

Evaluating Survivorship Experiences and Needs Among Rural African American Breast Cancer Survivors

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Abstract Disparities in cancer survivorship exist among specific populations of breast cancer survivors, specifically rural African American breast cancer survivors (AA-BCS). While effective survivorship interventions are available to address and improve quality of life, interventions must be culturally tailored for relevance to survivors. Here, we report the results of our formative research using focus groups and in-depth interview to better understand unique rural AA-BCS survivorship experiences and needs in the Alabama Black Belt. Surveys were used to gather sociodemographic and cancer treatment data. Fifteen rural AA-BCS shared their experiences and concerns about keeping their cancer a secret, lack of knowledge about survivorship, lingering symptoms, religion and spirituality, cancer surveillance, and general lack of survivorship education and support. Rural AA-BCS were unwilling to share their cancer diagnosis, preferring to keep it a secret to protect family and friends. Quality-of-life issues like lymphedema body image and sexuality were not well understood. They viewed spirituality and religion as essential in

copied and accepting cancer. Participants also discussed the importance of and barriers to maintaining health through regular check-ups. They needed social support from family and friends and health care providers. Overall, rural AA-BCS expressed their need for knowledge about survivorship self-management by providing a vivid picture of the realities of cancer survival based on shared concerns for survivorship support and education within the context of culture.

Keywords African American females · Breast cancer survivorship · Quality of life · Rural · Cancer education

Background

Nationally, breast cancer survivors (BCS) represent about 22 % of the 14.5 million cancer survivors and 41 % of all female cancer survivors making them the largest group of survivors [1, 2]. Breast cancer is the second leading cause of cancer mortality among all female cancers in the USA [3]. In Alabama, breast cancer is the second leading cause of death and accounts for 22.6 deaths per 100,000 [1–4]. Breast cancer among African American (AA) women accounts for 32.1 per 100,000 deaths in Alabama, compared to the national rate of 30.2 per 100,000 [4, 5]. For AA women, the incidence of breast cancer has increased by 0.3 % and is the most common cancer accounting for 33 % of new cases in the USA [4, 5]. Along with bearing an unequal burden of the disease with late-stage diagnosis, AA women have a lower overall survival compared with Caucasian women [1–5]. AA women in Alabama likewise have higher rates of late-stage diagnosis and higher death rates when compared to their Caucasian counterparts [4].

Alabama is a largely rural state, with 55 of its 67 counties (82 %) designated as rural [6]. AA BCS living in rural areas may be particularly vulnerable to barriers of access to cancer

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survivorship services. For instance, poverty is a major problem that can affect rural residents. Of the three counties in the Alabama Black Belt, which the authors sought to identify rural AA-BCS needs, 22 to 28 % of rural citizens live below the poverty level compared to the state average of 14.5 % [7, 8]. The unemployment rate is elevated within the three counties ranging from 8.7 to 11.5 % compared to the Alabama state average of 6.1 % [9, 10]. Access to care is limited based on the percentage of primary care physicians in the Black Belt rural communities, which is 4.6 %, a figure lower than the Alabama average of 6.5 % and the national average of 7.2 % [8].

Disparities exist in cancer diagnosis, treatment, morbidity, and mortality among minority BCS [11–14]. Recently, investigators identified unique challenges faced by rural BCS in North Carolina [13, 14]. They found that despite increased public awareness, silence on the topic of cancer remains pervasive within the AA community due to fear of the social stigma associated with a cancer diagnosis [13, 14]. Investigators also found that AA-BCS lacked access to adequate support services or culturally appropriate cancer resources across the cancer continuum (diagnosis to post-cancer care) [13, 14]. Rural AA-BCS expressed significant concerns about interactions with their health care providers, as they perceived a lack of empathy and patience [14]. Poor interaction with health care providers contributed to the overwhelming fear of cancer and the lack of information about pain, body image changes, and cancer recurrence [13, 14]. On the other hand, rural AA-BCS engaged in positive coping strategies through personal faith and support of family and friends [13, 14].

Given the paucity of data about rural AA breast cancer survivorship education needs and access to survivorship services, the aim of this descriptive study was to explore the survivorship experience, concerns, and needs of AA-BCS in rural Alabama with the goal of modifying an existing evidence-based breast cancer survivorship intervention for cultural relevance to rural AA-BCS.

Methods

Design and Approach

A qualitative research design using focus groups and individual interview was used to explore the experiences of rural AA-BCS in the Alabama Black Belt. The authors worked with the Deep South Network for Cancer Control (DSNCC) to establish local partnerships with local county coordinators and Community Health Advisors as Research Partners (CHARPs) in three rural Black Belt counties [14, 15]. The DSNCC is an academic-community-based infrastructure funded by the National Cancer Institute Center to reduce

cancer health disparities. Using the existing structure of the University of Alabama at Birmingham's Comprehensive Cancer Center since 2000, the DSNCC addresses cancer health disparities in AAs living in underserved communities [14, 15].

Participants for this study were recruited through the CHARP network within the rural counties. The CHARPs provided vital information to ensure study participation. For example, CHARPs noted that some community members would not likely participate on Wednesdays because of prior church obligations. Others may not participate because of transportation barriers. They also suggested that focus groups be held during early evening hours so that survivors would have time to manage their family responsibilities. They mentioned that both focus group and individual interview could be offered to enhance the acceptability of study participation. They advised against asking interested participants to call our 1-800 toll free number because they could be wary. County coordinators secured local facilities for the focus groups and distributed flyers with CHARP's assistance within their counties. Interested survivors provided their names and contact information via the CHARPs for study contact.

Inclusion criteria were as follows: at least 19 years of age, self-reported diagnosis of breast cancer, living in one of three rural Alabama Black Belt counties, and willing and able to participate in the focus group or interview. The study protocol was approved by the University of Alabama at Birmingham Institutional Review Board.

Data Collection

Two focus groups and one in-depth interview were conducted in three Black Belt counties. One focus group was held at the local county health department; the second focus group and the interview were held at the fellowship hall of a church. To create a comfortable and open atmosphere, participants were provided with refreshments before the start of the program. Consent and demographic forms were distributed for participants to complete.

Using a semistructured interview, participants were asked four open-ended questions: (1) how do you feel about being a BCS? (2) How do you find support as a BCS? (3) What is the experience of being a BCS? (4) What local resources are available for BCS in your community? The focus groups and the individual interview lasted from 60 to 90 min and were conducted by the two members of the research team. At the conclusion of each session, participants received a monetary incentive in form of a \$25 check.

Data Coding and Analysis

The focus groups and interview were digitally recorded and professionally transcribed. The completed transcripts were

uploaded into NVivo® software for data analysis about the four focus group question domains: being a rural AA BCS, finding support as a survivor, experiencing survivorship in a rural community, and identifying survivorship resources. Two research team members initially read the transcribed data. Based on an examination of the responses to each of the four questions, they generated 30 initial themes. A third research team member evaluated the initial themes and discussed overlap with the two research members. Together, the team collapsed the 30 initial themes into 14 subthemes. From the subthemes, they grouped the data into four overarching themes: cancer is a secret, we perish with lack of knowledge, start with a good prayer life, and need for survivorship support and education. Table 1 lists the four overarching themes, 14 subthemes, and illustrative quotes.

Results

Fifteen rural AA-BCS participated in two focus groups and one selected the individual interview. The typical participant was 56 years old (range 41–73 years; SD 10.7 years) with an average of 5 years in survivorship (range 0–16 years; SD 5.7 years). The majority (40 %) were married with either some college education (40 %) or were college graduates (20 %). They had an annual salary range between \$10,000 and \$30,000 USD. About 73 % were not aware of nor used cancer support services. Table 2 displays additional demographic details.

Cancer is a Secret

The majority of participants were highly reticent to disclose their cancer diagnosis and treatment, relegating cancer as a secret during their survivorship experience. A typical statement that summed up the sentiment is as follows: “but for some reason I didn’t share that [cancer] with anybody. I just kept it a secret.” Three subthemes maintained the status of cancer as a secret: fatalism at diagnosis, delay in treatment, and fear of disclosure. Cancer fatalism was prevalent in the focus groups. Sometimes, cancer fatalism was a shared family concern among mothers and sisters as in this statement, “Cancer to me wasn’t cancer to my mom and my sisters. To them, cancer was ‘oh Lord, let’s start making arrangements’. You know, it wasn’t to me.”

For others, fatalism was the first response when finding a lump in the breast. A lump was often deemed cancerous even before a confirmed diagnosis. They also expressed disappointment with their families’ negative perception of cancer as a death sentence. One stated, “And when I did tell her I said, you know I’ve got a lump. I’m going to go check it out. And she said, if it don’t bother you, you don’t you bother it. Lo and behold she didn’t know that I knew it was cancer and had

already set the date up.” Lack of familial support at the start of diagnosis tended to continue throughout the cancer journey.

Participants voiced that they delayed treatment from several months and up to a year, as they struggled to come to terms with having cancer. The large amount of information about the various treatment options led some to delay in an effort to understand what was being presented. Others explained that their delay was related to their families’ fatalistic attitudes and beliefs about cancer and feeling the need to protect their children and family from “catching” cancer.

Fear of disclosure was viewed as a common and accepted cultural norm. Nondisclosure was preferred over disclosure of one’s diagnosis with family and friends. Cancer remained a secret during active treatment. Being ill or looking bad was unacceptable because it was a signal to others that they were sick. Thus, participants went to great lengths to not disclose their breast cancer diagnosis or treatment. Others did not want to be pitied.

We Perish with Lack of Knowledge

Participants recalled that they were unaware of cancer treatment side effects such as lymphedema, sexuality and body image changes, menopausal changes, and fatigue. Lacking knowledge about side effects coupled with an inability to communicate with their cancer team led to an exacerbation of some problems. For example, one participant expressed surprise over having developed lymphedema, “Lymphedema? I didn’t know what it was, you know. Because I didn’t know what was causing the swelling.... And it was kinda scary too because my arm was swelling and I didn’t know why it was swelling.” Other participants echoed the lack of knowledge about lymphedema. Another survivor said, “Because I had a mastectomy, one of the hardest things for me to recover from was to getting my arm to work again.” For another, arm swelling prompted her to seek care at the Emergency Room (ER) of a local hospital. The participant further described that the ER staff did not know what caused the swelling and began to treat her for a blood clot until her oncologist was contacted and intervened.

Participants were reluctant to discuss other topics such as changes in sexuality and body image, often becoming quiet and reserved when the moderator introduced the topic of sexuality. They made vague statements like “see, that’s what I was talking about, those sexual issues.” Others redirected the topic to body image, for example, “because for me [sexuality], especially being young or old, I guess it doesn’t matter. You worry about the body image.”

Participants conveyed a strong need for more discussion on the topics of menopausal symptoms, anti-hormonal treatment effects, and fatigue. One participant stated it was important to address hormonal treatment effects because “if you are on the medication you are going to have side effects. Like, I have to do tamoxifen for five years.” Another participant went further on

Table 1 Selected quotes from the qualitative analysis of Black Belt rural breast cancer survivors

Themes	Subthemes	Quotes
Cancer is a secret		But for some reason I didn't share that with anybody, my doctor or anybody. I just kept it a secret.
	Fatalism at diagnosis	<p>“Cancer to me wasn't cancer to my mom and my sisters. To them cancer was oh Lord, let's start making arrangements. You know, it wasn't to me”</p> <p>I've got a lump. I'm going to go check it out. And she said, if it don't bother you, don't you bother it. Lo and behold she didn't know that I knew it was cancer and had already set the date up.</p> <p>For one reason I didn't want to share because I, I didn't want to hurt my children. I waited a whole year before I went back for another mammogram.</p> <p>Well, I wanted to say you actually have to be ready to accept the diagnosis because in 2008 I had a lumpectomy. And when I first went to the doctor he wanted to take the breast off, but I was in denial and I told him no.</p>
	Delay in treatment	<p>Everybody don't open up when they've been diagnosed because this is my cousin right here, [points to cousin] and she had been through it for a year before I even knew anything about it. She didn't even tell me. I didn't know.</p> <p>For some reason I think just the thought of cancer, it really, it, I don't know, I can't describe what it does.</p>
Perish with lack of knowledge		We perish with lack of knowledge.
	What is lymphedema?	<p>Because I had a mastectomy, one of the hardest things for me to recover from was to getting my arm to work again.</p> <p>Lymphedema I didn't, like I say, I didn't know what it was, you know. Because I didn't know what was causing the swelling.... And it was kind a scary too because my arm was swelling and I didn't know why it was swelling.</p>
	What are side effects of hormonal therapy	<p>And then if you are on the medication you are going to have side effects. Like, I have to do Tamoxifen for five years.</p> <p>But see, somebody needs to educate you on your medication.</p>
	Sexuality and body image	<p>See, that's what I was talking about, those sexual issues.</p> <p>Because for me, especially being young or old, I guess it doesn't matter. You worry about the body image.</p>
	Fatigue	<p>I guess I didn't expect to feel as weak.</p> <p>It makes me feel better to know that fatigue is an effect.</p>
	Fear of weight loss	<p>You might done lost a lot of weight and you might be looking bad.</p> <p>I told them, I'm still fat as you know what. I ain't lost no weight. I still look good, just ain't no hair. I said, you don't kill no hog for no hair, baby you want the meat.</p>
	Depression	<p>I just stopped everything I was doing. I think I was fixing to go into a depression.</p> <p>I mean I went through some changes you know...</p>
Start with a good prayer life		<p>If I was to give any advice to anybody who has been diagnosed with or going through or surviving, it starts with a good prayer life.</p> <p>And just again, you know, I prayed, I believe in supernatural healing, I do. I believe in medicine, but I believe in supernatural healing from God.</p> <p>I said Doctor, let me tell you something right now. You sit down. I said the God that I serve is all the psychiatrist that I need.</p> <p>But, I thank God who is the head of my life that I'm still here. I used to tell myself, you know, I used to ask myself, why me? And I thought about it, why not me?</p>
	Religion and spirituality	
Limited survivorship support and education	Family/ friend support	<p>So, my husband, he was in there, and he said 'well it's cancer' and he was almost crying. He said I'm supposed to be strong for you.</p>
	Education and support	<p>It really helpful if you have someone that can support you and give you literature, give you researches and put you in touch with somebody else that have gone through.</p> <p>I said we need a support group. We need a support group in [this] county.</p>
	Cancer surveillance	<p>You need to go and have check-ups.</p> <p>But beyond that I try to eat well.</p>
	Awareness of breast cancer advocacy	<p>If it is I don't know anything about it [advocacy organization]</p>

Table 2 Demographic and survivorship characteristics ($n=15$)

Marital status	Number	Percent (%)
Single	4	26.7
Married	6	40
Separated	1	6.6
Divorced	4	26.7
Widowed	0	0
Education		
<High school	4	26.7
High school graduate	2	13.3
Some college	6	40.0
College graduate	3	20
Work status		
Full-time/part-time	7	47
Work at home	0	0
Retired	4	26.7
Do not work	4	26.7
Income (USD)		
<10,000	4	26.7
10,000–30,000	6	40.0
30,001–50,000	2	13.3
>50,000	1	6.7
Did not respond	2	13.3
Support services		
Breast cancer support	3	20.0
Nonbreast cancer support	1	6.7
Counseling	0	0
Support groups	0	0
Online	0	0
None	11	73.3

to say “Exactly, but see somebody needs to educate you on your medication.” Participants also expressed little knowledge about how fatigue could change their day-to-day living with statements such as “I guess I didn’t expect to feel as weak,” and “...it makes me feel better to know that fatigue is an effect.”

Participants collectively expressed that they did not understand that weight gain was a common treatment effect. Instead, they expected weight loss. They explained that profound weight loss was commonly seen within their community among survivors nearing the end of life. To them, losing weight meant nearing death. One participant shared that friends refused to visit her during treatment because “you might have lost a lot of weight and you might be looking bad.” The majority of participants expressed similar sentiments surrounding their concern about weight loss.

On the other hand, some participants welcomed weight gain after treatment ended. They viewed weight gain as a positive sign of health and overcoming cancer. As one participant said, “I told them, I’m still fat as you know what. I ain’t

lost no weight. I still look good, just ain’t got no hair. I said, you don’t kill no hog for no hair, baby you want the meat.”

The topic of depression prompted discussion. Participants were aware that depression was a side effect and felt comfortable discussing it. Over half of the participants said that they had been depressed. When discussing their experience of depression, most of the participants explicitly stated being depressed. “I just stopped everything I was doing. I think I was fixing to go into a depression.” However, a few participants were reticent in stating that they experienced symptoms of depression. Instead, these participants would allude to it or agree with others who were more forthcoming in expressing depressive symptomatology: “Yeah. I mean I went through some changes you know.”

Start with a Good Prayer Life

Religion and spirituality exerted a major role in the lives of our rural Black Belt AA-BCS. Religious and spiritual beliefs aided them to cope on their journey of cancer diagnosis, treatment, and survivorship experiences. Several voiced that they worked hard to stay “in the word” and allow their religious and spiritual beliefs to help them meet the challenges and overcome the hurdle of cancer. For instance, one participant stated, “But, I thank God who is the head of my life that I’m still here.”

One participant also expressed a different view of religion and spirituality, “although religion can be seen to be a facilitator, it also has shown to be a barrier for survivors.” One particular participant articulated her belief that God alone would heal her physically, which was one factor that prompted her to delay her treatment. She waited a year before seeking cancer care. The belief that God would heal them prompted other survivors to delay seeking help for psychosocial concerns. A participant recalled refusing psychosocial services for her recovery telling her physician, “I said why? I said Doctor let me tell you something right now. You sit down. I said the God that I serve is all the psychiatrist that I need.”

Limited Survivorship Support and Education

Participants reported having a good follow-up on regular and cancer care. They scheduled and attended appointments routinely. Adherence to follow-up was seen through comments like “You need to go and have checkups” and “but beyond that I try to eat well.” However, participants indicated that transportation was a significant barrier since they lived nearly an hour away from the cancer treatment facility. They found the commute a stressful experience particularly when follow-up appointments occurred in quick succession. Yet, participants were eager to learn more about maintaining their health, nutrition, and follow-up care.

Participants described the differential types and amount of survivorship support received. Regarding spouses, one participant stated, “My husband, he was in there and he said, well, it’s cancer, and he was almost crying. He said I’m supposed to be strong for you.” Others agreed that they had received family support from sisters and spouses. The majority agreed that employers tended to support them when they were absent from work to receive treatment.

Regarding professional support, participants discussed the limited resources available and offered in their communities. Other than CHARPs who served their communities, participants acknowledged a general lack of awareness about other sources of survivorship support. For example, few participants were aware of some survivorship programs at local cancer organizations. Most participants replied along the same line as one participant did when asked about cancer advocacy, “I don’t know anything about it.”

Survivorship programs offered at their cancer treatment facility have failed due to lack of transportation; thus, participants expressed a strong desire for more support in terms of group support. Our rural AA-BCS admitted to wanting more conversations with other survivors for more support that some failed to receive from other sources. Indeed, a participant commented, “It really helpful if you have someone that can support you and give you literature, give you researches [research]and put you in touch with somebody else that have gone through.”

Discussion

This qualitative study of rural AA BCS highlights common themes and expands our cultural understanding. First, cancer as a secret with related subthemes of fatalism, delay in treatment, and fear of disclosure have consistently been cited in other studies of AA-BCS over the past dozen years [11–14]. Understanding the cultural relevance of keeping secrets and how it may influence treatment seeking, fear of disclosure, and survivorship are vital to bringing evidence-based interventions to underserved communities [16]. Rural AA-BCS dealt cumulatively with a cancer diagnosis coupled with the negative perception of cancer held by their family and social circle [16, 17]. Delay in treatment appeared to be related to the fear of dealing with negative evaluation of community members. While previously documented in studies with urban BCS [11–13], our findings are consistent with Torres and colleagues [14] where rural AA-BCS acutely experience cancer as a secret. Regardless of urban or rural residence, future studies can acknowledge the cultural context of cancer as a secret and evaluate ways to address and overcome the barrier of secrecy. By potentially targeting the association between cancer being a death sentence and fear of negative evaluation from loved ones, future studies also can inform public health

messages that extinguish this negative association and encourage AA-BCS to seek treatment beyond screening mammography.

Second, our finding of lack of knowledge about the usual and expected late effects of treatment was another consistent theme identified by a growing cadre of investigators [13, 14, 16, 18, 19]. Participants expressed that they did not receive essential survivorship education about lymphedema, fatigue, hormonal side effects, sexuality, and body image. This lack of knowledge may have related to their subsequent confusion and fear that something was wrong when they experienced physical changes. Further, sexuality was a side effect that our participants were noticeably uncomfortable discussing unless the topic was framed in the context of body image. Thus, future investigators working with rural AA-BCS may consider re-framing the cultural and community understanding about sexuality starting with use of terms like body image and then help steer discussion into particular concerns about sexuality.

Our findings about the need for essential survivorship information emphasize the urgent need for all cancer survivors to receive information about survivorship care planning (SCP) and related side effect self-management occurring earlier in the trajectory before active treatment ends. Such discussion about SCP would provide a basis for understanding the common side effects after treatment ends and a springboard for discussions about how to self-manage side effects.

Third, our participants expressed concern about weight *loss* rather than weight *gain*. Losing weight was akin to nearing death and was consistently viewed in a negative light. Views of weight loss among our participants differed from other reports on weight change. For example, Weathers et al. [20] and Halbert et al. [21] explored the topic of weight change among AA-BCS in Philadelphia [20, 21]. Acknowledging weight gain as a common side effect of treatment, they found little empirical data regarding behavioral and psychological reactions to weight change. Using a qualitative design, they interviewed 19 AA-BCS who expressed a lack of knowledge of weight gain as a side effect of treatment [20, 21]. Forty-seven percent ($n=9$) of AA-BCS participants gained weight for an average of 13.7 lb which they viewed as distressing. They indicated a desire to lose weight through healthy activities such as exercise and diet [20].

Thirty-two percent reported weight loss that was generally viewed quite positively particularly if they had been heavy before their diagnosis [21]. Yet, a few who experienced weight loss echoed the same sentiments expressing displeasure in appearing “gaunt and sick” as did our study participants [21]. Nevertheless, our findings about weight change with distressing responses are consistent with Weathers et al. and Halbert et al. and the cultural nuances and differences in weight change and perceived response from the individual survivor, family, and community deserve additional cultural evaluation. Thus, further study is warranted to evaluate perceptions of weight change among a broader population of AA-

BCS, whether urban or highly rural. Additionally, the sentiment that maintaining heavy weight to “look good and healthy” expressed by rural AA-BCS in the current study warrants further review. Fourth, depression was another symptom demonstrating that our rural AA-BCS were not receiving the help that they needed. Our rural AA-BCS were hesitant to discuss the depression that they experienced and even resisted physician’s recommendations to seek further care for depression. Rather, they sought help in spiritual healing from God. Previous investigators found that depression is underreported among AA-BCS. Further, measurements including self-report, used to identify depression, tend to be inadequate in identifying depressive symptomatology within this population [22–24]. For example, Zhang and Gary examined measurements to assess for depression and found that AA-BCS were less likely to say the word “depression” or discuss depressive symptoms compared to their Caucasian counterparts [22]. Although our findings support those identified by Zhang and Gary, over half of our participants felt comfortable discussing their experience with depression. Possibly, our participants were more open and comfortable in discussing this topic among their rural counterparts. Yet, it is not known and an under-explored topic as to why AA-BCS are reluctant to have frank and open discussions about depression particularly because depression is generally undertreated. Thus, there is need for cultural strategies to accurately gauge and evaluate the severity of depression among rural AA-BCS. Finally, our rural AA-BCS lacked access to institutional support/services after treatment. This lack of information for support/services was also consistent with Torres and colleagues study of rural AA-BCS in North Carolina [14]. Limited to no information led to little or no access to vital services that may have facilitated earlier recovery. Furthermore, given the family and friends’ negative perception of cancer, rural AA-BCS were less inclined to discuss their diagnosis. Survivors tended to remain isolated within their own community lacking a vital outlet for discussion of their survivorship needs and reducing avenues for social support, which has been well documented as a positive coping mechanism [11, 13, 14, 16]. The one consistent support expressed by our rural AA-BCS was through religious and spiritual beliefs. Religion and spirituality provided a steady source of strength and a sense of purpose [25].

The CHARP network was a powerful connection between the rural AA-BCS community and our team [15, 26]. The CHARP network allowed us to gain a rich understanding of the experiences and needs of rural AA-BCS. CHARPs had the trust of and linkage with the community. Through their existing relationship, CHARPs helped us gain the trust and involvement of our rural AA BCS who shared and created a rich imagery of their lives. Additionally, we have gained useful tips in working with community partners and leaders, which can be the critical step for future interventions among cancer survivors.

Limitations

A few limitations are noted. First, our sample of 15, while considered reasonable for a qualitative study, was small. Thus, themes identified are considered preliminary and not representative. While our participants provided vivid descriptions of their personal breast cancer journey, a larger number of rural AA-BCS participating in qualitative work need further study. Second, the topics of weight change and depression remain largely unexplored areas of survivorship particularly among underserved survivors. Here too, we chose to tread quietly and listen to the words expressed by those experiencing the problem with fewer probing questions or comments. Despite these limitations, however, our findings have shed additional cultural considerations on weight change and depression.

Conclusion

Our findings support several observations by other investigators working with rural AA-BCS communities. Our findings also suggest that evidence-based BCS interventions can be culturally tailored and tested by including the following areas. First, a discussion and exploration of cancer secrecy and its cultural meanings that may have unintentionally led to lack of knowledge about survivorship, bothersome symptoms, and difficulty with cancer surveillance.

Second, understanding cancer secrecy can lead to factual and informative education and support about topics that are relatively easier to discuss and digest (i.e., lymphedema, hormonal side effects, and fatigue), to topics that are not as easy to discuss (i.e., sexuality and depression). Topics about lingering and troublesome symptoms such as fear of weight loss and depression can subsequently be broached. Third, raising up a champion AA-BCS who has the trust and understanding of the community can be engaged and educated to serve as the vital link between rural AA-BCS and survivorship researchers. Finally, the religious and spiritual elements that are vital to aid rural AA-BCS recovery are essential along with the balancing limits of religious and spiritual elements that impede rural AA-BCS recovery. Taken together, future research can move toward testing the cultural adoption or modification of existing evidence-based interventions rather than continued reliance on descriptive studies.

References

1. National Cancer Institute (2015). SEER cancer statistics review, 1975–2012. Bethesda, MD. http://seer.cancer.gov/csr/1975_2012/sections.html. Accessed 22 Jul 2015

2. American Cancer Society (2015) Cancer facts & figures 2015. American Cancer Society, Inc., Atlanta
3. American Cancer Society (2014) Cancer treatment and survivorship facts & figures 2014–2015. American Cancer Society, Inc., Atlanta
4. National Cancer Institute (2014). State cancer profiles: incidence rate report for Alabama by county (2008–2012). <http://statecancerprofiles.cancer.gov/index.html>. Accessed 22 Jul 2015
5. American Cancer Society (2013) Cancer facts and figures for African Americans 2013–2014. American Cancer Society, Inc., Atlanta
6. Association Alabama Rural Health (2012). Rural versus urban Alabama comparisons. <http://www.arhaonline.org/data/rural-urban-comparisons/>. Accessed 22 Jul 2015
7. U.S. Census Bureau (2015). State & county quickfacts: Alabama. <http://quickfacts.census.gov/qfd/states/01000.html>. Accessed 22 Jul 2015
8. Office of Primary Care and Rural Health, Alabama Department of Public Health and Alabama Rural Health Association (2007). Selected health status indicators: Black Belt action commission. <http://www.arhaonline.org/data/rural-urban-comparisons/reports-for-improving-rural-healthcare/>. Accessed 22 Jul 2015
9. U.S. Department of Labor (2015). Local area unemployment statistics: unemployment rates for states. <http://www.bls.gov/web/laus/laumstrk.htm>. Accessed 22 Jul 2015
10. Alabama Department of Labor (2015). County unemployment rates: Jun 2015 unemployment data. <http://www2.labor.alabama.gov/LAUS/clfbycnty.aspx>. Accessed 22 Jul 2015
11. Ashing-Giwa KT, Padilla G, Tejero J, Kraemer J, Wright K, Coscarelli A, Clayton S, Williams I, Hills D (2004) Understanding the breast cancer experience of women: a qualitative study of African American, Asian American, Latina and Caucasian cancer survivors. *Psycho-Oncol* 13(6):408–428
12. Miller AM, Ashing KT, Modeste NN, Herring RP, and Sealy DT (2015) Contextual factors influencing health-related quality of life in African American and Latina breast cancer survivors. *J Cancer Surviv* doi:10.1007/s11764-014-0420-0
13. Haynes-Maslow L, Allicock M, and Johnson L (2015) Cancer support needs for African American breast cancer survivors and caregivers. *J Cancer Educ* doi:10.1007/s13187-015-0832-1
14. Torres E, Dixon C, and Richman AR (2015) Understanding the breast cancer experience of survivors: a qualitative study of African American women in rural eastern North Carolina. *J Cancer Educ* doi:10.1007/s13187-015-0833-0
15. Hardy CM, Wynn TA, Huckaby F, Lisovicz N, White-Johnson F (2005) African American community health advisors trained as research partners: recruitment and training. *Fam Community Health* 28(1):28–40
16. Wolff M, Bates T, Beck B, Young S, Ahmed SM, Maurana C (2003) Cancer prevention in underserved African American communities: barriers and effective strategies—a review of literature. *WMJ* 102(5):36–40
17. Royak-Schaler R, Passmore SR, Gadalla S, Hoy MK, Zhan M, Tkaczuk K, Harper LM, Nicholson PD, Hutchinson AP (2008) Exploring patient-physician communication in breast cancer care for African American women following primary treatment. *Oncol Nurs Forum* 35(5):836–843
18. Azuero A, Benz R, McNees P, Meneses K (2014) Co-morbidity and predictors of health status in older rural breast cancer survivors. *SpringerPlus* 3:102
19. Hulett JM, Arner JM, Stewart BR, Wanchai A (2015) Perspectives of the breast cancer survivorship continuum: diagnosis through 30 months post-treatment. *J Pers Med* 5(2):174–190
20. Weathers BW, Barg FK, Collier A, Halbert CH (2006) Perceptions of changes in weight among African American breast cancer survivors. *Psycho-Oncol* 15(2):174–179
21. Halbert CH, Weathers B, Esteve R, Audrain-McGovern J, Kumanyika S, DeMichele A, Barq F (2008) Experiences with weight change in African-American breast cancer survivors. *Breast Journal* 14(2):182–187
22. Zhang AY, Gary F (2013) Discord of measurements in assessing depression among African Americans with cancer diagnoses. *Int J Cult Ment Health* 6(1):58–71
23. Sheppard VB, Llanos AA, Hurtado-de-Mendoza A, Taylor TR, Adams-Campbell LL (2013) Correlates of depressive symptomatology in African-American breast cancer patients. *J Cancer Surviv* 7(3):292–299
24. Frazzetto P, Vacante M, Malaguarnera M, Vinci E, Catalano F, Cataudella E, Drago F, Malaguarnera G, Basile F, Biondi A (2012) Depression in older breast cancer survivors. *BMC Surg* 12(Suppl 1):S14
25. Gibson LM, Hendricks CS (2006) Integrative review of spirituality in African American breast cancer survivors. *ABNF J* 17(2):67–72
26. Partridge EE, Fouad MN, Hinton AW, Hardy CM, Lisovicz N, White-Johnson F, Higginbotham JC (2005) The Deep South Network for cancer control: eliminating cancer disparities through community-academic collaboration. *Fam Community Health* 28(1):6–19