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## "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 recommend ing

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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.

#### **Keywords**

Breast Cancer; Risk Factors; African American; Focus Groups; Community Perceptions; Risk Communication

### 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, Miller, & Jemal, 2018). Among women newly diagnosed with breast cancer, women of European American (White) descent have higher incidence rates (Hunt, Whitman, & Hurlbert, 2014; Jones, 2015; Siegel et al., 2018; Smith, Conway-Phillips, & Francois-Blue, 2016; Williams, Mohammed, & Shields, 2016); however, disproportionate racial differences exist, with African American women consistently having the highest rates of breast cancer mortality (Ban & Godellas, 2014; Williams et al., 2016). African American women are 42 percent 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 stageappropriate treatment, and are more likely to have lower stage-for-stage survival rates (Allicock, Graves, Gray, & Troester, 2013; Ban & Godellas, 2014; Brawley, 2013; Dunn, Agurs-collins, Browne, Lubet, & Johnson, 2010; Williams et al., 2016). Factors such as cultural norms, societal injustice, and concentrated poverty also contribute to racial breast cancer disparities (Freeman & Chu, 2005; Hempstead, Green, Briant, Thompson, & Molina, 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, Boggs, Wise, Adams-Campbell, & Rosenberg, 2012; Rochman, 2017; Tian, Goovaerts, Zhan, Chow, & Wilson, 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 & Rudel, 2003; Hiatt, Haslam, & Osuch, 2009; Potts, Dixey R, & Nettleton, 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 Andreotti, Yull, Grau, & Compas, 2013; Mosavel & Genderson, 2013; Mosavel, Genderson, Ports, Carlyle & Genderson, 2015; Mosavel & 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 Andreotti, Yull, Grau, & Compas, 2013; Sinicrope, Brockman, Patten, et al. 2008; Sinicrope, Patten, Clark, 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 & 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, Teitelbaum, McGovern, Pinney, Windham, Galvez et al., 2015; Wolff, Teitelbaum, McGovern, Pinney, Windham, Galvez 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 minutes 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 faithbased 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 protocol can be found in the Appendix.

Prior to the focus group, participants were asked to complete a demographic survey and reading comprehension assessment which was a modified version of the Cloze procedure (Estey, Kemp, Allison, & Lamb, 1993; Angela Estey, Musseau, & Keehn, 1994; Friedman & Hoffman-Goetz, 2006). The demographic survey included items related to employment and marital status, household income, highest level of education, health-related information seeking, and knowledge about environmental factors may lead to breast cancer. The modified-Cloze test procedure involved deleting every seventh word from a passage of existing written materials and providing response options for participants to select from to fill in the blanks. Given that individuals possess different literacy and numeracy skills, assessing comprehension assists with the development of effective strategies and educational materials for communicating breast cancer risk.

In order to create the comprehension assessment, study coordinators first selected online breast cancer resources published by credible websites based on their readability. After consulting with community partners, materials from the Mayo Clinic (Mayo Clinic, n.d.) and National Institute of Health's National Cancer Institute (National Institute of Health, 2012) site were chosen for inclusion. The paragraph taken from the Mayo Clinic had a Flesch Reading Ease score of 64.6 and a Flesch-Kincaid Grade level score of 8.2 (scores reflecting more readable content). The paragraph taken from the National Institutes of Health had a Flesch Reading Ease score of 48.2 and a Flesch-Kincaid Grade level score of 11.6 (scores reflecting less readable content). Participants' comprehension assessments were scored based on the following rubric: (1) >56% (or .56=1.0) = adequate comprehension; (2) 44%–56%= marginal comprehension; (3) <44% = inadequate comprehension with one hundred percent correct responses yielding a score of 1.0 (Friedman & Hoffman-Goetz, 2006). Additional information about participants' scores can be found in Table 1. Following each focus group session, participants were provided with a small monetary incentive for their participation.

#### 2.3 Data Analysis

Audio recordings of the focus groups were transcribed verbatim by a professional transcriptionist. Personal identifiers, such as names, were removed from the transcripts to protect participants' confidentiality. Qualitative data analysis software (Atlas.ti) was used to explore and code the data using the codebook created by the research team. The themes generated through close reading and making notes (i.e., memoing) of the focus group participants' narratives resulted in the first pass of a coding framework. A qualitative

codebook was developed by selecting two transcripts that were independently reviewed and coded using a paper-and-pen method by three of the authors. The coding strategy utilized a combination of open coding (i.e. delineating concepts and categories) and axial coding (i.e., relating concepts and categories to each other) (Corbin & Strauss, 2007; Patton, 2001). Field notes that were collected during the data collection process also aided in data analysis. Moreover, this analytic approach allowed for themes and patterns to emerge from the data that may not have been anticipated by the research questions or by previous research.

## 3. Results

The sample (n=50) for the study was African American and 98% female (n=49), with the mean age being 49.4 years. Additional demographic information, collected through a paper-pencil survey, showed that 16% of the sample population earned a household income of \$50,000 or above per year, while 32% earned less than \$10,000 per year (Table 1). Less than half of participants had some college education.

#### 3.1 Thematic findings

Twenty-one emergent themes were identified from the qualitative data analysis and interpretation. The themes were organized as follows: (1) general knowledge and beliefs about breast cancer, (2) perceived environmental risk factors for breast cancer, (3) importance of seeking knowledge about breast cancer and the environment, and (4) recommended communication strategies.

**3.1.1 General Knowledge and Beliefs about Breast Cancer**—The first theme, general knowledge about breast cancer, comprised the information and views that focus group participants held about breast cancer rates among African American women. Three salient subthemes emerged from the discussions (1) normative (common) knowledge, (2) culturally situated beliefs, and (3) myths and misconceptions about breast cancer.

Participants' normative knowledge about breast cancer entailed discussions concerning the genetic component of breast cancer, the varying efficacy of treatment options for breast cancer, racial and ethnic differences in breast cancer mortality, common methods of breast cancer prevention, and the rare occurrence of breast cancer among African American males, in addition to other sentiments. What follows is a representative quote that highlights many of the participants' general breast cancer knowledge,

I know that the, the older you get, the more your risk, post-menopausal. I know that you're more susceptible if you have a family history of breast cancer. That it can be cured, and it can be fatal. It depends on how early you catch it and diagnosis.

As discussion around breast cancer knowledge progressed, participants consistently emphasized the importance of mammograms, screening, and the growing debate around its efficacy. For example, one focus group participant stated,

And mammograms are helpful, but sometimes you need a more in-depth screening they say. There's this argument around mammograms even as far as insurance companies and the recommendations coming from the federal level on whether

mammograms are actually significant in, in detecting breast cancer, whether or not insurance companies still want to pay for them or not.

Participants also shared how culturally influenced beliefs shaped their knowledge about breast cancer. These discussions occurred mainly around the impact of surgery and frequency of doctor appointments and was mirrored by many participants who said that "Well, another thing in the African American community you know that old adage you cut, it's gonna spread so we don't cut", and "our culture, you cut, it spreads". One participant recounted how she was taught to not seek medical related help at a young age and how the adage "if you cut it, it will spread" translated into her initial trepidation to receive surgery for a breast cancer diagnosis.

Now one thing I will say I'm not one of those that like I've been told, I've gone from being raised in a family where my daddy didn't rush me to the doctor or the hospital for nothing. If I went to the hospital, it was because it was serious. And then I found out later on that I, I had a certain situation that happened and they wanted to do surgery and daddy told them no and it went back down the generations to Aunt Missy. Aunt Missy said no, you don't let them – like you, I think you said and maybe you said no, you don't do no cutting.

Common myths and misconceptions expressed by the focus group participants included the use of herbal medications to treat breast cancer. Some participants, particularly those who were older, shared the myths they assumed were related to breast cancer with one of the most common being the sentiment expressed below,

Now I, I don't know if this is a myth or not but you hear, I have heard over the years that you look more at the mother's side than at the father side for breast cancer risk. Have you heard that? You look at where the cancer is if it's on the mother side then you, you tend to the risks are greater.

#### 3.1.2 Perceived Environmental Risk Factors for Breast Cancer—Common

environmental risk factors linked to breast cancer that participants mentioned included personal care products (e.g., deodorant, talcum powder, lotions, soap, and sunscreen), plastic, medication (e.g., birth control pills), aluminum coated items (e.g., kitchenware), pollution, and certain chemicals found in food. For example, when asked what they thought were some of the risk factors for breast cancer, a number of responses included, "It could be anything, they say anything you eat, you get cancer off of something" "the food, the deodorant, the toothpaste you use", "pesticides", and "it's the food we eat, the things we drink and what we put in - it's what we put in our bodies".

When probed to learn more about their perceptions of environmental risks of breast cancer, many participants discussed food as one of the main sources of perceived environmental risk of breast cancer. For instance, participants made assertions such as, "the antibiotics that they used to feed these chickens", "the pesticides, those different things of the fillers that they're putting in, in foods", and "one time they used to have inspected, government inspected on your meat, stamped on your meat, they don't have that no more".

In addition to food, many participants discussed the role of plastic and pollution as an environmental risk, particularly Bisphenol A (BPA) and pollutants. For example, one participant recounted learning about the potentially detrimental effects of leaving plastic water bottles in her car, "the chemicals are in this plastic can give you breast cancer. Yeah, they did a research on that. The chemical out of this plastic can give you breast cancer or any other cancer. So basically, if you got hot water – you know, water in plastic, just throw it away". Another focus group participant stated, "You always hear like plastics, not leaving your water or anything in the car because of the properties change and could – in the plastic and can cause breast cancer".

With regard to pollution, many conversations emerged highlighting contaminated water and radioactive waste as common environmental risk factors for breast cancer. For example, one focus participant stated,

Like things they were talking about, pollution, like waste, radioactive, things that they were talking about that's real scary, about you don't know what type of disease that you can get from these different types of materials that's in the environment.

Mirroring this sentiment another of focus group participant stated,

Sometimes, the area where you live, if there's been factories, manufacturers and stuff like that, and contaminated water. Even the fumes and stuff from the cars and air conditioning, stuff like that.

Both participants highlight, in their own words, a possible connection between breast cancer and environmental factors.

## 3.1.3 Medical Mistrust and the Importance of Seeking Knowledge about

**Breast Cancer and the Environment**—The theme of medical mistrust and the importance of seeking knowledge about breast cancer and the environment encompassed participants' beliefs surrounding the value of acquiring knowledge about breast cancer and the environment and the influence that it could have on the African American community, particularly the younger generation. Participants' admission of their mistrust of the medical community also emerged within their conversation about the importance of having breast cancer related knowledge. Discussions centered around participants' desire to seek knowledge about breast cancer, the importance of knowledge as a means of ending the silence around conversations about breast cancer within the African American community (particularly among the younger generation), and the ways in which mistrust influenced their perceptions of the medical community.

Discussions around the importance of awareness and seeking knowledge emerged in all of the focus groups. Common responses included, "maybe ain't nobody ever told you about breast cancer and awareness is about the best thing because awareness is power", "what you don't know, you don't do anything about it, but once you know, you do something about it", and "once you have knowledge you can pass it on". When asked about the importance of having knowledge about breast cancer and the environment, one participant shared a sentiment that received support from many of the focus group participants, "Knowledge. It's knowledgeable to us, and it's gonna help. Because like I said, for lack of knowledge, our

people will perish". Another focus group participant mirrored this view when she stated that, as a member of the African American community, it is important to have factual information about breast cancer and the environment "In order to save the next generation. People perish from lack of knowledge. You know, ignorance is not bliss. Ignorance is just ignorance".

An additional subcategory within this theme called attention to the impact such knowledge will have on the African American community, particularly the younger generation. One participant stated,

So that is something that we need -a cycle that needs to be broken, and we need to be more verbal. And you don't have to really have no conferences, or no long talks, or no long -j ust mentioning it, and sometimes that will stick longer, and it'll let the family knows that then. I think knowledge trumps fear. Information. Information eliminates fear, and takes the, uh, takes the, the power and the sting out of fear if you have more information and more knowledge, you're not as afraid of something, and even conversations.

This theme also captured the participants' mistrust of the medical community and how it impacted how they approached seeking knowledge about breast cancer. For example, common sentiment shared by the focus group participants centered on a historical mistrust of the medical system, in which one participant stated,

African Americans have a historical distrust of medical systems, and medical information. They experimented on Black slave women with – doing surgery without anesthesia all the way up through the Tuskegee. So it's not like something from way back in slavery. We can go back to all the years. And not until some years ago did they even apologize for what happened at Tuskegee. So there is a mistrust. They operated on people and especially African-Americans saying that they didn't hurt. Those kind of issues happen and so that's why it's important to know who's taking care of you and let them know that you can go back and check it.

The historical implications of the medical experiments conducted on African American slaves and freed individuals impacted how participants sought treatment for and information about breast cancer. In particular, the participants discussed how past medical injustices within the African American community made them feel as if their doctors were "always trying to tell you what to do with your body" and that you should "always seek a second opinion" from other medical outlets. For instance, one participant recounted seeking additional information outside of her primary doctor about breast cancer because she felt as if her doctor was prescribing medicine without taking into account how the side effects may impact her body. The participant stated,

I mean, you always ask for a second, even with your doctor, you want a second opinion. You don't take the first one. And then like when you go to a doctor sometimes they say, "Well, I don't see nothing." But you ain't in my body. You don't have my body, so you can't see what I see or feel what I feel. So you can't tell me I'm not hurting when I'm telling you I am hurting. Sometimes the doctor is really trying us on medicine, and it seems like we are basically guinea pigs. You know what I'm saying? I'm just being upfront because I had doctors that actually tell me

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when I went to go and get a check, and tell me, well, your body needs estrogen. But, but the prescription I'm prescribing you may cause cancer. So I say to him, why should I take a drug that's gonna cause cancer, may cause cancer, when I don't have cancer? And so we have to sometimes speak up and say, no, because sometimes these doctors seem like they're just really trying to sell drugs, they don't know what we actually need for the body.

**3.1.4 Recommended Communication Strategies**—A large portion of the focus group discussions centered on participants' recommendations for strategies that can be used to communicate information about breast cancer within the African American community. Even though the participants' recommendations focused on ways to construct breast cancer materials and present disease-related information, the lack of reference to environmental risk factors may be indicative of the need for more targeted education on these topics. Overall, participants preferred to receive physical (tangible) breast cancer information that was race specific and that contained graphics and simple language without technical jargon. For example, participants stated, "I would like something that I can look at", "Something I can go back and reference", and "I want a pamphlet, a booklet, or something". One focus group participant suggested a "hard plastic or laminate item, something you can put on the refrigerator or in your bathroom or something like that". One participant suggested,

Oh I was just gonna say what would you like to see in the pamphlet, you know, the different layers of the breast to determine the technical names of it so you know what you're looking for and then examples of how it should look and how it shouldn't look. Where you should, you know, get some follow up information on if something doesn't look quite right, you know, what does that look for. 'Cause I don't know if there's such thing as a normal breast because you know everyone has a different, you know, type of breast but just give you some type of information or format of it should kind of resembles.

When probed to learn more about the preferred graphics, participants' responses ranged from suggestions of animations, realistic (real-life) images, and instructional (how-to) graphics. When responding to format questions, one participant stated "I'm thinking in the line of a graphic novel form front and back, one, one page. I'm just thinking about that size front and back, colorful graphic novel kind of thing". Participants also suggested realistic/ real life images be used, such as "anatomically correct images of breasts" and "the real life faces of people who went through breast cancer, survivors", while also indicating that the chosen realistic pictures be positive. For example, one focus group participant stated,

Survivors. Positive images, not images that we see are gonna be sad and bring you down instantly, but something that is gonna educate. It would probably be good, too, to have survivors going to these kind of information. Because you know they're firsthand, to what's going on. That would be really impactful.

Another participant stated,

Something that look like a breast. Now, that catches your attention. Yes. That would definitely catch your attention. A picture of breasts and they'll show like a normal

breast and then they may have some like she said, with the density or, you know, spots in 'em and things like that.

Instructional/how-to graphics were commonly suggested to present information related to breast cancer self-examinations and the different stages of breast cancer. For example, one participant stated,

I would like to see it as, well, normal, you know, stage, like stage one, stage two... And the stuff that comes along with each stage. Or the things that, you know, you have to do in each stage. I look for in each stage, you know, what side effects, what things you should look for, you know, things like that. So informative, but like plain language.

As highlighted in the quote above, participants unanimously pushed for plain language breast cancer materials. Statements such as "keep it simple", "use layman's terms", and "no medical terminology" were frequently cited as many of the participants wanted common medical terms presented in plain language. For example, when asked in what format they would like to receive breast cancer information, one participant stated, "my language, you know, something easy to understand, you know, Something not too complicated or too scientific, or too many words and all that kind of stuff". Another participant stated,

If it's long and it's got a lot of reading, it's –. Overwhelming. Too much. I might not have time to read all of that. Too much detail. You know, I just want to get to the meat of it. Not a 50-page booklet that I got to hunt for what I'm looking for.

## 4. Discussion

Studies examining the impact of environmental risk factors for breast cancer are typically quantitative in nature and primarily involve samples of European American women (Brody et al., 2007; Dumalaon-Canaria, Hutchinson, Prichard, & Wilson, 2014; Gammon et al., 2002). There is a paucity of research involving African American women that focuses on environmental risk factors for breast cancer. This qualitative study explored how a sample of African American parents/guardians perceived and deciphered information related to breast cancer and the environment. Our findings illustrate participants' concerns about their environment and whether environmental factors negatively affect their health and the health of their families. Moreover, the participants provided clear and explicit recommendations for how this information should be disseminated within African American families and communities. The findings from this study contribute to our understanding about perceptions of breast cancer and the environment, and additional research can aid in the creation of culturally appropriate communities.

The four themes that emerged from the qualitative data analysis illustrated the depth of knowledge the participants possessed about breast cancer and environmental risk factors, as well as their concerns about the importance of possessing accurate knowledge, and how culturally appropriate health communication strategies can be used to disseminate knowledge in the community. Participants' general knowledge and perceptions about breast cancer risk (e.g., heredity/genetics, myths, and treatment/diagnosis) was consistent with

previous literature (Ferrera, Feinstein, Walker, & Gehlert, 2016; Jones, 2015; Mosavel & Ports, 2015; Passmore, Williams-Parry, Casper, & Thomas, 2017). For example, participants' narratives illustrated how their culturally situated beliefs about medical establishments had the potential to affect their health seeking behavior as it relates to breast cancer (Ferrera et al., 2016). These findings were similar to that of Jones (2015) who found that among a sample of African American women exploring their knowledge, beliefs, and feelings about breast cancer, issues of medical mistrust was a recurring theme that influenced how they interpreted breast cancer knowledge. In their research exploring perceptions of breast cancer treatment held among a sample of African American men and women, Masi and Gehlert (2009) found that mistrust of the medical establishment was the most common concern voiced by participants and subsequently impacted how they navigated the medical system. Given the goals of this study, gaining a better understanding of the historical significance of African American communities' mistrust of the medical community could lead to the development of more direct and culturally specific health communication materials (Molina, Kim, Berrios, & Calhoun, 2015).

Participants' perceptions of the environmental risk factors linked to rates of breast cancer within the African American community was another central theme within this study. Common environmental risk factors linked to breast cancer, that participants mentioned, included personal care products (deodorant, talcum powder, lotions, soap, and sunscreen) plastic, medication (birth control pills), aluminum coated items (kitchenware), pollution, and certain chemicals found in food. Additionally, there is very little empirical literature that explicitly uses qualitative methodologies to examine African Americans' perceptions of breast cancer and the environment. Such a lack of information calls attention to the need for more nuanced qualitative data involving communities most impacted by breast cancer mortality.

Throughout each focus group, participants underscored the role that accurate breast cancer knowledge plays in helping their community. Namely, participants discussed how communication between family members was integral to circulating knowledge that could impact future generations. The narratives from the focus group participants demonstrated how they conceptualized breast cancer knowledge as a means of taking control of their health (Freedman, Kouri, West, & Keating 2015; Sadler et al., 2007). In line with the importance of knowledge about breast cancer and the environment were the strategies the participants suggested in order to disseminate breast cancer knowledge. Overall, participants preferred to receive physical (tangible) breast cancer information that was race specific, and that contained graphics and simple language, without technical jargon, which is uniform across the literature (Adedoyin et al., 2016; Davis, Darby, Moore, Cadet, & Brown, 2017; Silk et al., 2014). The insight provided by the participants can help when targeting efforts and interventions much more precisely and effectively within the African American community (Powell, Bell, Shepperson, & Coaxum, 2008).

Given the dearth of qualitative literature that exists on breast cancer and the environment, this study examined in-depth perceptions of the relationship between the environment and breast cancer risk among African Americans living in a southeastern state. Understanding this perspective enables us to assess what this community is knowledgeable about, what they

would like to know, and how to best craft health-related messages. While many studies focus on diagnosis, treatment, or access to health care, our study adds to the literature by focusing on the preventive aspect of knowledge, attitudes, and perceptions, and captures the specific communication preferences this community holds for breast cancer related information. Moreover, this research adds to a growing body of literature utilizing qualitative methodologies to create health communication strategies to reduce the breast cancer disparities experienced by African American women (Mosavel, Genderson, Ports, Carlyle, & Wilson Genderson, 2015; Mosavel & Ports, 2015; Powell et al., 2008).

#### 4.1 Limitations

It is important to note some of the limitations of this study. Given the qualitative nature of this study, and the sampling methods used, the findings cannot be generalized to other populations. Additionally, the focus group moderator was race concordant but the remainder of the researchers involved in this study were not, which may have increased social desirability of responses. Lastly, the limited knowledge of participants about environment and breast cancer may have resulted in less tangible and less actionable communication recommendations. Despite these limitations, this exploratory study provides in-depth and nuanced data that can be used in the development of strategic and targeted health materials that address the challenges faced by this community (Passmore et al., 2017).

## 5. Conclusions

The study findings have important implications for environmental health communication. Given the dissemination strategies suggested by participants, educational materials illustrating an array of culturally specific breast cancer related topics need to be developed and tested. Health messages for this population should also address the mistrust of the medical community and positive actions that can be taken, which participants discussed, in an effort to decrease the disparity affecting this population. Participants' perceptions about breast cancer and the environment provide evidence for the need to expand our educational and communication efforts so that they more cogently address health disparities among this population (Powell et al., 2008).

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#### Appendix: Focus Group Protocol

1. What do you know about breast cancer in general?

PROMPT: In your opinion, what are some of the risk factors for breast cancer?

PROMPT: What are some of the signs and symptoms?

PROMPT: How do people get screened for breast cancer?

PROMPT: What do you know about treatment options?

PROMPT: Where have you learned or heard about breast cancer?PROBE: Have you learned about it from family or friends?PROBE: What about from television programs or news articles?

- When thinking about risk factors for breast cancer, what comes to mind?
  PROMPT: genetics; family history; environmental; personal care products, etc.
- **3.** The body can be vulnerable to exposures from the environment during time periods such as puberty. You are caring for a young African-American girl(s) 18 years or younger. Scientists in the Breast Cancer and the Environment Research Program—which is supported by the National Institutes of Health—are exploring whether exposure to certain chemicals and foods may change how girls' bodies mature. Can you tell us about your participation in discussions about puberty and the environment?

PROMPT: Who have you talked to about this topic?

PROMPT: Do you know of places in your community that provide education about this topic?

PROMPT: Of those places, or other places in your community, where do you think you and others would feel most comfortable going for education?

PROMPT: Why do you think it is important for you to receive this information?

The next few questions will ask about your sources of breast cancer information and where or how you would like to receive cancer information in the future.

**1.** Where do you get information about breast cancer? What format do you get the information in?

PROBE: Do you get it from newspapers or magazines?

PROBE: What about from TV shows or programs?

PROBE: Format of information - prefer a lot of text, images, graphs, etc.

2. Have you looked for information online about breast cancer?

PROBE: What types of websites have you visited?

PROMPT: How would you like to receive information about breast cancer?

**3.** If you were in charge of getting the word out about breast cancer and environmental exposures in your community, what would you do to make sure everyone knew about this topic?

PROMPT: What groups, organizations, people, or businesses in your community might help spread the word?

PROBE: Should we work with churches? Local radio stations? Schools?

PROMPT: What groups of people might be the hardest to reach when spreading the word?

PROBE: For instance, do you think people who live in certain areas or hold certain beliefs might be harder to reach?

PROMPT: How do you suggest we reach these populations?

PROBE: Are there certain groups, people, or organizations who you think could help?

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## Highlights

• Culture may influence perceptions about breast cancer risk.

- Participants stressed the importance of having knowledge about environmental risks.
- Communities' cancer perceptions can guide culturally appropriate education.

#### Table 1.

## Focus Group Participant Demographics, N=50

Age	
Age Range	23-86
Mean Age	49.4
	(SD=13.78)
Gender	
Male	1 (2%)
Female	49 (98%)
Race	
African American	49 (98%)
European American	1 (2%)
Employment	
Full-Time	19 (38%)
Part-Time	4 (8%)
Retired	8 (16%)
Disabled	9 (18%)
Not Employed	9 (18%)
No Response	1
Marital Status	
Single / Never Married	25 (50%)
Married	10 (20%)
Separated	3 (6%)
Divorced	1 (2%)
Widowed	9 (18%)
Other	2 (4%)
No Response	0
Income	
Less than 10,000	16 (32%)
10,000-19,999	7 (14%)
20,000-29,999	4 (8%)
30,000-39,999	5 (10%)
40,000-49,999	3 (6%)
Over 50,000	8 (16%)
No Response	7
Education	
Less Than High school	3 (6%)
High school Graduate or	14 (28%)
GED	
Some College	19 (38%)
Bachelors	7 (14%)
Advanced / Graduate Degree	4 (8%)

Age	
No Response	3
Cloze Test Scores	
Cloze Test Percentage (lower grade-level document)	76.8
	N=49, (SD=18.53)
Cloze Test Percentage (higher grade-level document)	78.4
	N=49, (SD=17.32)