

Dignity, Shame, Stigma, or Ignorance in Avoidance of Breast and Cervical Cancer Screenings among Women of Caribbean Descent

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Abstract

Objectives: Black Caribbean women have a high prevalence of late-stage breast and cervical cancer diagnosis and a low prevalence of screenings. This study explored barriers to breast and cervical cancer screenings, beliefs, and practices, and how they could overcome those barriers. **Design:** Focus group discussions, audiotaped, transcribed in verbatim, and content analyzed along with context using thematic arrangement. **Results:** Of 42 attendees, 37 participated in three focus groups with majority foreign-born; mean age of 50 years; 68% were Christian, and others Muslim. Overall, 32% of 42 focus group attendees reported being screened for cancer. Barriers to screenings were fear of discomfort, finding something wrong “nerve-racking”, doctor not recommending, taking time off from work, and family commitment. Among Afro-Caribbean women, there was the misconception of no risk of reproductive cancer after menopause and no need to screen. The staggering 75% of Muslim women participants mentioned that they never had a Pap smear test in their lives. **Conclusion:** Lack of understanding of their own cancer risk and trust in the health system; dignity, stigma, shame, and ignorance may play roles in avoidance of cancer screening.

Keywords

Breast, Cervical, Cancer, Screening, Barriers, Enabling Factors, Caribbean, Black, Muslim, Women, Focus Group

1. Introduction

Breast cancer and cervical cancer remain the most common forms of diagnosed cancer for women in the United States. It is estimated that 276,480 women will be diagnosed, and 42,170 will die from breast cancer in the year 2020 (ACS, 2019a). It is also estimated that 13,800 women will be diagnosed, and 4290 will die from invasive cervical cancer in the year 2020. Despite Pap smear testing contributing to a 71% decline in cervical cancer mortality since 1969, and mammography screening contributing to a 40% decrease in breast cancer mortality since 1989, ethnic groups such as non-Hispanic blacks continue to report worse incidence and mortality rates than other ethnic counterparts (ACS, 2019b; Yoo, et al., 2017). Among Blacks, Caribbean women receive breast and cervical cancer screenings with much lower prevalence than U.S.-born African Americans (Kenya et al., 2015; Kim et al., 2017). Consequently, they had a higher rate of late-stage prevalence, delayed treatment, and mortality for these two forms of cancer (Kim et al., 2017; King et al., 1994).

The five-year survival rate for breast cancer is 99% for a localized stage of diagnosis and only 27% for late-stage diagnosis. In the case of invasive cervical cancer diagnosed at an early stage, this rate is 92%. However, if diagnosed at late stage, then the survival rate goes down to only 17% (ACS, 2019c; Noone et al., 2018). The late-stage diagnosis remains one of the primary reasons for high mortality from these cancers. Unfortunately, the late-stage diagnosis for cervical cancer was up to 70% of the cases, while that rate for breast cancer was up to 50% in the zip-code where there is high concentration of Caribbean population (Kobetz & Parker, 2010).

Health care-related factors such as the cost of the screening procedures, women's lack of understanding of medical information given by healthcare providers, and the lack of access to health care insurance have been reported as common barriers to breast and cervical cancer screening (Miller et al., 2019; Akinlotan et al., 2017). Due to the paucity of research on women of Caribbean descent, it is difficult to understand why a large portion of cases was late stages of diagnosis. It is also not clear what specific factors may be contributing not to taking advantage of these screenings and may result in late-stage diagnosis among women of Caribbean descent. There is a gap in knowledge of barriers to breast and cervical cancer screenings among this group of women. To address this gap, we conducted a qualitative study to identify these factors in Black women of Caribbean descent. Therefore, the aim of this study was to explore the enabling factors and barriers to women's beliefs and practices regarding breast and cervical cancer screening. In this paper, we report the results from focus group discussions among women of the Caribbean descent in Broward County, Florida.

2. Materials and Methods

The focus group questions were developed based on the literature review. The questions were debated and discussed among the investigators led by a qualita-

tive research expert in the team. Our goal was to identify barriers, enabling, and reinforcing factors among black, African American, and women of Caribbean descent. Learning about the factors which empowered and facilitated black Caribbean women's health-seeking behaviors, as these could be used to assist other women of the same ethnic group in receiving screenings. We used focus group discussions to explore women's breast and cervical cancer barriers, beliefs, and practices, and how they could overcome those barriers. The discussions were audiotaped, transcribed in verbatim, and a report was produced in corroborating with hand-written notes for accuracy and completeness. Then the researchers analyzed the content along with context using thematic arrangement.

2.1. Study Sample Recruitment

The target population for this study was women who were older than 18 years of age and of Caribbean descent. All flyers and recruitment materials were culturally relevant and inclusive of the target population (i.e., photos were representative of the community). The flyers were colorful and attention grabbing along with posters which clearly stated confidentiality, benefits of participation, and compensation for the participation. The recruitment was done through 1) religious organizations such as church and mosque leadership with an announcement at the congregations and posting and distributing flyers; 2) community centers leadership and announcement at the meetings and seminars; posting and distributing flyers; 3) health fair and ethnic community fairs; 4) service providers such as ethnic stores and restaurants via posting flyers.

2.2. Measures

After receiving the university institutional review board approval, a convenient central location was selected with a quiet and comfortable fully air-conditioned community center's large social rooms. The group participants were cordially received in front of the community center and escorted to the selected room. The purpose of the focus group discussion, its potential benefits, and the sensitivity of questions was discussed, and queries were answered. The informed consent form was presented, any concerns were clarified, then signed. A socio-demographic form was completed by the participants. The focus group questions were developed based on literature review and the specific need to address the low prevalence of screening that may have reflected in the high prevalence of late-stage cervical and breast cancer diagnoses. The guided questions asked during each focus group section were selected from a list of potential focus group conversation guided questions (see **Table 1**).

The well-trained moderator, who was racially and ethnically representative of the target population, introduced herself. Then, she presented the purpose of the study with emphasis on the impact cancer has had on this community of women and how the discussions may aid in the reduction of reproductive cancer disparities. There were two research assistants involved to take notes and monitor the

Table 1. Potential focus group conversation guided questions.

Potential Focus Group Conversation Guided Questions	
Demographics-Related Questions	Breast and Cervical Cancer-Related Questions
How would you describe your family of origin?	What do you understand about breast cancer prevention and screening? What about cervical cancer?
Are you employed and how would you describe your socio-economic status?	What concerns do you have about locating and participating in breast cancer screening? Cervical cancer?
Do you have health insurance? If no, why? If yes, what does your insurance cover?	How does your awareness level about breast and cervical cancer screenings influence your utilization of the available screening resources?
What type of health insurance do you have? (If applicable)	What are your personal barriers that have influenced your breast cancer screening behavior? What about cervical cancer?
How affordable is your health insurance, and what factor or factors determined your choice of insurance?	Do you see culture and stereotype as barriers to breast cancer screening? If so, in what ways? What about cervical cancer?
Where do you go if you need routine care, like a checkup?	What are your attitudes and beliefs towards breast cancer screening? What about cervical cancer?
Where do you go if you have a medical emergency?	How knowledgeable are you about breast cancer and cervical cancer screening recommendations? Please explain.
Tell me about your medical insurance (i.e. Quality, cost, etc.).	What are the resources available in your community for breast cancer screening? What about cervical cancer?
What are your thoughts or feelings about your healthcare?	Do you know how to get available breast cancer and cervical cancer screenings? Please describe the process.
How adequate do you think your health insurance is when compared to your health needs?	Have you ever had breast cancer screening? What about cervical cancer screening? Please explain what type of screening you had and your experience.
	What was the most challenging aspect of breast cancer screening? What about cervical cancer?
	What factors in your opinion would better enhance your experience and/or utilization of breast cancer screening?
	Does your socio-economic status influence your breast and cervical cancer screening habits?
	What is your advice for African American women about breast and cervical cancer screening?
	What advice do you have for healthcare providers to improve breast and cervical cancer screening services for African American women?

recordings of the discussion. There were three focus groups conducted with an average of 13 women. Each focus group session lasted 90-minutes in duration with discussion centered around aspects of the breast and cervical cancer screening including barriers, or hindering factors and how to, (if) they have overcome these barriers. After completion of the discussion, a \$25-dollar gift card was handed to the participants as an incentive. The research assistants sat quietly, and each created a document from their notes and these documents

were used to complement or clarify the discussion points. The recorded focus groups were transcribed by a third party. All documentation were cross-checked and verified for its content.

3. Results

3.1. Demographics

There were 42 potential focus group participants. However, due to late arrival, five of them were not allowed to participate in the middle of the progressing discussion session. Nineteen (51%) out of 37 of the participants were born outside the United States. Their average age was 50 years (range 23 - 75 years). Nine (24%) of them reported education less than 12th grade, ranging from elementary to college education. Their occupations were homemaker, service manager, nurse, schoolteacher, business owner or retired. Eighteen of them were married. Many of the participants (68%) were Christian, and the rest were Muslim.

3.2. Screenings and Barriers

When asked about cancer screening among the 42 focus group attendants, 12 (32%) of 37 never had received a cervical cancer screening. However, among Muslims, almost 75% never had received a cervical cancer screening. Additionally, 5% of Christians and 25% Muslims reported not ever having received a mammogram. Results from the focus groups showed interrelated factors that impact this population's cancer screening behaviors.

Our thematic analysis revealed five major themes as to what the barriers are: 1) lack of adequate insurance; 2) fear of cancer and screening outcomes, with an underlying theme of distrust of the physician and healthcare system in general; 3) inconvenience; 4) lack of knowledge of reproductive health cancer and awareness; and lastly; 5) cultural/religious barriers.

Not having health insurance or being underinsured and the potential cost presented as barriers to these women. One participant stated: (...) "you get sick, you end up not going to the doctor because it is expensive. No health insurance, it's not easy". Another participant admitted to never having had a mammogram. She had intersecting reasons as to why she had not had the mammogram. She stated, "I never had a mammogram". (...) "I heard it is painful, I heard [it's] too expensive".

The women felt that financial barriers were an issue that should be addressed. Many of the women suggested that hospitals offer free mammograms during October, breast cancer awareness month, and maybe more women would get them. Although not a widely voiced concern, a few of the women voiced that doctors were trying to make money from the patient's insurance. Fear was echoed by most of the women as a barrier to not only getting a preventative screening but also in returning to get the results of the screening. Pain and fear were associated with mammography due in part to their personal experience, and from stories, they had heard from friends and family. One participant men-

tioned that in the African American culture, there is (...) “fear among some women to get screened because they don’t want to know; There is the fear of finding out about it [cancer]”. “As an African American, there is no big discussion about it [breast cancer/screening]”.

For some women, a lack of time to be screened was a barrier. Many of the women felt it was an inconvenience for them to have to take time off from work for exams and follow-up exams. As one participant stated: “One day off work to go there. Then another day off to get the report. Then another day off work for appointment (...)”. Some participants went on to say that some women do not participate in screening because they are (...) “wrapped up in their own lives” and the (...) “time and convenience. I am busy”. These were responses that were echoed by several women. One woman went on to say that it was (...) “disruptive to your own life, it is hard”. Another participant went on to speak about her positive experience citing that she never has to take off from work because she can go to a location that is open at 7:00 am and they [providers] mail her results to her home. However, this was the exception for this group of women.

Another participant confirmed that African Americans, in general, have a lack of care about going to the doctor. “For cancer screening, I don’t know how to call it. Maybe fear like she said for African Americans, fear or it is not important”. One participant voiced that “People don’t trust [doctors]”, alluding to the historical distrust of the healthcare system in general. Another participant attributed the refusal for screenings to (women) feeling ashamed. “A lot don’t understand, so let’s talk about it. To get people to talk about that just like going to the doctor”. One participant explained that the nurse did not call back after they had told her they found something in her mammogram. “I tried to get in contact with the nurse but could not and this was ‘nerve racking’ for me. It ended up being nothing, but it was nerve racking. Maybe that is why some women do not want to know”.

3.3. Gaps in Knowledge and Awareness

Knowledge gaps and lack of access to reliable information on reproductive cancer was reported as a major barrier to women’s participation in cervical cancer screening. Some of the women cited inaccurate information. Most reported that their knowledge, especially about causes and symptoms, was speculative. When asked about recommendations for screenings, almost all could not state those recommendations. Almost all participants admitted to a lack of knowledge about the disease and available services as a reason for not going for screening. Participants made statements that lack of information or misinformation from their physician. One participant stated: “My doctor says that you do not have to get a pap smear after a certain age” (...). “So, I don’t even know that...how would I know to get a screening, the doctor wouldn’t tell me”. Another participant stated: “But my doctor has never told me about cervical screening, he should tell me about it?” Other participant responses reflected basic lack of information.

“Does the pap smear tell you if you have cancer? What can happen if you have the cancer...what do you call it? What are the symptoms?” These statements and questions were indicative of the need to increase health literacy, health promotion and education within this population of women. As one woman noted, (...) “you only hear about breast cancer awareness during the month of October, it should be all year round”.

When asked if they had received a cervical cancer screening, the majority of the women stated they had not. However, when the question was rephrased and they were asked if they had ever received a Pap smear, they all responded emphatically “yes”. This example of response indicates that these women may need more linguistically appropriate disseminated information. Cultural beliefs and attitudes have been identified as barriers to preventative screenings across the literature. Several participants responded in the affirmative when asked if they felt there were cultural barriers as to why screenings were not being done by African American/Black women. Some stated that there is a lack of care (by the health-care provider) when you are from the African American culture.

When asked if they discussed screenings with their friends, almost all participants stated no. The women discussed how screenings in the African American community health were not discussed as openly as they should. One woman voiced that (...) “it may be cultural but specifically within a family unit; some families don’t speak about it, others do”. (...) “secrets are killing us”. Two self-identified Muslim women completing each-other sentences explained: “Pap test involved the most intimate and private part of women. For religious, cultural or family reasons, women feel very uncomfortable to go for this kind of test”. Most of the other participants nodded their heads in agreement.

Some of the women elucidated on the notion of the role of the healthcare providers’ gender and its impact on women being more responsive to women clinicians versus men clinicians. One woman stated she preferred (...) “a woman doctor to do my examinations”. Another participant stated that (...) “more female healthcare providers could help, but we need heart-to-heart talk with the family and healthcare providers about the seriousness of cancer hitting this community”.

4. Discussion

4.1. Barriers

The present study provides salient points of black Caribbean women’s perception of barriers that may have affected breast and cervical cancer screenings practices. To our knowledge, this is the first study of its kind on a group of women of Caribbean origin, with diverse religious backgrounds (Christian and Muslim). Qualitative tools were used to explore the barriers to attending reproductive health cancer screenings among a sample of black women of African and Caribbean descent. The common barriers were: fear of discomfort; fear of the findings stated as “nerve racking”; doctor not recommending; take time-off from

work; and family commitment. Few studies report women's tendency to prioritize family health over their own health as an additional obstacle to screening (Kobetz et al., 2010; Kobetz et al., 2017). Fear of pain, medical transportation barriers, and religion have also been reported to influence women's care, treatment decisions, and coping mechanisms with breast and cervical cancer prevention (King et al., 1995). The cost of screenings and having no insurance barriers listed are also found in other studies (Miller et al., 2019; Akinlotan et al., 2017).

4.2. Awareness

A very important finding of this study was the fact that they have very little awareness of what extend they may be at risk of cancer for themselves. They never revealed feeling at risk for, nor were they aware of the overall higher risk that African American women are at for reproductive cancers. These findings are concerning, especially when the women may not be enabled or willing to engage in preventive measures, without feeling susceptible to cancer risk (Hall et al., 2019). Our findings are consistent with reports among racial/ethnic minorities, low education groups, and older groups and their low perception of breast cancer risk (Hall et al., 2019; Asiedu et al., 2014). These perceptions in the context of religion and immigration status should be further explored, especially among black Caribbean women. Our data showed that many participants had never received a Pap smear, and all but a few had never received a mammogram. The staggering percent of the Muslim women participants never received a Pap test in their lifetime. One-fourth of the Muslim participants never have a mammogram. When polled as to their most recent mammogram, the time frame varied between a month and 10 years since their last screening. Many of the women were in the range of 2 to 4 years since their last exam.

4.3. Access, Utilization, and Trust

Although the prevalence of mammography among this group is good, the irregularity of getting a mammogram is of concern. There were a few misconceptions found regarding reproductive cancer screenings amongst the participants. Lack of awareness and misinformation may be a strong contributing factor to misconceptions about cervical cancer and cervical cancer screening are noted among this group as found in other studies (Nolan et al., 2014; Park et al., 2016). Most of the women thought that there was no need for screenings once they entered menopause, which is problematic. They were unaware that age plays a substantial role in the increasing risk for reproductive cancers. All these factors or combination of them play role in the delayed or no screenings that might have reflected higher prevalence of late stage cancer diagnosis in this community especially up to 70% of the cervical cancer diagnosis at late stage. The differences in cervical screening uptake for older foreign-born women, resulting in higher mortality rates when compared to U.S. born women (Hallowell et al., 2019). Foreign-born women older than 65 years may have never been screened for cervical cancer, contrary to the U.S. taskforce recommendations for cervical cancer

screening (Endeshaw et al., 2019). There is ongoing argument about the differences in screening guidelines on the frequency of screening and age of discontinuation for older women (Hoover et al., 2019), which may be contributing to the rising prevalence late stage diagnosis in the older-age group. As others, our findings of attitudinal barriers including low perceived risk of cervical cancer due to sexual inactivity, belief about screening being unnecessary without symptoms, and difficulty in setting an appointment that suited their schedule should be explored (Marlow et al., 2015). Educational interventions for this particular group should be tailored to meet their generational needs.

Another important finding was the fact that the women in this study cited the lack of trust in the health care system and/or providers as another reason for their lack of interest for cancer screenings. These findings highlight the existing perception in the population of medical distrust as a social determinant for breast cancer risk tied to other determinants, including immigration status, inadequate housing, food insecurity, and neighborhood access to health services as geographical factors (Coughlin, 2019). Rebuilding confidence in the health care system may improve personal and public health by increasing minority women's utilization of preventative health services (Yang et al., 2011).

Overall, our participants were eager to have a better understanding of preventative healthcare related to reproductive cancers. They offered suggestions that would aid in reducing the numerous barriers for women such as themselves to getting preventative screenings from offering free to low cost screenings, more publicity outside of the customary months dedicated to the specific screenings (i.e., October and breast cancer awareness). These findings support the notion that with increased awareness, they may be more open to cancer screenings opportunities.

Of note, many of the participants personally knew women who had been diagnosed with one of the many reproductive cancers with breast cancer being the most frequent diagnosis. However, this awareness does not appear to have a direct effect on their own behavior. Race and ethnicity shape expectations, norms, and behaviors of women. Interventions need to focus special attention on how race/ethnicity shapes the experiences of minority women and affects the ways in which they mobilize formal and informal support for their own health and their cancer screening behaviors. This study revealed strong beliefs against cervical cancer screening and clearly a lack of reproductive cancer screening understanding and efforts among the Muslim population; among our participants, 75% of them never had a Pap smear. The cervical cancer diagnosis at a late stage is highly prevalent in the community. Other studies as stated that gender roles, women's cultural beliefs and perceptions towards cancer screening, including perceived embarrassment with the screening procedure, may suppress women's compliance with cancer screening and follow-up care (Kobetz et al., 2018; Madhivanan et al., 2016; Miller et al., 2018). The findings warrant urgent attention to address the cultural and religious barriers of cancer screenings. Religious organizations with their women leadership may be in a better position to arrange

and/or delivery health education messages on sensitive women's health issues within comfortable settings and supportive religious norms.

4.4. Strengths and Limitations

Our study had several limitations. The participants were recruited by community leaders and selection bias may have impacted the recruitment. Although the participants may not adequately represent the lowest socio-economic group, the barriers revealed in this study may be common with a less extent. Black women are not a monolithic group and there is both within and between group differences that may have gone uncaptured because the women were not separated by religion. Another limitation, the high number of participants per focus group was above the recommended number of 10 or less per focus group. This might have lent itself to some participants not having a fair chance to voice their input. However, our well-experienced moderator had created opportunities and encouraged everyone to share their views and those concerns may not be less significant.

5. Conclusion

This study has shown that black Caribbean women have a lack of clear understanding of their risk of cancer and several misperceptions may have impacted their breast and cervical cancer screening decisions. There is a need to further identify significant factors and quantify to the extent those that are contributing to these disparities in the context of age, race, ethnicity, socio-economic status, and religious background. Our findings should contribute to hypothesis development and inform future efforts to promote breast and cervical cancer screening awareness and educational needs among black women of Caribbean descent, especially Muslim women.

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Author Contributions

Ahmed involved in conceptualization, assisted in designing, recruitment, data management, analyzing, writing and in charge of the research. **Brewster** involved in moderating focus groups, data gathering, analyzing, and writing. **Cheng-Martinez** involved in assisting focus groups, data gathering and writing. **Thomas-DeVlugt** involved in recruiting women, assisting focus groups, data gathering, and editing. **Rodriguez** involved in gathering literature and editing the manuscript. All authors read and approved final manuscript.

Ethics Approval

This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the Internal Review Board of Florida International University (Date: 04/05/2018, IRB Approval Number: IRB-18-0135).

Consent to Participate

Informed consent was obtained from all individual participants included in the study.

Conflicts of Interest

The authors have no relevant financial or non-financial interests to disclose.

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