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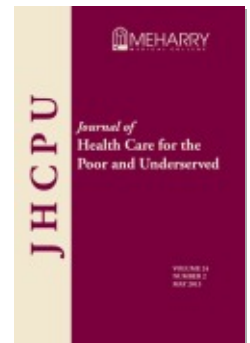
## **African American Women's Perspectives on Breast Cancer: Implications for Communicating Risk of Basal-like Breast Cancer**

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## African American Women's Perspectives on Breast Cancer: Implications for Communicating Risk of Basal-like Breast Cancer

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*Abstract:* African American women suffer a disproportionately high burden of basal-like breast cancer, an aggressive subtype that has no targeted therapy. While epidemiologic research has identified key prevention strategies, little is known about how best to communicate risk to this population. This study explored women's knowledge, beliefs, and attitudes about breast cancer to learn about risk perceptions. Six focus groups were conducted in North Carolina with 57 women (ages 18–49). Age, race (especially perceptions of cancer as a “White disease”), and lack of family history of breast cancer were all shown to contribute to women's perceptions of low breast cancer susceptibility. Perceptions of low risk were also attributed to conflicting risk information from family, media, and health providers. Women had little to no knowledge of breast cancer subtypes, and emphasized that health communications should be personally relevant, culturally appropriate, and convenient. These findings will assist in developing health communication tools that encourage prevention.

*Key words:* African American, breast cancer, focus groups, health communication.

**B**reast cancer is the most commonly diagnosed cancer among women worldwide, and in the United States it is the second leading cause of cancer death.<sup>1</sup> Despite improvements in breast cancer detection, diagnosis, and treatment, it is well documented that African American women remain disproportionately affected by the disease. Compared with White women, African American women are less likely to be diagnosed at an early stage,<sup>2</sup> have higher mortality rates,<sup>1,3–4</sup> and are more likely to be diagnosed before age 40.<sup>2</sup> The trends in breast cancer incidence and mortality demonstrate patterns that vary notably by race. While African American women have a lower lifetime risk of breast cancer, their mortality rates are higher than those of White American women.<sup>5</sup> The five-year survival rates for White women is 90%, while for African American women

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it is 78%, lower than that of any other ethnic and racial group in the U.S.<sup>5</sup> The roots of these inequalities are complex and involve inequities in work, wealth, income, education, housing, and overall standard of living, as well as barriers to high-quality cancer prevention, early detection, and treatment services.<sup>5</sup>

Recently, identification of distinct breast cancer subtypes has elucidated an important biological difference in the types of tumors most common in each racial group. African American women suffer a higher burden of basal-like breast cancers, an aggressive subtype that has no targeted therapy. Basal-like breast cancers are typically estrogen receptor, progesterone receptor, and HER2 negative (triple-negative breast cancer), are highly proliferative, and have poor overall and relapse-free survival. Approximately one-third of invasive breast cancers are basal-like among African Americans younger than 50 years old, making basal-like breast cancer approximately twice as prevalent in this group than in Whites.<sup>6</sup> Epidemiologic research has identified some of the key prevention strategies for reducing basal-like breast cancer, including increasing breastfeeding and reducing obesity;<sup>7</sup> however, public health messages around these topics will require targeted messages that address knowledge gaps among young African American women.

Research has examined breast cancer risk perceptions and related behaviors among African American women.<sup>8–15</sup> Qualitative studies have examined risk perceptions and lifestyle behaviors<sup>16</sup> and explored the meaning of being at high risk for breast cancer;<sup>17</sup> knowledge, attitudes, and practices for breast cancer prevention and detection;<sup>18</sup> and risk-reduction efforts.<sup>19</sup> Limited research exists that provides guidance on how best to design programs and messages regarding risk to African American women. Ford and colleagues<sup>20</sup> used focus group methodology for designing a survey tool to assess breast cancer risk among African American women. Another study conducted focus groups to understand breast cancer risk knowledge, perceptions, and risk communication formats<sup>21</sup> among low-income African American and Hispanic women. Findings indicated that women were interested in understanding and reducing risk, and preferred communication tools that included information about family history and personal risk in graphic and quantitative formats.

Although an extensive body of research exists on breast cancer and African American women, there are fewer studies that provide insights about communicating risk and none that have focused on obesity and limited breastfeeding as susceptibility issues for African American women related to basal-like breast cancer. The purpose of this study was to explore knowledge about risk, attitudes, and beliefs about breast cancer in general, to assess knowledge about basal-like breast cancer, and to determine preferred message sources and formats for communicating risk about basal-like breast cancer to African American women. This study was part of a larger investigation aimed at understanding how obesity alters basal-like breast cancer risk, and the focus groups were designed to help identify knowledge gaps as well as attitudes and beliefs that must be addressed as scientific research findings are disseminated to younger African American women. While scientific data accumulate to demonstrate that increasing breastfeeding and reducing obesity<sup>7</sup> can help reduce basal-like breast cancer incidence, research about what African American women know about breast-cancer risk, basal-like breast cancer, and genomics is lacking. This qualitative research allowed for explorations of

**TABLE 1.**  
**DEMOGRAPHIC CHARACTERISTICS OF AFRICAN AMERICAN**  
**FOCUS GROUP PARTICIPANTS (N=57)**

	N (%)
Age(years)	
18–24	12 (21)
25–29	11 (19)
30–39	17 (30)
40–49	17 (30)
Education	
High school	8 (14)
Some college	19 (33)
≥College degree	30 (53)
Annual household income	
<\$10,000	12 (21)
\$10,000-\$39,999	18 (32)
\$40,000-\$79,999	20 (34)
>\$80,000	6 (11)
Missing income data	1 (2)
Employment Status	
Employed	44 (77)
Not employed	12 (21)
Homemaker	1 (2)

thoughts on riskfactor communication and beliefs about breast cancer risk through focus group discussions.

**Methods**

**Participants and procedures.** Six focus groups (N=57) were conducted in Raleigh, Durham, and Chapel Hill, North Carolina. Participants met the following eligibility criteria: (1) African American, (2) ages 18–49 years, (3) not previously diagnosed or treated for breast cancer, and (4) not having an immediate family member, spouse, or partner who was diagnosed with or treated for breast cancer. These criteria ensured that participants were representative of the group that we ultimately plan to target with education and media messages and eliminated participants who, based on personal experience, had more detailed knowledge of breast cancer risk than a typical woman. Recruitment methods included phone calls and flyers on college campuses and in community centers, churches, and college and alumnae chapters of sororities.

Focus groups lasted approximately 90 minutes and participants received an honorarium of \$40. Group sizes ranged from eight to 12 participants. Table 1 provides par-

ticipant demographics. All methods and procedures were approved by the Institutional Review Board at the University of North Carolina at Chapel Hill.

**Conducting the focus groups.** All focus groups were conducted by the same research team member (race and gender-matched to participants) with another team member taking notes. All discussions were audiotaped for transcription with consent from participants. Participants were encouraged to respond candidly to each question, as opinions would differ. At the end of each focus group, women were asked to complete a brief written survey to assess knowledge about breast cancer terms regarding subtypes (Table 2), they were then debriefed and received their honoraria.

**Moderator guide.** The moderator guide was developed to assess the following: (1) overall concerns women have about their health; (2) knowledge about breast cancer causes, risks, and prevention strategies; and (3) health communication sources and preferences) for learning about breast cancer. Additionally, participants were asked to complete a survey about knowledge (yes/no) of the following terms and where they may have heard these: basal-like breast cancer, breast cancer sub-types, breast cancer microenvironment, clinical trials for cancer, genomics, personalized medicine, targeted therapy, and triple-negative breast cancer.

**Analysis.** Audiotapes of the six focus groups were transcribed. The transcriptions were read and analyzed multiple times by the authors to gain a general sense of the data. Preliminary coding of concepts followed, with categorization of themes, patterns, commonalities, and variation. Categories and conclusions drawn were validated continually by referring to the data. Each category had subtopics and themes that emerged across multiple participants. These themes were analyzed across the six focus groups. The raw data were revisited to ensure that appropriate conclusions were drawn. The results were then organized under these themes to allow for discussion of findings to be more logical and parsimonious. Descriptive statistics were used to present participant demographic data and the results of the brief written survey about knowledge of cancer terms. The final conclusions were also translated into implications for informing future research.

## Results

**Participant demographics.** Fifty-seven women participated in the six focus groups. Forty percent were between 18 and 29 years old, and 60% were between 30 and 49 years old. A majority (86%) had completed at least some college or had earned a degree. Most (77%) were employed, and (47%) had annual incomes of \$40,000 or more.

**Participants' perspectives.** The common themes and patterns centered around women's understanding of their perceived risk, knowledge, attitudes, and beliefs, and their views about how to communicate cancer risk information. Race was a strong thread that influenced how risk was perceived; knowledge, beliefs, and attitudes about breast cancer were shaped by women's core knowledge about the disease, age perceptions, understanding of cancer causes, and connotations of the disease. Finally, women discussed preferences for how, when, and where health behavior messages about risk should be presented.

*Knowledge, beliefs, and attitudes about breast cancer.* The written survey indicated

**TABLE 2.**  
**FOCUS GROUP RESPONSES REGARDING CANCER**  
**KNOWLEDGE (N=54)**

Question	(%)Yes
Have you heard of the following terms?	
Clinical trials for cancer	70
Breast cancer sub-types	31
Genomics	31
Targeted therapy	30
Personalized medicine	28
Basal-like breast cancer	22
Triple-negative breast cancer	15
Breast cancer microenvironment	4
Never heard terms	6
Where have you heard these terms?	(%)
TV	33
Internet	31
Clinic/Hospital	26
Medical journals/article	17
Work	15
Family/friends	13
Magazines	9
Newspapers	9
Research	6
School	6
Media in general	4
Health fairs/seminars	4
Other	6

that knowledge about cancer terms was quite low (Table 2). A majority of women had heard of clinical trials for cancer (70%), but far fewer had heard any of the other terms: breast cancer sub-types (31%), genomics (31%), targeted therapy (30%), personalized medicine (28%), basal-like breast cancer (22%), triple-negative breast cancer (6%), and breast cancer microenvironment (4%). Six percent of participants had never heard of any of the terms. Television (33%), Internet (31%), hospitals/clinics (26%), medical journals/articles (17%), and family/friends (13%) were cited as the top sources where these terms were heard or introduced.

*Breast cancer connotations.* When asked for their immediate associations with the words *breast cancer*, responses were overwhelmingly negative, with “death” being mentioned in nearly every focus group. Other negative responses included: lumps, chemo, mastectomy, pain, and hair loss. Some responses reflected perceived causes and

medical nature of the disease, including genetics, environmental factors (e.g., pollution, radiation, toxic waste/chemicals), mammograms, ovaries, hormone levels, sexuality, and spirituality. Other responses referred to risk: "You're not immune from it if no one in your family has it" and "Men can get it." Finally, a few responses referred to survivorship and prevention, including "the people that beat breast cancer" and "early detection makes a difference."

*Cancer causes.* Participants generally understood that breast cancer can be fatal and that heredity plays a role in breast cancer risk. They attributed a wide range of potential causes to breast cancer, sometimes providing responses in the form of a question (e.g., "Smoking, right?" and "Pollution?"), underscoring their uncertainty about their knowledge. They mentioned smoking, heredity, breast injury, poor diet, lack of exercise, stress, hormones, birth control, radiation, asbestos, wearing a bra when sleeping, age at childbirth, lack of breast feeding, and the environment as potential causes of breast cancer.

*Family history and risk.* A lack of family history made some women feel that their risk was lower. Having no family history of the disease was cited as a main reason not to be concerned about breast cancer.

*Age and breast cancer risk.* There were three distinct views about how age relates to breast cancer risk: 1) risk increases with age; 2) age provides a period of protection when a woman is young; 3) age doesn't relate to risk. Some participants clearly felt that as one ages, one's risk for a cancer diagnosis also increases.

For a minority of participants, there was a sense of a safety period where one was protected, but at some age, they were no longer in that zone. Other women clearly believed that a cancer diagnosis was not age specific. To support the latter belief, participants gave examples of young women who died or were diagnosed with breast cancer. The responses suggested that a cancer diagnosis can occur at any time in a woman's life; however, participants indicated that younger women may believe their risk to be less serious because of a sense of invincibility that often accompanies youth.

*Race and breast cancer.* Race widely shaped participants' perceptions about breast cancer risk. For instance, one participant stated, "... being a Black woman ... puts you at higher risk." Participants expressed the belief that race is associated with a variety of negative health outcomes, not just breast cancer, as in this statement: "I think African Americans are at a higher risk for everything."

*Race, risk, and socioeconomic status.* Participants noted that socioeconomic status (SES) influences risk, because lower SES women may not have access to the same level of health care and insurance, which contributes to poor health overall.

*Race, risk, and diet.* Participants described African American diets as higher in fat and less healthy, and identified those dietary choices as increasing cancer risk. For example:

We don't normally eat like they [Whites] do ... they might eat a lot of bell peppers and orange peppers just straight from the garden. We cook ours or fry it up ... it's a different lifestyle ... like, they might eat a steak. We might eat a steak with butter.

*Cancer as a White disease.* There was a general recognition and understanding across the focus groups that all populations are and can be diagnosed with cancer. However,

several participants pointed out that breast cancer is still depicted as a disease of White women. These portrayals were thought to be upheld in the media and reiterated by family members. One participant said:

I feel like the way they display it to us, like on television or even down to our relatives, I've heard words like, well, you know that's not common for Black people. It's very rare. And like I say when you look at the media, you typically see Caucasians in the commercials. You might see one Black girl.

Another participant added:

Or even those walks where you see the people in pink, there's never any Black people in those pictures, either.

The lack of visual representation of African Americans in breast cancer information and activities translated to lowered perceived relevance of the disease. For many of the women, heightened awareness was brought on because of one particular African American celebrity, Robin Roberts of ABC's Good Morning America.

I feel a little bit like Black women were brought more into the forefront with breast cancer when [Robin Roberts] was on TV and shaved her head and that sort of thing. I think that made me think more about the possibility that I could get breast cancer. Before that, I hadn't considered it because I hadn't seen anyone that looked like me with it.

*Breast cancer surveillance.* Women recognized mammography and breast-self exams (BSE) as core components of breast health. They talked about the importance of monthly BSEs and annual mammograms. However, gaps emerged regarding what they should look for when conducting a BSE. Several women expressed frustration over having no idea what they were looking for and when asking for clarification being told, 'You are really just feeling for changes in your breast so you have to do it consistently enough so that you will know that something has changed.'

The notion that African American women are at risk for breast cancer led some women to be hyper-vigilant about their breast health, while feeling that it was not a worthwhile endeavor.

Every month I was feeling something and I went to the doctor and they told me, 'Oh, you're fine, it's nothing.' . . . what's the point of doing this if I can't tell and I'm running there [for them to] tell me nothing is wrong.

**Basal-like breast cancer.** Focus group participants were aware of more aggressive forms of breast cancer found in African American women. Although participants' knowledge of basal-like breast cancer was limited (see Table 2)—none could identify it by name—several were able to identify that a more aggressive subtype existed and had worse outcomes in African American women than in Caucasian women.



It's the White women who are diagnosed more. But the African Americans, we die more.

**Breast cancer risk communication.** *Conflicting messages about cancer risk.* Women mentioned that at times, they had received conflicting messages about their breast cancer risk. These messages caused confusion about whether to be concerned, which they found frustrating. On one hand, they were aware of messages that women should be vigilant about their breast health by doing self-examinations and getting mammograms. However, when they perceived a breast problem, their health care provider was dismissive. One woman said:

I went for a mammogram and it was like this one little spot, it was like this little knot and it bothered me because it wasn't on this side. And it was small, and they were saying they couldn't feel it. I even had the lady put her hand there and she couldn't feel it. And the doctor, I guess, thought I was going crazy . . . And he was like, 'It's nothing to be concerned about.' To you, but to me it was, because it was different.

In other instances, women talked about hearing of women having gone to the doctor because they were told or heard that African American women are at high risk for the disease, only then to be told by the doctor that they were too young to be concerned about getting breast cancer.

*Online information sources.* In all of the discussions, participants confirmed that they used the Internet, especially health-related sites, as a primary source of information about general health and breast cancer. The most popular Websites were MayoClinic.com, WebMD.com, and AsktheDoctor.com. These were described as reputable and reliable sources of health information and "credible reference points." A majority of women discussed using the Internet to satisfy their curiosity or the need for information, while others said that they were encouraged by friends, family, and physicians to use it to supplement word-of-mouth information. One woman cited using the Internet specifically because of income constraints to find answers about health concerns before having to incur the cost for a doctor's appointment.

*Television.* Women said they drew on television programs as a source of health information. Some used those based on or hosted by medical professionals (e.g., *Doctors*, *Dr. Oz*, *Mystery Diagnosis* and the Discovery Health Channel), while others cited weekly entertainment shows with plots featuring medical issues, such as *House*, *Private Practice* and *Grey's Anatomy*.

*Physicians as sources of information.* Health care providers were cited as sources for obtaining information about specific health issues. Physicians, for example, were regarded as able to assess the relevance of breast cancer information needed for their patients, and to provide comprehensive, up-to-date information, based on breast health studies. Additionally, for several women, being educated by their health care provider about breast tumors and other signs and symptoms for breast cancer was important. One participant stated her wish to see breast models in all doctors' offices, so that women could have the BSE method explained and experiment in detecting lumps.

Women also recounted both negative and positive personal experiences in obtaining

information from their physicians. One woman disclosed that her lower income status required her to use a local health department for regular health care, and described this care as fast and impersonal, due to the volume of patients. Several participants told of positive experiences in getting sufficient information from their physicians, and a subset of them were particularly satisfied with having a female physician discussing breast cancer with them. One woman stated that her physician was particularly thorough in explaining important breast cancer information, because this doctor was herself a breast cancer survivor. Some participants were explicit about wanting an African American female physician, stating that a physician of the same racial background would know how best to convey information that is most relevant to African American female patients.

*Family and friends as information sources.* A majority of participants acknowledged obtaining breast health information from relatives, friends, and other acquaintances, saying that the message source made the information personally relevant and thus they paid more attention. Word-of-mouth, e-mail blasts, listserv notices, and social networking such as blogs were examples of how women exchanged information with family, sorority sisters, fellow church members, and other acquaintances. Someone in a participant's social network having a health issue was often the catalyst for seeking additional information or even taking action to reduce the risk for disease, such as getting screened.

*Breast cancer survivors as information sources.* Women noted that breast cancer survivors were sources of information and served as a reality check that they could also get the disease. Every discussion included mention of Robin Roberts, of *Good Morning America*. Because she is a nationally-known African American personality, her experience resonated with participants. Some women also cited local celebrities who battled the disease publicly, survivors who spoke during National Breast Cancer Awareness Month, or consumer products advertising cancer prevention as ways that heighten their awareness about risk. A subset of women also said that personal interactions with survivors provided them with a sense of hope that survival is possible.

*Effective communication about breast cancer risk.* Women noted that there may not be any one best method of providing information, but that they wanted information targeted to them. They believed that the information should come from culturally relevant sources, and that messages should be consistent across sources, provided frequently, and convenient for women to access.

Women mentioned several media sources for communicating messages to African American women. These included "Take a Loved One to the Doctor Day," an annual campaign featured by the *Tom Joyner Morning Show*, a nationally-syndicated radio show with a predominantly African American audience, and magazines popular among African American women, such as *Ebony* and *Essence*. Several participants shared that these sources primarily reflect stories and concerns of African American women. One woman said, "... I see me in those magazines."

Frequent messaging was described as a useful strategy for communicating important health messages, e.g., repeated public service announcements about flu vaccinations. In addition, because of women's busy schedules, convenience should be a consideration. Examples of convenient sources were health-oriented programming at churches, brochures distributed at store entrances, information on consumer products sold

at the local grocery store, and health fairs and workshops at employment sites and community-based organizations.

Though women were clear about sources, relevance, and frequency of breast cancer risk messages, there were conflicting opinions about how best to present risk information as it related to race. For example, some women benefitted from hearing comparisons between African American and White women, while others were discouraged by them. Some women wanted a comprehensive description of a health issue, while others wanted only the information that was most applicable to their own health.

## Discussion

In an effort to understand how to communicate risk regarding basal-like breast cancer to African American women, we sought to attain a baseline understanding about women's knowledge, beliefs, and attitudes about basal-like breast cancer and breast cancer risk in general. Findings from six focus groups painted a multi-dimensional picture of African American women's understanding of breast cancer. Despite advances in detection and treatment, women had overwhelmingly negative associations with the term *breast cancer*. The range of responses to questions about causation suggested widespread confusion, as well as a lack of understanding of the biological processes that support cancer cell growth. Misconceptions about cancer causes seem to have persisted over time, given that previous, older studies have reported similar findings. Studies by Greg and Curry<sup>22</sup> and Loehrer and colleagues<sup>23</sup> cite slow healing sores, bruises or bumps as perceived causes.

When discussing breast cancer risk, women in our focus groups presented their understanding *via* three lenses: family risk, age, and race. Regarding familial risk, women believed that a family history could predispose one to the disease and that, when there was no family history of breast cancer, their perceived susceptibility was fairly low or not a concern. Other studies have similarly identified beliefs that minority women do not think they are particularly susceptible to breast cancer due to race,<sup>24</sup> and have shown that family history is strongly related to perception of risk of breast cancer.<sup>25</sup> This contrasts with other cancer types where family risk had no relationship with perceived risk of prostate cancer for African American men.<sup>26</sup> Further, it is suggested that physicians should be responsible for initiating family health history discussions about cancer to inform patient health care practices.<sup>27</sup>

Age has been identified as a well-understood correlate of cancer risk by many studies of cancer risk perception. Participants in our focus groups believed that risk increased with age. There was also a sense that there was a period in one's (younger) life where one was essentially safe, but at some unknown point that changed. However, some women emphasized that the disease could strike at any time.

While perceptions of age-related risk followed patterns for the general population, race was perhaps the most influential lens through which women viewed breast cancer. Women had a prevailing sense that as African Americans they were at high risk for "everything." Race was discussed in the context of an association with lower socioeconomic status, thus having implications for reduced access to health care. Race was also

an indicator for cultural differences which manifested in diets and other poor health outcomes that further predisposed one to getting cancer. However, in marked contrast to these statements about disparities in general, there was a perception of breast cancer as a “White disease.” Participants noted that media portrayals of the disease mainly showed White women, which diminished the perceived severity of the problem for African American women.

One prevailing media image for African American women in all of the groups was Robin Roberts and her breast cancer story. Similarly, the risk of the disease became personally relevant when someone in a woman’s social network received a diagnosis or died from breast cancer. Studies have shown the importance of using personal narratives from peers. For example, the Witness Project promotes breast and cervical cancer screening through cancer survivors who talk about their experiences with other African American women.<sup>28–30</sup> McQueen and colleagues<sup>31</sup> showed that African American women randomized to watch a narrative video comprising stories from African American breast cancer survivors experienced more positive and negative affect, identified more with the message source, and were more engaged with the video compared to women who watched an informational video. These narratives reduced counter-arguing and increased cognitive rehearsal, which may increase acceptance and motivation to act on health information in populations most adversely affected by cancer disparities.<sup>31</sup>

Discussion of baseline knowledge, beliefs, and attitudes women had about breast cancer was a primary goal of the focus groups and provided a segue-way for discussing their understanding of basal-like breast cancer. We found that women had limited or no knowledge of this cancer type. Women had an awareness of some “aggressive” form of breast cancer in African American women, suggesting some penetration of scientific information into popular culture. It is striking that a large percentage of women in the focus groups (~30%) reported familiarity with the terms *breast cancer subtypes*, *genomics*, and *personalized medicine*. However, women had limited knowledge of breast cancer subtype-related terminology. The terms *triple-negative* and *basal-like breast cancer* were less familiar. Given that these terms have only recently (within the past several years) seen widespread clinical usage, recognition by approximately one-fifth of participants suggests that these concepts are noteworthy and may reflect a relatively rapid dissemination of these concepts. Predominantly, our participants were college-educated which may account for this level of knowledge. In contrast, scientific terminology such as *breast microenvironment* was not well recognized (4%). The specificity of the responses for particular terms demonstrates that knowledge of clinically relevant terminology is not simply due to scientific training or career specialization of particular respondents, but rather reflects broader recognition of these terms.

A main goal of this study was to gain perspective on how to communicate risk about basal-like breast cancer to African American women. Women pointed out that messages they were currently receiving from health care providers, media, and family and friends regarding breast cancer risk were inconsistent. Information about race-related risk was counterbalanced by feedback that they need not be concerned due to youth or having no family history, or by media messages that further reinforced the sense of low personal relevance. This conflict in information may reflect the difficulty of converting

population-based estimates of cancer risk into accurate perceptions about individual risk;<sup>32</sup> however, these results also indicate gaps in health education and opportunities for better delivery of tailored messages.

Physician-patient communications present a challenge for meeting the health information needs of African American patients. Studies have pointed out that providers often neglect recommending screening or providing information about risk to minority groups<sup>33</sup> highlighting issues with trust and discrimination. Even when family history is ascertained, African American women may be less likely than White women to be informed about familial risk of breast cancer.<sup>34</sup> In our study, women reported feeling that their concerns about risk were minimized. They pointed out that personally relevant, convenient, clear, and consistent communication was needed, and they preferred sources of information that depicted people like them. There was no clear answer about using race comparisons to communicate risk. Some women said they would like to hear how their risks as African Americans compared with risks in other races, while others indicated that race-based comparisons would be undesirable.

**Study implications.** There are several implications of these focus groups with young, African American women. First, messages must be accurate and clear when discussing age, family history, and race as factors for risk. These were important areas where women had misinformation, uncertainty, or no knowledge. In this study, misinformation about the link between race and risk lead to women thinking that they were not susceptible. This finding suggests the need to target and individually tailor messages about primary risk factors to African American women. The widespread perception of breast cancer as lacking personal relevance and being a “White disease” suggests that communications should include race-specific and culturally appropriate images and messages. Second, women viewed their health providers as a key source for comprehensive, relevant information tailored to their personal risk factor profile. Provider skill in sharing information may be critical to developing accurate perceptions of individual risk and for motivating patients to engage in surveillance or other preventive activities. As knowledge becomes more widespread, providers may be better able to specifically address this breast cancer subtype and its risks, along with providing appropriate information on the role of race in susceptibility. Health care providers will need to acquire understanding of the epidemiology and clinical behavior of breast cancer subtypes.

Another issue was frustration arising when women sought medical care and had their concerns dismissed by the medical provider. Regular preventive care with a primary care physician may contribute to relationship that could lessen the likelihood of a perceived dismissive attitude from medical personnel.

Finally, because resolving discrepancies between population-level statistics and perceptions of individual risk is a persistent problem, both in our focus groups and in other populations<sup>32</sup> researchers and public health practitioners may need to develop better ways to help women understand population risk and how it relates to their own risk profile.

While our study highlighted previously undocumented information gaps related to African American women's knowledge of basal-like breast cancer and breast cancer disparities more broadly, there are limitations when using focus group methodology. First, the interactive nature of this method may persuade some group members to conform

to a perceived majority opinion and hide divergent views. However, the focus group facilitator made an effort to draw out diverse opinions and encouraged each woman to contribute. Second, focus group data may not be generalizable to the larger population if the demographics of participating individuals differ from the population at large. Our population tended to be educated and employed, and therefore may not accurately reflect knowledge among African American women with lower socioeconomic status or with limited access to medical care. However, use of this strategy provided detailed information about knowledge, beliefs, and attitudes for use in the development of culturally relevant cancer education communication.

**Conclusions.** Our study demonstrates that among young African American women, addressing breast cancer risk is a multifaceted issue. The confusion about risk could possibly be clarified by communications that are culturally relevant, appropriate, and accurate. Women expressed the need to have messages that clarify the gravity of breast cancer incidence and mortality. Use of concrete strategies based on the suggestions of the young African American women should improve communication of basal-like breast cancer risk information and motivate screening behavior.

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