Cultural Beliefs About Cancer Screening: Are They Deadly?

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College of Nursing
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- Timothy Johnson
- Richard Warnecke
Community Partners

- Healthcare Consortium of Illinois
- American Cancer Society
- Chicago Chapter of National Black Nurses Association
- Chicago Family Health Center
- Greater Roseland Breast Cancer Taskforce
- National Black Leadership Initiative on Cancer
- National Cancer Institute Cancer Information Service
- Chicago Department of Public Health
- Sister’s Network
Breast cancer deadlier for blacks

African-American women in Chicago are much more likely than white women to die of breast cancer, and the racial gap is widening, according to a new study that calls the disparity “morally wrong, medically unacceptable and reversible.”

Just 10 years ago, black and white women in Chicago died at the same rate from breast cancer. But the most recent figures available, for 2003, show the mortality rate among black women was 78 percent higher. Researchers at Mount Sinai Hospital’s Urban Health Institute report in the study being released today.

Nationally, the gap was about half that — 57 percent.

The disparity in death rates appears to be the result of racism, “and it appears to be institutionalized,” said Alan Channing, chief executive of Sinai Health System.

In Chicago, white women are diagnosed with breast cancer at a rate 16 percent higher than the rate in black women.

So why are more blacks dying from the disease?

One site spotted few cancers

One explanation that’s been offered is that African-American women might be someti-

Age-Adjusted Female Breast Cancer Mortality for Chicago, Per 100,000 Population

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## Breast Cancer Mortality Rates, by Race, Chicago, 1996 - 2005

<table>
<thead>
<tr>
<th>Year</th>
<th>Black</th>
<th>White</th>
<th>How Much Higher is Black Rate?</th>
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<td>36.5</td>
<td>36.5</td>
<td>0%</td>
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<tr>
<td>1999</td>
<td>42.0</td>
<td>32.5</td>
<td>29%</td>
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<td>2000</td>
<td>41.1</td>
<td>29.5</td>
<td>39%</td>
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<tr>
<td>2001</td>
<td>37.3</td>
<td>24.4</td>
<td>53%</td>
</tr>
<tr>
<td>2002</td>
<td>41.0</td>
<td>24.7</td>
<td>66%</td>
</tr>
<tr>
<td>2003</td>
<td>40.4</td>
<td>24.0</td>
<td>68%</td>
</tr>
<tr>
<td><strong>2005</strong></td>
<td><strong>41.3</strong></td>
<td><strong>19.2</strong></td>
<td><strong>116%</strong></td>
</tr>
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</table>
Early Detection is the KEY

- When breast cancer is detected and treated early
  - almost all women (98%) will be alive five years later.

- When breast cancer is detected late
  - only 26% of women will be alive five years later.

Data from American Cancer Society

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Low Screening Rates

Dartmouth Atlas Project (2010):
- Chicago has some of the *lowest* mammogram screening rates in the nation
- *Even for women whose screening is paid for by Medicare.*

Primary Reasons (our focus group data):
- **Cost**
- **Beliefs**
- **Fear**


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Study 1.
Cultural Beliefs about Breast Cancer

*Do they matter?*

*Can they be deadly?*
Cultural Beliefs

- Identify cultural beliefs contributing to later stage of breast cancer at diagnosis for African American, Hispanic, and Caucasian women in Chicago.

- Focus on beliefs interfering with
  - Participation in Screening
  - Diagnosis of Suspicious Breast Symptoms
  - Follow through with Treatment
Identification of 17 Beliefs

Step One: Cultural Experts/ Published Reports
• Identify cultural beliefs about breast cancer that could contribute to late-stage diagnosis. (41 beliefs)

Step Two: Focus Groups (four groups, n = 37)
• Broad based: “Have you ever HEARD of these beliefs or known anyone who believed them?”

Step Three: Cognitive Interviews (n = 19)
• Determine interpretation and clarity of wording of 17 true/false questions.
Newly diagnosed breast cancer patients (n = 954)

Cultural beliefs were associated with:

- Breast cancer *detected with symptoms*, rather than mammogram.
- *Longer delay* (3+ months) before seeking diagnosis of suspicious symptoms.
- *Later stage of cancer* at diagnosis (Stage 2,3,4 vs 0,1).
- *Longer delay* (3+ months) in starting cancer treatment.
Misconceptions predict timing of care and later stage

Symptomatic detection

$P = 0.0185$

$0$ $0.2$ $0.4$ $0.6$ $0.8$ $1$

$0$ $5$ $10$ $15$

$>90$ days to medical presentation

$P = 0.0038$

$0$ $0.2$ $0.4$ $0.6$ $0.8$ $1$

$0$ $5$ $10$ $15$

$>90$ days to treatment

$P = 0.0003$

$0$ $0.2$ $0.4$ $0.6$ $0.8$ $1$

$0$ $5$ $10$ $15$

$>90$ days total delay

$P < 0.0001$

$0$ $0.2$ $0.4$ $0.6$ $0.8$ $1$

$0$ $5$ $10$ $15$

Later stage

$P = 0.0099$

$0$ $0.2$ $0.4$ $0.6$ $0.8$ $1$

$0$ $5$ $10$ $15$

Later stage (invasive)

$P = 0.0942$

$0$ $0$ $5$ $10$ $15$

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Participants

- General Population
  n = 117

- Suspicious Breast Symptoms (self-identified)
  n = 266

- Breast Cancer (diagnosed 3-4 months)
  n = 954

Face-to-Face Interviews
If a breast lump is not painful, it is not cancer.

<table>
<thead>
<tr>
<th>Category</th>
<th>AA</th>
<th>Latina</th>
<th>White</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gen Pop</td>
<td>5%</td>
<td>11%</td>
<td>0%</td>
</tr>
<tr>
<td>Symptoms</td>
<td>14%</td>
<td>18%</td>
<td>5%</td>
</tr>
<tr>
<td>Breast Cancer</td>
<td>6%</td>
<td>18%</td>
<td>1% (p&lt;.0001)</td>
</tr>
</tbody>
</table>
If a breast lump is not painful, it is not cancer.

<table>
<thead>
<tr>
<th></th>
<th>Gen Pop</th>
<th>Symptoms</th>
<th>Breast Cancer</th>
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</thead>
<tbody>
<tr>
<td>AA</td>
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<td>14%</td>
<td>6%</td>
</tr>
<tr>
<td>Latina</td>
<td>11%</td>
<td>18%</td>
<td>18%</td>
</tr>
<tr>
<td>White</td>
<td>0%</td>
<td>5%</td>
<td>1% (p&lt;.0001)</td>
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</table>

If a breast lump does not get bigger, it is not cancer.

<table>
<thead>
<tr>
<th></th>
<th>Gen Pop</th>
<th>Symptoms</th>
<th>Breast Cancer</th>
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</thead>
<tbody>
<tr>
<td>AA</td>
<td>13%</td>
<td>11%</td>
<td>13%</td>
</tr>
<tr>
<td>Latina</td>
<td>14%</td>
<td>4%</td>
<td>24%</td>
</tr>
<tr>
<td>White</td>
<td>0%</td>
<td>5%</td>
<td>3% (p&lt;.0001)</td>
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</table>
Characteristics of Breast Lumps

If a breast lump is not painful, it is not cancer.
- Gen Pop: AA 5%, Latina 11%, White 0%
- Symptoms: AA 14%, Latina 18%, White 5%
- Breast Cancer: AA 6%, Latina 18%, White 1% (p<.0001)

If a breast lump does not get bigger, it is not cancer.
- Gen Pop: AA 13%, Latina 14%, White 0% (p=.05)
- Symptoms: AA 11%, Latina 4%, White 5%
- Breast Cancer: AA 13%, Latina 24%, White 3% (p<.0001)

If a breast lump is touched/pressed often, the lump will turn out to be breast cancer.
- Gen Pop: AA 13%, Latina 3%, White 8%
- Symptoms: AA 7%, Latina 16%, White 5%
- Breast Cancer: AA 11%, Latina 30%, White 2% (p<.0001)
The more you worry about breast cancer, the more likely you will get it.

<table>
<thead>
<tr>
<th>Category</th>
<th>AA (%)</th>
<th>Latina (%)</th>
<th>White (%)</th>
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<tbody>
<tr>
<td>Gen Pop</td>
<td>8%</td>
<td>17%</td>
<td>8%</td>
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<tr>
<td>Symptoms</td>
<td>8%</td>
<td>16%</td>
<td>11%</td>
</tr>
<tr>
<td>Breast Cancer</td>
<td>7%</td>
<td>26%</td>
<td>4%</td>
</tr>
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(p<.0001)
The more you worry about breast cancer, the more likely you will get it.

<table>
<thead>
<tr>
<th></th>
<th>AA 8%</th>
<th>Latina 17%</th>
<th>White 8%</th>
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<tbody>
<tr>
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<td></td>
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<tr>
<td>Symptoms</td>
<td>AA 8%</td>
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<td>White 11%</td>
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<tr>
<td>Breast Cancer</td>
<td>AA 7%</td>
<td>Latina 26%</td>
<td>White 4%</td>
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If you take good care of yourself, you won’t get breast cancer.

<table>
<thead>
<tr>
<th></th>
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<th>Latina 24%</th>
<th>White 5%</th>
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<tbody>
<tr>
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<tr>
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<td>AA 18%</td>
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<tr>
<td>Breast Cancer</td>
<td>AA 8%</td>
<td>Latina 21%</td>
<td>White 2%</td>
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(p<.0001)
**Self-Help Techniques**

The more you worry about breast cancer, the more likely you will get it.

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<td>27%</td>
<td>11%</td>
</tr>
<tr>
<td>Breast Cancer</td>
<td>8%</td>
<td>21%</td>
<td>2%</td>
</tr>
</tbody>
</table>

If you have a breast lump, a “natural” remedy can help to get rid of it.

<table>
<thead>
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<th>White</th>
</tr>
</thead>
<tbody>
<tr>
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<tr>
<td>Symptoms</td>
<td>8%</td>
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<td>11%</td>
</tr>
<tr>
<td>Breast Cancer</td>
<td>12%</td>
<td>10%</td>
<td>6%</td>
</tr>
</tbody>
</table>

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If a woman has enough faith in God, she won’t need treatment for breast cancer.

- **Gen Pop**: AA 24%  Latina 11%  White 0%  (p = .004)
- **Symptoms**: AA 17%  Latina 6%  White 0%  (p=.04)
- **Breast Cancer**: AA 18%  Latina 16%  White 1%  (p<.0001)
If a woman has enough faith in God, she won’t need treatment for breast cancer.

- **Gen Pop**: AA 24%  Latina 11%  White 0%  (p = .004)
- **Symptoms**: AA 17%  Latina 6%  White 0%  (p=.04)
- **Breast Cancer**: AA 18%  Latina 16%  White 1%  (p<.0001)

Faith in God can protect you from breast cancer.

- **Gen Pop**: AA 39%  Latina 38%  White 5%  (p < .001)
- **Symptoms**: AA 38%  Latina 35%  White 5%  (p = .02)
- **Breast Cancer**: AA 29%  Latina 49%  White 3%  (p<.0001)
If a woman has enough faith in God, she won’t need treatment for breast cancer.

- **Gen Pop**: AA 24% Latina 11% White 0% (p = .004)
- **Symptoms**: AA 17% Latina 6% White 0% (p=.04)
- **Breast Cancer**: AA 18% Latina 16% White 1% (p<.0001)

Faith in God can protect you from breast cancer.

- **Gen Pop**: AA 39% Latina 38% White 5% (p < .001)
- **Symptoms**: AA 38% Latina 35% White 5% (p = .02)
- **Breast Cancer**: AA 29% Latina 49% White 3% (p<.0001)

If you pray enough, sometimes breast lumps will disappear.

- **Gen Pop**: AA 39% Latina 33% White 25%
- **Symptoms**: AA 43% Latina 18% White 11% (p<.001)
- **Breast Cancer**: AA 35% Latina 27% White 7% (p<.0001)
If breast cancer is cut open in surgery, it will grow faster.

- **Gen Pop**
  - AA 32%
  - Latina 14%
  - White 8%  
  (p=.019)

- **Symptoms**
  - AA 31%
  - Latina 33%
  - White 26%

- **Breast Cancer**
  - AA 19%
  - Latina 30%
  - White 10%  
  (p<.0001)
### Futility of Treatment

If breast cancer is cut open in surgery, it will grow faster.

<table>
<thead>
<tr>
<th>Category</th>
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<td>19</td>
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<td>&lt;.0001</td>
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If a woman is poor, she won’t get cured from cancer, because she won’t get the best treatment.

<table>
<thead>
<tr>
<th>Category</th>
<th>AA (%)</th>
<th>Latina (%)</th>
<th>White (%)</th>
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<tr>
<td>Breast Cancer</td>
<td>24</td>
<td>29</td>
<td>35</td>
<td>.002</td>
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</table>
If breast cancer is cut open in surgery, it will grow faster.
- Gen Pop: AA 32% Latina 14% White 8% (p=.019)
- Symptoms: AA 31% Latina 33% White 26%
- Breast Cancer: AA 19% Latina 30% White 10% (p<.0001)

If a woman is poor, she won’t get cured from cancer, because she won’t get the best treatment.
- Gen Pop: AA 29% Latina 25% White 42%
- Symptoms: AA 22% Latina 12% White 4% (p=.07)
- Breast Cancer: AA 24% Latina 29% White 35% (p=.002)

If breast cancer is treated correctly, it can be cured. (FALSE)
- Gen Pop: AA 13% Latina 19% White 10%
- Symptoms: AA 10% Latina 0% White 11% (p=.07)
- Breast Cancer: AA 8% Latina 6% White 13% (p=.007)
Futility of Treatment

If breast cancer is cut open in surgery, it will grow faster.
Gen Pop  AA 32%  Latina 14%  White 8%  (p=.019)
Symptoms  AA 31%  Latina 33%  White 26%
Breast Cancer  AA 19%  Latina 30%  White 10%  (p<.0001)

If a woman is poor, she won’t get cured from cancer, because she won’t get the best treatment.
Gen Pop  AA 29%  Latina 25%  White 42%
Symptoms  AA 22%  Latina 12%  White 4%  (p=.07)
Breast Cancer  AA 24%  Latina 29%  White 35%  (p=.002)

If breast cancer is treated correctly, it can be cured.  (FALSE)
Gen Pop  AA 13%  Latina 19%  White 10%
Symptoms  AA 10%  Latina 0%  White 11%  (p=.07)
Breast Cancer  AA 8%  Latina 6%  White 13%  (p=.007)

It doesn’t really matter if you get treated for breast cancer, because if you get cancer, it will kill you sooner or later.
Gen Pop  AA 13%  Latina 11%  White 13%
Symptoms  AA 3%  Latina 14%  White 0%
Breast Cancer  AA 7%  Latina 25%  White 1%  (p<.0001)
- American Cancer Society Guidelines
  - Released January 2011

- Report of the Metropolitan Chicago Breast Cancer Task Force
  - 37 Evidence-Based Recommendations

- Illinois Breast Cancer Disparities Act
Study 2.
Beating Breast Cancer Program

*Can cultural beliefs about breast cancer be changed?*
Beating Breast Cancer DVD

- Five African American women, all breast cancer survivors, are featured in the film.
- Unscripted; each woman tells her story in her own words.
- Addresses cultural beliefs and fear, which were identified as significant barriers in our earlier research.
- One of the featured survivors is a physician, and so provides the credibility of a medical expert.
- Professional production company
"What about your male friends? How are they going to look at you? And I looked at him and I said, 'It's not about them. It's about me. I'm still a woman...and I'm focusing on living.'"

Tasha, age 37
Beating Breast Cancer DVD

- Endorsed by the American Cancer Society.
- Endorsed by Chicago Department of Public Health.
- National Telly Award, Health and Wellness Category for short film, 2011.
- YouTube 1,328 views to date.
Evaluation of DVD

• 262 African American women participants

• Questionnaires completed (all within one continuous session):
  1. Before watching DVD
  2. Immediately following DVD
  3. After Q & A with African American nurse
Lump is not painful, it’s not cancer

Lump doesn’t get bigger, it’s not cancer

Lump is pressed often, turn out to be BC

Women with large breasts more likely to get BC

More you worry about BC, more likely to get it

Take good care of yourself, won’t get BC

Only need to get a mam if you find a problem

Mammograms can cause BC

BC is cut open in surgery, it will grow faster

No BC in your family, don’t need a mam

A poor woman won’t get cured from cancer, because she won’t ge...

If BC is treated correctly, it can be cured

It doesn’t matter if you get treated, because BC will kill you

Enough faith in God, won’t need Tx for BC

Faith in God can protect you from BC

Pray enough, breast lumps will disappear

A “natural” remedy can get rid of breast lumps
Responses to Beating Breast Cancer DVD:

- 99% thought the DVD was worth watching
- 89% stated they learned something new from the DVD
- **86% reported that the DVD helped them to decide to get a mammogram.**
Beating Breast Cancer Program

- **Events** within four African American communities with high death rates from breast cancer: Roseland, Pullman, West Pullman, and Riverdale. These events take place in a variety of locations, such as churches, beauty shops, food pantries, school events for parents, and others.

- **Short Film on DVD** addressing the worries about breast cancer that keep women from getting screened, presented by five African American cancer survivors.

- **Nurse Educators (n=36)** from the National Black Nurses Association and the Alpha Eta Chapter of the Chi Eta Phi Sorority provide expert information for women at our events.
Beating Breast Cancer Program

- **Tote Bags** distributed to those attending events, containing information on (1) where to go for low-cost and no-cost mammograms; (2) copy of the DVD to watch and share with others; (3) brochures on mammography and breast health.

- **Navigation**: Our staff provide personal guidance (one-on-one) for women who need help in finding a mammogram they can afford (requested by 15% of women)

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Dissemination: Beating Breast Cancer DVD

- 296 educational events have been held in the four target communities.
- 5,919 women have attended events and completed questionnaires
- Almost all women are African American (94%), so we are reaching the intended audience.
  - DVD provides a simple, cost-effective technique that can be easily used for wide dissemination.
With gratitude to our funders:

- Center for Population Health and Health Disparities, University of Illinois at Chicago (NIH National Cancer Institute P50 CA106743)

- Center of Excellence in Eliminating Health Disparities, University of Illinois at Chicago (NIH Institute on Minority Health and Health Disparities P60 MD003424)

- Roybal Center for Health Promotion and Translation, University of Illinois at Chicago (NIH National Institute on Aging P30 AG022849)

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