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Explaining and Improving Breast Cancer Information Acquisition among African American Women in the Deep South

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Abstract

Objectives—A major challenge facing contemporary cancer educators is how to optimize the dissemination of breast cancer prevention and control information to African American women in the Deep South who are believed to be cancer free. The purpose of this research was to provide insight into the breast cancer information-acquisition experiences of African American women in Alabama and Mississippi and to make recommendations on ways to better reach members of this high-risk, underserved population.

Methods—Focus group methodology was used in a repeated, cross-sectional research design with 64 African American women, 35 years old or older who lived in one of four urban or rural counties in Alabama and Mississippi.

Results—Axial-coded themes emerged around sources of cancer information, patterns of information acquisition, characteristics of preferred sources, and characteristics of least-preferred sources.

Conclusions—It is important to invest in lay health educators to optimize the dissemination of breast cancer information to African American women who are believed to be cancer free in the Deep South.

Keywords

African American women; breast cancer; focus group; information acquisition

Breast cancer continues to be a leading cause of morbidity and mortality among women living in the United States. It was estimated that in 2011, 230,480 women would be newly diagnosed with breast cancer and 39,520 women would be expected to die of the disease.¹ Despite recent overall declines in incidence of and mortality from breast cancer, disparities between whites and African Americans still exist. African American women tend to have a

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lower incidence of breast cancer; however, they have higher mortality rates. Evidence of this disturbing trend is apparent throughout the Deep South, particularly in the states of Alabama and Mississippi. In Alabama, the age-adjusted breast cancer incidence rate for African American women is 115.8/100,000 compared with 117.2/100,000 for white women. Statewide breast cancer mortality rates in Alabama for African Americans and whites are 32.3/100,000 and 22.7/100,000, respectively.¹ In Mississippi, the age-adjusted breast cancer incidence rate for African American women is 115.4/100,000 compared with 111.7/100,000 for white women. Statewide breast cancer mortality rates in Mississippi for African Americans and whites are 34.6/100,000 and 22.1/100,000, respectively.¹ These statistics highlight the importance of continued research to eliminate breast cancer disparities among African American women in the Deep South.

Increasing knowledge about breast cancer among African American women is one way to advance the nation's cancer disparities research agenda.² Research indicates that African American women have misconceptions about breast cancer that span the continuum of care. For example, researchers have found that some African American women believe that pain is always present among women with breast cancer or that bumping/bruising one's breasts causes breast cancer to develop.^{3–5} The incorrect belief that surgery causes breast cancer to spread is also a common finding among African American women in the literature.^{3,6,7} These and other misconceptions can have an indirect impact on breast cancer mortality, particularly when they influence women to forgo early detection and screening, persuade women to delay the initiation of evidence-based treatment, or encourage women to use nonmedically sanctioned treatments. To prevent this or other negative sequelae of events from occurring, better dissemination of breast cancer prevention and control information to African American women is an important goal.

Information behavior research focuses on how individuals acquire, organize, retrieve, and use information.⁸ A review of the information-acquisition research literature makes three issues clear. First, racial and ethnic minority subpopulations embrace and avoid information sources, channels, and messages differently than do white populations.^{9–11} Second, information acquisition patterns are context specific.¹² Third, people's decisions to interact with specific information sources are driven by a host of attitudes and beliefs.^{13–15} Much of the information-acquisition research to date has focused narrowly on the information-acquisition behaviors of white women, women with cancer, and women in geographic areas outside the southern United States. Before medical and public health practitioners can develop strategies to optimize the dissemination of breast cancer prevention and control information to African American women in the Deep South, formative research needs to be conducted with members of this high-risk, underserved population.

The purposes of this research were to provide insight into the breast cancer information-acquisition experiences of African American women in Alabama and Mississippi and to make recommendations on ways to more effectively reach members of this high-risk population.

Methods

Research Design

The focus group data included in this study were collected as part of a larger regional cancer information behavior project conducted in 2002–2003. Participants were eligible to participate in this part of the study if they were women, African American, 35 years old or older, never diagnosed as having cancer, and living in one of four counties in Alabama (Dallas or Jefferson counties) and Mississippi (Forrest or Humphreys counties). Two counties were selected in each state to maximize the likelihood that a broader range of

experiences could be captured from a diverse sample of women. The characteristics of each county are listed in the Table.

Four African American women trained as community health advisors as research partners (CHARPs) with the Deep South Network for Cancer Control were recruited as part of the research team. Each CHARP resided in the county where her focus group interviews were conducted. CHARPs were responsible for assisting with participant recruitment, planning focus group interviews, cofacilitating focus group sessions, and analyzing and interpreting focus group data. The CHARPs used a purposive sampling scheme. CHARPs recruited all of the participants by flyers, telephone, and face-to-face contact.

All of the focus group interviews were led by an experienced African American female moderator and an African American female assistant (second-year medical student). The moderator or assistant read an institutional review board–approved consent form to participants at the beginning of each focus group session to inform them that they had a right to refuse to participate, their participation was voluntary, and the focus group session would be recorded on audiotape. A semistructured, open-ended interview that was approved by the institutional review board at the University of Alabama at Birmingham guided all of the focus group discussions. Following each focus group, all of the participants received a monetary stipend as compensation for their contribution to the research. Participants also received lunch after focus group sessions were completed, which gave them time to fellowship and continue their discussions about cancer in their community. All of the focus group interviews were between 60 and 90 minutes in duration.

Data Analysis

All of the focus group interviews were transcribed verbatim by an experienced transcriptionist and entered into MAXQDA 10 software (VERBI GmbH, Berlin, Germany) for analysis. Two-hundred thirty-nine pages of text were produced from the focus group interviews. All of the verbatim text was analyzed by a two-member research team during a continuous data abstraction and data coding process. During the data abstraction phase, each investigator identified focus group excerpts (eg, words, sentences, phrases) that he or she believed were related to breast cancer information acquisition and/or the information environment. During the data coding phase, each investigator independently coded abstracted data until consensus about coding was reached. Guidelines specified by Lincoln and Guba¹⁶ were followed to ensure that transcript analyses were reliable and valid. Details about how study investigators ensured credibility, transferability, dependability, and confirmability are described elsewhere.¹⁷ All of the program materials and methods described above are summarized in the Figure.

Results

Participants

Sixty-four African American women participated in 10 focus group interviews. The average number of participants per focus group session was moderate (mean 6.4) and well within the guidelines specified for conducting focus group research. The mean age of focus group participants was 55 years. The age range of the focus group participants was 35 to 72 years.

Focus Group Categories

Themes that emerged regarding participants' breast cancer information-acquisition experiences and the information environment are presented below.

Sources of Cancer Information

When asked about ways through which they obtained breast cancer information, participants listed a variety of mass media and interpersonal sources. Television, radio, and newspapers were the most frequently mentioned mass media sources. Physicians and peers were among the most commonly mentioned interpersonal sources. The sources mentioned appeared to play a complementary role in the generation of knowledge. Participants stated that mass media sources helped them to learn basic facts about breast cancer prevention and control such as basic statistics, available screening tests, breast cancer risk factors, and treatment options. Participants noted that interpersonal sources provided them with opportunities to probe and ask questions about how prevention and control information applied to them and other women in their community.

Information-Acquisition Behaviors

Themes related to two types of learning emerged from the focus group transcripts. Some women mentioned that they actively sought out breast cancer prevention and control information, whereas others mentioned that they learned about breast cancer serendipitously. Those who were active learners mentioned that they wanted to learn more for a variety of reasons. Some mentioned a general need to know as a reason for acquiring information. As exemplified by one woman's statement, "Knowledge is power, the more you know, the better you are." These women believed there was an overabundance of information that was just waiting for them to access it. There was a sense among some of these active seekers that there was a lack of general knowledge about breast cancer among women in their community and somebody needed to be informed. As one woman said, "You know, a lot of people don't understand the different possibilities of what can happen to them because they haven't been told and they don't have anyone to come around and tell them." This sentiment was echoed by another active information seeker who remarked, "We don't have information like we should." Even though incidental learning was not as commonly mentioned as active learning, incidental learning was still viewed as an important way to acquire knowledge. As one woman indicated, "I just found a lot of information about breast cancer and I wasn't even looking for it. I was just trying to get my son to the WIC."

Characteristics of Preferred Cancer Information Sources

Even though participants mentioned using a variety of sources, many stated that physicians and friends were their preferred sources. Physicians were viewed by many as the gold standard of information and women trusted that the information they received from physicians would be trustworthy and reliable. One woman stated, "Physicians can give you better information than anyone else. They can explain things to you in ways that others can't." Along these same lines, another woman stated, "It's best to go to a doctor [for information] because he is trained."

Although physicians were thought to be the authorities on providing women with reliable procedural information, focus group participants trusted that female peers who had direct screening and treatment experiences would provide them with reliable sensory information. One woman stated, "When you get information from someone who has gone through something, it is really helpful. I know everyone is different, but they have gone through what you are probably going to go through and they can tell you things that other people can't. I think that is important."

Characteristics of Least-Preferred Cancer Information Sources

In addition to stating their most preferred sources for information, several women stated that the Internet was their least-preferred information source. The major concerns discussed

regarding information on the Internet were information reliability and volume of information. The perception of reliability was captured by one woman who stated, "Anybody can put up a Web site and say whatever they want to on it, you know, and you read this thinking it is trustworthy and it's not... ." As for the perception of there being too much information on the Internet, one woman remarked, "I'm not knocking the Internet but if you ask a person a question they can answer you right back. But a lot of times when you ask the same question on the Internet, you don't get the answer you really need that is important to you. You get a lot of other stuff, but not the information that you need."

When women were asked their opinions about what could be done to make breast cancer information more available to women in their community, several ideas were provided. A few women stated that the language used when communicating cancer information was too complex and that simple and straightforward communication was preferred. One woman commented, "I attended a seminar the other day and they had really good information. But, you know, it would have been better if they didn't use all of those big words. They could've just put what they said in common language so that everybody understood it. I have a good idea of what they were talking about. But I believe some things need to be put in plain laymen's language, you know?" The problem of complex language was not limited to face-to-face communications. Several focus group participants mentioned that the words used in printed materials also could be simplified.

Several women believed that existing breast cancer information does not permeate the African American community enough and suggested that educators use more culturally appropriate dissemination channels to enhance its reach. One woman said, "We need to do a better job in getting people out into places where community people are and get on their level. I have only seen a couple of workshops where people have explained cancer information. Now what is good is that these people used language that everyday people could understand. They were all African American physicians, which was another good thing. They got a couple of these groups that go around now to different churches with different information... yeah, they go wherever the people are." Adding to this theme of culturally appropriate dissemination channels, another woman expressed that she believed disseminating information at family reunions would be an effective way to improve reach. She stated, "Since cancer runs in the family, why not talk about it when everyone is there? You'd be surprised at how much family can help one another. Why not talk about things when everyone is there? You got the kids, the parents, the grandparents, and sometimes even the greats. Convenience is a big part of people getting information. At least I think so."

Discussion

Ensuring access to cancer information is an important first step in the elimination of breast cancer disparities. By conducting elicitation research with African American women in rural and urban areas of Alabama and Mississippi, our study sought to increase the understanding of how these women perceive and interact with the information environment and provide recommendations about ways to improve their access to breast cancer prevention and control information. This study contributes to the sparse literature on cancer information acquisition among underserved women of color who are at high risk for dying of cancer.

The women in our sample indicated that African American women in Alabama and Mississippi who do not have breast cancer use a variety of mass media and interpersonal sources to acquire breast cancer prevention and control information. Peers and physicians were the most commonly mentioned interpersonal sources. The finding that physicians are a frequently consulted source is similar to other studies in which information-acquisition behaviors were evaluated with large samples of white women.¹⁸⁻²⁰ The finding that peers

are a preferred source of information appears to be a phenomenon that is embraced more by women of color than by white women. Knowing that African American women who have not been diagnosed as having breast cancer are receptive to receiving prevention and control information delivered by peers suggests that efforts to train community health advisors/lay health workers need to be continued.^{21–23} Training community residents to deliver reliable and accurate cancer prevention and control information is a low-cost health-promotion strategy that can be particularly useful for women in rural areas where direct access to physicians is harder to achieve.

We were not surprised to learn that focus group participants cited the Internet as the least-preferred source for breast cancer information. Racial and geographic disparities in Internet use, commonly referred to as the digital divide, are well documented.^{24–26} We believe that the reasons given for not preferring the Internet are modifiable and can be eliminated with education and training. For example, community health workers can be trained to present modules from the National Cancer Institute program Using What Works to help women distinguish reliable and unreliable Web sites. Lay health workers also can be trained to teach women how to conduct focused Internet searches to minimize feelings of being overwhelmed with information.

As demonstrated in other studies, our focus group participants described two types of learning behaviors—passive reception and active information seeking.^{27–29} We were not surprised to learn that most focus group transcripts surrounding learning behaviors referred to active information seeking. Although the concept of passive learning has intuitive appeal, with cancer information passive learning has been shown to be inferior to active learning.^{27, 30} Based on this finding, we recommend that medical and public health practitioners find culturally appropriate ways to motivate passive receivers to become active seekers. It is conceivable that one of the factors that differentiate active seekers from passive receivers is the presence of salient cues to action. Future studies should include quantitative investigations with African American women to gain additional insights into this possibility.

Like other studies on racial and ethnic minority subgroups, women in our study mentioned that increased use of culturally appropriate venues can enhance the reach of cancer information into the African American community.³¹ Traditionally, spirituality and religion have been important aspects of the African American culture.²² This is true especially in Deep South states such as Alabama and Mississippi, which are a part of the so-called Bible Belt.³²

Our study had several limitations. The population sampled was limited to African American women 35 years old or older, who had never been diagnosed as having breast cancer, who resided in one of four areas in Alabama and Mississippi. Also, all of the focus group participants were recruited via convenience sampling. Given these conditions, it is likely that respondents included in this study do not represent the population at large. Thus, the generalizability of our findings may be limited.

Conclusions

Our results imply that African American women in the Deep South who are believed to be cancer free acquire breast cancer information through numerous pathways. Lay health advisers are seen as playing a critical role in the information-acquisition process. Future studies should focus on verifying these qualitative findings with a random sample of African American women, using a quantitative or mixed-method design. Findings from these next-step studies can generate knowledge that can serve as the basis of culturally appropriate information-acquisition interventions.

Key Points

- African American women use a variety of mass media and interpersonal sources to acquire breast cancer prevention and control information.
- African American women are receptive to receiving and want to receive breast cancer information from peers.
- Training lay health advisors to deliver breast cancer prevention and control information is a low-cost health-promotion strategy that can be particularly useful for women in rural areas.
- Increased use of culturally appropriate venues can enhance the reach of cancer information into African American communities throughout the Deep South.

Brief Description

The authors sought to improve the understanding of ways to optimize breast cancer information dissemination to African American women in the Deep South. Ten focus groups were conducted with African American women. Women were eligible to participate if they were African American, 35 years old or older, never diagnosed as having cancer, and resided in one of four counties in Alabama (Dallas or Jefferson counties) and Mississippi (Forrest or Humphreys counties). Data from 10 focus group interviews revealed that African American women who are believed to be cancer free evaluate information resources differently. Axial-coded themes emerged around sources of cancer information, patterns of information acquisition, characteristics of preferred sources, and characteristics of least-preferred sources. Lay health educators play a critical role in the breast cancer prevention and control information acquisition process.

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Fig.
Program design.

Table

County demographic characteristics

State and county	County classification	Economic dependency code	Low-employment county	Physician shortage or surplus area	African American, %	Region of state
Alabama						
Jefferson County	County in metropolitan area with 1 million population	Services dependent	No	Shortage	39.4	Appalachia
Dallas County	Nonmetropolitan county with urban population of 20,000, adjacent to a metropolitan area	Manufacturing dependent	Yes	Surplus	63.3	Black Belt
Mississippi						
Forrest County	County in metropolitan area <250,000 population	Federal/state government dependent	No	Surplus	33.6	Coastal
Humphreys County	Nonmetropolitan county with urban population of 2500–19,999, not adjacent to a metropolitan area	Farming dependent	Yes	Shortage	72.0	Delta

Adapted from Measuring rurality: 2004 county typology codes. <http://www.ers.usda.gov/briefing/rurality/typology>. Accessed March 14, 2012.