

## Symptom Distress, Spirituality, and Quality of Life in African American Breast Cancer Survivors

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### Abstract:

This study examined the relationships among the demographic characteristics, symptom distress, spirituality, and quality of life (QOL) of African American breast cancer survivors. A convenience sample of 30 survivors with a mean age of 56 years and a mean survival of 6 years was recruited from African American breast cancer support groups and churches in the Southeastern United States. Data were collected through face-to-face interviews using a demographic questionnaire, the Quality of Life Index-Cancer Version, the Symptom Distress Scale, and the Spiritual Perspective Scale. Statistically significant relationships were found between symptoms and QOL ( $r = 0.62$ ,  $P < .05$ ) and between spirituality and QOL ( $r = 0.70$ ,  $P < .05$ ). No statistically significant relationships were found between age at diagnosis, income, or education and QOL. This research suggests that symptoms and spirituality are associated with QOL. Culturally appropriate care should be provided to these women to reduce health disparities and to improve their QOL.

### Article:

Breast cancer is the second leading diagnosed cancer and the second leading cause of death among American women. Breast cancer is also the most common cancer among African American women.<sup>1,2</sup> Furthermore, the incidence of breast cancer in African American women continues to rise.<sup>3</sup> Only 74% of African American women with breast cancer survive, compared with 88% of white women.<sup>4</sup>

Quality of life (QOL) defined as a "person's sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him/her"<sup>5</sup>(p15) has become an important outcome indicator in health. Increased quality and years of healthy life and the elimination of health disparities among different segments of the population are the major goals of Healthy People 2010.<sup>6</sup>

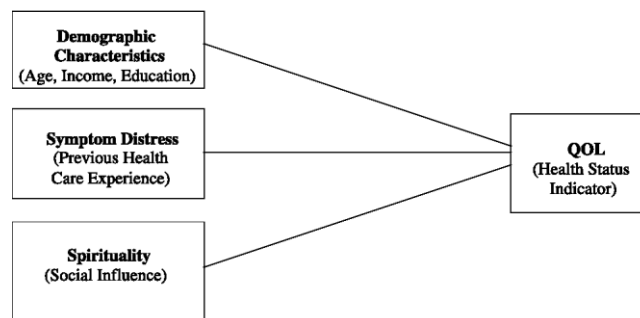
The Interaction Model of Client Health Behavior of Cox <sup>7,8</sup> was used to guide the study and examine client singularity variables that might explain factors related to QOL in African American breast cancer survivors. The model describes multiple interacting antecedents of health-protective and risk taking behaviors and identifies provider behaviors that affect health outcomes. The model is organized into 3 elements: client singularity, client-professional interaction, and health outcome. Client singularity was represented by demographics, symptom distress, and spirituality; QOL was viewed as a clinical health status indicator and health outcome (Figure).

Breast cancer has a potential influence on QOL.<sup>9</sup> Numerous researchers <sup>10-16</sup> have examined the influence of breast cancer on QOL among African American women. Symptom distress is the degree of discomfort from the specific symptom being experienced as perceived by the patient.<sup>17</sup> Studies of the relationship between symptom distress and QOL in these patients with breast cancer found that symptoms, such as fatigue and pain, had a clear impact on QOL. Bower and colleagues <sup>18</sup> found that approximately a third of breast cancer survivors reported severe fatigue, which was associated with high levels of

depression, pain, and sleep disturbance.

Spirituality is also an important variable influencing QOL for African American breast cancer survivors. Spirituality and faith-based practices have been found to be highly regarded in the African American community.<sup>19</sup> Brady and colleagues,<sup>20</sup> for example, examined spirituality and QOL in an ethnically diverse sample of breast cancer survivors and found positive associations between spiritual well-being and QOL. Spirituality is an important factor in coping with breast cancer by African American women.<sup>19</sup> Hope, coping strategies, and a relationship with God have been identified as the common themes related to spirituality and religion. Faith may give a cancer patient the ability to find meaning in life.<sup>21</sup> African American women rely on their faith and spiritual beliefs when dealing with QOL concerns.<sup>22</sup>

Age, sex, education, and income may also influence QOL. One study of long-term cancer survivors (N = 687) found that being female and having a partner/spouse and income greater than \$40,000 had significant positive influences on QOL.<sup>23</sup> Age at diagnosis and marital status were significantly related to QOL after diagnosis.<sup>24</sup> Several studies have found that women younger than 50 years reported lower QOL than did those older than 50 years.<sup>25-27</sup> Younger women reported more economic problems related to their diagnosis than did those older than 50 years.<sup>28</sup> Breast cancer survivors who had received a diagnosis at an older age (>65 years) had significantly worse QOL outcomes in the physical domain, whereas those who had received a diagnosis at a younger age (27-44 years) showed worse QOL outcomes in the social domain.<sup>29</sup> Education, family history of breast cancer, cancer stage, and treatment modalities were not significantly related to QOL.<sup>24</sup>



**Figure ■** Conceptual framework.

African American women with breast cancer are living longer than in past years because of early detection and preventative screenings. However, few studies have explored African American breast cancer survivors' symptom distress, spirituality, and QOL. This study therefore examined the relationships among demographics, symptom distress, spirituality, and QOL in African American women. Research questions in this study include the following:

1. What are self-reported QOL, symptom distress, and spirituality in African American breast cancer survivors?
2. What are the relationships among the demographic characteristics (age at diagnosis, income, and education) and QOL in African American breast cancer survivors?
3. What is the relationship between symptom distress and QOL in African American breast cancer survivors?
4. What is the relationship between spirituality and QOL in African American breast cancer survivors?

## *Methods*

### **Design**

A descriptive, correlational design was used to examine the relationships among demographic variables, spirituality, symptom distress, and QOL in African American breast cancer survivors.

### **Sample**

The convenience sample included 30 women who have completed breast cancer treatment in rural and urban areas of North Carolina. Inclusion criteria were self-identified African American; ability to speak and read English; self-reported confirmed diagnosis of breast cancer; completion of treatment that included chemotherapy, radiation therapy, hormonal therapy, or surgery completed between January 1, 1980, and June 1, 2004; and age 21 years or older. Women were excluded if they had recurrent breast cancer, were in current treatment, or had another cancer in the past 12 months.

### **Procedure**

Approval for the study was obtained by The University of North Carolina at Greensboro Institutional Review Board. Recruitment flyers were distributed to support and civic groups, churches, and community programs. An African American breast cancer support group and local churches were the primary recruitment sites. Women who were interested in participating in the study contacted the first author via a telephone number on the flyer, and the first author met potential participants in a private place or private room. Once the study had been explained and questions about the study were answered, potential participants were given the informed consent to sign. Participants were then asked if they preferred to complete the questionnaire or would have the first author ask the questions. It took 45 to 60 minutes for participants to complete the questionnaires. After completing the questionnaire, a \$10 gift card was given for appreciation of the participant's time.

### **Instruments**

#### DEMOGRAPHIC QUESTIONNAIRE

The demographic questionnaire included information about the subject's age, racial or ethnic background, educational level, socioeconomic information, health conditions, and other demographic information.

#### SYMPTOM DISTRESS

The Symptom Distress Scale (SDS) is composed of 13 items that use a Likert scale to measure symptoms experienced by cancer patients.<sup>17</sup> The symptoms include nausea, mood, appetite, insomnia, pain, mobility, fatigue, bowel pattern, concentration, and appearance. Each symptom is rated from 1 = "normal or no distress" to 5 = "experiencing the symptom almost constantly." Total scores range from 13 to 65, with higher scores indicating more symptom distress. A score less than 25 indicates mild symptom distress, 25 or greater indicates moderate symptom distress, and 33 or greater indicates severe symptom distress. Reliability and validity have been well established in patients with cancer.<sup>17</sup> Cronbach [ $\alpha$ ] in this study was .81, indicating adequate internal consistency reliability for the scale.

#### SPIRITUALITY

The Spiritual Perspective Scale (SPS)<sup>30</sup> was used to measure individuals' perspective on spirituality. The 10-item SPS is scored on a Likert scale with answers from 1 = "not at all/strongly disagree" to 5 = "about once a day/strongly agree." A total of mean score is calculated, and scores range from 1 to 5, with higher scores indicating higher spirituality. The reliability and validity of the SPS have been established.<sup>30</sup> Internal consistency reliability in this study was indicated by a Cronbach [alpha] coefficient of .86.

## QUALITY OF LIFE

The Quality of Life Index (QLI) of Ferrans and Powers <sup>31</sup> was used to measure QOL in terms of satisfaction with life. This instrument measures satisfaction with various aspects of life and the importance of those same aspects in 4 domains: health and functioning, psychological/spiritual, social and economic, and family.<sup>5,15,31-34</sup> Items are scored from 1 = "very dissatisfied" to 6 = "very satisfied." Scores are calculated by weighting each satisfaction response with its paired importance response.<sup>33</sup> Summed scores range from 0 to 30, with higher scores indicating higher QOL. A Cronbach [alpha] of .96 was reported in women with breast cancer after treatment (8 weeks),<sup>35</sup> and an [alpha] of .95 was reported in breast cancer survivors.<sup>5</sup> Content validity and construct validity have been established.<sup>5,31,36</sup> Cronbach [alpha] in this study was .92, indicating adequate internal consistency reliability for the scale.

## Data Analysis

Frequencies were examined to assess for missing data. Scores for the scale variables were calculated by adding individual scale scores. Reliabilities of the SPS, SDS, and QLI scales were calculated using Cronbach [alpha]. Descriptive statistics were used to describe the characteristics of the sample, study variables, and research question 1. Pearson correlation coefficient was used to answer research questions 2, 3, and 4. An [alpha] level of significance was set at  $P < .05$  for all analyses. SPSS 11.0 was used for data analyses.

## Results

### Demographics

Women were recruited to the study from breast cancer support groups (60%) and churches (40%). The 30 women who participated were at least 1 year post surgery, radiation therapy, and intravenous chemotherapy. The mean (SD) age was 55.5 (8.97; range, 43-77). One-third were married, and the others were either single or divorced. Approximately 77% of the participants were Baptist or had other religious affiliations. The average household included 2 members (SD, 1.10). Most (90%) participants had a high school or higher education (Table 1).

Most participants rated their health as good to very good. Stage of cancer at diagnosis ranged from unknown to stage 3. Mean (SD) age at diagnosis was 49 (8.96) years. The average (SD) self-reported number of years of survival was 5.6 (3.72; range, 1-17). Major health problems reported by participants included hypertension, diabetes, arthritis, high cholesterol, and heart disease (Table 2). The most commonly reported symptoms were sleep disturbances (70%), followed by some degree of fatigue (63.3%), some degree of pain (63.3%), problems concentrating (56.7%), concern about their appearance (40%), mild or severe pain (33.3%), and worries about the future (30%).

### Quality of Life, Symptom Distress, and Spirituality

The mean (SD) score on the SPS was 5.65 (0.55), indicating that participants had a high level of spirituality. The mean (SD) score on the SDS was 20.8 (6.2), which indicates that, overall, the women experienced mild symptom distress. Most (73.3%) participants had an SDS score below 25, indicating that participants had mild symptom distress. Approximately a fourth (23.3%) of the participants had moderate symptoms with a score of 25 or more. The mean (SD) score on the QLI was 26.6 (2.92), which indicates relatively high QOL.

**Table 1 • Demographic Characteristics  
(N = 30)**

Variable	Frequency	Percentage
<b>Religion</b>		
Baptist	15	50.0
Pentecostal	2	6.7
Presbyterian	1	3.3
Muslim	1	3.3
Methodist	2	6.7
AME Zion	1	3.3
No affiliation	1	3.3
Other	7	23.3
<b>Marital status</b>		
Single	7	23.3
Married	10	33.3
Divorced	9	30.0
Separated	1	3.3
Widowed	2	6.7
Dating	1	3.3
<b>Household size</b>		
1	5	16.7
2	14	46.7
3	8	26.7
5	3	10.0
<b>Education</b>		
3rd Grade	1	3.3
11th Grade	2	6.7
12th Grade	8	26.7
Some college	12	40.0
Completed college	7	23.3
<b>Income, \$</b>		
<10,000	4	13.3
10,000–19,999	3	10.0
20,000–29,999	9	30.0
30,000–39,999	8	26.7
40,000–49,999	4	13.3
>50,000	2	6.7

### Quality of Life, Symptom Distress, and Spirituality

The mean (SD) score on the SPS was 5.65 (0.55), indicating that participants had a high level of spirituality. The mean (SD) score on the SDS was 20.8 (6.2), which indicates that, overall, the women experienced mild symptom distress. Most (73.3%) participants had an SDS score below 25, indicating that participants had mild symptom distress. Approximately a fourth (23.3%) of the participants had moderate symptoms with a score of 25 or more. The mean (SD) score on the QLI was 26.6 (2.92), which indicates relatively high QOL.

### Pearson Correlations

No significant relationships were found between age at diagnosis, income, or education and QOL ( $P > .05$ ). A statistically significant relationship was found between symptom distress and QOL ( $P < .05$ ). This was an inverse correlation, indicating that women who reported severe symptom distress also reported a lower QOL. The symptom distress also reported lower scores on QOL. The relationship between spirituality and QOL in African American breast cancer survivors was statistically significant ( $P < .05$ ). This was a positive correlation, indicating that the higher the spirituality, the higher the QOL (Table 3).

* <b>Table 2 • Medical Conditions (N = 30)</b>		
Variable	Frequency	Percentage
Age at diagnosis		
37–59 y	26	86.7
60–70 y	4	13.3
Stage at diagnosis		
Unknown	14	46.7
1	6	20.0
2	5	16.7
3	5	16.7
Self-reported cancer-free, y		
≤5	12	40.0
>5	18	60.0
Existing health problems		
High blood pressure		
Yes	14	46.7
No	16	53.3
Diabetes		
Yes	9	30.0
No	21	70.0
Arthritis		
Yes	8	26.7
No	22	73.3
High cholesterol		
Yes	6	20.0
No	24	80.0
Heart disease		
Yes	2	6.7
No	28	93.3
Kidney failure		
Yes	0	0
No	30	100.0
Other health problems		
Yes	6	20.0
No	24	80.0

\* **Table 3 • Pearson Correlations Among Demographic Characteristics (Age at Time of Diagnosis, Income, and Education), Symptom Distress, Spirituality and Quality of Life (N = 30)**

Variable	Age at Diagnosis	Income	Education	Symptom Distress	Spirituality	Quality of Life
Age at diagnosis	–	–0.23	–0.52 <sup>a</sup>	–0.05	0.07	–0.12
Income		–	–0.55 <sup>a</sup>	–0.27	–0.14	0.14
Education			–	0.07	–0.09	0.08
Symptom Distress				–	–0.50 <sup>a</sup>	–0.62 <sup>a</sup>
Spirituality					–	0.70 <sup>a</sup>
QLI						

Abbreviation: QLI, Quality of Life Index.

<sup>a</sup>*P* < .001.

## Discussion

This study examined the relationships among demographic characteristics, spirituality, symptom distress, and QOL among African American breast cancer survivors. The findings of the study support Cox's model that spirituality (social influence/intrinsic motivation) was positively associated with a woman's overall QOL and that symptom distress (previous healthcare experience) was negatively associated with QOL.<sup>34</sup>

Self-reported spirituality and QOL were relatively high. The majority (77%) had religion affiliations that might have contributed to the high level of spirituality.<sup>37</sup> This finding is in congruence with literature stating that

spirituality was considered important for many African American women for coping with disease and provide peace during adverse events in life and times of stress.38,39

Existing health problems did not greatly influence the subject's overall symptom distress score. The participants reported low levels of symptom distress, which might be related to the years of survivorship. The majority rated their health as very good (40%) or good (43.3%); this might have been related to their high perception of QOL. Ninety percent of the sample in this study had high school education, with 23.3% having an income of less than \$19,999. These statistics are not typical for this household population. A previous study 11 indicated that a woman's mean net income was \$1,236, with a range of \$0 to \$3,500. The demographic characteristics of the sample of a fairly high level of education and income might be related to their higher perception of QOL.

The finding of no significant relationships among demographic characteristics (age at diagnosis, income, and education) and QOL in these African American breast cancer survivors differed from the findings of previous studies 24 in which age at diagnosis and marital status were significantly related to QOL after diagnosis. Participants in this study, however, had a mean of 5.6 years as a survivor, which might be related to an increased QOL.

Sleep disturbance, fatigue, and pain were the most commonly reported symptoms, and symptom distress was associated with QOL in African American breast cancer survivors. This suggests that symptom distress is an important factor in an individual's perception of QOL. These findings are consistent with previous research results of Eversley and colleagues 11 that symptoms may be associated with poorer functioning and QOL among African Americans. Bower and colleagues,18 in a sample of breast cancer survivors (N = 1,957), found that minority survivors experienced more persistent fatigue resulting in a negative association between symptoms and overall QOL. The findings from the study support previous studies related to symptom distress in women with breast cancer.40

The findings of a positive relationship between spirituality and QOL in African American breast cancer survivors is consistent with previous studies,22,41 which also found that spirituality was associated with a woman's perception of overall QOL. Religious practices, belief in God or a higher power, a spiritual leader, and support from family and friends are the primary sources of spirituality for African Americans.19 Spiritual beliefs and religiosity have an important role in African American lives, especially in making health decisions.42 These findings are consistent with the conclusion that women relied on their spiritual belief and higher power related to QOL.22,43 Although there are limited research studies that compare spirituality in African American breast cancer survivors with other ethnic groups,44 our findings support previous studies that African American survivors rely on God for support and encouragement more often than their friends and families.40

## **Limitations**

This study has several limitations. First, the small convenience sample of African American breast cancer survivors limits the generalizability of the study findings. Second, the stage of cancer and years of survival were not analyzed for their possible confounding effects.

## **Clinical Implications**

The findings of this research are important for nursing practice. Oncology nurses must be advocates for these populations and must provide culturally appropriate care and interventions to reduce health disparities and improve QOL. Holt and Klem 45 found that a spiritually based breast cancer education program for African American women was an effective approach for African American women in the church settings. African

American women cancer survivors rely heavily on prayer, and God and their spiritual relationship with God provide them with comfort, challenge, and effect change in their lives.<sup>38</sup> Culturally appropriate and spiritual-based interventions on symptom management to improve QOL of African American women with breast cancer should be developed. Nurses should work with congregations to emphasize the power of prayer with the spiritual support group. Nurses can work with churches to develop spiritual-based breast cancer pamphlets for African American women with breast cancer, with emphasis on health promotion, symptom, and stress management. Congregational nurses could also provide resources and oncology services and implement the spiritual-based intervention programs. The nurse and healthcare provider must be resourceful and knowledgeable about available resources for African American women who all represent varying socioeconomic levels.

This research filled a gap in the literature related to African American women and QOL. The conceptual framework of Cox <sup>7</sup> guided this research, in which symptom distress (previous healthcare experience) was negatively correlated with QOL and spirituality (social influence/intrinsic motivation) was positively correlated with a woman's overall QOL. Cox's model supported the study with 2 elements. Future research is warranted to investigate the client-professional interaction and the relationship of trust between client and professional. This model is supported for future research in cancer population. Cox's model has the potential to categorize health behaviors, health promotion activities, and interventions to support overall improvement of QOL.

This research has a different perspective than previous studies. Interestingly, this sample had a fairly high educational level. In these findings, the women had little knowledge about their stage of cancer at diagnosis. Their lack of knowledge of the extent of their disease may have influenced their treatment options and overall QOL. Nurse educators, practicing nurses, and communities must provide resources to these women. Nurses must establish a relationship with these women and begin discussions related to spirituality and symptom distress and how it affects the overall QOL of these women. Several recommendations for future research are needed to explore the impact of symptom distress and spirituality on QOL with a larger sample size in African American women with breast cancer. Replication of the study would also allow for more confidence in generalizable results. Conducting a qualitative analysis exploring women's perception of symptom distress, spirituality, and QOL through interviews or focus groups and in combination with the quantitative approach may provide additional insight and a broader perspective of how various personal factors influence QOL among African American women with breast cancer. Other recommendations would include expanding the recruitment sites to different locations and attending support group meetings as a means to recruit one on one. A final recommendation is to examine whether there are groups among African American women (age at diagnosis, socioeconomic, or comorbidities) that are different with respect to factors that impact QOL after breast cancer. Future research studies will expand on how women cope, strategies used to decrease severity of symptoms, and spirituality factors that help a woman manage.

## *Conclusion*

In conclusion, the findings from the study describe how African American breast cancer survivors are affected physiologically and spirituality by the disease. Symptom distress was negatively correlated with QOL, and spirituality was positively correlated with overall QOL in African American women breast cancer survivors. Symptom distress and spirituality played a major role in QOL in African American breast cancer survivors. Oncology nurses should establish a relationship with these women and begin discussions related to spirituality and symptom distress and how it affects overall QOL. Nurses have a major role in assessing and identifying women who are at an increased risk for symptom distress and psychosocial distress. Culturally appropriate care and interventions must be provided to these women to reduce the health disparity and to improve QOL.



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