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An Exploratory Analysis of Fear of Recurrence among African-American Breast Cancer Survivors

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Abstract

Background—Fear of recurrence (FOR) is a psychological concern that has been studied extensively in cancer survivors but has not been adequately examined in African-American breast cancer survivors.

Purpose—This exploratory study describes the extent and nature of FOR in African-American breast cancer survivors. FOR is examined in relation to socio-demographic characteristics, treatment-related characteristics, psychological distress, and quality of life (QOL).

Methods—Participants completed questionnaires assessing FOR, psychological distress, QOL, and demographic and treatment characteristics. Pearson *r* correlations, *t* tests, and ANOVAs were used to determine the association between FOR and demographic and treatment-related characteristics. Hierarchical multiple regression models were performed to investigate the degree to which FOR dimensions account for the variance in QOL and psychological distress.

Results—Fifty-one African-American breast cancer survivors participated in this study. The mean age of participants was 64.24 (*SD* = 12.3). Overall fears as well as concerns about death and health were rated as low to moderate. Role worries and womanhood worries were very low. Inverse relationships were observed between age and FOR dimensions. FOR was positively correlated with measures of psychological distress and negatively correlated with QOL. FOR significantly accounted for a portion of the variance in QOL and distress after controlling for other variables.

Conclusions—This study suggests that African-American women in this sample demonstrated some degree of FOR. Results indicate that FOR among African-American breast cancer survivors decreases with age and time since diagnosis and co-occurs with psychological distress as well as diminished quality of life.

Keywords

Fear of Recurrence; African-American; Breast Cancer Survivors

Introduction

African-Americans experience a disproportionate burden due to breast cancer especially as it relates to mortality and survival [1]. Although the data is mixed, [2, 3] research shows that in some cases, rates of breast cancer recurrence is higher in African-Americans when compared to Caucasians. For example, in a study examining outcome parameters between

African-American and White breast cancer survivors, it was reported that at a 10-year follow-up, African-American patients demonstrated higher breast cancer recurrence rates compared to their White counterparts (17% vs. 13%, respectively) [4].

Data suggest that breast cancer recurrence poses a significant threat to survivors and is known to generate fear and worry [5–8]. Vickberg and colleagues [8] describe FOR as the fear or worry that cancer will return in the same organ or in another part of the body. Across separate studies, 22% to 99% of women with cancer are beset by ongoing fears that cancer will recur [8–14].

Despite the significant impact FOR has on breast cancer survivors, few studies have been conducted on FOR among African-American breast cancer survivors. For example, Vickberg [6] examined FOR via semi-structured interviews among a mixed race sample of breast cancer survivors (Total $N=16$; six African-American, four Latina, six White). Results showed that in general, women reported low to moderate levels of fear. Several factors were identified as possible modifiers of African-American women's fears. Specifically, interactions with other people who had cancer appeared to influence African-American women's fears. One African-American participant commented "...So this is the thing that upsets me, when I hear from someone else what happened to them, I always think it could happen to me (p.241)" [6]. It was also stated that the possibility of recurrence made African-American women become concerned about future-oriented activities including "being around" for children. For example, an African-American woman commented "When you have children, you know, that's what you want.... you want to be around for your children (p.240)" [6]. Although this study offered relevant information, there is still much to be learned about FOR among African-American women. Particularly, it is important to understand what factors are associated with FOR as well as the nature of these fears in African-American breast cancer survivors.

Given the significance of FOR, it is important to identify background characteristics that may be related to FOR in African-American women. Research investigating FOR and background characteristics have been conducted primarily in Caucasian samples and have reported that the most consistent correlate of FOR is age, with several studies showing stronger fears among younger women [5, 8, 15–19]. A few studies have also investigated the relationship between FOR and time since diagnosis but have yielded mixed findings. Some studies [5, 20–23] report that as time progresses FOR dissipates, while others suggest that time makes no difference [8, 13].

Several treatment-related factors have also been identified as correlates of FOR. For example, there has been mixed support regarding the degree to which FOR is experienced in response to breast conserving surgery in comparison to mastectomy [8, 17, 24–26]. "The Trade-off hypothesis" proposes that breast preservation may enhance a woman's body image but increase FOR [26]. Others have contradicted the Trade-off hypothesis. For example, Kemeny and colleagues [25] reported that mastectomy patients were, in fact, more concerned with cancer recurrence than those receiving conservative treatment. Other studies have shown no difference in FOR between mastectomy and breast conserving patients [8, 27].

Previous research has found associations between FOR and psychological distress [8, 28, 29]. Simard and Savard [28] examined FOR and its association with psychological distress among male and female patients who had been treated for breast, prostate, lung, and colorectal cancer within the past 10 years. As expected, higher levels of FOR were significantly associated with both increased anxiety ($r=.64$) and depressive symptoms ($r=.43$). FOR has also been shown to be related to impaired quality of life (QOL). Everdingen et

al. [18] studied a sample of breast cancer survivors and found that FOR was negatively correlated to both physical ($r = -.22, p < 0.01$) and mental ($r = -.57, p < 0.01$) quality of life.

As previously mentioned, some data show that African-American women suffer disproportionate breast cancer recurrence rates, potentially putting them at risk for post-treatment psychological sequelae. Fear of recurrence is a psychological concern that has been studied in other populations but has not been adequately examined in African-American breast cancer survivors. To address this issue, the current exploratory study sought to (1) measure the extent and nature of FOR in African-American breast cancer survivors, (2) determine if significant relationships exist between FOR and socio-demographic characteristics and treatment-related characteristics, (3) determine if positive relationships exist between FOR and global psychological distress and negative relationships exist between FOR and QOL, and (4) to determine the degree to which FOR accounts for the variance in quality of life and global psychological distress.

Methods

Study Sample

To meet eligibility requirements, the participant needed to (a) have been diagnosed with local or regional breast cancer, (b) have no recurrence (defined as breast cancer coming back in the same breast or another area of the body, or a new breast cancer in either breast) [8], (c) have completed treatment including surgery and chemotherapy/radiation (with the exception of Tamoxifen), (d) be at least 18 years of age or older, (e) be African-American, Afro-Caribbean or African, and (f) be fluent in English.

Instruments

Participant Characteristics—Demographic characteristics (age, education, annual household income, and marital status) were assessed via a background questionnaire. Treatment-related characteristics including surgery type, time since diagnosis, stage, and treatment type were measured via a questionnaire.

Fear of Recurrence—Was measured with the Concerns of Recurrence Scale (CARS) [8]. The CARS systematically assesses the extent and the nature of women's concerns about breast cancer recurrence. It has two main parts. In the first part, overall fear index is assessed with four questions on frequency, potential for upset, consistency, and intensity of fears. Scores are given on a six-point Likert scale that ranges from 1 (not at all) to 6 (continuously). The second part of the scale measures the nature of women's fears about recurrence and is assessed with 26 items subdivided into four domains: health worries, womanhood worries, role worries, and death worries. Health worries are assessed with 11 items that refer to concern about future treatment (e.g., chemotherapy, radiation, and surgery), emotional upset, physical health, carrying out planned activities, and loss of breast(s). Womanhood worries are assessed with seven items referring to femininity, sexuality, womanhood, body image, romantic relationships, identity, and spirituality or faith. Role worries are measured with six items pertaining to roles and responsibilities at work and at home, relationships with friends and family, physical ability to complete daily activities, financial problems, and self-confidence. Death worries are assessed with two items that pertain to the possibility that a recurrence of breast cancer could lead to death [8]. Scores range from 0 (not at all), 1 (a little), 2 (moderately), 3 (a lot), to 4 (extremely), to indicate the extent to which they worry about each item. Scores for the overall fear index and each subscale were summed and averaged. Based on our sample, total scale responses indicated good internal consistency (Cronbach's $\alpha = .87$ to $.93$).

Global Psychological Distress—Was measured using the Brief Symptom Inventory-18 (BSI-18) [30]. The BSI-18 has 18 items, measuring dimensions of Somatization (items assessing distress caused by the perception of bodily dysfunction) (e.g. “Within the last 7 days how much were you distressed by faintness or dizziness”), Depression (items representing core symptoms of clinical depression) (e.g. “Within the last 7 days how much were you distressed by feeling no interest in things”), and Anxiety (items assessing symptoms of nervousness, tension, and apprehension) (e.g. “Within the last 7 days how much were you distressed by nervousness or shakiness inside”). Participants use a scale ranging from 0 (not at all), 1 (a little bit), 2 (moderately), 3 (quite a bit), to 4 (extremely). Global distress scores [range 0–72] were obtained by adding the sum of 18 items and converted to a normalized T score. In the present study, the global distress scale indicated good internal consistency (Cronbach’s $\alpha = .96$).

Quality of Life—Was assessed by the Functional Assessment of Cancer Therapy-Breast (FACT-B) scale [31]. The FACT-B scale consists of nine breast cancer specific quality of life items that the participant experienced within the past 7 days (e.g. “I worry about the effect of stress on my illness”). Each item is rated from 0 (not at all) to 4 (very much). FACT-B items are summed to obtain a total score [range 0–36]. Higher scores indicate a higher quality of life. The FACT-B has been widely used in breast cancer studies and has been found to be reliable, valid, and easy to administer [32]. In the present study, the FACT-B responses indicated good internal consistency (Cronbach’s $\alpha = .90$).

Procedure

This study received approval from the Howard University Institutional Review Board. Research participants were identified from the Howard University Cancer Center registry. Approximately 600 letters were mailed to potential participants identified through the registry instructing the recipient to call the study center for more information about the study. In addition to direct mail, flyers (approximately 200) were placed in the hospital cancer clinic describing the study and providing a phone number for interested participants. Members of the Cancer Center support group ($n = 10$) were also recruited.

All interested respondents were screened either in person or over the telephone to determine current eligibility. Eligible participants were either mailed a questionnaire or completed the questionnaire in the study center. Participants who were mailed a questionnaire were asked to mail the completed questionnaire back or bring it in to the study center. Informed consent was obtained from all participants after the nature of the procedure had been fully explained to them.

Approximately 130 women responded to the study mailings and flyers. Twenty-six women were deemed ineligible due to having had a recurrence. Six women were not interested in participating, 16 women were scheduled but did not show for the scheduled appointment, and 31 women were not able to be re-contacted. Over the course of approximately 18 months (2006–2008) a total of 51 participants were found to be eligible and completed the study requirements.

Data Analysis

Means, standard deviations and percentages were used to conduct descriptive analyses for this study. Pearson’s r correlations, t tests, and ANOVAs were used to determine the association between FOR dimensions and the demographic and treatment-related characteristics listed in Table 1. Hierarchical multiple regression models were performed to investigate the degree to which FOR dimensions account for the variance in quality of life (FACT-B) and global psychological distress (BSI-18 Global Severity Index). Correlations

among independent variables were calculated, to identify potential predictor variables. The variables used in the quality of life model included: BSI-18 Global Severity Index, education level, annual household income, and CARS Overall fear. The block function was utilized to include demographic characteristics entered in Step 1 and the CARS overall fear index was entered in Step 2. A similar procedure was used for the global psychological distress model with surgery type, treatment type and FACT-B entered in Step 1 and CARS subscales entered separately in subsequent steps beginning with womanhood worries which had the strongest correlation with psychological distress.

Results

Descriptive Characteristics

The mean age of participants was 64 years ($SD = 12$ years). Over half of the sample had a college education and had an income of \$50,000 and above. Fifty-three percent of women had mastectomy compared to 45% who had breast-conserving surgery. Additional participant characteristics may be found in Table 1.

Prevalence of Concerns of Recurrence

Our first aim was to determine the extent and nature of FOR among this group of African-American breast cancer survivors. Approximately 67% of participants reported at least some degree of FOR based on a score of at least two on the overall fear index. Women indicated low to moderate levels of overall fears ($M = 2.65, SD = 1.44$) as well as concerns about death ($M = 1.52, SD = 1.56$) and health ($M = 1.34, SD = 1.07$). Women reported significantly lower levels of role worries ($M = 0.95, SD = 1.01$) and womanhood worries ($M = 0.52, SD = 0.85$) compared to both health and death worries ($p < .01$).

Relationship Between FOR and Background and Treatment-Related Characteristics

Our next goal was to determine which demographic and treatment-related characteristics were associated with each dimension of the FOR scale. Based on our analyses, we found that overall fear was negatively associated with time since diagnosis ($r = -.35, p < .05$). Health worries were negatively related to age ($r = -.44, p < .01$). Role worries were negatively related to age ($r = -.28, p < .05$). Death worries were also negatively related to age ($r = -.44, p < .01$). Womanhood worries were not related to any background or treatment-related characteristics.

Correlation of FOR with Quality of Life and Psychological Distress

The next aim was to determine the relationship between FOR and psychosocial dimensions (quality of life and psychological distress). Overall fear of recurrence was negatively related to quality of life ($r = -.38, p < .01$). No other dimensions of FOR were related to quality of life. With regard to global psychological distress, our results revealed that overall fear ($r = .43, p < .01$), health worries ($r = .41, p < .01$), womanhood worries ($r = .49, p < .001$), role worries ($r = .48, p < .001$), and death worries ($r = .31, p < .05$) were all positively related to global psychological distress.

Predictive Value of FOR as It Relates to Quality of Life and Psychological Distress

Our last goal was to determine the extent to which FOR accounts for quality of life and global psychological distress utilizing hierarchical regression analyses. Demographic and treatment variables that significantly correlated with FACT-B were included as predictors in Step 1 and included education level, annual household income and global psychological distress (BSI-18) (see Table 2). Among the FOR dimensions, only the overall fear index was correlated with the FACT-B and was included in Step 2. Taken together, the variables

included in Step 1 accounted for 30% of the variance in FACT-B scores. Overall fear of cancer recurrence accounted for an additional 6% of variance in Step 2 with a significant R^2 change, indicating that Step 2 did significantly improve the amount of variance predicted by Step 1.

With regard to global psychological distress, participant demographic variables were not correlated with BSI scores. However, surgery type, treatment type, and quality of life were variables significantly associated with BSI scores and were therefore included in Step 1 of the hierarchical regression analysis (Table 3). The treatment characteristics and quality of life variables included in Step 1 accounted for 20% of the variance in global psychological distress. Although womanhood worries were endorsed at a lower rate relative to other CARS subscales, it had the highest correlation with psychological distress and was chosen for this reason as the first CARS subscale to be entered in Step 2 of the regression model. Womanhood worries accounted for an additional 23% of variance in Step 2 with a significant R^2 change, indicating that Step 2 did significantly improve the amount of variance accounted for by the variables included in Step 1. Additional CARS subscales were entered separately in subsequent steps but they did not account for any additional variance in global psychological distress above and beyond womanhood worries.

Discussion

Although FOR has been identified as a psychological disturbance among breast cancer survivors, no study to date has examined this issue exclusively in African-American breast cancer survivors using a multidimensional assessment of FOR. Findings from the current study suggest that African-American breast survivors report low/moderate FOR scores, and over half of this sample of women report some degree of fears of recurrence. These results echo what was reported by Vickberg's CARS validation study [8] which reported low/moderate reports of FOR among a sample of breast cancer survivors. Results also indicate that FOR among African-American survivors are associated with experiences of psychological distress as well as impaired quality of life.

The CARS scale is the first of its kind to measure the nature of a woman's concerns of recurrence. This was the first study, using the CARS scale, to identify specific types of concerns experienced by a group of African-American breast cancer survivors. Findings suggest that concerns revolved mainly around health worries (e.g. concern about future treatment, emotional upset, carrying out planned activities, and loss of breast) as well as the possibility of death. Women were less concerned about womanhood worries (e.g. body image, sexuality) and role-related worries (e.g. relationships with friends and family, physical ability to carry out tasks). These findings coincide with other studies [8, 18] that reported greater health- and death-related concerns and fewer womanhood and role-related concerns in a group of survivors.

With regard to the relationship between FOR and socio-demographic characteristics, it was observed that a higher degree of FOR was reported more frequently in younger patients. Prior research has generated similar results [8, 18]. Vickberg [8] suggests that this finding may be attributed to the fact that in younger women, there is a sense that a cancer diagnosis early in the life cycle is particularly unexpected or "off schedule." A recent Australian study [33] found that younger survivors especially those without children, stated that children would be the greatest concern. Younger participants' concerns were related to how the children themselves were going to cope with the possible death of their mother. Our study did not collect data regarding the number of children of each participant; however, this is a potential area of future research.

A sizable portion of the FOR research has concentrated on how breast conserving surgery versus mastectomy may influence a woman's concerns of recurrence. Findings from this study did not reveal a difference between worries depending on surgery type. Although some data contradict this finding [24], other studies also report no significant differences. For example, Lasry et al. [27] found that mastectomy patients were no less concerned about recurrence than those who had lumpectomy.

Another treatment-related characteristic that has been shown to influence a women's FOR is time since diagnosis. This study found that as time from diagnosis increased, overall FOR decreased. A study by Lampic et al. [34] corroborated these findings by reporting that cancer patients who were more recently treated reported more worries than patients who had been treated in the past. We did not find an association between stage and FOR. Our findings were similar to Vickberg [8] who also did not find FOR to be related to stage. As Vickberg [8] suggests, this information about stage informs us that women's fears about recurrence are influenced less by awareness of cancer stage than by other factors. More research is needed that uses the CARS to examine what those other factors might be.

This study also sought to determine the association between FOR and psychological distress. Consistent with other studies [8, 18], the current data indicated a positive relationship between FOR and global psychological distress. Our results confirm findings by both Vickberg [8] and Menhert [16] and underscore the need for health care providers to create services that target FOR as well as other related psychological factors. Although women in this study endorsed lower levels of womanhood worries compared to other dimensions of FOR, we found that womanhood worries significantly accounted for a portion of the variance in global distress even after controlling for other variables. This may suggest that womanhood worries may still have an important impact on survivors' psychological states. Further research is needed to elucidate this matter.

Our data showed that overall worries about breast cancer recurrence were significantly associated with decreased quality of life. This finding has been demonstrated in breast cancer samples [16, 18] as well as in prostate cancer patients [35]. Implications drawn from this result indicate that FOR has an important impact on QOL, and there is a need to develop specific interventions that address FOR and QOL.

There are important limitations that need to be addressed when interpreting these results. First, the cross-sectional nature of this data does not allow conclusions to be drawn about the temporal relationships between FOR, QOL, and distress. Future research would be improved by adopting a longitudinal approach to examining factors associated with FOR and QOL in breast cancer survivors over the course of recovery. Second, interpretation of our results is somewhat limited due to the homogeneity of several sample characteristics which included well-educated participants and individuals with relatively high incomes. While we are not sure if results would differ in other socio-demographic groups, it would be informative to examine these findings in other samples.

Despite these limitations, our study was the first to examine FOR among African-American breast cancer survivors, a largely understudied population. Results from this study provide valuable information regarding FOR and its correlates in a minority population. This study supports growing evidence of the extent and the nature of FOR among minority breast cancer survivors. It is important for health professionals to acknowledge this as a significant psychological health concern that requires proper supportive services.

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Table 1Sample characteristics ($N = 51$)

Characteristic	Descriptive statistic
Age	M = 64 years (SD = 12.3)
	[range 31 to 87 years]
Marital status	
Single, never married	15.7%
Married	35.3%
Divorce	19.6%
Separated	5.9%
Widowed	21.6%
Has a partner, living as married	2.0%
Education	
Up to high school diploma	13.7%
Some college/vocational school	25.5%
College Degree	17.6%
Post graduate degree	41.2%
Missing	2.0%
Annual income	
Less than \$19,999	11.8%
20,000 to 49,999	17.6%
50,000 to 99,999	47.1%
100,000 to 149,999	13.7%
\$150,000 or more	5.9%
Refused/do not know	2.0%
Missing	2.0%
Time since diagnosis	M = 7.2 years (SD = 4.3)
	[range 1 to 18 years]
Surgery type	
Breast conserving surgery	45.1%
Mastectomy	52.9%
Missing	2.0%
Treatment type	
Surgery only	9.8%
Surgery and radiation only	33.3%
Surgery, chemotherapy only	15.7%
Surgery, chemotherapy, and radiation	31.4%
Surgery, hormone and other	7.8%
Missing	2.0%
Stage	

Characteristic	Descriptive statistic
DCIS	27.5%
Stage 1	43.1%
Stage 2	19.6%
Stage 3	9.8%

Quality of life predicted by demographics, psychological distress, and concerns of cancer recurrence (CARS)

Table 2

Variable	R ²	ΔR ²	F	B	SE	B
Step 1	.30	.30	6.27**			
Education				6.22	2.41	.36*
BSI-18				-.41	.22	-.24
Income				3.26	2.43	.18
Step 2	.36	.06*	6.00**			
CARS: Overall fear				-3.92	1.99	-.27*

* $p = .05$,
** $p = .001$

Global psychological distress predicted by treatment characteristics, QOL, and concerns of cancer recurrence (CARS)

Table 3

Variable	R ²	ΔR ²	F	B	SE	B
Step 1	.20	.20	3.50*			
Surgery Type				8.43	3.55	.36*
Treatment Type				9.40	5.42	.25
Quality of life (Fact-B)				-0.12	0.09	-.20
Step 2	.43	.23**	7.76**			
CARS: Womanhood worries				6.80	1.67	-.51**

* $p < .05$,
** $p = .001$