

THE IMPACT OF COMMUNITY HEALTH AGENCIES ON THE PREVENTION OF  
BREAST CANCER IN UNDERSERVED POPULATIONS

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## The Impact of Community Health Agencies on the Prevention of Breast Cancer in Underserved Populations

With early detection and treatment, breast cancer survivorship is vastly improved, yet many characteristics prevent some women from getting these services. Breast cancer health disparities have been found in relation to racial and ethnic differences, socioeconomic status, geographic residence, and age. Although the incidence of breast cancer is just as common among Caucasian women, it has been shown that African American women are less likely to have the screening opportunities (Brooks et al., 2013). Latina women are also disproportionately affected. Latinas are more likely to present with clinical signs of breast cancer at younger ages and at a later stage of disease (Mays et al., 2012). Low socioeconomic status and geographic residency in medically underserved communities intersects with race and ethnicity causing these women to be at an even greater disadvantage (Ka'opua et al., 2011). For localized breast cancer, the five year survival rate is 98.4%. In late stages of cancer, the survival rate drops to 23.8% (Zeinomar & Moslehi, 2013). However, many of these women are not utilizing life-saving prevention measures, such as mammograms, to safeguard themselves against advanced stage cancer. Health care professionals and communities can promote early detection through screening and decrease the mortality rate associated with breast cancer. This project will evaluate a breast cancer prevention program in a rural county in eastern North Carolina that works towards this goal.

### **Literature Review**

A literature review was conducted using the databases CINAHL, PubMed, and Onesearch to locate articles relevant to breast cancer screening barriers and the programs that address these barriers. Articles published between 2010 and 2015 that focused on screening programs and barriers targeting underserved populations were included in the review. Search

terms included breast cancer screening, underserved populations, breast cancer special events, and barriers. The literature review was organized by barriers to cancer screening, screening programs, and educational programs.

### *Barriers to Cancer Screening*

There are three main categories of barriers to cancer screening: structural, clinical, and personal. Inequalities in social and economic status contribute to differences in cancer screening adherence and mortality. Genetic predisposition, cultural factors, and lack of awareness also modify risks and create obstacles to maintaining breast health (Jimenez et al., 2011). Young et al. (2011) reported that all 178 women in their study, who had not been screened for breast cancer in the past two years, experienced all three types of barriers.

Structural barriers include the obstacles that prevent women from physically obtaining breast health care measures. The most significant structural barriers were lack of health insurance, lack of a primary health care center, and lack of transportation (Young et al., 2011). In a study consisting of 53 participants, 61% reported lack of funds as the primary reason for not receiving a mammogram (Northington et al., 2011). Structural barriers can be the most difficult to overcome. Also, eliminating these structural barriers does not automatically improve screening rates. In spite of availability of free mammography screenings, there were many instances when screening gaps and low utilization of services remained constant (Young et al., 2011).

Clinical barriers are those that involve patient education and communication between women and health care professionals (Young et al., 2011). Many women living in underserved areas receive no education concerning breast cancer symptoms, screening guidelines, and

prevention and treatment options. This is made worse when fewer health care professionals are available in these areas and those professionals are forced to limit education due to time constraints (Anderson & Hoskins, 2012). Many patients have reported that their physician failed to explain mammography or refer them for a mammogram. This is especially problematic considering many African American females expect their doctor to initiate these conversations (Young et al., 2011).

Personal barriers are associated with a lack of trust and knowledge. Women can be affected by misconceptions about breast cancer and a lack of knowledge concerning their own personal risk factors. It has been shown that many African American women believe they are at a lower risk when they are actually more likely to be diagnosed at a more advanced stage than Caucasian women (Young et al., 2011). Anxiety and worry are also associated with non-adherence (Anderson & Hoskins, 2012). Fear of pain and unfavorable results deter some women from getting mammograms. Lack of trust seems to be a significant barrier as well (Young et al., 2011). Previous bad experiences with health care professionals can influence future encounters and prevent women from seeking care. In addition, religious and cultural beliefs can keep women from utilizing screening services. For example, some women doubt the effectiveness of medical treatment and rely solely on their faith to protect them or may believe that their health status is completely out of their hands (Northington et al., 2011). Structural, clinical, and personal barriers experienced by underserved populations result in delayed diagnosis and treatment. In an effort to address these barriers, special events and programs including free or low-cost screening opportunities and education sessions are employed to increase the number of women following breast health recommendations (DeGroff et al., 2014).

### *Screening Programs*

According to the US Preventive Services Task Force (USPSTF), women who are asymptomatic should begin biennial screenings at age 50 and continue this schedule until they turn 74. In contrast, the American Cancer Society (ACS) recommends yearly screenings beginning at age 45 and switching to biennial screenings at age 55 for women who are asymptomatic. The ACS also suggests that women ages 40-44 be given the choice to have yearly screenings and they suggest continuing screening as long as the client is healthy and is projected to live another 10 years. Neither the USPSTF nor the ACS recommend performing self-breast exams and both have reported there is insufficient evidence to support either beneficial or detrimental effects of clinical breast exams (U.S. Preventive Services Task Force, 2014; American Cancer Society, 2015). In order to provide the best care for each patient, individual cancer risk assessments are performed to guide screening behaviors and provide necessary resources and support (Anderson & Hoskins, 2012). Screening programs are able to collect information about a patient's personal and family history as well as factors that increase cancer risk, such as smoking, age, and ethnicity, and refer patients to the appropriate services (Brooks et al., 2013). Mobile mammography units have demonstrated effective screening outreach for underserved populations (Brook et al., 2013).

Screening programs are useful in addressing many structural and clinical barriers by eliminating costs, making services geographically available and providing the opportunity for one-on-one, focused interactions with health care providers. In addition to providing screening mammograms, these programs also allow providers to screen women for hereditary risk factors, such as family history, that may place them at an increased risk of developing breast cancer. Risk evaluations allow providers to make informed decisions about the best plan of action for each patient. Interventions that increase access to clinical services and are planned individually for

each patient based on their personal history and risk factors help patients navigate through cancer care services and address many complex issues associated with low screening adherence (Mays et al., 2012).

### *Educational Programs*

A study conducted by Zeinomar and Moslehi (2013) reported low levels of awareness and knowledge concerning breast health among the general population. In this study, baseline knowledge was assessed through a pre- and post-test on the effectiveness of an educational tool. Educational tools included PowerPoint presentations, seminars, workshops, and focused discussion groups, video breast health kits, and culturally targeted booklets. Using educational tools such as these has been shown to significantly improve breast cancer knowledge among participants (Zeinomar & Moslehi, 2013). Many women have reported learning new information including the importance of prevention and screening practices, signs and symptoms of breast cancer, and how to share this information with others after completing educational programs (Northington et al., 2011).

These types of programs are useful in addressing personal barriers. Emotional beliefs, language barriers, and perceived importance of screenings are potentially modifiable factors that education can address (Jimenez et al., 2011). Educational programs also have the opportunity to incorporate cultural aspects into care. A lack of social marketing designed specifically to inform minority women about risk factors and preventive measures could be interpreted by these women that breast cancer is not an issue for them or that they would rarely develop the disease (Northington et al., 2011). In an educational program designed for the Hispanic population, a Spanish language church-based curriculum was designed and implemented by Hispanic physicians. Lay community health workers were there to help participants understand the

material the physician presented. The PowerPoint presentation contained pictures of Hispanic women and discussion of healthy food included foods associated with Hispanic culture (Jimenez et al., 2011). In the Hispanic culture, patients are more likely to respect the opinions of physicians than that of nurses or other health care professionals (Jimenez et al., 2011). By having a physician and lay community workers provide education and including culturally relevant material, participants were more receptive towards the information and were able to see the significance of this disease and the importance of prevention and screening (Jimenez et al., 2011).

Ka'opua et al. (2011) also demonstrated the benefit of a culturally tailored educational program. In the Hawaiian culture, spirituality and the extended family system are important. In this program, an educational session was delivered during a church service that incorporated relevant scripture. Participants reported they appreciated being treated as more than just research subjects and now felt more comfortable working with health care professionals (Ka'opua et al., 2011). This program was able to positively impact the opinions of many women concerning screenings by including spiritual beliefs and the extended family.

Lack of knowledge is a huge concern when attempting to reduce screening barriers among underserved populations. Teaching women about breast cancer, specific risk factors, and diagnostic and treatment procedures has been shown to reduce fear and correct misconceptions (Mays et al., 2012). Providing underserved, high risk groups of women with a community based program in association with churches, community organizations, and local health centers has the potential to reduce personal barriers and improve acceptance to screening recommendations.

### *Conducting a Successful Program*

Effective programs require integration of patient outreach and recruitment, client and provider reminders, patient navigation, and provider assessment and feedback (DeGroff et al., 2015). These programs should include culturally significant and inclusive material as well. Successful events usually incorporate two to four strategies including improved access to screening by reducing structural barriers, one-on-one or group education, small media and provision of cancer educational materials (Escoffery et al., 2015). Success is also due in large part to community partnerships; strong relationships between health care providers, community groups, and religious leaders has shown to improve outcomes of many breast cancer screening and education programs (Teal et al., 2012).

The purpose of this senior honors project was to evaluate a federally-qualified health center (FQHC) Breast and Cervical Cancer Control Program (BCCCP) in a rural county in eastern North Carolina compared to evidence-based practice guidelines. This program evaluation had two exploratory questions: How does a FQHC that provides BCCCP address the structural, clinical, and personal barriers concerning breast health screening and is BCCCP reaching the target population in this eastern North Carolina rural county?

## **Methodology**

### **Project Design**

This program evaluation was conducted in a rural county in Eastern North Carolina at a FQHC, a quality care designation given by the U.S. Bureau of Primary Health Care and the Centers for Medicare and Medicaid Services. Although the Affordable Care Act requires most insurance plans to cover breast cancer screenings, a vast majority of the patients seen at the FQHC do not have health insurance. In order to be a FQHC, the facility must serve an

underserved area or population, offer a sliding fee scale, provide comprehensive services, have an ongoing quality assurance program, and have a governing board of directors (Health Resources and Services Administration, n.d.). The sliding fee scale is enforced to provide quality care at an affordable level based on services, income, and household size. This policy is also used to screen women for BCCCP eligibility. Without these public policies, many women lacking health insurance would not have the opportunity to receive the same prevention available to the rest of the population. This program evaluation had four components, 1) a chart audit of women receiving BCCCP, 2) observations of the delivery of BCCCP services, 3) collaboration with BCCCP staff and 4) interviews with key informants.

The BCCCP at this FQHC serves eight counties in Eastern North Carolina. The breast cancer incidence rate for the state is 157.0/100,000 women and the breast cancer mortality rate is 21.6/100,000. One county in this region most affected has a breast cancer incidence rate of 153.4/100,000 and a mortality rate of 26.0/100,000. The current goal of Healthy People 2020 is to reduce Breast Cancer Mortality to 20.7/100,000 (HealthyPeople.gov, 2014). Whites, African Americans, and Hispanics in the state had an incidence rate of 160.1/100,000, 160.5/100,000, and 157.9/100,000 respectively. The White population had a breast cancer mortality rate of 20.1/100,000 in the state and the African American population a rate of 28.8/100,000, while the Hispanic population a breast cancer mortality rate of 12.4/100,000.

The BCCCP provides eligible women with free or low-cost breast and cervical cancer screenings and follow-up. Eligibility is determined by age, sliding-fee scale status, and whether or not potential cancer symptoms are present. Women ages 40-64 are eligible for clinical breast exams whether they are presenting with symptoms or not; women ages 18-39 are eligible only if they are experiencing symptoms. Screening mammograms are provided to women between the

ages of 50 and 64 as long as they are asymptomatic and have a documented normal clinical breast exam within the last 12 months. Women ages 18-75 qualify for diagnostic mammograms and breast ultrasounds if they are symptomatic and have a clinical breast exam documented within the last 12 months. BCCCP also covers surgical consultations when further evaluation is needed. If a woman is found to have breast cancer and she was enrolled in BCCCP before diagnosis, she may be eligible for BCCCP Medicaid for assistance with treatment costs.

Although FQHCs serve the most vulnerable populations, a woman may qualify for BCCCP funding for a screening or diagnostic procedure, but may not qualify for Medicaid. Although a referral has technically been provided after a diagnosis, patients with no insurance are not likely to have the means to pay for cancer treatment out of pocket and will be left without care. The same applies to non-citizens who are registered with BCCCP and cannot apply for Medicaid. Fortunately, there are cancer centers that will provide care for these women, though it may not be feasible for the patient to travel to these locations.

The cultural factors that contribute to barriers in care include language differences and the transitory nature of migrant farm work in the region. All referral agencies do not have sufficient interpreter capacity, which may lead to inappropriate use of family members as interpreters or the reliance on an individual's limited English ability. The fact that many of these patients are migrant workers causes a concern with continuity of care. There is no guarantee that the next place of residence will have the same access to care and routine screening.

### **Setting and Sample**

The FQHC, in this project, currently has three sites with mammogram units with a fourth site to be operating by May of 2016. These clinic sites are able to offer in-house mammograms,

thereby lowering costs preserving funding to assist more women. These health centers also have privileges at three local hospitals and maintain multiple referral relationships with county health departments, surgical associates, and diagnostic centers. These partnerships allow the FQHC to provide care at a reduced cost while also making services more accessible at multiple locations. Outside agencies were the only option available to BCCCP for years before the FQHC obtained their own mammography machines. These agencies became the primary source for screenings once again because of damage to the mammography machines. Fortunately, the FQHC was able to receive funding to replace the broken equipment and bring additional units to other sites. The sample for this program evaluation were all women, age 22-68 receiving services through the BCCCP program at the FQHC.

The FQHC operates 25 medical practice sites and three dental clinics dispersed over eight counties. Approximately 25% of these sites are accessible by public transit, including a facility with a digital mammogram onsite. In 2015, 35,808 patients were seen in the facility at which this project took place; in this county, 29% are uninsured, 27.7% are living in poverty, and 23% are females between the ages of 40 and 65. The county's population is 26% African American and 21.6% Hispanic. One of the eight counties with the highest breast cancer incidence and mortality rates also has the largest percentage of African Americans (NC State Center for Health Statistics, 2013).

This region of the state is rural with farms, textile factories, and small businesses. A community hospital and a local health department are located in the county seat of government, 20 miles from the FQHC. The health department provides many programs and services. Bilingual signs, literature, and interpreters are available at health care facilities. The grocery

stores have a variety of foods available and they accept food stamps and the WIC program. There are multiple mainstream churches in the area.

There is no public transit system, however if a ride is needed, residents can contact the transportation department for assistance. Health concerns for this farming community include exposure to the sun, tobacco, and possibly pesticides.

### **Data Collection**

A chart audit was conducted, in collaboration with a registered nurse preceptor, to collect information on the demographic characteristics of the patients served through BCCCP. The chart audit included race, age, income, zip code, family and personal breast health history, smoking history, BMI, and diagnosis including tumor presentation, as well as the patients past experiences with breast cancer screening and their reason for visiting the health center at the time of their mammogram. Charts were chosen based on whether or not the patient qualified for and received BCCCP funding for breast cancer screening and if the patient had completed the screening process. For clients who received a diagnosis, charts were chosen based on whether or not they had been successfully enrolled in BCCCP Medicaid and had begun the treatment phase. This subsample included 52 cases from 2009-2015. This data was recorded in a matrix format.

I interviewed four key informants. They were a mammography technician, two FQHC site leaders, and a health department nurse regarding their perspective on the BCCCP program. The five questions were: how does BCCCP address educational needs regarding mammography; how does BCCCP address structural barriers, such as transportation and access concern; what personal barriers, such as fear and lack of knowledge, have been reported by patients; how does BCCCP address personal barriers; and how does this agency reach the target population?

## Findings

Of the 52 women chosen for the chart audit, the majority were White women (46.15%), followed by 23.08% African American, and 5.77% Latino. Thirteen women (25%) either chose not to report their race or were not asked about their race. Ages ranged from 22-68 with an average age of 49.9 years. Breast symptoms, including lumps, pain, and lesions, brought over half of the women (n=27) in for BCCCP services and 66.6% (n=18) of these women were diagnosed with breast cancer. One woman had been experiencing breast pain for three years before seeing a doctor while another women experienced symptoms for two years and presented with lesions and discharge. Family history of breast cancer was recorded in 69.2% (n=36) of the women. Thirty seven women had a smoking history and 20 reported daily smoking. Nine of the women who reported a history of tobacco use were diagnosed with breast cancer. Body Mass Index was available in 41 charts and, 65.4% were found to be overweight or obese. Nineteen of these women were diagnosed with cancer. When reviewing mammogram history, 10 women reported they had never had a mammogram while 14 had a time span longer than two years between mammograms. No mammogram history was available for 16 women. Of this sample, only 12 had maintained a biennial screening schedule. Since BCCCP teaches clients how to perform self-breast exams, history of self-breast exams was also reviewed. The record audit revealed that 11 women performed monthly self-breast exams; three of these women found a mass during exams. In order to qualify for BCCCP, a patient must be at or below 200% of the federal poverty guidelines, however 47.2% of these women were living at or below 100% of the federal poverty line.

BCCCP addresses educational needs regarding mammography by providing educational handouts in English and Spanish. The program gives patients the opportunity to have one on one time with providers, nurses, and or technicians who provide information on screening recommendations as well as the importance of adhering to these recommendations. Patients are

also provided information by providers and nurses on self-breast exams and common signs and symptoms of breast cancer.

Multiple personal barriers were noted when conducting key informant interviews including the fear of the unknown, the associated costs of diagnosis, and the stress on their family. Fear of the unknown stems from not knowing how mammograms work and what the tests will consist of as well as the possibility of receiving a cancer diagnosis. There is also a lack of knowledge concerning the necessity of screenings. Many women do not understand why they need to have medical interventions if they are not sick. Understanding signs and symptoms as well as the recommended screening practices presents a knowledge deficit as well. In order to address these barriers, health care providers and nurses educate patients on recommended screening practices and what could happen if they do not take preventive measures. Emotional support is also provided during visits and patients are given the opportunity to ask any questions or voice any concerns they may have including the cost and availability of further treatment.

Although the FQHC never experiences a shortage of clients who meet the BCCCP requirements, outreach is still conducted to encourage women to seek preventive services. At these events, cards are usually handed out for free breast cancer screenings. The health center also stays in close contact with local hospitals and health departments to promote BCCCP and let women know there are services available.

### **Discussion**

This FQHC provides an essential preventive service through the BCCCP in this service area. Still, the majority of recipients of this BCCCP were White women (46.15%), followed by African American and Hispanic women. Because 25% of charts did not provide information on

race, improved staff training in the BCCCP documentation is crucial in order to obtain complete medical histories. This may have been a language barrier or misunderstanding on the part of the client. This issue can be combated by improving patient- provider relationships and establishing trust. By meeting with the health care team and engaging in meaningful, supportive conversation, patients can begin to feel more at ease answering questions about themselves and their health. In addition, the majority of women presented with symptoms. In order to better reach the minority populations for routine clinical breast exams and mammography, BCCCP could consider conducting outreach programs in culturally relevant locations such as churches, hair salons, and women's groups. Surprisingly, the age range (22-68 years) was also younger than expected considering most women covered under BCCCP are usually between ages of 50-64. There is also an evident need for modifiable risk factor education. In addition to breast cancer education, providers could also include information on how to achieve and maintain a healthy weight and smoking cessation.

BCCCP addresses all three types of barriers to cancer screening: structural, clinical, and personal. The digital mammography provided in house at the FQHC along with the partnerships formed throughout the neighboring communities allows for patients to be closer to care than they were before. This care is also provided at little or no cost to eliminate the issue of health insurance. Considering mammography was only available through outside agencies in the past, it is important for the FQHC to inform the community that services are now available at their locations. Although public transportation is not offered everywhere, multiple health centers are working to be incorporated into their cities routes. There is one county that will provide transportation out of the public transit route, but this is in just one small portion of the service area. Expanding transportation services all across the service area would greatly benefit these

communities. The county with the second highest number of BCCCP patients also has the highest Latino population. There are many women living in this county who have an undocumented or non-resident status and therefore are not eligible to receive treatment at a local facility. These women have to travel farther to a medical center that provides care to all women with breast cancer. Many women living in poverty and without health insurance are not receiving the preventive care they need. Implementing a transit system in this county that could provide transportation to and from the available treatment center has the potential to save many lives in this area.

The biggest clinical barrier facing women concerning breast cancer is miscommunication at numerous levels. BCCCP addresses this barrier by having providers offer BCCCP education to all women coming through the door who qualify for services. This includes women presenting for physicals, follow ups to unrelated problems, and even acute care patients. In addition to providing information to patients, BCCCP also provides educational information for providers so they can better serve this community of women.

The education that is provided through BCCCP as well as the one on one interaction with multiple health professionals helps to address personal barriers. There is a great deal of fear associated with the discomfort of the test and uncertainty of results. However, when patients are able to sit down with a professional and become informed on the step by step process, some of that fear subsides and they are able to better understand why these tests are necessary and the long term consequences. This is especially true in patients who do not understand the concept of preventive care; those who believe they don't need medical attention if they are not sick. Many misconceptions and inaccurate information lead to late stage cancer diagnoses. Some women believe if they do not feel a lump during a self-breast exam they won't need to have a

mammogram. Self-breast exams are not diagnostic, however education is required when enrolling patients in BCCCP. Others try to schedule mammograms before they reach the recommended age or do not schedule their mammograms in an appropriate time frame. Because BCCCP provides this education, more women are improving their health practices and they are becoming more comfortable taking the necessary steps to safe-guarding themselves against breast cancer.

There are some differences between BCCCP's practices and those recommended by the USPSTF and the ACS. The USPSTF recommends that women between the ages of 50 and 74 maintain a biennial screening schedule, however BCCCP only covers women up to 64 years old unless they are symptomatic. The ACS recommends screenings begin earlier at age 45 (40 if preferred by the patient) and continue as long as the patient is healthy. Both the USPSTF and BCCCP agree that only certain women should receive mammograms before age 50 and there is insufficient evidence to determine if women over the age of 75 should receive mammograms at all. The biggest difference is seen in clinical as well as self-breast exams. The USPSTF and the ACS do not recommend women to perform self-breast exams and has determined there is insufficient evidence on the benefit of clinical breast exams (U.S. Preventive Services Task Force, 2014) (American Cancer Society, 2015). However, BCCCP requires any patient receiving a screening or diagnostic mammogram to have a clinical breast exam documented within the last 12 months and they provide education on how to perform self- breast exams.

## **Conclusion**

This program mostly served White women, so there is a need to improve outreach to minority women. Structural barriers persist for women who are not eligible for treatment.

Clinical barriers are that staff training is necessary in order to fully serve all woman and capture accurate programmatic data. There are now three mammography units, with another in progress, available for patients on site at the FQHC and its satellite sites. Before these units were in use, patients had to receive care from outside agencies. The FQHC, along with BCCCP funding, fills a gap but it is not enough. They need to work to improve coordination with the local health departments. An expanded transportation system would greatly improve their impact on the communities they serve.

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