

Continuing to Reduce the Excess Burden of Breast Cancer Incidence and Mortality among California Women

Ngina Lythcott, Dr.P.H.

2004



University of California
Office of the President
300 Lakeside Drive, 6th Floor
Oakland, CA 94612-3550
www.cbcrp.org

Continuing to Reduce the Excess Burden of Breast Cancer Incidence and Mortality among California Women

By
Ngina Lythcott, Dr.P.H.

The California Breast Cancer Research Program commissioned this white paper in the summer of 2003 to help inform our tri-annual priority-setting process.

Introduction

This paper is written from the perspective of a breast cancer survivor-advocate. While the writer is trained as a public health professional and is a fifteen-year survivor of breast cancer, she writes this paper from her experience working with and supporting many hundreds of women who have had an initial diagnosis of breast cancer or a reoccurrence of the disease. It is this experience that motivates the writer's interest in and influences much of her thinking about the important role of breast cancer research in the reduction of excess burden and the eradication of the disease.¹²

The focus of this paper is the reduction of excess incidence and mortality due to breast cancer among subpopulations of women in California. Variables given the most attention are race/ethnicity and SES. Especially useful to writing this paper was having access to eleven manuscripts in publication, provided as a confidential resource by the California Breast Cancer Research Program.

Ngina Lythcott, DrPH

For more information, contact
Janna Cordeiro, M.P.H.
Coordinator of Special Projects



University of California
Office of the President
300 Lakeside Drive, 6th Floor
Oakland, CA 94612-3550
Toll-Free: 1 888 313-2277
(510) 987-9884
www.cbcrp.org

© 2004 Ngina Lythcott, Dr.P.H.

Excess Burden of Morbidity and Mortality

The United States

In the United States, non-Hispanic White women have the highest incidence rate of breast cancer while Black women have the highest breast cancer mortality rate. It is widely held that the excess mortality is largely due to the lack of availability and/or accessibility of health care resources. Research looking at breast and then prostate cancer done at the National Cancer Institute, reported that equal treatment resulted in equal outcomes.²⁰

However, there are growing data that suggest that access to early, regular and appropriate cancer screening, detection, and treatment, likely explains only part of the burden of excess mortality.^{2, 5, 6, 21}

California

In California, breast cancer remains the most commonly occurring invasive cancer diagnosed among women. Between 1995 and 1999, the most recent five-year period for which data are available, among women under 50 years of age, the average incidence rate of newly diagnosed in-situ or invasive breast cancer, was 48/100,000 (52.7/100,000 for non-Hispanic White women, 48.4/100,000 for Black women, 46.3/100,000 for Asian/Pacific Islander women, and 35.2/100,000 for Latinas). Among women 50 years of age or older, the average incidence rate of newly diagnosed in-situ or invasive breast cancer, was 426.2/100,000 (484.1/100,000 for non-Hispanic White women, 372.8/100,000 for Black women, 265.4/100,000 for Asian/Pacific Islander women, and 256.9/100,000 for Latinas). During the same period of time, the breast cancer mortality rates among California women had a different racial profile. The age-adjusted breast cancer mortality rate among all California women was 26.4/100,000 (28.9/100,000 for non-Hispanic White women, 35.8/100,000 for Black women, 14.4/100,000 for Asian/Pacific Islander women, and 18.0/100,000 for Latinas).¹ When looking at trends of these rates, each of these reported incidence and mortality rates is lower for each population than the immediately two previous time periods, except for Asian/Pacific Islander women, whose incidence and mortality rates have increased over the last eleven years.

As is true for the United States, despite an overall decline in breast cancer mortality in California, racial and ethnic disparities persist. While the incidence of

breast cancer among Black women is lower than in non-Hispanic White women, Black women continue to die of breast cancer at a higher rate than any other racial or ethnic group. While it is important that we as scientists, clinicians, and survivors focus our attention on the eradication of breast cancer for all women, I believe that we have an additional moral imperative to address the increased burden of mortality due to breast cancer among African American women.

Unique Importance of the State of California

The tremendous racial and ethnic diversity of California, its long-term commitment to the collection of breast cancer data, and its commitment to funding breast cancer research, create a rich opportunity for the State to have a tremendous impact on both the eradication of breast cancer and the reduction of racial and ethnic disparities.

California is a populous State with a diverse population. In addition to geography (urban vs. rural), California is also diverse by race, culture, class, age and environmental factors. It is especially the presence of so many, large, racial and ethnic communities that makes California such a rich resource for research.

Second, the California's State Legislature has been supportive by passing and funding legislation to support breast cancer research. As early as 1985, the California

Legislature passed a State Law establishing the California Cancer Registry, which was created in 1988. In addition, the entire State participates in the Center for Disease Control and Prevention's SEER data program.^{14, 15}

Third, both the leadership and other California citizens seem committed to not only reducing cancer disparities among selected populations, but also to reducing the morbidity and mortality of breast cancer among all State residents. Evidence for this began in 1995 with the annual funding for the California Breast Cancer Research Program, the largest state-funded (from tobacco tax) breast cancer research program in the country, and in the identification of the California Breast Cancer Research Program as the number one nonprofit organization identified for a voluntary donation by State taxpayers.

Suggested Research Questions For Consideration By the CBCRP:

1) Nasseri reports in his manuscript that when looking at the breast cancer mortality trends in California from 1970 to 1999, nearly all of the 26% decline in breast cancer mortality over this period was due to reducing mortality among non-Hispanic White women. He further reports that while there was some reduction in mortality among Latinas, there was almost no reduction among African American women and that there was a 78% increase among Asian/Pacific Islander women.¹⁵ The Hoegh and Davis manuscript reports that the data for Asian/Pacific Islander women are due to increased reporting because these women are newer immigrants and so have been slower to avail themselves of mammograms; they further suggest that this population will reach steady stabilization rate.⁷

While this is good news for non-Hispanic White women, it is shocking that so little reduction in breast cancer mortality has occurred among women of color. Unless there is a wide difference in breast cancer histology between White women and women of color, these data suggest that while early, annual mammograms, detection and diagnostic programs, and state-of-the-art treatment may be available to all California women, they are apparently not equally accessible to women of color. The term available means that the services exist; it does not speak to whether the end users of available services consider them accessible and so choose to use them. More research needs to be done to better understand why available services are not accessible to all populations of California women.

This disparity in breast cancer mortality needs immediate and focused attention by the California Breast Cancer Research Program. Especially because of its diverse population, California has the opportunity to do innovative research among its diverse populations of women, to tease out specifically what variables, in addition to race and ethnicity are responsible for this seemingly intractable occurrence.

2) Yost says in her manuscript that in California, there is an association between socioeconomic status (SES) and breast cancer (not causal), and that the reason for the association is not known. She hypothesizes that it “may be due to differences in diet, lifestyle, delayed or no

childbearing or delayed or no breastfeeding.” In order to begin to address this association, it is important to first determine whether it exists.

Currently, California uses census block group data to approximate an individual’s SES level by creating an index combining measures of occupation, income, education and cost of living.¹³ California was one of the states that led the way in developing what was then considered an effective formula for SES; it may not longer be a state-of-the-art measure. Over the last 10 years a multidisciplinary, intellectual discourse on this complex subject has continued in refereed journals; it is time for California to participate in and learn from the current dialogue. SES is extremely important variable to measure with greater accuracy, in order to better understand its impact on breast cancer disparities, especially as it is confounded by race (or color) and ethnicity. The current formula used by California has components that make assumptions that are no longer considered valid. For example, the average cost of a home within a census track is based upon the inaccurate assumption that the average cost of a home is evenly distributed across the census track, as opposed to it’s being bimodal, for example. It is quite possible that there is a large up-scale housing stock in a particular census track with a small neighborhood of poor housing stock, in which very low income people live. In this case, averaging such data might result in the erroneous deduction that this particular census track contains only middle class people. A measure of average income may suffer from the same false assumption, and could be further confounded by another erroneous assumption, that the average income within a census track has the same impact across all racial groups within that census track. However, because wealth is not measured and/or culture as it impacts on expenditure priorities is not measured, it is very likely that we are not measuring what we think we are, which could have a huge impact on understanding the role of SES on breast cancer mortality disparity.

There is a growing literature in peer-reviewed journals on the measurement of SES.^{9, 10, 18, 19} It is very important that California review and better refine the way that it

measures SES. In the meantime, if the current methodology is used in the short run, it should enhanced by interviewing a sample of women from each census track, to validate then accuracy of the proxy formula that is used.

Without a more accurate measure of SES, we don't know whether the question is why do African American Women have such a high breast cancer mortality rate, or whether the correct question is why do poor women (of any race/color) have such a high breast cancer mortality rate. Until California has a better measure of SES, it is impossible to know the role SES plays in breast cancer mortality disparities, or how to address it.

3) The Morris manuscript says that stage at diagnosis represents the best prognostic factor for breast cancer (tumor characteristics are also important).¹⁴ According to the Hoegh and Davis manuscript, non-Hispanic White and Asian Californian women are diagnosed with breast cancer at an earlier stage than African American and Latina Californians, who receive annual mammograms at a later age and later stage of disease. Is the diagnosis of breast cancer at a later stage of disease among Latina and Black Californians as cited by Hoegh and Davis¹⁴, due to: 1) having breast cancer at a younger age; 2) having a first mammogram at an older age than recommended, or less frequently than annually, or 3) a more aggressive breast cancer that was not present at the previous annual mammogram? Depending on the answer, two other questions might also be considered: 1) should African American women be encouraged to initiate annual mammograms before age 40? And/or 2) should they be encouraged to have them more frequently than annually? These are important questions to answer if we are to address the increased burden of breast cancer mortality among women at highest risk.

The Mills and Jain manuscript says that rates of early breast disease in California are highest among the urban and among the affluent, with lower rates of early disease reported among the rural and among those in impoverished areas.¹³ This is surprising given the monograph that was recently published by the Journal of the National Cancer Institute, which examines the association between cancer and socioeconomic status. Relying on SEER data, the Report says that women in poor areas are more likely to have breast cancer, that the breast cancer is likely to be diagnosed at a later stage and that the women are more likely to die from their disease.¹⁶ If

breast cancer rates nationally are highest among the poor, California's lower early cancer detection rates among rural women and women in impoverished areas are likely to have an adverse impact on the breast cancer mortality rates in these populations.

It is important for the CBCRP to continue to do research on timely, annual mammography among these women at higher risk: 1) African American women, 2) Latinas and 3) those women, across all races/ethnicities with lower education, 4) lower SES, or 5) who reside in rural areas, to obtain annual mammograms and to start the practice at an earlier age, when disease is more likely to be found at an earlier stage.

4) Many researchers report that all or nearly all of the disparity in breast cancer mortality is the result of reduced access that African American and low SES women have to early detection and treatment.^{2, 20, 21} However, several years ago, research was published on differences in treatment recommendations by provider physicians for African American women and men with cardiovascular disease.¹⁷ The Morris manuscript says that surgical treatment (BCS vs. mastectomy) for breast cancer in California varied with stage (as one might expect), race/ethnicity and SES. Non-Hispanic White women were more likely to receive radiation post BCS than women of color.¹⁴ When working to reduce breast cancer mortality in California, it is important to ask whether populations of color, especially African American women and low-income women of any race, are receiving the appropriate standard-of-care treatment.

The question is, do all California women receive same treatment given stage of disease? Standard-of-care should be driven by current scientific research. In order for the California Breast Cancer Treatment Program to do research on this question for California women with breast cancer, it would be important to develop a partnership with a national professional organization of oncologists to determine the stage-of-disease-based standard of care during a particular period of time and then look retrospectively at patient records to determine whether there is evidence as to whether 1) that standard of care was recommended and 2) whether the patient received that standard of care. The hypotheses to consider would be race/ethnicity, socioeconomic status, method of payment for health services and/or geography increases the likelihood of physicians recommending substandard treatment for breast cancer.

5) With the identification of the human genome, it has become clear that there are more differences within a racial group than there are across racial groups and that race is not a biological construct, but a social one. However, because of persistent racism in the United States and its impact on access to education, the ability to earn income, and access to services that require payment, race continues to be a reasonable measure of equal access to health information, screening, detection, diagnosis, and treatment. Until these social justice issues are resolved, race continues to play an important role in how we evaluate the outcomes of health promotion, disease prevention and treatment programs. Thanks to the recent failure of Proposition 54, California will continue to collect breast cancer data by race and ethnicity as a means to determine whether there are racial disparities in breast cancer incidence and mortality. California breast cancer data continue to show racial and ethnic disparities persist.

However, as the U.S. population becomes more racially mixed, it is important to identify more accurate measures of the impact of barriers to access, on health status, illness behaviors, and treatment outcomes, especially as we work to better address breast cancer disparities.

Given this, there is some value in the breast cancer research community, and especially the California breast cancer research community to begin considering that race may be a proxy for something else that may be easier to collect and a more accurate measure. For example, is race a proxy for color; for socioeconomic status; for some combination of color and class? Given California's commitment to reducing racial and ethnic disparities and its ethnically and diverse populations, the CBCRP is ideally situated to begin this important research conversation.

Summary

The California Breast Cancer Research Program is in a unique position to better understand and ultimately address the excess burden of breast cancer incidence and mortality among those at highest risk. The data show that important research priorities to address are: funding research that identifies real and perceived barriers to early and regular screening and diagnosis for those at highest risk; monitoring whether high risk populations are receiving standard of care treatment; and identifying more accurate measures of socioeconomic status and race.

These issues are of course equally important for the nation as a whole. So important, that given California's unique population and commitment to funding breast cancer research, that it would be valuable for the CBCRP to ask the NCI and/or the DOD breast cancer research programs for additional resources to supplement and extend the CBCRP's efforts to better understand and reduce the disparity of disease and death due to breast cancer.

Bibliography

- 1) Campleman SL, and Curtis RL. Demographic aspects of breast cancer incidence and mortality in California, 1988-1999 (Chapter 3). Manuscript in publication.
- 2) Dignam JJ, Redmond CK, Fisher B, Costantino JP, Edwards BK. Prognosis among African American women and White women with lymph node negative breast carcinoma. *Cancer*. 1997 Jul 1;80(1):80-90.
- 3) Geronimus AT. Understanding and eliminating racial inequalities in women's health in the United States: the role of the weathering conceptual framework. *JAMWA*. 2001 56:133-136.
- 4) Geronimus AT, Bound, J. Use of census-based aggregate variable to proxy for socioeconomic group: evidence from national samples. *American Journal of Epidemiology*. 1998 148:475-86.
- 5) Gordon NH. Association of education and income with estrogen receptor status in primary breast cancer. *American Journal of Epidemiology*. 1995 Oct 15;142(8):796-803.
- 6) Gordon NH, Crowe JP, Brumberg DJ, Berger NA. Socioeconomic factors and race in breast cancer recurrence and survival. *American Journal of Epidemiology*. 1992 Mar 15;135(6):609-18.
- 7) Hoegh H and Davis BD. Utilization of screening mammography in California, 1987-2000 (Chapter 7). Manuscript in publication.
- 8) Kaufman JS, Cooper RS, McGee DL. Socioeconomic status and health in Blacks and Whites: the problem of residual confounding and the resiliency of race. *Epidemiology*, 1997 Nov 8(6):621-8.
- 9) Krieger N. Overcoming the absence of socioeconomic data in medical records: validation and application of a census-based methodology. *American Journal of Public Health* 1992 82:703-10.
- 10) Krieger N, Williams DR, Moss NE. Measuring social class in U.S. public health research: concepts, methodologies, and guidelines. *Annual Review of Public Health*, 1997 18:341-78.
- 11) Lehrman S. Color blind racism. Electronically published on AlterNet, September 18, 2003. Can be found at www.alternet.org/story.html?storyID=16792.
- 12) Lythcott N, Green BL, Brown ZK. The perspective of African American breast cancer survivor-advocates. *Cancer* 2003;97(1 Supp 1):324-328.
- 13) Mills PK and Jain R. Stage at diagnosis of female breast cancer in California, 1988-1999 (Chapter 8). Manuscript in publication.
- 14) Morris CR. Risk of developing invasive female breast cancer in California (Chapter 6). Manuscript in publication.
- 15) Nasser K. Trends in female breast cancer incidence and mortality in California (Chapter 5). Manuscript in publication.
- 16) Reynolds T. Report examines association between cancer and socioeconomic status. *Journal of the National Cancer Institute*. 95:19, 1431-1433, 2003
- 17) Schulman KA, Berlin JA, Hartless W, et al. The effect of race and sex on physicians' recommendations for cardiac catheterization. *New England Journal of Medicine*. 1999; 340:616-626.
- 18) Williams DR. Race/ethnicity and socioeconomic status: measurement and methodological issues. *Annals of the New York Academy of Sciences*. 1996 26(3): 483-505.
- 19) Williams DR. Socioeconomic status and health: the added effects of racism and discrimination. *Annals of the New York Academy of Sciences*, 1999 896:173-188, 1999.
- 20) Woljick BE, Spinks MK, Optenberg SA. Breast carcinoma survival analysis for African American and White women in an equal access health care system. *Cancer*. 1998 Apr 1;82(7):1310-8.
- 21) Yood MU, Johnson CC, Blount A, Abrams J, Wolman EM, McCarthy BD, Raju U, Nathanson, DS, Wolman SR. Race and differences in breast cancer survival in a managed care population. *Journal of the National Cancer Institute*. 2000 Oct 18; 92(20):1690-1.
- 22) Yost K. Socioeconomic status and breast cancer incidence in California (Chapter 4). Manuscript in publication.



Printed on recycled paper using soy-based ink