



“For lack of knowledge, our people will perish”: Using focus group methodology to explore African-American communities' perceptions of breast cancer and the environment



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ABSTRACT

Among women living in the United States, breast cancer is the second leading cause of cancer death. Disproportionate racial disparities in breast cancer exist, with African American (AA) women consistently having the highest rates of breast cancer related mortality despite lower incidence. This study attends to the Institute of Medicine's (IOM) call to action recommending the identification of effective strategies for communicating accurate and reliable breast cancer risk information to diverse audiences. Using focus group methodology, this study explores how AAs perceive and decipher information related to breast cancer and its relationship to their environment. Six focus groups were conducted. The sample (n = 50) was African American, 98% female, with an average age of 50.1 years. The focus group protocol consisted of open-ended questions designed to elicit information about participants' perceptions of their environment and its link to breast cancer. Focus groups were audio recorded and professionally transcribed. Analysis of the focus group transcripts revealed themes pertaining to these categories: (1) general knowledge and beliefs about breast cancer, (2) perceived environmental risks factors for breast cancer, (3) importance of seeking knowledge about breast cancer and the environment, and (4) recommended communication strategies. The emergent themes reflect the knowledge participants possessed about breast cancer and environmental risk factors, in addition to concerns about the importance of possessing accurate information, and how culturally appropriate health communication strategies can be used to disseminate breast cancer knowledge in the community. Findings from this study can be used for culturally appropriate communication about breast cancer and the environment with AA communities.

1. Introduction

Breast cancer is a major public health priority. Among women living in the United States, breast cancer is the second leading cause of cancer death (DeSantis et al., 2016). Current trends indicate that, in 2018, an estimated 268,670 cases of breast cancer will be diagnosed, and 41,400

deaths from breast cancer will occur (Siegel et al., 2018). Among women newly diagnosed with breast cancer, women of European American (White) descent have higher incidence rates (Hunt et al., 2014; Jones, 2015; Siegel et al., 2018; Smith et al., 2016; Williams et al., 2016); however, disproportionate racial differences exist, with African American women consistently having the highest rates of breast

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cancer mortality (Ban and Godellas, 2014; Williams et al., 2016). African American women are 42% more likely to die from breast cancer compared to White women or any other racial/ethnic group in the United States (American Cancer Society Cancer Action Network, 2017; National Cancer Institute, 2017). This persistent health disparity exists because African American women are more likely to be diagnosed with breast cancer at a later stage, are less likely to receive stage-appropriate treatment, and are more likely to have lower stage-for-stage survival rates (Allicock et al., 2013; Ban and Godellas, 2014; Brawley, 2013; Dunn et al., 2010; Williams et al., 2016). Factors such as cultural norms, societal injustice, and concentrated poverty also contribute to racial breast cancer disparities (Freeman and Chu, 2005; Hempstead et al., 2018). There is a critical need for more targeted and advanced approaches to ameliorate this growing disparity.

Although research on breast cancer risk factors has traditionally been conducted with predominately European American women, there is a growing body of literature that attends to how certain risk factors for breast cancer differentially impact racial and ethnic minorities, with studies mainly focusing on factors such as socioeconomic status, genetics, and lifestyle/behavior (Boggs et al., 2010; Chandran et al., 2014; Mitro et al., 2014; Palmer et al., 2012; Rochman, 2017; Tian et al., 2012). Limited attention has been paid to the role of the environment and communities' perceptions about the link between breast cancer and the environment. The National Institute of Environmental Health Sciences' (NIEHS) Interagency Breast Cancer and Environmental Research Coordinating Committee (IBCERCC, 2013) separate environmental risk factors of breast cancer into four distinct categories: (1) lifestyle and behavioral factors (e.g., smoking, alcohol consumption, diet, and physical activity), (2) chemical agents (e.g., pesticides, industrial pollutants, consumer products, and medications), (3) physical agents (e.g., radiation from medical and other environmental sources), and (4) social and cultural influences (e.g., family, community, psychosocial/social, and societal factors). While there is a growing body of laboratory studies examining the relationship between common environmental toxins and risk factors for breast cancer (Brody et al., 2007; Brody and Rudel, 2003; Hiatt et al., 2009; Potts et al., 2007), there is a dearth of empirical literature that focuses on community held beliefs and perceptions. Qualitatively exploring African American women's beliefs about the relationship between breast cancer and the environment may lend itself to new insights among this high-risk population.

Our study on the environmental risk factors of breast cancer is guided by the call to action released by the Institute of Medicine (IOM) (Institute of Medicine, 2012.). This report recommended the identification of effective strategies for communicating accurate and reliable breast cancer risk information to diverse audiences, given that individuals possess different literacy and numeracy skills and may prefer different formats for receiving and responding to health-related information. The purpose of this study was to explore how African Americans perceive the environment to be linked to breast cancer risk. Focusing breast cancer risk research on environmental factors has the potential to contribute critical new knowledge about prevention of the disease, which is a national public health priority (Institute of Medicine, 2012). The current dearth of information on this topic limits our understanding of African American communities' awareness and information needs regarding breast cancer and environmental risk. This study employed focus group methodology to learn more about how African Americans perceive and decipher information related to breast cancer and the environment.

The overall goal of this study was to gain a better understanding of the factors that play a role in African American parents' and guardians' understanding of environments risk factors for breast cancer. This study focused specifically on the knowledge and perceptions of a sample of African American parents and guardians in a southeastern state. Given that breast cancer is the leading cause of cancer mortality for women between the ages of 40 and 55, much can be learned from parents/guardians when creating health communication materials for African

American families (Halverson et al., 2015). A growing body of research has established the importance and need for continued research that focuses on family communication about cancer (Berlin et al., 2013; Mosavel and Genderson, 2013; Mosavel et al., 2015; Mosavel and Ports, 2015). A common theme within this body of work calls attention to how family focused communication, typically between mother-daughter dyads, has the potential to increase health knowledge and help family members make more informed health decisions related to cervical and breast cancer screening (Berlin et al., 2013; Sinicrope et al., 2008; Sinicrope et al., 2009). For example, among a sample of mother-daughter dyads, Sinicrope et al. (2009) found that participants who reported communication about reducing risk were more likely to adopt breast cancer screening and risk reduction behaviors. This study builds upon the research previously mentioned in order to create more tailored health communication materials specifically focused on environmental risks.

2. Material and methods

2.1. Participants and recruitment

This study used a qualitative approach. Data were collected through focus groups (N = 6) with African American parents and/or guardians who resided in both rural and urban counties in a southeastern state. Purposive and convenience sampling techniques were employed to recruit the target population (Corbin and Strauss, 2007; Patton, 2001). Eligibility criteria were limited to African American male or female parents and/or guardians with at least one daughter/female family member under the age of about 18 years. The research discussed in this article is part of a larger interdisciplinary study that aims to develop plain language and culturally appropriate health education materials for African American communities to communicate effectively the relationship between breast cancer and the environment. The eligibility criteria were constructed in order to ensure that this exploratory study could aid in the development of health communication materials that would be applicable to the target community. Parents and/or guardians of adolescent African American girls were the study population given that adolescence can be a vulnerable time period in which young girls may be more susceptible to environmental risk factors for breast cancer (Wolff et al., 2015; Wolff et al., 2014).

Recruitment involved collaborating closely with five community and faith-based partners who provided guidance and assistance as needed. For example, the community and faith-based recruitment efforts involved “word of mouth” (person-to-person) recruitment and disseminating flyers within their local faith-based or adult literacy organization. In addition to the recruitment efforts of the community and faith-based partners, the research assistants used flyers and printed posters in public spaces, advertisements on local radio stations, and direct engagement with potential study participants for recruitment.

2.2. Focus group protocol

This study was approved by the sponsoring university's Institutional Review Board. A total of 6 focus groups were conducted and audio recorded. Each focus group ranged from 45 to 90 min in length. Individual focus group sessions were conducted in a roundtable format consisting of 6–15 participants, 2–3 research team members, and 1–2 community and faith-based partners. In addition to their recruitment efforts, partners helped with focus group logistics. Their main role was to help participants sign in at the sessions and to introduce the sessions and research team members. The semi-structured focus group protocol consisted of open-ended questions that were designed to elicit information about participants' perceptions of their environment and its link to breast cancer. Research team members also held additional roles such as the note taker and moderator. Race concordance between the moderator and focus group participants was employed. The focus group

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