



An overview of the unique challenges facing African-American breast cancer survivors

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Abstract

Purpose The existence of cancer disparities is well known. Focus on alleviating such disparities centers on diagnosis, treatment, and mortality. This review surveyed current knowledge of health disparities that exist in the acute survivorship period (immediately following diagnosis and treatment) and their contributors, particularly for African-American breast cancer survivors (AA-BCS).

Methods Utilizing the ASCO four components of survivorship care, we explore disparities in surveillance and effects of cancer and therapies that AA-BCS face within the acute survivorship period (the years immediately following diagnosis). A literature review of PUBMED, Scopus, and Cochrane databases was conducted to identify articles related to AA-BCS acute survivorship. The search yielded 97 articles. Of the 97 articles, 38 articles met inclusion criteria.

Results AA-BCS experience disparate survivorship care, which negatively impacts quality of life and health outcomes. Challenges exist in surveillance, interventions for late effects (e.g., quality-of-life outcomes, cardiotoxicity, and cognitive changes), preventing recurrence with promotion of healthy living, and coordinating care among the healthcare team.

Conclusions This overview identified current knowledge on the challenges in survivorship among AA-BCS. Barriers to optimal survivorship care inhibit progress in eliminating breast cancer disparities. Research addressing best practices for survivorship care is needed for this population. Implementation of culturally tailored care may reduce breast cancer disparities among AA-BCS.

Keywords Breast cancer · Acute survivorship · Health disparities · African-American · Cultural competence

Introduction

There is limited research on survivorship care that is tailored to minorities, specifically African-American (AA) breast cancer survivors (BCS), despite the fact that breast cancer disparities, including higher cancer-related mortality and poorer quality of life, are frequently seen in AA women [1–5]. Moreover, the incidence of breast cancer among AA women is rising and converging with rates among White women [3].

However, there is little research among AA-BCS populations during the acute survivorship, or the period immediately following diagnosis and treatment [6].

The Institute of Medicine (IOM) and ASCO have outlined four critical components to optimal survivorship care: 1) *Surveillance* for the spread of cancer, recurrence, or secondary cancers; 2) *Interventions* for late effects of cancer and treatment (e.g., other medical problems or quality-of-life changes); 3) *Prevention* to reduce recurrence and development of new cancers; 4) *Coordination* among specialists and primary care providers to ensure that all the survivors' needs are met [7]. Disparities exist within each component and the causation of disparities in survivorship is complex and multivariate, ranging from several factors that cut across the breast cancer care continuum: stage at diagnosis, comorbidities, access to care [3, 8, 9]. The purpose of this study is to present health disparities that exist in the acute survivorship period for AA-BCS and their contributors, based on the current IOM guidelines for adequate survivorship care [7].

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Methods

A literature review was performed to present health disparities within the four components of survivorship care among African-American breast cancer survivors based on current IOM guidelines. This overview includes English-language articles published in peer-reviewed journals from January 2008 to June 2018. Articles were retrieved from three multidisciplinary academic databases: Pubmed/MEDLINE, Scopus, and Cochrane review. Keywords and MESH search terms were as follows: “breast cancer,” “survivorship,” “disparities,” OR “African-American.” The search yielded 82 PubMed, 12 SCOPUS, and 3 Cochrane references—a total of 97 articles. Each of the articles were reviewed based on inclusion criteria: sampled African-American breast cancer survivors within at least 10 years of diagnosis, discussed medically relevant survivorship issues, and had statistically significant data. There were no limitations based on sample size; data from articles with a sample size less than 20% AA-BCS are presented with an acknowledgement of the number of AA-BCS. Fifty-nine of the reviewed articles were discarded (33 did not specifically discuss acute survivorship disparities, 17 did not specifically discuss evaluating race, 5 did not specifically address AA-BCS or presented aggregated data, 1 had statistically insignificant data). Thirty-eight articles remained and were included in this review. Data were abstracted and analyzed, grouping findings based on the four survivorship components (see Table 1 for more full article list). The following section details the state of acute survivorship care among African-Americans as addressed in this literature.

Results

Surveillance

Surveillance for secondary cancers is an important part of care given during the acute survivorship period. Given the increased risk of mortality and recurrence, survivors require routine follow-up care based on standard breast care guidelines (seen every 3–6 months in the first 5 years) [10]. Imaging with mammography is routine follow-up care for women who do not undergo mastectomy to remove all breast tissue. AA-BCS are more likely to withdraw from breast cancer survivorship care and treatment (mammography adherence OR = 1.35, 95% CI; clinic visits OR = 1.62, 95% CI) than White BCS [11]. Further, Nurgalieva et al. found that lower surveillance rates among AA women was also linked to higher mortality within 2 years of diagnosis [12].

Considering rationales for disparity in follow-up care, many AA-BCS report that the medical cost of health care during surveillance is a major barrier to accessing survivorship care [13]. In a survey of diverse survivors, Palmer et al.

found that AA women were more likely to report out of pocket expenses as a major barrier (51.6%) than White women (28%), which was similar to other health care costs (45.2% in AA and 21.3% in white women, $P = 0.01$) [14]. Such costs include transportation, prescription medication, and dental care expenses. The direct effect of the high cost of health care increases the likelihood of AA women forgoing medical care and/or following-up with providers [15].

Interventions for late effects

In addition to surveillance, follow-ups are important to screen for late effects from cancer treatment that may require intervention. Late effects discussed within the selected articles that include quality-of-life changes, lymphedema, sexuality concerns, cardiotoxicity, neuropathy, and cognitive changes. Late effects can lead to functional disability, which was noted to be more prevalent among older African-American breast cancer survivors compared to their White counterparts [16].

Quality-of-life outcomes

Russell et al. noted the importance of recognizing the more immediate quality of life, or well-being, concerns that exist in acute survivorship as well as long-term [17]. Another article discussed quality of life in survivors that were at least 1 year out from treatment [18]. Health-related quality of life in these breast cancer patients was dependent on the presence or absence of certain comorbidities. AA women were shown to have many other chronic conditions (e.g., hypertension and arthritis) that negatively impacted their overall quality of life [18].

Lymphedema

A major issue faced by breast cancer patients after surgery is lymphedema, or swelling of extremities due to reduced lymphatic drainage. Beaulac et al. found that lymphedema rates were similar in women undergoing mastectomy and conservative surgery [19]. When evaluating quality of life, women who experience lymphedema report relatively lower quality of life on the Functional Assessment of Cancer Therapy-Breast (FACT-B) than those who do not experience lymphedema [19]. It is also well established that AA-BCS experience greater upper extremity disability as a result of lymphedema and lack of follow-up care which increases survivorship disparities in AA women [20].

Sexuality concerns

Barsevick et al. found that AA-BCS reported sexuality concerns and educational resources compared to a mixed group of breast cancer survivors. Sexual concerns were greater in

Table 1 Overview of selected articles

Reference number	Reference	Design	Participants	Age	Time since diagnosis	Results
[11]	Advani, P. S., J. Ying et al. (2014, Mar 15). "Ethnic disparities in adherence to breast cancer survivorship surveillance care." <i>Cancer</i> 2013/11/22. Retrieved 6, 120, from http://www.ncbi.nlm.nih.gov/pubmed/24258799 .	Retrospective cohort	4535 (11.9% African-American Breast Cancer Survivors—AA-BCS)	Not specified	< 48 months	AA and Hispanic women were less likely to follow adherence guidelines for mammography (odds ratio = 1.35, 95% confidence interval) and clinic visits (odds ratio = 1.62, 95% confidence interval) when compared to White patients
[28]	Alderman, A. K., S. T. Hawley et al. (2009). "Racial and ethnic disparities in the use of postmastectomy breast reconstruction: results from a population-based study." <i>J Clin Oncol</i> 27(32): 5325–5330.	Qualitative	806 (202 were AA-BCS)	20–79 years	Not specified	Latinas with less acculturation, and African-Americans, were much less likely than Whites to receive breast reconstruction after mastectomy (immediate or early delayed). The low use of reconstruction for less acculturated Latinas and African-Americans was not explained by lower demand for the procedure. Minority patients were the least likely to report that reconstruction was not important, were the most likely to desire more information about reconstruction, and were the least likely to be satisfied with their surgical treatment decision
[58]	Ashing-Giwa K et al. Are Survivorship Care Plans Responsive to African-American Breast Cancer Survivors? Voices of survivors and advocates. <i>J Cancer Surviv.</i> 2013;7:283–291	Community-based participatory research (CBPR)	28	29–79 (mean 56.2 years)	0–5 years (40%), 6–10 years (36%), > 10 years (24%)	Survivorship care plan (SCP) template should have input from the African-American community of breast cancer survivors in order to have relevant information that will improve responsiveness by these survivors
[18]	Ashing, K., M. Rosales et al. (2014). "Occurrence of comorbidities among African-American and Latina breast cancer survivors." <i>J Cancer Surviv</i> 8(2): 312–318.	Health-related quality of life (HRQOL) psychoeducational intervention study	320 BCS (27% were African-American—AA)	Between 50 and 64 years (median: 54.2)	More than 1 year out from treatment	75% of the overall sample endorsed at least one major comorbid condition. African-American BCS reported high prevalence of diabetes (20%), arthritis (48%), and elevated blood pressure (49%). Our findings highlight the importance of screening, monitoring, and treating comorbid conditions not only among older survivors, but also among middle adult and premenopausal survivors.
[21]	Barsevick AM, Leader A, Bradley PK, Avery T, Dean LT, DiCarlo M, Hegarty SE (2016) "Post-treatment problems of African American breast cancer survivors." <i>Support Care Cancer</i> 24: 4979–4986	Survey	296 AA-BCS	Between 31 to 70 years (median age: 57.5 years)	3 to 5 years after diagnosis	AA-BCS experienced significant problem burden in the early years after cancer diagnosis and treatment. This sample was more likely to report sexuality concerns and lack of economic and informational resources. Acknowledging African-American women's experience with racism and discrimination and understanding its influence on perceptions of health and illness are crucial steps for health providers in developing trustworthy relationships with AA-BCS.

Table 1 (continued)

Reference number	Reference	Design	Participants	Age	Time since diagnosis	Results
[35]	Bhatnagar B, Gilmore S, Goloubeva O, Pelsler C, Medeiros M, Chumsri S, Tkaczuk K, Edelman M, Bao T (2014) "Chemotherapy dose reduction due to chemotherapy induced peripheral neuropathy in breast cancer patients receiving chemotherapy in the neoadjuvant or adjuvant settings: a single-center experience." <i>Springerplus</i> 3: 366	Retrospective	123 (57% AA-BCS)	18 years and older	Treated between 2008 and 2011	African-American race appeared to correlate with a higher risk of developing chemotherapy-induced peripheral neuropathy (CIPN) necessitating dose reduction
[59]	Burg MA et al. "The Potential of Survivorship Care Plans in Primary Care Follow-up of Minority Breast Cancer Patients." <i>J Gen Intern Med</i> 2009;24(Suppl 2):S467–471	Focus groups/- qualitative	29	Not specified	Not specified	SCPs are well regarded by minority breast cancer survivors, but the particular American Society of Clinical Oncology (ASCO) template can be too technical. Psychosocial support was determined to be particularly important for African-American survivors
[2]	Daly, B. and O. I. Olopade (2015). "A perfect storm: How tumor biology, genomics, and health care delivery patterns collide to create a racial survival disparity in breast cancer and proposed interventions for change." <i>CA Cancer J Clin</i> 65(3): 221–238.	Literature review				AA women are diagnosed with breast cancer at later stages and hormone receptor negative disease, suggesting that genetics play a role in survivorship disparities as well
[61]	Davis C, Darby K, Likes W, Bell J. "Social Workers as Patient Navigators for Breast Cancer Survivors: What do African-American Medically Underserved Women think of this idea?" <i>Social Work in Health Care</i> 2009;48(6).	Qualitative	36	29–84 years	Few months to 30 years	Patient navigators can provide emotional support for the patient, for the family members. They can serve throughout the continuum of cancer care. Oncology social workers can play the role of navigator in order to be a participatory member of the treatment team
[20]	Dean, L. T., A. DeMichele et al. (2015). "Black breast cancer survivors experience greater upper extremity disability." <i>Breast Cancer Res Treat</i> 154(1): 117–125.	Longitudinal	610 (98 were AA)	Median age 65 years	Median time since diagnosis from diagnosis	After accounting for physical characteristics and treatment-related factors, Black breast cancer survivors experience greater upper extremity disability than White breast cancer survivors, even several years post-treatment. The differences in race may be partially explained by higher body mass index (BMIs) among Black breast cancer survivors.
[47]	Ganz PA. "Survivorship: Adult Cancer Survivors." <i>Primary Care: Clinics in Office Practice</i> . 2009; 36: 721–741	Review	N/A	N/A	N/A	Coordinating follow-up between the primary care physician and the oncologist is a recommendation for improved survivorship care. This includes follow-up advice and information on appropriate cancer screening, but also non-cancer-related health information.
[43]	Hair BY et al. "Racial Differences in Physical Activity Among Breast Cancer Survivors: Implications for Breast Cancer Care." <i>Cancer</i>	Prospective cohort	1735 (48% AA)	20–74 years (mean)	Unspecified	BCS who did have increased physical activity after their diagnosis were more likely to have a high

Table 1 (continued)

Reference number	Reference	Design	Participants	Age	Time since diagnosis	Results
	2014; 120(14): 2174–2182.			55.9 years (median)		income and recipients of radiation therapy versus chemotherapy
[31]	Hasan S, Dinh K, Lombardo F, Kark J (2004) "Doxorubicin cardiotoxicity in African Americans." <i>J Natl Med Assoc</i> 96: 196–199	Retrospective	100	32–84 years (median: 46)	Unspecified	There is a nearly three-fold greater rate of cardiotoxicity in this population of African-American patients in comparison with earlier studies with unknown racial distribution. While African race is a risk factor for hypertensive and atherosclerotic cardiovascular disease, this risk would be approximately 1.25–to 1.3-fold at the median age of our study population (46 years). Therefore, it is unlikely that most of this increased risk was due to concurrent cardiovascular disease
[53]	Kantsiper M et al. "Transitioning to Breast Cancer Survivorship: perspectives of patients, cancer specialists, and primary care providers." <i>J Gen Intern Med</i> 2009;24(Suppl 2):S459–466.	Qualitative	4	Not specified	Not specified	This group of AA-BCS expressed the importance of spirituality in cancer care, the social taboo of breast cancer in their communities, and the issues in access to care and clinical trials
[51]	Kooken WC, Haase JE, Russell KM. "I have been through something: Poetic explorations of African-American women's cancer survivorship." <i>Western Journal of Nursing Research</i> . 2007;29(7):896–919	Qualitative focus groups, using interpretive phenomenology	21	38–78 (mean 59)	Not specified	Poetry from AA-BCS was used to elicit that culturally competent care is important
[22]	Lewis PE, Sheng M, Rhodes MM, Jackson KE, Schover LR (2012) "Psychosocial concerns of young African American breast cancer survivors" <i>J Psychosoc Oncol</i> 30: 168–184	Telephone survey	33 AA-BCS	45 years and younger	1-year post-diagnosis	Several participants believed that physicians were more likely to discount African-American women's concerns about fertility. 73% of participants did not recall any mention of sexuality by their oncology health care providers. Rates of sexual dysfunction in our sample were similar to or somewhat lower than those in cohorts of predominantly Caucasian survivors of premenopausal breast cancer
[55]	Lopez, E. D., E. Eng et al. (2005). "Quality-of-life concerns of African American breast cancer survivors within rural North Carolina: blending the techniques of photovoice and grounded theory." <i>Qual Health Res</i> 15(1): 99–115.	Literature review	13 AA-BCS	44–82 years	Range from 1 to 53 years	Social context affects rural African-American breast cancer survivorship and multiple pathways through which QOL can affect and be affected by social forces that persist within rural African-American communities. The model also reveals how these social forces drive four QOL concerns that survivors must address throughout their lives, including seeking safe sources of support, adjusting to the role of cancer survivor, feeling comfortable with their futures, and serving as role models. The women in this study declined services available through providers and

Table 1 (continued)

Reference number	Reference	Design	Participants	Age	Time since diagnosis	Results
[49]	Maly RC et al. "The Impact of Primary Care Physicians on Follow-up Care of Underserved Breast Cancer Survivors." <i>J Am Board Fam Med.</i> 2013;26(6):628–636.	Longitudinal observational	579	18 years and older	36 months	other sources whom they considered to be racist or a threat to their social standing Primary care providers (PCPs') involvement in the medical care of low-income BC survivors results in better follow-up care, particularly with regard to cancer preventive services.
[60]	Mollica MA et al. "Peer Navigation in African-American Breast Cancer Survivors." <i>Patient Relat Outcome Meas.</i> 2014;5:131–144.	Mixed-method, proof of concept	4	18–75 years	Within 1 month of treatment	AA-BCS (> 1 year from treatment) can serve as effective support for current AA-BCS (< 1 month since treatment) through emotional support and home visits. Longer follow-up time (> 2 months) is suggested, but recruitment peer navigation can be difficult
[62]	Mollica M, Nemeth L (2015) "Transition from patient to survivor in African American breast cancer survivors." <i>Cancer Nurs</i> 38: 16–22	Qualitative	15	35–85 years (mean age: 51 years)	6–18 months	AA-BCS experience and transition to survivor are greatly supported by their relationship with God. Participants indicated that they were not prepared for the persistent physical issues that lasted well after treatment had ended. Many assumed that because treatment was over, their treatment adverse effects would be also. Speaking to another AA woman who had survived breast cancer may have helped them be better prepared for the stress of cancer survivorship. Participants stressed that emotional issues were as important as physical
[64]	Nolan TS, Frank J, Gisiger-Camata S, Meneses K (2018) "An Integrative Review of Psychosocial Concerns Among Young African American Breast Cancer Survivors." <i>Cancer Nurs</i> 41: 139–155	Integrative review	1477 AA-BCS	37–56+ years	3–10 years	Younger AA survivors reported greater fear of recurrence, death, and familial role changes; fear of recurrence was also positively associated with distress and negatively associated with quality of life. Young AA survivors are likely to be single, want children, and report greater psychosocial concerns. Young AA survivors reported lack of information related to sexuality and fertility. Healthcare providers have knowledge that can connect young AA survivors with specific survivorship resources, but some survivors were not referred
[12]	Nurgalieva, Z. Z., L. Franzini et al. (2013). "Surveillance mammography use after treatment of primary breast cancer and racial disparities in survival." <i>Med Oncol</i> 30(4): 691.	Retrospective cohort	28,117 (1058 AA)	66 years or older	At least 30 months	Non-White breast cancer survivors underwent surveillance mammography less frequently than White breast cancer survivors. While "adjustment for surveillance mammography receipt and physician visits reduced differences in disease-specific mortality between Hispanics and Whites and between Blacks and Whites,

Table 1 (continued)

Reference number	Reference	Design	Participants	Age	Time since diagnosis	Results
[16]	Owusu C, Schluchter M, Koroukian SM, Mazhuvanchery S, Berger NA (2013) “Racial disparities in functional disability among older women with newly diagnosed nonmetastatic breast cancer” <i>Cancer</i> 119: 3839–3846	Cross-sectional	190 (32% were AA)	65 years and older (mean: 74 years)	Median time was 2.1 months from diagnosis	these survival disparities were not significantly different” Relative to non-Hispanic Whites, older AA women were nearly two times more likely to experience functional disability at diagnosis of stage I through III breast cancer. In addition, the study found that although the racial difference in functional disability was partly explained by differences in median household income, educational status, chronic medical conditions, and obesity, residual racial differences in functional disability remained after accounting for these factors.
[14]	Palmer, N. R., K. E. Weaver et al. (2015). “Disparities in barriers to follow-up care between African American and White breast cancer survivors.” <i>Support Care Cancer</i> 23(11): 3201–3209.	Cross-sectional	191 (31 were AA)	> 50 years	6–24 months	Survivorship outcomes are affected by multiple barriers. For the AA population, cost of treatment and fear of recurrence are associated with less timely follow-up care and receipt of appropriate therapies
[42]	Paxton RJ, Nayak P, Taylor WC, Chang S, Courmeya KS, Schover L, Hodges K, Jones LA (2014) “African-American breast cancer survivors’ preferences for various types of physical activity interventions: a Sisters Network Inc. web-based survey” <i>J Cancer Surviv</i> 8: 31–38	Descriptive analysis	475 AA-BCS	Mean age: 54 years	Mean time since diagnosis: 7 years	AA-BCS have similar interests in and preferences for physical activity interventions. The majority of women were interested in interventions that promoted walking and resistance activities. Data regarding their choice of exercises differ from the data reported in previous studies in that this question was open-ended. Thus, we were able to capture specific activities in which AA-BCS are interested.
[44]	Royak-Schaler R et al. “Exploring Patient-Physician Communication in Breast Cancer Care for African American Women Following Primary Treatment.” <i>Oncology Nursing Forum</i> . 2008; 35(5): 836–843	Qualitative	39 AA-BCS	30–75 (mean 55)	< 1 years 13%, 1–5 years 41%, > 5 years 46%	Among AA-BCS, there were significant gaps in guidelines for surveillance, symptoms after treatment, and prevention
[17]	Russell KM et al. “Quality of Life of African-American Breast Cancer Survivors: How much do we know?” <i>Cancer Nursing</i> . 2008;31(6):E36-E45	Literature review	375 AA-BCS	Median age 74.6 years	Median time was 68.4 months	A review of the quality-of-life issues, especially as they relate to the more immediate needs of survivors, and not only long-term issues. Over a fifth of patients reported poor physical (20.1%) and mental (27%) health-related quality of life. Advanced age, tumor size, > 2 comorbidities, inability to perform > 2 of 6 activities of daily living (ADLs), modified or radical mastectomy, infiltrating lobular carcinoma, advanced stage of disease, and administration of radiation treatment were all associated with poorer physical

Table 1 (continued)

Reference number	Reference	Design	Participants	Age	Time since diagnosis	Results
[40]	Rust C, Davis C (2013) "Chemobrain in underserved African American breast cancer survivors: a qualitative study" <i>Clin J Oncol Nurs</i> 17: E29–34	Qualitative	24 AA-BCS	46–60+ years	Mean time since diagnosis: 6.1 years	component scores. Comorbidities, inability to perform ADLs, and lower income were associated with poorer mental QOL. After controlling for other factors, only inability to perform ADLs was noted to be independently associated with poorer mental HRQOL AA-BCS experienced cognitive challenges, which they described as chemobrain resulting from their cancer treatment. Lack of information given to the women by their healthcare providers was an issue of concern. Self-reported reduction of quality of life from the impact of chemobrain was a common thread throughout both focus groups. Recognition of the phenomenon of chemobrain by healthcare professionals was not apparent to the women in the current study
[23]	Salsman JM, Yanez B, Smith KN, Beaumont JL, Snyder MA, Barnes K, Clayman ML (2016) "Documentation of Fertility Preservation Discussions for Young Adults with Cancer: examining compliance with treatment guidelines." <i>J Natl Compr Canc Netw</i> 14: 301–309	Qualitative	454 BCS (11.8% were AA)	Between 18 and 39 years	Unspecified	White patients were twice as likely as non-White patients to be informed of the potential effect of treatment on their fertility.
[36]	Schneider BP, Lai D, Shen F, Jiang G, Radovich M, Li L, Gardner L, Miller KD, O'Neill A, Sparano JA, Xue G, Foroud T, Sledge GW (2016) "Charcot-Marie-Tooth gene, SBF2, associated with taxane-induced peripheral neuropathy in African" <i>Americans Oncotarget</i> 7: 82244–82,253	Gene-based case control analysis	386	Unspecified	Unspecified	The focus on a genetically defined AA population, a subgroup with a substantially increased risk for treatment-induced peripheral neuropathy (TIPN) in E5103 (ECOG-5103 was a phase III adjuvant breast cancer trial). Whole exome sequencing in a subset of the E5103 AA subsample and identified a gene, SBF2, with a higher burden of rare deleterious variants among individuals developing grade 3–4 TIPN
[27]	Schover LR, Jenkins R, Sui D, Adams JH, Marion MS, Jackson KE (2006) "Randomized trial of peer counseling on reproductive health in African American breast cancer survivors" <i>J Clin Oncol</i> 24: 1620–1626	Descriptive analysis	48 AA-BCS	30–77 years (median: 49 years)	At least 1-year post-diagnosis (mean: 4.52 years)	The SPIRIT intervention improved hot flashes, increased women's knowledge about reproductive health issues after breast cancer, and was highly rated in terms of its relevance and impact. An unanticipated benefit was the improvement over time in emotional distress
[25]	Schover LR, Rhodes MM, Baum G, Adams JH, Jenkins R, Lewis P, Jackson KE (2011) "Sisters Peer Counseling in Reproductive Issues After Treatment (SPIRIT): a peer counseling program to improve reproductive health among African	Randomized pilot intervention	185 AA-BCS (who fully completed the pilot)	Median age 49 years	At least 1-year post-diagnosis	Women gained significantly in knowledge about breast cancer and reproductive health and reported significant decreases in hot flashes. This intervention may be more powerful if targeted to premenopausal African-American women diagnosed with cancer

Table 1 (continued)

Reference number	Reference	Design	Participants	Age	Time since diagnosis	Results
	American breast cancer survivors" <i>Cancer</i> 117: 4983–4992					
[45]	Stolley, M. R., L. K. Sharp et al. (2009). "A Weight Loss Intervention for African American Breast Cancer Survivors, 2006." <i>Preventing Chronic Disease</i> 6(1).	Intervention study	20 AA-BCS	30–70 years	Unspecified	The success of Moving Forward is most likely due in part to the involvement of AA-BCS in developing the intervention. Participants in Moving Forward exhibited significant weight loss, improved diet, increases in vigorous physical activity, and increased social support related to healthy eating and exercise. At the start of Moving Forward, women reported low levels of family and friend support for both healthy eating and exercise. However, significant increases in social support were noted over time
[13]	Thompson, H. S., M. Littles et al. (2006). "Posttreatment breast cancer surveillance and follow-up care experiences of breast cancer survivors of African descent: an exploratory qualitative study." <i>Cancer Nurs</i> 29(6): 478–487.	Qualitative	10 AA-African-Caribbean BCS	Age 38–63 (mean 50)	Between 1 and 6 years post--treatment	Motivators and barriers consistent with enabling resources include coordination of care, medical care costs, and lack of awareness of financial assistance resources. A need-related motivating factor in follow-up care was physician recommendation.
[26]	Vadaparampil ST, Christie J, Quinn GP, Fleming P, Stowe C, Bower B, Pal T (2012) "A pilot study to examine patient awareness and provider discussion of the impact of cancer treatment on fertility in a registry-based sample of African American women with breast cancer" <i>Support Care Cancer</i> 20: 2559–2564	Cross-sectional	48 AA-BCS	45 years and younger	Unspecified	A substantial proportion of breast cancer patients were unaware of the impact of breast cancer treatment on fertility. 56% of the participants reported that providers discussed the potential impact of treatment on future fertility.
[15]	Weaver, K. E., J. H. Rowland et al. (2010). "Forgoing medical care because of cost: assessing disparities in healthcare access among cancer survivors living in the United States." <i>Cancer</i> 116(14): 3493–3504.	Unspecified	14% of National Health Interview Survey from 2003 to 2006 (6602 cancer survivors, including breast) were AA	Age 18 years and older	within 1-year of diagnosis to 10 + years since diagnosis	Rates of forgoing care were not consistent across cancer sites. Consistently, women with cervical cancer reported higher rates of forgoing care compared to breast, prostate, melanoma, and multiple cancer survivors. In the total sample of cancer survivors, Hispanic and Black cancer survivors were more likely to forgo prescription medications and dental care than White survivors and Hispanic survivors were more likely to forgo medical care. Adjusted models suggest that race/ethnicity disparities were largely due to difference in socioeconomic status and medical insurance coverage. The occurrence of medical comorbidities may also contribute to differences in forgoing care.
[52]	White-Means, S., M. Rice et al. (2015). "African American Women: Surviving Breast Cancer		10 AA-BCS	38–62 years	Unspecified	Prayer, family, and survivor support were central to coping with breast cancer. Lack of provider

Table 1 (continued)

Reference number	Reference	Design	Participants	Age	Time since diagnosis	Results
	Mortality against the Highest Odds." <i>Int J Environ Res Public Health</i> 13(1).	Descriptive qualitative analysis				sensitivity to survivors' concerns about pain was a repeated complaint. Difficulty in meeting financial responsibilities and lack of sexual desire were also reported. African-American women perceived that there were differences between themselves and White women in their attitudes about prevention, and that they thought these differences were culturally acceptable.

younger and unmarried women [21]. In a qualitative study, AA-BCS less than 45 years old reported difficulty with sexual intercourse, sexual dysfunction, and decreased sexual desire [22]. Lewis et al. also found that young AA-BCS were less inclined to discuss sexual side effects with their health care providers. Additional concerns that were impacted by sexuality were fertility preservation and reconstructive surgery [22].

Fertility preservation

Studies have shown that younger women can suffer from distress related to infertility issues [23]; yet, over 20% of AA-BCS reported not receiving fertility information [23–25]. Another study found that nearly half of the AA-BCS in their cohort had no fertility discussions with their oncologists about treatment-related risks to fertility [26]. As a possible solution, Schover et al. suggests the benefit of the SPIRIT intervention for AA-BCS [27]. The SPIRIT intervention was designed to improve knowledge and reduce symptoms related to sexual dysfunction, menopause, and distress about infertility in AA-BCS. The study showed reproductive health knowledge increased, and the women's emotional distress related to sexual dysfunction, and loss of fertility decreased [27].

Impact of reconstructive surgery

Reconstructive surgery can also impact sexuality concerns as women come to terms with their new bodies. Alderman et al. evaluated the use of reconstructive surgery or information regarding the procedure around the time of diagnosis in different racial/ethnic groups [28]. Results showed significant variation in the receipt of reconstructive surgery based on race/ethnicity with a 40.9% rate in White women as opposed to 33.5% rates in AA women. Women from minority groups were less likely to see a surgeon before surgery and minority women without reconstructive surgery had low surgical decision-making satisfaction rates when compared to white women ($P < 0.001$) [28]. It was shown that these women had less counseling from their surgeon in regard to reconstructive surgery options [28].

Cardiotoxicity

Anthracycline-based therapies, like doxorubicin, have well-documented cardiotoxicity effects, such as dilated cardiomyopathy [29, 30]. A retrospective study noted a nearly threefold increase in the rate of cardiotoxicity among their AA breast cancer patients compared to their non-White counterparts [31]. Grenier and Lipshultz performed a review of childhood cancers and found that AA survivors were at an increased risk of early cardiotoxicity [32]. It is unclear if the same is true in adult AA cancer survivors. The etiology of this disparity is unclear, but may be partially due to genetics and complicated

by other medical comorbidities such as hypertension and diabetes [32]. Additional research in this area is needed.

Neuropathy

Peripheral neuropathy is a major taxane-based chemotherapy side effect [33, 34]. AA-BCS had a higher prevalence of taxane-induced neuropathy compared to non-AA-BCS (53% vs. 22%) [35]. Further, Schneider et al. found that AA-BCS are at increased risk of developing both moderate and severe neuropathy secondary to taxane-based chemotherapy [36]. In further analyses, they find a genetic variation (polymorphism) in the Charcot-Marie-Tooth gene (SBF2), which can predict an increased risk of taxane-induced neuropathy in AA breast cancer patients [36]. Other polymorphisms have been associated with an increased risk of therapy-associated neuropathy but not associated with race [33, 34]. As with cardiotoxicity, additional research is needed to better understand clinical and genetic risk factors for this very common treatment-related complication [35–38].

Cognitive changes

Cognitive side effects from chemotherapy, also known as “chemobrain,” have been reported among breast cancer survivors [39]. It is characterized by a range of symptoms, including memory loss, difficulty thinking, and inability to concentrate and multitask. This has been shown to impact quality of life [39]. However, further research is still needed on how this “chemobrain” may differently affect minority populations. One study performed focus groups among underserved AA-BCS [40]. One of the main issues the women expressed was not knowing about the existence of “chemobrain” as their healthcare professional never mentioned it prior to treatment [40]. As discussed later, provider-patient communication in survivorship is an area that needs further improvement for AA-BCS.

Prevention

Prevention is a key component of survivorship care. Unlike surveillance, prevention and detection of new cancers and recurrent cancer underscore care measures taken to decrease the risk of developing cancer recurrence and/or lasting late effects. The selected articles detail prevention among AA-BCS focused on physical activity and diet for recurrence risk reduction.

Physical activity

AA women are at higher risk of increased rates of obesity and lack of physical activity, which negatively affects overall breast cancer survivorship and quality of life [41, 42]. A study

by Hair et al. examined the different determinants of activity levels of women with breast cancer before and after diagnosis [43]. Participants reported a decrease of about 59% in physical activity after diagnosis; AA women when compared to White women were less likely to meet their physical activity target (OR, 1.38; 95% CI) [43]. The study concluded that post-treatment interventions need to be directed towards encouraging physical activity in order to reduce breast cancer survivorship disparities in AA women [43].

Diet

Diet is also an important factor in determining breast cancer survivorship outcomes. Lower survival rate seen in AA-BCS is partly attributed to obesity and high fat diets [44]. Royak-Schaler et al.’s study examined behavioral modifications, such as diet and physical therapy [44]. Patients report not being informed by their providers on a recommended diet or level of physical activity [34]. Though the rates of obesity are very high in AA women, weight reduction programs targeting breast cancer survivors in AA communities are few [44]. Stolley et al. evaluated the feasibility of a weight loss program in AA-BCS known as Moving Forward and noted significant weight improvements after a six-month period as a result of diet, physical exercise, and social support [45]. Results showed that physical activity, healthy diet with more vegetables, and less fat intake improved quality of life of the participants [45]. Paxton et al. noted that AA-BCS were interested in culturally sensitive interventions on physical activity, but are underrepresented in clinical trials promoting positive health behaviors [46].

Coordination between specialists and primary care providers

Appropriate patient follow-up requires coordination between oncology specialists and primary care providers. When AA-BCS complete treatment, they are faced with the complex challenge of transitioning out of treatment and into primary care, seeking to gain the support and resources needed for managing life as a survivor [47]. The selected articles detail patient-provider communication, survivorship care plans, and systemic factors to delivery of survivorship care.

Patient-provider communication

Articles in this review identified patient-provider communication as a potential barrier to care coordination. In considering ways to strengthen communication, patient engagement in their own care can be improved by paying attention to non-verbal cues and by requesting the patient’s perspective into how their disease process and treatment are coming along [48]. Maly et al. evaluated factors that affect preventive care

and breast cancer survivorship outcome 3 years after breast cancer diagnosis in low-income women (4.3% of whom were African-American) [49]. They found that women who visited their primary care providers in addition to their oncology specialists or surgeons had better outcomes than those who only visited their oncologist, indicating that low-income populations require timely follow-up care after breast cancer diagnosis [49]. It is still unclear as to who is the best provider to coordinate this communication between the patient and provider and between providers in the follow-up period [47]. It is recommended that the oncologists send communications and updates in plan, including surveillance, to the primary care provider [47].

Cultural competency Cultural competence requires the demonstration of awareness of cultural norms and beliefs, knowledge of how culture may differ across groups, being sensitive to culture, and ultimately making adjustments to accommodate culture [50]. This review identified culturally competent interventions for this group including significant others in patient conversations and address spirituality and faith [51–55]. A focus group of AA-BCS noted the importance of culturally competent care, where practitioners (primary care and oncologists) understand these women's past experiences and family histories, as these contribute to the survivors' psychosocial standing [51]. White-Means et al. found factors that negatively impacted their survivorship which were inadequate provider care in the treatment of pain, lack of needed support from friends and family, and disability limitations that can be mental or physical [52]. A study by Kantsiper et al. found that spirituality and personal growth were important issues for these AA women, especially since there is still a social taboo about breast cancer in AA communities [53]. A unique study provided their participants with personal cameras that were used to record their daily activities during their breast cancer survivorship experience [55]. Careful analysis of their recorded survivorship experience showed that the quality of life was highly dependent on three social factors, which included racism, cancer stigmatization, and what the culture aspects of AA women [55].

In addition, African-Americans have reported a distrust of the health care system because of past discriminatory practices; for example, some women reported continued fear and suspicion from the Tuskegee airmen case by the US Public Health Service [53].

Utilization of survivorship care plans (SCPs)

Regarding more comprehensive follow-up care, a cancer survivorship care plan (SCP) was suggested as an intervention to improve follow-up care, per the Institute of Medicine. One of the first studies dealing with follow-up information presented to AA-BCS showed that there were significant gaps in

guidelines for surveillance, symptoms after treatment, and prevention [7]. The study points out the importance of addressing the diverse needs of survivors, particularly AA in this setting, in order to develop practical and feasible care plans. Kvale et al. found that the transition to survivorship care is an individualized process and that a survivor's response to behavioral change is dependent on their personal and past experiences [56, 57].

Ashing-Giwa et al. focused on formatting the SCP to the AA-BCS to ensure more efficacy [58]. Ashing-Giwa et al. and Burg et al. found that survivors themselves preferred the information to be presented in a way that was particularly relevant for AA-BCS [58, 59]. This included a cover page outlining follow-up providers who are more culturally competent towards AA, and healthy lifestyle practices. They also comment on the importance of spirituality and quality of life for these survivors, and that reflection in the SCPs. Psychosocial support was again emphasized by Burg et al. through focus group discussions [58].

Patient navigators

Another strategy suggested is the use of patient navigators. A study by Mollica et al. examined the use of peer navigators exclusively in the AA population who were also breast cancer survivors. The qualitative results showed that the breast cancer survivors felt support from the peer navigators as they "shared a common journey" [60]. Survivors and navigators also reported that home visits were beneficial. The study does point out the limitations of peer navigation, as there were issues with navigator recruitment and finding the right person for the role, along with commitment to follow-up and prior work commitments. The use of patient navigators, who are breast cancer survivors themselves, has been shown to improve patient outcomes in terms of coping with the disease and assisted with adherence to follow-up care [61, 62]. Davis et al. also found that peer navigators could help provide emotional support as needed for AA-BCS [61]. Not only were these navigators available for the patient, but they also provided coping strategies for the family members. They showed that navigators can be used across the continuum of cancer care [61].

Many studies are patient-focused and address issues such as patient education and training. However, Daly and Olopade discuss how very few studies address changing the healthcare system and delivery [2]. They suggest that a focus on combining insurance coverage, patient education/communication, and patient navigation in interventions can be further researched to assess its effectiveness in breast cancer approaches. Furthermore, the concept of a medical home, a centralized location/physician where patient care is coordinated, has been shown to

reduce ethnic and racial disparities in general health care, not just cancer [63].

Discussion

Breast cancer survivorship can be a complicated journey for some survivors, particularly if there are long-term side effects of treatment and challenges with health maintenance and health promotion. This review summarizes how survivorship care management can be challenging for AA-BCS. These women bear a larger burden of disease, including more advanced disease at diagnosis and greater potential for comorbidities, than White women. The acute survivorship period is particularly important as many AA-BCS need culturally competent care to address coping needs and strategize follow-up care. Unfortunately, survivorship care among AA-BCS is understudied. There is paucity in our understanding of how AA-BCS perceive their lives after breast cancer [42, 62, 64]. This review places greater perspective on how AA-BCS experience survivorship and how their particular social and racial context shapes their experience of survivorship and survivorship care.

Given the converging breast cancer incidence rates between AA and White women, surveillance and preventative practices are paramount in this already at-risk population of women [3]. Timely detection and management of disease increase likelihood of achieving remission. It is clear that current survivorship guidelines recommend surveillance and preventative practices [10]; however, our review indicates that there are barriers in meeting these guidelines and reciprocal issues with compliance.

Culturally competent post-treatment interventions may increase the likelihood of AA-BCS meeting survivorship guidelines [10]; unfortunately, such interventions are lacking for AA-BCS. This review identified that cultural competency among AA-BCS involves the use of spirituality and social support to cope with their disease and treatment. Recognition that culture even among those that consider themselves as AA may be different is key. Therefore, personalizing the approach to each patient may yield better intervention effects and highlights the importance of individual assessment of supportive care needs [10].

Further, this review demonstrates that there is a lack of integration of care across the breast cancer care continuum. Often there is confusion about who should deliver survivorship care across the continuum, as well as how health information in the form of SCPs is communicated in a culturally competent manner. Another suggested approach by Daly and Olopade is the concept of an oncology medical home [2]. Elaborating on the concept of an accountable care organization, this concept has shown success by focusing on long-term coordinated care where reimbursement

is based on performance and outcomes, and not traditional fee-for-service models.

Review findings indicate areas for future research including identifying the best ways to ensure quality survivorship care for AA-BCS, seeking to eliminate survivorship disparities. The presented literature supports the use of system-wide approaches to reduce racial disparities, such as the idea of a medical oncology home [2]. Another strategy is the Public Health Action Model for Cancer Survivorship [65]. This model uses a social ecological framework (i.e., individual, community, organization, and policy) within the National Action Plan for Cancer Survivorship to enhance public health collaborations and provide more effective survivorship care [65]. Within such systems, a large concern is determining who is the most appropriate person to deliver survivorship care plans [44], and if patient navigators are used to improve care coordination, who should be recruited as patient navigators [60]. More importantly, research is needed to understand how to best apply cultural competence across survivorship interventions. As we strive towards these healthy initiatives, evidence-based care may help reduce breast cancer disparities.

There were limitations to this overview. Though we used an organized approach to literature review, we did not perform an expansive systematic review. Therefore, our search may have missed relevant articles that would deepen understanding of the reviewed topic. We also acknowledge that some articles included in the review had small samples of AA-BCS. Given the limited articles describing acute survivorship for AA-BCS, we included such articles to give more perspective. This literature review provides an overview to generate discussion and promote future research in this area.

Conclusion

This overview identified what is known about challenges of survivorship and survivorship care among AA-BCS. Understanding of this phenomenon centers on how AA-BCS approach surveillance, provision of interventions for addressing late effects, promotion of healthy living strategies, and coordinating care throughout the care continuum. Barriers to optimum survivorship care inherently inhibit progress in eliminating breast cancer disparities. Research on best practices to deliver survivorship care in this population is needed. Implementation of culturally tailored care may reduce breast cancer disparities among AA-BCS.

Compliance with ethical standards

Conflict of interest There are no financial disclosures. There are no companies that have sponsored this research. The authors have full control of all primary data, and we agree to allow the journal to review any data.

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