

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

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	*

* Data is not available

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.^{xxxi} 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.

References:

- ⁱ Breast Cancer.org Accessed Oct 7th, 2013 at http://www.breastcancer.org/symptoms/understand_bc/statistics
- ⁱⁱ Gomez, SL, Clarke, CA, Shema, SJ, Chang, ET, Keegan, THM, and Glaser, SL. Disparities in Breast Cancer Survival Among Asian Women by Ethnicity and Immigrant Status: A Population-Based Study. *Am J Public Health*. 2010 May; 100(5): 861–869.
- ⁱⁱⁱ Miller BA, Chu KC, Hankey BF, Ries LA. *Cancer incidence and mortality patterns among specific Asian and Pacific Islander populations in the U.S.* *Cancer Causes Control*. 19:227-256, 2007.
- ^{iv} Breast Cancer Facts and Figures, 2013-2014. American Cancer Society.
- ^v Miller BA, Chu KC, Hankey BF, Ries LA. *Cancer incidence and mortality patterns among specific Asian and Pacific Islander populations in the U.S.* *Cancer Causes Control*. 19:227-256, 2007.
- ^{vi} Wingo PA, King J, Swan J, et al. Breast cancer incidence among American Indian and Alaska Native women: US, 1999-2004. *Cancer*. 113(5 Suppl):1191-202, 2008.
- ^{vii} Wingo PA, King J, Swan J, et al. Breast cancer incidence among American Indian and Alaska Native women: US, 1999-2004. *Cancer*. 113(5 Suppl):1191-202, 2008.
- ^{viii} Cancer Facts & Figures for Hispanics/Latinos, 2012-2014. American Cancer Society
- ^{ix} Cancer Facts & Figures for Hispanics/Latinos, 2012-2014. American Cancer Society
- ^x Espey, D.K., Wu, X.C., Swan, J., et al. Annual report to the nation on the status of cancer, 1975-2004, featuring cancer in American Indians and Alaska Natives. *Cancer*. 2007;110: 2119-2152.
- ^{xi} Wingo, P. A., King, J., Swan, J., Coughlin, S. S., Kaur, J. S., Erb-Alvarez, J. A., Jackson-Thompson, J. and Arambula Solomon, T. G. (2008), Breast cancer incidence among American Indian and Alaska Native women: US, 1999–2004. *Cancer*, 113: 1191–1202. doi: 10.1002/cncr.23725
- ^{xii} Wingo, P.A., King, J., Swan, J., et al. Breast cancer incidence among American Indian and Alaska Native women: US, 1999-2004. *Cancer*. 113(5 Suppl):1191-202, 2008.
- ^{xiii} Breast Cancer Facts and Figures, 2013-2014. American Cancer Society.
- ^{xiv} Bleyer A, Welch HG. *Effect of three decades of screening mammography on breast cancer incidence*. *N. Engl. J. Med.* 367, 1998–2005 (2012).
- ^{xv} 1) *The New York trial or HIP trial* (1963) - enrolled 60,495 women ages 40-64, 2) *The Malmö trial* (1976) - enrolled 42,283 women ages 45-69, 3) *The Two-County trial* (1977) - enrolled 133,065 women over age 40, 4) *The Edinburgh trial* (1978) - enrolled 44,268 women ages 45-64, 5) *The Canadian trial* (parts 1 and 2; 1980) - enrolled 89,835 women ages 40-59, 6) *The Stockholm trial* (1981) - enrolled 60,117 women ages 40-64, 7) *The Göteborg trial* (1982) - enrolled 49,924 women ages 39-59, 8) *The Age trial* (2006) – enrolled 160,921 women ages 39 – 41.
- ^{xvi} Freedman, R. A., He, Y., Winer, E. P. and Keating, N. L. (2013). *Racial/Ethnic Differences in Receipt of Timely Adjuvant Therapy for Older Women with Breast Cancer: Are Delays Influenced by the Hospitals Where Patients Obtain Surgical Care?*. Health Services Research.
- ^{xvii} Li CI, Malone KE, Daling JR. Differences in breast cancer stage, treatment, and survival by race and ethnicity. *Arch Intern Med*. 2003 Jan 13; 163(1):49-56.
- ^{xviii} Prehn AW, Topol B, Stewart S, Glaser SL, O'Connor L, West DW. Differences in treatment patterns for localized breast carcinoma among Asian/Pacific islander women. *Cancer*. 2002 Dec 1; 95(11):2268-75.
- ^{xix} Gomez SL, France AM, Lee MM. Socioeconomic status, immigration/acclulturation, and ethnic variations in breast conserving surgery, San Francisco Bay area. *Ethn Dis* 2004;14(1):134–140.
- ^{xx} Prehn AW, Topol B, Stewart S, Glaser SL, O'Connor L, West DW. Differences in treatment patterns for localized breast carcinoma among Asian/Pacific islander women. *Cancer* 2002;95(11):2268–2275.
- ^{xxi} Lin SS, Phan JC, Lin AY. Breast cancer characteristics of Vietnamese women in the Greater San Francisco Bay Area. *West J Med* 2002;176(2):87–90.
- ^{xxii} Morris CR, Cohen R, Schlag R, Wright WE. Increasing trends in the use of breast-conserving surgery in California. *Am J Public Health* 2000;90(2):281–284.
- ^{xxiii} Goel MS, Burns RB, Phillips RS, Davis RB, Ngo-Metzger Q, McCarthy EP. Trends in breast conserving surgery among Asian Americans and Pacific Islanders, 1992–2000. *J Gen Intern Med* 2005;20(7):604–611.
- ^{xxiv} Fiscella, K., Humiston, S., Hendren, S., Winters, P., Jean-Pierre, P. and Idris, A. Eliminating Disparities in Cancer Screening and Follow-up of Abnormal Results: What Will It Take? *Journal of Healthcare for the Poor and Underserved*. Vol. 22, Num.1, February 2011. pp. 83-100
- ^{xxv} Freedman, R. A., He, Y., Winer, E. P. and Keating, N. L. (2013). *Racial/Ethnic Differences in Receipt of Timely Adjuvant Therapy for Older Women with Breast Cancer: Are Delays Influenced by the Hospitals Where Patients Obtain Surgical Care?*. Health Services Research.
- ^{xxvi} Wilson, R.T. Adams-Cameron, M. Burhansstipanov, L. Roubidoux, M.A.Cobb, N. Lynch, C.F. and Edwards, B.K. Disparities in Breast Cancer Treatment among American Indian, Hispanic and Non-Hispanic White Women Enrolled

in Medicare. *Journal of Health Care for the Poor and Underserved*, Volume 18, Number 3, August 2007, pp. 648-664.

xxvii Janz, N. K., Mujahid, M. S., Hawley, S. T., Griggs, J. J., Hamilton, A. S. and Katz, S. J. (2008), Racial/ethnic differences in adequacy of information and support for women with breast cancer. *Cancer*, 113: 1058–1067

xxviii von Friederichs-Fitzwater, M.M. and Tammie Denyse, T. *The Unmet Needs of African American Women with Breast Cancer*. *Advances in Breast Cancer Research*, 2012, 1, 1-6.

xxix Joseph, G. and Dohan, D. (Feb 2009). Diversity Of Participants In Clinical Trials In An Academic Medical Center. *Cancer*, 115: 608–615.

xxx Breast Cancer Facts and Figures, 2013-2014. American Cancer Society.

xxxi Morris CR, Epstein J, Nassere K, Hofer BM, Rico J, Bates JH, Snipes KP. Trends in Cancer Incidence, Mortality, Risk Factors, and Health Behaviors in California. Sacramento, CA: California Department of Public Health, Cancer Surveillance Section, January 2010.

xxxii Native Hawaiian Cancer Fact Sheet, Honolulu: 'Imi Hale Native Hawaiian Cancer Network, Fall 2004. Accessed at http://www.hawaii.edu/hivandaids/Native_Hawaiian_Cancer_Fact_Sheet.pdf

xxxiii Miller, B.A., Chu, K.C., Hankey, B.F., Ries, L.A.G. Cancer incidence and mortality patterns among specific Asian and Pacific Islander populations in the U.S. *Cancer Causes Control* 2008 Apr;19(3):227-56.

xxxiv BCAction does not see 5 year survival rates as a significant marker for breast cancer survival because breast cancer can and does recur at any time, regardless of how many years have passed since an initial diagnosis. The use of five-year survival in place of cure denies the reality of women living with the disease and downplays the urgency of finding true cures for breast cancer.

xxxv Goggins, W. B., and G. K. Wong. 2007. Poor survival for US Pacific Islander cancer patients: Evidence from the Surveillance, Epidemiology, and End Results Database: 1991 to 2004. *Journal of Clinical Oncology* 25(36):5738-5741.

xxxvi Miller, B.A., Chu, K.C., Hankey, B.F., Ries, L.A.G. Cancer incidence and mortality patterns among specific Asian and Pacific Islander populations in the U.S. *Cancer Causes Control* 2008 Apr;19(3):227-56.

xxxvii Ooi, S.L., Martinez, M.E., Li, C.I. *Disparities in breast cancer characteristics and outcomes by race/ethnicity*. *Breast Cancer Res Treat*. 2011 Jun; 127(3):729-38.2010.

xxxviii Sheppard VB, Harper FW, Davis K, Hirpa F, Makambi K. *The importance of contextual factors and age in association with anxiety and depression in Black breast cancer patients*. *Psycho-Oncology*. 2013 Oct 22.

xxxix Lewis, P.E., Sheng, M., Rhodes, M.M., Jackson, K.E. and Schover, L.R. *Psychosocial Concerns of Young African American Breast Cancer Survivors*. *J Psychosoc Oncol*. 2012 March; 30(2): 168–184.

xl Rosenberg SM, Partridge AH. *Premature Menopause In Young Breast Cancer: Effects On Quality Of Life And Treatment Interventions*. *J Thorac Dis*. 2013 Jun;5(Suppl 1):S55-61.

xli Lewis, P.E., Sheng, M., Rhodes, M.M., Jackson, K.E. and Schover, L.R. *Psychosocial Concerns of Young African American Breast Cancer Survivors*. *J Psychosoc Oncol*. 2012 March; 30(2): 168–184.

xlii Sheppard VB, Harper FW, Davis K, Hirpa F, Makambi K. *The importance of contextual factors and age in association with anxiety and depression in Black breast cancer patients*. *Psycho-Oncology*. 2013 Oct 22.

xliiii Haynes MA, Smedley BD, editors. *The Unequal Burden of Cancer: An Assessment of NIH Research and Programs for Ethnic Minorities and the Medically Underserved*. Institute of Medicine (US) Committee on Cancer Research Among Minorities and the Medically Underserved; Washington (DC): National Academies Press (US); 1999.