



Disparities in Breast Cancer: Through the Breast Cancer-Care Continuum

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We know that underserved communities experience extreme health disparities in many diseases and breast cancer is no exception. The rate of most diseases is higher among poorer communities that are predominantly comprised of people of color; however, the reverse is true for breast cancer. There are actually higher rates of breast cancer in higher income communities. However, the greater disparity lies in breast cancer after diagnosis. African American women have a 40% higher chance of dying from breast cancer than white women. These disparities are rooted in a complex interplay of economics, power, racism and discrimination that lead to a variety of social injustices, including major inequities in healthcare.

This factsheet describes the landscape of breast cancer disparities from diagnosis through treatment, survival and mortality to understand how inequities, social injustices – political, economic, and racial inequalities – lead to disparities in breast cancer incidence and outcomes.

Breast Cancer Action (BCAction) recognizes that a number of diverse communities, including young, old, gay, transgender, disabled, immigrants, and under-educated, are disproportionately and uniquely impacted by breast cancer. However, the lack of available data on inequities in these diverse communities limits the focus of factsheet primarily to race and class.

Incidence

Breast cancer incidence rates show white women with the highest rate, followed by African American women. Asian American/Pacific Islander, Hispanic, and Native-American women show a lower risk of developing breast cancer.ⁱ Unfortunately, for some of these communities, the true disparities in incidence rates are masked by aggregating smaller groups into larger categories and ignoring regional variations.

For example, the large racial category of Asian and Pacific Islander encompasses many smaller ethnic groups that are highly diverse in terms of socioeconomic status, educational attainment and other social determinants of health. These large categories obscure important ethnic differences. For example, trends show that breast cancer incidence is on the rise for Asian American communities; yet this data does not reflect accurately the increase in incidence rates occurring among Japanese women.ⁱⁱ For example, while Laotian women have a low rate of breast cancer incidence (35.9/100,000) compared to white women, Japanese and Hawaiian women have a very high rate at 126.5 and 175.8 per 100,000 respectively.ⁱⁱⁱ

* Data is not available

Incidence & Mortality Rates of Breast Cancer by Race/Ethnicity		
Race/Ethnicity	Incidence Rate per 100,000	Mortality Rates of Breast Cancer
White ^{iv}	123.3	22.4
African American	118	31.6
Hispanic/Latina	93	14.9
Asian American	85.9	11.9
• Hawaiian ^v	175.8	33.5
• Japanese	126.5	15.1
• Filipina	100.4	17.2
• Samoan	102.5	36.2
• Tongan	118	*
• Laotian	36.9	*
• Kampuchean	38.2	*
American Indian/Alaska Native	89.1	16.6
• Alaska Native ^{vi}	139.5	*
• Native American ^{vii} (Southwest region)	50.4	*

When positive gains in breast cancer treatment are announced and celebrated, these gains are not shared across all communities. For example, rates of non-invasive breast cancer for Latina women are decreasing at a slower rate compared to white women.^{viii} Latina women also present with more advanced breast cancer at earlier ages and are 20% more likely to die of breast cancer than white women.^{ix}

Failure to identify where women live is an additional way in which important information on incidence and mortality rates can be masked. For example, American Indian/Alaska Native women (AI/AN), who

generally have lower overall rates of breast cancer (although they are more frequently diagnosed with late stage breast cancer) suggest geographical differences in breast cancer rates. Alaska Native women have rates as high as 139.5/100,000 (similar to non-Hispanic white women),^{x,xi} while AI/AN women who live in the Southwest have incidence rates as low as 50.4/100,000^{xii} (*see table*).

These examples illuminate the ways in which national data on breast cancer presented through large racial categories can mask the true disparities of this disease in smaller ethnic communities.

Screening & Diagnosis

After decades of focus on awareness and screening to promote early detection, we now see that screening rates are similar among women of different races/ethnicities (regardless of age), with 67% of white women, 66% of African American women and 69% of American Indian/Native American women having undergone a mammogram in the past two years.^{xiii} However, statistics show women of color being diagnosed at an earlier age than white women and with more aggressive breast cancers than their white counterparts, suggesting that early detection is not impacting late stage breast cancer diagnoses.^{xiv} A continued focus on screening access to remedy inequities in breast cancer is insufficient to reduce disparities.

There are no evidence-based screening recommendations for women of color. Current evidence to date evaluating the impact of mammography on breast cancer mortality is based on 40 years of randomized clinical trials.^{xv} Very few women of color were included in these clinical trials. As a result, conclusions from the research that has been conducted to date around screening and breast cancer have not been shown to be applicable to women of color.

Treatment

While creating healthcare access for all increases *who* gets care, the simple expansion of services without a focus on differences in the quality and delivery of these services *does not* eliminate health inequities.

Treatment is one area where disparities are very clear. Institutionalized barriers prevent many women from fully utilizing healthcare and can result in subpar care. Subpar care includes inadequate or insufficient treatment (under-treatment), excessive treatment

(over-treatment) or the wrong/incorrect treatment (mis-treatment).

We see that even when access to healthcare is equal, African American women receive chemotherapy, hormonal therapy and radiation with breast conserving surgery at different rates than white women.^{xvi} Certain Asian American communities, such as Chinese women, are also less likely to receive adjuvant radiation after breast-conserving surgery^{xvii,xviii} and breast-conserving treatment instead of mastectomy.^{xix,xx,xxi,xxii,xxiii}

Fewer women of color start treatment in a timely manner (within 60 days of diagnosis) compared to white women.^{xxiv,xxv}

Similar delays in time between diagnoses and cancer treatment are also evident among American Indian and Alaska Native women and the delays are at least two times greater than among White women.^{xxvi}

Furthermore, many women of color do not participate in clinical trials and are not offered information on support services that might meet their needs.^{xxvii,xxviii} Reasons for lack of participation in clinical trials stems from both the individual and the researchers. On the one hand, a long history of medical mistreatment in communities of color has developed into a culture of mistrust and suspicion; and on the other hand research investigators set research parameters that often determine how accessible a trial is to a specific community of participants as well as which patients are deemed "good subjects" for trials.^{xxix}

These treatment inequalities, particularly in the first few years after diagnosis, play a role in worse outcomes and increased mortality. Adequate and appropriate care play an enormous role in health outcomes, but the ability to effectively utilize available healthcare depends on numerous factors including, but not limited to, cultural appropriateness of care, trust, additional medical issues and other life circumstances.

Mortality

We know that breast cancer is not one single disease but rather a collection of diseases with distinct features. Furthermore, we know that not all breast cancers are created equal. Unfortunately, if you are diagnosed with an aggressive breast cancer, you are more likely to die regardless of who you are. Although women from all communities are diagnosed with different breast cancer subsets, women of color

have a higher rate of more aggressive breast cancers (i.e. triple negative) and harder to treat breast cancers and are diagnosed at younger ages. There is a large gap in the research explaining why this is and how to address it.

As with incidence rates, the overall mortality rate for breast cancer has slowly declined since 1990, but rates of decline have not been equal for all populations.^{xxx} In some communities, death rates continue to rise. In California, for example, the breast cancer death rate for Asian American/Pacific Islander women is going up.^{xxxii} However, when we look more closely at this large group, we see that breast cancer mortality rates are also increasing among Native Hawaiian women.^{xxxii, xxxiii}

We see a similar pattern in survival rates. While white women have a 5-year survival rate^{xxxiv} of 91%, American Indian/Alaska Native women have the lowest survival rate of 63%. Furthermore, Samoan women have the worst survival rates for breast cancer and they tend to be diagnosed younger with a more advanced stage of breast cancer.^{xxxv, xxxvi} This data tells us that although incidence, mortality and survival rates vary among different communities, all communities of color present with more advanced or aggressive breast cancer at younger ages with much lower survival rates.^{xxxvii} As these rates continue to decline or increase at different speeds, the survival gap between white women and communities of color continues to widen.

Even when research controls for age, stage of breast cancer, socio-economic status (SES) and treatment, African American women continue to have worse outcomes.

When these isolated pieces of information around risk, diagnosis, treatment and survival are connected, we see a picture of disadvantage for women of color at nearly every stage of the breast cancer continuum.

Living with Breast Cancer

After going through the emotional and physical toll of a breast cancer diagnosis, treatment and the numerous side effects that accompany treatment, there are a host of physical and psychosocial experiences that women continue to live with. These experiences can profoundly impact quality of life. They include anxiety and depression, reproductive health problems, early menopause, weight gain and sexuality.^{xxxviii, xxxix, xl} They can also have repercussions on a woman's employment status, long term health, relationships, financial situation and more.

For communities of color, there may be a more profound impact. Some studies note higher rates of reproductive health problems.^{xli} There may also be higher rates of anxiety and depression, although sample sizes to date have not been representative.^{xlii}

We must bridge the large gap in knowledge surrounding how to meet the specific needs of women of color living with and dying from breast cancer.

Conclusion

From existing research and knowledge, we clearly see strong evidence that major disparities in breast cancer exist. Women of color have differences in disease presentation – with more aggressive breast cancers developing at earlier ages – and lower survival rates compared to white women.^{xliii}

These disparities are an indicator of larger social inequalities. We need a systemic approach that addresses the underlying inequities if we are to attempt to address breast cancer disparities.

Inequities in breast cancer – political, economic and racial inequalities – are the invisible, underlying forces that drive the disparities we see in this breast cancer epidemic. These disparities are increasingly apparent at every step of the way along the breast cancer-care continuum: from diagnosis and treatment through end of life and living with breast cancer whatever the outcome

Breast Cancer Action's mission is to achieve health justice for all women at risk of and living with breast cancer. We believe that breast cancer is a public health crisis and a social justice issue and we envision a world where lives and communities aren't threatened by breast cancer. For more information go to www.bcaction.org.

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