

Improving Quality and Reducing Disparities in Breast Cancer Mortality in Metropolitan Chicago

Executive Summary
October 2007

The full Report as summarized below may be found online at: www.chicagobreastcancer.org

INTRODUCTION

The Metropolitan Chicago Breast Cancer Task Force was formed in response to a report from the Sinai Urban Health Institute describing the growing Black:White breast cancer mortality gap and from other published research regarding breast cancer in Chicago. The Task Force held a founding Summit on March 23, 2007, which was attended by more than 200 concerned advocates and professionals and received wide media coverage, including spots on more than a dozen radio and television stations and prominent newspaper articles.

The morning of the Summit featured speakers discussing issues related to three key hypotheses (Box 1) proposed to explain the growing breast cancer disparity in Chicago. In the afternoon, the participants divided into three Action Groups focusing on the three hypotheses. These Action Groups, comprised of over 100 people in all, met regularly from March until mid September to explore these hypotheses and prepare this report.

Background: Disparities in Breast Cancer Mortality in Chicago

The main findings stimulating this work are presented in Figure 1. As can be seen, breast cancer mortality rates were the same for Black and White women in Chicago in 1980 (at about 38 per 100,000 women, age adjusted). Rates stayed more or less equivalent until the early 1990s when they began to diverge. By 2003 a large disparity is evident, with the Black mortality rate (40.4) 68% higher than the White rate (24.0). Thus, since the period of equality in 1980, a huge disparity opened up by 2003. This means that in those 23 years in Chicago, Black women experienced no improvement whatsoever in breast cancer mortality.

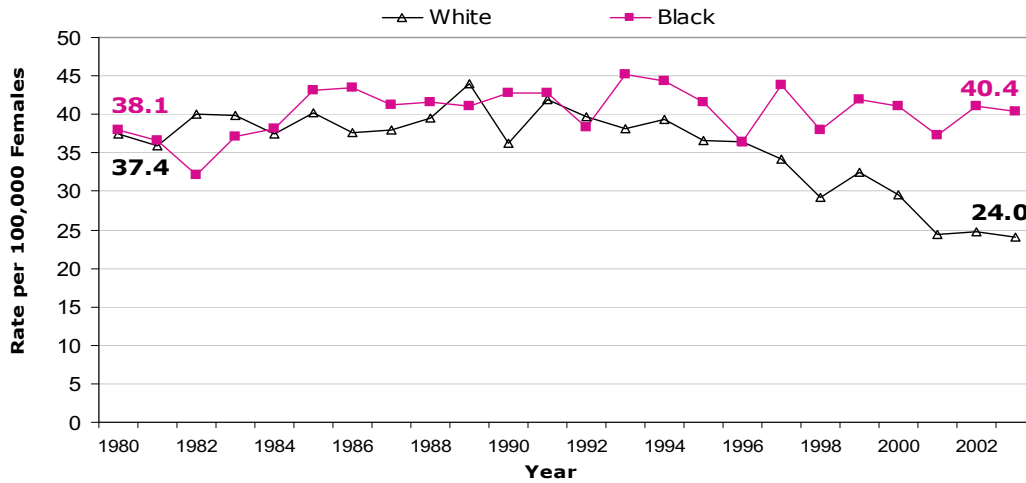
A table presented in the Introduction to the Report shows the dramatic increase in these disparities in recent years. The accompanying bar chart shows that the most recent difference between Black and White women in Chicago was 68%; whereas it was only 11% in New York City and 37% for the entire country. Furthermore, the figures for New York City and the U.S. have been rather constant since 2000, compared to Chicago's rapidly widening disparity.

It is important to note that the disparities seen in Chicago are not the result of biological differences in breast cancer between Black and White women, although recent studies have noted that there is biological variability in the presentation of breast cancer. The comparisons with New York City and the entire U.S. make it clear that biology cannot be blamed for the disparity in mortality rates in Chicago. We suggest the answer lies in the system – a system of care in Metropolitan Chicago that has failed in the most basic of ways to preserve the health of Black women. The system must be repaired, and this may best be accomplished by focusing on the recommendations in this Report offered by the Task Force.

Box 1. Three Hypotheses Explaining Breast Cancer Disparities

1. Black women receive fewer mammograms;
2. Black women receive mammograms of inferior quality; and
3. Black women have inadequate access to quality treatment once a cancer is diagnosed.

Figure 1. Black and White Breast Cancer Mortality Rates in Chicago, 1980-2003



Based on many years of work in this field, on the data presented in the publication, and on an extensive review of the literature, the Task Force posits three main hypotheses that could explain the racial disparities in breast cancer mortality in Chicago (Box 1). This Report is organized according to these three hypotheses. Decisive action must be taken now. This is the view of our Task Force and the purpose of this Report.

CHAPTER 1: Access to Mammography

After correcting for bias in self-reported data, it is estimated that 70% of White women in Chicago over the age of 40 have received a mammogram in the last 2 years, as compared to 55% of Black women. Because early detection is essential to reduce breast cancer mortality, the Task Force strongly supports the elimination of barriers to equal access to mammography and other diagnostic services for all women. These barriers are identified in this Report, along with associated recommendations to remedy the problems.

Barriers to Access to Mammography

Based on a comprehensive literature review, landmark studies conducted at both the University of Illinois at Chicago and the University of Chicago, and feedback from our Town Hall meetings, we identified the

following barriers to obtaining breast cancer screening. Each is described further in the Report:

- Cost of screening and diagnosis, including lack of insurance, rejection of Medicaid because it pays too little, and out of pocket expenses;
- Inability to navigate the medical system, particularly the complex web providing breast health care to women without insurance;
- Lack of knowledge about where to obtain a no-cost or low-cost mammogram;
- Distance to providers of no-cost or low-cost mammography;
- Lack of trust in health care providers and institutions;
- Fear and anxiety;
- Cultural beliefs and misconceptions about breast cancer;
- Language and health literacy issues;
- Work and family responsibilities.

Interventions to Overcome These Barriers

In an effort to overcome these barriers, advocates, researchers, and health care providers have tested a wide variety of interventions. Many have proven to be successful. After listening to the experiences of women who attended the

Town Hall meetings and studying more than 100 articles in the field, we have identified the following interventions that have demonstrated effectiveness in overcoming the barriers cited above:

- Mitigating the costs associated with mammography through safety net programs, improvement in insurance coverage, the elimination of co-pays, etc.;
- Assuring that mammography sites are geographically distributed and not just concentrated in affluent sections of the city and suburbs;
- Helping providers to be more welcoming to women seeking breast screening as many women report racist behaviors towards them as well as other forms of disrespect;
- Encouraging physicians to recommend mammography screening to their patients by using computer reminders, post cards, notes placed in charts, etc. to substantially increase mammography use;
- Using patient advocates and navigators to help overcome barriers such as language, health literacy, logistics, and fear. They should come from the community, be culturally sensitive, and have personal experience with breast cancer, for example breast cancer survivors;
- Addressing entire communities through education and awareness programs to improve and enhance the understandings of breast cancer and screening mammography.

The most critical need is to remove the financial barriers to screening and diagnosis. The cost of a mammogram must be eliminated as a barrier to breast health. This, in concert with the additional recommendations, will allow us to narrow and even eliminate the racial and ethnic disparities in access to breast cancer

screening. All that is needed is for us to marshal the will and the resources to implement what has already been demonstrated to be effective.

The Capacity of Mammography Availability

We posed the following question: If all the age-eligible women decided to get mammograms as recommended by the guidelines, would the Chicago metropolitan area have adequate capacity to provide them? Although we could find the names of the mammography providers, we found little additional information to allow us to answer this question. We thus contacted the institutions that provide mammograms to women living in Chicago and asked them to complete a comprehensive survey. We were able to locate 87 such institutions and obtained responses from 82% of them. Based upon these data, and for the first time in Chicago as far as we know, we have an estimate of current capacity for screening mammography of 207,000 women, with a maximum potential of 384,000. Both of these are far smaller than the number of mammography age-eligible women in Chicago - 588,000 women according to the Census.

We also found that there are differences in access to mammography and diagnostic follow-up services that favor White women in Chicago. The largest difference by far appeared to be with respect to access to a breast imaging specialist when having mammograms interpreted. Prior research has shown that breast imaging specialists tend to do a better job interpreting mammograms. We also found large differences in access to factors related to better image quality (digital mammography) and timeliness of follow-up (same day mammogram readings). Overall, these results suggest that differences in image quality, interpretation quality, and timeliness of follow-up of a suspicious mammogram finding may be contributing to the greater breast cancer mortality for Black women as opposed to White women in Chicago.

Our Recommendations

All of the work summarized here will only have meaning if we can use the information to improve the system of breast health care in Metropolitan Chicago and minimize disparities in breast cancer mortality. Toward this end, we have formulated 37 actionable recommendations which, if implemented, will move us in this direction. The Recommendations follow below in summarized form. Some are ready to be implemented today; others require further study and definition. For purposes of brevity, some of the individual recommendations in the Report have been blended into a combined recommendation here that falls into eight categories. Complete details are contained in the full Report. We also support the rigorous evaluation of the effectiveness of all the recommendations.

1. Access and Cost

Mammography and treatment for breast cancer must be available for all women in Illinois. Thus, cost must be removed as a barrier for screening and treatment. The Illinois Breast and Cervical Cancer Screening Program and the Stand Against Cancer Program need to be fully funded. The Cook County Bureau of Health Services needs to adequately fund breast cancer screening for its patients. State insurance laws need to be modified to eliminate co-pays and deductibles for breast cancer screening and treatment. Providers in Metropolitan Chicago will be asked to provide screenings and treatment in a coordinated manner to women in need.

2. Education and Outreach

There needs to be a combination of culturally relevant community education and outreach as well as targeted media campaigns to increase awareness about the importance of early detection and treatment of breast cancer. Culturally relevant educational materials need to be collected and distributed widely. Providers need to receive training in cultural awareness. Providers will be encouraged to establish systems to remind patients of the need for mammography. There needs to be one Metropolitan Chicago number where women can call to access screening and treatment services.

3. Capacity

A unique survey conducted by the Task Force revealed that there is not enough capacity (only about 65%) in Metropolitan Chicago to screen all the eligible women. Screening and treatment facilities for underserved women are limited and poorly distributed across the area. A blue ribbon committee will be assembled to address capacity issues for breast screening, diagnosis and treatment in Metropolitan Chicago and will report back by October 2008.

4. The Quality of the Mammography Process and Quality of Treatment

In order to improve the quality of mammography screening and breast cancer treatment across Metropolitan Chicago, a number of Chicago area health care organizations have agreed to create a Metropolitan Chicago Breast Cancer Consortium to identify, measure and share quality measures that have been shown to be important in breast cancer screening and treatment. A quality initiative will provide free consultations to institutions to improve breast cancer outcomes. All Metropolitan Chicago hospitals providing screening and treatment will be asked to voluntarily participate.

Our Recommendations

5. Diagnostic Follow-up and Communication

The mammography follow-up process is complicated and fraught with multiple breakdowns. Women need to be able to self-refer for breast cancer diagnostic tests and there needs to be a state law to allow this. There also needs to be a systematic manner in which diagnostic breast testing results are communicated, especially because Black women are less likely to attend facilities where results are directly communicated. An expert panel will be assembled to make recommendations on diagnostic follow-up that can be adopted across Metropolitan Chicago. Timely access to breast diagnostic services must be made available by coordinating access to services at all institutions.

6. The Healthcare Safety Net

Vast gaps in the safety net have likely contributed to the breast cancer mortality disparity in Chicago. There is not enough capacity in Metropolitan Chicago to screen all the eligible women. Screening and treatment facilities for underserved women are limited and poorly distributed. The Cook County Health System cannot manage the volume of patients in need of diagnosis and treatment. The Task Force suggests that a public-private collaboration including strategic placement of digital screening facilities across the area, linked with a centrally located accessible state-of-the-art diagnostic and consultation center (staffed by experts) be established. This would provide a level of care currently not available to underserved women and could serve as a model to the nation. A blue ribbon committee will be assembled to address the feasibility of creating such a facility in Metropolitan Chicago and will report back by October 2008.

We also recommend that proven programs such as the use of navigators who help women get timely care should be implemented more widely.

7. Mammography Specialist Workforce

There is a limited workforce of trained mammography specialists in Metropolitan Chicago. We recommend expanding mammography specialty training within physician training programs. We also propose creating a “mini” fellowship to train general radiologists at safety net hospitals to improve the quality of their mammography readings.

8. Illinois State Cancer Registry

The Illinois State Cancer Registry needs to be enhanced to include breast cancer treatment data. It is currently under-funded and thus cannot provide adequate data on disparities in care in Illinois. This is an important deficit which needs to be remedied.

CHAPTER 2: Quality of Mammography

The second of our three hypothesized causes for the racial disparity in breast cancer mortality involves the quality of mammography. Specifically, it is known that the quality of mammography varies considerably and we suspect that it is often inferior for Black women. This would result in, among other things, missing small tumors and thus losing the opportunity to successfully treat them. This hypothesis is supported by a growing number of anecdotes and data collected here in Metropolitan Chicago. The issue then becomes: How can we improve the quality of mammography for all women and thus help eliminate the disparity in breast cancer mortality? We were able to delineate four main aspects of this issue.

The Need to Report and Evaluate Measures of the Quality of Mammography

Although the American College of Radiology recommends that measures of the quality of mammography process be collected and reported, very few mammography centers in Metropolitan Chicago do this. We think that it is imperative for such data to be gathered, examined, and then used for continuous quality improvement. Although there are about a dozen such measures, we suggest that four of these are most essential: (1) the number of cancers detected for every 1,000 screening mammograms, with a benchmark of 6 or a rate of 0.006; (2) the proportion of detected cancers that are less than 1 cm in size, with a benchmark of 30% or more; (3) the proportion of cancers detected at an early stage of 0 or 1, with a benchmark of 50% or more; and (4) the proportion of women with an abnormal mammogram who are lost to follow-up, with a benchmark of 10% or less.

Workforce Issues

It is well established that radiologists who specialize in mammography and read

primarily mammograms in their practice are significantly better at identifying small, early stage cancers. As is the case in the rest of the country, Chicago has too few of these expert mammographers. Not surprisingly, these experts tend to work at large university facilities rather than the safety net institutions that serve poor women and women of color.

Diagnosis and Follow-Up Communication

After a woman's mammogram is judged to be abnormal, she must return for diagnostic procedures as soon as possible to determine whether she has cancer. If she does have cancer, then treatment must be started in a timely manner. These issues of timeliness are crucial, because delays of several months can mean the difference between saving the breast with lumpectomy or removing the breast with mastectomy, as well as the potential for cancer to spread. Ideally, there should be no more than three months between the time of the abnormal mammogram and the start of treatment. Yet, data collected in Chicago showed that delays are frequently much greater than they should be for poor women. One technique that has been found to be effective in minimizing these delays and the loss of women to follow-up is the use of patient navigators. For example, at two Chicago institutions in which the loss to follow-up rates were over 25%, navigators have been able to reduce the loss to almost zero.

The Safety Net and Stroger Hospital

For good breast health care to be provided to disadvantaged women, it is essential that safety net institutions function well. There are several safety net institutions in Chicago and they function remarkably well considering the inadequate resources they are provided by our health care system. In Chicago, the center of the safety net is John H. Stroger Jr. Hospital of Cook County (a.k.a. Cook County). At the current level of funding, this hospital cannot possibly provide mammography for all the women who need it.

Nor is it reasonable to expect that one institution will ever be able to adequately serve all the health care needs for the financially disadvantaged in Cook County. In contrast, New York City has eleven safety net hospitals distributed throughout the metropolitan area to serve the health care needs of the disadvantaged.

CHAPTER 3: Quality of Treatment

In recent years, significant advances have been made in breast cancer treatment, so that it now is considered a curable disease. Nevertheless, studies have shown that higher percentages of Black women die from breast cancer than White women, even when their cancer is diagnosed at the same stage. The National Cancer Institute's Black:White Survival Study showed that 21% of Black patients failed to receive the minimum expected standard of care, as compared to 15% of White patients. Thus, our third hypothesized cause of the racial disparity in breast cancer mortality in Chicago is that Black women have reduced access to high quality treatment.

As this Action Group proceeded with its task, it became clear that the etiology for differences in treatment were complex and multi-factorial, resulting from variations in the treatment that a patient is offered, accepts, and receives. The group explored many issues that can contribute to decreasing the survival disparity in Chicago and focused on those that are amenable to change. Importantly, several themes emerged such as issues of access to care, socioeconomic factors, environmental factors, comorbid conditions, health literacy, cultural beliefs, and lack of trust in the health care system. All of these may play a role in affecting what treatment is actually received.

We were encouraged to find that there are many effective interventions that can overcome almost all of these barriers. Among these are:

- Expanding insurance coverage;
- Improving proximity to treatment sources and increasing proximate access to specialists;
- Providing and expanding availability of disability coverage;
- Minimizing logistical barriers (transportation, childcare, etc.);
- Decreasing fragmentation in care and improving coordination of services;
- Addressing issues of cultural beliefs, health literacy, and trust in the medical system;
- Educating the public regarding breast cancer;
- Educating providers regarding cultural barriers to care;
- Decreasing the impact of comorbid conditions on breast cancer treatment/outcome.

In addition, we need to create systems to measure and evaluate the quality of treatment provided across Metropolitan Chicago in order to use this information for continuous improvement. Finally, we thought it would be essential to improve Cancer Registry Data by coordinating communication among registrars to improve treatment and follow-up measures, and we recommend working with the Illinois State Cancer Registry to streamline this effort.

The Appendices

One of the unique features of this Task Force has been a great deal of original work that we were able to accomplish even beyond our meetings and the written Report. Much of that is presented in appendices of the Report. We would like to call your attention to these. They may be found at the end of our Report and on the website: www.chicagobreastcancer.org.

- Appendix A presents a detailed report of the capacity survey of Metropolitan Chicago mammography facilities, the first of its kind, as far as we know;
- Appendix B presents a summary of the four Town Hall meetings that were held in vulnerable communities across the Metropolitan Chicago. Over 150 women came out to inform us, often passionately and in great detail, about their experiences in seeking breast health care;
- Appendix C presents details on creating a Metropolitan Chicago Breast Cancer Consortium, one of our most important recommendations;
- Appendix D presents the findings from a series of Focus Groups conducted with health care providers about the quality of mammography, detailing what is wrong and how to fix it;
- Appendix E presents an overview of how a Regional Health Information Organization (RHIO) works. Developing a RHIO in Chicago is a long-term goal but an important one;
- Appendix F provides a summary of research findings from Focus Groups with women conducted by the Center for Interdisciplinary Health Disparities Research at the University of Chicago;
- Appendix G provides a summary of interviews conducted with various health care providers on barriers women face in accessing treatment.

The full Report entitled
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as summarized above may be found online at:

www.chicagobreastcancer.org

Hard copies are available for \$30 and may be ordered with a check or money order made out to:

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