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Exploring Quality of Life Experiences and Concerns of Black Breast Cancer Survivors: a Narrative Approach

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Abstract

Black breast cancer survivors (BCS) in comparison with White BCS are more likely to experience suboptimal quality of life (QoL). QoL is a multi-dimensional concept that focuses on different aspects of well-being (e.g., emotional well-being). There is limited evidence on the perspectives and experiences of QoL (e.g., the influence of breast cancer on QoL) and the QoL concerns (e.g., negative perceptions of body appearance) among Black BCS. The purpose of this study was to explore the QoL experiences and QoL concerns of Black BCS. Primary data was collected in semi-structured interviews and analyzed using a thematic analysis. A narrative approach (detailed stories or life experiences of a small group of people) was used to better understand the research topic among the target group. Ferrell's Conceptual Framework on QoL in Breast Cancer was used to guide the development of the interview questions, codes, and themes. There were 10 Black BCS, averaging 58 years of age. Two coders achieved a moderate level of agreement (i.e., Kappa) of 0.77. Five major themes were identified: defining QoL (what QoL means to them), behavioral changes (e.g., altering behaviors due to cancer), phases of cancer (e.g., breast cancer diagnosis), QoL experiences and factors affecting QoL, and impactful statements from cancer survivors (other meaningful information shared by the participants). The survivors reported multiple QoL concerns and body image issues. The study findings warrant cancer education interventions or programs to address the relevant survivorship issues of Black BCS.

Keywords Cancer survivor · Quality of life · Narratives · African American · Women · Breast cancer

Introduction

Black women have a lower incidence of breast cancer compared to White women but the highest breast cancer death rates in the United States (US) compared to all other races [1–3]. Overall, the cancer survivor population will increase over time [4]. Despite the improvements in survival rates, there are still racial disparities in the 5-year breast cancer survival rates between Black and White women (82% vs 91%) [3]. In addition to racial disparities in breast cancer survival rates, there are racial differences in quality of life (QoL) between Black and White breast cancer survivors (BCS). Specifically, Black BCS are more likely to report poorer QoL (a multidimensional concept that focuses on different aspects of well-being such as emotional well-being) and experience unmet needs (e.g., financial support) than White BCS [5–13].

Quality of Life Experiences

Previous studies have identified racial differences in QoL and explored the QoL experiences of Black BCS. For example, Bowen and colleagues (2007) found that Black women experienced significantly poorer physical functioning ($p < 0.01$) but higher mental well-being ($p > 0.05$) than White and Hispanic women [14]. Mogal et al. showed that low income (< \$30,000) was a predictor of poor mental well-being ($p < 0.01$) in Black women (2017) [15]. Further, tumor

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size and advanced stage (e.g., III/IV) was a predictor of poor physical wellbeing in Black women ($p < 0.01$). Another group of researchers observed significant associations between race (Black or African American) (OR = − 1.17; 95% CI, − 2.19 to − 0.16; $p < 0.05$), age (OR = − 2.83; 95% CI, − 3.5 to − 2.15.; $p < 0.05$), high school education (OR = − 1.60; 95% CI, − 2.18 to − 1.03; $p < 0.05$), advanced stage of cancer (OR = − 1.78; 95% CI, − 2.38 to − 1.18; $p < 0.05$), metastatic disease (OR = − 3.69; 95% CI, − 4.35 to − 3.04; $p < 0.05$), and poor health-related QoL (a person's perceived physical and mental health status, [HRQoL]) in Black and White cancer survivors [16]. A more recent study demonstrated that Black cancer survivors who had at least one unmet social need (e.g., housing instability) reported lower HRQoL than those who had no social needs [17]. Schootman and colleagues (2020) showed that built environment factors (e.g., presence of graffiti) were associated with poorer QoL in Black BCS [18]. Taken together, these studies suggest that overall, Black cancer survivors have worse QoL when compared to White cancer survivors. In addition, the evidence demonstrates that individual, socioeconomic, biological, and environmental factors can contribute to poorer QoL outcomes among Black cancer survivors.

Quality of Life Concerns

Previous studies have examined the QoL concerns and issues of Black BCS, specifically among those living in North Carolina. Black BCS have reported multiple QoL concerns including seeking safe sources of support (e.g., increased risk for rejection or discrimination), taking on the role of being a cancer survivor (e.g., adapting to physical limitations), feeling comfortable about the future, serving as positive role models in the community, struggles with sexual attractiveness related to dating and courting due to the side effects of breast cancer treatment, negative reactions from the opposite sex due to a cancer diagnosis, feeling self-conscious, and loss of femininity [19, 20]. Overall, only a few qualitative studies have investigated the QoL experiences and QoL concerns of Black BCS, specifically among contemporary samples. Therefore, the purpose of this study was to explore the QoL experiences and QoL concerns of Black BCS.

Methods

Study Population

Ten out of thirteen participants were eligible and consented between December 2020 and January 2021. The majority of the participants ($N = 9$) were recruited in Pennsylvania through community-based organizations. Eligible participants were female, Black or African American, diagnosed with breast cancer (excluding metastatic cancer), fluent in written and spoken English, not undergoing chemotherapy, surgery (e.g., mastectomy), and/or radiation therapy (hormonal therapy was acceptable), and between the ages of 18 and 85 years.

Data Collection

The primary construct was QoL, which was operationalized by more than one indicator including social well-being, emotional/mental well-being, and body image [6, 12, 13, 21]. Ferrell's Conceptual Framework on QoL in Breast Cancer was used to guide the development of the interview questions, codes, and themes [10]. A narrative approach was used to better understand the research topic among a small group of Black BCS [22]. Based on the qualitative approach, a sample size of 10 participants was needed to complete the research procedures, answer the research questions, and reach data saturation. An interview guide with open ended questions was developed and used to conduct the semi-structured interviews. The strategic sampling approach for this study was purposeful sampling [23]. Verbal consent was obtained from all eligible participants. All study procedures and interviews were conducted remotely by telephone or zoom. Approval from the Institutional Review Board (IRB) of the Pennsylvania State University College of Medicine preceded all study procedures.

Data Analysis

The interviews lasted about 9 minutes to 1 hour depending on the respondent. Some respondents were more engaged, communicative, and had more words to express than others. On the other hand, the length of the interview did not influence the quality of the interviews and richness of the data. The interviews were transcribed verbatim using a text transcription software called Otter.ai [24]. After transcribing, proofreading, and reviewing the transcripts, the procedures for conducting narrative research were followed (e.g., reorganizing the stories into chronological sequence) [22]. A qualitative data analysis computer software called NVivo (version 12) was used to organize, manage, and code the data [25].

One to two transcripts were reviewed to develop the initial codes and codebook. About 20% ($N = 2$) of the interview transcripts were analyzed by two coders to assess interrater reliability (i.e., Cohen's kappa coefficient). The codebook was refined by two coders to create the final codebook. Discrepancies were resolved by calibrating on the codebook until a Kappa statistic of 0.70 or better (at least a moderate level of agreement) was achieved for the primary construct. After a Kappa value of 0.70 or better was reached, an inductive and theoretical thematic analysis was used to provide detailed descriptions of the stories and themes [22]. Data saturation was reached after analyzing 10 transcripts.

Results

Table 1 displays the demographics and characteristics of the study population. The average age of the participants was 58 years (SD = 12.80). Many of the survivors (90%) had at least some college education. Over half of the women (80%) were postmenopausal. About 40% of the BCS were divorced or separated. Less than half of the participants (30%) had breast cancer-related lymphedema. The time since diagnosis ranged from 3 to 20 years. Five major themes were identified, which were defining QoL, behavioral changes, phases of cancer, QoL experiences and factors affecting QoL, and impactful statements from cancer survivors (see supplemental table II).

Defining Quality of Life

The participants described the meaning of QoL from their perspectives and based on their experiences (see supplemental table III). All the participants had favorable views about the meaning of QoL. Quality of life consisted of doing whatever makes one happy, family interactions, being fair to others and oneself, having the ability to engage in activities of daily living, having a will to live a life that one wants to live, and having a connection with God or something bigger than oneself. For example, one of the participants stated, "*Being able to take care of yourself and being reasonable, happy, independent*."

Behavioral Changes

Survivors discussed the negative and positive influences of breast cancer, cancer treatments, or other major life events (e.g., COVID-19) on their lifestyles (see supplemental table III). One survivor expressed her strong and newly found desire for chocolate after receiving chemotherapy: "*Okay, you may find one of my responses to be really crazy. But prior to cancer more so the treatment I didn't care for chocolate. I don't know what that the chemo did, but I like chocolate*."

Table 1 Characteristics of the study participants ($N = 10$)

Variables	Number (*N*)	% or mean (SD)
Age	10	58 (12.80)
Education		
Less than high school	1	10%
Some college (junior or technical college)	3	30%
4-year college grad	3	30%
Graduate degree	3	30%
Marital status		
Never married	3	30%
Currently married or living with a partner	2	20%
Divorced or separated	4	40%
Widowed or widower	1	10%
Retired		
Yes	2	20%
No	8	80%
Menopausal status		
Postmenopausal	8	80%
Premenopausal	2	20%
Lymphedema		
Yes	3	30%
No	7	70%
Cancer stage		
0- < 1	1	10%
1- < 2	3	30%
2- < 3	4	40%
3- < 4	2	20%
4	0	0%
Time since diagnosis, *y*	10	11 (7.01)

> "I think I was really active before I was diagnosed with cancer. And I feel like going through those treatments took a lot from me. So now I don't have the energy I used to have. And I have to force myself to do things."

Phases of Cancer

Three participants reported being diagnosed with breast cancer twice. One of the participants was diagnosed with breast cancer under the age of 30. A few survivors reported finding their cancer through breast cancer screenings (e.g., mammogram) or self-discovery. Most survivors received chemotherapy, radiation, and had breast surgery (e.g., mastectomy). At the time of the study, three participants were receiving hormonal therapy (e.g., Zoladex). In addition, survivors expressed multiple QoL concerns including fear of recurrence, rapid aging, body deterioration (e.g., brittle bones), weight issues, suboptimal mental well-being, fear of the adverse cancer treatment effects, staying healthy, lack of blood tests to detect cancer, and financial challenges (see supplemental table III). Two participants were concerned about having to undergo more surgeries to remove or replace their breast implants in the future (see supplemental table III). Two participants felt that they did not know the causes of their primary cancer or what could cause the cancer to develop again.

> "Basically, right now is financials like I said since my husband passed you know it makes a difference when you go from two incomes to one. So that's my biggest challenge now."

Quality of Life Experiences and Factors Affecting Quality of Life

Survivors noted that breast cancer and cancer treatments had positive and negative influences on their QoL (e.g., emotional/mental wellbeing) (see supplemental table III). As one women explained, "*I really went through a lot mentally after I lost my breasts. And I just had told myself if it came back again that I would just die with it. Because at one point, I didn't want to survive anymore, because I didn't want to not have my breasts*." In addition, the participants described the influence of other factors (e.g., physical activity, [PA]) on certain aspects of QoL (e.g., mental well-being). For example, one of the survivors stated, "*I think that physical activity can make you have a clear mind, help you like blow off some steam from stress, and just keep you active. I'm quite sure it will strengthen my bones a bit more. I think you feel better about yourself when you're able to move around and do things physically*." Along with PA, a few survivors believed that healthy eating or weight management (including weight loss) could make their QoL better.

> "I have to do something, some type of physical activity, because that also affects my mental well-being it helps me to sleep better, helps me to cope better with the stresses of life. You know, I know that I am at my best mentally, when you know when I'm working out regularly, and when I am closer to my ideal weight."

Specific to their body image, the participants had mostly unfavorable views about their physical appearance due to breast cancer and cancer treatments. For example, as this survivor explained, "*I think it changed my body because first of all, all the surgeries I went through my body looks like a map*."

Impactful Statements from Cancer Survivors

During the interviews, there were a few significant statements cited by the survivors (see supplemental table III). One woman described her experiences as a young adult cancer survivor and as a Black woman: *"If you're diagnosed with cancer in your 30 s it's a complete groundbreaker like it shapes your whole world. So, you know, what you thought you would want to be able to do with the rest of your life is just put on hold. I think being a cancer survivor and patient, you learn tenacity you know what I mean? And being black let's be honest, you learn a thick skin when things are thrown at you, you just learn to duck and dodge and just keep it moving the best way you can."*

Conclusions

We used a narrative approach to explore the QoL experiences and QoL concerns of Black BCS. The thematic analysis revealed five major themes that were reflective of a contemporary sample of Black BCS. The survivors reflected on their breast cancer experiences from early detection to survivorship. The QoL experiences (e.g., the influence of breast cancer on emotional well-being) in the current sample were positive and negative, which supports the study hypothesis. Also, the survivors reported multiple QoL concerns (e.g., fear of recurrence), which is consistent with the study hypothesis. In addition, the survivors had positive views about the meaning of QoL, which supports the study hypothesis.

Previous studies have investigated the QoL experiences and concerns among Black BCS. For instance, Russell and colleagues (2008) conducted a systematic review on the QoL issues among Black BCS [26]. The authors noted that the research on this topic became more evident among this population starting in 1998. Similar to the current study findings, fear of recurrence and financial difficulties were reported as significant QoL concerns. In the previous review, Black cancer survivors reported social difficulties, relationship issues, and multiple body image issues (e.g., negative perceptions of body appearance), which were all cited in the current study. Some of the other QoL issues (e.g., lack of prostheses for people of color) were not reported as concerns in the current sample, which suggests that some of the previous study findings might not be relevant to contemporary samples of Black BCS. Another group of researchers utilized grounded theory and found multiple QoL concerns (e.g., seeking safe sources of support) among a group of Black BCS living in North Carolina [19]. The current sample did not report the same QoL concerns, which indicates that the previous study findings might not be generalizable to contemporary samples of Black BCS.

A few years later, Torres et al. conducted an exploratory sequential mixed methods study and identified three major themes including breast cancer diagnosis, quality of care factors, and psychosocial well-being (e.g., fear) among a different group of Black BCS living in North Carolina (2016) [20]. Breast cancer diagnosis emerged as a major code rather than a major theme in the current study. Breast cancer had a positive and negative influence on the survivors' psychosocial and social well-being in the previous study, which is consistent with the current study findings. Fear of recurrence and fear of adverse cancer treatment effects were significant QoL concerns in both studies. The other QoL issues (e.g., negative reactions from the opposite sex due to a cancer diagnosis) were not reported as specific concerns in the current study and might not be relevant to all Black BCS.

Two more recent studies explored the unique challenges and experiences in survivorship among Black BCS [27, 28]. Husain and colleagues (2009) conducted a literature review on the four key components of survivorship care (e.g., intervention for late effects of cancer and treatment) among this group [27]. The late effects noted in the included studies were quality of life outcomes, lymphedema, sexuality concerns (e.g., reconstructive surgery), cardiotoxicity, neuropathy, and cognitive changes. Some of the survivors in the current study experienced breast cancer-related lymphedema and suboptimal mental health (e.g., concentration issues). Access to and receipt of reconstructive surgery and other late effects (e.g., cardiotoxicity) were not mentioned as a survivorship challenges for Black BCS in the current study, which might not be relevant to all Black BCS. A major survivorship issue relevant to reconstructive surgery faced by some survivors in the current study was breast implant revision. In addition, previous studies in the literature review relevant to prevention focused on health behaviors (e.g., physical activity) in the context of cancer recurrence and QoL. Some survivors in the current study noted a decline in physical activity after their diagnosis, the positive influence of physical activity on QoL, and weight-related issues (e.g., weight gain), which is consistent with the previous study findings. Another group of researchers used a mixed-methods design and identified five major themes including long-term physical symptoms and treatment side effects, body image, fear and anxiety regarding recurrence, financial toxicity, and spirituality [28]. Survivors in the current sample noted fear regarding recurrence, fear of adverse cancer treatment side effects, and financial challenges as concerns in survivorship, which is consistent with the previous study findings. Spirituality was not one of the primary QoL constructs in the current study. Changes to the body after cancer treatment (e.g., breast surgery) was also reported as a major survivorship issue faced by survivors in the current sample.

Implications

The study findings indicate that Black BCS are likely to have multiple QoL issues and similar but different QoL experiences. This study highlights the need for a comprehensive assessment of the multidimensional aspects of QoL among Black BCS. Healthcare providers should evaluate the needs of Black BCS during routine or follow-up care so that they can advise and best meet the identified survivorship issues of this group. There is a need for clear explanations on the following cancer-related topics of concern: breast implants, risk of recurrence, blood tests to detect cancer, short and long-term adverse cancer treatment effects, risk factors associated with breast cancer and cancer recurrence, and healthy lifestyles. Clearer information about the relevant topics of concern may help to reduce the fears of Black BCS and improve their QoL. It is crucial for healthcare providers and researchers to learn from and consider Black women's experiences to ensure the development and delivery of cancer education programs or interventions targeting information that is relatable and valuable to Black BCS. Future cancer education programs or interventions should educate healthcare providers on the unique needs of Black BCS and incorporate effective methods (e.g., storytelling) to address the needs of Black BCS.

Strength and Limitations

This study targeted a diverse and contemporary sample of Black BCS to understand their breast cancer stories, QoL experiences, and QoL concerns. In addition, the experiences of breast cancer are a sensitive subject and by utilizing semi-structured individual interviews with a female researcher of the same race and a more convenient setting (i.e., zoom) made it possible to elicit detailed stories and experiences of an underrepresented group. However, the participants were selected based on certain individual characteristics (e.g., Black or African American BCS) and convenience sampling. Therefore, the current study findings might not be generalizable to other cancer types and races. Furthermore, the study consisted of a small group of participants. A large sample size was not needed for the qualitative approach (narrative) and to complete the research procedures.

Supplementary Information The online version contains supplementary material available at https://doi.org/10.1007/s13187-023-02381-x.

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Data Availability The data that support the findings of this study are available within the article and its supplmentary materials. The data are not publicly available due to the risk of loss of confidentiality.

Declarations

Research Involving Human Participants and/or Animals This study involved human subjects and was approved by the Institutional Review Board of the Pennsylvania State University College of Medicine.

Informed Consent Verbal consent was obtained from each study participant.

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Conflict of Interest The authors declare no competing interests.

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Natasha Burse has moved to the University of North Carolina at Chapel Hill since completing the research. This work is part of the first author’s dissertation.