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Are survivorship care plans responsive to African-American breast cancer survivors?: voices of survivors and advocates

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Abstract

Purpose African-American breast cancer survivors (AABCS) suffer the greatest from cancer recurrence, morbidity, and mortality in part due to the lack of cancer follow-up care and surveillance. To improve survival and survivorship, the Institute of Medicine advises that cancer survivors be provided a survivorship care plan (SCP). The current study investigated AABCS' understanding of SCP and gathered preliminary feedback on infusing cultural and socioecological responsiveness. **Methods** The study embraced a community-based participatory research framework. Three facilitated, structured, consensus meetings were conducted with AABCS ($N=25$) and advocates ($N=3$) to provide information towards identifying the content domains of an SCP that are culturally responsive to AABCS. **Results** AABCS recommended inclusion of patient-centered information on the purpose and use of the SCP. They raised concerns that higher mortality in AABCS may be due to greater comorbidities and inadequate surveillance and follow-up care. Participants recommended that the SCP document all comorbidities and medications, regardless of relationship to cancer; referrals for cancer-related providers; and culturally informed health advisories.

Conclusion Study findings indicate that the available SCP template lacked adequate content on health history,

comorbidity, health promotion, and functioning. These factors constitute the underlying clinical, psychosocial, and behavioral risks for poor disease outcomes that may be exacerbated in AABCS.

Implications for Cancer Survivors SCPs are intended to educate and activate patients to join their oncology care team as informed partners. However, the emerging science and implementation of SCPs seem void of patient input. Our investigation suggests a practical approach for survivor engagement in the SCP discourse to increase their cultural responsiveness and patient-centeredness.

Keywords Survivorship care plan · Breast cancer · African American · Health disparities · Community-based participatory research

Background

As a result of advances in cancer prevention, detection, and treatment, the cancer survivor population has reached 12 million and continues to grow [1]. Cancer survivorship, however, brings with it a host of additional health and life challenges, such as increased risk for the development of second cancers, comorbidities (e.g., diabetes, heart disease, osteoporosis), psychological issues (e.g., depression, anxiety), social concerns (e.g., family and caregiver issues), and economic problems (e.g., financial and job issues) [2–6]. Further, when compared to nonminority cancer survivors, ethnic minorities, and in particular African-American cancer survivors, tend to have poorer cancer outcomes characterized by greater morbidity and mortality [1]. While cancer survivors, in general, require ongoing surveillance and appropriate care, including medical care, psychosocial support, and monitoring of the late

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and long-term effects of treatment [7], African-American cancer survivors may be in even greater need of medical follow-up and information [8].

To facilitate best practice in clinical surveillance and follow-up care for survivors, the Institute of Medicine (IOM), the Centers for Disease Control and Prevention, the American College of Surgeons' Commission on Cancer, and the American Society of Clinical Oncology (ASCO) advise that cancer survivors be provided with personalized treatment summaries and survivorship care plans (SCP) [9–11]. Further, the American College of Surgeons' Commission on Cancer has mandated cancer centers' implementation of SCPs for all cancer survivors by the year 2015 [9].

While efforts to define the components that should comprise an SCP are ongoing, the IOM recommends that SCPs include the following core components: the cancer treatment history, information on the long-term and late effects of treatment, surveillance for the late and long-term effects, surveillance for recurrence and new cancers, and appropriate resources to address health and quality of life issues [11]. Similarly, emerging research suggests that an SCP should include (1) a treatment summary describing the cancer diagnosis, histology, stage, and primary treatments given [12, 13] and (2) a follow-up care plan, which includes information on recovery from treatment and the need for ongoing health maintenance or other recommended therapies to optimize continuity and coordination of care [14]. Finally, the literature also suggests that an optimal SCP should be personalized and patient-centered [10–13]. In summary, SCPs can serve to facilitate the transfer of knowledge between health care providers and patients, potentially increasing patients' knowledge of and adherence to posttreatment surveillance and follow-up care recommendations [8, 15].

Several advocacy groups and professional organizations have developed SCP templates and forms; albeit, there still remains a lack of consensus on the exact components and structure of an SCP [16, 17]. As the push to provide cancer survivors with SCPs increases, SCP template developers are likely to encounter increased challenges in their decision-making processes around what SCP components to prioritize. Challenges may also arise in developers' attempts to modify these templates in a way so as to increase the applicability and acceptability among the diverse ethnic minority, cancer survivor population [18]. SCP templates for African-American cancer survivors and other minority survivors will need to document race-specific treatment-related side effects as well [8]. Further, SCP template developers will need to take into account the cultural and socioecologic factors that can impact the survivorship of ethnic minority cancer survivors [19].

However, there is a current dearth in research on the development of SCP templates that consider the cultural factors that may influence surveillance and follow-up care

among ethnic minority and underserved survivors [20–22]. There are few, if any, studies that have investigated the knowledge and awareness and the applicability and acceptability of the available SCP templates among ethnic minority cancer survivors including African-American breast cancer survivors (AABCS) [8, 18, 23].

While templates designed for the general cancer population may be utilized with ethnic minority populations as well, the applicability and acceptability of available SCP templates cannot be known without further research. The need for more studies on the science and practice of SCPs with ethnic minority survivors is urgent, especially studies in which the voices of the cancer survivors who will directly benefit from SCPs are sought [8, 10, 24, 25]. Cancer survivors can offer a level of first-hand knowledge and expertise about the needs of survivors that medical researchers and providers might not be able to provide.

The current study aimed to respond to this notable gap in the research and literature by employing a community-based participatory research (CBPR) framework, involving members of the community in every aspect of the research process [26, 27]. The study reports input from AABCS and advocates on appropriate cultural and socioecological content for an SCP template.

Methods

Methodological framework

The current study embraced a CBPR framework. This study builds upon a series of research and projects conducted by the African American Cancer Coalition. This coalition is a partnership of scientific researchers and community-based advocates [28]. Researchers are increasingly collaborating with community partners in efforts to better understand health disparities and implement effective interventions to bring health equity [29]. CBPR is a process and methodological framework that adheres to a collaborative approach between scientific partners and community partners/researchers sharing ownership and involvement in all aspects of a research project [19, 30–32]. Further, all partners work together to conduct research that addresses an issue of import to the targeted community with direct community benefit [33, 34]. CBPR benefits from community partners' knowledge, insights into the community's social and health problems and community strengths, and ability to facilitate greater community engagement and participation [34, 35]. Therefore, the partnership between community members and researchers, like the African American Cancer Coalition, works to catalyze the translation of scientific knowledge into readily accessible and responsive community interventions [19, 30–32, 34].

Participants

All participants were current members of the African American Cancer Coalition or were recruited by the leadership of the coalition from local, African-American peer-based cancer support and health advocacy groups (see Table 1). The participants ($N=28$) ranged in age from 32 to 79 years old ($M=63.9$, $SD=11.48$). Almost all participants were AABCS ($N=25$), and three were community health advocates focusing on breast health and survivorship issues. The majority of AABCS were five or more years post initial diagnosis, while 36 % were <5 years post initial diagnosis. Most AABCS participants were initially diagnosed at stages 0 to 1 (52 %), 26 % was diagnosed at stage 2, 22 % was diagnosed at stage 3, and two participants were diagnosed with inflammatory breast cancer (BCA). Age at initial BCA diagnosis ranged from 29 to 79 years old ($M=56.2$, $SD=12.16$). Nearly 60 % of the participants had a college education. Reported income levels ranged from under \$15,000 to over \$75,000.

Procedure

Researchers facilitated three structured, consensus meetings with AABCS and advocates to share their thoughts about the

SCP and to obtain their input on AABCS access to and understanding of the SCP, as well as provide any cultural and socioecological contents that may be pertinent to AABCS. The consensus meeting is a data collection technique, typically involving a group of subject-matter experts or medical professionals who have been convened for the purposes of laying out best practice guidelines or recommendations for medical interventions for specific conditions or diseases [36–38]. These consensus meetings were held in conjunction with, yet as distinct components of, the multisession peer navigation training conducted by the African American Cancer Coalition. AABCS and community advocates served as subject matter experts at these consensus meetings.

At the first facilitated, structured, consensus meeting, all participants were informed about the objective of the informative facilitated, structured, consensus meetings and asked to sign informed consent forms to participate and video record discussions. Participants were informed that the information gathered from the consensus meetings would contribute towards culturally and socioecologically responsive modifications in the content and structure of an SCP template for AABCS. Participants completed a questionnaire that included demographic and BCA-related medical information and assessed their current knowledge of the SCP.

Initial consensus meeting discussions assessed participants’ current knowledge of the SCP. Participants were asked about their understanding of the SCP, including purpose and content, and if they obtained an SCP from their oncology providers. Next, participants were informed about the purpose of the SCP document. Participants were told that the SCP was intended to provide cancer survivors with a blueprint for quality cancer care—a personal record of their cancer and its treatments that could be used to help survivors to be more prepared to participate in their cancer care and monitor their ongoing health care needs. The participants were provided with information about the SCP’s general content and structure and the most widely, utilized ASCO SCP form as a sample or working SCP template. The ASCO SCP template includes the standard components recommended by the IOM, including cancer-related information (i.e., treatment history, medication, side effects), follow-up care/surveillance recommendations, health advisories, and quality of life information.

The three consensus meetings provided information towards identifying the content domains of an SCP that is culturally responsive to AABCS. Over the course of the three consensus meetings, the AABCS and advocates reviewed and made suggestions about the formatting and content of the SCP. Each consensus meeting was moderated by at least two experienced moderators, and a research associate took detailed notes to appropriately document the discussion [39]. Each consensus meeting ranged in duration

Table 1 Sample characteristics

Characteristics		Number	Percent
Race/ethnicity	Black/African American	28	100
Sex	Female	28	100
Age	31–40	1	4
	41–50	1	4
	51–60	4	16
	61–70	9	36
	71–80	6	24
Education	Graduate school	5	18
	College	11	39
	Some college	7	25
	High school	4	14
	Below 12th grade	1	4
BCA status			
Community partner/advocate		3	11
BCA survivors		25	89
Stage	0	3	12
	1	9	36
	2	6	24
	3	5	20
	Inflammatory BCA	2	8
	Years since diagnosis	0 to 5	10
	6 to 10	9	36
	Over 10	6	24

from 1.5 to 2 h. The first and second consensus meetings were video recorded. The first consensus meeting was held 2 weeks prior to the second consensus meeting, and the third consensus meeting was held 2 weeks after the second consensus meeting. The spacing of the consensus meetings allowed investigators the time to properly review participants' feedback and to integrate the participant's suggested changes into the development of the culturally responsive SCP template.

Data analyses

The consensus meetings were video recorded and detailed, copious notes were taken. After each meeting, the qualitative information and data were transcribed. Transcribed data were content analyzed, following a deductive approach in which they were organized into an unconstrained, categorization matrix [40, 41] by two independent members of the research team. The categories of this unconstrained matrix were developed based upon the general sections or domains found in the ASCO SCP template, including treatment

summary, providers, surveillance, health advisories, and health-related quality of life (HRQOL) sections. Following the content analysis, the research and community partners met to review and discuss the findings. The most relevant information that corresponded with the main sections of the SCP and new suggested sections/topics were identified. Lastly, we organized the categories to inform the SCP template content. This analytic process informed the type, content, structure, literacy level, and domains for a culturally and socioecologically responsive SCP for AABCS (Table 2).

Research and community partners offered their final insights into further modifications and content relevant to AABCS. At the second consensus meeting, the participants were given the initial, first draft, revised SCP template to review. Again, based on their feedback and input, the investigatory team developed the second draft, revised SCP template. During the third consensus meeting, the participants reviewed the second draft, revised SCP template and provided feedback and input that guided the third and final draft of the culturally and socioecologically relevant SCP template.

Table 2 SCP template: participant's input and the cultural and socioecological modifications

SCP template content/domain	Participants' review and input	Cultural and socioecological modifications
Overview of SCP	Many AABCS not familiar with SCP 1 out of 24 had a SCP	A preamble describing the use and content of the SCP was added Added information on where to find SCP information and resources
Cancer information (e.g., stage, treatment, side effects, follow-up)	No description of content areas for patient understanding Allow for multiple medications, and regimen that worked	Brief descriptions of each content area and notes specific to AABCS Include dates for treatment and dose modification for each agent
Contact information for health care providers (e.g., oncologist)	Need more space for health care providers (i.e., wound care specialists)	More lines were added for additional health care providers
Medical background information (e.g., family medical history, comorbidities)	Participants noted among African Americans comorbidities are common (e.g., diabetes, high blood pressure, obesity) SCP must detail comorbidities; and how comorbidities, medications for existing conditions, and cancer treatments interact and raises risk	The major comorbidities' section was expanded and organized to delineate pre-cancer and post-cancer comorbidities and associated medications This revised section allows for primary care provider input
Health advisories (e.g., risk reduction, nutrition, stress management)	AABCS need information to educate and guide them to maintain and monitor health for better survival and survivorship	Expanded advisories on nutrition, exercise, stress, health promotion This section was developed to educate and provide advisories about healthy practices
Quality of life (e.g., physical symptoms, emotional issues, health coverage)	AABCS have multiple needs Doctors would be better informed about BCS as whole persons with understanding the survivors' day to day life and lived experiences	Includes physical symptoms, career, health coverage, spirituality, family, sexual health-related issues caregiver, financial, legal, etc. Responsive to AABCS with community resources

Results

The results of these consensus meetings are presented below in the order of their occurrence during the course of the three consensus meetings.

What is your understanding of a survivorship care plan (SCP)?, and do you have an SCP?

SCP knowledge and current utilization

About 20 % ($n=5$) of the participants indicated that they had seen or heard about treatment summaries and SCP. Only 1 participant stated that she had a comprehensive SCP, while the other 24 AABCS indicated that they received an assortment of unorganized documents from their medical providers. However, all participants acknowledged that they believed that they would benefit from a well-organized document that included cancer-related information, medical provider information and appropriate referrals, medical history, follow-up care and surveillance components, and information about health and community resources to promote healthy lifestyle changes and access to supportive care. All 24 AABCS indicated that they were fully adherent to their health care provider recommendations for follow-up tests and medical care. However, they all acknowledged that they felt somewhat lost, regarding information about (1) health-related risk and long-term or late effects due to their cancer treatment (e.g., heart disease and bone loss); (2) other medical resources (e.g., wound care); (3) symptom management (e.g., lymphedema, pain, healthy lifestyle promotion); (4) familial and personal impact of BCA and its treatment (e.g., family caregiving and prosthesis resources); and (5) quality of life and psychosocial resources (e.g., legal resources and supportive care).

How can this SCP template document be modified to best meet its purpose(s) for AABCS?

Modifying the SCP template: content, structure, and layout to increase usability for AABCS

Participants were also asked to examine the SCP template and make comments on its content, structure, and layout during the first consensus meeting. Several participants noted that the usability and readability of the document could be improved by enlarging the text and adding more spacing between each of the document items. One participant commented that the current SCP template did not have a proper amount of space on it for documenting recurrences. She commented that, “BCS might need to make a second copy of the SCP template to provide space for recording information on cancer recurrences.”

Also, another participant suggested that sometimes doctors try one regimen of cancer medicines and then modify the regimen when it does not work like it was expected to. This participant suggested, “We may want to add some additional lines in order to better capture information on which of the medication regimens or ‘cocktails’ finally worked for the BCS.”

Suggestions for essential health-related information/referrals content

Also, during the first consensus meeting, several participants highlighted the number and severity of comorbidities among African Americans. Many participants indicated that there were certain comorbidities that might be present at higher rates in AABCS (e.g., high blood pressure, diabetes, overweight issues). One participant indicated, “I have diabetes, which might have affected the timing of my surgery and healing after surgery.” The group then discussed that the SCP template must clearly document the preexisting and potential post-cancer treatment comorbidities.

Another participant noted that the SCP might need a section where BCS could note referrals for other health care specialists, outside of their cancer-specific health care providers, such as wound care specialists. Several women mentioned complications they had with their reconstruction surgeries. As one woman recounted issues she had with her reconstruction surgery, she noted potential differences in the healing processes of African-descended and other ethnic groups for whom the risk of keloids, scarring, and differential healing are increased, all factors potentially warranting the referral to other specialists post surgery.

Two separate community health advocates suggested that African Americans may be less likely to know their family medical history because of the stigma associated with diseases like cancer and the taboos surrounding their discussion. Thus, some African-American women may not be privy to their increased risks for initial diagnosis at younger ages. The suggestion was made that the SCP should be used as a document to highlight the importance of genetic testing and referrals for African Americans diagnosed with premenopausal BCA and as a guidance tool to increase proper surveillance and management of BCA among younger survivors.

During the second consensus meeting, the questions were targeted towards the development and modifications of the health advisories domains. In relation to the health advisories listed on the original SCP template, one survivor noted that she obtained new and provocative information. She commented:

I was shocked when I read that the risk of breast cancer returning continues for more than 15 years after remission, if you did not have bilateral mastectomies. I

thought risk of recurrence only lasted for 5 years after initial treatment. It is now clear to me that even after five years post-cancer, I need to continue to get regular surveillance including screenings and tests to monitor my breast health and cancer. We really need to get this information out to the community....

Several participants recommended that the SCP section on health advisories should provide more guidance and information on issues, such as recurrences and maintaining or beginning healthier lifestyles (e.g., healthy eating and exercise), and symptom management.

How can the SCP provide resources to improve BCS' HRQOL?

Suggestions for essential HRQOL information/referrals content

During the second consensus meeting, participants also commented on other issues that many BCA survivors have, including emotional, financial, family, and sexual health-related issues. Survivors talked about their emotional issues; for instance, the stress they experienced at initial diagnosis and the ongoing fears of recurrence. Several of the survivors sought out support groups in order to connect with others with similar experiences, for emotional support and for information. Some survivors also received professional counseling in order to deal with some of their emotional issues.

Three participants noted that survivors often experience financial needs. While two other participants mentioned that they had experienced issues in obtaining transportation to and from appointments. Others noted that many survivors are not aware of available informational, medical, and supportive care resources and that these should be noted in the SCP.

Many survivors spoke of the strength they found in their spirituality. One survivor reported that her faith in God grew stronger following her diagnosis, and many others reported that they found strength to deal with the cancer through prayer and their relationships with God. Thus, spiritual care referrals and resources were identified as essential components for inclusion in the SCP.

Additional comments focused on family needs and issues. Many participants noted that they had to rely on family to serve as caregivers following treatment, and some participants noted that they felt uncomfortable and/or experienced strain in their relationships with their immediate family because of their inability to care for others and themselves as they had prior to BCA.

The subject of sexual health was prominently noted. In particular, some participants noted the need for information and resources on addressing the sexual side effects including information on lubricants to help ease the discomfort of

vaginal dryness and stiffening caused by menopausal status brought on by their cancer treatments.

How useful is this form for you, and how can we improve its usefulness?

The information in this SCP is useful

During the final consensus meeting, participants were asked to comment on the utility of the SCP. Several participants indicated that the SCP had been useful for helping them to revisit and organize all of the information they had received from their doctors in the past. For example, one woman commented:

It made me go back and look at all my paperwork and the papers I had gotten from the doctors. I had just stuffed all of the papers in a drawer. It felt good to put it all in one form; [it was empowering] to have all of the information in one place.

Others indicated that they were inspired to pay more attention to their health even though they were many years post-diagnosis.

Anticipated barriers and facilitators to obtaining SCP

Some participants commented on the difficulty they anticipated in getting the forms completed by their oncologists because they would have to schedule and pay for an additional appointment outside of their regular follow-up appointment. Or, even if they did not make an appointment, they would need to pay to have the doctor or his assistant fill in their treatment information. Participants expressed their concerns that doctors may not be motivated or have the time to complete the SCP forms. One participant noted, "Doctors won't care to look at all of this form, perhaps, we [breast cancer survivors] have a challenge in getting [doctors] to fill it out." Another participant indicated that, "Doctors might be unconcerned with non-cancer related, quality of life matters." Several participants acknowledged that obtaining a completed, comprehensive SCP might be difficult. However, the majority seemed to agree that it would be good for the doctors to be able to participate in completing or at least viewing the whole SCP document, including the information on their quality of life issues. A few participants noted that the doctors should be better informed about them as "whole persons." One participant stated, "If they understood some of the other issues that we were going through—outside of the actual cancer disease, then we might do better with treatment and suffer fewer deaths from this illness."

Participants were asked to discuss strategies for resolving these anticipated challenges in accessing a completed SCP. The participants came to the following conclusions, listed in

the order of their frequencies in occurrence during discussion—the patient/survivor should assist in completing the relevant sections of the family history, comorbidity, health advisories, and HRQOL sections, while the primary care provider(s) could contribute to the completion of the comorbidity, health advisories, and HRQOL sections. Also, the oncology team could complete the sections on the cancer treatment, follow-up care and medical care referrals, and—when appropriate—the sections on HRQOL and health advisories.

Discussion

The growth in the cancer survivor population, in addition to the successful work of BCA advocates, has encouraged a great increase in attention paid to the quality of follow-up care and HRQOL issues experienced by BCA survivors. According to the IOM, the more individualized and personalized the SCP is for the patient, the more helpful it will be. BCA treatment is becoming more personalized for patients [42]. Being able to document the nuances of a patient's personalized treatment regimens may be even more critical in AABCS because of the higher rates of triple-negative BCA diseases and late stage diagnoses among African Americans compared to their White counterparts [1, 43, 44]. The treatment of these cancers may require differing or more aggressive treatments, resulting in increased concerns about treatment side effects and medication regimens. Research indicates that the documentation of family health history and genetic counseling and testing may be an effective intervention for influencing risk perception and motivation for engagement in protective health behaviors in survivors [45]. Our AABCS informants suggest that the SCP should attend to medical factors such as adherence to surveillance, follow-up care, and other protective health behaviors for AABCS.

In developing resources, including an SCP for AABCS, it is essential to obtain the input from the AABCS community. Previous studies noted the necessity and usefulness of community input in the modification of SCP templates to increase the survivors' understanding and its utility [8, 23]. The findings of this study provided information on the understanding and utility of the SCP among AABCS and will inform the development of an SCP template to increase the cultural and socioecological responsiveness to AABCS. The modifications for the SCP template, based on data collected during the facilitated, structured consensus meetings, may be described as suggestions for improving the patient-centeredness of the SCP for AABCS. Participating AABCS suggested the inclusion of culturally responsive elements, such as a cover page that highlighted the relevance of the SCP especially for AABCS, a section on comorbidities and accompanying therapies, referrals for

providers who are culturally competent and knowledgeable of issues that might be more common in African Americans (e.g., keloids), and health advisories and quality of life factors that are of particular concern among AABCS.

Participants stated that the SCP template should include a section on healthy lifestyle practices that are relevant to AABCS [16, 17]. The nutrition recommendation must include foods that are enjoyed by AABCS, and the physical activities should include routines that are favored by AABCS. These recommendations corroborate recent research indicating associations between a healthy diet involving high intakes of fruits, vegetables, whole grains, fish, and poultry and decreased morbidity and enhanced quality of life [46]. Increasingly, studies are linking physical activity with improved survival, health, and quality of life among BCA survivors [47, 48].

Furthermore, participants agreed that specific, quality of life-related components and referrals should be included in the SCP because they were important for the overall HRQOL of survivors. Specifically, AABCS participants noted primarily cultural and some socioecological factors that may be readily prevalent in AABCS. In particular, the informant group noted the importance of spirituality and the disproportionately higher levels of low socioeconomic status in the community. While most mentioned that they had joined support groups, many of the survivors noted that they also found strength and comfort in their spirituality. Several studies have documented the significance of spirituality in the coping for AABCS [49–51] and the importance of addressing emotional distress among BCA survivors [52]. Moreover, participants noted that BCA survivors experience other issues related to concrete or physical needs for assistance, such as monetary or financial issues. The literature indicates that many BCA survivors experience financial issues in regards to paying for the treatment of their illnesses [6], which leads to delays and deficiencies in treatment.

Finally, participants highlighted several potential barriers to obtaining a completed SCP, such as needing to schedule or pay for an additional appointment outside ones' regularly scheduled appointment or the doctor's reluctance to complete the SCP. In addition, participants also pinpointed potential solutions for the perceived barriers to obtaining an SCP (e.g., having their various doctors, primary care, and oncologists complete relevant sections of the SCP or having the patient complete certain sections of her SCP). Although not noted by participants in this study, it has been suggested that doctors might benefit from expanded medical training opportunities on survivorship care so that they have more confidence in their abilities to manage the survivorship care needs of their patients [8]. In summary, AABCS and community advocates collaborated with researchers in the preliminary modifications of the SCP template. This modified SCP template was developed as a tool to be utilized in the provision of clear, comprehensive, yet simplified documentation of BCA

treatments, potential treatment side effects, recommended surveillance and follow-up care, and health advisories to improve survivorship. It was developed with input from AABCS and advocates to increase cultural and socioecological responsiveness to AABCS. Additionally, it must be noted that many of the recommended changes could be useful in improving SCP understanding and utilization with other populations as well.

Limitations

There were limitations to the findings in this study. First, the variety of opinions expressed during the consensus meetings may have been influenced by the nature of the data collection method. Oftentimes, in large groups, the opinions of the more outgoing and verbal members are the ones that are expressed, while the opinions of more reserved or shy members may not be as readily represented [39]. In other words, the group composition and dynamics likely influenced the contents of the consensus meeting discussions. Secondly, the consensus meetings did not include participation from the medical profession. Medical professionals may have offered additional insights about overcoming barriers to obtaining a SCP. Thirdly, the SCP modification process relied on process discussion. Future studies might benefit from the use of a mixed methods research approach that utilizes both the consensus review process and a quantitative evaluation of the modified SCP template in order to allow for more robust findings.

However, there are noted strengths. This is one of the first studies to report on cultural and socioecological content modifications to SCPs to increase their responsiveness and relevance for AABCS. The findings of this study can inform the development of a clinically and socioculturally responsive SCP template that considers the clinical characteristics and risks and the cultural and socioecological contexts of AABCS. It is posited that this type of patient-centered SCP may increase the appropriateness of and adherence to SCP recommendations to improve survivorship outcomes among AABCS.

Suggestions for further research

The SCP template modification process may benefit from the inclusion of physician participation. Additionally, the SCP modification process should include both process and quantitative evaluations of the newly revised SCP template. Further, along with barriers to obtaining SCPs, the impact of adherence to the SCP recommendations on survival and survivorship outcomes warrants more research. Therefore, longitudinal research that examines the long-term benefits of survivorship care planning must be conducted to shed light on these areas of uncertainty.

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Glossary of acronyms

ASCO	American Society of Clinical Oncology
AABCS	African-American breast cancer survivors
HRQOL	Health-related quality of life
BCA	Breast cancer
BCS	Breast cancer survivors
CBPR	Community-based participatory research
IOM	Institute of Medicine
SCP	Survivorship care plan

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