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## Understanding the Relationship between Positive and Negative Social Support and the Quality of Life among African American Breast Cancer Survivors

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### Abstract

**Purpose:** Social support improves several quality of life (QOL) domains among African American breast cancer survivors. Further, *how* different dimensions of social support are associated with QOL among African American breast cancer survivors may differ from other populations. This study explores this hypothesis by examining associations of positive social support (supportive interactions that promote affection) and negative social support (non-supportive interactions or interactions wherein the provider of support may not have the best intended actions) with QOL among Chicago-based African American breast cancer survivors.

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**Ethics approval:** Several institutional review boards approved the data collection procedures that involve study participants to ensure their accordance with the ethical standards of each institution.

**Availability of data and material:** Interested stakeholders may communicate with the corresponding co-author (YM) to access de-identified data sets.

**Code availability:** Interested stakeholders may communicate with the corresponding co-author (YM) to access syntax files for analyses.

**Methods:** Study participants were eligible if they: 1) identified as being an African American female, 2) were at least 18 years of age or older, and 3) were diagnosed with breast cancer during or after navigation was implemented at the study hospital. Participants completed validated questionnaires via telephone or in-person interviews.

**Results:** Among our sample of 100 participants, positive support was associated with greater mental well-being in non-imputed (Std  $\beta=1.60$ , CI: 0.51, 2.69,  $p=0.004$ ) and imputed models (Std  $\beta=1.67$ , CI: 0.68, 2.73,  $p=0.001$ ). There was also a weaker inverse association with negative support and mental well-being when using non-imputed data (Std  $\beta=-0.82$ , CI:  $-1.65$ , 0.02,  $p=0.05$ ).

**Conclusions:** Our findings suggest that positive support, in particular, is highly influential for improving mental well-being among African American breast cancer survivors. Simultaneously, negative support appears to be an independent, albeit weaker, determinant of mental well-being.

### Keywords

Breast cancer; social support; quality of life; African American

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### Introduction

A growing number of African American breast cancer survivorship studies have been observed in the literature over the years [1] due to progress in public health research and clinical practice. Despite these improvements, African American women continue to experience higher breast cancer mortality rates compared to non-Hispanic whites [2, 3]. The breast cancer mortality rate is 42% higher among African American women compared to non-Hispanic whites [4]. Further, African American women experience higher rates of more aggressive breast cancer diagnoses (e.g., triple negative breast cancer subtypes) and higher rates of late stage diagnosis compared to women of other racial groups [4], which could in create and differentiate survivorship needs, long-term side effects of treatment, fear of recurrence, and other health needs. Such racial disparities suggest that, despite advancements, the survivorship needs of African American breast cancer survivors are not being met when compared to their white counterparts [5, 6].

Social support, defined here as the perceived support made available to an individual by a member of their social network [7], is one major factor that may contribute to disparities in unmet needs and long-term survivorship outcomes. African American breast cancer survivors have unique, often unmet, social support needs that may result in negative health outcomes such as poorer quality of life (QOL) (defined as the perception of an individual's position in life based on their expectations, goals, and standards) [8] and potential death [9, 10]. This research has largely focused on two QOL domains [11]: physical well-being, defined as an individual's self-rated physical health in the absence of physical symptoms and side effects; [12] and, mental well-being, defined as a cognitive assessment of their ability to overcome stress [13]. There is a significant body of literature which has explored the role of social support for health among African American breast cancer survivors, including characterization of key relationships (e.g., family, friends, church members, and clergy leaders [14]), support types (e.g., emotional, instrumental, informational, belonging [15, 16])

and, quality of social support (i.e., positive support, negative support [17]). A growing body of work [18], albeit limited [19, 20], has begun to compare the relative roles of these different dimensions on well-being among cancer survivors in general. Such comparative research is crucial toward understanding *which* dimensions of social support may be the most influential targets for subsequent interventions and clinical practice, especially among underserved populations such as African American breast cancer survivors.

For our current study, we focus on two domains: positive social support (i.e., supportive social interactions that promote affection) and negative social support (i.e., non-supportive interactions and interactions wherein the provider of support may not have the best intended actions) [21]. Notably, a significant amount of literature has conceptualized negative support as the opposite or lack of positive support [20, 22]. Nonetheless, empirical research has highlighted that these factors are distinct and can co-occur [20, 22]. Specifically, negative support is not the absence of positive support or equivalent to social isolation – rather, it represents specific negative interactions and social constraints [23]. Accordingly, there have been recent calls to understand and compare the independent roles of positive and negative support directly [19, 20]. A recent systematic review [18] synthesized the state of the literature by comparing the roles of positive and negative support on mental well-being in cancer survivors. Rivera-Rivera and Burris [18] found that, across 32 independent studies, social constraint was more consistently and more strongly associated with well-being when compared to social support. This synthesis potentially clarified the limited impact that interventions whose focus is promotion of positive support may have [24]. Specifically, the state of the science suggests that interventions that work to reduce or prevent negative support may have stronger health effects for cancer survivors.

This systematic review largely summarized studies focused on breast cancer survivors [18]. However, included studies had predominantly non-Hispanic white samples (73–92%), except for one study that focused on Latinas [18]. Different patterns may emerge when exclusively examining the experiences of African American breast cancer survivors. For example while negative support may be particularly impactful for other populations, it may be less influential for African American breast cancer survivors. Due to historic and contemporary marginalization and exclusion, African American women face greater levels of negative support at large [25, 26]. In response, African American women have developed a different culturally based coping strategy to attenuate the impact of negative support, known as the Superwoman Schema [27]. The Superwoman Schema has resulted in common cultural prototypes that emphasize the strength, resilience, and independence of African American women [27, 28]. In the context of breast cancer, these cultural coping strategies may influence the magnitude of associations between positive support, negative support, and well-being. Specifically, they may weaken the impact of negative support on well-being. Simultaneously, positive support may be particularly important for well-being for African American women in terms of showcasing that they are not alone/don't have to be independent against challenges such as breast cancer. Nonetheless, of which we are aware, no studies have concurrently examined the roles of positive and negative support on mental well-being among African American breast cancer survivors.

Another gap in the literature concerns comparing the roles of positive and negative support on physical well-being. It is possible that physical well-being is more strongly associated within individual-level factors – including economic (e.g., individual or collective socioeconomic status), biological (e.g., cancer site), and cancer treatment-related factors (i.e. treatment-related symptoms) -- when compared to interpersonal-level factors (i.e., social support) [29]. Simultaneously, previous studies have also suggested that mental well-being is highly influenced by interpersonal-level factors [30]. Given this, the associations of positive and negative support on mental well-being may be stronger than their associations with physical well-being. However, no studies have attempted to examine the association between interpersonal-level factors such as positive and negative support with different quality of life domains among African American breast cancer survivors.

The purpose of this study is to address these two gaps in the literature and compare the associations of positive and negative support with mental and physical well-being among a Chicago-based sample of African American breast cancer survivors. Our findings have implications regarding: 1) what key components are needed for an effective social support intervention designed to improve well-being among African American breast cancer survivors; and, 2) the likely effects of such social support interventions on mental versus physical well-being.

## Methods

The current study is a secondary analysis of the Offering African American Survivors Increased Support (OASIS) study (R21CA215252; MPIs: Molina, Khanna, Watson), whose procedures and measures have been previously described in detail [31]. Below, we describe the parent study's procedures, which were approved by the Institutional Review Boards of three participating institutions (University of Illinois at Chicago (UIC), University of Chicago, and Advocate Health Care).

## Procedures

Trained Advocate Health staff reviewed electronic medical records and identified potential patients using the following eligibility criteria: 1) identified as an African American female patient, 2) were at least 18 years of age or older, and 3) were diagnosed with breast cancer during or after patient navigation was implemented in the study hospital [31, 32].

Eligible patients were first mailed a letter of invitation and flyer detailing the study. Interested women directly contacted UIC study staff. Approximately two weeks after mailed invitations, Advocate Health staff contacted women by phone to invite them to the study. Interested women consented to hospital staff sharing their contact information with UIC study staff. Study staff subsequently engaged interested women by phone to schedule interviews, depending on participant preferences, by telephone or in person (e.g., participants' homes, private rooms in libraries).

Interview duration was approximately ~90–120 minutes. Interviewers asked participants a combination of closed- and open-ended questions based on a 202-item questionnaire, all of which was recorded on paper surveys. Each participant received \$75 as compensation for

their time. All responses were subsequently entered electronically through an online survey software program, Qualtrics [33].

## Measures

**Study Processes:** Participants' navigation status (navigated, not navigated) and type of interview (in-person, phone) were abstracted from study tracking records.

**Demographics:** Year of birth was abstracted from medical records to calculate current age. The following demographic information was collected from each participant during interviews, using Behavioral Risk Factor Surveillance System survey items [34]: education, household annual income, insurance status, marital status, and household size. Given preliminary review of the data, a factor-based socioeconomic composite was generated with education, household annual income, and insurance status (private vs. not private) data.

**Type of Cancer Treatment:** Year of diagnosis was abstracted from medical records to calculate years since diagnosis. Navigation status was also abstracted from medical records. Type of active treatment (surgery, radiation, chemotherapy) was obtained from participants during surveys, using questions previously tested among Chicago-based African American breast cancer patients [35–37]. Based on a preliminary review of frequency distributions, we classified patients under a dichotomous measure of either having multiple types of treatment or not.

**Positive and Negative Support:** Participants also answered questions related to positive and negative support from the validated, reliable Health and Retirement Study Psychosocial Leave-Behind Participant Lifestyle Questionnaires [38]. Three items were related to positive support (e.g., “How much can you open up to them if you need to talk about your worries related to breast cancer?”). Four items were related to negative support (e.g., “How often did they make too many demands on you while you were being treated for breast cancer?”). Each item ranged from 0 (not at all) to 3 (a lot). The items related to positive support were summed, with a possible range of 0 (low positive support) to 9 (high positive support). The four items for negative support were also summed, with a possible a range of 0 (low negative support) to 12 (high negative support). Cronbach's alphas based on standardized items for positive and negative support were 0.68 and 0.65 respectfully.

**Mental and Physical Well-being:** Participants also completed the validated, popular Short Form (SF-12) questionnaire [39], which has items related to physical well-being and mental well-being. Range values for physical well-being are 32.73–62.87 with higher scores indicating better physical well-being. The score for mental well-being are 25.58–63.29 with a higher score also indicating better mental well-being. All QOL variables were weighted according to the general population within the United States [39].

## Statistical Analyses

All analyses were conducted using the statistical software program, SAS 9.4 [40]. Descriptive analyses included the frequencies and percentages for each categorical variable as well as means and standard deviations for each continuous variable. Covariates were

selected based on 1) crude bivariate analyses examining the association of study processes, demographic, and type of treatment variables with QOL domains; and, 2) past literature and theory regarding social support and health among African American breast cancer survivors [31, 41]. Accordingly, the following variables were included as covariates: navigation, type of interview, marital status, household size, multiple types of treatment, years since diagnosis, years since birth, years since last treatment, and socioeconomic composite score. Subsequent analyses examined the relationships between positive and negative support with physical well-being and mental well-being. To address missingness, we computed multivariable linear regression models by performing multiple imputations within SAS using the PROC MI and the PROC MIANALYZE commands. We also computed models with non-imputed data.

## Results

### Descriptive Statistics

Table 1 depicts the demographic characteristics and treatment types of the 100 participants within this study. We had relatively little missingness in the study, except for socioeconomic composite score and household income (both 18%). As planned, the study sample was equally divided in terms of navigation status (50% navigated, 50% non-navigated). Most participants were interviewed in person (82%). The average age was 66.28 years old (SD=9.54). The majority of participants had some or more college experience (74%), were not married at the time of the study (65%), living with at least 1 or 2 individuals (66%), possessed an annual household income of \$50,000 (49%), and had private insurance (64%). In terms of cancer-related characteristics, the average years since diagnosis was 6.87 (SD=1.54). The majority of the participants reported undergoing surgery (96%) or radiation (56%) for their breast cancer. Further, 72% of patients underwent multiple types of treatment. The average years since last treatment among study participants was 6.33 (SD=4.45). The mean values and standard deviations for positive and negative support were 7.50 (SD=1.78) and 2.14 (SD=2.52), respectively. The mean values for physical and mental well-being were 46.83 (SD=5.78) and 47.47 (SD=9.81).

### Multivariate Linear Analyses

Table 2 depicts the findings from the four fully adjusted multivariable linear regression models. Greater positive support was associated with greater mental well-being, when using models with non-imputed (Std  $\beta$ =1.43, CI: 0.41, 2.45,  $p$ = 0.01) and imputed data (Std  $\beta$ =1.43, CI: 0.47, 2.38,  $p$ =0.003). Greater negative support was associated with lower mental well-being scores with imputed data (Std  $\beta$ = -0.73, CI:-1.42, -0.04,  $p$ =0.04). Neither positive nor negative support were associated with physical well-being ( $p$ s = 0.29–0.87).

## Discussion

The purpose of this study was to compare the quality of social support -- i.e., positive and negative support -- on the QOL among African American breast cancer survivors. Our findings suggest the importance of simultaneously measuring positive and negative support, as their relationships to QOL were independent and distinct. Specifically, positive support

was positively associated with the mental well-being of African American breast cancer survivors. Simultaneously, negative support was independently and inversely associated with mental well-being for imputed data, although this relationship was smaller in magnitude and not consistent across models.

Our findings provide important insights into understanding the role of social support on well-being among African American breast cancer survivors – an underserved population. On the one hand, our findings align with recent calls that have emphasized the importance of measuring positive and negative support concurrently [19, 20], given they are distinct measures. Specifically, our study highlights that positive and negative support were both independently associated with mental well-being among African American breast cancer survivors. Our findings implicate the importance of social support interventions that explicitly address *both* positive and negative support in order to maximize well-being among African American breast cancer survivors.

On the other hand, a recent systematic review of 32 studies with predominantly non-Hispanic white studies found the opposite pattern, wherein negative support was a stronger, more consistent predictor of mental well-being. One reason for this discrepancy can be due to the study samples from the systematic review being predominately non-Hispanic white. It is possible that African American breast cancer survivors may have developed coping mechanisms (i.e. Superwoman Schema) to combat the adverse effects of persistent negative support arising from historic and contemporary marginalization [27]. Consequently, negative support may theoretically be a weaker predictor of well-being among this population relative to non-Hispanic white survivors. Simultaneously, the Superwoman Schema and other cultural coping strategies African American women have adopted to buffer the impacts of negative support have focused on women's often solitary resistance and resilience against challenges [27]. Thus, theoretically, positive support may be particularly important within this cultural context in terms of offering unexpected interpersonal reprieve from challenges. Additional research is needed to test these hypotheses concerning social support and coping mechanisms - specifically, future work should test the potential moderating effects of the Superwoman Schema and other coping mechanisms within the associations of positive support, negative support, and quality of life among African American breast cancer survivors. Such work may be particularly helpful for further adapting social support interventions to be maximally effective for African American breast cancer survivors.

Notably, neither dimension of support was associated with physical well-being, in line with past research [42]. Previous research has shown that individual-level economic factors (e.g., individual or collective socioeconomic status), biological factors (e.g., cancer site), and cancer treatment-related factors (i.e. treatment-related symptoms) may have a stronger impact on physical well-being compared to interpersonal-level factors (i.e., social support) [43]. Our findings align with these patterns. These findings implicate the importance of other complementary interventions that can tackle stronger determinants of physical well-being (e.g., financial burden, treatment-related symptoms) more so than social support interventions.

This study had several limitations. First, our study had a small convenience-based sample that comprised African Americans exclusively, which likely limited the generalizability of our study. Second, our cross-sectional study design inhibited an understanding of the potential causality between factors of quality of social support and the QOL domains of physical well-being and mental well-being within this study sample. Further, longitudinal research is particularly warranted to confirm findings, as positive support tends to increase immediately following a cancer diagnosis [44], while negative support can increase in the long-term post-diagnosis [45]. Third, most data were based on self-report, which may have led to misclassification bias. It is also important to note that our measures of positive and negative support had relatively low reliability/internal consistency in this study, which may have affected our study. Fourth, there was a limited assessment of other psychosocial factors associated with QOL, including spirituality and distress. Finally, the items used to assess both positive and negative support within this study did not ask participants to report the source of support and other dimensions of support, which could have clarified our findings. For example, it would have been helpful to understand if the same people were giving positive and negative support or if there were different people giving different types of support.

### Conclusions and Implications

In summary, the results of this study describe the importance of measuring different dimensions of social support among African American breast cancer survivors in regards to QOL. Specifically, positive and negative support had different relationships with the QOL domains of physical well-being and mental well-being. This study also has major future implications that benefit the QOL of African American breast cancer survivors. The findings of this study support the utility of interventions that focus on promoting positive support to improve mental well-being and overall QOL among African American breast cancer survivors. While it is believed that negative support may have a greater impact on the mental well-being of cancer survivors [18], we hypothesize that this relationship is not as influential due to potential coping mechanisms of African American breast cancer survivors. Future studies should test this hypothesis. It also suggests that interventions focused on mental well-being should train influential members of an African American breast cancer survivor's social network on strategies to avoid negative support while encouraging the use of positive support strategies.

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**Table 1:**

## Demographic and Cancer-Related Characteristics of Study Sample

<b>STUDY PROCESSES</b>	<b>Missing</b>	<b>Total Study Sample (n=100) n (%)</b>
<b>Navigation Status</b>	0 (0%)	
Navigated		50 (50%)
Non-navigated		50 (50%)
<b>Type of Interview</b>	0 (0%)	
In-Person		82 (82%)
Phone		18 (18%)
<b>DEMOGRAPHIC</b>		
<b>Education</b>	0 (0%)	
12 years of school		26 (26%)
Some college/associates degree		42 (42%)
Bachelor's degree		32 (32%)
<b>Marital Status</b>	0 (0%)	
Married		35 (35%)
Not married		65 (65%)
<b>Household Size</b>	0 (0%)	
Living with 1 or 2		66 (66%)
Living with 3 or more		34 (34%)
<b>Household income</b>	18 (18%)	
50,000		49 (49%)
\$50,001		33 (33%)
Missing		
<b>Insurance status<sup>a</sup></b>	0 (0%)	
Private		64 (64.0%)
Medicare		48 (48.0%)
Medicaid		14 (14.0%)
<b>Socioeconomic composite<sup>b</sup></b>	18 (18%)	
Tertile 1		28 (28%)
Tertile 2		26 (26%)
Tertile 3		28 (28%)
Missing		
<b>TYPE OF TREATMENT</b>		
<b>Surgery</b>	0 (0%)	
Yes		96 (96%)
No		4 (4%)
<b>Radiation</b>	0 (0%)	
Yes		56 (56%)
No		44 (44%)
<b>Chemotherapy</b>	0 (0%)	

<b>STUDY PROCESSES</b>	<b>Missing</b>	<b>Total Study Sample (n=100) n (%)</b>	
Yes		44 (44%)	
No		56 (56%)	
<b>Multiple Types of Treatment<sup>c</sup></b>	0 (0%)		
No		28 (28%)	
Yes		72 (72%)	

  

<b>CONTINUOUS M(SD)</b>	<b>Mean (SD)</b>	<b>Range</b>
<b>Age</b>	0 (0%) 66.28 (9.54)	51–93
<b>Years Since Diagnosis</b>	0 (0%) 6.87 (1.54)	3–9
<b>QUALITY OF SOCIAL SUPPORT</b>		
Positive support	0 (0%) 7.50 (1.78)	0–9
Negative support	0 (0%) 2.14 (2.52)	0–12
<b>QUALITY OF LIFE (QOL) DOMAINS</b>		
Physical well-being	0 (0%) 46.83 (5.78)	32.73–62.87
Mental well-being	0 (0%) 47.47 (9.81)	25.58–63.29

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Multivariable Linear Regression models between quality of social support and Quality of life (QOL)<sup>f</sup>

**Table 2:**

	Physical Well-being <sup>a</sup>		Mental Well-being <sup>b</sup>	
	Std $\beta$ (95% CI)	p	Std $\beta$ (95% CI)	p
<b>Using non-imputed data (n=82)</b>				
Positive support	-0.18 (-0.80, 0.44)	0.56	<b>1.43 (0.41, 2.45)</b>	<b>0.01</b>
Negative support	-0.04 (-0.50, 0.42)	0.87	-0.70 (-1.48, 0.07)	0.08
<b>Using imputed data (n=100)</b>				
Positive support	-0.15 (-0.77, 0.46)	0.62	<b>1.43 (0.47, 2.38)</b>	<b>0.003</b>
Negative support	0.23 (-0.20, 0.66)	0.29	<b>-0.73 (-1.42, -0.04)</b>	<b>0.04</b>

<sup>f</sup> All models were controlled for the following covariates: age, navigation (ref: non-navigated), in-person interview (ref: no), marital status (ref: not married), household size (ref: living with one or two people), multiple treatment, years since diagnosis, and the socioeconomic composite score (income, private insurance, and education).

<sup>a</sup> Range values for physical well-being are 32.73–62.87 with higher scores indicating better physical well-being.

<sup>b</sup> Range values for mental well-being are 25.58–63.29 higher scores indicating better mental well-being.