

Understanding the Breast Cancer Experience of Survivors: a Qualitative Study of African American Women in Rural Eastern North Carolina

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Abstract The purpose of this study is to gain an in-depth understanding of African American breast cancer survivors' experiences, barriers and facilitators in accessing breast cancer treatment, and challenges in adherence to follow-up care. We conducted seven focus groups with 32 African American women with breast cancer in three rural counties in eastern North Carolina during August–November 2013. Surveys were also utilized to gather basic demographic and breast health history information. Thematic analysis was performed using the immersion crystallization approach. Several common areas of life affected by breast cancer included faith and support networks, psychosocial well-being, and quality of care issues. Faith in God was an important coping mechanism essential to all women in the study and a critical facilitator in survivorship. Support networks consisted of family, church-family, friends, and co-workers. The concept of fear included the discovery of breast cancer and fear of death, negative side effects of treatment, and social stigma of having breast cancer. Factors that influenced provider-patient relationship were age of provider, perceived lack of empathy, and providers leaving during treatment. Participants also expressed their lack of knowledge regarding a number of the side effects they were experiencing during and after their treatment. Results of this study contribute to the assessment of potential coping

mechanisms used by African American breast cancer survivors (i.e., spirituality, positive attitudes, and support networks) that can potentially be effective and have a positive impact on the adjustment of life for survivors.

Keywords African American · Breast cancer · Eastern North Carolina

Background

Breast cancer is the most commonly diagnosed cancer and the second most common cause of cancer death among African American women [1, 2]. Although breast cancer mortality rates have been steadily decreasing, African American women have the highest death rate and shortest survival of any racial and ethnic group in the USA for breast cancers [1, 2]. The overall 5-year survival rate for breast cancer diagnosis from 2002 to 2008 among African American women was 78 %, compared to 90 % among Caucasian women [1, 2]. When looking at the burden of female breast cancer in North Carolina 2004–2008, the average crude incidence rate for breast cancer in eastern North Carolina (ENC) was 11 % greater (expressed as a ratio) compared to the rest of North Carolina (RNC) (201.5 per 100,000 women compared to 181.4 per 100,000 women) [3]. Similarly, the average crude mortality rate for breast cancer was 20 % greater in ENC compared to RNC (44.0 per 100,000 women compared to 36.1 per 100,000 women) [3]. Within ENC, breast cancer incidence rates were 15 % greater for white women than for African American women (212.1 per 100,000 women compared to 183.4 per 100,000) [3]. However, breast cancer mortality rates were 38 % higher among African American women than white women during the same time period (56.6 per 100,000 women compared to 38.4 per 100,000). The causes

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of these observed disparities are complex and are attributed to a number of factors including biological (i.e., disease pathology and genetic markers), behavioral (i.e., cultural norms, beliefs, and practices), and social (i.e., SES, access to care, and quality of care) [1–6].

There is an estimated 2.8 million breast cancer survivors in the USA, a figure that is expected to continue to increase due to advances in breast cancer detection and treatment [2]. As a result, researchers are beginning to study the distinct medical and psychosocial issues of long-term survivors, but studies to date have been limited by several weaknesses [7]. Some notable limitations include underrepresentation of minorities, the medically underserved, poor, rural, and other hard-to-reach populations and few studies have looked beyond 5 years after diagnosis and little is understood about long-term issues among survivors [7]. Therefore, research targeting geographically, demographically, and diagnostically diverse cancer survivors at various defined points of survivorship will begin to fill the gaps in our understanding of the factors that affect survivorship, as well as the medical and psychosocial well-being of survivors [7].

Most breast cancer survivorship studies, including quality of life studies, are predominantly conducted with Caucasian women. Studies that have included African American cancer survivors have found that breast cancer diagnosis and treatment have negatively affected survivors' physical and overall health directly related to their treatment and psychosocial well-being (e.g., economic stress, social support, relationships, and familial challenges), and many expressed particular concerns with their body image and sexuality [4–6, 8–11]. The quality of life of breast cancer survivors has been shown to be threatened by quality of care (i.e., quality of provider-patient relationship, access to care, and financial resources), physical and cognitive impairments, psychosocial stress, role functioning constraints, and emotional and social well-being [4–6, 8–11]. A study conducted by Kreling and colleagues investigated factors affecting chemotherapy use in older women female breast cancer patients [12]. Investigators found that African American participants reported feeling discriminated against because of their low socioeconomic status. All African American participants agreed that class and education were important factors in how they were treated by physicians [12].

In addition to our limited understanding regarding quality of life issues among African American breast cancer survivors, there are additional burdens when looking at this within a rural context. Rural residents are typically less educated, poorer, and older, and have limited access to cancer care services [13]. Rural populations also experience variation in the quality of care (i.e., access to cancer care services and specialists, limited access to new and effective therapies and technologies, and prohibitive costs of cancer treatment), as well as cancer services (i.e., support groups, education, and health promotion programs) [13]. Other barriers include

transportation issues, financial issues, and attitudes towards cancer (i.e., fatalism and fear of stigma due to cancer) [13]. These additional barriers experienced by rural populations may negatively affect health outcomes and quality of life for cancer patients, specifically as survivors.

In order to address issues relevant to breast cancer survivorship among rural African American women, it is critical to expand our understanding of these issues within the social and cultural context in which they occur. The purpose of this qualitative study is to explore the experiences of African American breast cancer survivors in rural North Carolina to expand our understanding of their experiences throughout the continuum of breast cancer care, specifically to better understand the barriers and facilitators in accessing breast cancer treatment and challenges in adherence to follow-up care.

Methods

Participants

We conducted seven focus groups with 32 African American women with breast cancer in three rural counties in ENC between August and November 2013. Eligibility criteria included self-identified as African American women who completed their breast cancer treatment within the last 10 years, who reside in either county where the study was conducted, and who were 18 years of age or older.

Procedures

This study employed a mixed methods study design, involving both paper survey and in-depth focus group interviews. The qualitative approach allowed for richer and a more in-depth exploration of breast cancer experiences throughout the continuum of care. The interview guide was informed by existing literature about quality of life and overall experiences of breast and cervical cancer survivors (see Table 1) [4, 5, 8–10, 14]. The interview guide included open-ended questions designed to elicit women's experiences regarding breast screening beliefs and practices, breast cancer experience from diagnosis through treatment and survivorship, support networks and coping mechanisms, facilitators and barriers throughout the continuum of breast cancer care, quality of life after treatment, and advice for improving the process for future breast cancer survivors. Screening questions were included to understand preventive screening behaviors among participants, since this has been identified as a critical factor in observed breast cancer disparities [1–6]. The quantitative component consisted of survey items that queried on basic demographic information, cancer-related information (i.e., breast cancer prognosis, age at which they were diagnosed, stage, and treatment), perceived quality of care, preventive

Table 1 Focus group interview guide

1. When you think about cancer, what are the first three things that come to your mind?
 2. Do you remember any specific time that your primary care doctor might have spoken with you about breast cancer?
 - a. If so, can you remember the information he or she gave you?
 3. When you found out you had breast cancer, what do you remember your doctor telling you?
 4. Think back to just before you found out you had breast cancer. Can you walk me through from the beginning of your experience until now?
 - a. How did you find out you had breast cancer?
 - b. Can you tell me about your treatment?
 - c. How long has it been since you've finished treatment?
 - d. Probe for specific examples/experiences.
 5. Tell me about your relationship with your breast cancer doctors.
 - a. What did your doctors tell you to do to get well?
 - b. In your opinion, what are things that may affect the quality of treatment a person gets from the medical staff or doctor?
 6. What are the things that helped you the most in recovery or coping with your cancer?
 7. Who gave you the most support to help cope with breast cancer?
 - a. Other cancer survivors, family, friends?
 8. What type of support do you receive from your supervisor or co-workers, if any?
 9. Has your coping with breast cancer been affected by your local community or neighborhood?
 - a. If so, how?
- Previous research suggests that many women do not have health insurance prior to their diagnoses, was this true for you?
- a. How did this affect your care?
 - b. Do you think if you had had health insurance you would have gotten regular screening?
11. Did your finances play a role in your breast cancer care decisions?
 - a. If so, can you tell me about that?
 12. Do you currently suffer any secondary effects (emotional, physical, or mental) because of your cancer treatment that make life a bit difficult for you now?
 13. Did you develop a follow-up plan after successfully completing breast cancer treatment (breast cancer survivorship plan) with your oncologist or doctor?
 - a. Can you explain what some positive or negative experiences in developing this plan?
 - b. Can you share with me what some barriers are to following this plan?
 14. Being a breast cancer survivor, do you have any advice for how to improve the process from diagnosis to treatment and then to survivorship?
 15. Some women feel discriminated against within the health care system which has influenced them to not want to go to the doctor. At any point in your life have you ever felt discrimination when getting medical care?
 - a. If so, can you tell me more about a specific experience?
 16. Is there anything else you would like to add that has not already covered today?

screening practices, barriers to screening and treatment, and family health history information from each participant. Study protocol and materials were approved by the East Carolina University and Medical Center Institutional Review Board.

Study recruitment methods consisted of multiple approaches. Women were recruited from August 2013 to November 2013 using informational flyers that included the overall purpose of the study, eligibility criteria, details about becoming a participant (e.g., length of participation, methodology, and compensation), as well as contact information. This study collaborated with community partners such as the Leo W. Jenkins Cancer Center, Vidant Oncology, local churches, and community centers in the three ENC counties where flyers were distributed. Women either called research staff directly to learn more about the study or were referred by community

partners as a potential participant. Snowball sampling methodology was also used by distributing flyers to participants after the focus group for referral to other African American breast cancer survivors that might be interested in participating.

Seven focus groups took place in three ENC counties (two in county 1, one in county 2, and four county 3) and were conducted in different settings (i.e., community center, church, local cancer center, university, and a soup kitchen) to provide a private, comfortable, and convenient environment. Focus group size varied from two to ten women, with five out of seven focus groups having a minimum of four and a maximum of ten participants. Although efforts to conduct focus groups with a minimum of four women were made, survivors from the smaller focus groups were highly involved

participants, maintained active discussions, and contributed important data to this study. Community partners assisted with the coordination and logistic of some focus groups. The authors (Torres and Ellis) moderated all focus groups. Women sat in a circle format to encourage openness and to foster a safe and supportive environment. Beverages, snacks, and tissues were available to the women, as many of these testimonials were an emotional journey for participants. At the end of the focus group sessions, women received a \$50 gift card for their participation. Verbal consent was obtained after a member from the research team read aloud the study's information sheet and answered any questions and/or concerns of the participants. This was done to ensure everyone understood the purpose of the study and her rights as a research participant, and each participant received a copy of the study information sheet to take home for future reference.

Data Analysis

Focus groups lasted approximately 1 h and were audio-recorded and transcribed verbatim to ensure the dialogue was accurately captured. A coding template was created and coding adjustments and additions were updated via an iterative data analysis process. To ensure coding consistency and reliability of results, both the lead researcher (Torres) and second coder (Ellis) read and coded all transcripts. During data analysis meetings, coders met to reconcile any differences in the coding, compare findings, and refine patterns until an agreement was reached about major content areas. Data analysis was conducted using the immersion crystallization approach by research team members to identify important themes [14, 15]. Researchers extensively examined the data by reading and memoing (immersion) and collectively reflecting and discussing potential themes found during the immersion process (crystallization) until the data had been completely analyzed and final themes have emerged by this iterative process [14]. Saturation during data collection was reached for all identified themes in the analysis phase.

Results

The main themes for this study include breast cancer diagnosis, psychosocial well-being (i.e., fear, coping mechanisms, quality of life, and body changes), and quality of care factors (i.e., doctor-patient relationship, side effects of treatment, being adherent to follow-up care, and financial resources). Table 2 presents the demographic and cancer-related characteristics of breast cancer survivors in this study. Overall, the mean age of the participants was 56 years old ($SD=11.89$), with 10 % younger than 40 years old, 26 % between 40 and 50 years old, 42 % between 51 and 64 years old, and 23 % 65 and older. The majority of survivors were divorced/widowed/

Table 2 Demographic and breast cancer-related characteristics of breast cancer survivors

| Total $N=31$ | Number of samples | Percentage |
|--|-------------------|------------|
| Age (years) | | |
| <40 | 3 | 9.7 |
| 40–50 | 8 | 25.8 |
| 51–64 | 13 | 41.9 |
| ≥65 | 7 | 22.6 |
| Marital status | | |
| Married | 10 | 32.3 |
| Divorced/separated | 9 | 29.0 |
| Widowed | 5 | 16.1 |
| Single | 7 | 22.6 |
| Educational level^a | | |
| ≤High school/GED | 15 | 48.4 |
| Some college | 9 | 29.0 |
| College/grad school | 6 | 19.4 |
| Health insurance status | | |
| No insurance | 3 | 9.7 |
| Medicaid/Medicare | 18 | 58.0 |
| Private insurance | 10 | 32.3 |
| Income^b | | |
| <\$20,000 | 13 | 41.9 |
| \$20,000–\$39,999 | 9 | 29.0 |
| \$40,000–\$59,999 | 0 | 0 |
| ≥\$60,000 | 2 | 6.5 |
| Adherent to breast cancer screening guidelines before breast cancer diagnosis^c | | |
| Yes | 14 | 45.2 |
| No | 17 | 54.8 |
| Breast cancer characteristics | | |
| Age at breast cancer diagnosis^a (years) | | |
| <40 | 6 | 19.4 |
| 40–49 | 9 | 29.0 |
| 50–59 | 8 | 25.8 |
| ≥60 | 7 | 22.6 |
| Type of breast cancer | | |
| Invasive ductal | 5 | 16.0 |
| Invasive lobular | 2 | 6.5 |
| Lobular carcinoma in situ (LCIS) | 2 | 6.5 |
| Distal carcinoma in situ (DCIS) | 3 | 9.7 |
| Do not know (unable to identify type of breast cancer) | 19 | 61.3 |
| Breast cancer treatment^d | | |
| Chemotherapy | 20 | 64.5 |
| Radiation therapy | 25 | 80.6 |
| Hormone therapy | 2 | 6.5 |
| Mastectomy | 11 | 35.5 |
| Clinical trial | 1 | 3.2 |
| Decided to have no treatment | 4 | 12.9 |

^a Reflecting one missing case

^b Reflecting seven missing cases

^c Based on the American Cancer Society's guidelines for early detection of breast cancer (i.e., clinical breast exam and/or mammogram)

^d Total adds up to more than 100 % because women reported more than one type of treatment

separated (45 %) or single (23 %), half had a high school education or less (48 %), and most were insured with Medicaid/Medicare (58 %) or private insurance (32 %). Approximately 42 % of survivors reported an annual income of less than \$20,000. In regard to breast cancer characteristics, the majority of survivors were diagnosed age 50 or older (48 %). However, it is important to note that 19 % of survivors were younger than 40 years old when diagnosed with breast cancer. Before being diagnosed with breast cancer, approximately half of the survivors (45 %) reported being adherent with the recommended age-appropriate breast cancer screening exam (i.e., clinical breast exam and/or mammogram). In regard to the type of breast cancer diagnosis, approximately 61 % of survivors could not recall their specific type of breast cancer. Chemotherapy (65 %), radiation (81 %), and mastectomy (36 %) were the most common type of breast cancer treatments reported by survivors in this study.

Breast Cancer Diagnosis

The most common ways survivors reported discovering their cancer were either self-discovery, via age-recommended screening, and/or their gynecologists. Some survivors reported finding a lump or having their significant other find a lump and then delaying follow-up because of the fear of discovering it was breast cancer. In a couple of cases, this led to an advanced stage of cancer.

...I found it myself and I just was home um...and I started um, preparing for the day, and I just saw something that didn't look right in my left breast and that's when I found it and I found it in February of 2011 and I didn't go to the doctor until June, cause' I was scared I didn't wanna, you know, hear the doctor say, that's what I had. So what I did was I started like putting like heat wraps or something; I said maybe it's a pulled muscle or something, but when I started experiencing pain with it, I had to go.

Some of the survivors reported their disbelief regarding their breast cancer diagnosis because they engaged in preventive measures such as a healthy lifestyle (e.g., exercise and healthy eating) and/or the recommended breast cancer screening exam (i.e., mammogram and/or clinical breast exam) on a yearly basis.

Well because I worked to make sure that I was as healthy as I could be with my eating habits, with my exercising because I am a large girl and after you get a certain age you start to put the pounds on and so I think when I was about...hmm...maybe 33 I began to change my eating habits, and- well even before that because I knew that hypertension which is something that I deal with now was in our family...so I started watching, you know, the

way I cooked, the way I ate, and things like that so when that happen, it was just really unbelievable for me.

Delivery of their breast cancer diagnosis was also a sub-theme that was discussed among some survivors. Although many expressed positive experiences from diagnosis to getting connected to their health care providers for treatment, others thought their experience could have been handled with more sensitivity. Some women reported receiving their breast cancer diagnosis over the phone and believed it should have been discussed in person, given the initial shock that comes with such a diagnosis.

Psychosocial Well-being

Fear The concept of fear was one that transcended throughout all the themes. These fears included the following: hearing the word cancer and thinking it was a death sentence, fear of the stigma of being diagnosed with breast cancer, fear of the side effects of treatment, fear of the interruption of their role as a caretaker, and fear of reoccurrence of their cancer.

Just to hear that it was breast cancer with a six week old, a newborn, I was like you mean to tell me I'm going to die. On top of that [I have] an 8 year old. I was like no one else can raise my boys. Like you said the word death, when you hear the word cancer you think of death. I was scared; I guess I was scared of the chemo at first because signing that paper saying you know it was fatal for taking these drugs. Oh my God, I could die just for taking the chemo, they have taken out the cancer, now they are saying the chemo could kill me...

Coping Mechanisms Several types of coping mechanisms were discussed by survivors. These mechanisms included faith (i.e., belief in God and power of prayer), support networks (i.e., family, church, work, breast cancer support groups, and other cancer patients/survivors), positive attitudes, and acts of empowerment.

Faith was the most prominent coping mechanism mentioned by all participants. Faith in God helped survivors cope with their diagnosis by providing them with acceptance of their cancer and reassurance they would survive. They felt God was guiding them through their experience and felt the power of prayers was an important component of their faith as a coping mechanism.

But I thank God today that he gave me the strength to go day to day to take care of myself, my kids and go through this process. ...like I said my church family and prayer and believing God and like is said without a test, there is no testimony.

Support networks provided emotional and spiritual support needed to overcome the many challenges survivors experienced during their journey. In particular, support networks encouraged survivors to get checked before initial diagnosis, assisted survivors with the side effects of treatment and their caregiver roles, and provided supportive work environments to help survivors maintain normal daily lives as best as they could. Breast cancer support groups were also mentioned by some survivors, and they stated these really helped them connect with other women who were experiencing a similar journey. There were a few survivors who were disappointed because their provider never mentioned or referred them to support groups and felt it would have been an excellent support network for them.

One of the most difficult side effects of treatment for many survivors was the loss of their hair. It was a physical reminder of their cancer and a side effect of their treatment. However, many women stated that their decision to cut off their own hair before losing it all to cancer was a way of empowering themselves and their families. They felt it was one of the few things they could control, and it gave them assurance that they had the strength to overcome their cancer.

...but that night when I shaved it, it was great. I was like what was this, this is a crazy feeling. So, it was almost an empowering feeling. It actually was. When I finally did it, you could actually see the glow back in my face...

Survivors also emphasized the importance of a positive attitude and laughter and how this approach helped them remain mentally strong throughout their treatment.

On this journey, you must...it's important that you keep a positive attitude and laughter is good for you. Laughter, that's what carries me through. I'm kind of a jokester and I love to laugh and I love to make folks laugh in a good way, in a good way...

Quality of Life Concerns Some survivors struggle with loss of their femininity after the removal of one or both breast(s). This "loss" was emotionally challenging for some to accept and overcome. Some women expressed feeling self-conscious because of the physically noticeable scars of their treatment. For example, survivors stated that the incision from their surgeries made them self-conscious about wearing specific clothing such as low-neck blouses and constantly making sure their incision was not visible. Survivors discussed how the side effects of their breast cancer treatment led some to some struggle with sexual attractiveness as it related to courting and dating. Survivors also mentioned the negative reaction to their diagnosis and treatment from male counterparts.

...that prosthesis is not the same thing. ... I told my daughter I said, 'just don't let me look at myself yet' because you got to get used to the fact that a part of your body is not there.

I am a vital young women and I'm single and the possibility of you know, maybe meeting someone, not necessary always to get married but you got to tell them that I am missing a part of my body and you know, men can be so cruel, not all of them, but some of them

Participants felt it was critical to their quality of life to continue to lead their normal lives. They reported working during their treatment and continuing their role as caretakers. Many would incorporate their treatment into their lives but did not allow the cancer to consume their lives.

I would go in before work, do my radiation, go to work, and work up until I was done.

... I thank God today, that he gave me the strength to go day to day to take care of myself, my kids and go through this process.

Quality of Care Factors

Doctor-Patient Relationship The quality and type of communication with health care providers varied among survivors. Some women reported a collaborative team-based approach, while others reported working with just their oncologist. Among the health care providers that were working collaboratively for their care, survivors reported feeling comfortable and felt their health care team was invested in them as patients which allowed them to trust any recommendations they suggested for their treatment. Some survivors did not have a team-based approach and reported trusting their provider's judgment and treatment decisions, mainly because they viewed them as experts in breast cancer.

My doctors which was Dr. she was very, very concerned, she was there for me and um...with me being so young I kinda sorta put, I trusted them, as far as my chemotherapy and treatments and stuff that I had to get.

A few survivors expressed their desire to be better informed of their diagnosis and treatment options, as well as the potential side effects from treatment. Survivors also described different characteristics of their providers that affected the quality of care received. Some women reported having an older provider and felt they lacked empathy and patience and did not have a vested interest in their survivorship. Women who had younger providers expressed the opposite and felt a genuine interest from their providers in making sure they

understood their treatment. Many survivors also discussed how difficult it was to adjust to a new provider either during or after treatment, after their oncologist left the facility.

I found out that it seems like when I get the older one... the first thing they see like, I feel like they are saying, 'you're going to die anyway' with the older ones, but the younger ones, they want to know everything that is going on with you so they can treat you.

In regard to faith, some women expressed how critical it was for their providers to respect their faith in God. In one case, the provider demonstrated this by praying with the participant, which was viewed as very meaningful to her and helped her cope with her diagnosis. During one of the focus groups, an unexpected challenge experienced by several survivors was getting their provider to comply with their request to have their ovaries removed. They wanted them removed as a preventive measure and expressed the frustration in having to convince their providers to comply, and many believed it was due to their young age. Some opted to switch providers due to this conflict of interest and were still in the process of having them removed.

Side Effects of Treatment Women expressed being offered different treatment options; some followed the suggested regimen and others made their own decisions about their treatment. Treatment options discussed included chemotherapy, radiation, mastectomy, double mastectomy, as well as oral medications. Some survivors expressed having reoccurring surgeries due to more cancer being discovered. To avoid this, some women opted for a mastectomy as a preventive measure. The aggression of the chemotherapy, radiation, and other treatments and the toll it took on them were often discussed. They experienced fatigue, body aches, pain, various types of neuropathy such as severe numbness and tingling in their extremities, blood clots, short-term memory loss referred to as "chemobrain," lymphedema, lingering cough, breaking down of skin and burn from radiation, a metallic taste in their mouth after receiving chemotherapy, weight gain, feelings of numbness and tingling in their bodies following their mastectomy, blurry eye sight, having their teeth removed, low blood counts, allergic reactions to medications, and severe burning near their breasts, under their arms, and all over their body.

I have cancer for a third time. I am doing chemo at my home. I am doing the chemo pills. I didn't even know about the pills. The first two times I had the chemo liquid, but now I am doing the pills. I didn't know that with the pills you have to have teeth pulled, at one time. I said Lord have mercy. I was fine with the hair loss and pulling my teeth was fine. I had to have 14 teeth pulled at one time.

I have lymphedema, I have all bone pain. I have the diabetic nerve pain in my feet. My feet hurt so bad sometimes I can feel my feet drawing up. I am drawing up, my foot drawing up, I have osteoarthritis now all over ...

Adherence to Follow-up Care Some survivors mentioned they were expected to see their doctors twice per year (i.e., every 6 months). They highly recommended going through with follow-up appointments and valued those times after overcoming their cancer. Some survivors reported a lapse in their insurance and having problems adhering to the follow-up appointments. However, the majority of survivors were adamant about the importance of the follow-up as an important part of survivorship.

Financial Resources The majority of women had insurance or was connected to the North Carolina Breast and Cervical Cancer Control Program (NC BCCCP) which provides free or low-cost breast and cervical cancer screenings and follow-up to eligible women. Many expressed not being concerned about being un- or under-insured once they were diagnosed with breast cancer, and none of the women believed their insurance status affected the treatment options available to them. Some women received assistance from the local American Cancer Society for treatment-related expenses, such as transportation. While most survivors did not express financial concerns around breast cancer treatment, some women experienced financial difficulties in regard to paying for non-treatment-related bills (i.e., water or electricity bills).

Conclusion

This qualitative study further expands our understanding of the experiences of African American breast cancer survivors along the cancer care continuum. Several common areas of life affected by breast cancer included faith and support networks, psychosocial well-being (i.e., fear throughout the participants' journey, issues with femininity and acts of empowerment), and quality of care issues, including doctor-patient communication, side effects of treatment, and follow-up care adherence.

Faith in God was an important coping mechanism essential to all women in the study and a critical facilitator in survivorship. Participants in this study relied on the power of prayer and their church-family as a source of strength and motivation as they endured their treatment. Participants also attributed their strength and resiliency on their faith in God and believed that God was guiding them through their journey. Most participants expressed the importance of having their health care providers respect their faith in God as part of their treatment

process and survivorship. This particular coping mechanism is supported by other studies with African American breast cancer survivors [4, 8–10] and has been found to be an essential facilitator throughout the continuum of breast cancer care for African American women. Further investigation is important to understand the role of faith and its potential benefit as a facilitator for African American breast cancer survivors.

Support networks consisted of family, church-family, friends, and co-workers. These networks were particularly important for participants as they continued to lead their normal lives. This included their roles and obligations such as caretakers, wives/significant others, employees, and church members. Lopez and colleagues [9] found that among African American breast cancer survivors in rural North Carolina, maintaining social standing was an important coping mechanism. Maintaining social standing involved these everyday interactions that would not diminish how they regarded themselves or how others regarded them and would help keep the stigma of being a breast cancer patient away [9]. Support networks are an important coping mechanism for African American breast cancer survivors and should be an important consideration when discussing quality of life factors, such as their caretaker roles in their daily lives, for patients undergoing treatment and transitioning into survivorship. It is important to note some survivors in this study lacked access to support networks and believed it would have provided needed comfort and emotional support during their journey. An unexpected comradery was created among some participants in this study via exchange of information regarding support services and offering support to fellow survivors.

Fear regarding discovery of breast cancer and side effects of treatment was fueled by negative perceptions associated with breast cancer such as death, negative side effects of treatment (i.e., loss of breast(s), hair loss, scars, and other physical effects), and social stigma of having breast cancer. Fear of cancer reoccurrence may influence treatment decisions (e.g., having a mastectomy even if less invasive treatment options can be effective) and in turn negatively affect the quality of life of breast cancer survivors (i.e., loss of breast(s) and issues with femininity). This particular theme among participants in this study resonates with existing research about the experience of African American breast cancer survivors due to lack of knowledge about their cancer diagnosis, treatment, and survivorship [4, 8–10]. Increased education efforts with recently diagnosed breast cancer survivors about their diagnosis, treatment and side effects, and potential for reoccurrence are a critical need among this population.

Decreased sexual attractiveness and sense of femininity remains an issue for many survivors who have undergone certain treatment measures (i.e., mastectomy) and has impacted their quality of life. Ashing-Giwa and colleagues [8] found that women across all racial/ethnic groups experience significant concerns with body image and sexual health. This sense

of “damaged womanhood” [8, 11] was commonly expressed by many survivors in this study, and these findings suggest a need for exploring factors related to body image and sexuality among breast cancer survivors and their partners.

Many survivors in this study expressed the importance of a positive attitude in overcoming some of the physical and emotional challenges that women experience during and after treatment. Among African American survivors in this study and other studies [8, 9], this positive attitude involved self-care, resilient self-determination, and acts of empowerment (i.e., shaving hair off as a sign of strength). This inner strength among African American survivors could be due to a combination of factors such as faith in God for inner strength and the importance of maintaining their social standing and their perception of not being a burden to their families and social networks [8, 9].

Finally, quality of care issues among survivors in this study did vary from other experiences reported by African American breast cancer survivors in other studies [8–10]. Survivors in this study did not experience racism or discrimination based on their insurance status. One factor that affected provider-patient relationship was age of provider, in which older providers were perceived to be less empathetic towards their patients’ needs during their treatment. Another factor was providers leaving during treatment and the need to start over with a new provider, something that might be attributed to retention challenges due to the rural location of the cancer treatment centers. Participants did express their lack of knowledge regarding a number of the side effects they were experiencing during and after their treatment. Survivors were familiar with the most common side effects such as hair loss and fatigue, but many were not aware of side effects such as short-term memory loss or neuropathy. This can be addressed with increased education for breast cancer patients throughout the continuum of cancer care. Although some women expressed some insurance-related barriers in getting the needed follow-up screening, all women did emphasize the importance of getting screened every 6 months for all survivors. Access to resources for follow-up screening was accessible for all survivors in this study.

This study offers some important insight in expanding our understanding of breast cancer survivors’ experiences among African American women. Some important limitations to this study are the results of this study are not generalizable to all African American breast cancer survivors, all participants expressed their deep faith in God which reflects the religious culture of North Carolina, most women were treated in the same cancer center which could have led to similar experiences and perceptions, and the small sample size. Moreover, although some focus groups had less than the recommended minimum for focus group sample size, focus groups were structured with a high level of moderator involvement. In addition, we conducted seven groups across multiple counties

and settings to compare discussions from across several groups to reach the criterion of saturation. However, this study contributes to the limited literature on African American breast cancer survivors' experiences. In particular, it enriches our understanding of the psychosocial and quality of care factors that affect survivors and helps identify important areas for intervention and further research needed to improve care throughout the breast cancer continuum of care.

Implications of this study include increasing health literacy among active breast cancer patients regarding their diagnosis, treatment, and potential side effects of their treatment. Specifically, it is important to discuss not only the physical but also the emotional side effects that might occur, such as sexual unattractiveness or loss of femininity. Including faith and support networks as part of both treatment and survivorship plans for African American women can potentially provide a source of emotional strength and effective support mechanisms to help cope with physical and psychosocial effects of breast cancer. African American women expressed, both in this study and in previous studies [9, 10], the importance of doctors respecting the role of spirituality as part of their treatment, which can improve patient-provider communication and trust. Future research needs to address the impact of treatment modalities on the psychosocial well-being of survivors (i.e., sexual attractiveness, loss of femininity) [11] and assess which existing coping mechanisms used by African American breast cancer survivors (i.e., spirituality, positive attitudes, and support networks) are most likely to be effective and have a positive impact on the adjustment of life for survivors.

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