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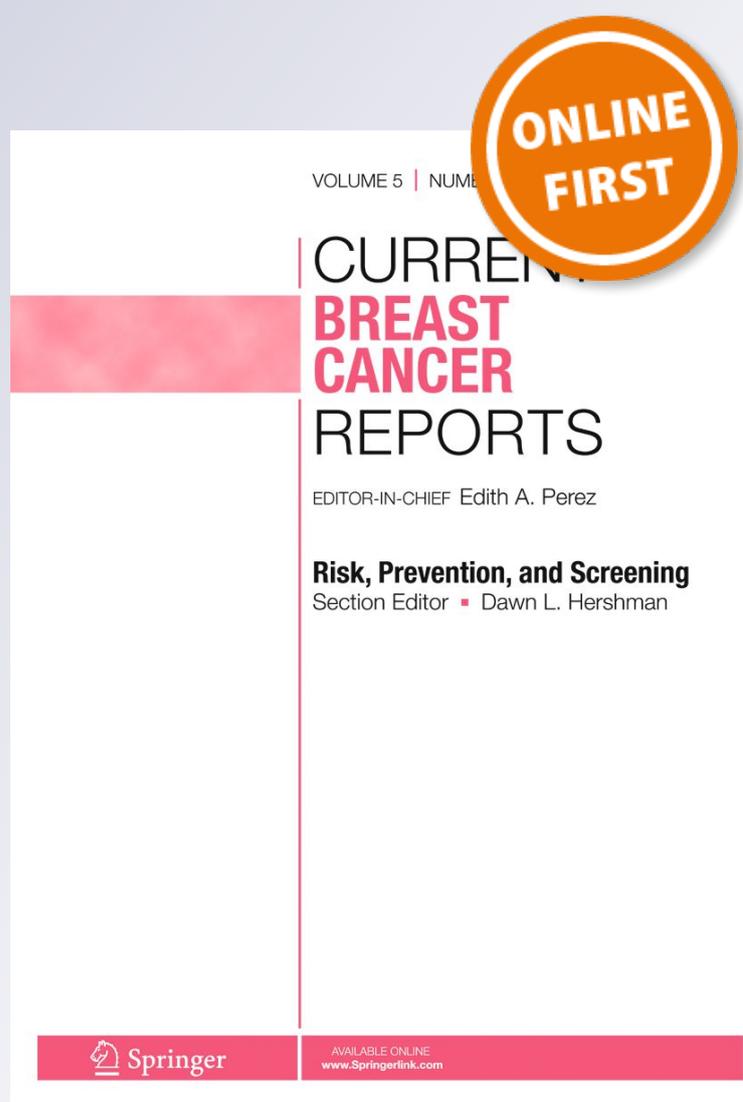
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Racial/Ethnic Disparities in Breast Cancer Incidence, Risk Factors, Health Care Utilization, and Outcomes in the USA

Annina Seiler¹ · Kyle W. Murdock¹ · Luz M. Garcini¹ · Diana A. Chirinos¹ · Jeffrey Ramirez¹ · Brielle Jackson¹ · Christopher P. Fagundes^{1,2}

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Abstract

Purpose of the Review This review examines racial/ethnic disparities in female breast cancer within the USA. Specifically, differences in breast cancer incidence, risk factors, health care utilization use, and outcomes among Caucasians and non-Caucasians are explored.

Findings In the USA, there are striking racial/ethnic disparities for female breast cancer. The etiology of these disparities is likely multi-factorial, including genetic, behavioral, socio-cultural, and environmental elements. Relative to Caucasian women, African American, Hispanic, and Asian/Pacific Islander breast cancer patients generally have a lower survival rate and worse prognosis despite lower incidence rates. They also tend to have more associated health problems and unmet psychosocial needs.

Summary Breast cancer patients are heterogeneous with respect to their race, cultural background, socioeconomic status, behavioral profile, and disease pathophysiology, and these factors impact health outcomes and health care needs. To reduce disparities and improve health outcomes in minority women, a multifaceted approach is required that includes efforts to minimize barriers to health care access, enhance cancer screening rates, and increase the use of culturally sensitive

interventions designed to reduce symptom burden and enhance quality of life.

Keywords Breast cancer · Health disparities · Race · Minorities · Psychosocial needs · Quality of life

Introduction

Breast cancer (BC) is the most common female malignancy among all racial/ethnic groups in the USA, with nearly 250,000 new diagnoses per year; it also is the second leading cause of death [1]. Improved detection and treatment of breast cancer has resulted in an increasing number of long-term breast cancer survivors. According to the American Cancer Society, *breast cancer survivor* is defined as anyone with breast cancer who has completed their initial treatment [2]. Given this definition, there are currently more than 3.1 million breast cancer survivors in the USA [3].

Significant racial/ethnic differences exist in both the incidence of breast cancer and likelihood of long-term survival. Racial/ethnic disparities in health and health care utilization have been a longstanding challenge in the USA, resulting in lower quality of health care services and poorer health outcomes in vulnerable groups. The National Cancer Institute defines *health disparities* as “adverse differences in cancer incidence, cancer prevalence, cancer mortality, cancer survivorship, and burden of cancer or related health conditions that exist among specific population groups in the United States” [4].

Women who belong to a racial/ethnic minority and women with low incomes typically experience worse breast cancer outcomes, which include higher recurrence and mortality rates despite having a lower incidence of breast cancer than Caucasian women [1] (see Table 1). Breast cancer disparities

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✉ Annina Seiler
annina.seiler@rice.edu

¹ Department of Psychology, Bioscience Research Collaborative, Rice University, 6100 Main Street, Houston, TX 77005, USA

² Department of Behavioral Science, University of Texas MD Anderson Cancer Center, Houston, TX, USA

Table 1 Female breast cancer incidence and mortality rates

Race/ethnicity	New cases	Mortality rates
White	128.0	21.0
Black	125.2	29.6
Hispanic	92.4	14.5
Asian/Pacific Islander	97.3	11.2
American Indian/Alaska Native	81.2	14.7

Statistics are for 2009–2013, age-adjusted, represent the number of cases per 100,000 persons by race/ethnicity of female breast cancer incidence and deaths rates per year in the USA [1•] (SEER, 2016)

have been observed for African Americans [5], Hispanics [6], and Asian/Pacific Islanders [7, 8•, 9]. Characteristics that could account for such disparities in breast cancer course are multi-factorial and include genetic, behavioral, socio-cultural, and environmental factors (Fig. 1). It is, therefore, not surprising that disparities among breast cancer survivors exist not only between different racial/ethnic groups but also among subgroups, including different ethnicities, within the same

race [10]. Given that the US population is continuously becoming more racially/ethnically diverse—with African and Asian Americans and Hispanics predicted to account for more than half of the population by the year 2044 [11]—increasing numbers of racial/ethnic minority breast cancer patients and survivors are expected [12].

Fears of cancer recurrence, other comorbidities, and persistent adverse treatment effects can significantly impact quality of life, including physical functioning [13]. Racial/ethnic minority women often encounter a greater burden of disease and more barriers during the transition from the primary to post-treatment period than the general population. Hypothesized explanations for these differences include genetic/medical, behavioral, sociocultural, and environmental factors [8•, 14]. This amplifies the importance of understanding the cancer experiences of racial/ethnic minority patients so that their needs during and after primary treatment can be better addressed and appropriate assistance provided [12]. Furthermore, addressing racial/ethnic health disparities is not only important from a social justice point of view, that is, achieving equity in health care, but also from the perspective of reducing

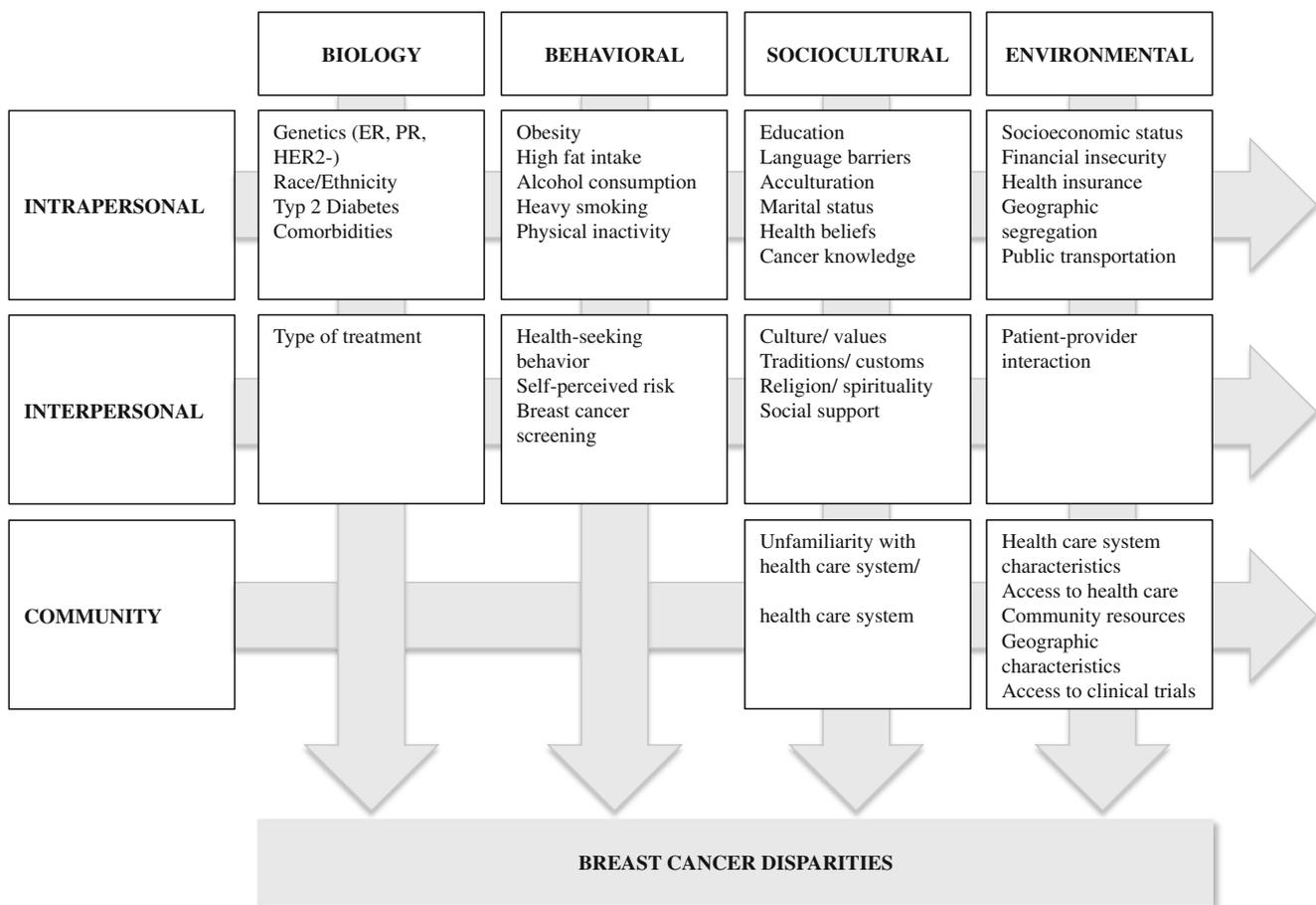


Fig. 1 A comprehensive model summarizing risk factors for breast cancer disparities in racial/ethnic minorities taking into account the complex interaction between genetic/medical, behavioral, sociocultural, and environmental factors on a social ecological framework. The social

ecological framework acknowledges that multiple-level factors in the social system (i.e., intrapersonal, interpersonal and community factors) influence health-seeking behaviors. *Abbreviations.* ER estrogen receptors, PR progesterone receptors, HER2- HER2-negative breast cancer

health care costs. In a recent analysis of US data from 2003 through 2006, 30% of direct medical costs were considered to be excess costs due to health inequalities in minorities. Furthermore, eliminating these health disparities for minorities would have reduced direct medical care expenditures by an estimated \$230 billion over those years 2003–2006 [15].

A broad range of interdisciplinary research has documented various adverse effects associated with cancer, its treatment, and long-term psychological sequelae including depression, anxiety, fatigue, body image issues, impaired sexuality, and reduced health-related quality of life [16, 17]. However, the vast majority of studies have been conducted on Caucasian women. Additionally, most of the research that has addressed racial/ethnic health disparities in the USA has focused on the cancer experiences of a single race, particularly either African Americans or Hispanics. Relatively little is known about the cancer experience of other racial/ethnic groups such as Asians and Pacific Islanders [7, 12, 18, 19]. In addition, the heterogeneity that exists between Asian subgroups has often been overlooked in randomized controlled trials. Instead of differentiating between different Asian subgroups, Asians have typically been grouped under the umbrella category of “Asian-Americans” or labeled as “Other” [18]. Moreover, studies on racial/ethnic differences have generally been limited by small sample sizes and/or the absence of any comparison groups with no history of cancer.

This review highlights racial/ethnic disparities in female breast cancer patients, in terms of breast cancer incidence and risk factors, health care service access and utilization, and outcomes, focusing especially on women who have survived their initial course of treatment. It ends by suggesting strategies that health care professionals might adopt to prevent, reduce, or eliminate these disparities.

Factors Contributing to Racial/Ethnic Disparities among Breast Cancer Patients

Socio-Demographic Risk Factors

When confronted with the diagnosis of breast cancer, racial/ethnic minorities encounter multiple unique adjustment challenges. At an individual level, factors that contribute substantially to differences in breast cancer outcomes between minorities and Caucasians include lower socioeconomic status (SES), lower education level, poorer health literacy, younger age (<50 years), and the lack of health care insurance [6, 9, 20]. Geographic segregation is another factor that contributes to health disparities, concentrating racial/ethnic minorities in more economically deprived neighborhoods where there is more restricted access to health care, recreational facilities, and transportation services than neighborhoods that are largely occupied by Caucasians [9]. In the USA, residential

segregation remains greatest among African Americans, Hispanics, and Asians [21]. The inability to work may impose an additional burden for minority breast cancer patients. Indeed, African American and Hispanic women who survive the initial treatment of their breast cancer appear to be more vulnerable to prolonged cancer-related work absences and job loss than Caucasian survivors [22].

Cultural Risk Factors

Culture encompasses the language, social behaviors, attitudes, beliefs, and traditions of a particular social group and consequently plays a critical role in how patients comprehend diagnoses, cope with illness, and make decisions about prevention and treatment [23]. Important barriers to health care include language constraints, restrictive cultural beliefs, and poor knowledge about cancer etiology, symptom recognition, and treatment options [24]. All of this may be associated with maladaptive behaviors, like avoidant responses to cancer, delayed help seeking, erroneous beliefs about cancer causation, and reduced acceptance of the diagnosis of cancer [23, 24].

Level of acculturation is another source of disparity between different races and ethnic groups, where acculturation is defined as the number of years one has lived in a new country or community and the level of adaptation that has been attained to the local culture, including language proficiency [14]. Some studies suggest that lower acculturation is accompanied by less knowledge and more misconceptions about cancer, which can result in fatalistic beliefs (for example, believing that the emergence of cancer is ordained by God and, as such, can neither be prevented nor controlled), less familiarity with health care resources, and reduced health care-seeking behavior [7, 14, 19, 23]. It has been recognized that knowledge about breast cancer and its treatment is generally low, irrespective of race, though minority women are less likely than their Caucasian counterparts to report accurate information about their tumor characteristics or treatments [25]. This emphasizes the need to better educate cancer patients about their tumors and treatments and to further investigate how knowledge about cancer may contribute to a given patient's acceptance of and adherence to treatment and, ultimately, their outcome [26]. Accordingly, attempts should be made to address faulty beliefs and misconceptions regarding cancer causes and treatment and augment cancer knowledge, especially among low-acculturated minority women or immigrants who seem less assimilated in the US culture [12, 23].

Behavioral Risk Factors

Modifiable factors associated with increased breast cancer risk and worse health outcomes include being overweight or obese, lack of physical activity, heavy alcohol consumption, long-term heavy smoking, and high fat intake [27]. Further

barriers to health care are low health-seeking behavior, low self-perceived risk [9], lower participation in screening programs [28], past negative experiences with medical system, and lack of confidence in primary care physician [29].

Protective factors associated with decreased breast cancer risk include breastfeeding for at least 1 year, regular moderate physical activity, a balanced diet consisting of reduced fat but high fruit and vegetable consumption, and maintaining a healthy body weight [30•].

Biological Risk Factors

Breast cancer is a heterogeneous disorder that consists of a number of subtypes with distinct risk factors, molecular characteristics, and responses to treatment [31]. Biological factors linked to increased breast cancer risk and reduced survival include a family history of breast or ovarian cancer, older age (≥ 50 years of age), inherited mutations in *BRCA1* and *BRCA2*, high breast tissue density, and type 2 diabetes mellitus [30•]. Indeed, several studies indicate that genetic differences account for a considerable percentage of the disparities between the races. Specifically, genetically related racial/ethnic differences are found in breast tissue density on mammography; breast cancer grade; and the expression of estrogen receptors (ER-), progesterone receptors (PR-), and human epidermal growth factor receptor 2 protein (HER2-) on cancerous cells [8•, 32]. Reproductive history is also known to affect the risk of breast cancer. This includes, for example, increased risks associated with early menarche and/or late menopause, the recent use of oral contraceptives, nulliparity, later age at the time of a woman's first live birth (≥ 30 years of age), high natural levels of sex hormones, and the current use of menopausal hormone therapy [30•].

Among US breast cancer patients, the likelihood of having breast cancer diagnosed at a later stage varies by race, which impacts the likelihood of long-term survival. As previously noted, African Americans and Hispanics in the USA tend to be diagnosed with breast cancer at a younger age (<age 50) but are also more likely to be diagnosed at an advanced stage, to generally have more aggressive forms of cancer and to have lower survival rates and an overall worse prognosis than Caucasians [8•, 14, 29, 33, 34]. Furthermore, in a large nationwide survey, African American, Hispanic, and Asian/Pacific Islander women had nearly twofold higher odds of being diagnosed with the form of breast cancer which is least responsive to treatment, *triple-negative breast cancer* (ER-; PR-; HER2-), than Caucasians. In the same study, they also were diagnosed more frequently at a younger age and with more aggressive forms of cancer, all portending a poorer prognosis [31]. Notably, being African American was identified as an independent predictor of greater cancer recurrence and increased likelihood of cancer-related death, regardless of age or SES, relative to being Asian or Caucasian [8•]. Accordingly,

racial/ethnic disparities in cancer mortality were found to be more pronounced among African Americans than in any other racial/ethnic group [8•, 9, 31].

Health Care System-Related Risk Factors

In addition to genetic variability between races, there are also differences in screening practices, as well as in how cancer is diagnosed and treated. That minority women are more likely to be diagnosed with advanced breast cancer suggests that there are delays in making the diagnosis. This delayed detection can be explained by significantly lower rates of breast cancer screening in minority and foreign-born women relative to Caucasians and US-born women [35]. Effective breast cancer screening can detect pre-cancerous lesions and early-stage cancers, the former significantly lowering the incidence of actual breast cancer, and the latter significantly reducing mortality rates [2•]. Breast cancer screening has additional advantages, which include educating women about breast cancer, including its genetics and risk factors and, by averting some cases of cancer altogether and catching other cancers earlier in their course, lowering health care costs [26]. The *National Comprehensive Cancer Network* (NCCN) guidelines [2•] recommend the following: that women between the ages of 25 and 40 who have an average risk of breast cancer undergo a breast examination and receive some sort of breast cancer awareness counseling every 1 to 3 years; women over age 40 should have a breast examination and screening mammogram every year. However, despite the proven effectiveness of breast cancer screening, the utilization rate among minority women remains low, with severe consequences [28]. Any delay in diagnosing breast cancer in minorities means that the disease may progress to a more advanced stage, necessitating more aggressive surgical interventions and other adjuvant therapy that may increase the risk of complications and adversely affect survival, all of which contributes to the poorer breast cancer outcomes generally observed in minorities [36]. The disparities in mammography rates are best explained by lower socioeconomic status, less cancer knowledge, limited access to health care resources, lower-level acculturation, and the lack of formal residency status, which is a requisite for health insurance and adequate access to health care services [25, 35]. Furthermore, for women in some cultures, breast cancer is an especially poignant source of anxiety, which can adversely impact a woman's willingness to undergo screening [37]. On the other hand, factors that might augment a woman's willingness to be screened include the detection of some breast abnormality, either by self-examination or by a physician, prompting by an insurance provider, and support from family members and/or friends [38]. Several studies have revealed increased risks of treatment delay among African American and Hispanic women relative to Caucasians, with

financial concerns the most common reason given for the delay [36, 38].

Long-Term Side Effects of Cancer Treatment

Regardless of race, breast cancer patients face many physiological and psychological challenges, which include coming to terms with their diagnosis, managing treatment regimens, and dealing with treatment-related side effects.

Mental Health

Cancer-related fatigue (CRF) is the most prevalent problem among breast cancer survivors [39]. It is defined as “a distressing, persistent, subjective sense of physical, emotional, and cognitive tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning and is not relieved by sleep or rest” [40]. Chronic CRF has a profound impact on the physical, emotional, and mental health of cancer survivors [41]; interferes with daily activities [42]; may have devastating social and economic consequences; and, ultimately, can adversely impact quality of life and hinder patients from fully participating in the roles and activities that make their life meaningful [43]. These adverse health outcomes persist many years beyond successful cancer treatment in a substantial number of cancer survivors [44, 45]. According to the literature, 30% of patients suffer from CRF even 10 years after the termination of cancer treatment [39]. Furthermore, pain, sleep problems, cognitive dysfunction, fear of cancer recurrence, body image concerns, and sexual concerns are commonly encountered cancer-treatment complications among breast cancer survivors [16, 46].

Women who belong to a racial/ethnic minority are often left without appropriate follow-up care after they complete their treatment, particularly secondary to inadequate financial resources and limited awareness of potential physical and mental health sequelae. Although the literature remains inconclusive regarding mental health outcomes in minority breast cancer survivors, a few studies have demonstrated more psychosocial distress post-diagnosis; higher rates of depression; and impaired health-related quality of life in African, Hispanic, and Asian Americans than among Caucasians in the USA [14, 19, 47, 48•]. Furthermore, regardless of race, low income predicts poorer mental health [49]. The differences in mental health outcomes between these racial/ethnic groups may be, in part, mediated by other factors, such as higher comorbidities and/or lower levels of physical activity [48•]. Furthermore, it has been hypothesized that adverse health outcomes are more pronounced in women with lower acculturation [50].

Psychosocial support from partners and family members also plays an important role in treatment-related adjustment and survival, with support from partners and family predictive of less depression and anxiety among breast cancer survivors [51, 52]. Interestingly, Caucasian women who are receiving psychosocial support tend to report higher levels of psychological distress and depression, while African American and Hispanic breast cancer survivors report better mental health. This difference might be explained by non-Caucasian women perceiving closer and more reciprocal relationships with their children, family, and community groups than Caucasian women [17].

A variety of mental health interventions have been studied, including exercise, weight training, dietary interventions, yoga and mindfulness-based treatments, support groups, and group therapy, as well as online interventions. Although most of these interventions have been proven to be effective at alleviating emotional distress and improving quality of life, few studies have focused specifically on minority women with breast cancer [28, 53–58]. Additional studies are needed to identify behavioral interventions for racial/ethnic minority breast cancer survivors from a culture and context-sensitive perspective.

Physical Health

Weight gain, including obesity, is a common complication after cancer treatment and is associated with the increased incidence of chronic conditions like cardiovascular disease, diabetes, and hypertension, as well as secondary cancers and primary cancer recurrence [59]. Up to 71% of cancer survivors are overweight or obese [29, 30•]. Although the NCCN guidelines highly encourage cancer survivors to maintain a healthy lifestyle—including weight management, healthy nutrition, and engaging in physical activity—it is difficult for most to achieve these healthy lifestyle goals [60]. As shown by multiple studies, physical activity has the potential to change cancer survivors' post-treatment symptoms [61, 62]. Furthermore, evidence suggests that regular physical activity and a healthy diet can help reduce treatment side effects including cancer-related fatigue (CRF) and enhance overall prognosis and survival [63, 64].

African American and Hispanic breast cancer survivors are more likely to be obese and less likely to be physically active 5 years or more after being diagnosed and to consume a reduced quantity of fruits and vegetables [27, 65]. Failure to adhere to cancer prevention guidelines may be associated with this lack of familiarity about the relationship between lifestyle behaviors and breast cancer recurrence [27]. Other patient-level social and behavioral factors that might explain poorer health outcomes in minorities include lower health literacy, personal preferences, a less extensive social network, poorer mental health, and less trust in the health care system, in turn leading to less health care-seeking behaviors [33].

Accordingly, evidence indicates that reduced mental health and functional status may inhibit health care-seeking behaviors among those with breast cancer [47, 48]. Moreover, evidence is accumulating that demonstrates how higher comorbidity burden among minority cancer survivors affects survival and health outcomes, with diabetes mellitus, hypertension, myocardial infarction, and other heart conditions more common among African American and Hispanic breast cancer survivors than in their Caucasian counterparts [66].

Sexual Health

After surgery and other breast cancer treatment, women with breast cancer must adapt to dramatic physical changes to their bodies, including hair loss, loss of skin elasticity, scars, and missing or asymmetrical breasts. They also must deal with sexual dysfunction, including vaginal dryness, painful coitus, and low libido, and perceive significant losses in their sexuality. Overall, roughly 75% of all breast cancer survivors report problems related to sexual function [67]. However, according to a recent study that explored sexual health among diverse survivors, minority women expressed significantly less sexual desire, greater difficulty enjoying sex, and more difficulty talking about sexuality and negotiating intimacy with their partners [46]. These results highlight the importance of health care providers being available and willing to discuss sexual concerns and strategies to improve sexual health in such women.

Biological Mechanisms of Adverse Health Outcomes

Minority women may be disproportionately exposed to adverse life events—including military combat, physical or sexual assault, a natural disaster, having to immigrate, or emotional or physical abuse or neglect during childhood [68]. Exposure to adverse life events is strongly linked with psychological symptoms and mental disorders [68, 69]. Potential biological pathways that might explain the link between increased stress and adverse mental health outcomes in minority breast cancer survivors include inflammation, disruption of the hypothalamic-pituitary-adrenal axis (involving the hormone cortisol), and vagal nerve activation [16]. Conversely, it is well documented that depression and sleep disorders, symptoms which frequently occur in fatigued breast cancer patients, are associated with greater risks of infection, prolonged infectious episodes, and delayed wound healing, all processes that indirectly promote pro-inflammatory cytokine production and resultant immune dysregulation [16].

Understanding the etiopathology of adverse health outcomes in minority breast cancer survivors is critical to identifying those individuals most at risk, reduce symptom burdens, and improve quality of life via targeted, individualized interventions. Today, little is known about the biological mechanisms that play specifically in minority breast cancer survivors.

Prospective, longitudinal studies are required to determine the role of neuroendocrine and immune alterations in the onset and persistence of adverse health outcomes in minority populations.

Strategies to Reduce Disparities

To effectively address health disparities between different subgroups of breast cancer survivors, some enhanced understanding of patients' socio-cultural context—including their beliefs and attitudes and barriers and facilitators to health care—is required. In particular, two steps that will be critical to reducing or eliminating racial/ethnic and ethnic disparities in breast cancer morbidity and mortality are as follows: first, enhancing prevention by improving adherence to recommended risk-reduction strategies and second, increasing early tumor detection via increased breast cancer screening [37]. Improved breast screening rates could be achieved through the mass media, tailored mailing, flyers, and the internet in multiple languages [7, 28]. A multidisciplinary approach that includes the support of health care providers, support groups, and social workers of the same racial/ethnic population might further augment both cancer screening and adherence to cancer prevention guidelines [70•].

Third, designing interventions to increase access to health care for racial/ethnic minorities, to promote cancer-related knowledge and improve adherence to cancer prevention recommendations (e.g., healthy behaviors), would also be pivotal to improving health outcomes. To eliminate racial/ethnic disparities in the use of such interventions, they must be culturally sensitive and target modifiable patient-specific barriers (physical activity, dietary behaviors, weight control) [6, 23, 25]. Fourth, clinical trials fuel the development of new and improved cancer therapies and are the major avenue for translating treatment-related discoveries into clinical practice. Unfortunately, racial/ethnic minority groups are usually under-represented in clinical research, for a variety of reasons that include relative inaccessibility and, within different ethnic groups, cultural biases and restrictions [71]. Therefore, future research should include improved minority representation and analyses by race, ethnicity, and sociodemographic characteristics [18]. Focusing future research on demographic subgroups of survivors will help to elucidate subgroup differences in health-related quality of life, thereby permitting investigators, clinicians, and health care policy makers to better understand specific needs. Potential strategies to enhance the enrollment of minorities in clinical trials include better equipping trial sites by expanding the language competencies of staff and outreach efforts, providing written study materials (e.g., information letters, consent forms, and supplement information) in simple common language that is understandable by patients with lower levels of health literacy, and creating versions of such materials in multiple languages [18, 19, 72].

Fifth, implementing after-care plans to enhance survivorship and treatment outcomes in specific racial/ethnic groups is imperative. Both health care provider and breast cancer support groups have important roles assisting minority breast cancer survivors during their transition from primary to after-care treatment and rehabilitation. Proactive discussions by health care providers prior, during, and after treatment, as well as referrals to relevant services as part of standard care, are essential to mitigate minority patient concerns and resistance and reduce the likelihood of persistent problems [20].

Sixth, developing community health programs to deliver health education would be helpful [18]. This could be realized by involving, empowering, and engaging breast cancer survivors from diverse racial and ethnic groups in program planning and the distribution of education materials and knowledge. In addition, health care workers from the same racial/ethnic background and those involved in community outreach and education could help minority women to gain access to cancer screening services, facilitate communication with health care providers, and help navigate patients through the health care system [73, 74].

Lastly, respecting diverse cultures and values, health service provisions must be culturally sensitive. In summary, paying attention to disparities between different breast cancer populations will be central to ensuring that all women diagnosed with breast cancer can make informed, preference-based decisions [70].

Conclusions

Breast cancer patients are heterogeneous in race, ethnicity, and cultural background. They also have different levels of socioeconomic status, behavioral profiles, and disease pathophysiology, all of which can impact health outcomes and survivorship care needs. As the US population becomes more racially and ethnically diverse, it will become increasingly important for the health care system to address racial and ethnic disparities in health care delivery and outcomes. Reducing the aforementioned disparities among breast cancer patients will require a multifaceted approach that recognizes the tremendous racial and ethnic diversity that exists within the USA. This must entail efforts to minimize barriers to health care services and increase cancer screening rates, as well as efforts to develop culturally and contextually sensitive interventions designed to reduce symptom burdens and improve quality of life.

Compliance with Ethical Standards

Conflicts of Interest Annina Seiler, Kyle W. Murdock, Luz M. Garcini, Diana A. Chirinos, Jeffrey Ramirez, Brielle Jackson, and Christopher P. Fagundes declare that they have no conflict of interest.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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