, p = 0.035 and p = 0.032, respectively and in the early phase, African American caregivers reported more preparedness for the caregiving role ($p < 0.001$) (Table 2).

Our hypotheses that African American caregivers would report more objective burden in both the early and later phases of caregiving were supported. In multivariable analyses (Tables 3 and 4), African American cancer caregivers reported more hours caregiving (26.5 ± 3.1 vs. 18.0 ± 1.7; $p = 0.01$) in the early and in the later phase of caregiving (31.9 ± 3.5 vs. 16.9 ± 1.9; $p < .001$). In the later phase of caregiving, African Americans also reported higher IADL counts ($p = 0.021$), and tended to have greater task counts ($p = 0.065$), although the latter was not significant.

Our hypotheses that African American caregivers would report fewer personal resources however were not supported. African Americans appeared better prepared for the caregiving role. In the early phase of caregiving, African Americans tended to have greater informational support ($p = 0.054$) and reported greater caregiver preparedness ($p = 0.006$). In the later phase of caregiving, African Americans reported greater instrumental social support ($p = 0.020$).

Discussion

To our knowledge, this is the first multi-site study to explore the caregiving experience in a racially diverse sample of lung and colorectal cancer caregivers in two phases of cancer caregiving. Our contribution to the literature is significant. In the context of African American cancer caregivers engaging in more paid work, having less marital support (because they were more likely to be unmarried), being younger, and having less income and more child care, African American caregivers perceived greater preparedness for the caregiving role. They rose to the challenge of caregiving as reflected in significantly more hours in this role.

Consistent with previous research across a range of health conditions, [14, 28–30] the African American caregivers in our study were younger and less likely to have a spousal relationship with the care recipient. The younger age may explain in part, the higher proportion of African Americans caring for a child and the greater involvement in full time work. Our study results suggest that caregiver interventions should be tailored to the individual’s stage of life and for African American caregivers, caring for their loved one with cancer may be in addition to other caregiving and work responsibilities.

Studies have documented cancer caregiving as burdensome for families and impacting quality of life, especially if resources are limited.[31–32] Few cancer-related studies, however, have been able to determine whether caregiving burden varies by race. In our study, African American cancer caregivers reported more hours of caregiving compared to white caregivers. African American caregivers in the later phase of caregiving also reported performing more IADLS. The finding that African Americans spent more time in the caregiving role compared to their white caregivers, independent of patient stage of disease and comorbidities, may reflect a relative lack of other instrumental care resources.

The greater objective burden African American caregivers carry may be buffered by greater perceived personal resources. In the early phase of caregiving, African American caregivers reported greater preparedness for the caregiving role. These findings may reflect what some researchers have described as a cultural orientation to the caregiving role, including a more positive appraisal of their caregiving experience among African Americans.[33] Interestingly, the greater preparedness for the caregiving role observed in the early phase of cancer later was not observed in the later phase. The reasons underlying this difference are not clear and suggest that factors other than individual level factors may influence how prepared a caregiver feels for the caregiving task.

African American caregivers in the later phase of caregiving reported greater instrumental support (i.e., help in completing tasks). This finding may reflect the fact that caregivers [34–35] feel less prepared for the caregiving role in the later phase and thus relied on greater social support to assist with caregiving. Future research should explore how this personal resource is integrated into the caregiving experience.

This study has limitations and strengths. The cross-sectional design does not allow us to infer causation. Longitudinal research is needed to test causal pathways in caregiving and to better understand the cumulative impact of caregiving on caregiver and patient outcomes. The differential response rates between African American and white caregivers may have also influenced results. We do not know if the African American caregivers who responded reflect the African American caregivers in the CanCORs study. Finally, our paper does not explore burden beyond caregiving duties or tasks, for example, we do not explore the financial burden of caregiving. Within this same study sample, in a separate paper and analysis, we found that the time spent by caregivers in the caregiving role exacted a significant financial burden on caregivers.[36]

Our paper also has several strengths. First, exploring the experience of caregivers providing support for this group of cancer patients we add to a small but growing literature that examines the caregiving experience in a racially diverse group of cancer caregivers. Second, consistent with the Pearlin Model of Stress, we included in our study a number of contextual factors associated with caregiving, including caregiver demographics, relationship to the patient, the caregiver’s own quality of life assessment and the patient’s health status as abstracted from medical records, before examining the association of race with objective burden indicators and personal resources. Our finding that racial differences in the caregiving experience persisted even after controlling for this constellation of factors should stimulate future research to better understand the factors that shape the caregiving experience for African Americans. Third, using the same study instruments, we examined caregiving in two phases allowing for comparisons of the two phases and providing important information on how the caregiving experience may differ at different time points in the cancer trajectory

In closing, providing quality cancer care should include support of the patient and their caregiver. Intervention research involving caregivers typically focus on patient-related outcomes, although interventions can improve caregiver outcomes (e.g., increasing caregiver self efficacy reduces caregiver strain).[37] For nurses and other healthcare providers, our study has several practical implications. First, our findings underscore the need for comprehensive and integrated care that includes patients, caregivers and providers in a plan that aims to address the needs of the both the patient and the caregiver. Second, providers may affect caregiving experiences and therefore should be careful about making assumptions about availability of, and access to resources such as social support and preparedness. Finally, health care providers can support caregivers and patients by understanding that like patients, caregiver experiences may change throughout the course of care. To better support caregivers, oncology nurses should regularly assess the caregiver experience so that interventions reflect the context of caregiving for that caregiver and reflects the changing needs across the cancer care continuum.

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Table 1

Sociodemographic and Clinical Characteristics of Caregivers and Care Recipients by Caregiving Phase and Race

	Early Caregiving Phase					Later Caregiving Phase				
	AA^a		W^b		Stat. Sign. (p value)	AA^c		W^d		Stat. Sign. (p value)
	No.	%	No.	%		No.	%	N o.	%	
Demographics										
Relationship to patient										
Spouse	48	46.6	328	60.2	0.010	45	50.6	332	65.4	0.008
Other	55	53.4	217	39.8		44	49.4	176	34.6	
Caregiver Gender										
Male	14	13.5	129	23.8	0.020	16	18.2	148	29.1	0.035
Female	90	86.5	414	76.2		72	81.8	361	70.9	
Caregiver Age										
< 65	84	81.6	342	63.1	<0.001	64	73.6	315	61.9	0.037
≥ 65	19	18.4	200	36.9		23	26.4	194	38.1	
Caregiver Household Income										
Less than $10,000	14	14.7	34	7.0		10	13.3	28	6.2	
$10,000 – $14,999	8	8.4	36	7.4		7	9.3	19	4.2	
$15,000 – $19,999	7	7.4	46	9.5		7	9.3	27	6.0	
$20,000 – $39,999	28	29.5	132	27.2	0.18	19	25.3	100	22.2	0.002
$40,000 – $59,999	17	17.9	94	19.3		16	21.3	84	18.7	
$60,000 – $79,000	10	10.5	52	10.7		10	13.3	56	12.4	
$80,000 +	11	11.6	92	18.9		6	8.0	136	30.2	
Caregiver Education										
< high school	19	18.3	61	11.2		5	5.6	53	10.5	
High school	22	21.2	158	29.0	0.14	23	25.8	110	21.7	0.098
Some college or 2 yr degree	43	41.3	224	41.2		41	46.1	184	36.4	
4 year degree or more	20	19.2	101	18.6		20	22.5	159	31.4	

	Early Caregiving Phase					Later Caregiving Phase				
	AA^a		W^b		Stat. Sign. (p value)	AA^c		W^d		Stat. Sign. (p value)
	No.	%	No.	%		No.	%	N o.	%	
Caregiver Marital Status										
Married	62	59.6	453	83.1	<0.001	56	62.9	419	82.3	<0.001
Unmarried (any reason)	42	40.4	92	16.9		33	37.1	90	17.7	
Caregiver Work Status										
Not working for Pay	35	33.7	275	50.5	0.006	41	46.1	249	48.7	0.61
Working Part-time	21	20.2	92	16.9		11	12.4	76	14.9	
Working Full-time	48	46.2	178	32.7		37	41.6	186	36.4	
Health Status										
Caregiver Health Status										
Physical (Mean ± SD)	47.4 ± 10.8		48.5 ± 11.4		0.39	45.3 ± 10.1		47.7 ± 11.7		0.087
Mental (Mean ± SD)	48.0 ± 10.4		47.3 ± 10.7		0.54	48.6 ± 11.1		46.8 ± 11.1		0.19
Care Recipient Cancer Stage										
I	26	25.0	146	27.4	0.35	24	28.2	152	30.6	0.66
II	22	21.2	92	17.3		22	25.6	113	22.8	
III	29	27.9	185	34.7		30	35.3	158	31.9	
IV	27	26.0	110	20.6		9	10.6	73	14.7	
Cancer Type										
Lung	41	39.4	313	57.4	<0.001	29	32.6	224	43.8	0.047
Colorectal	63	60.6	232	42.6		60	67.4	287	56.2	
Care Recipient ACE 27										
Comorbidity Score	30	30.0	99	20.0	0.026	18	24.3	111	24.7	0.25
None	35	35.0	175	35.2		35	47.3	176	39.2	
Mild	24	24.0	112	22.5		15	20.3	87	19.4	
Moderate Severe	11	11.0	111	22.3		6	8.1	75	16.7	

Footnotes:

[a] = Sample sizes range from 95 – 104

[b] = Sample sizes range from 486 – 545

[c] = Sample sizes range from 74 – 89

[d] = Sample sizes range from 449 – 511

Table 2

Caregiver Objective Burden, Additional Caregiving Responsibilities, and Caregiver Resources by Caregiving Phase and Race

	Early Caregiving Phase			Later Caregiving Phase		
	AA[a]	W[b]	Stat. Sign. (p value)	AA[c]	W[d]	Stat. Sign. (p value)
Construct	**M ± SD**	**M ± SD**		**M ± SD**	**M ± SD**	
Caregiver Objective Burden						
■ ADL	1.3 ± 2.4	1.2 ± 1.9	0.68	1.0 ± 1.8	1.0 ± 1.8	0.94
■ IADL	3.6 ± 2.2	3.4 ± 2.3	0.37	3.2 ± 2.6	2.7 ± 2.5	0.079
■ Clinical Tasks	8.0 ± 5.2	7.4 ± 5.3	0.24	6.7 ± 5.3	5.9 ± 5.8	0.25
■ Hours Caregiving/week	25.0 ± 28.7	18.2 ± 25.5	0.018	25.9 ± 30.0	16.7 ± 24.8	0.009
Additional caregiving						
■ Child care	23.8%	14.3%	0.017	22.5%	15.1%	0.081
■ Adult care	8.8%	5.2%	0.15	6.7%	6.0%	0.77
■ Paid care in the home	12.8%	13.1%	0.93	8.6%	16.4%	0.074
Caregiver Resources						
■ Received Training for clinical tasks	2.0 ± 2.2	1.6 ± 1.8	0.12	2.0 ± 2.0	1.9 ± 2.0	0.47
■ Global Social Support	3.9 ± 1.0	3.7 ± 0.9	0.081	4.0 ± 0.8	3.8 ± 0.9	0.098
■ Informational Support	4.0 ± 1.0	3.7 ± 1.1	0.035	4.0 ± 0.8	3.8 ± 1.0	0.032
■ Instrumental Support	3.7 ± 1.2	3.5 ± 1.1	0.19	3.9 ± 1.1	3.7 ± 1.1	0.11
■ Emotional Support	3.9 ± 1.1	3.8 ± 1.0	0.33	4.0 ± 1.0	3.9 ± 1.0	0.48
■ Caregiver Preparedness	3.9 ± 0.7	3.5 ± 0.8	<0.001	3.7 ± 0.8	3.6 ± 0.7	0.28
■ Caregiver Mastery	3.1 ± 0.8	3.0 ± 0.7	0.16	3.1 ± 0.7	3.0 ± 0.7	0.25

[a] = Sample sizes range from 88 – 104

[b] = Sample sizes range from 444 – 545

[c] = Sample sizes range from 69 – 89

[d] = Sample sizes range from 380 – 511

Table 3

Race Differences in Caregiver Burden and Social and Personal Resources after Adjusting for Caregiver Education, Income, Employment Status, Mental and Physical Functioning, Relationship to Patient, and Patient Cancer Type, Stage, and Comorbidity Score (Among Caregivers for Acute Caregiving Phase, n=649)[a]

	Overall	**Race**	**Least Squares Means ± SE**	**Least Squares Means ± SE**
Outcome of Interest	**P-value**	**P-value**	**African Americans**	**Whites**
ADL Count	0.018	0.35	1.3 ± 0.2	1.1 ± 0.1
IADL Count	< 0.001	0.63	3.5 ± 0.3	3.4 ± 0.1
Task Count	< 0.001	0.26	8.1 ± 0.6	7.4 ± 0.3
Hours per Week	< 0.001	0.011	26.5 ± 3.1	18.0 ± 1.7
Training (“Yes”)	0.56	0.32	1.8 ± 0.2	1.6 ± 0.1
MOS Social	< 0.001	0.12	3.8 ± 0.1	3.6 ± 0.1
MOS Informational	< 0.001	0.054	3.9 ± 0.1	3.7 ± 0.1
MOS Instrumental	< 0.001	0.30	3.6 ± 0.1	3.4 ± 0.1
MOS Emotional	< 0.001	0.43	3.9 ± 0.1	3.8 ± 0.1
CG Preparedness[b]	< 0.001	0.006	3.8 ± 0.1	3.6 ± 0.1

[a] Each outcome of interest was examined as a separate multivariate model. **ADL Count** = number of activities of daily living; **IADL Count** = number of instrumental activities of daily living; **Task Count** = number of clinical tasks performed; **Hours per week** = number of hours spent caregiving each week; **Training** = receipt of training to perform clinical tasks; **MOS Social** = global social support; **MOS Informational** = informational social support; **MOS instrumental** = instrumental social support; **MOS emotional** = emotional social support; **CG Preparedness** = how confident the respondent feels in caring for the patient’s needs, finding resources, and coping with the stress of caregiving.

All analyses were adjusted for caregiver education, income, SF-12 physical summary score, SF-12 mental summary score, employment status, and relationship to patient, and patient cancer type, cancer stage, and ACE 27 co-morbidity score.

[b] Caregiver Mastery was also included as a covariate in this analysis.

Table 4

Race Differences in Caregiver Burden and Social and Personal Resources after Adjusting for Caregiver Education, Income, Employment Status, Mental and Physical Functioning, Relationship to Patient, and Patient Cancer Type, Stage, and Comorbidity Score (Among Caregivers for Later Caregiving Phase, n=600)[a]

	Overall	**Race**	**Least Squares Means ± SE**	**Least Squares Means ± SE**
Outcome of interest	**P-value**	**P-value**	**African Americans**	**Whites**
ADL Count	< 0.001	0.45	1.4 ± 0.3	1.2 ± 0.1
IADL Count	< 0.001	0.021	3.7 ± 0.4	2.9 ± 0.2
Task Count	< 0.001	0.065	8.0 ± 0.8	6.6 ± 0.4
Hours per Week	< 0.001	< 0.001	31.9 ± 3.5	16.9 ± 1.9
Training (“Yes”)	0.005	0.22	2.3 ± 0.3	1.9 ± 0.2
MOS Social	< 0.001	0.18	3.9 ± 0.1	3.8 ± 0.1
MOS Informational	< 0.001	0.16	4.0 ± 0.1	3.8 ± 0.1
MOS Instrumental	< 0.001	0.020	3.9 ± 0.2	3.5 ± 0.1
MOS Emotional	< 0.001	0.90	3.9 ± 0.1	3.9 ± 0.1
CG Preparedness[b]	< 0.001	0.44	3.6 ± 0.1	3.6 ± 0.1

[a] Each outcome of interest was examined as a separate multivariate model. **ADL Count** = number of activities of daily living; **IADL Count** = number of instrumental activities of daily living; **Task Count** = number of clinical tasks performed; **Hours per week** = number of hours spent caregiving each week; **Training** = receipt of training to perform clinical tasks; **MOS Social** = global social support; **MOS Informational** = informational social support; **MOS instrumental** = instrumental social support; **MOS emotional** = emotional social support; **CG Preparedness** = how confident the respondent feels in caring for the patient’s needs, finding resources, and coping with the stress of caregiving.

All analyses were adjusted for caregiver education, income, SF-12 physical summary score, SF-12 mental summary score, employment status, and relationship to patient, and patient cancer type, cancer stage, and ACE 27 co-morbidity score.

[b] Caregiver Mastery was also included as a covariate in this analysis.