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ORIGINAL PAPER

Understanding Breast Cancer Disparities Affecting Black Women: Obtaining Diverse Perspectives Through Focus Groups Comprised of Patients, Providers, and Others

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Abstract
Black women have the highest death rate from breast cancer and a higher chance of developing breast cancer before the age of 40 than White women. Mammography screening is recommended for early detection which has led to decreased mortality and improved survival. Unfortunately, Black women are less likely to have breast cancer screenings. Environmental justice communities represent place-based structural disparity/racism leading to health inequality. Environmental justice specifically addresses situations where minority or low-income communities bear disproportionately poor human health outcomes and environmental risks. The purpose of this qualitative study was to gain a deep understanding of breast cancer screening disparity from multiple perspectives to enable collective solutions to barriers faced by Black women in an environmental justice community. Data were collected from 22 participants using a focus group approach from Black women with breast cancer (n = 5) and without it (n = 5), healthcare providers (n = 6), and community leaders (n = 6). An iterative and inductive thematic data analysis method was used to analyze data. The themes that emerged from the data included: (1) misconceptions and fear of mammograms; (2) breast cancer screening beyond mammograms; and (3) barriers beyond mammograms. These themes reflected personal, community, and policy barriers leading to breast cancer screening disparity. This study was an initial step to develop multi-level interventions targeting the personal, community, and policy barriers that are needed to advance breast cancer screening equity for Black women living in environmental justice communities.

Keywords Breast Screening · Breast cancer · Black or African American women · Environmental justice communities

Background

Breast cancer disparity in Black women continues in the United States. Black women have the highest death rate from breast cancer and have a higher chance of developing breast cancer before the age of 40 than White women [1, 2]. Mammography screening is recommended for early detection which has led to decreased mortality and improved survival [3]. Unfortunately, Black women are less likely to have breast cancer screenings [4]. Achieving breast cancer equity in Black women may rest with increasing the number of breast cancer screenings among Black women. In fact, research indicates that Black women are more likely to be diagnosed with late-stage breast cancer, due to a lack of screenings [4, 5]. Barriers to mammogram screening in Black women are multi-level. On the individual level, barriers identified by Black women can range from lower educational levels or health literacy; beliefs (not necessary), cancer fatalism [6, 7], fear of pain [8], and inability to make time (not a priority); and socioeconomic status, employment constraints, lack of childcare, lack of transportation [4, 8, 9]. System barriers include lack of or inadequate insurance

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coverage, lack of policies to address structural barriers, and a health system difficulty to navigate [9, 10]. Some interventions in the literature have shown success with more culturally sensitive and visual materials and pamphlets to encourage screening [11]. A study by Fung [12] supports this concept that more culturally and linguistically targeted education is needed to increase mammogram screening. Community resources and support, especially church-based prevention programs were shown to be effective in educating and promoting better health behavior such as early screening in Black women [13]. Other successful programs are ones that utilize community partners [14] and Lay Health Advisor (LHA) [15]. The utilization of *Patient Care Navigators* has proven to be effective in improving access to care by assisting patients through the system and helping them to identify potential solutions to problems they may encounter [16]. Yet, research is lacking in identifying and mitigating barriers faced by Black women in environment justice communities where existing place-based structural and racial determinants may exacerbate health inequity in Black breast cancer screening. Environmental justice communities represent place-based structural disparity and racism that leads to health inequality. Environmental justice specifically addresses situations where minority or low-income communities bear disproportionately poor human health outcomes and environmental risks [17–20].

The purpose of this study was to gain a deep understanding from the perspectives of Black women with and without breast cancer, healthcare providers, and community leaders to enable collective solutions to barriers faced by Black women in an environmental justice community to reduce breast cancer screening disparity. The ultimate goal of this line of research is to identify feasible and acceptable multi-level solutions that could lead to strategies to promote and increase breast cancer screening among Black women.

Method

Study Design

The study utilized a qualitative design with a focus group approach to obtain multiple perspectives related to breast cancer screening. The four different perspectives consisted of women with breast cancer, women without breast cancer, healthcare providers who directly or indirectly cared for women with or without breast cancer, and community leaders associated with some form of care or services. The focus group approach allowed the complex interplay between individuals who share similar experiences through information exchange and ongoing assessment of group norms, values, and attitudes. The interactive nature of this process allowed for greater insights regarding the origins of certain beliefs and opinions and highlighted commonalities and variations among participants. Semi-structured interview questions were used to guide the focus group process. The study was approved by the university institutional review board.

Setting

Breast cancer disparity in Black women is one of the distinctive health inequalities noted in New Jersey [21, 22], and is the second leading cause of death due to cancer among women in New Jersey, claiming more than 1,200 lives annually, the age-adjusted death rate due to breast cancer among New Jersey females stands at 20.1 per 100,000 with the rate highest among Blacks [21, 22].

Camden, New Jersey represents many environmental justice communities in the United States [23]. The 8.9-mile^2 city is home to 73,236 residents with an average household income of $41,180 and the poverty rate of 36% [21, 24]. The predominant races of the residents are Black (41.4%), Hispanic (27.6%), and White (23.5%) [22]. Breast cancer mortality rates among Black females in Camden is 28.6 / per 100,000 compared to White females at 20.5 / per 100,000 [21, 24]. Black women in environmental justice community may face additional barriers in addition to breast cancer screening barriers identified in prior research [23, 25]. Thus, to identify and mitigate the barriers related to place-based structural and racial determinants, our primary audiences were Black women who live in Camden, New Jersey. Our secondary audiences were healthcare providers and administrators of breast cancer screening facilities and community leaders who were able to disrupt the structural health inequality by setting and changing policies to eliminate the barriers faced by Black women in environmental justice communities (e.g., healthcare providers' attitudes, screening schedules, public transportation routes, and financial assistance).

Study Participants

We had a total of 22 participants in the study. All the participants were greater than age 21. The four focus groups consisted of: (1) Black women without breast cancer (n = 5); (2) Black women previously diagnosed with breast cancer (n = 5); (3) Healthcare providers (N = 6) who directly or indirectly cared for women with or without breast cancer, including oncologists (n = 2), an oncology surgeon (n = 1), a radiologist (n = 1), a primary care physician (n = 1), and an oncology nurse practitioner (n = 1); and (4) The community leaders' group (n = 6) consisted of community individuals that were associated with organizations that either directly

or indirectly work with women that need additional care or assistance with breast cancer education, screening, or transportation. Organizations such as the New Jersey Cancer Education and Early Detection (NJCEED) program. Participants received a $50 visa-gift card for participating in the focus group sessions.

Data Collection Management

The focus group sessions were scheduled for 90-minutes to allow adequate time for participants to express their thoughts and experiences. The sessions were conducted over 2-weeks in June of 2023. All focus group sessions were audio recorded. The same semi-structured questions and probes were used to obtain perspectives associated with breast cancer screening from all 4-groups. The audio recordings were transcribed by a professional transcriptionist service. Data were verified by reviewing the transcripts while listening to the recording.

Data Analysis

We used an iterative and inductive thematic data analysis method to analyze the data. This iterative data analysis method consists of 7 steps: (1) read multiple times of the interview transcripts; (2) Identify significant statements from the transcripts; (3) categorize quotations that express similar meanings; (4) repeat Steps 1–3 to determine the essential themes; (5) compile an exhaustive list of themes along with representing quotations; (6) validate themes among researchers; (7) achieve consensus through discussions with qualitative expert and research teams [25–27]. Two analysts were assigned to process each transcript in the following way: After analyst A coded a transcript, analyst B reviewed analyst A's coding with the understanding that analyst B was free to agree or disagree with analyst A's coding and was free to apply codes differently as warranted. Where there was an agreement between analysts A and B in the application of the codes, analyst A's coding stood (same with C and D analyst). Any disagreement was discussed during the research meeting where consensus was established. Through this rigorous data analysis procedure, essential themes were intuited to reflect Black women's experience of breast cancer screening in the context of an environmental justice community.

Rigor and Trustworthiness

Several steps were taken to safeguard the rigor and trustworthiness of the study. First, data collection continued until saturation was reached and no new ideas emerged from participants. Second, the researchers had prolonged immersion and engagement with the data. Third, the two primary researchers read the transcripts and analyzed the data to assure trustworthiness. The research team consisted of three senior nursing students who worked closely with the expert senior nurse researcher as analysts for the initial coding of the data. During research meetings, consensus agreement and themes were established.

Results

The themes that emerged from the data included: (1) misconceptions and fear of mammograms; (2) breast cancer screening beyond mammograms; and (3) barriers beyond mammograms. These themes reflected personal, community, and policy barriers leading to breast cancer screening disparity in an environmental justice community.

Misconceptions and Fear of Mammograms

Misconceptions about the mammogram procedure itself were recognized by all the group participants. Participants verbalized that more education and teaching about the purpose and the process needed to be done and started early in a woman's life. Many of the myths and false information could be reduced by more consistent and ongoing education about the breast, especially at a younger age. If women were educated and informed at a younger age, they may not avoid or drag the procedure later in life. There were also several untruth or myths discussed by all groups that early and ongoing education could help dispel.

> the pressure from the mammogram caused cancer.
> Oh, I don't wanna get a mammogram because a mammogram, I heard it could cause cancer.
> I just cried because they need to explain things better.
> patients need more education on the reason for the tightness of the views obtained.
> Nobody told me that the screening may have slight pain.

Both Black women with and without breast cancer felt that the mammogram procedure created pain and tenderness that probably contributed to women not coming back after the first experience. Like one participant stated, *"just always heard that it hurt. Mm I'm not going to get one cause it hurts."* Some Black women verbalized that technicians were "lack of tenderness," "not pleasant," and they needed to be more patient and tender, the technicians "lacked compassion and caring." Many women complained that "The room (for mammogram) was cold and uncomfortable."

Healthcare providers agreed that the mammogram procedure could be uncomfortable for some patients and felt that patients needed more education on the reason for "the tightness of the views obtained" and "to correct misconceptions about the procedure," such as *"the pressure from the mammogram caused cancer."* Lack of understanding of the procedure contributes to the *"fear"* many women have about mammogram screening. Fear that the procedure will hurt, fear of the unknown.

Breast Cancer Screening Beyond Mammogram

One major factor that was identified was the lack of support by major national agencies that currently do not support breast self-examination (BSE). All groups felt that the ongoing education of women to perform self-breast examinations was important and should be encouraged. Most healthcare providers stated, "*that they did not necessarily agree with this recommendation"* and most still encouraged or taught self-breast exams among their patients. Two women with a history of breast cancer credit self-breast examinations for early detection of breast cancer. They strongly felt that self-breast examinations were important to be continued with all women, "especially in younger women, where waiting for a mammogram at the age of 40 would be too late."

All the groups emphasized that other screening modalities besides mammograms should be offered, like family history evaluation and genetic testing. The women with a history of breast cancer felt the insufficiency of other screening modalities offered. Studies indicate that Black women tend to have a higher chance of developing breast cancer before the age of 40 than White women [2, 28], yet American Cancer Society (ACS) recommend starting mammogram screenings at age 40 and the United States Preventive Services Task Force (USPSTF) recommends starting even later at age 50.

> Some women felt that other screening beside mammograms needs to be offered.
> I was sent for a mammogram, and it was actually negative…But when I got the MRI, they found the cancer.
> If I didn't do a self-examination, by the time they found my cancer, I probably wouldn't have made it, I was 30.

Barriers Beyond Mammogram

All groups agreed that meeting transportation needs, addressing childcare issues, and extending hours of mammogram screening on evenings and weekends could significantly improve breast cancer screening. The healthcare provider group and community leaders acknowledged that disparity in breast cancer screening for Black women is multifaceted, thus, it necessitated multiple-level solutions.

Socioeconomic status (SES) plays a major part in Black women not getting screened. Transportation and lack of childcare can be a problem for many women [9]. Taking time off from work to get a mammogram is not an option for many women in an environmental justice community as well.

> they need to extend hours of mammogram screening on evenings and weekends.
> How can I get a test done when I can't afford it?
> Bring care to women through the use of mammogram buses and medical transportation, which would pick women up at their homes and bring them to the medical facilities to get screened.

Discussion / Conclusion

The goal of environmental justice policy or movement is to support a healthy environment and the health of people in that community [29]. Findings of our study from multiple perspectives demonstrated that disparity in breast cancer screening for Black women in an environmental justice community was multifaceted. The focus group approach allowed us to gain different perspectives on the complex interplay between individuals with similar experience. The themes that emerged from the data were: misconceptions and fear of mammograms, breast cancer screening beyond mammograms, and barriers beyond mammograms. These themes reflected personal, community, and policy barriers leading to breast cancer screening disparity among Black women in an environmental justice community.

For Black women, the theme of misconceptions and fear of mammograms remains a constant for breast cancer screening. Ensuring that Black women have adequate education about mammogram screening is essential in decreasing the disparities between White and Black women. Targeted education, simulation, or field trip that provide real experience of undergoing mammography may be a solution to address misconceptions and fear of mammograms. Breast screening clinics may consider an open house to demonstrate the procedure and explain the rationale for possible pain and discomfort.

The debate on breast self-examination continues, yet no other forms of screening are usually offered for young women [30]. Breast self-examination is adequate for young women when other screening methods are not available [30, 31]. Black women with and without breast cancer, healthcare

providers, and community leaders all agreed that the ongoing education of women to perform self-breast examinations was important and should be encouraged. This perspective is consistent with the recommendations from the American Society of Clinical Oncology which emphasizes the importance that women know their breasts well so that they are able to recognize any changes and report the changes to clinicians [32]. To help Black women to know their bodies and to detect changes or anomalies that may occur early, health organizations should consider a policy that reflects the needs of Black women living in environmental justice communities. Interventions targeting building competency of Black women how to perform breast self-examination and provision of images that help Black women to recognize the signs of breast cancer are needed [30]. Culturally relevant health information is vital to put Black women at ease and improve their understanding of breast cancer screening.

Black women's perception of "lack of tenderness" in breast cancer screening reflects the historical treatment of Black women, including the physical treatment of slaves and unethical medical research done on Black population. Some of our participants perceived that this lack of tenderness may be because of "racial discrimination." Professional training to provide tender care to patients is ultimately important. Future research may further explore the concept of "lack of tenderness" in care for Black women. The National Health Interview Study revealed that there was a difference in Black women in comparison to White women in terms of providers' recommendations for cancer screenings, contributing to the racial disparity in breast cancer mortality between Black and White women [2, 33]. Perhaps, in addition to the difference in recommendations, the care that Black women perceived as "lack of tenderness" may be another contributing factor that needs to be addressed in an effort to improve mammogram screening for all women of color.

Black women who live in this environmental justice community already face additional health disparity in terms of transportation, financial hardships, and pollution. That Black women view such disparities as part of their daily lives reflects the place-based structure that leads Black women "consider" these disparities as "normal" since they have no comparative experience with women in rich communities or non-environmental justice communities. Some solutions such as meeting transportation needs or extending hours of mammogram screening on evenings and weekends should strongly be considered to increase mammogram screening among Black women. Many Black women tend to be the primary provider (head-of household) in their families and cannot easily take off from work to get a screening [34]. Therefore, offering screening in the evenings and weekends could significantly increase breast cancer screening for Black women living in an environmental justice community.

In conclusion, the insights from multiple perspectives in our study provide a comprehensive understanding of multi-level barriers that contribute to place-based breast cancer screening disparity in an environmental justice community. Our study is an initial step to develop multi-level interventions targeting the personal, community, and policy barriers that are needed to advance breast cancer screening equity for Black women living in environmental justice communities.

Supplementary Information The online version contains supplementary material available at https://doi.org/10.1007/s10900-023-01227-3.

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Declarations

Conflict of Interest The authors confirm that there are no known conflicts of interest associated with this publication and there has been no significant financial support for this work that could have influenced its results or outcomes.

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