

## ORIGINAL ARTICLE

# Symptom distress and quality of life among Black Americans with cancer and their family caregivers

Katrina R. Ellis<sup>1</sup>  | Seyoung Oh<sup>1</sup> | Hillary K. Hecht<sup>2</sup> | Laurel Northouse<sup>3</sup>

<sup>1</sup>School of Social Work, University of Michigan, Ann Arbor, Michigan, USA

<sup>2</sup>Gillings School of Global Public Health, University of North Carolina at Chapel Hill, Chapel Hill, North Carolina, USA

<sup>3</sup>School of Nursing, University of Michigan, Ann Arbor, Michigan, USA

**Correspondence**

Katrina R. Ellis, School of Social Work, University of Michigan, 1080 South University Ave, Ann Arbor, MI 48109, USA.  
Email: [kahe@umich.edu](mailto:kahe@umich.edu)

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**Abstract**

**Objective:** Black Americans are disproportionately affected by cancer and chronic diseases. Black patients with cancer and their family caregivers may concurrently experience symptoms that influence their wellbeing. This study investigates the influence of mental and physical symptom distress on quality of life (QOL) among Black Americans with cancer and their family caregivers from a dyadic perspective.

**Methods:** One hundred and fifty-one dyads comprised of a Black American with breast, colorectal, lung or prostate cancer and a Black family caregiver were included in this secondary analysis of pooled baseline data from three studies. Self-reports of problems managing 13 symptoms were used to measure mental and physical symptom distress. Descriptive statistics and the actor-partner interdependence model were used to examine symptom prevalence and the influence of each person's symptom distress on their own and each other's QOL.

**Results:** Fatigue, sleep problems, pain and mental distress were prevalent. Patients and caregivers reported similar levels of mental distress; however, patients reported higher physical distress. Increased patient mental distress was associated with decreased patient QOL (overall, emotional, social, functional). Increased patient physical distress was associated with decreased patient QOL (overall, physical, emotional, functional) and decreased caregiver emotional wellbeing. Increased caregiver mental distress was associated with decreased caregiver QOL (overall, emotional, social, functional) and decreased patient overall QOL. Increased caregiver physical distress was associated with decreased caregiver QOL (overall, physical, functional), decreased patient emotional wellbeing, and better patient social wellbeing.

**Conclusions:** Supporting symptom management in Black patient/caregiver dyads may improve their QOL.

**KEYWORDS**

adults, Black Americans, cancer, caregiving, dyads, oncology, psycho-oncology, quality of life, symptoms

## 1 | INTRODUCTION

It is estimated that there are over one million Black Americans with a history of cancer living in the United States.<sup>1</sup> While there has been progress in decreasing racial disparities in cancer, Black men currently have the highest cancer incidence rate (549.1 per 100,000) and Black men and Black women have lower 5-year survival rates compared to White Americans (62% vs. 67%).<sup>1</sup> Among Black Americans with cancer, quality of life (QOL) is a pressing concern. QOL is a multidimensional concept, which encompasses individual health status and interpersonal aspects of health and wellbeing.<sup>2</sup> Studies of common cancer sites have noted racial disparities in QOL among Blacks compared to Whites, including poorer urinary functioning among Blacks prior to prostate treatment<sup>3</sup>; poorer mental wellbeing following lung cancer surgery<sup>4</sup>; and poorer health-related QOL among older, long-term Black colorectal cancer survivors.<sup>5</sup>

Symptom distress—or the perceived presence and intensity of physical or mental changes in functioning<sup>6</sup>—is one factor that affects the QOL of individuals after a cancer diagnosis. Inverse associations between patient symptom distress and QOL are documented.<sup>7-9</sup> Limited research, however, has concurrently examined symptom distress among Black patients and their family caregivers (hereafter referred to as caregivers). In addition to the well-known racial disparities in cancer,<sup>1</sup> chronic disease disproportionately affects Black Americans. For example, researchers have reported odds of multimorbidity 30% higher among Blacks ages 30–64 compared to Whites in this age group.<sup>10</sup> When comparing Medicare beneficiaries across race/ethnicity and gender, Black men ages 65–84 had a higher prevalence of four or more conditions compared to men of other races.<sup>11</sup> Similarly, Black women ages 65 and older had a higher prevalence rate of two or more conditions compared to women of other races. Thus, Black cancer caregivers may be managing health problems of their own (and associated symptoms) while also supporting a loved one in cancer treatment.

Considerable research has highlighted the need to investigate experiences of patients and caregivers as a dyad, acknowledging that the experiences of individuals who comprise relationally close dyads are often interdependent.<sup>12</sup> Moreover, a family comorbidity perspective recognizes how co-occurring health issues within families influence both individual and collective wellbeing.<sup>13</sup> Many existing studies of patients and caregivers in the context of cancer compare the experiences between racial groups. While racially comparative studies have merit, these studies are not sufficient for investigating and understanding experiences of people within specific racial groups.<sup>14</sup> Thus, the purpose of this study was to investigate symptom prevalence and independent and interdependent associations between symptom distress and QOL among Black American patient/caregiver dyads following a cancer diagnosis. Our hypotheses were as follows:

**H1:** *Patients will have a higher prevalence of common symptoms and more mental and physical distress, on average, than caregivers.*

**H2:** *Mental and physical symptom distress reported by patients and caregivers will be negatively associated with their own QOL (actor effects).*

**H3:** *Mental and physical symptom distress of one dyad member will be negatively associated with the other dyad members' QOL (partner effects).*

## 2 | METHODS

### 2.1 | Study design

Secondary analyses of pooled baseline data from three randomized controlled trials (RCTs) were conducted. Participants provided written informed consent and agreed to have their information used for subsequent research. Detailed information regarding study designs, procedures, and outcomes from the RCTs has been reported.<sup>15-17</sup> Institutional Review Board approvals for this study and the parent RCTs were obtained from the University of Michigan (#HUM00151748).

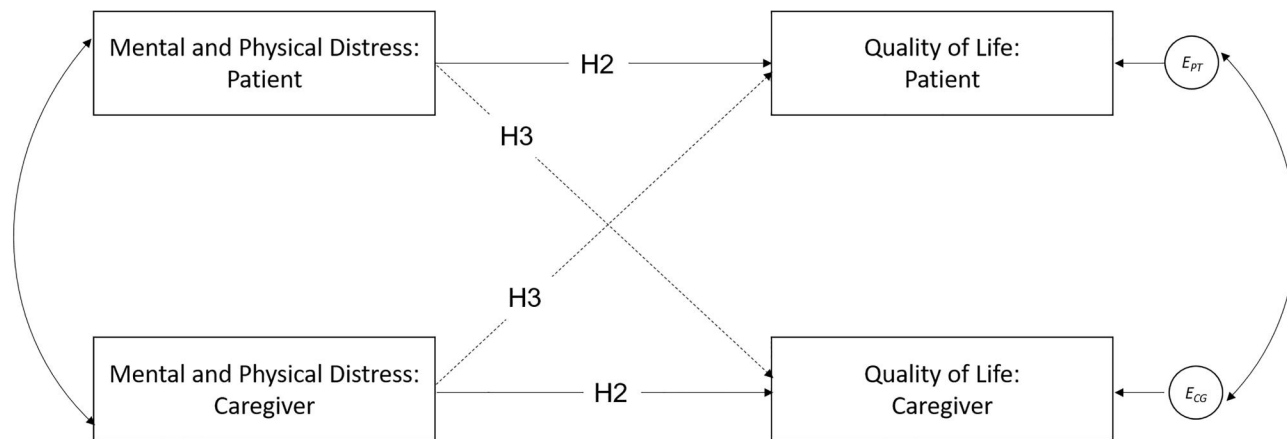
### 2.2 | Participants

The RCTs included 936 dyads (combined), with an adult diagnosed with breast, colorectal, lung, or prostate cancer and a family/friend caregiver (see Figure S1). The pooled analytic sample included middle-aged and older Black American patients with cancer (age 40 or older) and their Black American caregivers. Middle age is often conceptualized as beginning between the ages of 40–50 and cancer incidence rises substantially at this age compared to adolescents and young adults.<sup>18</sup> After excluding dyads due to non-Black patient race ( $n = 773$ ), patient age  $\leq 40$  ( $n = 6$ ), and non-Black caregiver race ( $n = 6$ ), the sample included 151 dyads.

### 2.3 | Measures

#### 2.3.1 | Physical and mental distress

Symptom distress items from the Omega Screening Questionnaire assessed patient and caregiver physical and mental symptom distress.<sup>17</sup> Patients self-reported the trouble experienced because of their cancer- and non-cancer-related symptoms during the past week; caregivers self-reported on their own symptoms during the past week. The number of symptom distress items included in versions of this scale in the parent RCTs ranged from 13 to 19 items. This study included 13 items used in all RCTs. *Physical distress* was based on 12 items: pain, fatigue, weight-loss, sleeping problems, skin problems, bodily sensations/sense of touch (i.e., loss of sensation, numbness), moving difficulty, stomach problems, bowel problems,



**FIGURE 1** Hypothesized model examining actor and partner influences of symptom distress on quality of life. The hypotheses (H2, H3) relevant to each path in the model have been noted. Independent effects (i.e., actor effects) are represented by solid lines. Interdependent effects (i.e., partner effects) are represented by dashed lines. Correlations are represented by curved double-headed arrows. CG, caregiver; PT, patient

urinating problems, breathing problems, heart problems. *Mental distress* was a single item. All items had a rating scale of (0) no trouble, (1) some trouble, and (2) a lot of trouble, with descriptive information for each symptom. For example, response options for “pain” were: (0) no trouble (no pain present), (1) some trouble (some pain present, but it’s tolerable), and (2) a lot of trouble (pain is severe; I’m very uncomfortable). Scores for each physical symptom were summed to create a physical distress score (possible range: 0–24); mental distress was based the score of the single mental distress item (possible range: 0–2). Higher scores indicated more symptom distress.

### 2.3.2 | Quality of life

The Functional Assessment of Cancer Therapy: General (FACT-G version 4) measured patient QOL.<sup>19</sup> Caregivers answered a modified version of this scale (adapted with developer permission) measuring caregivers’ own QOL.<sup>17</sup> The measure includes four dimensions of wellbeing physical, social, emotional, and functional wellbeing—and a five-point scale ranging from 0 (not at all) to 4 (very much). Some items were reverse scored, with total higher scores indicating better QOL. In this analysis, overall QOL scores and scores for each dimension of wellbeing were included (patient range:  $\alpha = 0.767$ – $0.896$ ; caregiver range:  $\alpha = 0.736$ – $0.898$ ).

### 2.3.3 | Covariates

Age, gender, education, cancer type, current treatment (yes/no), spousal caregiver (yes/no), income, advanced cancer (yes/no), metastatic disease (yes/no), cancer recurrence (yes/no), and caregiver living with patient (yes/no) were included as covariates in the analytic models.

## 2.4 | Data analysis strategy

The first hypothesis was tested using McNemar’s tests and paired sample *t*-tests. The remaining hypotheses were tested using the actor–partner interdependence model (APIM).<sup>20</sup> The APIM consists of pairs of key study variables corresponding to each dyad member: predictor variables (patient/caregiver mental distress and physical distress scores, tested in the same model) and outcome variables (patient/caregiver QOL; see Figure 1). Path analysis was used to estimate the model parameters using MPlus version 7. To account for missing data, we used full information maximum likelihood estimation. The root mean square error of approximation (RMSEA < 0.06), comparative fit index (CFI > 0.95), standardized root mean square residual (SRMR  $\leq 0.08$ ), and chi-square to degrees of freedom ratio ( $\chi^2/df$  ratio < 5) were used to determine adequacy of model fit.<sup>21</sup>

## 3 | RESULTS

### 3.1 | Sample characteristics

As noted in Table 1, patients in the sample were older on average (mean: 59.1 years, SD: 9.9;  $p < 0.001$ ) than caregivers (mean: 51.5 years, SD: 14.9). Most of the caregivers were the spouse or intimate partner of the patient (73.5%). Patients had breast (41.1%), prostate (33.1%), colorectal (13.9%), or lung (11.9%) cancer. Most patients were in treatment (92.7%) for advanced (76.2%) and/or metastatic (74.2%) cancer; many were recurrent cancers (45%).

### 3.2 | Symptom prevalence & distress

Fatigue was the most frequently reported symptom among patients (66.9%), followed by pain (62.3%), sleeping problems (60.3%), and

TABLE 1 Sociodemographic and health characteristics of participants

	Patients N = 151	Caregivers N = 151	p-value
Age (years)			
Mean (SD)	59.1 (9.9)	51.5 (14.9)	<0.001
Range	40–85	18–80	-
40 years or older, % (n)	100 (151)	80.1 (121)	-
Female, % (n)	57.6 (87)	66.9 (101)	0.202
Black American race, % (n)	100 (151)	100 (151)	-
Hispanic, % (n)	0.0 (0)	0.7 (1)	-
Highest level of education in years			<0.001
Mean (SD)	13.5 (2.8)	13.7 (2.8)	
Range	4–22	7–22	
Income <sup>a</sup> , % (n)			<0.001
Less than \$5000	13.7 (19)	11.8 (15)	
\$5000–\$15,000	19.4 (27)	13.4 (17)	
\$15,001–\$30,000	19.4 (27)	19.7 (25)	
\$30,001–\$50,000	20.1 (28)	16.5 (21)	
\$50,001–\$75,000	13.7 (19)	22.0 (28)	
More than \$75,000	13.7 (19)	16.5 (21)	
Patient cancer type, % (n)			
Breast	41.1 (62)	-	
Prostate	33.1 (50)	-	
Colorectal	13.9 (21)	-	
Lung	11.9 (18)	-	
Patient currently in treatment, % (n)	92.7 (139)	-	
Patient with advanced disease, % (n)	76.2 (115)	-	
Patient with metastatic disease, % (n)	74.2 (112)	-	
Patient with cancer recurrence, % (n)	45.0 (68)	-	
Caregiver relationship to patient <sup>b</sup> , % (n)			-
Spouse/Partner	-	73.5 (108)	
Daughter	-	10.2 (15)	
Son	-	6.8 (10)	
Other relative	-	4.8 (7)	
Friend	-	4.1 (6)	
Sibling	-	0.7 (1)	
Caregiver living with patient	-	70.9 (107)	
Symptom prevalence <sup>c</sup> , % (n)			
Fatigue	66.9 (101)	56.3 (85)	<0.001
Pain	62.3 (94)	47.0 (71)	0.013
Sleeping problems	60.3 (91)	53.6 (81)	0.031
Weight loss	55.6 (84)	45.0 (68)	<0.001
Mental distress	50.0 (75)	53.0 (80)	0.699

(Continues)

TABLE 1 (Continued)

	Patients N = 151	Caregivers N = 151	p-value
Bodily sensations	48.3 (73)	40.4 (61)	0.008
Heart problems	43.0 (65)	27.2 (41)	0.004
Breathing problems	43.7 (66)	15.9 (24)	<0.001
Moving difficulties	42.0 (63)	34.7 (52)	0.019
Stomach problems	41.6 (62)	37.3 (56)	0.210
Bowel problems	41.3 (62)	33.1 (50)	0.004
Urinating problems	28.0 (42)	9.3 (14)	<0.001
Skin problems	22.5 (34)	17.3 (26)	0.008
Symptom reported by both dyad members, % (n)			
Fatigue	55.0 (83)		
Sleeping problems	51.0 (77)		
Weight loss	43.7 (66)		
Bodily sensations	38.4 (58)		
Stomach problems	33.8 (51)		
Moving difficulties	31.8 (48)		
Mental distress	31.1 (47)		
Bowel problems	30.5 (46)		
Pain	28.5 (43)		
Skin problems	17.2 (26)		
Heart problems	13.2 (20)		
Breathing problems	10.6 (16)		
Urinating problems	4.0 (6)		

Note: <sup>a</sup>Income data reported by 139 patients (missing=12) and 127 caregivers (missing=24).

<sup>b</sup>Caregiver relationship reported by 147 caregivers (missing=4).

<sup>c</sup>Symptom prevalence in this descriptive analysis combines reports of "some trouble" or "any trouble" with the symptom to determine overall prevalence of the symptom (at any level of distress).

weight loss (55.6%). Caregivers also reported fatigue-related distress most frequently (56.3%); sleeping problems (53.6%), mental distress (53.0%), and pain (47.0%) were also common. Patients were more likely than caregivers ( $p < 0.05$ ) to report fatigue, pain, sleeping, weight loss, bodily sensations, breathing, heart, moving, bowel, urinating, and skin problems. There were similarities in patient and caregiver mental distress and stomach problems ( $p > 0.05$ ). Symptoms most frequently reported by both members of a dyad were fatigue (55.0%), sleeping problems (51.0%), and weight loss (43.7%).

As noted in Table 2, no differences were observed between patient and caregiver mental distress ( $p = 0.354$ ); however, patients' physical symptom distress was significantly higher than caregivers' ( $p < 0.001$ ). Patients reported lower overall QOL, and lower physical and functional wellbeing, but better emotional wellbeing than caregivers ( $p < 0.05$ ). Similar levels of social wellbeing were observed ( $p = 0.118$ ).

### 3.3 | Symptom distress → QOL

Results of five APIM models are reported in Table 3. Model fit was adequate (RMSEA range: 0.00–0.03; CFI range: 0.98–1.00; SRMR range: 0.00–0.01;  $\chi^2/df$  ratio range: 0.13–1.18). Patient and caregiver *mental distress* and *physical distress* were associated with their own lower overall QOL (actor effects;  $p < 0.05$ ). Associations between distress and QOL domains (actor and partner effects) are discussed below.

#### 3.3.1 | Actor effects

Among patients, increased *mental distress* was associated with decreased emotional ( $B = -2.88$ ,  $p < 0.001$ ), social ( $B = -1.91$ ,  $p < 0.015$ ) and functional wellbeing ( $B = -3.90$ ,  $p < 0.001$ ). Similarly, among caregivers, increased *mental distress* was associated decreased

TABLE 2 Descriptive statistics and correlations for study variables

	Mental distress		Physical distress		Overall QOL		Physical wellbeing		Social wellbeing		Emotional wellbeing		Functional wellbeing	
	PT	CG	PT	CG	PT	CG	PT	CG	PT	CG	PT	CG	PT	CG
Mean	0.54	0.60	6.73	3.25	77.75	81.89	20.23	24.17	21.91	21.03	17.69	16.40	17.93	20.29
SD	0.58	0.61	4.31	3.00	16.96	15.21	7.16	4.33	5.48	5.40	4.42	4.64	6.88	5.90
Paired-sample T-Test	$p = 0.354$		$p < 0.001$		$p = 0.007$		$p < 0.001$		$p = 0.118$		$p = 0.004$		$p < 0.001$	
Correlations														
PT mental distress	1													
CG mental distress	0.30***	1												
PT physical distress	0.33***	0.26**	1											
CG physical distress	0.20*	0.40***	0.16*	1										
PT overall QOL	-0.53***	-0.34***	-0.65***	-0.17*	1									
CG overall QOL	-0.13	-0.43***	-0.28***	-0.39***	0.33***	1								
PT physical wellbeing	-0.33***	-0.27**	-0.73***	-0.11	0.79***	0.34***	1							
CG physical wellbeing	-0.12	-0.28***	-0.18*	-0.49***	-0.23**	0.65***	0.24**	1						
PT social wellbeing	-0.27**	-0.18*	-0.12	0.00	0.54***	0.12	0.14	0.11	1					
CG social wellbeing	-0.03	-0.22*	-0.12	-0.11	0.22**	0.73***	0.19*	0.24**	0.19*	1				
PT emotional wellbeing	-0.44***	-0.20*	-0.23**	-0.21**	0.55***	0.16	0.30***	0.09	0.10	0.10	1			
CG emotional wellbeing	-0.20*	-0.43***	-0.29***	-0.29***	0.35***	0.72***	0.32***	0.39***	0.08	0.28**	0.28**	1		
PT functional wellbeing	-0.48***	-0.28**	-0.60***	-0.16	0.86***	0.26**	0.61***	0.17*	0.33***	0.12	0.33***	0.28***	1	
CG functional wellbeing	-0.06	-0.35***	-0.27**	-0.32***	0.20*	0.87***	0.27**	0.42***	-0.02	0.56***	0.03	0.53***	0.22**	1

Note: Mental distress scores: minimum possible: 0; maximum possible: 2. Physical distress scores: minimum possible: 0; maximum possible: 24. Minimal possible scores for overall QOL and subscale is 0. Maximum possible scores as follows: overall QOL—108; physical wellbeing—28; social wellbeing—28; emotional wellbeing—24; functional wellbeing—28.

Abbreviations: CG, caregiver; PT, patient; QOL, quality of life.

\* $p < 0.05$ ; \*\* $p < 0.01$ ; \*\*\* $p < 0.001$ .

caregiver emotional ( $B = -2.50$ ,  $p < 0.001$ ), social ( $B = -1.63$ ,  $p = 0.024$ ) and functional wellbeing ( $B = -2.04$ ,  $p = 0.006$ ). *Mental distress* was not associated with patient' and caregivers' own physical wellbeing.

Among patients, increased *physical distress* was associated with decreased physical ( $B = -0.91$ ,  $p < 0.001$ ), emotional ( $B = -0.19$ ,  $p = 0.018$ ), and functional wellbeing ( $B = -0.68$ ,  $p < 0.001$ ). Among caregivers, increased *physical distress* was associated with decreased caregiver physical ( $B = -0.52$ ,  $p < 0.001$ ) and functional wellbeing ( $B = -0.35$ ,  $p = 0.026$ ). *Physical distress* was not associated with

patients' and caregivers' own social wellbeing. Caregiver *physical distress* was not associated with caregiver emotional wellbeing.

### 3.3.2 | Partner effects

Increased patient *physical distress* was associated with decreased caregiver emotional wellbeing ( $B = -0.20$ ,  $p = 0.030$ ). Increased caregiver *mental distress* was associated with decreased patient overall QOL ( $B = -3.45$ ,  $p = 0.019$ ). Increased caregiver *physical*

TABLE 3 APIM associations between symptom distress and QOL

	B	SE	p
Overall QOL			
Actor			
PT mental distress → PT QOL	-9.75	1.60	<0.001
PT physical distress → PT QOL	-1.86	0.23	<0.001
CG mental distress → CG QOL	-6.68	1.78	<0.001
CG physical distress → CG QOL	-1.13	0.38	0.003
Partner			
CG mental distress → PT QOL	-3.45	1.48	0.019
Physical Wellbeing (PWB)			
Actor			
PT mental distress → PT PWB	-1.08	0.67	0.107
PT physical distress → PT PWB	-0.91	0.10	<0.001
CG mental distress → CG PWB	-0.52	0.55	0.343
CG physical distress → CG PWB	-0.52	0.12	<0.001
Emotional Wellbeing (EWB)			
Actor			
PT mental distress → PT EWB	-2.88	0.56	<0.001
PT physical distress → PT EWB	-0.19	0.08	0.018
CG mental distress → CG EWB	-2.50	0.59	<0.001
CG physical distress → CG EWB	-0.19	0.13	0.139
Partner			
PT physical distress → CG EWB	-0.20	0.09	0.030
CG physical distress → PT EWB	-0.32	0.20	0.003
Social Wellbeing (SWB)			
Actor			
PT mental distress → PT SWB	-1.91	0.78	0.015
PT physical distress → PT SWB	-0.08	0.11	0.481
CG mental distress → CG SWB	-1.63	0.72	0.024
CG physical distress → CG SWB	-0.08	0.15	0.615
Partner			
CG physical distress → PT SWB	0.32	0.15	0.036
Functional Wellbeing (FWB)			
Actor			
PT mental distress → PT FWB	-3.90	0.81	<0.001
PT physical distress → PT FWB	-0.68	0.12	<0.001
CG mental distress → CG FWB	-2.04	0.73	0.006
CG physical distress → CG FWB	-0.35	0.16	0.026

Note: Unstandardized coefficients are presented. All actor effects for main study variables are shown; only significant ( $p < 0.05$ ) partner effects shown.

Abbreviations: CG, caregiver; EWB, emotional wellbeing; FWB, functional wellbeing; PT, patient; PWB, physical wellbeing; QOL, quality of life; SWB, social wellbeing.

distress was associated with decreased patient emotional wellbeing ( $B = -0.32$ ,  $p = 0.003$ ) but increased patient social wellbeing ( $B = 0.32$ ,  $p = 0.36$ ). No other partner effects were significant ( $p < 0.05$ ).

## 4 | DISCUSSION

This study investigated mental and physical symptoms among middle-aged and older Black American cancer patients and their caregivers and the influence of symptom distress on their QOL. The overall QOL scores of Black patients and Black caregivers in this study were similar to normative data on overall QOL in the general US adult population and adults with cancer (i.e., score difference of less than 5 points).<sup>22</sup> However, on two QOL subscales, clinically meaningful differences were observed (i.e., score difference of 2 points or more). First, the mean patient social wellbeing score (21.9) was higher than the general population (19.1), reflecting a strength of social support and social connections among Black patients. Second, the caregiver emotional wellbeing mean score (16.40) was lower than the general population (19.9) and cancer-specific population (18.7), reflecting the toll that patient illness and caregiving takes on Black caregivers.

Fatigue, sleep, and pain were among the most commonly reported symptoms among Black patients and caregivers in this study. Problems with fatigue were reported by 66.9% of patients and 56.3% of caregivers. These data are similar to previously reported rates of cancer-related fatigue among other patients (59%–100%)<sup>23</sup> and caregivers (18%–76%).<sup>24</sup> In addition, sleep problems were also a concern for 60.3% of patients, similar to ranges seen in other research.<sup>25</sup> However, sleep problems of caregivers (53.6%) were lower than reported in a review of sleep disturbances among caregivers of patients with advanced cancer (72%).<sup>26</sup>

There may be several factors, in addition to cancer and caregiving, which influence efforts to assess and address sleep problems with this population. For example, broader research on sleep problems indicate Black Americans may not evaluate issues with sleep (e.g., short duration) as problematic.<sup>27</sup> Furthermore, they may use positive reframing to cope with sleep problems, which could contribute to underestimations of the potential harms of poor sleep.<sup>27</sup> Given that fatigue and sleep problems were major problems for both patients and caregivers, and that one dyad member may influence fatigue and sleep problems in the other,<sup>25</sup> addressing this issue from a dyadic (vs. individual) perspective may have added benefits.

Problems with fatigue and sleep among Black adults with cancer may also be related to pain.<sup>28</sup> In the current study, 62.3% of patients reported pain, making it the second most frequently reported symptom. This prevalence is higher than reported in a prior systematic review (55%) of patients during cancer treatment.<sup>29</sup> A significant proportion of caregivers (47%) also reported trouble with pain. Patients' pain may be due to cancer, cancer treatment, or health issues. Caregivers' pain could be a consequence of their own chronic

health problems or psychological pain (though the symptom measure used in this study did not distinguish between physical and psychological pain). Black patients often receive less-optimal pain management compared to Whites.<sup>30</sup> In addition, Black Americans, in particular, may use spiritual terms to express psychological pain, highlighting the importance of incorporating spirituality into health assessments and treatment.<sup>31</sup> Future studies should examine pain experiences in Black patient/caregiver dyads and interventions to promote racial equity in symptom management.

Mental distress among Black patients and caregivers had a negative influence on their QOL, specifically, their functional, emotional and social wellbeing. In addition, increased caregiver mental distress had a negative influence on patient overall QOL. It is important to note estimates of mental distress were similar for patients and caregivers. Given the noted disparities in access to and uptake of mental health treatment,<sup>32</sup> Black American caregivers and patients may need additional support to overcome barriers to mental health services.

Interestingly, patient and caregiver mental distress, but not physical distress, had a negative influence on their social wellbeing. This suggests dyads were better able to navigate their own physical symptom-related barriers to social engagement than mental distress-related barriers. In a qualitative study of social support among Black Americans with cancer, Hamilton & Sandelowski<sup>33</sup> found that Black patients emphasized several types of social support not commonly discussed in literature, including being present (without expectations of communication), prayer, support from church members, and assistance for maintaining social roles. Among Black Americans for whom spirituality and religiosity are important factors, supporting their continued involvement in faith practices and communities, particularly when facing mental distress, may be helpful.<sup>34</sup>

Physical distress was associated with several domains of wellbeing. In particular, increased physical distress among patients or caregivers was associated with poorer emotional wellbeing in the other member of the dyad, underscoring the interdependence of patients' and caregivers' wellbeing. Improving physical symptom distress of both members of the dyad may be particularly helpful for their emotional QOL early in the cancer treatment/caregiving experience when patients, caregivers, and families are adjusting to complex emotions and life changes associated with the cancer and caregiving. Unexpectedly, increased physical distress among caregivers was associated with better patient social wellbeing. It is possible that when caregivers were experiencing increased physical distress (which could be due to health issues and/or the stress of caregiving), dyads were able to mobilize resources from their support networks to compensate for the challenges caregivers were facing. It is also possible that family members and friends had previous experience providing support for cancer caregivers' ongoing health concerns, and this support continued following the cancer diagnosis.<sup>13</sup>

Interventions should seek to build upon strengths and resources related to family disease management<sup>35</sup> that may also promote effective family symptom management after treatment ends. Research indicates that self-efficacy is inversely associated with

symptom distress for both people with cancer and their caregivers<sup>36</sup>; familial beliefs regarding collective efficacy may also play an important role.<sup>37</sup> Future research should investigate interactions between, individual, dyad and collective family efficacy for symptom management and QOL.

#### 4.1 | Clinical implications

Targeted approaches to alleviate caregiver symptom distress and enhance their emotional wellbeing may be needed. Clinical interventions that provide caregivers with skills to support patient symptom management<sup>38</sup> could also incorporate caregiver symptom management with the goal of addressing patient and caregiver health concerns. Tailored intervention strategies are particularly useful for increasing access and uptake where health disparities are observed.<sup>39</sup> Culturally-tailored interventions for Black patients<sup>40</sup> may be a useful starting place for adapting interventions for dyads or families. Widening the focus of social support to include the broader family system could maximize support from individuals serving in caregiving roles for either/both members of the recognized patient/caregiver dyad.

#### 4.2 | Study limitations

This study included cross-sectional secondary data; thus, we are unable to report relationships between symptom distress and QOL in dyads over time or directionality. Significant estimates were primarily actor effects. Null partner effects may stem from the use of baseline data at diagnosis and treatment onset. Other partner effects could emerge over the course of the disease. There may be conceptual overlap in the measures of patient physical distress and patient physical and functional wellbeing; correlations between physical distress and these QOL dimensions are  $-0.73$  and  $-0.60$ , respectively. Differences also exist in inclusion criteria for the intervention studies, which has implications for the time since diagnosis, age of patient, and symptom distress. Of note, a majority of the sample had metastatic disease, which is typically associated with greater symptom burden and/or a cancer recurrence; thus, findings may not be generalizable to samples with early stages disease and/or primary diagnoses.

### 5 | CONCLUSIONS

Many Black patients and caregivers have concurrent health concerns. Findings suggest that when aiming to increase the QOL of Black adults with cancer, improving both patient and caregiver symptom management is important. Future research needs to examine symptom clustering in this population, develop measures and interventions to address their individual and dyadic symptom management, and assess the heterogeneity of Black Americans'



responses to illness and caregiving through within-group research. Lastly, given the long and troubling history of unequal treatment and health outcomes in the United States associated with racism, future studies examining the potential influence of racism and discrimination on symptom management among patient and caregiver dyads is warranted.

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#### CONFLICT OF INTEREST

The authors declare no conflict of interest.

#### DATA AVAILABILITY STATEMENT

Research data are not shared.

#### ORCID

Katrina R. Ellis  <https://orcid.org/0000-0003-1709-3912>

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## SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of this article.

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