

Appendix 7. Role of Health Disparities in Early Onset Breast Cancer

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INTRODUCTION

This review investigates the role of racial/ethnic, geographic, and other health disparities in the diagnosis and management of early onset breast cancer (EOBC). An evidence-based review to advance the understanding of EOBC would be incomplete without exploring the detrimental impact of health disparities on racial and ethnic minorities, along with other populations. These groups carry a disproportionate burden of illness, experience barriers to care, and consistently have been shown to have lower survival rates than white women. This section will define health disparities in the context of EOBC and will discuss factors affecting these women.

For this review, the current body of health disparities literature for EOBC was assessed using metrics such as screening and mammography rates, incidence and age at diagnosis, adequate treatment, and all-cause or disease-specific mortality. Many of these articles call for change to address systemic barriers and highlight the paucity of breast cancer data for specific ethnic groups, such as African Americans, American Indians and Alaska Natives, Asians, Hispanics, Native Hawaiians and other Pacific Islanders, women with low socioeconomic status, and people in rural areas.

This review addresses the impact of health disparities on EOBC and which groups are most affected. The review further considers potential actions that can be taken:

- How can health disparities in EOBC be mitigated?
- Are there changes in clinical practice or screening recommendations, such as earlier start to mammography, that may be beneficial?
- Will future demographic shifts in the United States necessitate adjustments in screening guidelines?

METHODS

The American College of Obstetricians and Gynecologists (ACOG) Resource Center conducted a literature search to identify studies involving health disparities and women aged 18–45 years diagnosed with breast cancer, selecting articles published from 2010 to 2019. Major society or organizational guidelines, systematic reviews, meta-analyses, and randomized controlled trials were also considered. Articles about male breast cancer, pregnancy, case reports and series, and non-English-language articles were excluded.

Additional relevant older articles meeting the criteria were collected when encountered in the review process. Lastly, two articles were found with a Google search for the combination of terms “health disparities breast cancer race.”

Several additional articles were added after correspondence with Dr. Patricia Dawson, a breast surgeon and subject matter expert in health disparities at the University of Washington. Dr. Dawson shared a presentation on breast cancer disparities, and her references included several articles that were not found in the initial search but were directly relevant to the topic.

RESULTS

Literature Summary

The ACOG literature search retrieved 23 papers. Three of these articles were excluded after manuscript review for lack of relevancy to the primary questions. There were no national guidelines, per se, available on this particular subject. The national organization publications found to be most helpful in outlining the content of health disparities in breast cancer care were the following ACOG Committee Opinions:

- Racial and Ethnic Disparities in Obstetrics and Gynecology
- Health Disparities in Rural Women
- Importance of Social Determinants of Health and Cultural Awareness in the Delivery of Reproductive Health Care

From these committee opinions, an additional 20 articles were identified for the review process. Many of the manuscripts reviewed determined that among individuals diagnosed with breast cancer, African Americans and other minorities in the United States face lower survival and worse prognoses than do white Americans, despite white women having a higher overall incidence of the disease.

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The majority of the articles reviewed fit into several categories:

- Large epidemiologic studies used national or state cancer registries to query breast cancer incidence, stratified by age or race/ethnicity, all-cause mortality, and disease-specific mortality.
- Some of these epidemiologic studies evaluated particular regions of the United States, such as a study that investigated early breast cancer in Asian Americans born in California by matching cancer registries to California birth certificate data.¹ Other studies in Southern states delved into socioeconomic status, using published census tract and county poverty levels, and mapped distances from hospitals and breast cancer care specialists to outcomes (Georgia,² South Carolina³).
- Several smaller studies used survey work or focus groups to assess community outreach efforts, elicit patient opinions on mammography access and acceptability, and so on.^{4,5}

Lastly, *Health Disparities: A Rural-Urban Chartbook*, from the Rural and Minority Health Research Center, and the National Institutes of Health (NIH) *Health Disparities Strategic Plan and Budget* served as foundational resources for accepted definitions of health disparities.^{6,7} These two documents also helped establish a framework for evaluation, with consideration given to disparities at the patient, provider, and health system levels.

The “Cross-Over Effect”

In general, EOBC poses a challenge. These tumors tend to have more aggressive biology and are found at more advanced stages, as young women are not routinely screened with imaging or breast

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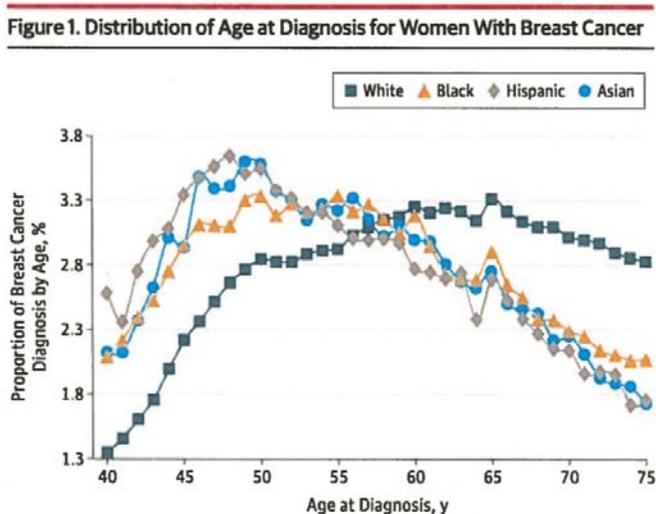
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evaluation, nor do they always present when symptomatic. The difficulties of identifying and treating early cancers are compounded by racial disparities. Breast cancer incidence is higher in young African American women and other ethnic groups, compared with young white women. In contrast, in the postmenopausal population, breast cancer incidences are highest in white women. This phenomenon is often called the “cross-over effect.”

In a review of the National Cancer Institute’s Surveillance, Epidemiology, and End Results (SEER) database, Liu et al reported that black women have the highest age-adjusted breast cancer incidence rate in women aged 18–39 years of all groups and found lower incidence in Hispanic and Asian groups in this age range.⁸ In a similar approach with SEER data, Stapleton et al reported that the proportion of breast cancer diagnosis by age of nonwhite patients with breast cancer peaks in the late 40s, while diagnosis of white patients peaks when they are in their 60s (see Figure 1).⁹

Figure 1. The Cross-Over Effect: Age at Diagnosis for Women With Breast Cancer, by Race*



* The proportion of breast cancer diagnoses by age for nonwhite patients with breast cancer peaks in the late 40s, while diagnosis of white patients peaks in their 60s.

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Race/ethnicity and age distribution of breast cancer diagnosis in the United States. *JAMA Surg*

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Health Disparities in Early Breast Cancer

As described above, racial/ethnic minorities and other populations carry a disproportionate burden of early breast cancer. They also experience barriers to care and, by some estimates, have not enjoyed the same gains in breast cancer survival observed in white women over time. According to the NIH, a

“health disparity population” is one in which there is a significant disparity in the overall rate of disease

incidence, prevalence, morbidity, or mortality in the specified population, as compared with the general Chelmos D, Pearlman MD, Young A, Bozzuto L, Dayaratna S, Jeudy M, et al. Executive summary of the Early-Onset Breast Cancer Evidence Review Conference. *Obstet Gynecol* 2020;135.

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population. African American, American Indians and Alaska Natives, Asians, Hispanics, Native Hawaiians and other Pacific Islanders, individuals with low socioeconomic status, and rural persons are currently designated as health disparity populations.

Patient Level Factors

BIOLOGIC

There are some clearly documented biologic factors contributing to health disparities, such as the increased incidence of more aggressive tumor types in African American women. Black women were more likely to have early onset aggressive basal-like tumors (a distinct molecular subtype) or triple negative breast cancers (for receptors for estrogen, progesterone, and human epidermal growth factor 2).

African American women also have a higher age-specific breast cancer incidence than white women between the ages of 35 and 40 and are more likely to undergo an early screening or diagnostic mammography before age 40, perhaps due to more common incidence of fibroadenoma.¹⁰ The inability to use targeted therapies such as tamoxifen for these women partially contributes to the mortality gap for African American women.¹¹ When studies control for both stage and tumor biology, black women still have a lower survival rate than white women.^{12,13} Furthermore, a small, registry-based study of young black women younger than age 50 diagnosed with breast cancer had an estimated 12% incidence of BRCA-positive test results, twice the rate than previously thought, in comparison with an estimated 6% rate of BRCA-positive test results in white women younger than 40 with breast cancer.¹⁴

SOCIAL

There is increasing recognition that social determinants of health, such as racism and discrimination, poverty and low socioeconomic status, and the environment can greatly impact the health of disadvantaged or underserved populations.⁷ Additional upstream forces that affect health include limited education and literacy, childcare concerns, financial difficulties, legal status, and trauma and exposure to violence.

Perceived racial discrimination in health care, mistrust of the health system, and cultural factors such as fatalism (eg, the perception that “everyone in my family gets cancer”) may decrease the likelihood of receiving preventive health services such as mammography or accessing genetic screening after breast cancer diagnosis.^{15,16}

GEOGRAPHIC AND SOCIOECONOMIC

The impact of geography, socioeconomic status, and environment have closely intertwined effects on accessing breast cancer care. Rural women are more likely to live in poor counties and encounter additional barriers to accessing regular primary care, hospitals, and specialists. For 2008, mammography screening rates were lower for women in high-poverty areas, with 72% of non-poor women undergoing mammography vs 51.4% of poor women.¹⁷ In general, poverty status correlates with more advanced disease stage at diagnosis, less aggressive treatment, and higher risk of all-cause mortality.²

Rural Hispanic women are less likely to have a regular primary care physician, and immigrant women are less likely to access mammography care. Not having a regular primary physician (odds ratio: 0.41, Chelmos D, Pearlman MD, Young A, Bozzuto L, Dayaratna S, Jeudy M, et al. Executive summary of the Early-Onset Breast Cancer Evidence Review Conference. *Obstet Gynecol* 2020;135. The authors provided this information as a supplement to their article. ©2020 American College of Obstetricians and Gynecologists.

confidence interval [CI]: 0.32–0.53) and not having physician-recommended mammography (odds ratio: 0.16, CI: 0.08–0.33) are most predictive of not having mammography.¹⁸

Perhaps because of transportation concerns, rural women are more likely to choose therapies that require fewer visits to providers. More rural women receive surgery than neoadjuvant treatments such as chemotherapy and radiation.

Physical proximity to urban academic centers is not a panacea, as evidenced by the outcomes of urban racial/ethnic minorities. Of black women with breast cancer in Georgia, those living in urban areas were 24% more likely to die than whites (adjusted hazard ratio [aHR]: 1.24, 95% CI: 1.16–1.33). The impact of a rural location simply makes the effect more pronounced, as black women living in isolated rural areas were 45% more likely to die than whites (aHR: 1.45, 95% CI: 1.25–1.69).²

Limitations of Available Evidence

Further efforts are needed to study breast cancer in racial and ethnic minorities, as the current paucity of data for some groups makes it difficult to draw conclusions. For example, large epidemiologic studies have shown mortality for breast cancer declining for nearly all groups in the United States from 1998 to 2007, with the greatest mortality decrease in white women. Alarming, there has been no documented decrease in mortality for American Indian women at all, although DeSantis et al commented that the available mortality data are severely limited to small geographic areas for Native women and must be interpreted with caution.¹⁹

Other studies have sought to reinforce the available body of evidence about breast cancer risk in minority groups, such as a study by John et al conducted in the Four Corners region to contribute to “the sparse and inconsistent epidemiologic data” on premenopausal breast cancer risk in Hispanics.²⁰

Health Care System Level Factors

Among developed countries, the United States stands alone in not recognizing universal health care as a right of citizenship. Although the Affordable Care Act has decreased the number of uninsured Americans from 44 million to just under 27 million, women of lower socioeconomic status continue to be adversely affected by lack of coverage in states without expanded Medicaid.²¹ The approximately 11.4 million undocumented immigrants living within the United States are also ineligible for most public benefits. Cost and lack of coverage limit access to primary care and constitute a factor in patient decision making regarding mammography. One study estimates that up to 37% of the mortality difference in black versus white breast cancer among individuals under the age of 65 can be attributed to disparities in health insurance.²² From 2004 to 2013, an estimated 22.7% of black women were uninsured or had Medicaid insurance, compared to 8.4% of nonelderly white patients.

Regional variations and the concentration of cancer specialists in urban areas also impact the quality of cancer care available. When investigating one marker of breast cancer care quality—the timely receipt of breast-conserving surgery and radiation therapy within 1 year of diagnosis—Samson et al found that South Carolina hospitals overall (71.1%) fell short of the nationwide rates seen in accredited programs (92.3%).³ This quality marker was even lower for African American women in the state, with 64.6% receiving such treatment.

It is noteworthy that in developed countries with guaranteed public coverage, similar disparities in breast cancer care persist. In New Zealand, a large epidemiologic study demonstrated that patients receiving public option care had increased risk of mortality from breast cancer compared with individuals with private insurance (hazard ratio 1.95, CI: 1.75–2.17).²³ Overall, Maori and other ethnic minority women living in rural areas had poorer outcomes compared with white women living in the Christchurch metro area. A portion of this survival disparity was explained by differences related to ethnicity, stage at diagnosis, and type of local or regional therapy or inadequate treatment. After controlling for these factors, Tin Tin et al estimated that the risk of mortality was still 14% higher in the public sector patients.²³ Unfortunately, even universal coverage with a public option does not guarantee health equity for all women with breast cancer.

Some studies have attempted to qualitatively describe health system complexities and suggest ways to counteract them. Participants in focus groups of young American Indian women discussing barriers to mammography described the high cost and complex referral systems within the Indian Health Service, difficulties with transportation and remote locations on reservations, and embarrassment or fear of mammography.⁴ Social factors contributing to disparities in the African American community include similar generalized fears about the health care system and fear of surgery or repercussions from cancer diagnosis and treatment.

- Karcher et al suggest using tools of community organizing to provide affected communities with targeted education about health disparities and to overcome cultural perceptions.²⁴
- A unique project by Wilson et al used hair stylists as lay health advisors to promote breast cancer screening practices in the community.²⁵

- Miranda et al advocate for further studies into the efficacy of neighborhood activism and community-driven policy efforts addressing breast cancer screening and education in high-risk communities.⁵

Practitioner Level Factors

Initial focus on provider factors in health disparities emphasized patient–provider communication, patient satisfaction, adherence to care plans, and culturally competent care.²⁶ More recently, attention is being brought to bear on the deleterious population effects of bias and discrimination by health care providers. Instead of emphasizing the perhaps misleading goal of cultural competency, providers are expected to examine personal bias and actively work to identify and mediate the social determinants of health that affect patients.

Although difficult to untangle, potential examples of provider bias and discrimination in breast cancer treatment exist. Several studies address how providers themselves contribute to disparate rates for breast cancer treatments and interventions for nonwhite patients:

- African American women are less likely to undergo genetic testing for BRCA and related mutations than are white women in instances when genetic testing is indicated by national guidelines.²⁷
- In a study by Cragun et al in Florida, 49% of African American women who met national criteria for genetic testing were not referred to genetic counseling and received no genetic services, and this finding correlated with socioeconomic status, as women with a college education or annual income of more than \$35,000/year were more likely to have a genetic counseling referral.²⁸

- Patients of lower socioeconomic status and educational attainment are less likely to be offered genetic screening and other services. The lower rates of genetic screening in African American women mean that mutation carriers may go undetected and do not benefit from advances in risk reduction strategies.²⁷
- Women younger than 40 with breast and other cancer diagnoses are less likely to be offered fertility preservation if they do not have a college degree.²⁹
- Black women are less likely to receive sentinel lymph node biopsy and are less likely to receive any type of lymph node surgery for axillary staging overall.³⁰

McCarthy et al attempted to investigate disparities on a provider-specific level, finding that, in general, health care by providers for black and white patients is highly segregated.³¹ Even among providers who primarily care for black patients, the researchers found that both oncologists and surgeons were less likely to recommend BRCA 1 or BRCA 2 testing to black women than to white women, after adjusting for the predicted risk of a mutation. Possible etiologies suggested by McCarthy et al include provider misperceptions about their black patients' insurance coverage, misperceptions about patient interest in testing, or misperceptions about the rate of mutations in black women.³¹

Indeed, some differences in screening may be a result of racially based provider misconceptions, such as providers who may think that black women are less likely to test positive for hereditary mutations than are white women. Some studies suggest that women of African ancestry at risk for breast or ovarian cancer are more likely to carry a BRCA mutation than at-risk women of non-Ashkenazi Jewish European ancestry (15.6% versus 12%).³²

DISCUSSION

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Strengths and Weaknesses of the Review

The epidemiologic evidence supporting the presence of health disparities impacting EOBC care were consistent and supported across multiple studies. Objective measures of health disparities included differences in mammography screening, age at breast cancer diagnosis, appropriate treatment, and survival for black women, rural women, and other racial/ethnic minorities compared with white women.

Gaps in Information Pertinent to Making Recommendations

- Particular disadvantaged demographic groups often have the smallest body of research available. For example, there are concerns about the available breadth of breast cancer survival data for American Indian women. Additional awareness of these limitations and calls for more research in these populations will continue to improve the current body of evidence.
- Other groups, such as sexual and gender minority persons (aka lesbian, gay, bisexual, transgender, and queer/questioning individuals), undocumented immigrants, and incarcerated women do not currently carry a “health disparity population” designation from the NIH, but they doubtless experience discrimination within health systems. For transgender populations, there is a small but growing amount of literature regarding incidence, diagnosis, and treatment.³³
- More studies are needed investigating how racial bias in health systems and among providers can lead to disparate rates of services being offered to patients. It is challenging to disentangle this issue from other factors, such as public insurance.

- No identified studies demonstrated an evidence-based method to address health disparities; current suggestions are mainly drawn from expert opinion and focus groups.

Potential Actions

How Can Adverse Outcomes Be Mitigated in At-Risk Groups?

- Focus on modifiable health system factors and primary care interventions in disparity populations would be beneficial for expanding screening for EOBC. Possible actions include expanding health insurance coverage, addressing transportation to appointments, and improving access to a regular primary care provider.
- General practitioners who provide counseling and recommendations on health preventive services can impact the rates of mammography completion for underscreened groups such as recent immigrants.³⁰
- Only half of African American women eligible for breast cancer chemotherapy receive it. To impact mortality, some emphasis should be placed on improving treatment after diagnosis.³⁴
- Patient navigators, translator services, and patient tracking systems across different health systems and electronic medical records can reduce the impact of limited health literacy, self-advocacy, and mistrust or discomfort with the health care system.³⁵
- Efforts to promote quality improvement, provider training, and adherence to national guidelines have been helpful in fields such as urology and may be relevant to breast cancer treatment providers as well.³⁵

- National quality metrics could be considered to compare the timeliness or completeness of breast cancer care in patients who belong to disparity groups with higher mortality.

In Groups With Health Disparities, Should Different Breast Cancer Screening Recommendations Be Considered?

- No national guidelines or evidence exist to address this question for breast cancer.
- Because the proportion of breast cancer diagnoses by age of nonwhite patients with breast cancer peaks in the late 40s, while diagnosis of white patients peaks in their 60s,⁹ providers should consider encouraging earlier mammography screening in racial and ethnic minorities in the United States. There is national precedence for recommending disparate screening guidelines for at-risk groups, and areas other than breast cancer offer some remarkable parallels. African Americans have higher incidence of colorectal cancer and the highest mortality among all groups. As early as 2005, national guidelines recommended an individualized strategy to screen African American groups 5 years earlier than low-risk patients, to mitigate the burden of increased mortality from health disparities. The colorectal cancer literature has shown earlier screening to be effective, with some studies suggesting there is an increase in life-years when blacks are screened 6 years earlier than whites. Potential drawbacks of individualized screening programs may include further confusion over correct age to commence screening for patients and providers, as well as further stigmatization of marginalized groups. Currently, the American College of Gastroenterology and the American Society of Gastrointestinal Endoscopists recommend colorectal screening in African Americans beginning at age 45.³⁶

How Might Screening Needs Change With Projected Demographic Shifts in the U.S. Population?

- The preponderance of breast cancer research to date has been conducted on white women. For example, the landmark Digital Mammographic Imaging Screening Trial included 42,760 women, of whom 84% were white, 3% were Latina, 9.9% were Black, and 0.1% were American Indian or American Native. In 2050, the demographic makeup of this country is predicted to be 49.7% white, 24.6% Hispanic, 13.1% black, 8% Asian, and 3.8% multiracial.³⁷
- National screening guidelines developed from predominately white patient data may adversely affect nonwhite populations both now and with future demographic shifts.

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