Breast Cancer in Chicago:

Eliminating Disparities and Improving Mammography Quality

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To Our Colleagues and To Those We Serve:

I am pleased and excited to present the following report to you on the state of breast cancer in Chicago. The epidemiology of this disease describes an epidemic. This report begins to address the background, the implications and the steps that will allow us to do better as we battle against it. The researchers in the Sinai Urban Health Institute and their colleagues who have written the papers that follow present several important findings. Notably, far too many women are dying of breast cancer, some for lack of effective treatment and some because of inadequate quality along with less than optimal frequency of mammography. It is not only that the situation is critical and needs to be improved but it is also that the racial disparities in breast cancer mortality are unacceptable and must be eliminated.

So we must improve both screening and treatment. Both must be available and both must be as effective as we can possibly make them. In some cases, women cannot afford mammography. In other cases, different programs provide free mammography to those who cannot afford it but then there are no programs to provide the needed treatment if cancer is diagnosed. In still other cases, the quality of the mammogram may be inadequate. Fortunately, this latter situation can be rather well-understood due to benchmark indicators of quality established by the American College of Radiology. The authors of the ensuing report discuss this issue with substantial energy and incisiveness.

They suggest that if we regularly examine these indicators and work to improve them, then our mammography services will be improved. Yet, to our knowledge, most radiology units do not calculate these indicators. Therefore, they cannot use them for quality improvement and cannot, in a move essential to a commitment to quality improvement, be transparent. In this report, two Chicago medical centers, Mercy Hospital and Mount Sinai Hospital, accept that challenge. Included in the report are their basic indicators of mammography quality. We hope that other providers in Chicago and throughout the country will follow suit – not just in the display of these indicators but in the effort to continuously improve them. The women we serve deserve no less.

Alan H. Channing
President and CEO
Sinai Health System

Forward

The attached report is an important one. We would like to use a few paragraphs to explain its structure, which is a bit unusual.

In Part I of the report, we present a manuscript that has been prepared by Jocelyn Hirschman, MPH, Steven Whitman, PhD, and David Ansell, MD, MPH. It has been submitted for publication and is printed here just as it was sent off to the journal. Because it was submitted recently, we do not know whether it will be accepted and/or whether changes will be required. This paper is the stimulus for this report.

Part II of this report was prepared by Paula Grabler, MD. It describes the quality assurance measures associated with the program she directed at the Breast Health Program at Mercy Hospital and Medical Center. We asked Dr. Grabler to prepare such a paper in order to explain the basic concepts employed in determining mammography quality and to illustrate how they appear. We thought this would help readers understand how to compare measures from a particular radiology center with the benchmarks determined by the American College of Radiology, the accrediting agency for mammography in the United States.

Part III was prepared by Kristi Allgood and Steven Whitman. It presents many quality measures based upon data generated at Mount Sinai Hospital's Radiology Department.

We are pleased that we have been able to assemble such a report and even more pleased that Mercy and Mount Sinai have decided to calculate these quality measures and present them to the public. Such a presentation is consistent with the principle of "transparency" that is often viewed as one of the lynchpins of quality improvement. We heartily express our appreciation to Sr. Sheila Lyne and Alan Channing, the respective CEOs, for having the vision and courage to make these measures public. We look forward to the day when all radiology centers in Chicago (and the U.S.) pursue such transparency.

Finally, a word about what will come next. For this research to matter, there must be a call to action to eliminate the racial disparities revealed herein and to improve the quality of mammography in Chicago. We asked three of Chicago's most prominent leaders of medical care and public health if they would chair a city-wide Task Force to pursue these tasks. All three agreed. They are:

- Ruth Rothstein – Former CEO of the Cook County Bureau of Health Services, current President of the Board of Directors, Rosalind Franklin University of Medicine and Science

- Sheila Lyne, RSM – CEO of Mercy Hospital and Medical Center, former Commissioner, Chicago Department of Public Health

- Donna Thompson – CEO of Access Community Health Network, the largest FQHC Group in the United States

These three co-chairs will proceed in the following manner. In December, a call will go out to all people interested in breast cancer quality and disparities in Chicago to attend a Summit that will be held in February, 2007. This Summit will constitute the founding meeting of the Task Force. The Task Force will then define its course and present a written report to the people of Chicago by December 31, 2007. The thrust and content of the report will be specific recommendations that will describe how we can improve the quality of mammography in Chicago and how we can eliminate racial disparities in breast cancer mortality.

Table of Contents

Executive Summary

Introduction

The following report, *Breast Cancer in Chicago: Improving Mammography Quality and Eliminating Disparities*, presents a comprehensive look at the epidemiology of breast cancer in Chicago. As far as we can determine, it is the first such report of its kind to be undertaken for the city.

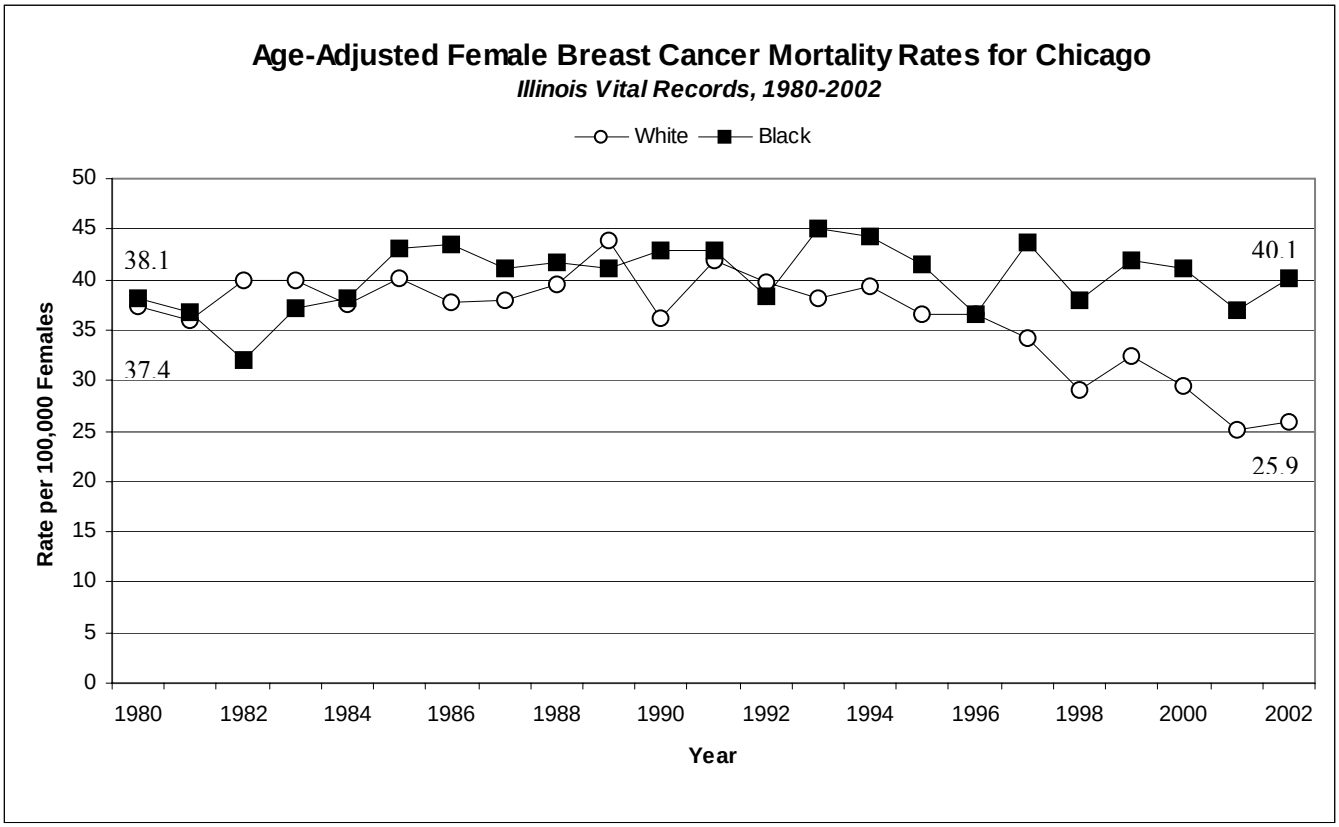
In order to generate the epidemiological profile that follows, we obtained and analyzed the Chicago portions of data from the Illinois State Cancer Registry, Illinois Vital Records files, the Illinois Behavioral Risk Factor Surveillance System, and the United States Census. Parts II and III contain information related to possible action steps.

Results

The central finding that cannot be overemphasized is contained in the figure below. Breast cancer mortality rates for African-American women and white women were the same in 1980, at about 38 per 100,000 women. By 2002 (the last year for which data were available), the rate for white women had declined significantly to 26 per 100,000 while the rate for African-American women had not improved at all; in fact it had risen slightly to 40 per 100,000. Thus, in 2002 the breast cancer mortality rate for African-American women was 54% higher than the rate for white women.

Although advances in mammography screening and breast cancer treatment in Chicago have benefited white women over the last 22 years, these advances have not helped reduce breast cancer mortality for African-American women at all.

All of this is compounded by the fact that white women actually have a higher incidence of breast cancer; that is, they get breast cancer more often. For example, in the latest five-year interval of data, the breast cancer incidence rate for African-American women was 126 per 100,000 and the incidence rate for white women was 149 per 100,000. Thus, although white women get breast cancer at a rate that is 18% higher, African-American women die from it far more often.



Detection of breast cancer is most useful if it occurs at an early stage. The proportion of breast cancers detected at an early stage has been increasing for both white and African-American women, but the early cancer incidence rate for African-American women is still only 69% of the rate for white women, indicating that African-American women are far more likely to be diagnosed in a later stage.

Finally, surveys of self-reported data show that most African-American and white women report having had a mammogram in the past two years (the standard question asked in this field). This, however, is inconsistent with the much later stage diagnosis for African-American women. Two important recent studies suggest that this incongruity is due to the fact that African-American women tend to over-report mammography, and that a substantial gap in access to mammography remains despite the fact that most studies of self-reported mammography data show no such gaps.

Implications

Some researchers suggest that differential biology and genetics between African-American and white women might be responsible for the differential mortality delineated in this report. Upon thorough examination of the literature, it becomes clear that even if there are some biological differences between the races across the breast cancer spectrum (and we are highly skeptical of the evidence of this), these differences, according even to the studies themselves, can account for only a small percentage of differences in outcomes. Thus, we must ask ourselves, what is responsible for the dramatic inequities we see in breast cancer mortality?

We pose three potentially valid explanations. With each, there are important implications for action.

1. **The mammography screenings received by African-American women might be of less than optimal quality.** (We explore this issue throughout this report.) This hypothesis should not be surprising since literally hundreds of studies, including a prominent Institute of Medicine report, conclude that African-Americans receive inferior care as indicated by many other health care measures. This hypothesis could be readily examined by utilizing the mammography quality indicators recommended by the American College of Radiology. There is anecdotal evidence in Chicago to support the hypothesis that poor quality mammography could be contributing to higher breast cancer mortality. We thus suggest that radiology centers providing mammography in Chicago compile their outcomes using the recommended American College of Radiology indicators, publicly share them, and then employ them to continuously and transparently improve quality. Parts II and III present these indicators.

2. **African-American women may receive delayed or less effective treatment for breast cancer once it is diagnosed.** This would be true in general and would likely become even more of an issue because the later the stage of the diagnosed cancer, the more treatment is needed and the more complicated such treatment will be.

3. **It may be that, despite surveys of self-reported mammography use showing equal use between African-American and white women, African-American women are still receiving fewer mammograms.** This is an empirical question and further studies should be implemented to determine the correct answer. It is foolish for us to be using studies that give us wrong answers simply because they are easier to conduct.

Conclusion

The racial disparity in breast cancer mortality in Chicago is morally wrong, medically unacceptable, and reversible. The larger medical community throughout Chicago must join together to repair this situation. This report includes solid recommendations for how to do this. The knowledge, tools, and data are there. The medical community must now have the will to take the necessary steps to measure, collect, and report that data; collaborate with one another and with the American College of Radiology; enact the necessary quality improvement programs; and conduct proactive patient follow-up. In eliminating these disparities, we will also increase quality for all women. The people we serve deserve no less.

Part I

The Black:White Disparity in Breast Cancer Mortality:

The Example of Chicago

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Abstract

Background

The black:white disparity in breast cancer mortality has been increasing in both the U.S. and Chicago. In order to gain insight into this disparity, we examined mortality data together with other important measures associated with breast cancer.

Methods

Trends in black:white female breast cancer mortality, incidence, stage at diagnosis, and mammography screening in Chicago were examined using data from the Illinois State Cancer Registry, Illinois Department of Public Health Vital Records, and the Illinois Behavioral Risk Factor Surveillance System.

Results

The breast cancer mortality for black women in Chicago is 39% higher than that of white women, but the disparity is a recent phenomenon. Mortality rates were similar in the 1980's and only started to diverge in the 1990's as a result of a sharp improvement in mortality among white women contrasted with no improvement for black women. This lack of progress for black women is perplexing given that self-reported mammography screening rates have been the same for blacks and whites in Chicago since at least 1996 and given that the early detection of breast cancer for black women has been increasing.

Conclusions

There has been no improvement in mortality from breast cancer for black women in Chicago in 22 years. This study, along with a review of the literature, lends support to the possibility that the disparities in breast cancer mortality are due to differential quality in mammograms and differential access to treatment for breast cancer. Fortunately, both are amenable to intervention, which would help ameliorate this unacceptable disparity.

Introduction

Breast cancer is the most commonly occurring cancer among women, causing more deaths than any other cancer except for that of the lung *(1,2).* Despite the fact that the Healthy People Initiative, in place for almost three decades, has been calling for the reduction *(3)* and elimination *(4)* of health disparities, there are black:white racial disparities in almost every step of the breast cancer process: from detection to treatment to survival *(5,6,7,8)*.

Recent reports from the National Center for Health Statistics have documented a substantial black:white disparity in breast cancer mortality for the United States, expanding from a rate ratio of near unity in 1980 to 1.36 in 2000 *(9)*. An analysis of black:white disparities for many health indicators showed an even larger increase in the disparity of breast cancer mortality in Chicago between 1990 and 1998 *(10)*.

Such data raise the important question about why the black:white disparity in breast cancer mortality is increasing at a time when the nation is striving to decrease disparities. For example, eliminating the breast cancer mortality disparity is one of the six areas selected for special concentration in the Healthy People 2010 pursuits *(11)* and the National Cancer Institute has named Overcoming Cancer Disparities as one of its 2015 Challenge Goals *(12)*.

This profile thus presents the trends in screening, incidence, stage of diagnosis, and mortality from breast cancer for Chicago. It will, we hope, delineate possible explanations for the black:white breast cancer mortality disparity, suggest interventions for improved detection and treatment of breast cancer and, eventually, allow us to eliminate disparities in this area.

Methods

According to the 2000 Census, Chicago is the third largest city in the United States with almost 3,000,000 people, of whom 16% are non-Hispanic white females and 20% are non-Hispanic black females *(13)*. To examine the incidence, stage of diagnosis, mortality, and screening of female breast cancer in Chicago, we used the following three data sources: Illinois State Cancer Registry, Illinois Department of Public Health Vital Records tapes, and the Illinois Behavioral Risk Factor Surveillance System.

Data sources

The Illinois State Cancer Registry (ISCR) was employed to analyze female breast cancers diagnosed between 1986 and 2002 in Chicago. ISCR is the population-based tumor registry for the State of Illinois and has had an estimated 88% statewide coverage since 1986 and greater than 97% coverage since 1994 *(14)*. Cancers in the ISCR are coded using ICD-O-2 (1986 through 2000) and ICD-O-3 (2001 and 2002) *(15,16)*. Tumors in the registry are assigned a stage of disease code (in situ, localized, regional, and distant) *(17)*. Consistent with national and state methodology, female breast cancer counts and rates in our analyses include only localized, regional, and distant-staged disease (i.e., invasive cancers). In situ cancers, when discussed, are presented separately.

To analyze female breast cancer mortality between 1980 and 2002 in Chicago, vital statistics data were obtained from the Illinois Department of Public Health Vital Records tapes (death files). Breast cancer deaths were identified using the ICD-9 (1980-1998) and ICD-10 (1999-2002) codes for "malignant neoplasm of the breast" *(18,19)*.

Mammography screening proportions (1996-2002) for women over 40 years of age were determined using Chicago data from the

Illinois Behavioral Risk Factor Surveillance System (BRFSS). Details regarding the methodology of the survey are available elsewhere *(20)*.

All data were provided to us without any personal identifying information.

Statistical analysis

Incidence and mortality rates were directly age-adjusted to the 2000 U.S. standard population and expressed as the number of cases or deaths per 100,000 population. Exponential interpolation between 1980, 1990, and 2000 U.S. Census figures for Chicago females was used to estimate population denominators for intercensal years. Estimates for 2001 and 2002 population denominators were provided by the Illinois Center for Health Statistics of the Illinois Department of Public Health. All measures were calculated separately for non-Hispanic blacks (hereafter referred to as blacks) and non-Hispanic whites (whites). In order to be consistent with rates published by the National Cancer Institute *(21)* and the Illinois Department of Public Health *(22)*, five-year average annual rates (1998–2002) were used in our analysis to discuss recent incidence and mortality rates for female breast cancer. Black:white rate ratios (calculated as the black rate divided by the white rate) were used to measure racial disparities.

We examined the temporal trend in age-adjusted incidence (1986-2002) and mortality rates (1980-2002) using a joinpoint regression model *(23)*. Each joinpoint denotes a statistically significant change in trend (straight line on a log scale). The overall significance was set at p=0.05 with a maximum of three joinpoints allowed. The annual percent change (APC) was used to describe the trend for each segment. We also examined the temporal trend in female breast cancer incidence rates by stage of the disease at time of diagnosis (localized, regional, distant).

The stage of disease code was also used to examine trends in the early detection of breast cancer. Specifically, early detection was defined as the incidence of in situ and localized tumors diagnosed per 100,000 women. The decision to combine the in situ and localized tumors as indicative of early detection was based on previously reported studies *(24, 25, 26)*. Tumor size, the other

Table 1. Female Breast Cancer Mortality and Incidence by Age, Chicago, 1998-2002

	Less than 50 Years			50 Years and Older			Total		
	%[a]	*Rate*[b]	*95% CI*[c]	*%*	*Rate*	*95% CI*	*%*	*Rate*	*95% CI*
Mortality									
White	8.3	4.8	3.7, 5.9	91.7	90.4	86.0, 94.8	100.0	28.4	26.5, 30.3
Black	20.6	11.2	9.7, 12.7	79.4	114.0	108.9, 119.1	100.0	39.6	37.2, 42.0
RR[d]		2.34	1.85, 2.95		1.26	1.15, 5.37		1.39	1.28, 1.52
Incidence									
White	18.6	49.4	46.0, 52.9	81.4	408.1	397.2, 418.9	100.0	148.5	144.0, 153.1
Black	25.4	44.4	41.4, 47.3	74.6	340.9	331.4, 350.4	100.0	126.3	122.1, 130.6
RR[d]		0.90	0.82, 0.99		0.84	0.79, 0.87		0.85	0.81, 0.89

[a] Proportion of deaths/cases
[b] Age-adjusted mortality or incidence rate per 100,000 women
[c] The 95% confidence interval for the age-adjusted rate or the black:white rate ratio
[d] Black:white rate ratio

Table 2. Trends in Breast Cancer Mortality and Incidence by Stage at Diagnosis, Chicago, 1986-2002

	Line Segment 1			*Line Segment 2*		
Race/Stage	**Years**	**APC[a]**	**95% CI[b]**	**Years**	**APC**	**95% CI**
Mortality						
White	1980-1994	0.3	-0.4, 1.1	1994-2002	-5.5*	-7.4, -3.5
Black	1980-1986	3.5	-0.2, 7.3	1986-2002	-0.4	-1.2, 0.3
Incidence						
White						
All stages	1986-2002	-0.0	-0.4, 0.3			
Localized	1986-2002	0.7*	0.1, 1.3			
Regional	1986-2002	-0.9*	-1.4, -0.4			
Distant	1986-2002	-2.8*	-3.6, -2.0			
Black						
All stages	1986-2002	1.2*	0.6, 1.7			
Localized	1986-2002	1.8*	1.2, 2.4			
Regional	1986-2002	0.6	-0.3, 1.4			
Distant	1986-1992	-5.9*	-10.2, -1.4	1992-2002	-1.1	-3.3, 1.2

* The APC, Annual Percent Change, is statistically different from zero ($p<0.05$)

[a] APC is based on rates age-adjusted to the 2000 US standard population and is determined by joinpoint regression program, with a maximum of three joinpoints (i.e., four line segments)

[b] The 95% confidence interval for the APC

commonly used marker of cancer-development, was not available since the ISCR did not include it before 1995 and the data collected on tumor size since then has been of questionable quality. For example, in 2002, tumor size was only known in 51% of the cases. Thus, for the purposes of this study, early detection was defined to include in situ as well as localized tumors, whereas late detection was defined to include tumors of regional spread and distant metastasis. Where proportions of early stage cancers are presented, they were calculated by excluding those with unknown or missing stage (about 5% of reported cancers).

The incidence of in situ cancers was also examined as an indicator of tumor detection by mammography screening *(27,28)*. This is consistent with a recent study that proposed the utility of using in situ cancers to compare mammography rates in different geographic areas *(29)*. Joinpoint regression and the APC were used to describe changes in trends in the incidence of in situ cancers and the incidence of breast cancers detected early.

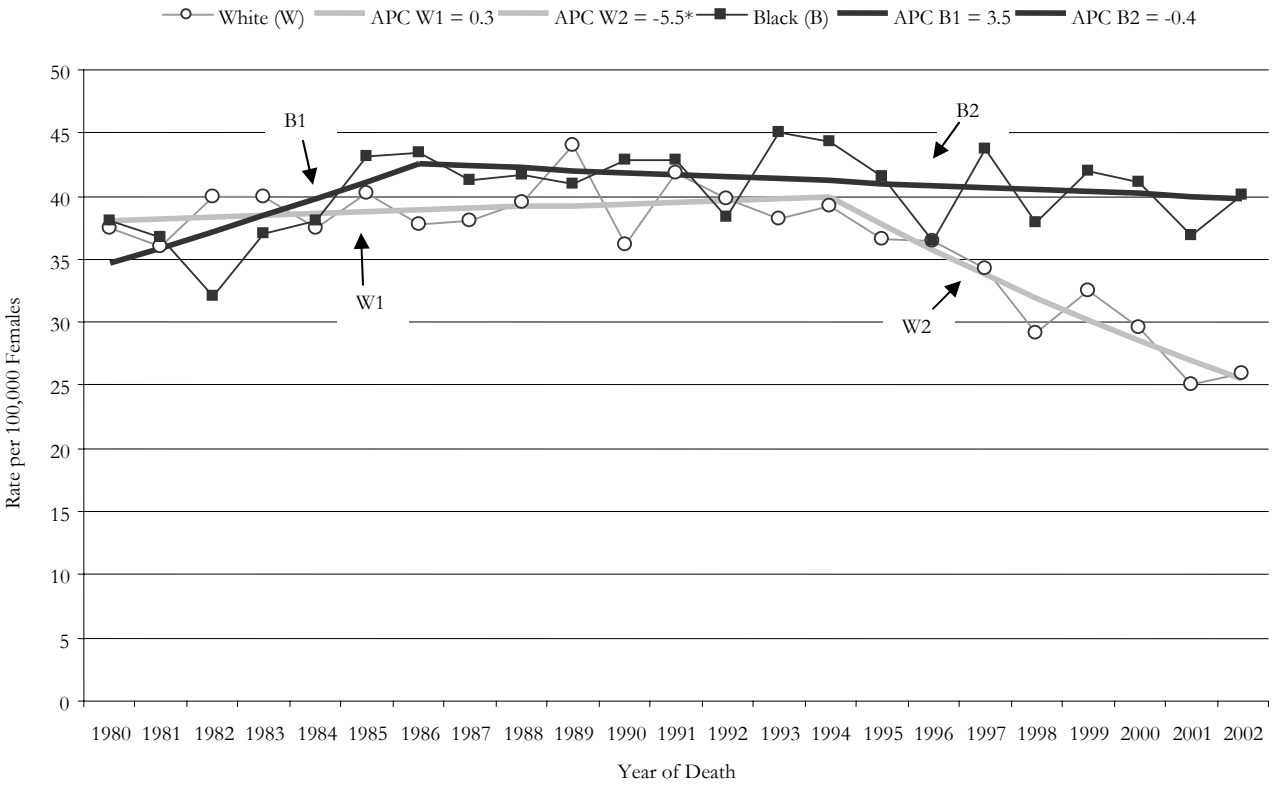
For all measures, 95 percent confidence intervals were calculated and tests of significance carried out at p=0.05 *(30,31)*.

Results

Mortality

The death rate from breast cancer is 39% higher in black women in Chicago than white women (RR = 1.39; 95% CI 1.28, 1.52) (Table 1). The same dynamic exists in the United States (RR = 1.32) *(21)*, but the disparity is even greater in Chicago. As Table 1 indicates, a higher proportion of black women die from breast cancer at a younger age. Specifically, 20.6% of breast cancer deaths in black women were in women less than 50 years of age compared to 8.3% for white women. However, for both women less than 50 years and women 50 years and older, black women have higher mortality rates.

Figure 1. Female Breast Cancer Mortality Rates,[a] Chicago, 1980 to 2002



* The APC, Annual Percent Change, is statistically different from zero ($p<0.05$)
[a] Rates are age-adjusted to the 2000 US Standard Population

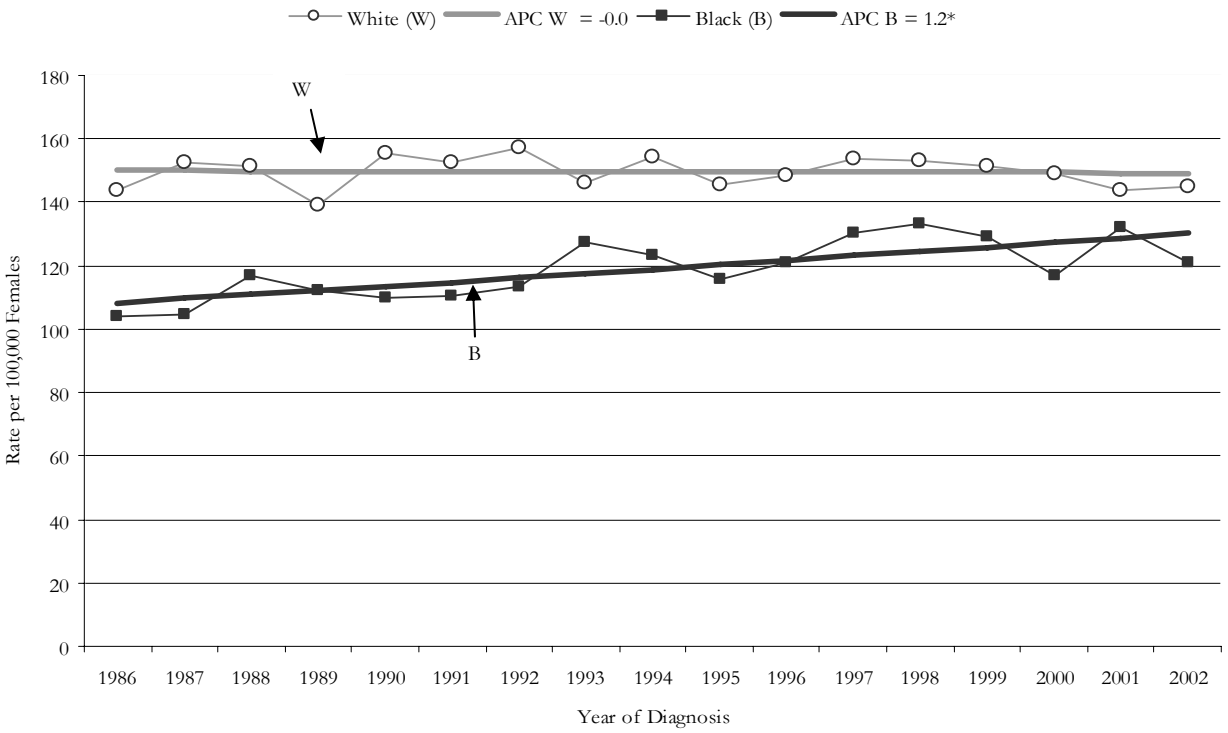
The black:white disparity in breast cancer mortality seen in Chicago in recent years stands in contrast to the more equitable mortality rates between black and white women seen prior to the 1990's (Figure 1).

Since the 1990's, however, there has been an increasing divergence in the rates. In particular, mortality rates in white women remained constant between 1980-1994 (APC = 0.3, $p > 0.05$), then dramatically decreased 5.5% per year since 1994 ($p < 0.05$) (Table 2). Black women in Chicago, in contrast, saw their rates increase 3.5% per year from 1980 to 1986 (but not significantly so) and then stabilize since 1986 (APC = -0.4, 95% CI -1.2, 0.3). Notably, the breast cancer mortality rate for black women increased slightly between 1980 (38.1) and 2002 (40.1) while the white rate fell by 31%, from 37.4 to 25.9.

Incidence

In contrast to their higher death rates, black women in Chicago have a lower incidence of breast cancer compared to white women (RR = 0.85; 95% CI 0.81, 0.89) (Table 1). When considering incidence rates by age, a higher proportion of black women (25.4%) are diagnosed with breast cancer at a young age compared to white women in Chicago (18.6%). Despite the higher proportion of breast cancers diagnosed in younger black women, the actual incidence of breast cancer in women less than 50 years old is still slightly lower for black women (RR = 0.90; 95% CI 0.82, 0.99).

Figure 2. Female Breast Cancer Incidence Rates,[a] Chicago, 1986 to 2002



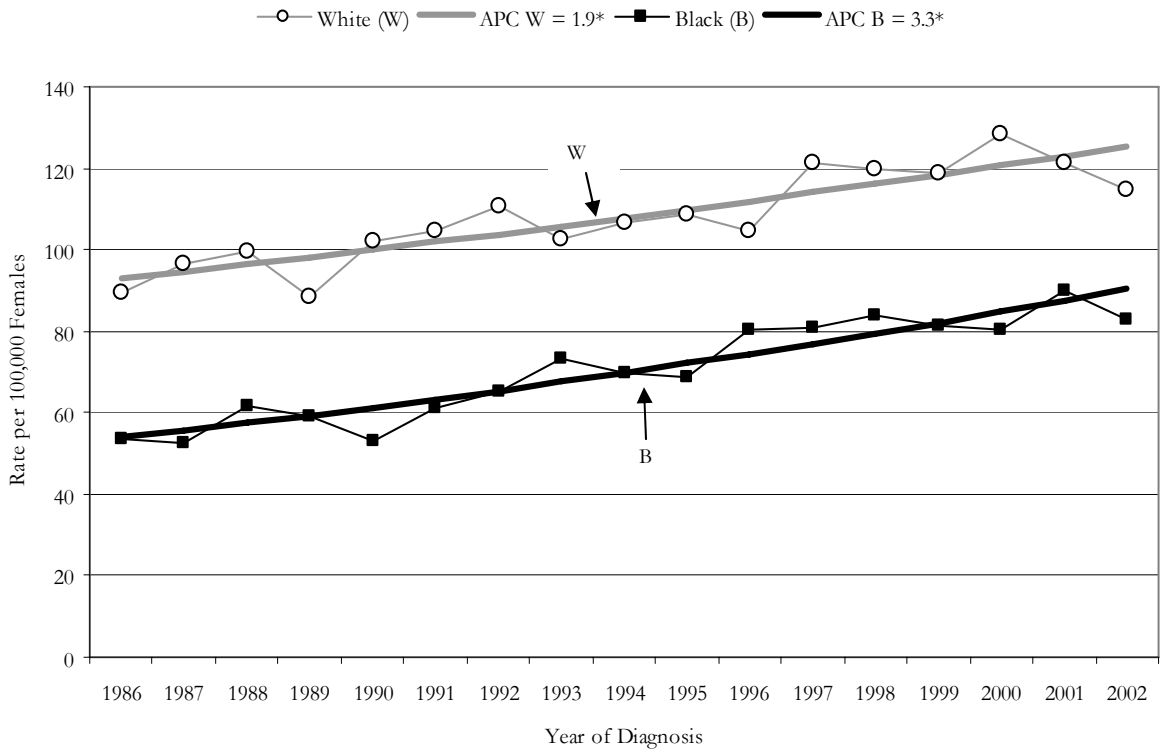
***** The APC, Annual Percent Change, is statistically different from zero ($p<0.05$)
[a] Rates are age-adjusted to the 2000 US Standard Population

Since 1986, breast cancer incidence rates for white women in Chicago have varied slightly but resulted in an APC = -0.0 overall. In contrast, incidence rates for black women in Chicago have been steadily increasing by 1.2% per year ($p < 0.05$) (Figure 2) with much of this due to an increase in localized-staged disease (1.8%, $p < 0.05$) (Table 2). Rates for localized-staged disease also increased for white women in the same time period, a modest but significant 0.7%. In contrast, the rates of regional-staged disease decreased for white women by –0.9% ($p < 0.05$), while levels of regional-staged disease remained constant for black women. Rates of distant-staged disease decreased for both white and black women from 1986 to 1992, but the rates stabilized for black women after 1992 while continuing to decline for white women.

Early detection

Since 1986, the incidence of early stage breast cancer has increased appreciably for both black and white women. For black women the increase was 3.3% per year ($p<0.05$), while for white women it was 1.9% ($p<0.05$) (Figure 3). However, there still exists a substantial black:white disparity in the early detection of breast cancers (1998-2002; RR = 0.69; 95% CI 0.66, 0.73; data not shown). Consequently, black women in Chicago are more likely than white women to be diagnosed with late stage disease.

Figure 3. Female Breast Cancer Incidence Rates at an Early Stage at Diagnosis,[a,b] Chicago, 1986 to 2002



* The APC, Annual Percent Change, is statistically different from zero ($p<0.05$)
[a] Rates are age-adjusted to the 2000 US Standard Population
[b] Early stage at diagnosis is defined as either in situ or localized-staged disease

Use of mammography

In Chicago, the proportion of black women age 40 and older that report having a mammogram in the last two years has been similar to (or higher than) that of white women since 1996, the first year that such data have been available (Figure 4). Since 1986, there has also been an increase in the incidence of in situ breast cancers for both white and black women (Figure 5). Overall, rates of in situ cancers have been increasing 6.7% per year in white women ($p<0.05$) and 9.7% in black women ($p<0.05$). However, as impressive as the increase in the incidence of in situ cancers is for black women in Chicago, it still lags behind the rate for white women (1998-2002; RR = 0.67; 95% CI: 0.64, 0.70; data not shown).

Discussion

Findings

Our profile of female breast cancer has allowed us to make several important observations about the black:white disparity in breast cancer mortality in Chicago. To begin, we found that, as in the rest of the U.S., breast cancer mortality is higher for black women than for white women in Chicago, confirming and extending the findings of

Figure 4. Proportion of Women 40 Years of Age and Older Who Report Having Had a Mammogram in the Past Two Years, Chicago, 1996 to 2002

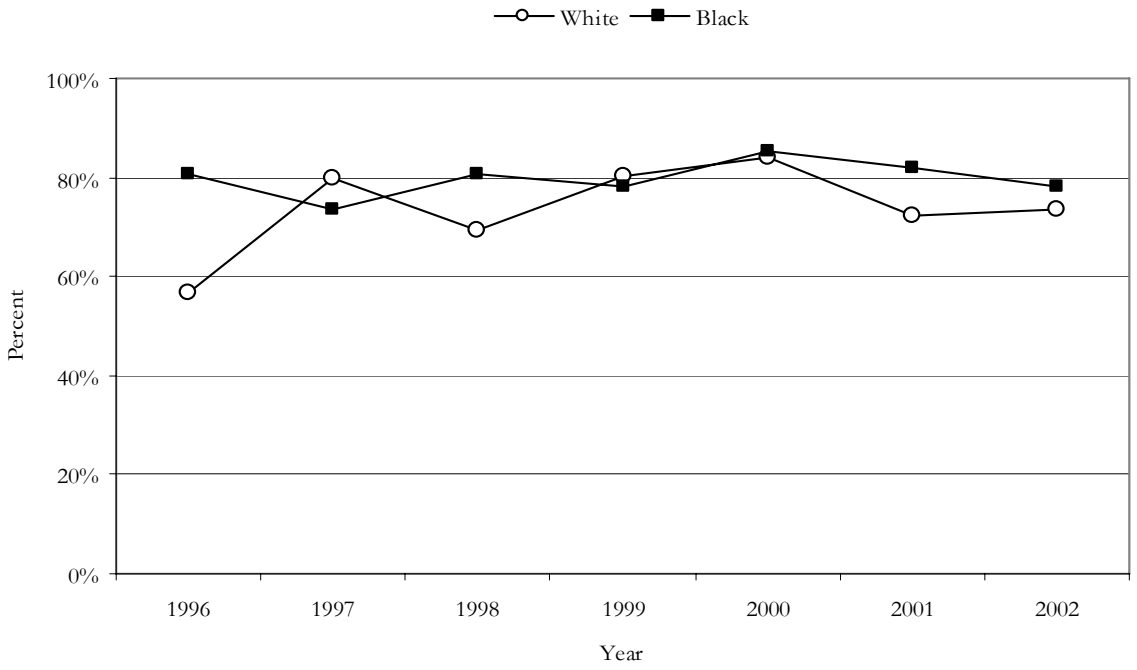
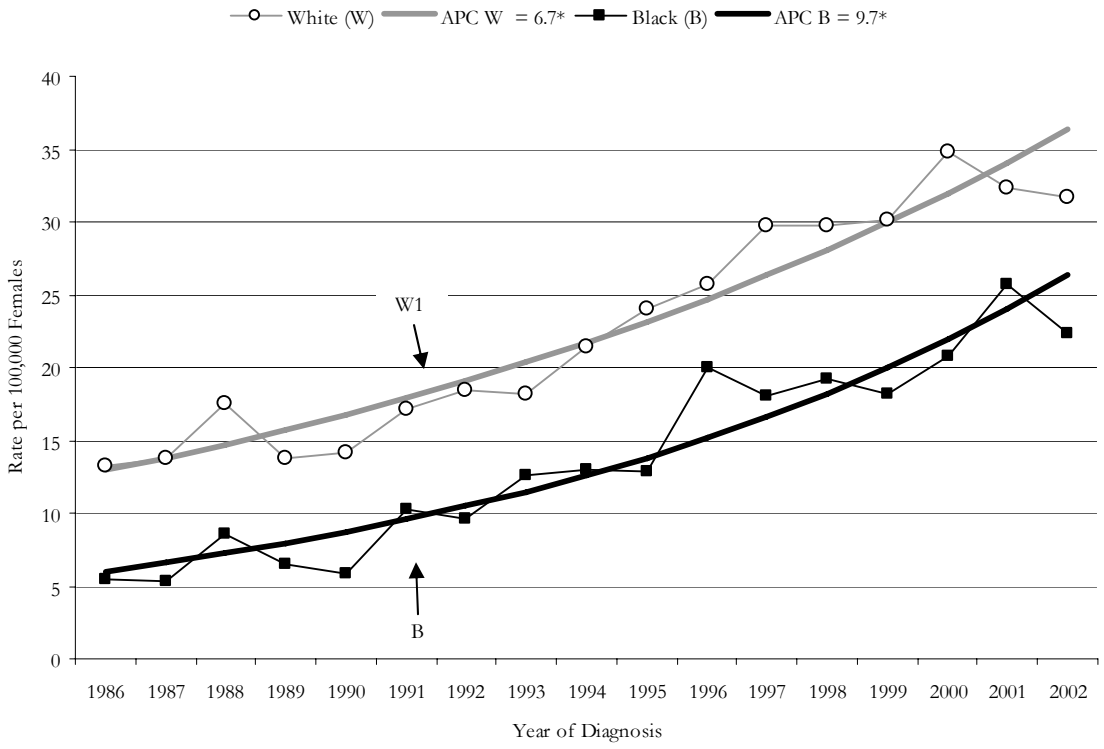


Figure 5. Female In Situ Breast Cancer Incidence Rates, Chicago, 1986 to 2002



* The APC, Annual Percent Change, is statistically different from zero ($p<0.05$)

Margellos et al *(10)*. In addition, this study adds the observation that the disparity in breast cancer mortality in Chicago is a relatively recent phenomenon. We found that the black and white mortality rates only started to diverge in the 1990's, and that this divergence was the result of a sharp improvement in mortality among white women contrasted with no improvement for black women (Figure 1).

In other words, in 22 years, despite substantial national and local efforts to reduce breast cancer mortality among black women by promotion of mammography *(32)* and advances in therapy*(33)*, we have not been able to improve mortality from breast cancer for black women in Chicago even though we have been able to improve it dramatically for white women. This is markedly different from other disparities in health where, while gaps persist (for example, in cardiovascular disease mortality), reductions in mortality have been seen for both races *(34,35)*.

The failure to find a reduction in breast cancer mortality among black women in Chicago is more perplexing given three other observations from our profile. First, self-reported mammography screening rates have been the same for blacks and whites in Chicago since at least 1996 (Figure 4). Second, black early breast cancer incidence rates have been increasing over time (Figure 3) as has the incidence of in situ cancer (Figure 5) while the incidence of distant breast cancers among black women has decreased (Table 2). Why has breast cancer mortality not been reduced by the growth of this early detection? Third, while the in situ and early breast cancer incidence rates have risen among black women they have lagged behind that of whites despite equivalent self-reported mammography rates. If screening rates are the same, should not early detection rates be equivalent as well?

While our data do not directly provide the answers to these questions there are only a limited number of possible explanations. Some of these explanations are related to mammography. We discuss these first.

The first mammography-related explanation is that self-reported mammography rates may not be accurate. Chicago BRFSS data show no differences in the proportions of black and white women over 40 who have received mammograms in the past two years (Figure 4). Similar findings have been reported for virtually all local and national surveys *(36,37)*. However, the data presented in this paper indicate that large disparities in early breast cancer detection rates and in situ detection rates persist. This observation is inconsistent with equivalent screening rates. In this context it is important to note that substantial literature suggests that self-reported mammography rates may be problematic *(38,39,40,41,42,43,44)* since poor and black women tend to over-report mammography rates by as much as 25-30% *(45)*.

A second possible mammography-related explanation for the conflicting information explicated in this analysis is that the mammography rates measured by receipt of a mammogram in the past two years may be correct, but black women may be less likely to receive an optimal mammography sequence like two mammograms in three years or three in five years. If black women are less likely than whites to receive adequately sequential mammograms, then mortality might not be affected even in the face of equal screening rates within the past two years. Unfortunately, sequential mammography screening data are rarely collected *(46)* making this hypothesis difficult to examine.

Nevertheless, the relationship between adequate utilization of screening mammography (measured by medical record rather than by self-report) and early and small tumor detection has recently been confirmed in a study examining breast cancer outcomes from more than one million women. Smith-Bindman and her colleagues found that black women were less likely than white women to have received adequate mammogram screening. However, when recency of mammography was controlled for, the disparities in early and small tumors were generally eliminated *(47)*.

A third possible mammography-related explanation, which is rarely discussed in the literature, concerns differential quality in mammography screening. For example, it may be that black women are getting mammograms as often as white women, but that the mammograms are of poorer quality. This poor quality could manifest itself in the administration of the mammogram (e.g., positioning), quality of the film, quality of the machine, quality of the radiologist, quality of the follow-up for abnormal screens, etc.

Some evidence suggests that such inferior quality may indeed exist in some locations. For many screening mammography series, the breast cancer detection rate has been in the range 0.005 – 0.007 *(47,48,49,50)*. Such values depend, of course, on many factors such as previous screening experiences, age, etc. However, these rates may be seen as good averages that one might expect for general series of population screens.

At one Chicago organization that serves low-income women, and where one of us worked, 15,501 mammograms were provided and only 37 breast cancers were detected for a rate of 0.0024. In other words, poor screening quality may have led to many undiagnosed cases at this site. In another example, the New York State Health Department audited a clinic that performs mammography in New York City after it came under suspicion for missing breast cancers. It was found that the breast cancer detection rate there was 0.001. After recalling 4,500 women who had already been screened at that clinic an additional 25 breast cancers were found *(51,52)*.

Taken together these observations suggest that a disparity in mammography quality may be a plausible hypothesis in explaining at least some of the black:white disparity in breast cancer mortality. However, we have been able to locate just one published report examining this hypothesis *(53)*. Differential quality in mammography could explain at least some of the black:white breast cancer mortality disparity. Yet, this issue has been explored in only one study despite the fact that black:white disparities in health care quality have been demonstrated in dozens of areas *(54,55,56,57)*.

There are, of course, other explanatory hypotheses for the black:white disparity in breast cancer mortality that are not related to mammography. One that is widely cited in the literature maintains that black:white biological differences in breast cancers are responsible for the differentials in the black:white incidence of early breast cancer and mortality, suggesting that breast cancer in black women is biologically more aggressive than that in whites *(58,59)*. However, biological differences could not explain the difference in stage at diagnosis unless one presumes that mammography screening is inefficacious in black women. Also, mortality rates only began to diverge for black and white women in Chicago in the past eight years, and similarly recently in Ohio *(60)* and the entire US *(61)*. This suggests that something other than biology, such as screening and treatment, might be the operant variable *(33)*. Finally, in randomized

controlled trials of breast cancer treatment, black women have had similar survival rates as white women *(62)*. Such information suggests that biological differences may be overemphasized as causal factors for black breast cancer mortality.

Another explanation that is offered concerns the differences in racial dynamics in breast cancer for those women under 50 and those 50 or older *(46,59)*. However, it is obvious from Table 1 that whatever one makes of this phenomenon, it could only impact on the larger question of black:white mortality disparities in a minor way since women under 50 constitute only a small part of the picture (21% of the black deaths and 8% of the white deaths) and substantial mortality disparities remain even after controlling for this age effect.

Finally, differential access to treatment and quality of care almost certainly explain part of the black:white differences in breast cancer mortality *(8,33,63)*. There is a body of literature that suggests that the quality of care for black and poor women diagnosed with breast cancer is different than that for whites. For example, black and poor women are more likely to experience delays in diagnosis and treatment and less likely to receive evidence-based treatment *(8,63,64)*.

Methodological Considerations

Our study has some limitations. First, vital records data and cancer registry data are regarded as some of the most complete and accurate of the public health data sources; however, neither adequately collects information on variables that may be of importance in breast cancer epidemiology, such as the women's socioeconomic status and co-morbid conditions. ISCR also does not have information on tumor size, tumor histology, hormone receptors, treatments received, or subsequent survival. Without such data it is not possible to know the extent to which the black:white disparities found in our study are explained by these factors.

Conclusions

Chicago, struggling to meet the Healthy People 2010 and National Cancer Institute 2015 Challenge Goals of eliminating disparities in breast cancer mortality, is an obvious setting for an attempt to improve racial inequities in breast cancer mortality. It is our hope that this profile will help stimulate the health care community in the city (and elsewhere as well) to investigate why the mortality rate for black women is not improving – especially at a time when the white mortality rate is decreasing so significantly. The analyses presented here represent only the first step. Thus, we offer some specific suggestions for pursuing racial equality in breast cancer mortality (see Box).

We hope this analysis helps give direction to the future development and funding of research and interventions to address the issues examined in this paper. This profile lends support to the possibility that the disparities in breast cancer mortality may be due to differential quality in mammograms and differential access to treatment for breast cancer, which is consistent with the findings from a recent prominent report *(34)*. Fortunately, both access to treatment and screening are amenable to intervention. Eliminating differences in quality and access has the potential to appreciably reduce disparities in breast cancer mortality.

As noted by Brawley and Freeman, "Deep ethical and moral questions [are raised] concerning how the research community, the American health care system, and society as a whole will move toward providing remedies for this unacceptable reality [disparities in health]" *(75)*. As Brawley wrote a few years later in an editorial about disparities in breast

Suggestions for pursuing racial equality in breast cancer mortality:

1) A definitive answer must be developed as to whether self-reported mammography experience is valid for different race and ethnic groups. Such an answer may be provided by meta-analyses or substantive detailed studies that examine this question. The recent paper by Kagay et al. is one example *(44)*. If self-reported mammography is found to be invalid then it should be discarded as a measure of this experience.

2) All studies that gather information about mammography use should measure not only receipt in the past two years, but some form of sequence. We suggest gathering data about the number of mammograms in the past three years or even the past five years.

3) Measures of mammography quality *(65,66,67)* should be examined and utilized by all mammography centers. Consistent with Recommendation 1 in the Institute of Medicine's recent study *(68)*, we suggest that the cancer detection rate per 1,000 screening mammograms be employed as at least one of the measures. As noted above, many studies suggest that this rate should be about 5-7 per 1,000. The two egregious examples we note above produced rates of 2.4 and 1.0. The calculation and display of this metric is part of a much larger quality improvement pursuit that often goes under the title of "transparency" *(69)* and is consistent with Recommendation 2 of the Institute of Medicine report *(68)*.

4) Many papers discuss racial differences in breast cancer biology *(70,71)*. This area of study concerns us given the historic misuse of biological differences and given that there is substantial literature which refutes the notion of the existence of "races" as biological groups as opposed to socially constructed ones *(72,73,74)*. We do not suggest here that biological factors in racial disparities in breast cancer mortality (or any other topic) cannot be discussed. We do mean, however, that such areas of investigation carry with them a greater burden of clarity and proof.

cancer outcomes, "The disparity remains an unacceptable reality, and it is an unsettling truth that we, as a society, have made meager efforts to even recognizing the problem. The solutions are not simple, but we must try" *(61)*.

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Part II

Quality and Mammography

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Introduction

Research has shown that screening mammography can reduce breast cancer mortality by 30% *(1,2)*. However, this is not nearly a foregone conclusion. Benefits from mammography will only occur under certain circumstances indicative of high quality. Research suggests that achieving these benefits is dependent on several factors, as described in the box below.

While the American College of Radiology (ACR) in 1998 instituted the Mammography Quality Standards Act requiring specific standards for accreditation, significant variation in the quality of facilities remain. Often mammograms reviewed for accreditation are pre-selected by the facility seeking accreditation and may not represent the typical work. And while the ACR recommends guidelines for Radiologists to use to evaluate their work, these guidelines are voluntary. That is, they are not requirements for accreditation.

At the center of mammography quality standards is a numbering system that describes the likelihood of abnormal findings (including cancer) on a mammogram. The system is called the Breast Imaging Reporting and Data System and is referred to as BI-RADS *(3)*. This system, which is essential for the following discussion, places a number 0 – 6 on each mammogram (Table 1).

The main six ACR recommended guidelines for a quality mammography program are presented in Table 2, along with the benchmarks for excellence *(4)*. When patients present for routine screening

Criteria for High Quality Mammography

- First, high quality breast screening programs are those that maintain meticulous quality control and closely monitor the equipment, film, and processing of the mammograms.
- Second, it is critical to employ highly skilled technologists who are experienced in appropriately positioning patients and applying the necessary compression.
- Third, a successful program will detect minimal cancers. This is dependent on the experience of the Radiologists who interpret the mammograms. Research has demonstrated that Radiologists who specialize in mammography and those who read many mammograms as part of their practice are more likely to be able to find small cancers than those who do not fit these characteristics.
- Fourth, a high quality program will not lose patients to follow-up. If it does, then these patients may have breast cancer and not even be aware of it. It is thus important to maintain tracking programs which ensure that patients are not lost to follow-up and which facilitate more rapid diagnosis and treatment.
- Fifth, patients presenting for annual mammography allow for the detection of smaller, incident (new) cancers as opposed to the larger cancers often found when patients delay screening.

Table 1. BI-RADS Ratings

BI-RADS Code	Definition
0	More information is needed to give a final mammogram report.
1	Mammogram is normal.
2	Mammogram shows only minor abnormalities that are not suspicious for cancer. No additional testing is needed.
3	Mammogram shows minor abnormalities that are probably benign. The radiologist may recommend follow-up testing in six months to make sure the suspicious area has not changed.
4	Mammogram shows a suspicious change, and a biopsy should probably be performed. However, less than half of women with category 4 mammograms will end up having cancer.
5	Mammogram shows a worrisome change. A biopsy is strongly recommended. More than 90% of women with a category 5 mammogram will end up having cancer.
6	Mammogram indicates cancer.

mammography, the mammogram is typically not evaluated by the Radiologist during the patient's visit. ACR requires that the mammographic interpretation occur within one month of the visit and the patient is required to receive a letter with the results. If an abnormality is noted on the screening mammogram (BI-RADS 0), the patient is requested to return for additional diagnostic evaluation or to provide prior mammograms for comparison. The ACR guidelines specify that the percent of patients recalled for additional evaluation should be 10% or less.

Of the abnormalities noted on screening mammogram which require additional imaging, 5 - 10% are expected to be malignant, based on ACR guidelines. Of the abnormalities evaluated on the subsequent diagnostic work-up and for which biopsy is recommended (BI-RADS 4 and 5), 25-40% are expected to be malignant.

The cancers found on screening mammography vary in size and stage of disease. Minimal cancers, which include ductal carcinoma in-situ and invasive cancers less than or equal to one centimeter in size with no lymph node involvement, provide the best opportunity for long-term, disease free survival. A quality screening program should have over 30% of the cancers detected in this category. Greater than 50% of screening detected cancers are expected to be Stage 0 and 1 (i.e., cancers 2 cm or less in size).

A critical number to consider when evaluating the quality of a mammography program is the cancer detection rate per 1000 mammograms. In most studies the average cancer detection rate is 6-7 per 1000 screening mammograms. The ACR recommends a cancer detection rate between 2 - 10 per 1000 screening mammograms. The lower number reflects incident cancers detected in women who are screened annually. The highest number reflects prevalent cancers in populations who have not been screened previously. Programs which serve women who do not obtain mammograms yearly and which detect cancers less than 4 detected cancers per 1,000 screening mammograms may not be performing at quality standards. See page 11 in the preceding paper for more information on this essential issue.

While the ACR recommends that all

Table 2. American College of Radiology Guidelines for Mammography Quality

Guideline	Benchmark
Percent patients recalled from screening for additional imaging	< 10%
Percent patients with suspicious findings (BI-RADS 4 and 5) and the biopsy demonstrates malignant histology	25 - 40%
Percent minimal cancers (i.e., cancers of small size)	≥ 30%
Percent cancers detected in earliest stages (i.e., Stage 0 and 1)	≥ 50%
Cancer detection rate per 1000 screened	2 - 10
Positive predictive value of an abnormal mammogram (BI-RADS 0)	5 - 10%

mammography programs maintain this data on quality, many programs do not and many do not achieve these standards. And there is no way to know without this data whether a mammography unit is providing excellent quality of care. These are crucial matters because if a program is not providing excellent mammography service, and is thus generating many false-positives and false-negatives, then participating women could be substantially damaged.

A Case Study

This report is concerned with mammography quality and also the disparities in breast cancer outcomes between black and white women. Having discussed above some of the basic concepts in quality, we can now pose the next question. Can some of the racial disparity in black-white breast cancer mortality in Chicago be explained by poorer quality of mammography programs that serve black women in Chicago? We are stimulated to raise this question because of the vast literature that shows that black people usually receive inferior medical care in general *(5,6,7)* and because of the two anecdotes presented in the preceding paper on page 11.

At this point there are no data that can answer this question. However, in 2005, Dr. Paula Grabler, then Director of Mercy Hospital's Comprehensive Breast Care Center, conducted an intensive review of all breast cancers detected through screening at the hospital from 1999 to 2005. This analysis shows that with a high quality mammography program that meets the ACR quality guidelines, the screening results are the same for black and white women. We share this data because the results are rare in demonstrating this equality and also because the array of information serves as a model for how all institutions can produce, display and share their data on mammography. Such "transparency" of medical outcomes is said to be the essence of quality assurance and improvement.

The Mercy Hospital Comprehensive Breast Center: Do black and white women have the same outcomes when they receive high quality mammography?

The Mercy Hospital Comprehensive Breast Center was begun in 1999. Efforts were made to promote annual screening for its patient population and a closely monitored tracking system ensured patient follow-up with only 6% of patients with findings suspicious for malignancy refusing diagnosis or treatment or lost to follow-up. As part of the Center's quality program, all outcomes for screening mammography were tracked. Table 3 presents the Mercy Comprehensive Breast Center's outcomes compared to the ACR's quality measures in the year 2004, the most recent year for which statistics have been completed. Note that these outcomes demonstrate that Mercy Hospital's Comprehensive Breast Center meets or exceeds almost all of the ACR quality standards (benchmarks).

Table 3. Mercy Hospital Comprehensive Breast Center Quality Outcomes and ACR Quality Standards

Guideline	Mercy Results	Benchmark
Percent Screening Mammograms Recalled	11.6%*	10%
Percent of BI-RADS 4 and 5 with Malignant Histology	33.0%	25 - 40%
Percent Minimal Cancers	63.0%	> 30%
Percent Cancers Stage 0 and 1	91.0%	> 50%
Cancer Detection Rate per 1000 Screened	7.5	2 - 10
Positive Predictive Value of an Abnormal Mammogram	7.7%	5 - 10%

Note: * While the recall rate is above the expected national standard, this can be justified by the 7.7% positive predictive value of a recalled mammogram demonstrating malignant findings.

Table 4 presents the racial and ethnic composition of patients with breast cancers diagnosed through screening at Mercy Hospital from 1999 to 2005.

There were a total of 311 patients who had breast cancer identified as a result of screening mammography. Of these, 76 (24%) were white and 196 (63%) were African-American. There were no differences between white and African-American women regarding their mammography histories or breast densities. Importantly, as Table 5 indicates, there was no significant difference in the stage of breast cancer at the time of diagnosis, with early cancer rates (Stage 0 and 1) similar for African-American (49.7%) and white (54.2%) women.

The grade of breast cancer, or how abnormal the breast cancer cells look (the higher the grade the more aggressive the cancer) is an important determinant of breast cancer survival. Next to stage, it is the most important predictor of breast cancer survival with those who have grade 1 cancers having better outcomes than those with grade 3 cancers. There were no statistically significant differences between whites and blacks in the grade of their breast cancers. These results are presented in Table 6.

Besides the stage and grade of the breast cancer, there are other biological factors that are said to affect breast cancer survival. These factors include receptors that sit on the cell of the cancer. For example women with positive estrogen, progesterone receptors, her-2 and ki-67 receptors have better outcomes, with the estrogen receptor status being the most important of the four. At Mercy Hospital between 1999-2005, there were no differences between African-Americans and whites with regard to other prognostic factors such as estrogen receptor status, her-2 receptor, and the ki-67 receptor status. The only favorable prognostic factor that differed for African-American and white women was that white women had statistically significant higher positive progesterone receptor status than African-American women.

Table 4. Race and Ethnicity among Mercy Hospital Breast Cancer Patients, 1999-2005

Race/Ethnicity	Number	Percent
White	76	24%
Black	196	63%
Hispanic	24	8%
Asian	9	3%
Unknown	6	2%
Total	***311***	***100%***

Table 5. Number and Percent of Individuals at Each Stage of Breast Cancer by Race

	Stage					
Race	**0**	**1**	**2**	**3**	**4**	**Total**
White	10 (13.9%)	29 (40.3%)	27 (37.5%)	5 (6.9%)	1 (1.4%)	72 (100%)
Black	30 (15.7%)	65 (34.0%)	75 (39.3%)	17 (8.9%)	4 (2.1%)	191 (100%)

Conclusions

The findings of this study of mammography at Mercy Hospital are different from most other studies of breast cancer screening that almost always suggest that breast cancer in black women has worse biological prognostic factors than for white women. However, as far as we know, this is the first time that the quality of mammography has ever been controlled. While this is a small study from one institution and it only evaluated non-clinically detected breast cancers, the findings of similar clinical prognostic factors between blacks and whites at least gives credence to the possibility that differences in the quality of care might be contributing to black:white breast cancer disparities.

We would welcome the findings from other mammography centers in Chicago and beyond that can present related data on this dynamic.

Table 6. Number and Percent of Individuals at Each Breast Cancer Grade by Race

	Grade				
Race	**1**	**2**	**3**	**Unknown/ Not Available**	**Total**
White	15 (19.7%)	32 (42.1%)	16 (21.0%)	13 (17.1%)	76 (100%)
Black	26 (13.2%)	77 (39.2%)	62 (31.6%)	31 (15.8%)	196 (100%)

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Part III

Measuring Mammography Quality

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Sinai Health System has served Chicago's West Side community for more than 80 years by providing community-based primary care, emergency care, maternal and infant care, women's health care, children's health care, and community programs in prevention and health management.

Sinai Health System has opened its doors to all who need quality health care, including the most vulnerable, those at highest risk of chronic health disorders and large numbers of the uninsured. As a leading urban community health care provider, we have not only made a commitment to provide health care to our community but to conduct groundbreaking community-based research such as this report that can be used to inform our health care delivery systems, as well as guide public policy.

Stand Against Cancer

Mount Sinai Hospital is among the top three leaders in providing breast cancer screenings and diagnostic services for women through the State of Illinois' Stand Against Cancer initiative. Stand Against Cancer is a community outreach and screening program for minority women conducted by a coalition of neighborhood organizations, churches and federally qualified health centers.

Of the 60 women diagnosed with breast cancer at Mount Sinai Hospital in 2005, at least half received *free* mammograms through the Stand Against Cancer program. Without it, they almost certainly would have gone undiagnosed.

Avon Foundation Grant

In 2005, the Avon Foundation awarded Mount Sinai Hospital a three-year $500,000 grant to improve timely diagnostics and access to care for patients with abnormal screening mammograms, to reduce the number of patients lost to follow-up care, and to provide timely care following abnormal screening results.

In Fiscal Year 2005, Mount Sinai Hospital provided $67.8 million in free health care to indigent patients. Almost 60% of our patients are enrolled in Medicaid. An additional 12% have no ability to pay for their care. Studies show that the uninsured are less likely to have a primary care physician and less likely to seek basic primary care, such as breast cancer and other screenings. They are therefore much less likely to be diagnosed, treated early or follow through on referrals to treatment following diagnosis.

Through the project funded by the Avon Foundation grant, we are using a collaborative, multi-disciplinary approach to identifying opportunities for improving breast health services, from screening mammography through breast cancer diagnosis and treatment. Other components of our program include navigation services to reduce barriers to breast health services, improving the prospective treatment planning process, and reducing the loss to follow-up for patients with abnormal mammograms. Due to this collaborative approach and the additional resources provided by Avon, we expect to increase the number of screenings performed, decrease our loss to follow-up rate and improve the quality and coordination of breast health care.

Since the start of the grant, we have developed the structure that will guide our work, selected the outcome measures that will be employed to evaluate our work, and hired a Breast Care Coordinator, a Patient Navigator, and Data Analyst. In addition to these individuals, representatives from medical

Table 1. Breast Cancer Quality Outcomes (2005)

Guideline	Sinai	Mercy	Benchmark[1]
Percent screening mammograms recalled	7.8%	11.6%	10%
Percent of BI-RADS 4, 5 with malignant histology	33%	33%	25-40%
Percent of BI-RADS 0, 4, or 5 with malignant histology[2]	4%	--	5-10%
Percent minimal cancers[3]	17%	63%	>30%
Percent cancers stage 0 or 1	44%	91%	>50%
Cancer detection rate per 1000 screened	4.0	7.5	2-10
Positive Predictive Value of an abnormal mammogram[4]	4.3%	7.7%	5-10%
Avon Specific Measures			
Loss to follow-up			
BI-RADS 0	33%	--	--
BI-RADS 4, 5	7%	--	--
Breast cancer treatment[5] (n=61)		--	--
Lost to follow-up	20%	--	--
Treated at another facility	10%	--	--
Treated at Sinai	64%	--	--
Death prior to treatment	3%	--	--
Patient refused treatment	3%	--	--
Percent of breast cancers not initiating treatment within 30 days of the cancer diagnosis (goal of Sinai's Cancer Committee)	50%	--	--

1. American College of Radiology (ACR) Guidelines for Mammography Quality.
2. In 2005, there were n=609 abnormal mammograms (n=567 BI-RADS 0 and n=42 BI-RADS 4 and 5).
3. Ductal Carcinoma in-situ (DCIS) or invasive cancer diagnosis with tumor ≤ 1cm with no lymph node involvement (not defined by cancer stage)
    a. Five screened breast cancer cases met these criteria (n=3 with DCIS and n=2 with Infiltrating Ductal Carcinoma with no node involvement and tumor size ≤1cm).
4. Positive Predictive Value (PPV_1): How often abnormal screening mammograms result in breast cancer.
    a. PPV_1=(# breast cancers diagnosed)/(# of abnormal screening mammograms)
5. Total number of cancers diagnosed at Sinai Health System, n=61. Total number of asymptomatic breast cancer cases found through Sinai Health System's screening mammography program, n=29.
    a. Breast cancer data are complete through August 15, 2006. Lost to follow-up is defined as not having treatment at Mt. Sinai Hospital or known to be treated at another facility.

onocology, radiation oncology, surgery, internal medicine, radiology, cancer registry, information systems and the hospital's administration actively serve on the Avon Steering Committee.

The long term goal of our program is to maximize the number of women we serve in our breast care programs and to deliver optimal treatment to all women who present at Mount Sinai Hospital for mammography and other breast care activities. Our nurse and patient advocate will identify and follow all women who have abnormal mammograms and those that are subsequently diagnosed and undergo breast cancer treatment. We have selected 31 quality measures that will be regularly reportable to Avon that will allow us to evaluate the progress of our grant. We have also selected another 65 quality measures that we will produce and study ourselves. The important aspect to emphasize here is that none of this work would be possible without the generosity and support of the Avon

Foundation and the thousands of individuals who walk and raise money for the foundation and for that we are extremely grateful.

The table in this part of the report presents various measures of mammography quality. The measures are presented for Mount Sinai and Mercy Hospitals and are aligned with benchmarks set forward by the American College of Radiology. We are not concerned here with analyzing these comparisons, but rather with illustrating how much more we can understand when such data are displayed in this comparative fashion.

Conclusion

Openness and transparency of mammography quality data across institutions is one way for both the public and the institutions themselves to know how they are performing compared to expectations. This open reporting of quality processes is currently being carried out for other health measures (such as pneumonia and heart failure), but is not yet required for mammography or breast cancer treatment. We believe that an open, Chicago-wide sharing of data quality about breast cancer screening and treatment is crucial to achieving the goal of eliminating disparities in breast cancer.