

Message Received: African American Women and Breast Cancer Screening

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African American women are more likely than other women to be diagnosed with breast cancer at a young age, to be diagnosed at a late stage, and to die from the disease. Yet we see evidence of irregular screening and follow-up. Previous research on psychosocial factors influencing decisions to screen reveals barriers: fear, fatalistic perceptions of cancer, inaccurate perceptions of risk, and associations with stigma. The current qualitative research with, largely, insured African American women (n = 26), health navigators (n = 6), and community stakeholders (n = 24) indicates both positive and negative factors influencing decision making. The women in our sample believe in the value of early detection and are motivated to screen in response to encouragement from health providers. However, they also report several factors that contribute to their decisions to delay or not screen. These include (1) perceptions that the health community itself is confused about the need for screening, (2) perceptions that White women are the priority population for breast cancer, (3) family roles that prohibit self-care and encourage secrecy, and (4) fear of diagnosis. Participants report not feeling included in national-level health promotion campaigns. It is argued that African American women, in particular, may benefit from more nuanced health information about their risk.

Keywords: breast cancer; cancer prevention and control; health disparities; health promotion; Black/African American; minority health

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► INTRODUCTION

During the late 1980s and through the 1990s, the United States witnessed a surge in breast cancer screening across all racial and ethnic populations attributable to the health promotion activities of a range of organizations (Breen & Kessler, 1994). However, since that time, despite the continued efforts and visibility of these organizations, there has been a “leveling” off of screening rates for all groups, which still fall below Healthy People 2020 goals (National Cancer Institute, 2015; Sabatino, White, Thompson, & Klabunde, 2015). Breast cancer is a persistent and unique challenge in the African American community where women are more likely than women of other racial and ethnic groups to get breast cancer at a young age, to be diagnosed at a late stage, and to die from the disease. Indeed, African

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American women have a mortality rate 42% higher than other women (DeSantis et al., 2016). Moreover, recent evidence suggests a convergence of incidence rates between African American and White women (DeSantis et al., 2016).

The cause of these disparities has been the subject of both medical and behavioral research and is likely complex and multifactorial. One concern is irregular screening behaviors and practices. A 2011 report by the American Cancer Society attributes late-stage diagnosis among African American women to lower frequency of, and longer intervals between, mammograms and to lack of timely follow-up of suspicious results (American Cancer Society, 2011). This underutilization of screening has been affirmed by other researchers (Highfield, Bartholomew, Hartman, Ford, & Balihe, 2014; Royak-Schaler et al., 2007; Royak-Schaler et al., 2008; Schueler, Chu, & Smith-Bindman, 2008; Smith-Bindman et al., 2006). A lack of access to screening due to insurance status or other “logistical” issues has been a concern (Schueler et al., 2008). Delays and failures to screen among African American women have also been tied to psychosocial factors such as fear of a range of things including diagnosis, pain, and partner abandonment (Consedine, Magai, Krivoshekova, Ryzewicz, & Neugut, 2004; Highfield et al., 2014; Jones et al., 2014); a fatalistic perception of cancer diagnosis (Mohamed, Skeel Williams, Tamburrino, Wryobeck, & Carter, 2005; Spurlock & Cullins, 2006); an inaccurate perception of risk (Kaiser, Cameron, Curry, & Stolley, 2013; Kidd, Colbert, & Jatoi, 2015; Orom, O’Quin, Reilly, & Kiviniemi, 2015); and an association of stigma with cancer diagnosis (Jones et al., 2014).

The current research was designed to explore the factors that influence decisions to screen or not to screen among African American women in Prince George’s County, Maryland. Several factors made this qualitative exploration unique. Initially, we choose to include a focus on *avenues* to screening in addition to *barriers*, to develop actionable results as, in part, this research was motivated by a desire to increase screening for a no-cost program at a local hospital. In addition, the setting for this research is unique. Prince George’s County borders Washington, D.C., and is majority African American (U.S. Census Bureau, 2010). The county is extremely economically diverse but includes some of the wealthiest minority communities in the country (Brown, 2015). Health care access is relatively high, with 84% of residents insured and 70% reporting to have a medical home (School of Public Health Study Team, 2012). Yet, between 2007 and 2011, the rates for breast cancer mortality among African American women in the county were the highest in the state of Maryland (Richardson,

King, Dwyer, Parekh, & Lewis, 2014), and the local Susan G. Komen (2015) chapter has recently identified the county as a priority area. The underutilization of breast cancer screening in Prince George’s County and other majority African American communities in the state has also been described by other researchers (Shirazi et al., 2015). Thus, the community setting facilitated a focus on decision-making factors other than access.

Barriers to screening figured prominently in this research and provide insight into why, despite 20 years of health promotion effort, we continue to find hesitancy to adopt regular screening especially among African American women. Our findings support the conclusion that while change in beliefs, social norms, and knowledge may be occurring regarding cancer in the population, these shifts have been insufficient to support increases in screening behavior. Moreover, we find evidence of unintended and negative impacts from health promotion messaging among this priority population.

► METHOD

Participants and Setting

As noted, we implemented a qualitative research design to explore breast cancer screening beliefs and self-reported behaviors among a sample of women living in Prince George’s County in the catchment area of the “Breast Care Center” of a local hospital partner. In total, six focus groups were held with 56 participants. The first four focus groups included 26 nonimmigrant, African American women with an age range of 42 to 64 years and a median age of 52.5. Participants for these initial groups were recruited from our partner’s records of patients who had, at least, once been screened at the Breast Care Center as we specifically sought women with some experience to explore pathways to screening. Center staff identified all female, African American residents of Prince George’s County, aged 40 years or more who appeared in patient records during the past 5 years. These women were contacted by phone by center staff to request participation in one of the four focus groups to be held. Participants self-selected a group, and all groups included women representing a range of ages. Participants had received at least one mammogram in the previous 5 years, but only 15% reported that they have a mammogram every year. Our participants were, on the whole, well-educated, healthy, and insured (88%). This was the population we sought to recruit as (1) the catchment area itself is majority African American and relatively well educated and

well insured (School of Public Health Study Team, 2012) and (2) we wished to explore barriers to screening other than basic access (i.e., insurance, transportation). Women's focus groups were held in community libraries across the county for the convenience of participants. A semistructured moderator's guide was developed with input from the research team and funders. Two experienced African American women moderated the groups. Each group ran approximately 90 minutes. A light meal was served, and participants received a \$30 gift card to compensate for time and any costs incurred. After each group, a representative from the clinical staff of the Breast Care Center offered to answer participants' specific questions about screening guidelines and procedure. Moderators refrained from addressing participant questions on these topics during the data collection period.

Findings from the initial four focus groups were presented at the two subsequent focus groups to elicit reactions and additional insight regarding concepts emergent in women's groups. The first of these second set of focus groups was held with six participants employed as health care navigators in three hospitals serving the county. These navigators were identified through their employers. The second group included 24 participants who were known stakeholders or leaders on the subject of breast cancer in the African American community in the county. This sample was created through a snowball sampling, in which a few well-known participants were first identified and, in turn, asked to identify more stakeholders in the county. Participants included representatives from community-based organizations serving African American women, health care providers, local government, and the faith community. These groups also averaged approximately 90 minutes and were facilitated by a trained moderator. Navigator and stakeholder groups were held at a local hospital.

The University of Maryland Institutional Review Board approved the study protocol. Patient confidentiality was maintained through the use of only first names in focus groups. At the onset of discussion, participants were asked to maintain the privacy of fellow group members, and neither last names nor other obviously identifying information was collected (i.e., addresses). As noted, recruitment and data collection were accomplished by two different groups, Breast Center staff and the university-based, research team, respectively.

Theoretical Approach and Analysis

All focus group sessions were audiotaped and transcribed verbatim. Analysis was completed using

Atlas ti 6.0 qualitative software. Our process was guided by an iterative application of grounded theory (Strauss & Corbin, 1997). While we approached this project with specific research questions, we did so in the absence of specific hypotheses about what factors contributed to women's decisions to screen or not screen. The research team met to discuss emergent themes and concepts at specific points in the process including (1) immediately following data collection, (2) following an initial immersion into the data set (3) following each coding session. During these meetings, a codebook was developed using both codes driven by the research questions and those that emerged from the raw data. Coding involved the identification of broad domains or initial codes. From there, more refined concepts or subcategories were explored in the process of focused coding (Sbaraini, Carter, Evans, & Blinkhorn, 2011; Strauss & Corbin, 1997). Discrepancies that emerged at any point in the coding were resolved through team discussion and consensus. In addition to the process of coding, we incorporated the six core phases of the *Sort and Sift, Think and Shift* approach—data inventory, written reflection, reflective diagrams, categorization, bridging, and data presentation—to fully explore the reflexive capabilities of software analysis (Maietta, 2006). Two coders working independently coded all six transcriptions. Interpretation and categorization of participants' statements were the result of an iterative, team-based process with specific reference to findings of navigator and stakeholder groups for confirmation and interpretation of themes from women's groups.

► RESULTS

A summary of the results is presented below with the most prevalent themes and relevant quotations across the groups. These themes were found in *all* discussions (four women's groups, navigator and stakeholder groups). The reader should note that quotations presented here were selected for clarity and do not represent the total number of participant statements related to each theme or concept.

Deciding to Screen

Women's groups began with a discussion of the specific motivators for screening. This discussion included two categories: internal "motivations" for being screened and what might be termed as *cues* to action. Motivations to be screened included having a personal connection to a woman diagnosed with cancer (breast cancer or another form). For example,

I had two aunts, one died of skin cancer, and the other one died from liver cancer. Just seeing how it affected them, even as they were going through their treatments and up to their final day. . . . You see somebody waste away like that and you just want to do better for yourself and for your kids. (Women's group)

Another motivation was "wanting to live." While it might seem obvious, "wanting to live" implies a belief in the power of early diagnosis. For example,

I want to live as long as I can. If I can erase a lot of things that has happened—like she said, it's going downhill. I want to pull it up and tuck it up and keep going as long as I can. (Women's group)

And,

I never knew that she never had a breast exam, never, wasn't thinking about it; and I just looked at her with and I said, huh, you got two boys and you got all of these grandkids and you never even thought about living a little longer? (Women's group)

Regarding "cues to action" or specific catalysts for being screened, we found that health professionals, especially primary care physicians, had a significant role in encouraging women to be screened for breast cancer. For example,

My primary just reminds me when I go for my physical, I have high blood pressure so if I go back in six months she will be like, "You didn't get your mammogram?" And then I say, I'm going, and then that's it. (Women's group)

In addition, print materials from providers were reported as having an encouraging impact.

Hospital just kept . . . sending me their little flyers to say, get your mammogram. (Women's group)

Deciding Not to Screen

Although the women in our sample were screened for breast cancer at least once in the previous 5 years, some also reported decisions not to screen. These "barriers"

can be broken up into three categories: (1) confusion about recommendations and risk, (2) family responsibilities/caregiving, and (3) fear.

Recommendations. Women reported being unsure of the breast cancer screening guidelines generally, but estimated that one should be screened every 1 to 3 years. A majority noted that screening is recommended beginning at age 40 for all racial and ethnic groups. However, several women questioned why screening begins at age 40 given what they perceived as the increasing evidence around them of diagnoses at younger ages. Some also wondered why mammography is not recommended for older women.

What happens after you turn 66? You can't get mammograms? We're not so important? (Women's group)

Among the women, there was little evidence of understanding that the risks and benefits of mammography vary by age. In general, however, there was a perception that guidelines do not make "sense" and seem idiosyncratic. All groups asked about guidelines in the question-and-answer sessions that were held immediately after data collection. It was often the first question asked. For example, one woman noted,

Well, I know they keep changing the data, before 40, at 40, 10 years, every year, every other year, every third year. (Women's group)

Navigator and stakeholder participants agreed that guidelines are confusing and were able to articulate a connection between this perception and differing screening recommendations from trusted organizations such as the American Cancer Society, National Comprehensive Cancer Network, and U.S. Preventive Services Task Force. Moreover, one stakeholder reported instances in which patients were unable to have annual mammograms due to health insurance policy. For example, one stakeholder observed the following:

We as health care professionals, we can't get the message straight. You've got one group saying every other year. You've got another group that says no, every year. You've got a group that says you've got to have an abnormal so that you can get a diagnostic . . . (Stakeholder's group)

Women in all groups also reported confusion about the relationship between race and breast cancer. Although there were a few who thought that African American women might be more at risk, in all four of our women's groups, there were participants who reported a strongly felt perception of breast cancer as a "White women's disease." For example,

This is just my opinion—I think for the most part, breast cancer is seen as a White woman's disease. So, it's not something that we feel that is running rampant in our communities at least. (Women's group)

Also in all groups, this belief was directly tied to perceptions of health promotion prioritizing of White women. These comments were frequently accompanied by direct references to Susan G. Komen and other similar organizations.

I'm assuming we probably are a high rate of breast cancer, African American women, we probably are. But do you hear it? I see a Susan G. Komen commercial, but nothing is geared as far as commercials to us. (Women's group)

And,

Particularly with Susan B. Komen [sic], the walk, that needs to be marketed differently. It's not marketed in certain communities. (Women's group)

And,

We see White women in the forefront of it. Whenever you see a commercial, whenever you see anything about breast cancer screening, whenever you see anything about breast cancer awareness, you see that image of [White women]—when you look at Race for the Cure, anytime I see that on TV, yeah, you see some African American women . . . but yet you still know. (Women's group)

Stakeholders heartily agreed with this perception. As we presented the women's views above, stakeholder group participants responded.

They don't see Black people—African American—people in those commercials. They don't see them out front. (Stakeholder group)

Family Responsibilities and Caregiving. On the simplest level, women's roles as caregivers made it difficult to carve out the time to go for screenings. For example,

I was saying, sometimes you just can't take that day off. When you're the only one providing for them kids, you got to make everything count. You got to take care of them kids, and you don't be thinking about yourself. (Women's group)

And,

Like my sister . . . She waited and she waited. She got to have a biopsy did. And she almost lost a breast, because she was a teacher substitute and she couldn't take off. At that time they were laying off people left and right, so she couldn't afford to take off. (Women's group)

At a deeper level, women reported feelings of responsibility to others that made even sharing news about poor health status difficult. To our surprise, a few participants told personal stories of how they or others dealt with a breast cancer diagnosis without telling family members. In one group, when a participant told a story of a woman who did not disclose her diagnosis to her family, a participant said quietly, "I did that." She went on to tell her own story of secrecy around her cancer diagnosis. When asked why she didn't disclose her diagnosis, she said, "They're all worriers, and I knew if I told them, they would worry." When this story, in turn, was related to stakeholders, a participant in that group added the following about her own experience.

And so I have one daughter and a granddaughter and I have . . . a sister. I didn't want anybody . . . I am the one that never has problems in the family. So just to keep everybody knowing that about me, I just didn't say anything . . .

Fear. There were a few beliefs that participants reported that gave them pause about getting screened for breast cancer. These included the fear of pain or discomfort of mammograms themselves,

The pain. When they called me for this study I told them, I said, that was my second one. She said, you haven't had one since 2012? I said, no, and I vowed after 2012 that was my last one because it was just so painful. (Women's group)

The fear of being diagnosed with cancer was expressed strongly as a deterrent. For example,

I don't want to know that I have it or that I don't have it, I mean honestly . . . (Women's group)

And,

We have had women that we have to call back for additional views and they're like, "No, I'm not going to come back because I don't want to know." And it's just kind of, again, the sooner you know about something the better. And you don't have to live with the stress of not knowing. But that's a tough one. (Navigator group)

Additionally, a third belief, mistrust of the medical profession, did arise in one women's group and in the leader's group. However, it was not as powerful a theme as the others in our groups. It is possible that this theme would have been more prominent in a sample of participants who had never been screened.

► DISCUSSION

Our findings are encouraging in several ways. Initially, women identified "wanting to live" as a motivator for screening. "Wanting to live" implies a belief in the connection between screening and treatment, as well as a belief in the power of early detection. This is interesting particularly in light of evidence from earlier studies of "fatalism" regarding breast cancer in the African American community (Gullatte, Brawley, Kinney, Powe, & Mooney, 2009; Phillips, Cohen, & Moses, 1999; Spurlock & Cullins, 2006). It is worthwhile to note that evidence of personally held views of fatalism was not found in any group. While several women expressed fear of a cancer diagnosis as a barrier to screening, none expressed doubt that one's chances of survival were greater in cases of early detection. Moreover, we did not uncover strong feelings of mistrust of health professionals, which has been previously reported (Gamble, 1997; Thomas & Quinn, 1991). In fact, our participants responded positively to doctor recommendations. It would be interesting to explore this belief in a larger sample including women from a range of socioeconomic and insurance statuses.

Also encouraging are findings that mass communication efforts have reached African American women. Unfortunately, the messages received seemed to differ from those intended. Despite the presence of the topic of breast cancer in the media, we find confusion

around screening guidelines and an association of breast cancer risk with White women. Both these messages remove a sense of the urgency and importance of screening among African American women. The lesson to learn from this finding is that health promotion must consider various impacts and interpretations among all potential audiences. It may be that women are ready for more nuanced and complex information about their risk. In this, we are in agreement with Woloshin, Schwartz, Black, and Kramer (2012) who argue against the trend of persuasive over informative approaches in health education. Increasingly, incidence rates among African American women are on par with White women, but even without this trend, African American women have long been at greatest risk of mortality related to breast cancer (DeSantis et al., 2016). These are important pieces of information for women making the decision to screen or not to screen. The perception of breast cancer as a White woman's disease is certainly an important avenue for further, perhaps quantitative, exploration with a larger sample.

The perception that African American women are not a "priority" population for breast cancer may be compounded at the interpersonal level by secrecy around diagnosis, because this secrecy effectively limits the visibility of those with breast cancer to other African American women. Also interesting is that this secrecy was not built around fatalistic perceptions of cancer as previously reported (Phillips et al., 1999). Instead, our participants spoke of secrecy as related to roles of caregiving. For example, our participants noted a desire to avoid family members "worrying" about them. This finding is similar to that of Carthron and Ward (2012), who find evidence of secrecy among African American diabetics because of a perceived need to seem "under control."

Overall, caring for others was a barrier to taking the time to be screened. As one participant explained, Black women are "usually the pillar that keeps the family, the African American family together . . . and if something is wrong with that pillar the family starts to fall apart." In this role, women may have an especially difficult time finding space for self-care. This perception of the "superwoman" role is described in African American studies (Lindsay, 2014) and has also been recently tied to specifically to health (Nuru-Jeter et al., 2013; Speight, Isom, & Thomas, 2013) and health secrecy (Carthron & Ward, 2012).

A final note is that none of the themes revealed in this research should be taken as discrete. Each is connected to one another in a complex of factors that influence screening. For example, although knowing someone who had been through an experience with

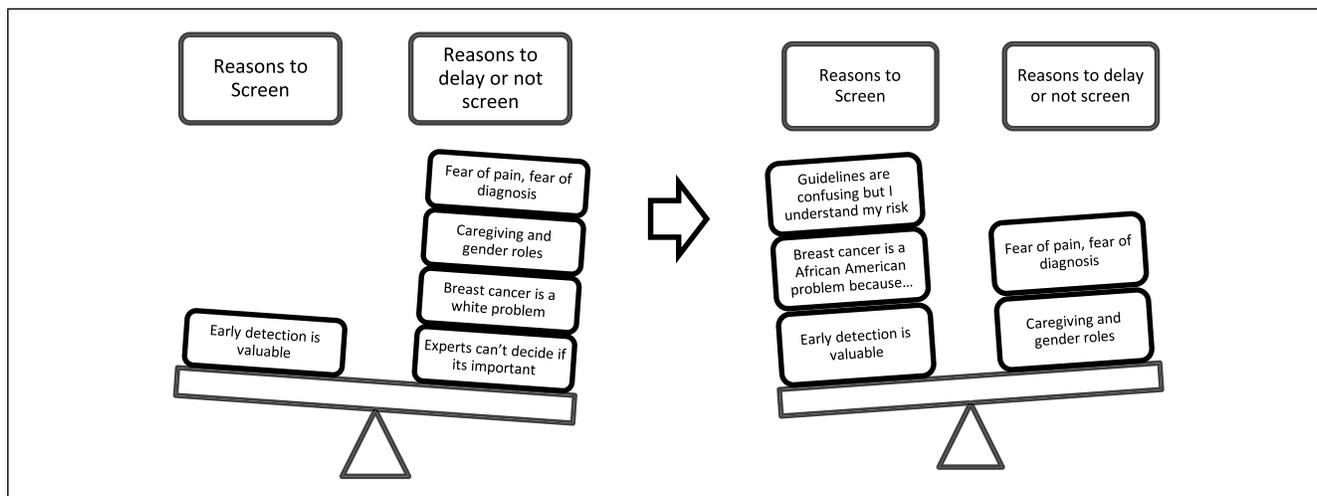


FIGURE 1 Factors Influencing the Decision to Screen for Breast Cancer

breast cancer was a powerful motivator, we see that a tendency toward secrecy in this population and a perceived lack of images in the media may add to the perception that few African American women actually have experiences with breast cancer and, thus, an inaccurate assessment of “risk.” All these factors are weighed against one another in a woman’s decision to have or not have a mammogram. Figure 1 is a simplified illustration of how our participants perceived the decision not to screen and also how even minor shifts could realign these psychosocial factors to “tip the scale” in a direction favorable to regular screening.

CONCLUSION

Our findings are both positive and encouraging. African American women in our sample did not question the importance of early detection. Our results also support the evidence that African American women are responsive to mass media campaigns (Hall, Rim, Johnson-Turbes, Vanderpool, & Kamalu, 2012). This is an opportunity to expand the successes of relatively small and intensive health education efforts to reach larger audiences (Mason et al., 2013; Ochoa-Frongia, Thompson, Lewis-Kelly, Deans-McFarlane, & Jandorf, 2012). However, our findings also include a warning about how messaging may interact with cultural, social, and contextual factors to create a quite different meaning. Regular explorations with diverse audiences may help to bring more understanding and effectiveness. Overall, we find that while the factors influencing decisions to be screened for breast cancer are complex, there are clear avenues to pursue to shift decisions in favor of screening.

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