

# Perceptions of Breast Cancer Treatment among African-American Women and Men: Implications for Interventions

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**BACKGROUND:** While breast cancer mortality has declined in recent years, the mortality gap between African-American and white women continues to grow. Current strategies to reduce this disparity focus on logistical and information needs, but contextual factors, such as concerns about racism and treatment side effects, may also represent significant barriers to improved outcomes.

**OBJECTIVE:** To characterize perceptions of breast cancer treatment among African-American women and men.

**DESIGN:** A qualitative study of African-American adults using focus group interviews.

**PARTICIPANTS:** Two hundred eighty women and 165 men who live in one of 15 contiguous neighborhoods on Chicago's South Side.

**APPROACH:** Transcripts were systematically analyzed using qualitative techniques to identify emergent themes related to breast cancer treatment.

**RESULTS:** The concerns expressed most frequently were mistrust of the medical establishment and federal government, the effect of racism and lack of health insurance on quality of care, the impact of treatment on intimate relationships, and the negative effects of surgery, radiation therapy, and chemotherapy.

**CONCLUSIONS:** In addition to providing logistical and information support, strategies to reduce the breast cancer mortality gap should also address contextual factors important to quality of care. Specific interventions are discussed, including strategies to enhance trust, reduce race-related treatment differences, minimize the impact of treatment on intimate relationships, and reduce negative perceptions of breast cancer surgery, radiation therapy, and chemotherapy.

**KEY WORDS:** breast cancer; treatment; African-American; qualitative research; interventions.

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## INTRODUCTION

As the second most common cause of cancer mortality among US women, it is estimated that breast cancer will claim the lives of over 40,000 US citizens in 2008.<sup>1</sup> A disproportionate number of victims will be African-American women, whose breast cancer mortality rate (32.8/100,000) exceeds that of white women (23.3/100,000).<sup>2</sup> This disparity is especially apparent in Chicago, where the African-American/white breast cancer mortality ratio increased from 1.27 in 1990 to 1.68 in 2003.<sup>3</sup> Racial disparity in breast cancer mortality has been attributed, in part, to differences in screening,<sup>4</sup> follow-up testing,<sup>5</sup> stage at diagnosis,<sup>6</sup> tumor biology,<sup>7</sup> quality of mammography reading,<sup>3</sup> quality of treatment,<sup>8,9</sup> and a combination of these factors.<sup>10,11</sup>

Racial differences in the quality of breast cancer treatment are well documented. For example, compared to their white counterparts, African-American breast cancer patients report fewer conversations with their physicians about what to expect during treatment, the rationale for chemotherapy and radiation therapy, the risk of tumor recurrence, post-treatment appearance,<sup>12</sup> and breast-conserving surgery.<sup>13</sup> These differences may explain why African-American women are more likely to receive a first course of surgical and radiation treatment that does not meet the National Comprehensive Cancer Network standard<sup>14</sup> and are less likely to receive adjuvant treatment, including radiation therapy following breast conserving therapy, chemotherapy for hormone receptor-negative tumors, and hormonal therapy for hormone receptor-positive tumors.<sup>9</sup>

Current strategies to reduce mortality disparities and standardize therapy include systems navigation and decision aids. Systems navigation typically assists patients with logistical concerns, including appointment-making, child care, transportation, coordination of services, and health insurance benefits,<sup>15–18</sup> while decision aids provide detailed information regarding treatment options, side effects, and disease prognosis.<sup>19–23</sup> Systems navigation and decision aids address many, but not all, of the concerns that women have regarding breast cancer treatment.<sup>24,25</sup> Johnston-Polacek et al. hypothesize that for minority women, contextual issues, such as pressure not to miss work or be absent from family responsibilities, may make certain treatment options, such as mastectomy, more attractive than options requiring multiple visits (i.e., lumpectomy and radiation therapy).<sup>26</sup> However, research regarding the impact of contextual issues on treatment decisions is limited.<sup>26</sup> By conducting focus group interviews in neighborhood settings, our goal was to gain a better understanding of the range of concerns that African-Americans have when

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considering breast cancer treatment for themselves and their loved ones.

## METHODS

### Study Sample

After obtaining IRB approval, study participants were recruited from 15 primarily African-American communities on Chicago's South Side. The study was initially publicized through letters to community agencies, community leaders, health clinics, and churches. This was followed by a grassroots campaign in which research assistants posted recruitment fliers in local businesses and distributed them on street corners. The fliers indicated that the study was designed to solicit feedback from women and men, in their own voices, regarding breast cancer and its treatment. Adults who called our office to inquire about the study were queried regarding their contact information and demographic characteristics. We used this information to invite approximately 12 participants for each focus group. Decisions regarding whom to invite reflected our interest in creating focus groups that were diverse with respect to sex, age, living arrangement, and employment status. We included both men and women in each focus group to gain a more complete understanding of community beliefs and opinions regarding breast cancer treatment and because previous research has shown that partner beliefs and opinions are important to treatment decision-making among breast cancer patients.<sup>27,28</sup>

### Focus Group Procedures

The investigators used a literature review and advice from a community-based advisory board to develop guiding questions (Text Box 1). Each focus group interview was conducted in a public building within one of the 15 neighborhoods. The number of participants in each group varied from 8 to 12, and all focus groups included both women and men. Focus groups were moderated by trained research staff, most of whom were female and African-American. After introductions, the moderator distributed an informed consent document and an anonymous demographics questionnaire, which included questions regarding gender, age, breast cancer experience, living situation, and employment status. The discussion then

#### Text Box 1. Examples of Guiding Questions

- What comes to mind when you think about breast cancer, the disease itself?
  - Please share with us your own idea of what goes on inside the body with breast cancer?
  - If a woman told you she was at risk for breast cancer, what would that mean to you?
  - Based on what you think goes on inside the body with breast cancer, how do you think it should be treated?
  - What concerns do you have about locating and receiving treatment for breast cancer?
  - In thinking about what you hear and learn about different diseases in your day-to-day life, do you feel that there is a lot of attention paid to certain diseases in your community?
  - Where does breast cancer fit in with what you hear and learn about different diseases in everyday life?
  - When you think about things that concern you on a day-to-day basis, how does breast cancer fit it?
- How does it fit with your other health and life concerns?

commenced with guiding questions and prompts as needed for clarification. One research assistant facilitated the group discussion, while the other observed the process, linking specific comments to the seat numbers of participants as determined by the position of individual seats in the seat grouping. These were in turn linked to the demographics questionnaire on which the seat number was noted. Facilitators allowed each group to take its own course, while ensuring that each guiding question was addressed, allowing a maximum of 30 min of discussions for any one question. Each focus group lasted approximately 90 min, and all participants received \$30 for their time.

## ANALYSIS

Each audiotaped session was transcribed and analyzed using a grounded theory approach, which included data coding, category development, and theme identification.<sup>29</sup> The authors (C.M.M., S.G.) read each transcript independently to identify comments related to breast cancer treatment. The authors then compared findings to develop a list of keywords related to treatment. The transcripts were then subjected to line-by-line analysis using the keyword search capacity of NVivo software.<sup>30</sup> This process identified additional treatment-related comments that were added to the initially identified comments and then sorted by the authors into categories of treatment perceptions. With these categories in mind, the authors re-read the transcripts to ensure that the categories chosen reflected the diversity of comments identified. Through further discussion, the authors reached consensus regarding a core set of themes related to treatment perceptions. Depending upon the flow of discussion within each focus group, treatment-related comments were found throughout each transcript and not solely in response to treatment-related questions.

## RESULTS

Recruitment efforts resulted in over 1,300 telephone calls from adults interested in the study. Of the 503 individuals invited to the focus groups, 445 attended for a participation rate of 88%. Reflecting the racial make-up of the 15 target communities, 97% of the participants were African-American. Also in keeping with community demographics, participants were diverse with respect to gender, age, living arrangement, employment status, and breast cancer experience (see Table 1). Our analysis revealed a core set of themes related to treatment, including mistrust of the medical establishment, concern about the effect of racism on treatment quality, a perceived link between health insurance quality and treatment quality, the negative effects of treatment on intimate relationships, and concern about complications from breast cancer surgery, radiation therapy, and chemotherapy (Text Box 2). With a few exceptions, all of the quotes below are from individuals who had a friend or family member with breast cancer. Quotes from breast cancer survivors or from participants who peripherally knew someone with breast cancer are so indicated. We did not include quotes from individuals who had no personal experience with breast cancer.

Table 1. Characteristics of Focus Group Participants

Characteristics	Total (n=445)	Proportion
Sex - female	280	63%
Race - African American	432	97%
Mean age (years)	43.3	
18-34 years	129	29%
35-49 years	178	40%
50-64 years	107	24%
65+ years	31	7%
Living arrangement		
Living with spouse	80	18%
Living with non-spousal partner	63	14%
Living with family members	151	34%
Living with friends	22	5%
Living alone	129	29%
Employment status		
Has one or more jobs	159	36%
Unemployed and looking for work	125	28%
Unemployed, not looking for work	9	2%
Homemaker	18	4%
Disabled	58	13%
Student	31	7%
Not reported	45	10%
Experience with breast cancer		
Had a friend or family member who had been treated for breast cancer	267	60%
Knows someone, not very well, who has been treated for breast cancer	76	17%
Personal history of breast cancer	22	5%
Does not know anyone with breast cancer	80	18%

## Trust

When asked about concerns related to breast cancer treatment, mistrust of the medical establishment was expressed in almost every focus group. A 58-year-old female said, "What if you don't trust a doctor's word. I don't trust them." For some, this mistrust was rooted in past abuses by physicians and scientists. As one 33-year-old female said, "I know it's been repeated a million times but the Tuskegee thing is very real in the community. It's not a trust for the treatments and things you are going to inject into our bodies." For others, this mistrust is associated with fear, as indicated by a 36-year-old female who had an acquaintance with breast cancer, "I think there is a fear that if we get treatment, we may be experimented upon." Conflicts of interest among health-care professionals also contributed to patient mistrust. A 42-year-old male who also had an acquaintance with breast cancer said, "Here you have American doctors being paid by pharmaceutical companies to prescribe these drugs that might not have nothing to do with the treatment that you are supposed to be on." In a similar vein, a 25-year-old male said, "I think it should be illegal for them to give doctors free trips because everybody knows, if I give this man a free trip in advance, I'm going to want something in return. They are expecting doctors to prescribe certain medications."

The federal government was also viewed with skepticism by several participants. Some suggested that the government has played an active role in creating or perpetuating illness among African-Americans. Referring to high cancer mortality rates, a 35-year-old female said, "The government has to do a thing called population control. How they do it and the way they do it, I don't know but it goes back to the environment and the chemicals." A 25-year-old male who shared a similar view said,

"I would hope that we aren't still living in that day and age where we really think that they are actively trying to kill us off, even though I do think they are trying to kill us off." Finally, several participants suggested that the federal government is not pursuing cancer research aggressively enough. A 49-year-old male who had an acquaintance with breast cancer said, "I think that there's a cure. People are spending billions and billions of dollars overlooking it or not really trying to find it. It's politics." In response, a 20-year-old female said, "I don't put anything past the government."

## Race

Another frequently cited concern was that African-Americans are less likely to receive high quality breast cancer treatment compared to their white counterparts. This was attributed to both financial resources and to racism on the part of physicians. One participant attributed lack of medical care to unemployment, "Our community, no jobs, no insurance." But a 26-year-old female indicated that the relationship between employment and health insurance is not straightforward: "What about those of us who are caught in the middle? We work too much where we can't get medical care from public aid so we are stuck in the middle of the system. We work hard every day but there's no help for us as far as benefits."

References to racism were both subtle and overt. A 52-year-old female said "I feel like a disease or a cancer that tends to stay within a culture like say African-Americans, they don't do as much research." In response to a question about why African-Americans receive inferior care, a 46-year-old female said, "Because this is a racist country. It's racist and capitalistic (but) if you got enough money, they will overlook the race." A 73-year-old female said, "I know that minorities just don't get the treatment that other folks get. Minorities just don't get it," while a 46-year-old female said, "I prefer a black doctor because I think they understand our needs a lot better than white people."

## Health Insurance

Participants in almost every focus group expressed a concern that quality of breast cancer care depends upon type of health

### Text Box 2. Major Themes Elicited from the Focus Groups

#### Trust

- Lack of trust in the medical establishment
- Physicians have financial conflicts of interest
- Concern about being experimented upon

#### Race

- Minorities receive lower quality of care
- Concern about being harmed
- Preference for African-American physicians

#### Health insurance

- Quality of care is related to quality of health insurance
- Public health-care facilities are overburdened
- Lack of health insurance limits treatment opportunities

#### Effect of treatment on relationships

- How partner will cope
- Concern about separation or divorce
- Impact on sexuality

#### Negative perceptions of breast cancer treatment

- Surgery
- Radiation therapy
- Chemotherapy

insurance. A 35-year-old woman said, "When I think about the African American community in Chicago, I think about women being poor and not necessarily having access to doctors. You don't know which hospital to go to. Are they going to treat you right? Are they going to treat you like a number? I mean, these are very real issues for any poor person in Chicago." Several participants expressed doubt that individuals with no or low-quality health insurance can receive care that is as good as that received by individuals with higher quality health insurance. A 27-year-old male who had an acquaintance with breast cancer said, "the better the insurance, the better the health care," while a 49-year-old female said, "if your insurance is raggedy, you're going to get raggedy treatment."

Cook County Department of Public Health clinics provide medical care to many low-income and uninsured individuals in the Chicago area. While these clinics offer essential services, many participants believed they lack sufficient resources to provide high quality care. A 48-year-old female commented on clinic ambience and customer service: "The quality of care you get from a public health clinic is not going to be the same quality of care you get from a private physician, where you got nice lights, TV, and soft jazz playing and you got coffee and snacks, and 'can I help you?' as soon as you walk in the door. If you go to the Board of Health Center, there are 30 people all at the same time, and you got to sit there and wait." A 48-year-old woman who had an acquaintance with breast cancer added, "A lot of poor women get breast cancer and they have to have their breast removed because they don't have all this technology that a rich person might have. And their breast could have been saved if they didn't have to go to Provident or Stroger (Hospitals), where there are 50 billion people."

### Effect of Treatment on Intimate Relationships

For participants in nearly every focus group, the impact of breast cancer treatment on intimate relationships was a significant concern. A 52-year-old female said, "The emotional impact is hard. If you are married, it might be a difficult situation for your husband to be able to cope. My friend's marriage broke up because she had her breast taken off." This story was echoed by a 50-year-old female survivor who said, "My husband left me because I told him I had breast cancer." A younger woman (age 33) who knew someone with breast cancer asked, "How am I going to cope with the things I'm going through - my family, my lover, what else is going to happen?" Male participants acknowledged the potential impact of breast cancer treatment on intimate relationships. Said one 40-year-old male, "A female would probably think that her husband or her better half would not want to be with her."

### Perceptions of Breast Cancer Treatment

**Surgery.** A concern that surgery can activate breast cancer and cause it to spread was expressed by many participants, as has been reported in other studies.<sup>31,32</sup> Of the 38 comments related to cancer surgery, 26 referred to this idea. Said a 55-year-old female, "What I've heard about cancer, if air touches it, it spreads," while a 58-year-old female asked, "My mother had colon cancer. She had the surgery and she died within 3 months. My father had lung cancer, he didn't have the surgery and he survived longer." Referring to a relative, a 48-year-old

male said, "I had one auntie, she had been surviving for about 3 years and as soon as she had the surgery, in a matter of a couple of weeks, she was gone." Others were skeptical of the idea that surgery causes cancer to spread. Typical of this perspective were comments from a 45-year-old female who said, "I don't believe it, but I've heard it all of my life. If they cut you open and the air hits it, it's going to spread. That's what the elders say."

**Radiation Therapy.** Most (24 of 30) of the comments regarding radiation therapy reflected significant concern regarding this form of treatment. For example, a 42-year-old female said, "I think radiation probably makes it spread faster than anything else." This sentiment was shared by a 54-year-old female who said, "It's not the cancer that kills the person, it's the treatment. I saw my cousin die. We just buried her. And it was not the cancer that killed her, it was the treatment. I believe they killed her. They over-radiated her. They burned her." On the other hand, participants who had positive experiences with radiation therapy expressed confidence in this form of treatment. A 47-year-old female said, "Yeah, it works because it worked for me for 10 years," while a 59-year-old male survivor said, "Well I've had breast cancer twice. I had it 12 years ago. I took radiation therapy and I had my breast removed, so I know it's okay."

**Chemotherapy.** Several participants expressed concern regarding the side effects of chemotherapy as well as doubt regarding its effectiveness. Of the 31 comments regarding chemotherapy, 22 referred to negative effects or bad outcomes. A 38-year-old male who had an acquaintance with breast cancer said, "Chemo, actually I think, it's not a good thing. Because I haven't seen or heard anyone who goes through chemo and they get better. I'm sorry, I haven't heard that." Echoing this sentiment, a 47-year-old male said, "Having that chemotherapy, if you don't have it, you might live longer. My auntie had it and that's what she died from." A 26-year-old female said, "I believe if I had breast cancer, I would fight to the bitter end. But please, somebody give me a better alternative than the ones you are offering me besides surgery and chemotherapy. I've seen a lot of people suffer at the hands of medical technology." In contrast, a few participants reported success with chemotherapy. For example, a female breast cancer survivor said, "They caught it in time and with the chemo, I only had six treatments. And that's been 6 years ago."

## DISCUSSION

Newly diagnosed breast cancer patients face not only the shock of diagnosis, but also challenges related to the complexity of treatment and coordination of care among specialists in different fields.<sup>33</sup> Low-income and minority patients often must overcome additional challenges, including those related to health insurance, dependent care, and transportation.<sup>25</sup> Certain interventions, including systems navigation and decision aids, have proven useful in meeting the logistical and information needs of many breast cancer patients.<sup>16,17,19,20</sup> However, a better understanding is needed regarding the context of treatment decision-making.<sup>26</sup> Using qualitative research, we found that contextual issues, such as mistrust of physicians, racism among health-care providers, the link between health insurance and quality of

care, and complications related to breast cancer treatment represent significant concerns for African-Americans as they consider breast cancer treatment options.

In the eyes of many study participants, the issues of trust, race, and quality of care were closely intertwined. For example, mistrust of physicians and the federal government was discussed in terms of the Tuskegee Syphilis Study, population control, and conflicts of interest among physicians. Similarly, race was discussed in terms of low rates of health insurance among African-Americans and discrimination in care based upon race and type of health insurance. Others have documented concerns among African-Americans regarding the links between race, trust, and quality of care,<sup>34-36</sup> and most research suggests mistrust is rooted in both personal experience and the history of unethical treatment of African-Americans by physicians and the federal government.<sup>37-39</sup> Our results support that conclusion, but new to the literature is our finding that significant mistrust among African-Americans arises from the perception of financial ties between health-care providers and the pharmaceutical industry.

As in other studies, our participants expressed concerns regarding the impact of mastectomy on intimate relationships.<sup>40,41</sup> While lumpectomy followed by radiation therapy is less disfiguring, this option may be less attractive due to family- or job-related demands<sup>26</sup> or concerns regarding radiation-associated tissue changes. Studies show that both breast-conserving surgery and breast reconstruction are not as common among African-American women as their white counterparts,<sup>14,42</sup> suggesting that the impact of treatment on intimate relationships is higher among African-American women.

While a minority of comments regarding surgery, radiation therapy, and chemotherapy were positive, the majority were negative. Concerns that surgery can lead to cancer metastasis<sup>43</sup> or that the treatment in general can be worse than the disease<sup>27,44</sup> have been noted previously among African-American women. Our results are consistent with those studies, but we also identified specific concerns related to radiation therapy (risk of burns and disease progression) and chemotherapy (risk of suffering and death). While such apprehension may seem obvious, previous studies<sup>27,43,44</sup> did not elicit the specific concerns we found related to these treatment strategies.

Because qualitative research primarily is hypothesis-generating, inferences that can be drawn from this study are limited. Nevertheless, our results suggest several possible avenues of intervention. For example, to enhance patient trust in the health-care system, financial conflicts of interest among health-care providers should be eliminated. In their recent report, the Association of American Medical Colleges (AAMC) acknowledged that close ties between academic medical institutions and the pharmaceutical, biotechnology, and device industries reduce the objectivity and integrity of clinical practice.<sup>45</sup> As a result, the AAMC recommends banning gifts from industry to physicians and medical trainees. This recommendation is an excellent first step, and its implementation will hopefully enhance trust in the health-care system among all patients, including minority patients. Increasing the number of community-based participatory research projects, such as this one, may enhance research transparency and increase trust in the health-care system. In addition, efforts to increase minority students in medical school should be encouraged, as trust increases when racial concordance exists between patients and their health-care providers.<sup>46</sup>

Concerns about racism in health care will continue as long as race-based differences in treatment persist. Fortunately, an increasing number of medical schools are addressing this issue by developing health disparities curricula.<sup>47,48</sup> Teaching patient-centered care may also reduce race-based treatment differences. According to a recent study, having a patient-centered perspective is associated with improved medical student performance with African-American patients.<sup>49</sup> Tracking and reminder systems, as well as provider education, also show promise in reducing race-based differences in the quality of health care.<sup>50</sup>

Specific measures can also be taken to address health insurance concerns. One approach is to help uninsured breast cancer patients obtain health insurance through the Breast and Cervical Cancer Prevention and Treatment Act of 2000, which extends Medicaid eligibility to uninsured women regardless of their income or assets.<sup>51</sup> A second approach is to increase Medicaid reimbursement rates so that a higher proportion of private health-care institutions, including those that specialize in breast cancer care, accept this form of insurance. Improving access to centers that specialize in breast cancer care is also important as timely coordination of therapies can mean the difference between tumor recurrence and cure.<sup>33</sup>

Publicizing success stories and connecting newly diagnosed breast cancer patients to breast cancer survivors can be effective ways to help patients overcome negative perceptions of breast cancer treatment.<sup>52</sup> The concerns we noted regarding surgery, radiation therapy, and chemotherapy suggest that the risks and benefits of these treatments should be thoroughly discussed prior to treatment and also should be included in general breast cancer education. To address concerns regarding the impact of surgery on intimate relationships, it is critical that health-care providers discuss this topic at the outset of treatment discussions.<sup>33</sup> While decision aids often include information about surgical options, only a few present information<sup>20</sup> or images<sup>22</sup> related to breast reconstruction. Such information is essential to the decision-making process and should become a standard component of surgically oriented breast cancer decision aids.

## LIMITATIONS

This study has several limitations. While focus group moderators were trained to be objective, their conscious or unconscious biases may have influenced the opinions expressed by study participants. Also, despite efforts to encourage equal participation, some participants were more outspoken than others, and their opinions may have unduly influenced the opinions and comments of others. Finally, most of the comments included in this report were from individuals who had friends or relatives with breast cancer, while fewer were from breast cancer survivors. Our results therefore more likely reflect the opinions of the former group than the latter. Nevertheless, we believe comments from both groups provide important insights into perceptions of breast cancer treatment among African-American women and men.

## CONCLUSION

Despite efforts to reduce breast cancer mortality disparities in the US, the racial gap has increased in recent years.<sup>2</sup> Efforts to

close this gap include programs that facilitate the detection, diagnosis, and treatment of breast cancer among African-American and other minority women.<sup>25</sup> Current treatment interventions are designed to meet the logistical and information needs of breast cancer patients. Using a community-based approach, we found that contextual factors, such as trust, racism, health insurance, and treatment complications, are also critically important to African-Americans considering breast cancer treatment. Expanding current interventions to address important contextual issues may be necessary in order to eliminate the breast cancer mortality gap.

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