Breaking down death-rate disparity

New breast cancer data show the gap widening between blacks, whites here

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In 1980, black women and white women in Chicago with breast cancer were equally likely to die.

Since then, death rates for white patients have improved dramatically. But that is not the case for their African-American counterparts, who are now dying at a rate 116 percent higher, according to data released Wednesday by the Metropolitan Chicago Breast Cancer Task Force.

Moreover, the gap has widened. Last year, the group analyzed data through 2003 and found a 68 percent higher death rate for black women. The latest study, conducted by researchers at Sinai Urban Health Institute, looked at vital records through 2005, obtained from the Illinois Department of Public Health.

Experts say genetics or biology alone cannot explain the difference. The racial gap in Chicago was twice that of the United States and sevenfold that of New York City.

"It was as if no screening or treatment was going on for black women, which we knew was not true," said Dr. David Ansell, chairman of the task force, made up of 74 health-care groups and more than 100 breast cancer physicians, researchers and advocates.

Black women are less likely to get mammograms, the task force notes, and when they do, the mammograms are more likely to be of inferior quality. Those diagnosed with cancer also are less likely to have access to quality treatment.

Personal finances are a factor, as Carole Alexander knows. She was unemployed and uninsured and had spent the last of her savings on essentials when she was diagnosed with breast cancer in February. She waited two months after finding the lump to have it checked, hoping it would go away. "There are probably a lot of women like me," said Alexander, 54.

Grants are being awarded Wednesday to two local groups working to educate and assist black women. One is Sisters Embracing Life, an Austin-based cancer awareness support group that helps women navigate through the health-care system and find free or low-cost services.

"When you don't have insurance, you feel embarrassed to go to the doctor," said Lula Gordon, founder and president of the group. "I tell women, 'You call me, I'll go with you. I'll hold your hand.'"

Other task force recommendations include eliminating co-pays and deductibles for breast cancer screening and treatment as well as improving the distribution of screening facilities.

Below, find interviews about the causes of the disparity and possible solutions.

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BREAST CANCER SURVIVOR AND ACTIVIST ANGELA WALKER

Breast cancer coordinator for the American Cancer Society and secretary of the Chicago chapter of Sisters Network, a support organization for black women with breast cancer

Q. How did you find out you had breast cancer?

A. I was in the shower and found a lump in my left armpit. I was like, what is this? And I looked at my breast and I knew something wasn't right. The cancer had already spread to my lymph nodes. My treatment from start to finish took nine months. I'm done with treatment and cancer-free.

Q. Did you have a family history?

A. My mom, Bertrice Walker McGrath, had breast cancer. The initial diagnosis was that everything was OK. Then she had a recurrence, and that's when the dynamics changed. I didn't think my mother would die. Then to have her pass away from it [in 1999 at age 46] and have me be diagnosed [in 2006 at 34], it really changed how I was going to deal with it. I had my family, friends, church, co-workers and the Sisters Network there to support me.

Q. What is the most important news coming out of this report?

A. The work of the task force can open the eyes of health institutions. It's not just Chicago, but the south suburbs, where the mortality rate is ridiculous and the incident rate is also high.

I really want the hospital systems to say: "We take on the burden for caring for women in the community."

Q. What are other solutions?

A. Providing universal health care for women and eliminating the burden of having to pay for mammograms. Also we have to get to a point where we are changing behavior. Diet and changing lifestyles -- it's a domino effect. One is going to impact the other.

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RESEARCHER STEVE WHITMAN

Director of the Sinai Urban Health Institute

Q. You conducted the studies on breast cancer disparities in Chicago, including the one being released Wednesday. What is the most important finding?

A. White women have benefited enormously from the gains made since 1980 in early detection and treatment. Black women have gained nothing whatsoever. The premise of the task force is that black women have to gain equal access to mammography, early diagnosis and rapid entry into effective treatment. We see structural issues in society like racism and poverty converging to prevent black women from gaining access to resources that would change their lives.

Q. How does all of this play out in the real world?

A. Some women have to get on three buses to get their treatment. The financial burdens are huge. Even when you have insurance, the co-payments for medications are enormous. Several women told us their co-payments were easily $200. In order to make the medicine last, they would take it every other day instead of every day. ... If their income was needed for family support or if they were single parents, they had to choose between getting treatment and losing their job.

Q. Why have you made this a priority in your work?

A. It's a basic matter of fairness and decency that all people -- in this case, all women -- get the same access to health care. Right now we're allegedly fighting for democracy in different countries around the world. What does it mean if people can't have the same access to life-saving detection and treatment right here in Chicago? ... And if we make these improvements to remedy the disparity, it should make things better for all women because the system is inadequate for all women, not just black women.

Q. So what's next?

A. Our underlying belief is that one can't just fix one small part of the picture. It wouldn't be good enough for all women to get mammograms if the quality of the mammograms was poor and the cancers were missed, which happens. Or if women couldn't get into treatment. ... We think the entire system has to be fixed.

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CARE PROVIDER DR. DAVID ANSELL

Chief medical officer at Rush University Medical Center and chairman of the breast cancer task force

Q.Why is this disparity between black and white women happening?

A. Women are not being screened appropriately. We think it's probably true of women of other backgrounds and probably tied to poverty as well as the availability of health-care services.

Q. What can be done to lower black women's death rates?

A. .To detect cancer requires a woman to have a medical home [and] be referred for a mammogram. The mammogram has to be of high quality technically and someone has to be well-trained to read it. It can require referral for additional testing before you even make the diagnosis and then you have to be referred for treatment. So it is a complex array.

We have created a consortium, that is just getting off the ground, to study quality standards from screening to diagnosis to treatment. A group of Chicago hospitals has agreed to participate, and we'll be the first in the country to systematically measure the quality of breast cancer screening and treatment.

Q. What would make the racial disparity in Chicago different from other cities?

A. We think it has to do with access, quality and delay. ... We would to like to develop a system to measure it.

Q. What is the significance of this disparity?

A. When the rates were 68 percent higher for African-American women, we knew it meant that each year 80 black women were dying needlessly, just because we didn't have equal outcomes.

We don't think women get the same level of care. Different institutions provide a different quality of care. We have to get institutions to look at it, measure it and improve. To the extent that women have different outcomes at different institutions that predominantly serve one group over another, we think it's de facto segregation. ... I find it personally reprehensible that a disparity like this exists when we know we can detect and treat breast cancer early.