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RESEARCH ARTICLE

Minority Women's Perceptions of Breast Cancer and Mammography: A Qualitative Study Using the Health Belief Model

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Abstract

Women of ethnic minority groups are more affected by breast cancer than women of other ethnic origins and tend to suffer disproportionately from the burden of the disease. The purpose of this ethnographic study was to explore the experiences of ethnic minority women regarding breast cancer screening and the consequences of breast cancer including their perceptions of discrimination and racism in their decisions about breast cancer screening procedures. The study was guided by the health belief model (HBM). Data collection was by individual interviews of women from 3 different ethnic groups (16 African American, 16 Asian, and 16 Hispanic women) and from a mixed focus group discussion of all participants (N = 48). The data were analyzed using codes based on the HBM, and an exploratory process of theme identification. Findings revealed multiple barriers to screening for these women, especially a fear of the detection of breast cancer, leading to denial of risk. At the same time, there was a desire for more information about breast cancer and breast cancer screening, and an expressed motivation to get screened based on personal experience with known victims of breast cancer. Improving the providerpatient relationship, and establishing more extensive collaboration between healthcare providers, insurance companies, program managers, breast cancer research organizations, and health and social services departments, are recommended so that the barriers to breast cancer screening among ethnic minority women are significantly reduced in the long run across ethnic groups.

Introduction

Breast cancer is a cancer that starts in the tissues of the breast. The two main types are ductal carcinoma, which starts in the ducts, and lobular carcinoma, which starts in the lobules that produce milk (Chen & Zieve, 2010). Breast cancer affects about one in every eight women in the United States, and a small but significant proportion of men (CDC, 2016). White women

have the highest risk of developing breast cancer; African American women are second, followed by Hispanics, Asia/Pacific Islanders, and American Indian/Alaska native women. In general, African American women have significantly higher mortality rates than all other ethnic groups (CDC, 2017).

Mammography screening and improvement in treatment have contributed to the decline of death by breast cancer (California Breast Cancer Research Program [CBCRP], 2013).

According to the ACS (2012d), the 5-year survival rate for localized breast cancer is 99%, regional breast cancer 84%, and distant-stage breast cancer 23%. Overall, "60% of breast cancers are diagnosed at localized stage when treatment is beneficial to the patient resulting in a five-year survival rate of 99%" (ACS, 2012b, p. 35). Choi et al. (2018) described a recent study in Austria which indicates that mammography for women aged 40-49 years decreased significantly, and in Norway, 50% of breast cancers were localized in the post-breast cancer screening program era. Ahmadian and Samuel (2013) examined factors influencing breast cancer screening in Asian countries.

In the United States, breast cancer screening has been on the increase for the past decade among the various ethnic groups, but persistently continues to decline among the racial/ethnic minorities and women of low-income status. Some of the reasons for the decline include lack of health insurance, poor economic condition, low level of education, and geographic variations in the screening rates across the United States (ACS, 2018). Cultural and social injustice can also serve as barriers. Cultural barriers include perceived vulnerability, folk beliefs, and lack of trust in the health care system, while social injustice barriers are related to discrimination and racial profiling (Ataollahi, 2015). Poverty-related barriers include lack of adequate health insurance

coverage, no primary care physician, and poor access to health care facilities (Siegel et al, 2018; Kline & Huff, 2007).

In an effort to improve the screening rate and bridge the disparity between African American women and other ethnic groups, the CDC National Breast and Cervical Early Detection Program provides opportunity for low-income, uninsured women to obtain free or low-cost access to screening for breast and cervical cancer and access to the Medicaid program for treatment if diagnosed with either breast or cervical cancer (CDC, 2016). Notably, there has been a decline of breast cancer mortality among the medically uninsured female population in Idaho, and a marked difference in response to diagnostic follow-up exams for abnormalities detected in breast screening among African American women and White women. (Johnson et al., 2015). The African American woman is less likely to follow up for inconclusive results, resulting in delays in diagnosis and treatment (Jones & Chilton, 2002; Plescia et al, 2014), which may explain the disparities in the mortality rate among various women groups. American College of Radiology (2012) stressed the importance of screening beginning from the age of 40 for women of all ethnic groups. Race, ethnicity, and socioeconomic factors affect significantly the attitude of women to breast cancer screening (Monnat, 2014).

Methods

The research method selected for this study was qualitative and the design ethnography (Creswell, 2009; Janesick, 2011). A convenience sample of 48 ethnic minority women aged between 40 and 74 years was drawn. Participation criteria included: residing in Houston, Texas, a baseline mammogram at 40 years old according to ACS guidelines, able to speak English. All the women were high school graduates and a few held a college degree. All were actively employed. Participants were contacted through local churches, clinics, women's forums, and

beauty shops. Data were collected through focus groups to encourage group dynamics and expression of a range of perceptions about breast cancer and breast health.

The theoretical framework for the study was based on the Health Belief Model (HBM). The HBM is a psychological model aimed at explaining and predicting health behavior by focusing on the attitudes and beliefs of the individual, based on the assumption that people only take a health-related problem seriously and follow recommended actions if they feel that a negative condition can be avoided (Glanz, Rimer & Lewis, 2002; Bandura, 2004). The six constructs of the HBM are: (a) perceived susceptibility – the fear of being diagnosed or identified as at risk; (b) perceived severity – the belief about consequences of the disease; (c) perceived benefits – the gain to be made by taking the action to reduce the seriousness of the disease; (d) perceived barriers – obstacles to taking the action; 9e) cues to action – readiness to change; and (f0 self-efficacy – the belief that a change in behavior will result in a valued outcome (Kline & Huff, 2007). The model assumes that having a positive expectation and taking a recommended health control measure will result in avoidance of a negative health condition.

Results

The results of the study are presented in relation to the elements of the Health Belief Model (HBM).

Perceived Susceptibility to Breast Cancer

All participants focused more on their fear of the disease (including possible death) and the side effects of the treatment (example loss of hair) than factors that made them more susceptible to breast cancer. However, they all reported that a family history of breast cancer, a polluted environment, and being a woman of increasing age made them more susceptible to

breast cancer. And all groups recognized that a stressful lifestyle, physically and emotionally, made them more susceptible. African-American women emphasized that poor diet and poor health were also risk factors. Asian women added the use of contraceptive pills and the effect of microwave radiation as important factors, while Hispanic women believed that large breast size, not having children, and a poor diet or dangerous environment made them more susceptible. They also seem to know that a poor diet and lack of exercise make a person more susceptible.

Perceived Severity of Breast Cancer

The women from all ethnic groups reported their concern about mastectomy with emotion. There also was intense discussion of the treatment effects, including metastasis, medication side-effects and fear of the unknown, as well as the effects of stress, depression and other psychological factors. As stated by one participant, "the effect is debilitating; the victims lose their hair, muscle tones and look sick; most of them will not eat because they do not have appetite" The Asian women added economic burden on self and family, and changes in one's life (because the disease takes a toll on one's life). Hispanic women were more concerned about the stage at diagnosis, and the statistics of yearly diagnosis. A participant stated: "I have seen women who went to have a mammogram and were diagnosed at very late stage. Although they started treatment immediately, they did not benefit from it because the cancer had spread".

Perceived Benefits of Screening

Collectively, the women of all ethnic groups acknowledged the benefits of breast screening to be timely diagnosis and improved prognosis, early detection (with positive test results), reassurance (with negative test results), and increased knowledge of breast health. The Asian women added the benefit of education and information in relation to screening, and support groups. The Hispanic women emphasized the importance of early prevention to save life.

The focus group discussion focused more on individuals taking responsibility for their health and the availability of free screening services during breast cancer month.

Perceived Barriers to Screening

All these women emphasized a lack of funds, distance to the screening facilities and lack of transportation as key barriers to screening. A lack of education (because one cannot seek something of which she does not understand the benefits) was also frequently mentioned. Many respondents of all ethnic groups added their fear of painful experience with screening as a significant challenge, and their experience of negative attitudes among healthcare providers. Probing revealed that many had experienced a lack of professional competence, and cultural insensitivity among screening personnel. The Asian women added fear of the unknown as a barrier to screening, while the Hispanic women discussed the issues relating to age and laziness as barriers to screening.

Perceived Ways to Overcome Barriers to Screening (Cues to Action)

The women of all ethnic groups reported similar ways to overcome barriers to screening. These included (1) providing free or subsidized mammograms; (2) using published materials and role models from among breast cancer survivors to create more awareness; (3) improving access to screening facilities; (4) better training of providers in professional and cultural competences, and (5) the use of reminder cards and calls. The Hispanic women added that education – about treatment options, the effects of radiation and the availability of counseling – needed to be more extensive, and the Asian women added the importance of learning one's family history of breast cancer, and listening to the experience of known victims, as motivating factors. Many were optimistic about the use of pastors in disseminating information in the churches, the benefits of

comfort during screening and the power of understanding that breast cancer is treatable if diagnosed early.

Perceived Self-Efficacy to Access Screening

The women of all the ethnic groups reported personal experience with known victims, age (because breast cancer increases with age), the feeling of being at risk for breast cancer, as well as problems with proximity to a screening facility, the lack of availability of transportation, and inadequate education. Generally, the women felt they were limited in their ability to deal with all the issues related to breast cancer accessibility. Most understood the benefits of breast cancer screening and the role of a family history of breast cancer, but expressed concerns at the limitations they face in dealing with constraints associated with screening access. The focus group members also discussed age and education, but stressed family history of breast cancer, being a woman, part of a routine check-up, use of publication materials, offering incentives, use of reminder cards, and making reminding calls (because some of the women forget their appointments due to their busy schedules) as reasons to access screening as recommended.

Discussion and Conclusions

This study looked into the beliefs and attitudes of breast cancer screening among ethnic minority women. One of the major findings was that ethnic minority women appeared to have a fear of their susceptibility to breast cancer. There was also a universal fear of detecting breast cancer and the consequences of the treatment. Despite their fear, these women acknowledged the benefits of early detection and better protection, encouragement from support groups (for the Asians), and wide acknowledgement of mammography as ways of taking care of their own health. Notably, multiple barriers stood in their way to screening. These barriers were lack of money and transportation; lack of understanding of the benefits of screening by some

participants due to ignorance; fear of the unknown, as reported by the Asian women; other diseases that could prevent screening, according to the Hispanic women; controversy about screening age; laziness; negative experience of encounters with healthcare providers; and pain during the procedure.

Another major finding of this study was the negative experience of the women during mammography, specifically providers' lack of professional incompetence, disrespect of patients' culture, and poor communication skills. This ugly experience was reported as the reason some of the participants who experienced it had not gone back for another mammogram. But still, most of the participants agreed on the need for breast cancer screening awareness to encourage women to take action for their health. Some women expressed the need to receive more information from their local pastors in the church because they trust their words, or from published materials, while others wanted to hear from survivors as evidence that treatment works if cancer is detected early. Other reasons for suggesting greater breast cancer awareness were the fear of breast cancer, death statistics, increasing age, friendly/very professional providers, and comfort during the exam, in addition to lack of education (according to the Asian women), and family history (according to the Hispanic women).

The women agreed exposure to the personal experience with known victims would likely inspire them to get screened because they would realize that they might be at risk due to some risk factors and understand the benefits of early detection. All these women recommended having easy access to facilities, and free mammograms because of cost. They believed it is part of a woman's wellness exam, and that the use of reminder calls/cards and incentives would help them to get their appointments. The women expressed fear of susceptibility to breast cancer.

More professional training and easier access to mammograms are required to address these fears

and encourage screening practices. Healthcare providers should emphasize the need for these women to recognize their susceptibility to breast cancer. The use of community-based efforts to make screening more accessible to minority women should be explored.

Attitudes of the providers towards patients and the integration of cultural competence in the provider's education to enhance communication and encourage screening should be enhanced. Healthcare providers should understand the need to create breast cancer screening awareness and find the resources to navigate the barriers to screening. Understanding the barriers that promote screening among minority women and packaging it with other screening programs would likely have a long-lasting impact. Also, health care providers should consider culture when promoting screening of minority women.

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Key words: mammograms, minority health, breast cancer screening