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Advancing Breast Cancer Survivorship among African American Women

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Abstract

Purpose—Advances have occurred in breast cancer survivorship but, for many African American women, challenges and gaps in relevant information remain.

Methods—This article identifies opportunities to address disparities in breast cancer survival and quality of life, and thereby to increase breast cancer survivorship among African American women.

Results—For breast cancer survivors, common side effects, lasting for long periods after cancer treatment, include fatigue, loss of strength, difficulty sleeping, and sexual dysfunction. For addressing physical and mental health concerns, a variety of interventions have been evaluated, including exercise and weight training, dietary interventions, yoga and mindfulness-based stress reduction, and support groups or group therapy. Obesity has been associated with breast cancer recurrence and poorer survival. Relative to white survivors, African American breast cancer survivors are more likely to be obese and less likely to engage in physical activity, although exercise improves overall quality of life and cancer-related fatigue. Considerable information exists about the effectiveness of such interventions for alleviating distress and improving quality of life among breast cancer survivors, but few studies have focused specifically on African American women with a breast cancer diagnosis. Studies have identified a number of personal factors that are associated with resilience, increased quality of life, and positive adaptation to a breast cancer diagnosis.

Conclusions—There is a need for a better understanding of breast cancer survivorship among African American women. Additional evaluations of interventions for improving the quality of life and survival of African American breast cancer survivors are desirable.

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Conflict of Interest Statement

The authors declare that they have no conflict of interest to report.

Keywords

African Americans; breast cancer; cancer survivorship; health status disparities; quality of life; survival

With continued progress in medicine and public health, the number of breast cancer survivors has increased [1]. In the U.S., there are 2.5 million breast cancer survivors and the number is likely to continue to increase because of the aging of the population and the obesity epidemic. In recent decades, there has been progress in understanding how women diagnosed with breast cancer respond to health challenges and cope with their diagnosis over long periods of time. Relatively few studies, however, have examined the experiences of women who are African American breast cancer survivors. Black-white differences in breast cancer survival and findings from qualitative studies suggest that there are unmet needs among these survivors [2–4].

In the follow-up of breast cancer survivors, oncologists and primary care providers provide surveillance for cancer reoccurrence and health promotion [5]. Nevertheless, there is a continuing need for better coordination of care provided to breast cancer survivors in order to optimize the quality and completeness of the care and to manage symptoms and to prevent chronic diseases [6]. Cancer survivorship plans provide an example of how care coordination can be improved [7]. These plans help with the transition of breast cancer treatment from an acute care model to a wellness model in which health promotion and management of symptoms over time figure prominently [8,9].

To advance breast cancer survivorship among African American women, the present article identifies opportunities to address disparities in breast cancer survival and quality of life. First, black-white disparities in breast cancer treatment and survival are summarized, along with the long-term potential side effects of breast cancer treatment and developments with breast cancer survivorship care plans. Also covered are topics in breast cancer survivorship, including quality of life, cancer-related fatigue, physical activity and dietary interventions, yoga and mindfulness-based stress reduction, pain management, and the alleviation of depression and anxiety. At the end, a discussion and several conclusions are provided.

Black-White Disparities in Breast Cancer Treatment and Survival

The survival of patients with breast cancer differs based upon race/ethnicity and socioeconomic status. The 5-year relative survival rate for patients with breast cancer is 79% for African American women and 92% for white women [1]. When this cancer is detected at a localized stage, the 5-year survival improves. African American women, however, are less likely than white women to be diagnosed at an early stage and they have poorer stage-specific survival on average [1]. Relative to white women, African American women are more likely to have estrogen receptor-negative, progesterone receptor-negative, and HER2-negative (“triple-negative”) tumors [10, 11].

Racial differences in cancer outcomes may be due to a variety of factors such as, decreased access to quality care, differences in tumor biology resulting in increased aggressiveness or

resistance to treatment, socioeconomic factors influencing treatment options, increased comorbid conditions, and/or suboptimal patient-physician interactions [12]. Qualitative studies have shown that African American breast cancer survivors sometimes experience deficits in the information provided to them by their physicians about their diagnosis, treatments, side effects, and recommendations for follow-up care [13]. A recent survey of 31 African American and 160 white breast cancer survivors found that financial barriers prevent many minority and underserved survivors from accessing follow-up care [14]. Over half of the African American survivors identified out-of-pocket costs and anxiety/worry as barriers to receiving follow-up care [14].

The causes of racial differences in breast cancer treatment and survival include factors relating to the patient, the provider, and the healthcare system. Racial disparities in the quality of care among breast cancer patients may contribute to differences in outcomes and patient misperceptions about cancer [15]. In addition, mistrust of the healthcare system can interfere with cancer treatment and structural problems, such as lack of transportation may be involved. Black-white differences in patient attitudes, beliefs, and knowledge about breast cancer, may contribute to racial differences in receipt of appropriate treatment. When symptoms occur, patient attitudes, such as fatalism and denial, can lead to delays in presenting for medical evaluation [15, 16].

In addition, there are differences in the understanding of breast cancer among different racial/ethnic and socioeconomic groups and individuals from disadvantaged backgrounds may be more likely to have misperceptions about their risk of breast cancer.

Potential Long-term Side Effects of Breast Cancer Treatment

Some side effects of breast cancer therapy can persist for years. The chronic and delayed effects vary by treatment, coexisting health conditions, and other factors. Common side effects of breast cancer treatment include lymphedema, fatigue, loss of strength, difficulty sleeping, and sexual dysfunction [17]. There may also be adverse effects on cognitive functioning related to treatment with chemotherapy [18]. There are associations between long-term symptoms. For example, sleep disturbances are associated with fatigue and depression [19]. Appropriate follow-up care for survivors of breast cancer, for which clinicians have a key role to play, includes medical surveillance to detect recurrences or secondary cancers, monitoring to identify and address potential late effects of cancer treatment, providing advice about risk reduction, and assessment of cancer risk among biological family members [7, 20]. The potential late effects of cancer treatment includes second malignancies, cardiovascular disease, obesity, osteoporosis, bone fractures, and other chronic conditions affecting physical and emotional well-being [21–24]. The increased risk of cardiovascular disease among breast cancer survivors is due in part to the toxic effects of anticancer therapy (e.g., anthracyclines, trastuzumab, and radiation) on the cardiovascular system [25, 26].

Care Plans for Breast Cancer Survivorship

The Institute of Medicine (IOM) recommends for cancer survivors, the use of care plans that include a treatment summary and a follow-up plan intended to assist with the coordination

and completeness of post-treatment care [7]. A detailed survivorship care plan includes follow-up schedules for visits and testing, recommendations for early detection, and management of treatment-related effects and other health problems [27]. However, such plans provided to breast cancer survivors often do not address all of the recommendations by the IOM, and few oncologists and primary care providers provide a written survivorship care plan to patients or have survivorship discussions with their patients [28–32]. In a national survey of medical oncologists and primary care physicians, less than half of the oncologists reported always or almost always providing treatment summaries [33]. Oncologists who used electronic medical records and those who had received training in late- and long-term effects of cancer were more likely to report provision of a survivorship care plan [33]. Barriers to more widespread use of such plans include lack of personnel, limited time of providers, difficulties with accessing information, inadequate knowledge of cancer survivor issues, and lack of third-party reimbursement [27, 34]. A recent multicenter trial involving 139 breast cancer survivors showed that the participants frequently used materials in survivorship care plans to make decisions about exercise (64%), which tests to receive and when (62%), and dietary changes (62%) [35]. After receipt of survivorship care plans, perceived knowledge about survivorship improved [35]. A qualitative study of breast cancer survivors in Canada examined their preferences for the content and format of survivorship care plans [36]. The patients preferred elements such as a treatment summary, information on nutrition and exercise, anticipated side effects, signs and symptoms of recurrence, a recommended follow-up schedule, and information being sent to one's primary care physician, and updates about changes [36]. Breast cancer survivors often have concerns about their sexual well-being, childbearing, presence of a positive family history of cancer, and other survivorship issues [37]. Information about long-term follow-up care after primary treatment for breast cancer should be tailored to the specific needs of survivors from diverse racial, ethnic, socioeconomic, and educational backgrounds, and age groups [13].

Quality of Life among African American Breast Cancer Survivors

The quality of life of breast cancer survivors can be adversely affected by physical and mental conditions, such as cancer-related fatigue, pain, obesity, sleep difficulties, depression, and anxiety about recurrence. Younger women (aged < 50 years) who are treated for breast cancer often have concerns about premature menopause, menopausal symptoms, and infertility [38]. In a study of 248 African Americans and 244 whites with a history of breast, prostate, or colorectal cancer, African American respondents had poorer mental health quality-of-life scores than whites [39]. Factors associated with physical health quality-of-life scores among both African Americans and whites included being unemployed, being uninsured, and the presence of medical comorbidities.

Weight gain and physical inactivity can occur following breast cancer treatment. For addressing physical and mental complaints among breast cancer survivors, a variety of interventions have been studied, including exercise and weight training, dietary interventions, yoga and mindfulness-based stress reduction, and support groups or group therapy. Although considerable information exists about the effectiveness of such interventions for alleviating distress and improving quality of life among breast cancer survivors, few studies have focused specifically on African American women with a breast

cancer diagnosis. Other factors that influence quality of life among breast cancer survivors include employment status; concerns about fertility, sexuality and relationships; and socioeconomic factors. Low socioeconomic status and socioecologic stress are inversely related to health-related quality of life among breast cancer survivors in California [40].

Because of racial differences in stage-at-diagnosis; survival; cultural factors; economic resources; and the quality, affordability, and accessibility of health care, some quality of life issues that affect the short and long-term survivorship experiences of women with breast cancer may be different for African American women. Torres et al. [3] examined breast cancer survivors' experiences in follow-up care and treatment by conducting 7 focus groups with 32 African American women with breast cancer in rural counties in North Carolina. From the qualitative studies, several themes emerged, including faith in God as a coping mechanism and support networks consisting of family, church-family, friends, and coworkers. The participants expressed their lack of knowledge about treatment side effects [3]. African American women have long used spirituality to bring hope in with dealing with hardships and this is true of those who are striving to cope with physical, psychological, and emotional burdens that can accompany a breast cancer diagnosis [41–43]. Culturally appropriate, tailored assessments and interventions are needed for enhancing the quality of life among African American breast cancer survivors [44–46].

Reducing Cancer-related Fatigue among Breast Cancer Survivors

For breast cancer survivors, cancer-related fatigue is a common symptom in breast cancer survivors [47]. About one-third of cancer survivors have clinically significant fatigue up to 6 years following treatment [48]. Exercise (e.g., strength training, resistance training, walking, cycling, yoga, or Tai Chi) improves overall quality of life and cancer-related fatigue [49]. A meta-analysis of 9 high-quality studies found that supervised aerobic exercise was more effective than conventional care in improving cancer-related fatigue among breast cancer survivors (standardized mean difference [SMD] = -0.51 , 95% confidence interval [CI] -0.81 to -0.21 [47]. Similar effects were found for resistance training on cancer related fatigue (SMD = -0.41 , 95% CI -0.76 to -0.05).

Physical Activity and Dietary Interventions for Breast Cancer Survivors

In addition to alleviating cancer-related fatigue and improving quality of life, exercise has been found to have positive effects on breast cancer concerns, body image/self-esteem, emotional well-being, sexuality, sleep disturbances, social functioning, anxiety, and pain as determined at various follow-up periods after cancer treatment [49]. In a meta-analysis of studies of breast cancer survivors, Lahart et al. [50] found an inverse relationship between physical activity and all-cause, breast cancer-related death and breast cancer events, which supports the view that physical activity reduced death and breast cancer events among breast cancer survivors. Among older, overweight, and obese cancer survivors, physical activity and improved diet are positively associated with weight loss and higher physical functioning [51–53]. Although current evidence does not show that adherence to a higher quality diet after a breast cancer diagnosis has a substantial effect on risk of breast cancer death or

recurrence, consuming a healthy diet is associated with a reduced risk of non-breast cancer mortality among breast cancer survivors [54] and with reduced cancer-related fatigue [55].

In the RENEW trial, which included survivors of breast, colorectal, and prostate cancer aged 65 to 91 years, a tailored intervention consisting of telephone counseling and mailed print materials on diet and exercise delivered over a 12-month period was effective in increasing exercise, improving diet, reducing weight, and increasing quality-of-life [51]. Lifestyle interventions that focus on physical activity and improved diet reduce functional decline among older cancer survivors [52]. Among the many randomized trials of physical activity and/or dietary interventions for breast cancer survivors, few have examined the maintenance of outcomes post-intervention, examined mediators of intervention effects, or focused on African American survivors [56, 57]. In trials initiated in the U.S. and Australia, the theoretical frameworks for the interventions have been specified and more attention has been given to potential threats to scientific validity [58, 59]. Nevertheless, additional studies are needed to determine how to sustain the positive effects of exercise over time and to identify the optimal mode, intensity, frequency, duration, and timing of exercise for breast cancer survivors, particularly among African American women. Maintaining a healthy body weight is a factor for the prevention of cancer recurrence and for reducing a woman's risk of diabetes and cardiovascular diseases [60]. Among women who have already been diagnosed with breast cancer, obesity is associated with breast cancer recurrence and poorer survival [61]. Obesity is also a risk factor for breast cancer-related lymphedema [62, 63]. Interactive, web-based interventions may offer a useful approach for increasing physical activity, improving diet, and controlling weight among breast cancer survivors [64, 65].

African American breast cancer survivors are more likely to be obese and less likely to engage in physical activity than white survivors [66]. In a study of 724 African American and 116 white breast cancer survivors, the African American survivors were over twice as likely to have diminished physical functioning (odds ratio [OR] = 2.29, 95% CI 1.57, 3.34) [67]. However, much of this disparity was due to racial differences in body mass index and other variables. A cross-sectional analysis of data from the 2009 Behavioral Risk Factor Surveillance System showed that African American breast cancer survivors were more likely to report obesity but less likely to report heavy alcohol consumption than their white counterparts [68]. In a pilot study of 17 African American breast cancer survivors (stage 0 to IIIA) who were within 2 years of completing primary cancer treatments, in which the participants completed weekly exercise logs and received weekly motivational phone calls, a 16-week training program involving home-based aerobic and resistance physical activity improved cardiopulmonary fitness, strength, and functional movement [66].

Because breast cancer survivors are at risk for declines in physical function, injuries through falls, and bone fractures, the value of weight lifting in this patient population has been examined. Although upper body weight lifting has not been recommended for breast cancer survivors who suffer from lymphedema or who are at risk of the condition, a randomized trial of slowly-progressing weight lifting among breast cancer survivors at risk of lymphedema demonstrated benefits in upper-body strength and less physical function decline without an increased incidence of lymphedema [69].

Yoga and Mindfulness-based Stress Reduction for Breast Cancer Survivors

Complementary and alternative medicine modalities have been widely applied for breast cancer patients and survivors [70–74]. The potential benefits of yoga include reduced distress, anxiety, depression, and fatigue and improved quality of life, emotional function, and social function [70, 73]. Mindfulness-based stress reduction also has beneficial effects on anxiety and depression among survivors [71, 72, 74]. Only a few studies, however, have involved African American cancer survivors [75]. Studies on other cancer prevention and control topics (e.g., cigarette smoking, alcohol use, and stress) show that many African Americans are willing to try yoga and mindfulness-based stress reduction techniques.

Pain Management among Breast Cancer Survivors

Chronic pain is a frequent problem among cancer survivors [76]. Optimal pain management can improve the quality of life of cancer patients and cancer survivors [77]. For breast cancer patients, there are differences between African American women and women from other racial/ethnic groups with respect to treatment pain management and treatment patterns [78]. The reasons for these differences have not been thoroughly studied. Potential barriers to optimal pain management in cancer survivors include concern about side effects, fear of addiction, inadequate professional knowledge about pain management, and lack of timely access to pain medications due to reimbursement issues [79].

Alleviating Depression and Anxiety among Breast Cancer Survivors

Breast cancer survivors often have concerns, such as fear of progression of their illness, disability or premature death [17]. However, levels of psychological distress vary, and not all survivors experience unusual fear or anxiety [16]. This variation is likely explained in part by inter-individual variation in personality traits, coping strategies, and resiliency. Anxiety and depression among breast cancer survivors are associated with other patient-reported symptoms that include perceived cognitive impairment and fatigue [80]. As noted above, exercise has positive effects on emotional well-being and anxiety among breast cancer survivors [49]. Exercise may also have a moderating effect on perceived cognitive impairment among breast cancer survivors who received chemotherapy [81]. In a randomized controlled trial, Stagl et al. [82] found that a group-based, cognitive-behavioral stress management intervention delivered to patients who had undergone treatment for nonmetastatic breast cancer was associated with fewer depressive symptoms at 1 and 5 years of follow-up. Even after 11-years, the women who received the intervention reported fewer depressive symptoms and better quality-of-life than the controls [83]. Lechner et al. [84] examined the effectiveness of a community-based stress management intervention and breast cancer wellness and education program (Project CARE) on psychological outcomes among 114 African American breast cancer survivors. This was a 10-session, group-based, and evidence-based intervention, culturally adapted for African American women. Participants in both intervention groups showed significant improvement on indices of psychological well-being, such as overall quality of life, intrusive thoughts, depressive symptoms, and stress levels [84]. Among survivors, complementary and alternative

medicine techniques such as yoga and mindfulness-based stress reduction had beneficial effects on anxiety and depression [70–74].

Discussion

Breast cancer survivors often experience long-term symptoms and are at increased risk for second malignancies, comorbid conditions, and functional decline. Breast cancer survivors often want to know what they can do to reduce their chance of having a recurrence or worsening of their illness and how to improve their overall physical and psychological health. Lifestyle interventions that promote physical activity and improved diet among older, overweight and obese cancer survivors have been shown to provide benefits in physical functioning, body weight, and quality-of-life [51, 52]. Among breast cancer survivors, a healthy diet is associated with reduced cancer-related fatigue and a reduced risk of non-breast cancer mortality among breast cancer survivors [54]. African American breast cancer survivors are more likely to be obese and less likely to engage in physical activity than white survivors [66]. Obesity is associated with breast cancer recurrence and poorer survival [61]. Additional research is warranted to examine the effects of life-style interventions among African American breast cancer survivors who, in general, have a poorer survival than their white counterparts. Engaging in behaviors such as physical activity, avoidance of cigarette smoking and heavy alcohol consumption, eating a healthy diet (e.g., a diet low in fat and high in fruits and vegetables), and learning stress-reduction techniques offers cancer survivors control over their health and lessens their fear of disease recurrence or progression [20]. Advice given to survivors of cancer by their health care providers can guide and reinforce such efforts. Getting adequate rest, learning how to effectively deal with psychological stress, and paying attention to the spiritual aspects of life are likely to be helpful.

Strategies used by people to cope with cancer have been examined [16, 85, 86]. These strategies are complex, dynamic processes that change over time and which are related to other personal characteristics [86]. Cancer survivors often face challenging situations, such as painful and/or frightening symptoms, uncertainty about their prognosis, and changes in social relationships [85]. Coping strategies used by cancer patients have been categorized by researchers as active versus avoidant, although such a simple categorization does not capture the full range of strategies employed. Active coping refers to strategies whereby persons accept the issue at hand and actively attempt to deal with it through problem solving, planning, and seeking emotional support [87]. For example, one may try to learn more about the problem or talk with family and friends. Avoidant coping, which includes denial, refers to strategies whereby persons avoid facing an issue by mentally or physically distancing themselves from it. For example, one may become busy with other things and avoid thinking about the situation. Cancer patients and survivors use a large repertoire of important strategies to cope with different aspects of their illness and treatment [85].

Hopefulness and optimism are mediators of coping and resiliency to illness. There are important connections between hopefulness, coping, resilience, and adaptation to illness [88]. Measures of hopefulness are positively associated with indices of life satisfaction and well-being. Among women with breast cancer, optimism is associated with short- and

longer-term emotional well-being [25]. Hopefulness is a positive coping strategy that people may use to deal with stressful events. People who lack hope may be more likely to use negative coping strategies (e.g., overeating or consuming too much alcohol) to alleviate stressful circumstances. The psychological concept of resilience focuses on the ability of individuals to survive or even thrive despite an adverse event and incorporates individual traits, such as hardiness, and external factors, such as social support [16].

Although the experience of having breast cancer taxes an individual's resilience and ability to cope, it can also lead to positive adaptation and increased ability to thrive despite difficult circumstances. The positive responses that people may show to adverse events have been referred to as post-traumatic growth [89]. Such favorable responses include positive psychological or social outcomes. Social support, spirituality, and active coping strategies are predictors of post-traumatic growth, as determined in longitudinal studies of breast cancer survivors [89, 90].

Following a diagnosis of breast cancer, people often reach out to caregivers, family, and friends and draw on their existing sources of social support or develop new sources of support. This may include patient support groups. Studies of breast cancer survivors have shown that social support reduces depression and psychological distress [91, 92]. Support groups and group therapy have been shown to provide psychological benefits for patients with cancer [93]. Social support and social connectedness have been shown to improve patient outcomes and enhance overall health and quality of life. African American breast cancer survivors can assist newly diagnosed women in coping with their illness and treatment [94].

In conclusion, gaps currently exist in understanding of breast cancer survivorship among African American women. Although obesity has been associated with breast cancer recurrence and poorer survival, African American breast cancer survivors are more likely to be obese and less likely to engage in physical activity than white survivors [61, 66]. For addressing physical and mental health concerns among survivors, a variety of interventions have been evaluated, including exercise and weight training, dietary interventions, yoga and mindfulness-based stress reduction, and support groups or group therapy. Exercise improves overall quality of life and cancer-related fatigue. Despite evidence of the effectiveness of such interventions for alleviating distress, reducing risk of chronic illness, and improving quality of life among breast cancer survivors, few studies have focused specifically on African American women with a breast cancer diagnosis. Additional studies of interventions are needed for improving the quality of life and survival of these breast cancer survivors.

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