BREAST CANCER SCREENING DISPARITIES
IN AFRICAN AMERICAN WOMEN

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To the faculty of Washington State University Vancouver:

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The incidence of breast cancer in African American women is lower than Caucasian women. However, the death rate from breast cancer in African American women is much higher. The reason for the high mortality rate from breast cancer has multiple factors. Socio-economic factors and common beliefs and attitudes all contribute to this health disparity. This article focuses on the role of beliefs and attitudes to breast cancer screening in African American women. Fear, fatalism, mistrust of the health care system, myths and lack of knowledge about cancer are characteristics of common healthcare attitudes in the African American community. Strategies that have been effective in addressing this disparity and the clinical implication of these barriers to nurse practitioners are discussed.
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**Introduction**

Breast cancer is the most common form of cancer in women and the second leading cause of cancer death in women in the United States.¹ Identifying breast cancer early is the key to long-term survival and positive outcomes. Early detection using mammography and clinical breast exam is the best-known method to date in identifying and treating tumors at early stages.² ³ Although the incidence of breast cancer is lower in African American women than Caucasian women, African American women are more likely to die from breast cancer than Caucasian women.⁴ According to the American Cancer Society (ACS), in 2000 the death rate from breast cancer was about 32% higher in African American women than Caucasians.⁵ The five year survival rate from breast cancer also shows a disparity between the races. In the time period of 1995 to 2000 only 75% of African American women survive five years after being diagnosed with breast cancer compared to 89% of their Caucasian counterparts.⁶

A number of factors contribute to the disparity in death rate from breast cancer between African American women and their Caucasian counterparts. Under-utilization of life saving breast cancer screening and early detection by African American women is by far the major factor that often results in a delay in diagnosis leading to a late stage of cancer which can have a negative outcome.⁷ There are two broad categories of barriers to breast cancer screening in African American women, socio-economic obstacles and common beliefs and attitudes about breast cancer.

The primary socio-economic barrier is limited access to comprehensive health care which is linked to the lack of health insurance as a result of high rates of unemployment.⁸ This limited access to care results in less breast cancer prevention, screening, early detection and treatment in the African American community.⁹ Barriers such as lack of transportation to a screening site, lack of affordable child care, and lack of access to educational materials are also contributing
factors to the under-utilization of breast cancer screening among African American women. Some African American women cite the lack of provider recommendation for breast cancer screening as a barrier that prevents them from seeking a mammogram. The influence of socio-economic barriers to breast cancer screening in African American women is well understood and easier to remedy than other barriers. Beliefs and attitudes that serve as barriers are less tangible and more difficult to identify and resolve. Addressing these barriers is an important step toward remedying the disparity in breast cancer outcomes. Attitudes and beliefs about breast cancer that are prevalent in this community are a major contributor to the low rate of breast cancer screening among African American women.

Beliefs and Attitudes as Barriers to Breast Cancer Screening

Although no longer a homogeneous group, African Americans still share common identity, values, beliefs and attitudes. These shared cultural ties offer African Americans collective voice and serve to advance racial equality and justice.

The forms of marginalization often experienced by this group have impacted their beliefs and attitudes towards health, wellness and illness. Barriers that are based on beliefs and attitudes encompass fear, fatalism, mistrust of the health care system and myths and lack of knowledge about breast cancer.

Research shows that health care beliefs and attitudes significantly contribute to the health disparity seen in African American communities and contribute to the disproportionate burden of mortality and morbidity in most health indicators. Belief system barriers are often less well understood than other barriers. Increased understanding of these issues and barriers can increase the ability of nurse practitioners to work with African American women and successfully promote appropriate breast cancer screening. Efforts to eliminate breast cancer disparity must
focus on addressing the causes of the disparity. Health care providers must consider designing interventions which target the causes and implement strategies that deal with fear, fatalism, mistrust, myths and lack of knowledge that is found in the African American community.

**Fear:**

Fear is a universally shared emotional response to an actual or perceived threat. African American women express four types of fear as it relates to breast cancer screening: fear of pain, fear of radiation exposure, fear of positive diagnosis, and fear of being subjected to unethical medical treatment. Some African American women express fear of pain as a result of a routine mammogram as a contributing factor to their decision for not participating in breast cancer screening. Some African American women perceive the routine mammogram screening as a potential breast cancer causing agent and thus are deterred from seeking this and other potentially lifesaving screenings. One study quoted an African American woman as saying: “You should not do the mammogram too often because of that electricity.” Another study quoted a 52 year old African American woman as saying: “Those x-ray machines are full of radiation that leads to breast cancer.” One study found that African American women cited fear of the actual procedure coupled with the cost of getting mammography as the most significant deterrent to seeking breast cancer screening.

Although fear of the mammography procedure itself has been identified as a barrier in seeking early screening measures for breast cancer, fear of being diagnosed with breast cancer is also cited as a barrier. Although the purpose of screening is to identify cancer at an early, treatable stage, some African American women report that they would not seek screening measures for fear of receiving a diagnosis of cancer and its implication to their role as mothers, spouses, and providers. While these fears may be common within other communities as well,
they are heightened by the fear of possible maltreatment by the health care system in African American women. These fears underlie and exacerbate another barrier, fatalism.

**Fatalism**

Cancer fatalism is a belief system that perceives cancer as a death sentence and strips the individual of control over the outcome.\(^{24,25}\) Research shows that cancer fatalism affects individuals’ health seeking behavior and plays a significant role in why individuals fail to seek preventative health care.\(^{26}\) This belief system is more common among African American women.\(^{27}\) Powe and Finnie assert that: “Cancer fatalism is the perceived collapse of meaning in the presence of despair about the future and a lived experience of coping with feelings associated with meaninglessness, hopelessness and despair.”\(^{28}\)

There is an established relationship between cancer fatalism and other barriers, such as poverty, low educational level, and low socio-economic status, and seeking early screening procedures.\(^{29}\) African American women who are poor and less educated are often preoccupied with meeting their day to day needs such as food and shelter and have little time or energy for long term planning including preventive care.\(^{30}\) Poverty and hopelessness go hand-in-hand and foster the fatalistic belief seen in this population. It is these interrelationships that strengthen the negative outcome of cancer mortality in African American women.\(^{31}\) Spirituality is a vital part of African American life. There is strong association between religion and the belief of predetermined destiny in this community. Cancer fatalism is strengthened by the notion that cancer is a punishment from God for a life not lived according to God’s teaching.\(^{32}\) This fear is also reinforced by the mistrust of the health care system that is evident in this community.\(^{33}\)
Mistrust of the Health Care System
Due to past and ongoing unequal health care treatment, there is a widespread and well-founded mistrust of the healthcare system in the African American community. According to Giarratano, there is a pervasive mistrust that is reinforced by the memory of the Tuskegee syphilis experiment which is still fresh in the minds of many African Americans. She asserted that because African Americans have been subjected to unethical medical experimentation without their knowledge and consent, these past experiences continue to affect the perception of the healthcare system in the African American community. Mistrust of the health care system plays a major role in not seeking breast cancer screening and discourages preventive healthcare seeking behavior in the African American community.

African Americans perceive a great deal of cultural difference between themselves and non-African American providers who they feel usually do not listen to their concerns. Among many African Americans there is a feeling of exclusion and not being an active participant in the health care decision making process. One study reports an African American woman as saying: "After a test is done, all they want to do is cut on you. Most of the time you don't know if they are telling the truth or not." On the other hand, once a trusting relationship between patients and providers is established, having a provider recommend screening has been cited as a factor that encourages African American women in seeking breast cancer screening.

Myths and lack of knowledge
Many African American women perceive breast cancer to be a "white women’s" cancer and underestimate their own risk for breast cancer. Furthermore, most African American women associate lack of symptoms as meaning that they are cancer free and as a reason to delay or avoid screening. This myth is fueled by the lack of cancer knowledge provided to this community. There is a significant knowledge gap between African American women and their
Caucasian counterparts about cancer and cancer screening guidelines. Addressing the gap in cancer knowledge is essential to overcome the knowledge gap that is prevalent in this community.

**Strategies to Overcome Barriers**

Strategies to reduce breast cancer morbidity and mortality should include four components: prevention, early detection, treatment and post-treatment follow up care. Each component is equally important in overcoming the disproportionately higher breast cancer mortality rate among African American women. Strategies and programs that have been effective in addressing the breast cancer screening disparity in African American women are of particular significance. Clinician-patient interactions and outreach programs that provide the necessary education and emotional support to African American women in overcoming their fear and other barriers will reduce the magnitude of disparity seen.

For more than a decade there have been nationwide efforts to address the disparity of early breast cancer screening among African American women. These efforts have been at the federal, state and local levels. It is important for nurse practitioners to be aware of initiatives and resources that are available in their local communities so that they are able to use these services to help change health care seeking behavior.

In 1990, the United States Congress enacted into a law the Breast and Cervical Cancer Mortality Prevention Act. As a result of this law, the National Breast and Cervical Cancer Early Detection Program was established in 1991. Under the administration of the Centers for Disease Control and Prevention (CDC), this program funds different federal, state and local programs that promote breast and cervical cancer screening among low income and uninsured women. This federal initiative works in partnership with state and local governments to fund
clinical services that make breast and cervical cancer screening accessible to low income women. The program also funds initiatives that increase screening participation by providing various outreach programs that serve to eliminate barriers responsible for the low rate of utilization. Many educational and outreach programs that are culturally sensitive and tailored to the needs of African American women within their community have been implemented.46

One innovative program is the Missouri Breast and Cervical Cancer Control Program which trains and employs women who are transitioning from welfare to work as outreach coordinators in recruiting women for breast and cervical cancer screening. This effort has been successful in reaching underserved women who otherwise would not have been aware of the available services.47 Programs like this are effective because the outreach workers share the same cultural background and ethnic identity as the women who are served and bring unique insight to the program. These outreach workers have first hand experience with the issue and have sympathy for the plight of the women with whom they work. They provide peer support to reduce the anxiety and fear associated with mammography. This approach reduces mistrust of the health care system because the outreach workers are seen as part of the community.

Another example of a successful grassroots program is the District of Columbia’s Breast and Cervical Cancer Early Detection Program. This project, which is also known as “Project WISH”, Women into Staying Healthy, trains members of the community as lay health care workers to help African American women and low-income women keep their breast and cervical cancer screening appointments. The lay health navigators, as they are also known, provide reminders, assist in transportation to and from screening centers, and provide emotional support to alleviate fear of the screening procedure. In addition, the lay health care workers help women navigate the healthcare system and access resources in their community for follow-up care. This
program has been credited in assisting women in keeping their appointments as much as five times more than the women that are not in the program.\(^{48}\) This approach often helps establish a one-on-one interaction and face-to-face education that helps dispel the myths and reduces mistrust. Establishing long term relationships that foster trust is vital in the African American community.

Partners in Health is another program that is striding in the direction of increasing breast and cervical cancer screening in African American and other low income women in the state of Louisiana. This program was developed by the Louisiana State University Health Sciences Center’s Stanley S. Scott Cancer Center. From its inception in 1997, this program has been a collective effort of the university, hospital mammography and breast centers, the National Cancer Institute, Louisiana Public Health Department and various community and neighborhood groups. Partners in Health increases participation in breast cancer screening by bringing together community-based groups and professionals and assembling and educating Community Lay Health Educators (CLHE) to promote the necessary education and outreach work in areas where underserved women live.\(^{49}\)

CLHE target churches, beauty shops, workplaces as well as private residences in order to spread their message about the importance of screening and early breast cancer detection. After providing educational sessions, CLHE offer to make appointments at clinics. The health professionals in many of the clinics are typically advanced practice nurses who are culturally competent and provide culturally appropriate education and care to African American and low income women. CLHE not only provide initial education but also assess and reinforce learning on an ongoing basis.\(^{50}\) The success of this program is in its outreach to community-based organizations, including churches, and by incorporating cultural values and spirituality. This
program is effective because it engages the individual and the community. The outreach workers are aware of the issues that surround mammography in the local area and are trained to empower, educate and assist women in overcoming barriers in culturally appropriate way.

**Implications for Nurse Practitioners**

Awareness and understanding of the health beliefs and attitudes that deter African American women from participating in breast cancer screening is the most important first step to remedy this problem. Awareness of these barriers will allow the nurse practitioner (NP) to provide care that incorporates appropriate education. NPs have an excellent opportunity to increase breast cancer screening in African American women. By establishing a trusting relationship, nurse practitioners can help eliminate the mistrust that is pervasive in African American women.

NPs can bridge the breast cancer disparity gap by focusing on educating African American women about breast cancer and the importance of screening and early detection. This information should also include providing education about breast cancer risk factors. This will help to dispel the myth that some African American women have about breast cancer being a white women’s cancer and combat the lack of knowledge about breast cancer that exists in this community. One factor in achieving this goal is to provide educational materials that are culturally sensitive and easy to understand.

Establishing a trusting provider/client relationship is important to any encounter, but especially so with African American. One aspect of establishing this trusting relationship is to use open and honest communication and encourage and engage African American women in their care. NPs should be aware of all the barriers that African American women face. This awareness should also extend to being mindful of issues that are unique at the local level, such as
transportation and location of local clinics that are accepting of state funding. Nurse practitioners should network with area providers who will provide follow up care if breast cancer is identified as result of screening. Making timely and appropriate referral improves long-term survival among African American women with breast cancer.

It is also important that NPs stay current on screening guidelines and recommendations as well as be aware of resources that are available for low income, uninsured women in their localities. As studies have indicated, African American women who receive recommendations from their health care providers are more likely to seek preventive care including annual mammography. NPs need to work on the premise that every woman deserves to be cared for with the utmost respect and dignity. Each encounter should be seen as an opportunity to teach and screen women regardless of their race or economic status. African American women have cited provider bias and prejudice coupled with communication barriers as a deterrent to seeking preventive care. NPs should be aware of this perception and work toward eliminating their own bias that interferes with the care they provide to this population.

Lack of knowledge about breast cancer is prevalent in the African American community and is cited as one of the most important deterrents to seeking breast cancer early detection in African American women. NPs can address these issues by educating women about cancer and cancer related risk factors. Concurrently, nurse practitioners can educate women about modifiable risk factors and the relationship between life style and cancer risk. Nurse practitioners who are well positioned to listen to the concerns of African American women and develop a positive, caring relationship with them can have a far reaching impact in reducing the breast cancer health disparity between African American and Caucasian women.
Conclusion

Despite a lower incidence of breast cancer, African American women suffer a higher mortality rate from breast cancer compared to Caucasian women. A combination of socio-economic barriers and belief systems and attitudes have been cited as contributing factors to this disproportionately higher rate of breast cancer mortality in African American women. The common attitudes and belief system barriers to breast cancer screening include fear of mammography, fear of receiving cancer diagnosis as a result of routine screening, a fatalistic view of cancer as an untreatable illness, mistrust of the health care system and lack of knowledge about breast cancer. There have been numerous initiatives and outreach programs at the federal, state and local level that are aimed at overcoming this disparity. Any outreach program must incorporate efforts to eliminate barriers that stem from beliefs of fear, fatalism, myths and mistrust. Nurse practitioners are in a unique position to provide care, that incorporates culturally sensitive and culturally competent education and to empower African American women to overcome their fear and mistrust in order increase their screening participation.
Reference:


17 Legler, 1-9.
18 Legler, 1-9.


21 Giarratano, 1-6.


27 Ibid., 454-467
28 Ibid., 454-467.


31 Powe and Finnie, 454-467.


33 Fouad, et al.; 53-60.

34 Fouad, et al.; 53-60.

35 Giarratano, 1-6.

36 Giarratano, 1-6.

38 Giarratano, 1-6.


43 Ibid., 35-51.


48 National Center for Disease Control and Prevention, (January 2005).

49 Giarratano, 1-6.

50 Giarratano, 1-6.

51 Lukwago, et al.; 1271.