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A SOCIOECOLOGICAL VIEW OF ATTITUDES AND PERCEPTIONS TOWARDS UPTAKE OF BREAST CANCER SCREENING IN MULTICULTURAL POPULATIONS

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ABSTRACT

Individual attitudes and perceptions are seen as the basis for determining health screening behavior. Preventive behavior is also influenced by factors acting at the individual and community levels. Interventions are likely to be more effective when they address determinants at all levels because significant and dynamic interrelationships exist among different levels of health determinants. The following papers identify structural, organizational, and sociocultural influences that may preclude women from using preventive health care, specifically breast-screening services, and affect individual attitudes toward breast cancer screening. The *Evaluation of a Breast Cancer Screening Program in Nigeria* examines the objectives and resources of a nonprofits breast cancer screening program to determine if its expectations are realistic and achievable within its current in the context. *The Association of Chronic Diseases and Mammography among Medicare Beneficiaries Living in Appalachia* examines the associations between the number and prevalence of chronic health conditions and adherence to breast screening guidelines among Medicare beneficiaries in four Appalachian states. *Breast Cancer Screening and Health Care System Distrust by Race and Nativity in Philadelphia* examines the influence of health care system distrust on breast cancer screening utilization among residents of southeast Pennsylvania by race and nativity. These studies offer a socioecological view of attitudes and perceptions toward uptake of mammograms in three different populations. These attitudes, whether perceived or actual, act as barriers that prevent vulnerable women in multicultural societies from using breast cancer screening services. A better understanding of these women's perceptions and beliefs allows for sustainable macro and micro level approaches to lowering barriers and achieving greater participation of women from minority or other disadvantaged social groups in breast cancer programs.

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Chapter 1

Introduction

The effects of multi-level social structures on health and health utilization are important contributors to differences in health among people of similar socio-demographic background living in different regions.[1] It is important to not just note that people living in different regions are different but also understand that these multi-level structures may influence individual's perceptions and attitudes toward health care. This dynamic relationship is made even more complex by inter- and intra-country migration. Moving from one place to another exposes individuals to different sets of health risks, barriers, and behaviors. [2]

Socioecological models were introduced to understand the dynamic interrelations among population-level and individual-level determinants of health and interventions.[3] Bronfenbrenner's ecological framework for human development popularized the thought that multiple levels of the environment play important roles in health outcomes and is considered to be the most recognized and utilized social ecological model.[4] Socioecological models "emphasizes the importance of the social and structural environments that strongly shape patterns of disease and injury as well as our responses to them".[5] This way of thinking is based on evidence that no single factor can explain why some individuals or populations are at higher risk of certain health outcomes while others are more protected.

This dissertation examines how multi-level social structures influence or affect attitudes and perceptions toward breast cancer and breast cancer screening among women. The structural, social, and cultural environments that influence these perceptions and attitudes highlight the multiple levels at which women face barriers to receiving screening. The studies in this

dissertation ask novel questions on how negative perceptions of health, the health care system, and health care delivery, born from various levels of the environment, matter and highlight the indirect ways in which the structural and social environments influence breast cancer screening uptake in various populations.

Health care service utilization is determined by influences at multiple levels such as national health policy and institutional and intrapersonal factors, and a socioecological approach considers both individual- and community- related issues. [3] These factors may influence characteristics of the people, organizational climate, and/or cultural and social characteristics of the community. [6] Because significant and dynamic interrelationships exist among these different levels of health determinants, interventions are most likely to be effective when they address determinants at all levels.[6] Hence, instead of focusing on individual-level health determinants, this dissertation identifies structural, organizational, and sociocultural factors that may preclude women from using preventive health care, specifically breast-screening services, and affect individual attitudes toward breast cancer screening.

Breast Cancer Screening

Breast cancer is the most frequently diagnosed type of cancer worldwide and the most common cause of cancer death among women, accounting for 16% of all cancer deaths.[7] The incidence of breast cancer varies by as much as 10 fold across the world with higher rates observed in the United States and Europe. [8] Breast cancer screening is a method to detect breast cancer before any signs or symptoms occur. [9]A mammogram is a breast x-ray and is a cost effective method of detecting breast cancer early and reducing mortality from the disease.[9] Routine preventive screening and early diagnosis are two effective ways to reduce breast cancer

mortality.[10] When diagnosed at earlier stages, treatment success and survivorship rates are high.[11] Worldwide, mammography screening among women age 50–69 reduces mortality from breast cancer by 15–25%.[10]

The United States Prevention Services Task Force (USPSTF) recommends that women who are 50-75 years old and at average risk for breast cancer receive a mammogram every two years. [12] Other cancer organizations, such as the American Cancer Society (ACS), have kept the previous screening recommendation of an annual mammogram beginning at age 40 for average-risk women. [13] Screening recommendations for high-risk women include annual mammograms beginning at age 30. [14] Furthermore, women at moderate risk are advised to discuss the timing for beginning routine mammograms and the frequency of receiving mammograms with their physicians. [14,15] In contrast, many low-income countries have no national policy on breast screening and very few facilities with the necessary equipment to screen or treat breast cancer.[7]

Within high-income countries, variation occurs among screening rates. Disparities are associated with age, education, geographic location, income, and race/ethnicity. [9,16–21] Women who are uninsured or underinsured have higher incidence of breast cancers and tend to be diagnosed with more advanced disease than the general population.[9,19] In low-income countries, many women are cut off from health centers and providers due to geographic location as dependable transportation. Hence, women may have to travel far distances on foot to seek medical care.[22]

A dynamic relationship exists among these measures of diversity; hence, disparities may result from the multiplicative effect of some or all these factors. For instance, race and poverty are predictors of having received a mammogram.[19] In the U.S., racial minorities are more likely to be poor and lack health insurance.[23] Being poor and/or lacking health insurance may result in more experiences that are negative with the health care system compared to non-minority women, women with health insurance, and the combination of non-minority women with health insurance.

Do these negative experiences translate to a system wide distrust of the health care system that discourages breast cancer screening utilization? Poor women are also less likely to have access to a usual source of care and a primary care physician and are more likely to suffer from a chronic disease.[19] Do health status and access to care influence breast cancer screening uptake in the same way? Finally, cultural perceptions that immigrants bring from their home country could influence their attitudes toward preventive screening. What are the perceptions around breast cancer screening in populations outside the U.S?

This dissertation explores these questions by emphasizing a socioecological approach to understand barriers to breast cancer screening uptake. Sociocultural factors are examined in the first study, entitled *Evaluation of a Breast Cancer Screening Program in Nigeria*. This study used semi-structured interviews of women attending a cancer screening facility in Lagos, Nigeria, to describe culturally relevant factors that shape attitudes toward breast cancer and breast cancer screening. Little to no information describes how culture influences beliefs and attitudes toward breast cancer and breast cancer screening in Nigeria, so this study provides useful information on social barriers toward screening. In addition, women who are motivated to obtain services may be hindered by structural barriers such as lack of available services, cost, lack of transportation, recommendation from a health care provider, health insurance, translation services, or social ties.[21,24,25] Programs that address the range of personal, structural and institutional barriers to screening can change breast cancer screening behavior. Hence, this study also examined the objectives and resources of a nonprofits' breast cancer screening program to determine if its expectations are realistic and achievable within its current context. Recommendation were provided on areas for improvement, including steps to alter the program to reach goals.

The second paper examines the influence of structural and individual factors on breast cancer screening. These factors include socioeconomic and community level characteristics, access

to health services, appropriate recommendations, transportation issues, etc.[26] Here, individual health status and county deprivation are examined to determine their influence on the utilization of breast cancer screening services. This paper entitled *The Association of Chronic Diseases and Mammography among Medicare Beneficiaries Living in Appalachia* examined the associations between the number and prevalence of chronic health conditions and adherence to breast screening guidelines among Medicare beneficiaries in four Appalachian states. The study focused on the impact of 16 different chronic conditions while adjusting for potential confounders. The results of this project could highlight an additional barrier preventing elderly patients from adhering to clearly beneficial screening recommendations and possible physician bias against screening elderly women with chronic diseases in an insured population.

The final paper examines institutional influences on breast cancer screening access. These factors involve interactions with the health care system and could include difficulty navigating the health care system, communicating with medical staff, and discrimination in treatment. This paper examines the influence of health care system distrust on breast cancer screening utilization among residents of southeast Pennsylvania by race and nativity, entitled, *Health System Distrust and Breast Cancer Screening in Southeastern Pennsylvania*. The paper first determined whether foreign-born or minority women had higher levels of health system distrust compared to U.S.-born and non-Hispanic White women. Next, the paper examines whether higher levels of distrust and race/nativity were associated with breast cancer screening adherence after controlling for socio-demographic and health resources variables known to influence screening decisions. Finally, the study looked within race and nativity groups to observe if and how any association of health system distrust and mammography adherence varied. Women with higher levels of health care system distrust may be less likely to receive a mammogram. If racial minorities are more likely to exhibit higher levels of health system distrust,

then improving trust at the system level of care would be an important intervention point to improve screening rates among these women.

Chapter 2

Evaluation of a Breast Cancer Screening Program in Nigeria

Background

Nigeria

Nigeria is located in West Africa and is boarded by Cameron on the East, Chad in the Northeast, Niger on the North, Benin to the West, and on the South by the Gulf of Guinea. [27] Nigeria is divided into 36 states, plus the federal capital territory Abuja. States are subdivided into 774 local government areas (LGAs). Nigeria is the most populated country in Africa and with 190 million people; it is the seventh most populated country in the world.[28] The population has been increasing over the years, currently growing at 2.6 percent per annum. [28] More than 500 ethnic groups live in Nigeria, each with its own unique dialects.[27] The life expectancy at birth is about 54 years up from just about 38 years in 1960.[28] The total population is mostly youthful with a median age of 18 years.[27] Nigeria is experiencing a high rate of urbanization. The proportion of the population currently living in urban areas is 50%, up from 15% in 1960 and projected to reach 75% by 2050.[27] Lagos is the smallest state in terms of area but its population of 13 million makes it the most populated state and the largest city in Africa. Lagos state is made of the entire Lagos metro area and is the industrial capital of Nigeria.[29]

Breast Cancer in Nigeria

Breast cancer is more prevalent among younger, premenopausal women in Nigeria [30,31] compared to Black women in high-income countries, even though the death rate in African women is lower than in high-income countries. [32]Low screening levels, leading to late stage diagnosis have been cited as the biggest cause of breast cancer mortality in Nigeria.[30,32] Adesunkanmi et al. (2006) examined breast cancer patients in a Nigerian hospital over an 8 year period and found that 80.6% patients had been diagnosed with breast cancer at stages III and IV.[31] Treatment is more successful when breast cancer is detected in stages I, II, or III [33] and could be 10 times less expensive than treatment for stage IV disease. [34] In addition, a 5-year survival rate after treatment in developed countries is 70% but under 10% in Nigeria.[35]The cost of living varies widely in Nigeria, but in Lagos State, the average monthly disposable salary (net after tax) is $372. In a low cost private clinic, a physician breast exam is $8, a breast scan is $48, and a mammogram is $111.

Over the past 20 years, the U.S. death rate due to breast cancer has decreased by 30%.[36] This decrease is attributed to early detection, better treatment, and increased awareness among women and physicians.[36] Low levels of breast cancer knowledge decrease the likelihood that women undergo screening; therefore, symptoms are ignored until later stages. Over the past 15 years, the knowledge and awareness of breast cancer risk factors, screening methods, and treatment have been studied among different communities in Nigeria.[37–39] Among health care workers, knowledge of breast cancer risk factors and screening methods were low.[37,39] A 2009 study found that only 3.1% of female health care workers who qualify for routine annual screening had received a mammogram.[37] These levels are concerning since these women serve as health care role models to the community.[40] Not surprisingly, the level of breast cancer awareness was lower in the general population. [35,38]

No national policy, screening guideline, or government organized programs promote breast cancer prevention or screenings. This means that even if awareness was improved, women have limited options for low cost screening. Lack of financial and human resources; poor health care systems; competing health care needs such as infectious diseases; war and civil unrest; the personal nature of screening tests; and the social position of women have all been cited as barriers to breast cancer screening in Nigeria.[25]

Optimal Cancer Care Foundation (OCCF)

The Optimal Cancer Care Foundation (OCCF) is a non-profit in Lagos, Nigeria, and is the only stand-alone breast cancer screening and treatment center in the state. It was established in 2012 by Dr. Femi Olaleye. The foundation currently provides subsidized breast, cervical and prostate cancer screenings, and diagnosis, referrals and treatment services. OCCF was founded to address the issue of cancer screening and awareness in Lagos and provides its services without long waiting periods or crowds associated with public hospitals. In addition, the health care staff is adequately trained in breast cancer screening and treatment and is not over burdened with competing health care needs. Every Friday, OCCF also hosts a free screening program, as well as a health seminar on risk factors, signs, and symptoms associated with breast cancer. Ongoing assessment of program implementation and effectiveness is necessary for OCCF to provide the maximum benefit.

Program evaluations are integral to any health intervention and are used to measure program success.[41] Health programs in developing countries often do not have the resources needed for comprehensive evaluations.[42] An evaluability assessment is a systematic process that links program planning, development, and evaluation.[43] It has been used as a cost effective and quick alternative to traditional methods of evaluation to improve program practices and

management.[42,44] Evaluability assessment reveals whether stakeholders agree on program goals and whether assumptions about the program are plausible given the resources, context, and timeline. Finally, evaluability assessment identifies programs that are unlikely to be successful in current form and those that show promise by helping to develop performance measures so the program is more likely to succeed when a more formal evaluation is done.

The Influence of Culture on Breast Cancer Screening

Breast cancer beliefs and knowledge serve as a unique cultural barrier that contributes to the low screening rates observed among Nigerian women. Culture has been shown to influence health beliefs and health-related behaviors because it influences the type of health information women have been exposed to and shapes health and illness perceptions and practices. [45,46] One significant cultural barrier is the belief that breast cancer is not a serious risk. [18,47] Other barriers related to culture, knowledge, and attitudes, such as anticipation of negative emotional reactions, stigma, family-related guilt associated with testing, fatalism, and viewing mammogram as an inconvenience or uncomfortable, could also play an important role. [9,18,47]

Cultural influences should be considered as important correlate of screening behaviors for breast cancer in order to increase screening rates among Nigerian women.[48] When addressing these barriers, culture should not be presented as a problem. Instead, preventive services should be examined within the context of the cultural environment in which these women reside. A program that is sensitive to diverse cultural perspectives will customize educational messages, identify the best person to deliver the program content and locate the most appropriate program delivery venue.[49] Residents of Lagos state include a diverse population of women based on tribe, socioeconomic status, generational and language status. A culturally sensitive program "is one that reflects shared perspectives, beliefs, practices, life experiences" [49] of the community it serves.

Objective

The purpose of this study was to: 1) describe culturally relevant factors from interviews that may be influential and deserve consideration in the OCCF breast cancer screening program and 2) perform an evaluability assessment in partnership with the OCCF to determine if the program is achieving its stated objectives and to adjust OCCF activities to improve outcomes. The PEN-3 model was used to determine if the OCCF program addresses the cultural identity and relationships and identity domains of the PEN–3 model so that cultural empowerment may be encouraged.

Conceptual Framework

The PEN-3 cultural model [50] (Figure 2-1) was developed as a thinking tool to help guide research and program interventions and provide insight and meaning about health behaviors within the context of African culture [51] and has been used to examine numerous cancer outcomes.[52–54]

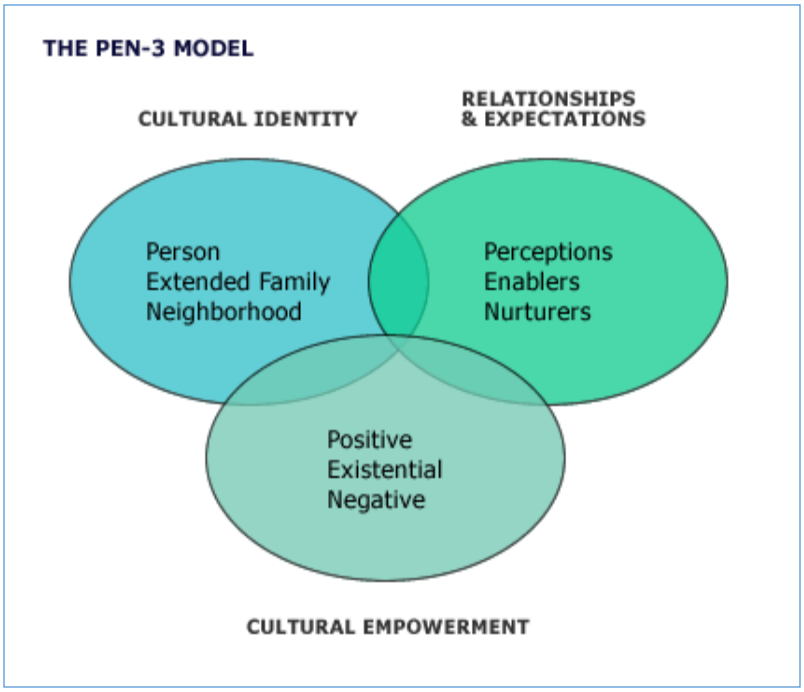


Figure 2-1. The PEN-3 Model.

The PEN-3 model addresses three domains of culture: cultural identity; relationships and expectations; and cultural empowerment. Each domain contains three specific components that influence health behaviors and form the acronym PEN: Person, Extended Family, Neighborhood (Cultural Identity Domain); Perceptions, Enablers, Nurturers (Relationships and Expectations Domain); and Positive, Existential, Negative (Cultural Empowerment Domain). [50]

The cultural identity domain allows program designers to locate potential points of implementation and potential intervention. It recognizes that interventions can take place at the person, extended family, neighborhood level. This is important to study in the African context because health decisions are often made or influenced by family units.[55] Questions related to who makes the health care decisions in the home and if women prioritize their health above the well-being of their families were asked. Therefore, OCCF might want to incorporate the family into its program design.

The relationships and expectations domain recognizes that interventions should address perceptions, enablers, and nurturers that influence the health actions of the individual, family, and neighborhood.[50] Perceptions are the knowledge, attitudes, values, and beliefs that enable or deter a change in breast cancer practices. Enablers are cultural, societal, systematic, or structural influences that may enhance or act as a barrier to change in health beliefs or practices related to breast cancer screening. Enablers include the availability of financial resources, accessibility of mammogram services, and physician referrals. Nurturers capture the extent to which health beliefs, attitudes, and actions are influenced by extended family, peers, and the community. This domain was used to categorize responses that reflect 1) individual beliefs (perceptions), e.g. specific knowledge about breast cancer risk factors, 2) societal or structural influences (enablers), e.g. a woman's ability to access breast screening, and 3) those that are influenced by close family (nurturers), e.g. Husbands/fathers knowledge of women's health issues.

The cultural empowerment domain assesses the role of breast cancer beliefs and behaviors related to the relationships and expectations domain as positive, existential or negative.[50] These factors were used to qualify responses on how they influence health behavior. Behaviors that are positive promote breast cancer screening; those that are existential are specific cultural values or beliefs that do not have harmful or beneficial effects on breast cancer screening behavior; and those that are negative are those that discourage the use of breast cancer screening.[53,56] These domains are interrelated so that perceptions, enablers, and nurturers of the individual, extended family, or community might be considered culturally positive, existential, or negative.[52]

Methods

Data Collection Procedure and Measures

The study took place at the Surulere office of OCCF in Lagos, Nigeria, in June and July 2015. The data collection process lasted approximately five weeks. The primary data sources were semi-structured interviews with program staff and participants at the clinic. The methodology used for the evaluability assessment was adapted from Wholey, (1979), who developed a model that comprised the following cyclic steps:

1. Review program documentation
2. Engage stakeholders
3. Interview stakeholders
4. Explore program reality
5. Clarify program objectives
6. Plausibility analysis

The overall purpose of this evaluability assessment was to determine if the program's objectives were measurable, whether all the stakeholders agreed on these objectives, and whether the program had the resources needed to reach program goals. Details of the methodology follow.

Review program documentation

Documents containing the mission of OCCF, description of program goals, grant proposals, application for non-government organization (NGO) status, annual report, information sheets, and education flyers were reviewed. These documents provided background information

on program activities and program goals and helped identify all major stakeholders who are affiliated with the design and implementation of the program.

Engage stakeholders

A preliminary meeting with the program director and OCCF staff identified the evaluability assessment and its procedures and addressed questions.

Interview Stakeholders

Semi-structured interviews with program stakeholders were conducted to determine program objectives, resources, and expectations. Interview questions for the program director, program staff, and patient participants are in appendices A-C.

Program staff interviews were conducted separately to encourage open discussion and to determine the extent to which consensus existed regarding the objectives of the program. They were asked questions about challenges in fulfilling their roles, program standards, implementation issues, and feasibility of the desired outcomes and program activities.

Program participants were interviewed before and after the program to gauge their levels of satisfaction with the program; identify barriers that may hinder them from being screened or understanding the seminars; issues and concerns about breast cancer in general; experiences with the medical system; traditional medicine and beliefs about breast cancer; and screening and treatment. Only women 18 and older and able to speak English or Pidgeon English were eligible to participate. Women filled out the clinic registration form and those eligible were invited to participate in the study via a verbal recruitment script and consent form (Appendix D). The study summary and objectives were described to potential participants, and a verbal agreement was

noted. Each woman was assured that her participation was not mandatory. Participants filled out a survey before screened and were interviewed in a private room after being screened. The clinic registration fee (approximately $3) was covered as compensation for participating in interviews. A convenience sample of women were interviewed until theoretical saturation had been reached, i.e. the point at which no new information was identified.[57] No personal identifiers were used as participants were given identification numbers. Data instruments were tested on a focus group of patients before the actual start of the study in order to refine questions and determine their feasibly in the setting. The following data instruments were used:

a) Survey questions at the start of the program determined each participant's knowledge in three areas: risk factors for breast cancer and common symptoms; methods of early detection and diagnosis; and attitudes and practices toward breast cancer.
b) Open-ended questions related to how the program is implemented and cultural attitudes toward breast cancer were asked after the program had been administered.

The lead author and a local volunteer at the clinic, both of whom were familiar with local language, customs, and traditions, conducted all interviews. All interviews were recorded and transcribed verbatim. Descriptive statistics were employed to assess patient demographics using Stata 14. Transcribed interviews related to participants' breast cancer screening perceptions were extracted by thematic and PEN-3 analyses using Nvivo 12. Themes relevant to each category in the PEN-3 model were examined and categorized accordingly and used to develop the logic model.

Explore program reality

The implementation of the free screening program on Friday was observed in order to gain a better understanding of issues surrounding implementation of the program and to observe any discrepancy between expected and actual program activities. During the observation period, all staff activities were noted and several patients were followed from intake up until leaving the clinic. All activities related to the free screening program were observed by the lead author and field notes were taken.

Clarify program objectives

Document review, observations and interviews were used to develop a logic model. A logic model is a graphic depiction of the activities, resources, and expectation of the program.[42] It is widely used to help design health interventions and guide program management and evaluation. The logic model was shared with the program manager for further development and revision as more information was obtained.

Perform plausibility analysis

Evidence from other successful programs, the logic model, and program activities were used to determine if program outcomes are achievable and to develop recommendations for further improvement. Details about existing breast cancer screening programs in Nigeria and elsewhere and their evaluations were reviewed to assist in the development of the final logic model and program recommendations. Programs were deemed potentially suitable if they targeted or involved low resource settings, were simple to implement, and had similar goals and outcomes as the OCCF program.

Results

Document Review

All available program documents were reviewed to determine program function and purpose. The objectives of OCCF, identified from the organization's application for non-governmental organization status, were:

1) Provide cancer screening services
2) Increase awareness of cancer in the community, highlighting the importance of regular screening
3) Assist women who cannot afford to be screened regularly or to obtain follow up treatment

OCCF offered the following services:

- Clinical breast examination
- Visual cervical cancer screening
- HPV vaccine in three doses
- Cervix polypectomy
- Cryotherapy
- Breast and cervical biopsy
- Breast scan with ultrasound technology
- Mammograms
- Lumpectomy
- Aspiration breast biopsy
- PSA test

Product services document showed that OCCF collaborates with diagnostic labs and other nearby medical facilities to provide services they do not offer such as mastectomy and chemotherapy. An interview with the program director revealed that patients were referred to either a private medical facility or public hospital, depending on what they could afford.

Financial reports and staff wage payroll showed that the resources for the organizations were limited in terms of the number services they currently provide. The program consisted of seven full-time staff, volunteers, and office supplies. The free cancer screening program is funded through private donations and payments received for services given on Monday-Thursday. OCCF has 20 large donor organizations, including Deliotte and Glaxo Smith Kline.

Patient information was maintained in Excel spreadsheets that showed the number of women screened monthly, complied into quarterly and annual statistics. An average of 200 women were seen monthly with 66% attending on Fridays and 33% on Mondays-Thursdays. The center also published information leaflets that were available for women to take home and were distributed at events or venues where large number of women gathered. Finally, the clinic disseminated information through media outlets such as Facebook and TV. and radio appearances.

An initial logic model was developed based on the results of the document review. First, logic models that have been used to develop reproductive as cancer screening programs were reviewed to determine the appropriate format. The input-activities-output-outcomes format was chosen for simplicity and an illustration on how program activities can be directly linked to program outputs. This format consists of four main components: input, activities, outputs, and outcomes and shows the relationship among long-, intermediate- and short-term desired outcomes and program activities that need to be implemented to achieve the desired outcomes. The

document review was used to fully develop the input section.

The document review identified the following potential stakeholders: the program director, Dr. Femi Olaleye; board of trustees, collaborating doctors, nurses and support staff of OCCF; staff in collaborating laboratories where tests are conducted; and patients receiving the program.

Engage Stakeholder

Ongoing interviews with the program director revealed that stakeholders varied in their degree of direct involvement in the OCCF program, activities, and power or influence to implement changes. The program manager was the only person involved in all aspects of the program and, hence, was the only one to have influence over program activities. Convenient interview times could not be arranged for the board of directors or collaborating doctors. Therefore, the manager, program staff, and patients were the only groups interviewed as part of the assessment.

Stakeholder Interview

Program Director

As determined by his interview, the program director clearly stated the program's objectives, which were consistent with program documentation. He was very knowledgeable about cancer statistics and risk factors in Nigeria, the target population of the program, and the problem the program was trying to address. He explained the main objectives as 1) improving cancer awareness in the community through health promotion activities such as education

seminars, media campaigns and outreach programs and 2) providing cancer screening and treatment services that are easily accessible and affordable to all women.

The program director explained that the program's target population for breast cancer services was women 25 and older due to the average age of breast cancer incidence and the general lack of awareness in the community. While the free screening program is available to all, it was mostly targeted toward those who were low income and would not be able to afford frequent screening due to cost. At his discretion, low-income women who could not afford treatment were given subsidies or put on a payment plan. The program director also provided details on how the program should operate weekly from the educational seminar, screening, diagnostics, treatment plans and referrals.

The program director discussed the various roles he had to fill for the running of the program. His clinical role included performing screening and diagnostic services for patients. He also had a management role in the organization, which ranged from organizing waste management to managing and training staff. He is also the chief fundraiser, and a large part of his time is spent seeking private donations from sponsors.

The program director believed the program had been successful in achieving its goals as evidenced by the growth in the number of women screened monthly and the demands of their services by organizations and groups. He explained that this program is set apart from other screening programs in Lagos State by their ability to provide evidence based information and high quality services to all women regardless of income. He was especially happy that the program was interactive with the community and was self-sustaining. Finally, OCCF hosted a Pink Ball in 2014, a gala designed to raise awareness and raise funds for the clinic. He noted that

while the gala raised 10 million naira, it cost about the same amount to host the event. Even though the gala raised awareness for the program, he will not be hosting another ball.

The program director acknowledges that is a lot of work still needs to be done in terms of increasing breast cancer awareness in the community. One of his biggest challenges is funding the program and providing services at affordable rates. For instance, the outreach programs are largely determined based on their donations. While his passion and dedication is easily observed, this comes with frustrations with managing the staff and program activities on his own. He makes all decisions regarding the program direction, and he explained that staying motivated is difficult.

The program director's hope is that the success of the program ultimately influences national policy. At the moment, cancer screening and treatment is not a priority for the Nigerian government. His long-term goal is to show the government that providing good quality cancer screening and treatment services to all women affordably is possible, hoping it would in turn set up cancer screening center in every local government (county) in Nigeria.

Clinical and Administrative Staff

The staff of OCCF is made up of three nurses, two doctors, two volunteer field workers and three administrative staff. Most of the staff had been with OCCF for at least a year. These front line staff participated in 20-45-minute in person interviews.

Program staff stated the goal of the program was to create and increase awareness of cancer screening, especially among women with low incomes and little or no education. Some staff members stated that the Nigerian government is doing little to improve cancer awareness or establishing screening centers; hence, OCCF is an important entity to fill this gap. In addition,

staff said that even among women who had some knowledge of breast cancer screening, some might be scared to be screened, not fully understand the importance of recurring screening, or see that screening is a preventive not diagnostic measure. Therefore, staff felt a secondary goal of the program was to provide comfort, care, compassion, and hope to patients receiving treatment and to follow up with patients who were due to be screened or had missed a screening appointment.

Staff duties ranged from clinical to administrative tasks. All staff members were trained to give cancer screenings but this, however, blurred the lines regarding who was responsible certain tasks. All interviewed staff members experienced some concern toward the lack of explicit guidelines on their job duties. For instance, the primary task of the medical records keeper was to enter or retrieve patient information, but her tasks could also include working at the reception desk, screening patients, or performing administrative roles at any given time.

A few staff members were aware of other places that conducted breast cancer screening, but they stated that these places were either public or private hospitals that did not specialize in cancer screening. In the public hospital, patients would be given screening appointments but could have their appointments canceled upon getting there or made to wait for hours. Successes of the program as highlighted by staff members included the high number of women currently being screened compared to the number being screened when the clinic first opened, the number of women who returned for repeat screening, the number of women who came in because they had heard of OCCF from other patients, and the increase in the number of outreach programs to which they were being invited. Finally, all staff members praised the commitment shown by the program director to ensure the success of the program and his passion for the cause.

The biggest challenge staff faced was dealing with patients who were rude or unruly during service delivery. Staff members explained that sometimes patients would become angry

for issues beyond the staff's control such as: the cost of treatment, how long they were made to wait, or the results of screening. Outreach programs were another major challenge. Staff members explained that some locations, were not adequately set up for their arrival and they would have to clean up and setup beds at the locations which was not part of their duties. This would delay the start of the outreach program, reflecting poorly on OCCF staff. Finally, program staff members felt they had no avenue to voice concerns or give suggestions or recommendations to the program director. Since the director was not present all the time, they felt they should have an avenue to voice their concerns or opinions without fear of repercussion. Some staff also explained that they would like to receive training on current cancer screening methods and guidelines.

Program Participants

Participant Characteristics

One hundred and twenty-nine women were approached to be interviewed and ninety-four interviews were conducted with a 72.8% response rate. No significant differences in demographics were between women who were or were not interviewed. The majority of those who declined the interview explained that they did not have time for the interview or were concerned about privacy. Table 1 shows the demographic distribution of women who were approached for interviews.

Table 2-1. Demographic distribution of participants.

Sample Characteristics (Total interviewed = 94)	**N (%)**
Age (years)	
Mean	35.7
Range	18-61
Education	
Less than high school/no high school	0 (0)
High school degree	23 (24.5)
Vocation training	23 (24.5)
College degree	35 (37.2)
Graduate degree	10 (10.6)
Missing	3 (3.2)
Marital status	
Single	33 (35.1)
Married	59 (62.8)
Widowed	2 (2.1)
Employment status	
Unemployed	22 (23.4)
Self-employed	30 (31.9)
Professional employment	29 (30.9)
Missing/did not answer	13 (13.8)
Religion	
Christianity	79 (85)
Islam	15 (15)

The average age of respondents was 36 (range of 18-61 years). Forty-eight percent of the women had a college or graduate degree, 24% had a high school education, and another 24% had received vocational training. Sixty-three percent of the women were married and 2% were widows. Twenty-three percent of the women were currently unemployed, 30% were self-employed, and 29% had some other professional employment. Finally, 85% were Christian and 15% were Muslim.

Pre-program survey

Eighty-three percent of the women did not know their current risk of contracting breast cancer. Thirty-three percent believed that breast cancer was a disease only common among the elderly,

while 66% believed that breast cancer could be inherited. Five percent believed that breast cancer was caused by evil spirits, while 12% were not sure if breast cancer could be caused by evil spirits. Finally, 50% of the women had never been screened for breast cancer prior to coming into OCCF.

Post program interviews

A series of open-ended questions were asked after women had been screened. These questions were analyzed in two ways. First, questions related to the programs delivery and implementation were summarized. Then the PEN-3 cultural model was used to interpret interview responses related to perceptions about breast cancer causes, prevention, and treatment within a cultural framework.

Summary of Program Responses

Most program participants heard about OCCF through word of mouth from friends, family, or colleagues or from seeing a flyer or poster of the clinic. A majority of the participants said they were happy with the way the program was implemented, the services they received, and the education seminar. Of the women who had received screening elsewhere, many were happy with the services and professionalism of the staff at OCCF, specifically highlighting: 1) the quality of service rendered being much better than any they had received, 2) the condition of the facility, noting its cleanliness, and 3) the expertise of the staff and the modern technology used. Some women also liked that the cancer center was a “one stop shop” in which they could receive screening, diagnostic, and treatment services all in the same location. They also appreciated staff effort to follow up with them when the time came for additional screening or treatment. Patients’ main criteria for selecting this screening clinic were convenience and affordability. One woman noted that if she had gone to the public hospital, she would not have been seen in a timely

manner. Finally, patients noted that the nurses were attentive and answered the questions they had. One women reported that since she did not understand English very well, it was helpful that the nurse was 'Yoruba' and could explain things in greater detail.

Patients were asked about any barriers they faced in accessing the services provided by OCCF. Some reported that Friday was not a good day to offer the program due to work, family, or religious obligations. Other reasons for not coming back for screening when due were: they had forgotten their appointment, they traveled from far away and could not make it back, or the cost of transportation back to the clinic. A few patients complained about the costs of clinic services, and this concern manifested in two ways. Some women felt the services offered were too expensive compared to other screening programs they had attended and felt they were being cheated by OCCF. However, one women said that compared to other places she had been to, the services at OCCF were actually too inexpensive, causing her to question the quality of the services.

In general, participants felt that the cleanliness of the clinic was a good indicator that the procedures at OCCF were safe, as well as staff competence. Participants offered suggestions to promote the program, such as distributing flyers in places frequented by women and placing promotional advertisements on TV and radio. Finally, even though the Friday program was free, some women were so impressed by the work OCCCF conducted that they made private donations to help pay for the treatment of low-income women.

Results of PEN-3 Analysis

Cultural Identity

The cultural identity domain examined the role of each woman, her extended family, and her neighborhood/community in health behaviors.

Most women chose to come in for screening of their own accord without external persuasion. Most heard about the screening from aunts, siblings, and other family members such as friends and church members. Some women came in because they had a specific physical aliment and wanted to be examined. However, many women said that they just wanted to know their status, which they believed was important for their health after hearing about breast cancer or after hearing information about the screening center.

Well the thought of not knowing what it is pushed me basically. (34-year-old, single)

… I decided to come because it's something I will benefit from at least to know my status on it. (59-year-old, married)

I want to live; I don't want to die from what is preventable. I want to enjoy my life. So that's why I came. (39-year-old, married)

When asked about reasons that could prevent them from coming back for their screening, many women said nothing could prevent them from coming back. Instead, their responses indicated that their family served as a source of encouragement and motivation to keep them coming in for screening in order to stay healthy. They said:

Because I don't want to die young. I have five children and I love them. Who will take care of them for me? No one. (47-year-old, married)

He [her husband] *plays a big role because when I told him about this breast cancer of a thing he said it is better for one to go and check. I said 'but I don't think I have it so it's not necessary,' but he said 'no, God forbid; you won't have it, but it's better for one to go and check.' (42-year-old, married)*

Mixed responses were received when women were asked if they thought men should be involved in the breast cancer conversation. Some women felt it was not important because breast cancer did not affect men and more efforts should be placed on increasing awareness among women. Others felt it is would just be awkward talking to men about it.

…not really that important. If we can discuss it among ourselves, then…men don't really have too much [of a] *role to play in it. (21-year-old, single)*

Not all men. Maybe a man that you think can help you. But not ordinary men. (41-year-old, married)

Well if you have it, you should talk to your husband. But if you don't have it…why should you talk about it. (51-year-old, married)

Others felt discussing breast cancer with men was very important in order to increase awareness of the breast cancer in the general population as a whole, pointing out that some women do not work or leave the house.

> *Yeah. So that they* [men] *will be conscious of it* [breast cancer]. *In case if their wife is not aware of that, they will be able to educate them on that. Get them to go for screening. (35-year-old, married)*

> *…because men definitely have moms, sisters, their friends, wives. They always have female members in their lives. (50- year-old, married)*

> *Yes. Women; they think less of themselves. When a man is aware, it's like he will push you to like …go and …just like my husband...I was like I'm just feeling pain and …he said you have to go you just have to go because he is aware. (30-year-old, married)*

Another woman said it would be more important for men to know this information so they can offer support to their wives and understand what they have to go through if diagnosed. She recounted a story of her best friend with breast cancer and how that affected her marriage.

> *…when she discovered she had breast cancer, she was getting tired easily, you know. She was going through chemo. But her husband still expected her to be cooking, to be taking care of him, to do all the things she was doing before… the things expected of a wife...she was on a very high stress level. She had her baby and she was still doing everything for*

her big baby, husband, because the woman is expected to do and do and keeping doing everything despite being sick or whatever she is going through. When she couldn't do, he couldn't understand that it's not like she's being lazy…they are separated. He couldn't deal with the fact that this woman is sick. And now she has to take care of herself and her baby by herself. (39-year-old, married)

Relationships and Expectations

Perceptions

Overall, women believed that breast cancer was a serious disease, but there was variation in what they thought caused the disease and how it could be treated. The responses received indicated that many women knew that breast cancer could be inherited, while others blamed current dietary choices.

I think it's what we are eating because, at times, we don't even eat balanced diet …you find out that people just eat pastries…there's no time to cook or eat vegetables. (42-year-old, married)

These days, most of the food we are eating are chemicalized food. Our mothers in the village, there is nothing like fertilizer to plant food. But now you see mothers carrying chemicals to go and plants vegetables. (47-year-old, married)

Many women mentioned canned, tinned, and preserved food in particular.

Well based on what I read, I don't know if it's true, but they said it's junk food, fatty food, canned whatever whatever. That's what I read online. *(4- year-old, married)*

Based on what I have heard sometimes on TV, they say... I don't know but some say canned food; some say carbonated drinks. I don't know. (27-year-old, single)

Others blamed women's behavior or lifestyle choices.

Smoking…when you smoke, you drink. (38-year-old, married)

It could be lack of taking note of your body. As we are entering Internet age, something like x-rays. It can be not taking care of your body as a lady, washing properly. (26-year-old, single)

Having the naira [local currency] *note in the bra could cause it. That's what I have heard. Because the people that have breast cancer are older women. And you see them in the market; all these women that have the note in their bra and they have been doing it for years. Also I have heard wearing dirty bra or you know when you first buy bra or undies you have to wash them well. Not doing that can maybe cause breast cancer. (28-year-old, single)*

And others blamed spiritual forces as the cause.

...people have said maybe an attack, spiritual attacks. I don't know. (41-year-old, married)

…And even if a woman eventually dies, someone may say that it is the gods that took her away or maybe her mother-in-law or her husband's girlfriend or first wife or something like that. (26-year-old, single)

A 33–year-old married woman discussed her sister in law, showing how these superstitions can affect behavior.

My sister-in-law has breast cancer….she had lumps. She went to the hospital, and they operated on her. But it (the lump) *came back. And she is afraid of going for the second operation. She said that someone told her that it's a spiritual thing and that if she goes for the operation she will die. We have been telling her to go for the operation. That it is better for her now that it is in the early stage before it will spread all over the breast. She is still there and she has not gone for the operation. (33-year-old, married)*

Fear and fatalism emerged as a notable theme in this domain. This was captured as fear of receiving a positive breast cancer diagnosis and fatalism was associated with treatment.

Women are afraid…they are really scared that… when they go, they will be tested positive, so they don't want that. (35-year-old, married)

There are some women… they believe that when one starts having discharge [from the breast]*, they feel it's abnormal. And so they hide it and not tell anybody. (26-year-old, single)*

They don't want to hear they have it. Some people… if they tell them that they have cancer, naturally, they think they are dead because they will be thinking that 'ah anybody that has cancer is going to die, whether they treat it or not. They are going to die.' (45-year-old, married)

Many women felt that a diagnosis of breast cancer meant death or that a mastectomy was the only way to treat breast cancer once diagnosed.

I just feel like the ultimate decision to treat yourself is just to cut it [the breast] *off. You know or death. There's no other option. (32-year-old, single)*

At the earlier stage of lumps, it can be operated. But after is death. (33-year-old, married)

I have heard they have to cut off the breast. That's the only way. (23-year-old, single)

A few women expressed concerns about the quality of life after a mastectomy, such as would their husbands leave them or would they feel like less of a woman. A young woman discussed her mother's battle with breast cancer. She had brought her mother into the clinic eight months before.

She did a mammogram, and when they brought the results, they said she had to do a biopsy. She spoke to some people who said they will cut off her breast. So she got scared and said she wasn't doing it. She said 'how can I lose my breast; it's like I might as well just die.' By the time she finally agreed to go to the hospital, even before treatment started, she died... The thing that kills people with breast cancer is fear because it happened with my mom. She was afraid she wouldn't be a woman if they cut off the breast. 'What will people say; how will I live...' (20-year-old, single)

With this fear, though, some women expressed the importance of faith. Faith can help cope with fear, if diagnosed.

You know, I believe in God, and I believe that even if I have it, I will be cured. (23-year-old, single)

I believe in God, and I know God has the final say. If something is going to kill someone, it will. But as human beings, you just want to do your own part so that you will know that it is not because of negligence that someone has befallen you. (32-year-old, married)

Women's perceptions and behaviors were also influenced by religion, God, and the power of prayer. Some women felt they could be healed with prayer and God; hence, conventional treatment is not needed. Other felt that because of their faith, God would not let them become sick.

I have heard of churches where a member comes and gives testimony. They say that they used to have breast cancer and the doctors said they have to cut off their breast, but thank God after prayer … they are now free of cancer. (28-year-old, single)

…some people believe as long as they have God and they are righteous in everything, they should not have any sickness. No sickness shall befall them. (33-year-old, married)

Many women retold anecdotes of responses from people they had tried to encourage to undergo screening. These people felt that because they were religious and spiritual, they were not at risk for breast cancer and going for screening would invite the disease.

…my sister, I told her I was coming today. She said 'and you call yourself Christian, but you are going to do check up in the hospital'... (50-year-old, married)

… if you mention it [screening] *in church and to our women's group and they say 'ahh you don't have faith, let's pray about it, it is not our portion in Jesus name.' And they believe if you go to the screening, you are inviting the alignment. (39- year-old, married)*

A colleague of mine, she is a church person…And I said to her that 'oh I heard that there is a free screening for women' and she said to me 'really! Cancer! You said that to me. God forbid.' That was what she said. And I never said that to her. That's just one person.

I could name like four or five that I have had such experiences with. (39-year-old, married)

A 50-year-old who was the women's leader in her church where her husband was the pastor had invited one of the doctors at the clinic to speak to the congregation.

...after the doctor left us, a number of people complained. They said that if the church can be bringing such thing (someone to talk about cancer screening), *that they don't have power. That we should be able to pray that things should not happen. I had to go around and tell them that thing is not like that. It's God that's given them knowledge. If I have not told them, they would not have come. Out of those people that I went around to; it was five that came. And after that 'I don't have money to deal with this.' And 'in the first place you shouldn't have brought me here'. They would have preferred not to know because now they have to look for money. There is one woman [*and] *her own is advanced, but she is not too bothered. Her breast is so big but all she is doing is praying. We in the church are brainstorming on how to raise money to bring her here. To even bring her, it's like you are dragging a horse to drink water. And it is not her money. (50-year-old, married)*

The final theme that emerged was the lack of preventive medicine culture in the community, and for some women, their health may not be their priority. Most women only had contact with the health care system during pregnancy or delivery or in relation to their children being ill or being vaccinated.

…you know, most women are too concerned about a lot of things except their health. They think of a 1,001 things, but the last thing they think of is themselves… (30-year-old, married)

We don't have that culture of let's go for screening for prevention. We only go to the hospital when something is wrong. (43-year-old, married)

They think about other priorities, and most women tend to put themselves as last. Sacrificially every, other person comes first. It is just our way. (39-year-old, married)

Enablers

Enablers include the availability of financial resources, accessibility of mammograms, and physician referrals. Not surprising, the most common barriers were the cost associated with cancer screening, the cost of transportation, the opportunity cost of going to the screening center, and the location of the screening center.

Some people feel they don't have the money to spend on such. (26-year-old, single)

How many people can afford it? What are the alternatives? Who has 2,000 to spend on breast screening that can feed my children? That can make a pot of soup. (39-year-old, married)

Another barrier mentioned was lack of awareness of breast cancer in general, the

importance of screening, breast cancer facilities, and the services offered by the screening center.

> *... 80% of women are not aware of the importance of the screening and, secondly, they do not know the effect of not getting the screening. Or they do not know the side effects of having the cancer without treating it on time. (21-year-old, single)*

> *... lack of exposure. They are not well enlightened. That opportunity is not there. How I first heard... it was because of I was opportune to be in that church program. And I now notice that I am having something like pain, and I decide to follow it up. Let's say I did not go; I will be going...not knowing that I have something in me that needs attention. At least ...I think it is lack of enlightenment and lack of exposure. (37-year-old, married)*

Societal stigma emerged in this category. Being ill is generally looked down upon, and some women thought about what people in the community would say or do after diagnosis and treatment.

> *... I might feel stigmatized. ...when they see you in a hospital, they automatically think something is wrong with you. (43-year-old, married)*

> *... when you are going for ...like when you tell someone you are going for vaccine for cervical they say, 'ah god forbid oo do you have it?' because the awareness is not there. They always believe that anytime you are going for something, you already have it. (32-year-old, married)*

> *…don't want to be looked on as a bad person or like that I go around* [have sex] *with many people. Because this thing that I saw today made me feel like I have not been taking care of myself or I am this kind of girl that is loud* [flirtatious]. *(58-year-old, married)*

Many women discussed the influence of cultural beliefs and traditional medicine.

> *Most of them think it cannot happen to them because you think it may not happen to their family or it is a disease for white women. (19-year-old, single)*

> *Some traditional aspect of it, they believe maybe if something happens to me, it is somebody that throw it* [a spell] *to me. (35-year-old, married)*

> *…I was in a neighborhood somewhere in Sango, and a woman just died of breast cancer, and all they could say was that it was an 'ofa' it was an arrow, evil arrow, that the arrow was fired to her breast. And this is a group of women, they are semi illiterate. And I started to lecture them that look it is not an 'ofa,' they said yes it is. (50-year-old, married)*

Others discussed a preference for traditional medicine over conventional medicine. Traditional medical could be in the form of herbal treatments or in the form of spells.

You know when you go to hospital, they will charge you a large amount of money. Some prefer using herbs and anything else that would cut costs. (53-year-old, widow)

Like in my area, Ajah, you have this belief that it can never happen to them. So they believe if you take one or two concoction [herbal medicine]*, everything will be ok and you will not be affected by anything. (42-year-old, married)*

… some people will say its spiritual attack. When they see the symptoms they start casting and binding [casting out demons with prayers]. *(30-year-old, married)*

When asked about breast cancer treatment, one women said,

I believe that those that are spiritual with prayers can be cured, and that is God. The others I don't know. Maybe from operation. (38-year-old, married)

Finally, women discussed using a combination of prayer and conventional medicine i.e. having faith in the power of God but still doing what they can in terms of treatment.

I think it's important for women to be more knowledgeable about the screening …religion is important but to understand what cancer is and what everything is all about is important, too. Sometimes even if prayer can heal you, you have to take actions to help yourself. (19-year-old, single)

Nurturers

Husbands or male heads of household emerged as a strong influence but with mixed responses. When asked, all married women said their husbands would not prevent them from receiving screening services. Some said their husbands had been supportive through the process.

> *He is very supportive. When I am sick, he takes over house duties. I don't have to cook; he takes care of everything. Me, the children. He is good because I know men are not like that. (50-year-old, married)*

> *He is very supportive, and he encourages me… when I was coming today, I was very nervous. He just hugged me and said it will be fine. You know men are stronger than women. He held me and just prayed, and I was ok. (36-year-old, married)*

Other women felt their husbands would not be supportive. A 39-year-old married women said she did not and would not tell her husband she was coming from screening regardless of the results.

> *…because if I say I need to check this out, the next thing I hear is 'you have too much money' or 'you just want to cause a problem were there isn't one. You are not sick, why would you go'… Even for my male friends, I won't tell them I have come for this screening because some become religious or philosophical about it, saying 'you don't trust God, you are looking for a problem when there's no problem…' (39-year-old, married)*

Religious influence emerged once again in both a supportive and obstructive role. A woman talked about how influential religious leaders could be in informing women about the benefits of screening.

> *If pastors will talk about it and tell them to go for screening. If they make it ...the way they ask for donation…maybe the awareness will be more. If only religious people church, mosque can talk about it…when there are gathering of women ...then focus the attention on breast cancer. It will appeal to them …church they will not miss. Mosque they will not miss. If the pastor will say, 'my wife has already gone' or the imam will say 'my daughter and wife has been there, they were saved because of the screening'; it will go a long way. (50-year-old, married)*

Other women gave examples of how organized religion can also be obstructive.

> *There are some churches that do not believe in hospitals, treatment, no matter how sick the person is. They feel that it's just to pray, and it will be well. Pray and faith. (28-year-old, single)*

> *There are some that …we don't think that you can have this kind of disease, and since you don't accept it, you don't have any business with screening. (42-year-old, married)*

The final theme that emerged in this domain was how important it was for women to discuss breast cancer with each other to motivate and encourage each other to go for screening.

There are so many people that might wish to go for the screening. They may be feeling reluctant about it. But when you see other women talking about it, telling you it's not really expensive, you know and you see that they have gone to do it …you will be gingered to go and do it. (38-year-old, married)

Some women may be shy; maybe they don't want to come and talk about it maybe with other men, but you know if you talk to each other, and discuss with each other it is easier for them to open up to each other in that way. (19-year-old, married)

Cultural Empowerment

Table 2-2 shows the results of cultural empowerment analysis. Religion was the most prominent theme across all categories. The influence of religion and cultural beliefs among Nigerian women was observed to have a positive influence for some women in helping women cope with the realities of a positive diagnosis. For others, that same level of faith and belief prevented them from seeking screening and may be considered harmful in this model. Some women saw no influence of their religion on their health behavior at all. Likewise, the role of the husband was primarily seen as positive in the provision of emotional support and money but also observed to be neutral in its effect on screening behavior.

Table 2-2. Categorizing themes by cultural empowerment and relationships & expectations.

	Positive	Existential	Negative
Perceptions	Belief that breast cancer is a serious disease Involving men in the breast cancer discussions Faith in God to help cope with fear	Involving men in the breast cancer discussions	Low awareness of breast cancer screening centers, causes, and treatment Superstitions beliefs Fear of positive diagnosis Fatalism associated with treatment Power of prayer to prevent illness Lack of preventive medicine culture Loss of femininity after mastectomy
Enablers	Availability of traditional/conventional medicine	Faith in God	Cost associated with screening Loss of work time associated with going to screening center Location of the screening center Stigma associated with treatment
Nurturers	Role of husband and family Religious institutions Support from other women	Role of husband Religious institutions	Religious institutions

Explore Program Reality

Every Friday, OCCF hosts free breast and cervical cancer screening and conducts a seminar by the doctor or nurse at the clinic. The health seminar occurred first around 9 a.m. and again at 1 p.m. at the clinic. The seminar consists of a breast and cervical cancer overview, guidelines regarding screening, signs, symptoms, and risk factors. Women were also taught how to perform self-breast exams. The administration manager is the first point of contact when people walked into the clinic. Patients were given clinic registration forms and a screening information leaflet that explained what would happen during the screening. Returning patients were asked to see the records officer to collect their file and update personal information if needed. New patients filled out detailed medical history forms and then were referred to a doctor or nurse for screening. A breast and cervical exam was then conducted and any abnormalities were discussed and explained to patients. In addition, the nurse or doctor went over the content from the seminar, ensuring patients understood what was said and answered any follow-up questions. A treatment or diagnostic plan was discussed with the patient if necessary. Patients were also given clinic cards with an ID number and the date of their next screening. Patients rarely had their clinic card with them when they returned.

The program was implemented as designed and explained by the program director. However, examination of the program activities indicated that the duties of the staff were not well defined and were wide ranging. For instance, the administration manager who also acted as the receptionist might be called away to open the store cupboard to get supplies, make payment for a delivery, or attend to other matters that would require that she leave the reception area. In these cases, the records keeper would be asked to act as the receptionist, requiring the records keeper to go back and forth from receiving patients at the reception and registering new patients to performing her primary duties and retrieving and updating patient files. In addition, having only

one doctor at the screening sessions was problematic. While nurses could screen patients, diagnosis and scanning could only be done by the doctor. On other occasions, the doctor would be called back and forth between patient screening rooms.

OCCF also conducted outreach services in one of two ways. The first is by invitation whereby a church, company or organization such as bank branch invited and paid OCCF to provide screening services to women and to conduct health talks. The second was by OCCF reaching out to women in places they usually gather, such as large local markets or trading centers. These outreach activities were conducted all over Nigeria. On average, OCCF conducts one outreach activity per week.

Clarify Program Objectives

Based on the preceding steps, the initial logic model was revised. Field notes taken during the observation of the program were used to develop the activities section of the logic model. Program activities were directly linked to program goals and objectives. Goals or objectives that could not be measured and could not be directly linked to an activity were revised.

Two follow-up unstructured interviews were held with the program director to determine how his perception of the program differed from the model and to clarify all components. Recommendations suggested during these follow up interviews included strategies to (i) identify activities that needed more program staff, (ii) clarify program objectives and set reasonable short, medium and long term goals and outcomes, (iii) show the relationship between desired outcomes and program activities, and (iv) identify operationalizable benchmarks to measure success. The director reviewed the logic model and his feedback was incorporated into the final version.

Perform Plausibility Analysis

Based on reviews of program documents, interviews, program observations and review of the literature, recommendations and a final logic model were developed. This final model clarified program goals and objectives, highlighted necessary inputs and identified program activities necessary to meet short- and long-term goals. Table 2-3 shows the final logic model.

The program purpose and objectives were appropriate as stated for the cancer screening facility. However, the objectives were too general and not easily measurable. In the development of the logic model, formal goals and objectives were developed with the program director. Furthermore, the content analysis of stakeholder interviews was used to identify common goals, expectations, and challenges among staff members.

The inputs include the staff OCCF currently employs and the clinic from which the program operates. The program activities were conceptualized as: (i) education and skill development seminars targeting women on breast cancer symptoms and screening, (ii) free screening events once a week targeted to all women, and (iii) outreach activities to women. The assumptions underlying the success of program activities are shown as outputs and outcomes. The final logic model framework positioned long-term desired outcomes at the far right of the diagram to emphasize that desired outcomes are determine by program activities through outputs. These outcomes capture what the program hopes to change in target population.

Short term outcomes highlight changes in attitudes, behaviors and knowledge of breast cancer screening related activities and can be directly tied to the intervention. The short-term outcomes given in Table 2-3 are measured at the end of the program activities or soon after the program has finished. Medium term outcomes describes any changes in behavior or decision making in the target population based on the program activities. Medium outcomes are measured

within several months after the end of the program. Long term outcomes describe any changes in population status that the program hopes to achieve and are measured a year or several years after program completion. These outcomes can be less directly attributed to the program.

Increasing awareness of cancer knowledge in the community is depicted as a longer-term desired outcome, whereas knowledge about the program within the target groups and women being able to conduct self-breast exams is shown as a shorter-term desired outcome. These outcomes are influenced by the program outputs. For an illustration, some underlying assumptions of the program are:

- In order to reduce mortality and increase survival rate of breast cancer, breast cancer needs to be diagnosed in early stages.
- In order for breast cancer to be diagnosed in early stages, women will need to adhere to screening guidelines.
- In order for women to adhere to screening guidelines, women need to be initially screened for breast cancer screening and given a follow-up plan.

Finally, benchmarks on how to measure success of each activity are provided in the model. These include conducting brief surveys during each visit and keeping detailed records of women who come back for screening at the prescribed time.

Table 2-3. The final logic model.

Inputs →	Activities →	Outputs	Outcomes: Short	How to measure success	Outcomes: Medium	How to measure success	Outcomes: Long
Buildings Equipment Website Educational Pamphlets Staff Program director One medical doctor Two full-time nurses 2 part-time nurses 2 office administrators 1 medical records officer Volunteer field workers	Conduct seminars/class on breast, cervical, prostate cancer risk factors, causes, symptoms, screening and treatment.	Breast and cervical cancer awareness seminars offered to community in each location Provide information about screening guidelines Show how to conduct self-breast exam	Women are aware of the risks, causes and symptoms of breast/cervical cancer Women will know how and how often screening should be done Women will be able to conduct self-breast exams	Survey during repeat screening	Women who attend the seminars more empowered and have the tools needed to reduce their risk of breast/cervical cancer Increase awareness about breast cancer screening centers in the community OCCF serves as resource for information	Track number of new patients	Increase breast/cervical cancer knowledge in the community
	Conduct (subsidized on Fridays) clinical breast and cervical exam. Provide clinical breast exam, scans and mammograms.	Women will be aware of breast cancer status and given follow-up plan	Women will follow up with treatment and adhere to screening guidelines	Improve recurring screening for each women (Screening recall)	Breast cancer caught in early stages	Number of breast/cervical cancer cases diagnose	Shift stage of diagnosis Reduce mortality/Increase survival rate
	Conduct surveys	Measure cancer knowledge	Track/measure the influence of seminar on awareness and knowledge	Document improvement among score per woman			

		Local outreach to community women, religious groups, businesses, clubs organizations about breast/cervical cancer. Seminars and screening services offered		Women will follow up with treatment and adhere to screening guidelines Women who cannot come to clinic will have mobile access to services	Women will follow up with treatment and adhere to screening guidelines Information/knowledge about OOCF will increase by word of mouth/social media	Improve recurring screening for each women (Screening recall) Track number of referrals from past clients using "how new patients heard about OCCF?"	Increase community participation.	Percentage increase in the number of women attending the classes Number of community linkages (to promote overall goal) established	Funding from local partners due to impact Attention from Nigerian government
		Media outreach (social media, TV, radio, newspapers)		More women come to OCCF for screening, treatment and information after hearing about it from media outlets	Knowledge of OOCF will improve by word of mouth/social media	Track the number of new patients as a result of media outreach using "how new patients heard about OCCF?"	Increase community participation.	Percentage increase in the number of women attending the classes Number of community linkages (to promote overall goal) established	Funding from local partners due to impact Attention from Nigerian government

Discussion

Early detection of breast cancer through regular screening plays a vital role in reducing breast cancer mortality.[58] Interventions that increase women's breast cancer knowledge and change negative beliefs associated with decreased screening can lead to improved screening rates in this population. Understanding why people do or do not use health resources is important for the success of public health interventions. This study analyzed patient interviews with the PEN-3 cultural model to gain a better understanding of the context in which a breast cancer screening program exists and operates in Lagos, Nigeria. Analyzing responses using the PEN-3 model aided in categorizing themes that emerged from the qualitative data into meaningful and discrete domains. This analysis could help program designers at OCCF identify and target vulnerable populations and tailor program activities to the needs of the population it serves.

The qualitative analyses of patient interviews revealed that religion was the most prominent theme observed across all domains, confirming results from other studies showing the importance of religion and spirituality in influencing health decisions among Black communities[59] and how this influence is complex.[60] Health behavior and decisions made by many women were strongly influenced by the teachings of religion, and the words of its leaders were deeply valued. Notably, participants were predominantly Christians and described experiences in their church; others speculated about the influence of Islam. Despite what these women said, the few Muslim women interviewed did not mention religion as influencing their decisions to seek any medical treatment, including breast cancer screening.

Religion was also seen to act as a barrier to screening. Some of the women who decided to come to the clinic were ridiculed and labeled as unfaithful. This belief or faith in God

somehow removed the personal responsibility of each woman to actively seek screening,[61] contradicting the goals of many breast cancer screening programs that promote early detection. This observation suggests that if women do not believe they have control of their own destinies, they may be reluctant to go for screening.[52] Furthermore, if people do not believe they are susceptible to a disease, they may be unwilling to seek preventive health services.[62]

The effect of traditional beliefs also manifested in participant thoughts on causes of breast cancer and treatment sought. Illnesses were often diagnosed according to superstitious beliefs, and these beliefs drove treatment choices. [39,63,64] Many believed that breast cancer was caused by evil spirits, curses, or promiscuity, hence only leaving a spiritual solution. Other studies found that distrust of Western medicine was also responsible for the health decisions made by African [65] and African American women.[66] Health care system distrust was not mentioned by any woman in this study, even though those who preferred traditional medicine in the form of herbs or spells did so because of their thoughts on the implicit causes of breast cancer.

Previous studies have observed the influence of family and community on health and health behavior studies using the PEN-3 to study in the African context since health decisions are often made or influenced by family units.[55] Participants in the study indicated that their husbands were mostly positive or neutral. Husbands were a primary source of support and comfort for many women, as well the financial provides. Furthermore, health decisions were, for the most part, made by the wife or as a couple. Even though many women explained that it was not important for men to be informed about breast cancer, some noted that increasing the level of awareness in the general population would be beneficial in general. Additionally, the few women who thought their husband's role did not influence their decision were gainfully employed and had their own means of financial support. All respondents thought it was important for women to talk to each other about breast cancer, to act as a reliable source of information for women who may not be aware, and to act as a support system and motivator for each other. Social support has

been shown to reduce risk of depression, [67] produce higher levels of health-promoting behavior,[68] and lead to a better prognosis after breast cancer treatment.[69] However, since men are more likely to be exposed to mass media, such as television, newspapers and radio, than women,[70] secondary efforts should also focus on workplaces and mass media outlets where information reaches both men and women.

Program Recommendations

The OCCF screening program consists of education and service delivery components aimed at increasing awareness of breast cancer in the community and providing an access point for affordable screening, diagnosis, and treatment. Overall, the evaluability assessment found that the program's goals were realistic and measurable. However, the program's objectives needed to be clarified further and specific program activities needed to be linked to short- and long- term goals. Based on the findings from these studies, the following recommendations are offered to improve OCCF's program.

1) Staff interviews revealed that the programs components and goals need to be clarified to all staff members. Staff members are in general agreement that the overall goal of the OCCF program is to provide cancer screening services and improve awareness of breast cancer in the community. However, the mechanism through which program activities lead to these goals needs to be explained to all involved with the program, highlighting the important role each person plays in achieving those goals. The passion and dedication of the program director was observed by all staff and it is important to ensure staff are equally motivated so they are able to withstand challenges. This can be achieved by showing them how vital they are to the success of the program.

2) Review of OCCF background documents shows that the program needs to develop benchmarks to measure outputs and outcomes from the logic model. Benchmarks could be developed from a brief survey of women's knowledge each time they come in for screening and what effect, if any, the program had on their lives. A program monitoring system could also be put in place that gathers and summarizes patient information, creating a profile of women attending seminars, services utilized, and staff workload. In addition to information on the number of women screened per month, knowing how many of those women return for repeat screening is important. Finally, a program service or treatment protocol needs to be developed that details what should happen when patients attend the program. This protocol could be as simple as a checklist to ensure accurate and consistent implementation.

3) Observation of the program reality showed that the heath education seminars were helpful in improving knowledge among women, but some participants did not fully understand seminar content. The educational seminar should be carefully examined to determine if the issue is with the content or the method of delivery and redesigned to better meet the needs of the community. It is important to include relevant factors reflecting cultural attitudes in the process of obtaining breast cancer screening services that are salient to the population. Patients should be made aware of the dangers of trusting in faith healers and non-medical professionals when it comes to cancer screening and receiving medical treatments in general. This awareness could be better established through more collaboration with religious leaders in the community to show a joint show of force in fighting cancer. Screening barriers mentioned by patients included transportation to OCCF and limited hours and days the clinic offers the program. Hence,

the availability and accessibility of the program needs to be carefully examined. Perhaps working with women in the community on alternative approaches to delivering the program could be helpful. Finally, outreach education programs should also target men. Men played an important role in some women's perceptions and uptake of health care services. Education programs that target or include men will not only increase awareness in the community in general, but men may be more likely to show emotional and financial support to the women in their lives and encourage them to go for screening.

4) Content analysis of staff interviews showed that issues related to staff concerns need attention. First, staff members need to be given clear instructions on the duties they are to perform as part of the program to help prevent confusion as to what tasks each person is supposed to do and when they are to perform them. Second, an avenue for staff to voice concerns or make suggestions about the program to senior management needs to be created. This could take the form of an anonymous monthly evaluation form or a staff suggestion box. Third, staff training seminars or workshops are needed. The number one challenge raised by staff was dealing with rude or unhappy patients. Hence, training should cover health education techniques and customer service training. Finally a staff meeting should be held at least once a month.

5) In order to keep service provision efficient, more staff need to be hired, possibly on a part-time basis, to relive the burden placed by the current small numbers. As more demands are made for OCCF services, current staff levels will not be sufficient to sustain growth. To help guide this process, an organizational chart should be created, showing current staff and their roles. Next, staffing gaps that need to be filled should be identified

and highlighted in the chart to help show how the program needs to grow and will prioritize staffing needs.

6) Finally, it is recommended that a process evaluation be conducted once such an evaluation is deemed worthwhile, benchmarks have been put in place, the program goals have been explained to all staff members, and the program monitoring system has been put in place. An evaluation is helpful to document the progress of the program and if it is meeting the needs of its target population.

The result of this study should be interpreted in light of some limitations. The convenience sample used in this study limits generalizability of the results to women in other areas of Nigeria. This study was conducted in a large city in Lagos State, and the demographic distribution of the sample was different from that of the rest of the country. For example, 52% of women interviewed had more than a high school education compared to the national average of just under 10% of women.[70] The participants were those who were at a screening clinic and, hence, had some awareness or knowledge about the importance of breast cancer screening. Furthermore, different cultural and environmental factors in other geographic areas will need to be examined. Finally, the majority of respondents were in their 30s and 40s, meaning that perceptions from older women were not well represented in this sample.

Conclusion

A document review, stakeholder interviews, and program observation were performed to revise a breast cancer screening and health promotion program. A logic model based on the program priorities was developed, which diagrammatically describes the program. Investing time

to consult program participants and stakeholders to incorporate their priorities yielded a more comprehensive logic model, which provides a realistic program plan that is reasonable to monitor and evaluate.

This study specifically highlighted the social contexts that influence screening and the cultural context driving participation in the program. Often in Nigeria, illnesses are diagnosed according to superstitious beliefs, and these beliefs drive treatment choices.[39,63,64] Interviewing women provided insight into social and historical barriers that influence screening decisions, which is particularly important for women living in a region with limited resources and competing health care needs. The success of the screening program is also dependent on increasing its demand by increasing breast cancer awareness in the community. Therefore, this project allowed programmers to understand how best to disseminate educational information. Through better understanding of traditions, these strategies are likely to help change health behaviors of these women.

The project was also important for the sustainability of the program in Lagos by examining the objectives and resources of OCCFs breast cancer screening program to determine if its expectations are realistic and achievable. The recommendations provided information on areas for improvement and explained steps to alter the program to reach its goals and provide measureable outcomes. In addition, the project provided meaningful benchmarks of the program's successes, which can be used by the foundation to apply for funding grants, ensuring the program's sustainability and perhaps garnering the attention of the Nigerian government. The revised culturally appropriate program could serve as a template to be used in similar settings across Nigeria and Africa for other screening programs.

Chapter 3

The Association Of Chronic Diseases And Mammography Among Medicare Beneficiaries Living In Appalachia

Background

Appalachia is a large and diverse region of the United States, and its residents often have worse health characteristics than the rest of the country.[71,72] The region has a higher cancer mortality rate compared to other regions, resulting in cancer-related health disparities.[72] Its residents tend to be older, poorer, less educated, and more likely to be uninsured. They also exercise less, have poorer diets, are more obese, and consequently suffer higher rates of disease and disability than those in non-Appalachian regions.[21,71,73] The prevalence of chronic diseases among this region's rural residents is higher compared to urban counterparts,[73–75] and the presence of one or more chronic diseases may make receipt of cancer screening more complex for these residents.

Mammograms are a cost effective method of detecting breast cancer early and reducing mortality from the disease.[9] When people are diagnosed at earlier stages, treatment success and survivorship rates are high.[11] The United States Prevention Services Task Force (USPSTF) recommends that women who are 50-75 years old and have average risk for breast cancer should receive a mammogram every two years. [12] Other cancer organizations, such as the American Cancer Society (ACS), have kept the previous screening recommendation of an annual mammogram, which is beginning at age 40 for average-risk women. [13] Screening recommendations for high-risk women include annual mammograms beginning at age 30. [14] Furthermore, women at moderate risk are advised to discuss the timing for beginning routine mammograms and the frequency of receiving mammograms with their physicians. [14,15]

Despite these guidelines, a substantial number of women eligible for screening are still not receiving routine mammograms.[76,77] Medicare provides health insurance coverage for eligible individuals 65 and older, and Medicare Part B covers most preventive services.[78] Mammography has been covered under the Medicare program since 1991,[79] and women over 65 make up a third of all mammograms conducted each year. [80] Even in this insured population, preventive services use, including mammogram receipt, is low.[20,79] According to the American Cancer Society (2009), only 64% of women age 65 years and older received a mammogram consistent with recommended guidelines.[81]

Previous studies have identified a number of factors that predict lower rates of mammography use among the elderly. Minority women, women with less education, those not having a usual source of care, or those in poverty are all less likely to receive a mamogram.[82–84] Physicians' role in screening practices has also been shown to be important, especially among older patients.[85] Women reported being unaware of the advantages of mammogram or were not advised to obtain a mammograms by their physician.[85] Availability of transportation, distance from metropolitan areas, a limited number of health care visits, a lack of related physician recommendations, and fewer available health care professionals have all been cited as barriers to cancer screening in Appalcahia.[21,86–88] Finally, access to health insurance and race/ethnicity have been associated with variation in receiving appropriate cancer screening, especially in Appalachia. [88,82]

About half of U.S. adults have at least one chronic disease[89,90] while 25% have two or more chronic conditions. [91,92] Ninety percent of those age 65 and older have at least one chronic condition.[89,93,94] Similar to preventive services, challenges to accessing chronic disease care are widespread in rural areas due to limited numbers of health care specialists and transportation barriers.[73,75] Research on the association of between chronic disease and cancer screening have produced mixed results. Some studies have shown a negative association between the presence

of chronic diseases and cancer screening. [11,95–99] Beckman et al. (2001) examined women who received primary care services at a multispecialty group practice and found that women with diabetes were less likely to have had a mammogram within the past year compared to women without diabetes after controlling for insurance status and race.[11] Lipscombe et al. (2005) found a similar result in a retrospective cohort study of Canadian women. They showed that women with diabetes had significantly fewer mammograms (with the previous two years) than those without diabetes even if the diabetic woman visited a primary care physician several times during the year. [96] Kiefe et al. (1998) examined women who received care at two primary care clinics to examine whether chronic diseases acted as a barrier to breast and cervical cancer screening. Their results suggest that women are screened less frequently for breast cancer and cervical cancer as their burden of chronic disease increases.[97] Liu et al. (2014) also found that an increase in the number of chronic conditions was associated with decreased breast, cervical, and colorectal screening rates in a population in two rural Oregon communities.[98]

Several hypothesized mechanisms could lead to decreased cancer screening in patients with chronic diseases. Patients with chronic disease may face increased time constraints with physicians or complicated disease management care[100] and, therefore, be more vulnerable to receiving inadequate preventive care.[97] Physicians themselves maybe less likely to recommend cancer screening for elderly patients or those they believe would not have shortened life expectancy due to cancer.[96,101] Patients may also not value cancer screening for that same reason.[11,95,96] Finally, cancer screening may compete with chronic disease management in terms of resources and attention.[97]

On the other hand, some studies found that the presence of chronic diseases was associated with compliance with cancer screening guidelines.[97–99,102–106] In a population based study, Bostick et al. (1994) found that having a chronic condition was associated with having had a pap smear and clinical breast exam.[103] In the same study, women with chronic disease

conditions were more likely to have received a mammogram within the past two years compared to those without a chronic disease.[103] Yasmeen et al. (2011) found an increased uptake in mammography among women with more than three chronic diseases.[105] Fleming et al. (2011) examined the relationship between multiple chronic diseases and the prevalence of colorectal screening among residents in Appalachian Kentucky and found that individuals with more chronic diseases were more likely to have received colorectal screening.[106] More frequent clinic visits and a greater amount of time spent with a physicians could be responsible for observed cancer screening compliance in patients with chronic diseases.[98,103]

These conflicting results may be due to the different study settings, geographic locations, and time periods, during which recommendations for breast cancer screening and awareness about the disease changed. Age is also an important consideration. The 65 and older age group is the fastest growing segment of the U.S. population,[107] and cancer screening decreases with increasing patient age.[102,108] This subgroup of women also has the highest rate of comorbidity.[97] Although an extensive body of literature exists on the determinants of breast cancer screening, little is known about how the presence of chronic disease affects screening behavior, especially among people with elevated cancer mortality risk and comorbidity, such as those living in Appalachia.

Objectives

The objective of this study is to examine the associations between the number and prevalence of chronic health conditions and having received a mammogram according to screening guidelines among older women in four Appalachian states. This study focused on receipt of a mammogram within a single time period and geographic location and specifically examined the impact of 16 different chronic conditions on being up to date for breast cancer

screening. while adjusting for potential confounders. Insurance status and race may act as barriers to preventive care;[109,110] hence, this study examines Medicare beneficiaries in a region that is predominantly non-Hispanic Whites, and race is included as a control variable. This study addresses the following research questions: a) is the presence of a chronic disease after controlling for other correlates of breast cancer screening independently associated with having received a mammogram? and b) is the number of chronic conditions after controlling for other correlates of breast cancer screening independently associated with having received a mammogram?

The increasing older adult population, the escalating rate of chronic disease in the Appalachian region, and the unresolved relation between chronic disease care and cancers screening enhance the significance of this focus. Previous studies have used a combined comorbidity index[97] or focused on a specific diseases.[11,96] The strengths of this study include the focus on both individual and number of chronic diseases, as well as the analysis of population-based data obtained from cancer registries from four states.

Conceptual Framework

The conceptual framework used in this study is presented in Figure 3-1.

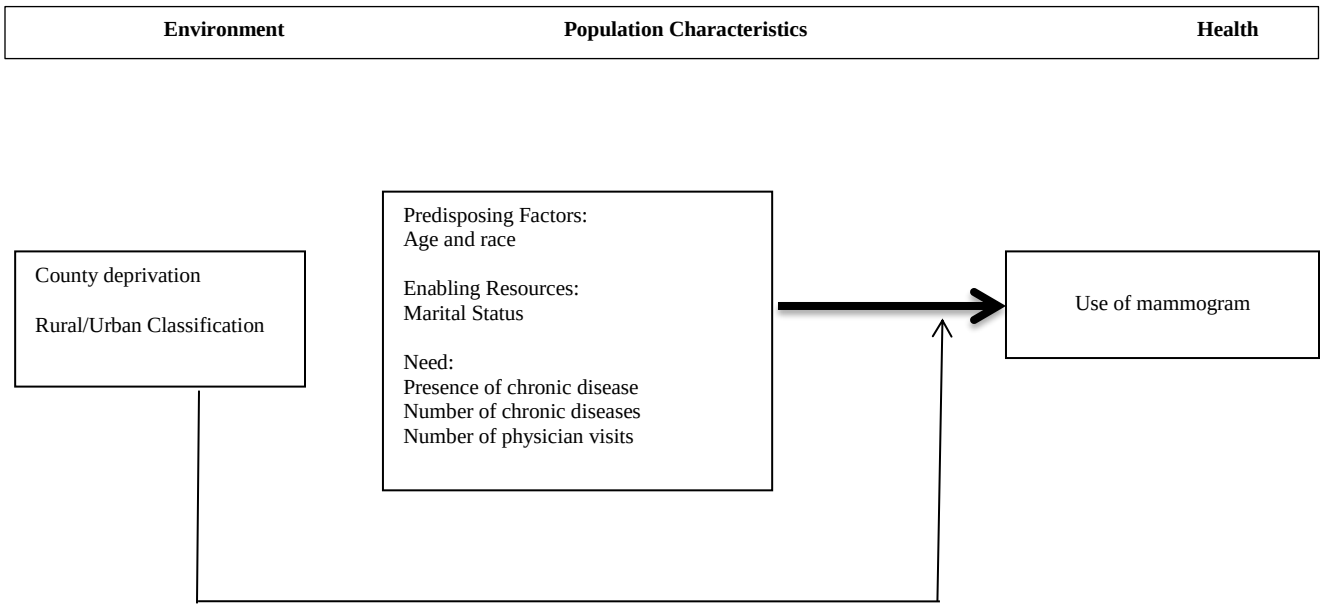


Figure 3-1. Conceptual framework adapted from the Andersen Health care Utilization Model.

The framework is adapted from the Andersen Health care Utilization Model[111]and demonstrates how chronic disease status could influence mammography use. The framework suggests that participation in breast cancer screening is a function of predisposing and enabling factors and treatment needs. Predisposing variables are demographic factors that influence a woman's propensity to use mammograms. Findings regarding the relationship between age and breast cancer screening have been mixed. [48] Some studies show that older women are more likely to participate in breast cancer screening due to their increased risk of breast cancer. Others conclude the opposite since older, women are perceived to be in poor health status. Race has been shown to be major predictor of breast cancer screening among minority women being screened at lower rates than non-Hispanic whites.[24] Enabling variables are economic and social resources that

enhance or impede participation in breast cancer screening. [111] Married women are more likely to participate in breast cancer screening because they are more likely to have family support.[112] Need characteristics capture self-perceived health status. Here, it is captured by the number of physician visits and the presence of and number of chronic diseases. The arrows shown in the conceptual model reflect those under investigation in this study.

Methods

Data

Data from cancer registries in four Appalachian states, Kentucky, Ohio, Pennsylvania, and North Carolina, were analyzed to identify women diagnosed with breast cancer from 2006-2008 and living in Appalachian counties as defined by the Appalachian Regional Commission (ARC). Patients were linked to Medicare fee for service files available from the Center for Medicare and Medicaid Services for 2005-2009 using patient identifiers. Patient information was also geocoded and linked to the Area Resource File (2007-2009). A total of 3,306 women were included in the sample.

Sample

Women 65 and older, having a positive breast cancer diagnostic histology, cytology, or microscopic confirmation (excluding autopsies) were included in the study sample. Only women who could be linked to Medicare data and were enrolled at least two years prior to and one year after diagnosis were included. Respondents were also restricted to those with a first ever diagnosed breast cancer tumor. Women with multiple or concurrent tumor, mismatched gender

and birth dates, and without complete Medicare Parts A and B insurance, or with some managed care (e.g., health maintenance organization) coverage during the 24 month period before and including the month of cancer diagnosis were excluded.

Measures

The outcome variable of interest was breast cancer screening (BCS) adherence. Women were examined for compliance with mammography guidelines prior to their breast cancer diagnosis. Adherence to breast cancer screening was based on 2009 U.S. Preventive Services Task Force (USPSTF) guidelines,[12] and women were categorized as adherent to mammography screening if they reported having a mammogram in the previous two years. A 90-day to 24-month window prior to breast cancer diagnosis was used to classify prior use of mammography.[113] The 90-day restriction was put in place to reduce the chances that diagnostic mammograms would be erroneously counted as screening mammograms.

The primary independent variable included the presence of one of the following chronic conditions: arthritis, musculoskeletal disease, degenerative joint disease, asthma, emphysema, chronic obstructive pulmonary disease, chronic lung disease, cardiovascular disease, hypertension, chronic digestive disease, chronic pain, low-back pain, diabetes mellitus, depression, anxiety, and substance abuse. These variables were identified from diagnostic codes in Medicare data from the two-year period prior to breast cancer diagnosis. Each chronic condition was coded as a binary variable (1=condition present, 0=condition absent) and categorized to 0, 1-2, 3-4, and 5+ number of chronic diseases.

Other patient factors known to influence breast cancer screening were included as covariates.

- Demographic variables*:* Race was categorized as either non-Hispanic White or non-White. Marital status was coded as single or married. Age was included as a continuous variable in multivariate analyses.
- Health care access and utilization variables: The number of visits to a primary care provider (PCP) in the previous year was included as an indicator of medical need.
- Environmental variables: County level economic statutes defined by 2009 Appalachian Regional Commission (ARC) were included. The index used the three-year average unemployment rate, per capita income, and poverty rate to create five levels of county deprivation: distressed, at risk, transitional, competitive, and attainment.[114] No county in this study was at the attainment level during study time window. In addition, counties were categorized based on rurality as determined by the USDA rural/urban continuum code.[115] Finally, state of residence at the time of diagnosis was also included to control for unmeasured differences among states.

Analyses

Descriptive statistics were estimated to examine the characteristics of the study sample. Bivariate analyses examined the associations among BCS adherence, chronic diseases, and the covariates representing sample characteristics. Multiple logistic regression models were used to determine the association between BCS adherence and 1) the presence of a chronic disease and 2) the number of chronic diseases present. In each regression model, each independent variable was entered to obtain the unadjusted estimate on mammography. Next, each set of covariates were sequentially added to the model to develop a logistic regression model for each independent

variable. The fully adjusted models examined the unique associations of the independent variables and BCS adherence after controlling for each set of covariates. All analyses were carried out using Stata 14.

Results

Table 3-1 shows the characteristics of the sample and results of bivariate tests of associations among the independent variables, covariates, and BCS adherence. The mean age of women in the sample was 76 years with a minimum of 65 and a maximum of 99 years (not shown). Ninety-seven percent of the sample was non-Hispanic White and a little over half of the sample lived in Pennsylvania at the time of diagnosis. About half of the sample (50.2%) had received a preventive mammogram before being diagnosed with breast cancer, while nearly 16 percent of the sample had no chronic disease. The percentage of women who adhered to BCS was higher among those 70–74 and 75–79 years than among younger or older women. More than half (59 %) of women had 1 or 2 chronic diseases; 19% had 3 or 4 chronic diseases, and 6% of women had 5 or more chronic diseases. Having a mammogram within the past two years was associated with having at least one chronic disease, having one or two chronic diseases, being married, having seen a physician within the past two years, and living in a transit county.

Table 3-1. Characteristics of sample by breast cancer screening status

	Received Timely Mammogram					
	No		Yes		Total	
	No.	%	No.	%	No.	%
Total sample	1646	49.79	1660	50.21	3306	100
Presence of chronic disease						
No	291	17.68	227	13.67	518	15.67
Yes	1,355	82.32	1,433	86.33	2,788	84.33
Total	1,646	100	1,660	100	3,306	100
Pearson chi2(1) = 10.0304 Pr = 0.002						
Number of chronic diseases						
0	291	17.68	227	13.67	518	15.67
1-2	896	54.43	1,058	63.73	1,954	59.10
3-4	335	20.35	286	17.23	621	18.78
5+	124	7.53	89	5.36	213	6.44
Total	1,646	100	1,660	100	3,306	100
Pearson chi2(3) = 30.8970 Pr = 0.000						
Age category						
65-69	288	17.50	318	19.16	606	18.33
70-74	390	23.69	479	28.86	869	26.29
75-79	360	21.87	414	24.94	774	23.41
80-84	347	21.08	319	19.22	666	20.15
85+	261	15.86	130	7.83	391	11.83
Total	1,646	100	1,660	100	3,306	100
Pearson chi2(4) = 59.3766 Pr = 0.000						
Race/ethnicity						
Non-Hispanic White	1,595	96.90	1,607	96.81	3,202	96.85
Not White	51	3.09	53	3.19	104	3.14
Total	1,646	100	1,660	100	3,306	100
Pearson chi2(4) = 3.6370 Pr = 0.457						
Marital status						
Single	962	60.24	815	50.37	1,777	55.27
Married	635	39.76	803	49.63	1,438	44.73
Total	1,597	100	1,618	100	3,215	100

Pearson chi2(1) = 31.6518 Pr = 0.000						
Number of primary care visits in previous two years						
0	152	9.23	19	1.14	171	5.17
1-4	337	20.47	204	12.29	541	16.36
5-10	537	32.62	656	39.52	1,193	36.09
11 +	620	37.67	781	47.05	1,401	42.38
Total	1,646	100	1,660	100	3,306	100
Pearson chi2(3) = 166.4569 Pr = 0.000						
State of residence at diagnosis						
KY	204	12.39	149	8.98	353	10.68
NC	297	18.04	354	21.33	651	19.69
OH	313	19.02	300	18.07	613	18.54
PA	832	50.55	857	51.63	1,689	51.09
Total	1,646	100	1,660	100	3,306	100
Pearson chi2(3) = 14.1469 Pr = 0.003						
Rural/urban category						
Metro	915	55.59	903	54.40	1,818	54.99
Urban	642	39.00	676	40.72	1,318	39.87
Rural	89	5.41	81	4.88	170	5.14
Total	1,646	100	1,660	100	3,306	100
Pearson chi2(2) = 1.2735 Pr = 0.529						
ARC class						
Completive	335	20.35	296	17.83	631	19.09
Transit	1,004	61.00	1,127	67.89	2,131	64.46
At-Risk	171	10.39	136	8.19	307	9.29
Distress	136	8.26	101	6.08	237	7.17
Total	1,646	100	1,660	100	3,306	100
Pearson chi2(3) = 18.6100 Pr = 0.000						

Table 3-2 shows the association between having a chronic disease and BCS adherence, estimated in four models. In the unadjusted model, the presence of a chronic disease was associated with BCS adherence. Women with at least one chronic disease had 35% (CI: 1.122-1.637) higher odds of BCS adherence compared to women who did not have a chronic disease. This significance level remained (OR: 1.40, CI: 1.159-1.696) in the presence of county level variables (model 2), but with the addition of demographic variables (model 3), the coefficient for chronic disease was no longer statistically significant. In the fully adjusted model (model 4), having a chronic disease was not a strong predictor for BCS adherence. The number of PCP visits was a strong predictor of BCS adherence, and the strength of the association increased as the number of PCP visits increased. Being married also increased that odds of BCS adherence (OR 1.29, CI: 1.066-1.450). Finally, the odds of BCS adherence decreased with increasing patient age.

Table 3-3 shows the association between number of chronic diseases and breast cancer screening adherence. The unadjusted model showed that having one or two chronic diseases was associated with an increased likelihood of BCS adherence (OR: 1.51, CI: 1.25-1.84). This significance remained when country level variables were added to the model (model 2). When demographic variables were added to models 3 and 4, women with more than three chronic diseases were less likely to adhere to BCS guidelines. Model 4 shows that women with 3-4 chronic conditions had odds that were 33% (CI: 0.51,0.88) lower than the reference group to adhere to BCS guidelines, while women with 5 or more chronic diseases had odds that were 41% (CI: 0.42,0.86) lower. As in the previously analyses, BCS adherence decreased with increasing patient age, whereas being married (OR: 1.24, CI: 1.07, 1.45) and an increasing number of doctor visits was associated with greater BCS adherence.

Table 3-2. Logistic regression showing association between the presence of a chronic disease and having received timely mammogram.

	Model 1	Model 2	Model 3	Model 4
The presence of at least one chronic disease (ref=none)				
	1.356**	1.402***	0.938	0.976
	[1.122,1.637]	[1.159,1.696]	[0.756,1.165]	[0.784,1.214]
Urban/rural (ref=metro)				
Urban		1.145		1.135
		[0.973,1.348]		[0.956,1.349]
Rural		1.191		1.313
		[0.821,1.727]		[0.873,1.975]
ARC class (ref=Competitive)				
Transit		1.236*		1.1846
		[1.020,1.499]		[0.969,1.452]
At-risk		0.872		0.833
		[0.626,1.214]		[0.586,1.184]
Distress		0.928		0.979
		[0.593,1.453]		[0.606,1.582]
State (ref=PA)				
NC		1.217*		1.074
		[1.010,1.467]		[0.881,1.310]
OH		0.940		0.854
		[0.771,1.146]		[0.693,1.052]
KY		0.776		0.705
		[0.559,1.076]		[0.495,1.006]
Age			0.965***	0.956***
			[0.946,0.968]	[0.945,0.968]
Race				
Non-White (ref=white)			1.071	1.170
			[0.750,1.737]	[0.764,1.791]
Marital status				
Married (ref=single)			1.319**	1.269**
			[1.102,1.495]	[1.089,1.479]
Number of primary care visits in previous two years (ref=0)				
1-4			4.590***	4.452***
			[2.737,7.698]	[2.650,7.478]
5-10			10.76***	10.42***
			[6.483,17.85]	[6.270,17.33]
11+			11.24***	10.82***
			[6.765,18.66]	[6.502,18.00]

Exponentiated coefficients; 95% confidence intervals in brackets
* p<0.05, ** p<0.01, *** p<0.001

Table 3-3. Logistic regression showing association between numbers of chronic diseases and having received timely mammogram

	Model 1	Model 2	Model 3	Model 4
The number of chronic diseases (ref=0)				
1-2	1.514***	1.556***	1.055	1.090
	[1.245,1.840]	[1.279,1.894]	[0.846,1.315]	[0.872,1.361]
3-4	1.094	1.131	0.644**	0.669**
	[0.866,1.384]	[0.893,1.433]	[0.492,0.843]	[0.510,0.878]
5+	0.920	0.971	0.559**	0.597**
	[0.666,1.271]	[0.701,1.345]	[0.390,0.802]	[0.415,0.859]
Urban/rural (ref=metro)				
Urban		1.145		1.134
		[0.972,1.349]		[0.953,1.348]
Rural		1.181		1.311
		[0.813,1.715]		[0.870,1.976]
ARC Class (ref=Competitive)				
Transit		1.235*		1.188
		[1.018,1.498]		[0.969,1.456]
At-risk		0.856		0.829
		[0.614,1.193]		[0.582,1.179]
Distress		0.917		0.975
		[0.585,1.437]		[0.602,1.579]
State (ref=PA)				
NC		1.199		1.045
		[0.994,1.445]		[0.856,1.276]
OH		0.963		0.871
		[0.789,1.175]		[0.707,1.074]
KY		0.793		0.724
		[0.571,1.102]		[0.506,1.035]
Age			0.958***	0.957***
			[0.947,0.970]	[0.946,0.969]
Race				
Non-White (ref=white)			1.078	1.087
			[0.762,1.773]	[0.781,1.838]
Marital status				
Married (ref=single)			1.255***	1.243**
			[1.077,1.463]	[1.066,1.450]
Number of primary care visits in previous two years (ref=0)				
1-4			4.532***	4.421***
			[2.703,7.600]	[2.633,7.426]
5-10			10.80***	10.53***
			[6.510,17.91]	[6.336,17.50]
11+			12.90***	12.45***
			[7.751,21.47]	[7.464,20.76]

Exponentiated coefficients; 95% confidence intervals in brackets
* p<0.05, ** p<0.01, *** p<0.001

Discussion

This study aimed to determine the relationship between the presence and number of chronic diseases and BCS adherence among Medicare beneficiaries who reside in Kentucky, Pennsylvania, North Carolina and Ohio. By controlling for factors known to predict breast cancer screening, results from this study highlight the presence of multiple chronic diseases as an additional barrier preventing elderly women from adhering to clearly beneficial screening recommendations. Half of the sample was being screened for breast cancer. Screenings rates of 50% are low given that this population of women have health insurance that covers mammograms.[82,83] In addition, 84 % of the sample reported the presence of at least one chronic disease, highlighting the importance of considering preventive services when patients are managing chronic conditions.

An association between the presence of a chronic disease and BCS adherence was not observed. However, adherence to breast cancer screening was inversely related to the number of chronic diseases, whereby women with three or more conditions had half the odds of having guideline-concordant screening compared to those without a chronic condition after controlling for socio-demographic, health, and county characteristics. These results confirm previous findings that having several chronic diseases presents a barrier to achieving guideline-concordant mammography screening.[11,98,116] Other studies have found that higher burden of chronic diseases was associated with increased rates of late stage cancer diagnosis,[114] further highlighting the importance of preventive screening for patients managing chronic diseases. Breast cancer screening strategies can be aimed specifically at increasing the number of screenings among vulnerable individuals who do not have a regular medical provider for the treatment of chronic conditions.

This study also found that women with more primary care visits were more likely to adhere to BCS guidelines. Since people with more chronic disease, theoretically, have more contact with health care providers throughout the year than those without chronic diseases,[103] our results would have been expected to show that women with more chronic diseases were also more likely to be screened. There are several possible explanations for this discrepancy. Yasmeen et al, 2011 found that life-threatening or difficult to control chronic conditions were associated with increased uptake of screening mammography while non life-threating conditions were associated with decreased uptake of screening mammography. This suggests that the type of chronic disease or the severity of each condition may have an indirect influence on screening adherence and not just the presence of a chronic disease. Future studies will need to consider if the presence of certain chronic condition or the severity of a disease predicts the number of provider visits. Another possible explanation is that Appalachian women with more chronic diseases are less likely to visit a primary care provider. Appalachia is an underserved region with a relative shortage of primary care providers.[117] Having a chronic disease may further act as barrier that prevents women from seeking care from a provider due to lack of accessibility or high cost of care.[75]

To investigate these points further, the study sample was stratified by number of primary care provider visits and the relationship between the presence, and number of chronic diseases was re-examined (Table 3-4). Among women with no primary care visits, those with a chronic disease were more likely to adhere to BCS guidelines. This effect grew stronger as the number of chronic diseases present increased. Women in the category with the highest number of primary care visits (11 or more) were less likely to adhere to BCS guidelines implying that among women with chronic diseases, those without primary care provider visits adhere to BCS guidelines indicates while those with primary care visits did not adhere to BCS guidelines. Despite having more PCP visits, some women may not follow through with cancer screening recommendations.

Alternatively, women without a regular primary care provider may rely more on urgent treatment centers, public health clinics, or emergency rooms for treatment for chronic conditions, and women do not always need a referral from a primary care provider to receive a mammogram. Reynold et al. found that some woman refer themselves for mammograms without a physician recommendation.[118] Flemming et al. 2011 found that among three of the major health insurers in Kentucky, only one of them required a mammogram referral from a doctor. In many cases, once an initial screening was conducted, subsequent appointments could be made at the screening center by the patient.[119] In addition, various local health departments offer free breast cancer services to those who are uninsured and less likely to have a usual source of care. [119]

Table 3-4. Logistic regression showing association between the presence- and number of chronic diseases and having received timely mammogram within each PCP category.

	Model 1 No PCP visits	Model 2 1-4 PCP visits	Model 3 5-10 PCP visits	Model 4 11+ PCP visits
The presence of at least one chronic disease (ref= none)				
	7.725**	1.142	1.029	0.444***
	[2.036,29.31]	[0.769,1.697]	[0.719,1.474]	[0.276,0.715]
The number of chronic diseases (ref=0)				
1-2	7.010**	1.261	1.152	0.523**
	[1.785,27.52]	[0.844,1.884]	[0.801,1.657]	[0.322,0.851]
3-4	27.02*	0.415	0.647	0.375***
	[1.518,480.8]	[0.168,1.021]	[0.405,1.034]	[0.226,0.619]
5+	18.35*	0.944	0.440	0.327***
	[1.034,325.6]	[0.157,5.662]	[0.191,1.014]	[0.186,0.574]

Exponentiated coefficients; 95% confidence intervals in brackets
* p<0.05, ** p<0.01, *** p<0.001

These findings are not consistent with other studies that show the level of rurality and county level economic status act as a barrier to seeking health services among Appalachian residents. The observed associations seem to be explained by the individual level factors, race, marital status, and primary care visits rather than the county level variables included. One

possible explanation is that chronic disease management is enough to overcome geographic barriers and leads women to seek care wherever they are, despite living in remote regions.

These results should be interpreted with a few limitations. As previously stated, an indicator for the severity of each chronic disease was not included. Future studies could use this variable to assess each woman's probability of death from non–breast cancer causes or their risk of developing breast cancer and the possible influence that would have on screening decisions. Half of the women sampled were from Pennsylvanian counties. The level of heterogeneity within the Appalachian region and the fact that the sample was largely non-Hispanic White implies these results may not be generalizable to other parts of Appalachia or the rest of the country. Finally, the screening interval used to determine adherence to screening guidelines may be different in different parts of the states analyzed and does not necessarily represent long-term screening patterns for individuals resulting in misclassification between screening and diagnostic mammograms.

Despite these limitations, this study has several strengths. It uses claims data and not self-reported use of mammograms or chronic disease diagnosis. This improves validity since self-reported information about cancer screening practices may differ from actual practice as individuals tend to over report their use of screening.[116] Having a homogenous sample served as an advantage as lack of health insurance, screening costs and race/ethnicity have been found to be barriers for preventive services for women living in Appalachia. Results from this study may also help identify underserved, elderly populations that are under-screened for breast cancer based on health status yet face the highest rates of diseases. It may be important for specific age groups to be targeted for screening interventions especially those without a usual source of care; an important driver of screening.[114] Finally, having a physician recommendation is an important predictor of breast cancer screening utilization among women, even with regular visits.[120] Therefore, physicians need to be aware of any conscious or unconscious bias they may have

toward screening recommendations for women with chronic conditions and also to understand barriers preventing women from following through with screening.

Chapter 4

Breast Cancer Screening and Health Care System Distrust by Race and Nativity in Philadelphia

Background

The benefits of cancer screening has not reached all women in the United States.[121] In 2015, 22 million foreign-born women were living in the U.S.[122] and despite its known benefits, the use of mammograms among immigrants remains significantly low.[123] The 2013 National Health Interview Survey (NHIS) showed that 69% of all women in the recommended age bracket reported receiving a mammogram and the rates of screening among minority women were similar to White non-Hispanic women (black/African American=70%, White =69%, American Indian/Alaska Native= 61%, Asian= 69%, Hispanic=64%).[123] However, foreign-born women in the United States reported consistently lower rates of mammography screening compared to U.S.-born women. In the same NHIS, 38% of recent immigrants reported receiving a mammogram. [124] Although the Healthy People 2010 goal of eliminating disparities in mammography screening among Blacks versus non-Hispanic whites has been achieved, equitable access to cancer screening remains a problem for immigrant women. [125] Furthermore, Black and Hispanic women continue to be diagnosed with advanced breast cancer at higher rates compared with Whites.[126] In order to increase screening rates in all women, relevant factors that act as barriers need to be identified. Therefore, identifying factors that prevent women from receiving breast cancer screening is an important health goal.

Socio-demographic and health access factors, both of which disproportionally affect immigrants and minority women, have been shown to act as barriers to cancer screening.[9,18,47,127]

Specific factors related to mammogram screening decisions in these populations include English proficiency and citizenship status; health insurance; and usual source of care, income, education, and age. [9,16–18,128–130] Use of mammograms is in part determined by a woman's individual perception of the health care system. Hence, another potential barrier to breast cancer screening uptake may be distrust of the health care system.[131,132]

The U.S. health care system is vast and complex and a bad experience with one sector might have left women with negative feelings toward the entire system. Poor, disenfranchised women may have had more negative experiences with physicians, nurses, hospitals, and insurance providers.[127,133] Furthermore, immigrants may not have received the resources necessary to navigate the health care system, or undocumented immigrants may not seek health care services for themselves or their children to avoid detection or deportation.[130] Also, racial minorities may have been discriminated against and treated poorly by medical personnel[66] or believe they received inadequate or inappropriate medical treatment because of their race or a combination of race and class.[134] Phillips et al. (2000) showed that compared to non-Hispanic Whites, Hispanics were more likely to believe their medical provider failed to listen to their issues, did not provide them with enough necessary information, and experience longer wait times.[135] Van Ryn and Burke (2000) found that physician perceptions of patients were highly influenced by race, where Black patients were viewed more negatively than White patients.[134] This, coupled with the history of mistreatment and medical experimentation on Blacks in America, such as the Tuskegee Experiment, has reduced the confidence of people of color in the health care system. [66]

Distrust has a negative influence on health-seeking behavior in any population. It has been associated with lower adherence to treatment recommendations,[136] delays in seeking care,[137] reduced participation in clinical trials,[138] reduced acceptability of health care institutions,[139] lower patient and provider satisfaction,[140] and increased disenrollment from care,[141] all which indirectly

contribute to and lower health outcomes. A small number of studies have examined the effect of distrust in preventive services utilization among immigrants and minority populations. Jones and Wenzel (2005) found that African-American men with prostate cancer refused treatment due to their distrust with providers. Studies in Baltimore[142] and Philadelphia[143] found that distrust of providers and the health care system prevented men from receiving prostate cancer screening. Distrust led to more time since last mammogram among women in a West Coast city[120] and caused low utilization of breast cancer screening services among Black women in DC[144] and Philadelphia.[145] Understanding predictors of patient trust and how they impact the use of preventive services is useful because a decline in patient trust may lead to lower attainment of necessary services in these population.

Objective

Having a physician recommendation is an important predictor of breast cancer screening utilization.[120] Hence, trust, as an important aspect of the patient–provider relationship,[137] is important to understand as it relates to screening uptake. It is reasonable to assume that women with a high sense of health care distrust may believe receiving a mammogram is unnecessary. Women with high distrust may also be reluctant to seek preventive screening or be discouraged from talking about regular screening.[120] Data is limited regarding the influence of patient trust on use of preventive services, particularly among vulnerable women. Therefore, the purpose of this paper is to examine whether foreign-born and racial minority women living in southeast Pennsylvania exhibit a higher level of health system distrust compared to other groups. This study further adds to the breast cancer screening literature by examining a) the importance of health system distrust in breast cancer screening guideline adherence among women after controlling for socio-demographic and health resources variables, such as usual source of care and having health

insurance, and b) how any association of health system distrust and mammography adherence varied within each nativity and racial group.

Conceptual Framework

The conceptual framework used in this study is presented in Figure 4-1. The framework is adapted from the Health Behavior Model (HBM),[146] a theoretical model developed to understand how individual decisions are related to the use of health care services. It is used to demonstrate how women's perceptions of the health care system, in this case relating to distrust, are associated with the likelihood of health actions to prevent breast cancer i.e. mammography adherence.

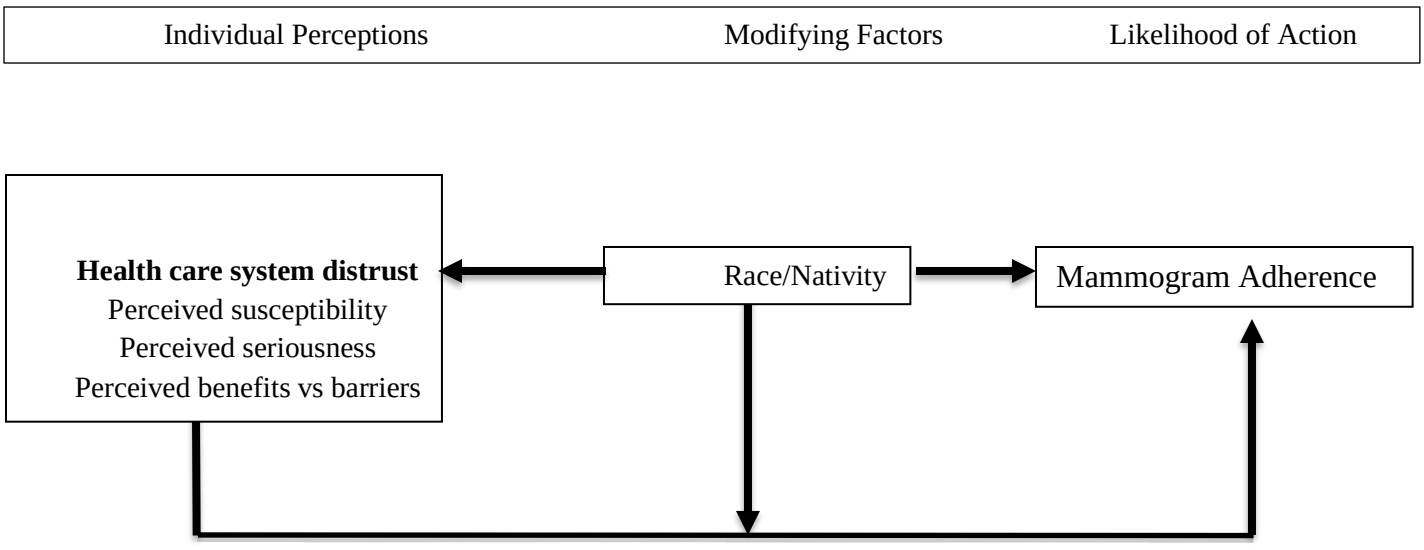


Figure 4-1. Conceptual framework adapted from the Health Behavior Model

In this model, a high distrust of the health care system as it relates to mammography may be affected by low-perceived susceptibility and seriousness (i.e., women believe their risk of

developing breast cancer is low), low-perceived benefits (i.e., positive outcomes from breast cancer screening is low), and high perceived barriers (i.e., many obstacles to getting screened). Health care system distrust may also influence the likelihood of action differently by race and nativity of the individual. Breast cancer screening uptake is also a function of factors that mediate the effects of health systems distrust:

- Age: Older women may be more likely to participate in breast cancer screening due to their increased risk of breast cancer or less likely due to poor health status and competing health needs.
- Marital Status: Married women may be more likely to participate in breast cancer screening because they are more likely to have family support
- Socioeconomic Status (SES) – level of education, poverty and employment status: The higher a woman's SES, the more likely she is to have the means to participate in breast cancer screening and be more aware of breast cancer risk
- Health Care Resources (usual source of care and insurance status): Women who have more access to health care resources may be more likely to participate in breast cancer screening because they have the means to undergo screening, as well as benefit from a usual care provider to recommend screening

Methods

Data and sample

This study uses data from the Philadelphia Health Management Corporation's (PHMC) 2008 Southeastern Pennsylvania Household Health Survey. The survey collects information on health behaviors, health status, and health care access of adult and child residents in five

Pennsylvania counties in the Philadelphia metro area.[147] These counties are Bucks, Chester, Delaware, Montgomery and Philadelphia. The survey also collects information on socioeconomic status and demographic information on respondents and is representative of the people in the survey area. The PHMC is the most comprehensive health survey for people in this area and has been conducted biannually since 1983. The 2008 survey includes many questions that have been administered and tested in national and local health surveys, including items from instruments developed by organizations such as the National Center for Health Statistics (NCHS) and The Behavioral Risk Factor Surveillance System (BRFSS). The 2008 PHMC was conducted through telephone (landline and cellphone) interviews with people 18 and older living in 10,000 households in southeastern Pennsylvania. All interviews were conducted over the phone in English or Spanish, depending on participant preference.

Adult respondents were selected for interviews using the last birthday method. In households with more than one eligible adult, the adult who last had a birthday was selected as the adult respondent. Two types of weights were given in the PHMC dataset, balancing weight and projection weight.[147] Although percentages can be calculated using counts obtained by applying either weight, the sample size based on the balancing weight was used because it preserves the actual sample size and causes the data to appear less random by adjusting over- and underrepresented demographic sectors. All adult women in the sample were used to examine the influence of nativity and race on the level of health system distrust (n=4825). Only women 40 years and older were asked if they had received a mammogram. Hence, for the remaining analysis, only those 40 years or older were included (n=3524).

Measures

The main outcome variable of interest was mammogram guideline adherence. Women

were asked: “About how long has it been since you last had a mammogram?” Responses were categorized as “One year or less,” “More than one year—up to 2 years,” “More than 2 years—up to 5 years,” “More than 5 years—up to 10 years,” “More than 10 years,” and “Never.” At the time the survey was fielded, the U.S. Preventive Services Task Force (USPSTF) recommended women over 40 received a screening mammography, every 1-2 years.[148] The American Cancer Society recommends screening women 40 and over every year.[149] Due to these recommendations, the adherence variable used in this study was created as a binary outcome from which women who received a mammogram within the last two years were coded as 1 (yes) and women who did not as 0 (no).

Distrust variables were created from nine questions asked in the survey. The items asked were “health care system does its best to make patient’s health better,” “the health care system covers up its mistakes,” “patients receive high quality medical care from the health care system, the health care system makes too many mistakes,” “the health care system puts making money above patients’ needs,” “the health care system gives excellent medical care,” “patients get the same medical treatment from the health care system, no matter what the patients’ race or ethnicity,” “the health care system lies to make money,” and “the health care system experiments on patients without them knowing.” Responses to these questions were given on a Likert scale. This health system distrust scale was developed by Shea et al. (2008) and has been used in other studies that investigate the influence of health system distrust on health services utilization. [21] Shea and colleagues identified two dimensions of health care system distrust from the question items namely; competence and values distrust. The competence dimension identified respondents thoughts surrounding the health care system’s ability to improve patients health while the values dimension examined thoughts around the health care system’s truthfulness and equity in provision of services.[150] Factor analysis using varimax rotation method was used to generate

scores for these dimensions of distrust. Factor analysis weighs each question to give scales. The resulting eigenvalues was 3.94 for the values dimension, and 1.06 for the competence dimension; the total variance explained by the two dimensions was 55.6% of the nine items. Each item was categorized into one of the two dimensions when its factor loading score was higher than 0.5 for that dimension and less than 0.5 for the other dimension. Table 4-1 shows the results of the factor analysis of the nine items.

Table 4-1. Factor loadings with varimax rotation for health care systems distrust variable in the PHMC health survey

	Component	
Survey questions	**Values**	**Competence**
Health care system does its best to make patient's health better	0.2011	0.7316
Health care system covers up its mistakes	0.7026	0.0383
Patients receive high quality medical care from the health care system	0.1948	0.8087
Health care system makes too many mistakes	0.6414	0.2953
Health care system puts making money above patients' needs	0.6876	0.3293
Health care system gives excellent medical care	0.1905	0.8043
Patients get the same medical treatment from the health care system, no matter what the patients' race or ethnicity	0.3012	0.5525
Health care system lies to make money	0.7124	0.3049
Health care system experiments on patients without them knowing	0.6516	0.2346
Eigenvalues	3.937	1.064
% of variance explained	43.7	11.8

Missing data on the nine item distrust scale ranged from 2-12% percent, and missing values were imputed. The two distrust variables (values and competence) were used as an outcome and predictor variable in the rest of the analysis.

Other predictor variables of interest were nativity and race. Nativity was categorized as U.S.-born and foreign-born. Foreign-born women were defined as those born outside the United

States and the District of Columbia. Race was categorized as non-Hispanic White (from here referred to as White), non-Hispanic Black (from here referred to as Black), Hispanic, and other.

Numerous socio-demographic individual level characteristics were also included. These were: age (in years), level of education (did not graduate from high school, high school graduate, some college, and college graduate), employment status (employed, unemployed, and other, which includes those not in the labor force), poverty (living in poverty, not living in poverty), and marital status (married and not married). Two health resource variables were also included. Access to health care was measured using presence of health insurance (yes or no) and usual source of care (yes or no).

Analysis

Means and percentages of the sample characteristics were calculated across mammogram adherence status. Next, regression analysis was used to determine the extent to which nativity and race predicted health system distrust along both dimensions of distrust. Further analysis used logistic regression to predict the likelihood of having a mammogram in the last two years (adherence) given the level of health care system distrust, race, and nativity and controlling for demographic and health resource variables. Finally, interaction terms were added to the logistic regression model to examine the impact of the distrust variables on mammogram adherence on those foreign-born versus those U.S.-born, as well as the differential relationship within racial groups. Survey weights were used to preserve the sample size by adjusting for over- and underrepresented groups. All analyses were carried out in Stata 14.

Results

The descriptive statistics for the variables used in this study by mammogram adherence are given in Table 4-2. In the study region, 80% of women age 40 and older received a mammogram within the past two years. Seventy-four percent of the sample was non-Hispanic White while 93% were U.S.-born. The average age of the sample was 56, 57% were married, 16% lived in poverty, 57% of the sample had received some college education or more, and just 3% were unemployed. Finally, analysis of the health resource variables show that the majority of the sample had a usual source of care (94%) and some form of health insurance (95%). The average of the values distrust score of the sample was -0.06 (range -4.18 to 3.43), while the average competence distrust score was 0.03 (range: -3.73 to 3.15).

Table 4-2. Descriptive statistics of variables by mammogram status

	Received a timely mammogram					
	No		Yes		Total	
Total sample	No.	% or mean	No.	% or mean	No.	% or mean
	700	19.87	2824	80.13	3524	100
Distrust Variables						
Average Values Average Competence						
Nativity						
U.S.-born	3246	92.1	3295	93.49	3285	93.21
Foreign-born	278	7.9	229	6.51	239	6.79
Total	3524	100	3524	100	3524	100
Race						
Non-Hispanic White	2710	76.9	2591	73.53	2614	74.19
Non-Hispanic Black	582	16.52	721	20.47	694	19.69
Hispanic	143	4.07	135	3.82	136	3.87
Other	88	2.5	77	2.18	79	2.25
Total	3524	100	3524	100	3524	100
Poverty Status						
Nonpoverty	2789	79.14	2997	85.05	2956	83.87
Poverty	735	20.86	527	14.95	568	16.13
Total	3524	100	3524	100	3524	100
Employment Status						
Unemployed	209	5.92	87	2.46	111	3.14
Employed	2044	58.01	2323	65.91	2267	64.34
Other	1271	36.07	1115	31.63	1146	32.51
Total	3524	100	3524	100	3524	100
Level of Education						
No high school	354	10.05	225	6.38	251	7.11
High school graduate	1364	38.7	1226	34.8	1253	35.57

Some college	791	22.46	693	19.67	713	20.23
College graduate or more	1015	28.8	1379	39.14	1307	37.09
Total	3524	100	3524	100	3524	100
Marital Status						
Not married	1817	51.57	1462	41.49	1533	43.49
Married	1707	48.43	2062	58.51	1991	56.51
Total	3524	100	3524	100	3524	100
Usual source of care						
Yes	3136	88.99	3346	94.94	3304	93.76
No	388	11.01	178	5.06	220	6.24
Total	3524	100	3524	100	3524	100
Insurance status						
Insured	3051	86.58	3407	96.69	3337	94.68
Not insured	473	13.42	117	3.31	187	5.32
Total	3524	100	3524	100	3524	100

Eighty percent of U.S.-born women had received a timely mammogram compared to 77% of foreign-born women. Eighty-three percent of black women had also received a timely mammogram compared to 80% of white women, 79% of Hispanic women, and 78% of women in the other category. With respect to the other explanatory variables, a higher proportion of women living in poverty, unemployed, with less than a high school degree, and not married did not receive a timely mammogram compared to women not living in poverty, employed, with least a high school degree, and married. Similarly, a greater proportion of women who had a usual source of care (81%) had also received a timely mammogram compared to those who did not (65%). Eighty-two percent of women who had health insurance had received a timely mammogram compared to 50% of women who did not have health insurance. Other analysis showed that women who had received a timely mammogram showed lower levels of competence

distrust and values distrust scores than those who did not receive a timely mammogram. White and Hispanic women showed higher levels of competence distrust compared to Black and other women. Conversely, Black and other women showed higher levels of values distrust compared to White and Hispanic women.

Table 4-3 presents the regression results of factors that predict values and competence distrust. Foreign-born women gave on average 0.18 higher scores on competence distrust dimension but 0.16 lower scores for value distrust dimension compared to those U.S.-born. Black women gave 0.25 higher scores on the values distrust scale but 0.13 lower scores on the competence distrust scale compared to White women. The only other significant result by race and distrust was seen with other women. Compared to White women, those in the other category gave 0.3 higher scores on the values distrust scale. Older respondents were less trusting of the health care system on both dimensions than were younger respondents, as were those without a usual source of care compared to women with a usual source of care. Finally, women with a high school degree and some college education were more likely to have higher values distrust than women with less than a high school education.

Table 4-3. Regression coefficients showing factors that predict the two dimensions of distrust

	Values	Competence
Nativity		
U.S.-born (ref)		
Foreign-born	-0.160*	0.178*
	(0.0717)	(0.0719)
Race		
White (ref)		
Black	0.248***	-0.129**
	(0.0405)	(0.0431)
Hispanic	0.0298	0.077
	(0.0744)	(0.0838)
Other	0.304***	-0.174
	(0.0886)	(0.101)
Age	0.0052***	0.0045***
	(0.00122)	(0.00130)
Poverty Status		
Not living in poverty (ref)		
Living in poverty	0.0699	0.0026
	(0.0548)	(0.0561)
Employment status		
Unemployed (ref)		
Employed	0.0697	-0.0635
	(0.0877)	(0.103)
Other	0.0716	0.0158
	(0.0933)	(0.109)
Level of education		
Did not graduate from high school (ref)		
High school graduate	0.194*	0.0376
	(0.0816)	(0.0842)
Some college	0.171*	-0.104
	(0.0851)	(0.0877)
College graduate	0.00192	-0.0185
	(0.0844)	(0.0868)
Marital Status		
Not married (ref)		
Married	-0.0625	0.0733*
	(0.0346)	(0.0369)
Has a usual source of care		
Yes (ref)		
No	0.126*	0.153*
	(0.0629)	(0.0657)
Insurance status		
Insured (ref)		
Uninsured	0.131	0.0964
	(0.0712)	(0.0733)

Standard errors in parentheses, n=4,825; * p<0.05, ** p<0.01, *** p<0.001

Table 4-4 presents logistic regression results for mammogram adherence in three models. The first model examines the influence of race and nativity on adherence, controlling for other socio-demographic and health resource variables. Compared to White women, Hispanic women were almost twice as likely (OR: 1.9, 95% CI: 1.1, 3.2) and Black women were twice as likely (OR: 2.0, 95% CI: 1.6, 2.6) to have received a timely mammogram. Women who were employed (OR: 1.9, 95% CI: 1.2, 3.1) and those with a college degree or more (OR: 1.9, 95% CI: 1.3, 2.7) were both twice as likely to have received a timely mammogram compared to women who were unemployed and had less than a high school degree, respectively. Married women had odds that were 43% higher of having received a timely mammogram (OR: 1.4, 95% CI: 1.2, 1.7) compared to the reference group. Not surprisingly, women who did not have a usual source of care were half as likely as those who did have a usual source of care to have received a timely mammogram (OR: 0.5, 95% CI: 0.4, 0.7), and women without health insurance were associated with a 74% reduction in the odds of having received a timely mammogram (OR: 0.3, 95% CI: 1.2, 0.4).

Table 4-4. Odds ratio showing factors that predict mammogram adherence in three models

	Model 1	Model 2	Model 3
Nativity			
U.S.-born (ref)			
Foreign-born	0.861	0.767	0.737
	[0.581,1.274]	[0.480,1.227]	[0.462,1.174]
Race			
White (ref)			
Black	2.033***	2.261***	2.075***
	[1.615,2.559]	[1.714,2.982]	[1.560,2.759]
Hispanic	1.854*	1.979*	2.115*
	[1.088,3.157]	[1.072,3.653]	[1.149,3.893]
Other	1.321	0.967	0.901
	[0.749,2.329]	[0.540,1.731]	[0.508,1.598]
Age	1.012*	1.026***	1.027***
	[1.003,1.021]	[1.014,1.039]	[1.014,1.039]
Poverty status			
Not living in poverty (ref)			
Living in poverty	0.975	0.944	0.944
	[0.756,1.257]	[0.681,1.307]	[0.680,1.310]
Employment status			
Unemployed (ref)			
Employed	1.914**	2.099**	2.067**
	[1.201,3.052]	[1.241,3.551]	[1.217,3.509]
Other	1.331	1.096	1.079
	[0.825,2.146]	[0.638,1.885]	[0.627,1.859]
Level of education			
Did not graduate from high school (ref)			
High school graduate	1.353	1.038	1.062
	[0.975,1.877]	[0.678,1.589]	[0.691,1.631]
Some college	1.307	1.032	1.039
	[0.916,1.864]	[0.655,1.626]	[0.656,1.644]
College graduate	1.921***	1.530	1.551
	[1.349,2.737]	[0.970,2.413]	[0.978,2.460]
Marital status			
Not married (ref)			
Married	1.425***	1.296*	1.301*
	[1.186,1.713]	[1.039,1.617]	[1.043,1.624]
Has a usual source of care			
Yes (ref)			
No	0.496***	0.506***	0.501***
	[0.368,0.667]	[0.351,0.729]	[0.347,0.723]

	Model 1	Model 2	Model 3
Insurance status			
Insured (ref)			
Uninsured	0.266*** [0.188,0.376]	0.274*** [0.184,0.408]	0.268*** [0.179,0.401]
Health system distrust			
Values		0.929 [0.836,1.032]	0.893 [0.789,1.010]
Competence		0.882* [0.576,1.239]	0.912* [0.708,1.380]
Nativity and distrust interactions			
U.S.-born*values (ref)			
Foreign-born*values			1.012 [0.645,1.588]
U.S.-born* competence (ref)			
Foreign-born*competence			0.813** [0.696,1.748]
Race and distrust interactions			
White*values (ref)			
Black*values			0.740* [0.411,1.743]
Hispanic*values			0.768 [0.432,1.365]
Other*values			1.052 [0.604,1.833]
White*competence (ref)			
Black*competence			0.893 [0.695,1.146]
Hispanic*competence			0.610* [0.384,0.967]
Other*competence			0.812 [0.485,1.358]

N= 3524; Exponentiated coefficients; 95% confidence intervals in brackets; * p<0.05, ** p<0.01, *** p<0.001

Model 2 adds the competence and values distrust variables to the regression model. The competence dimension significantly predicted mammogram adherence. A unit increase in competence distrust score was associated with a 12% decrease in the likelihood of having received a timely mammogram (OR: 0.88, 95% CI: 0.6, 1.2) controlling for all other factors. In

this model, the odds of having received a timely mammogram were also associated with being Black, being Hispanic, increasing age, being employed, and being married. As in the previous model, women without a usual source of care and without health insurance were significantly less likely to have received a timely mammogram.

In the final model, the study examined how the main effect varied by racial and nativity subgroups by adding a series of interaction terms. The presence of a significant interaction in the logistic regression model indicated that the effect of distrust on mammogram adherence was different at different values of nativity and race. Significant results are seen in three of the eight interactions.

The following figures show how between group probability difference varies with changes in the values of the two distrust variables. The impact of values distrust on mammogram adherence did not differ for those foreign-born vs those U.S.-born. However, the effect of competence distrust on mammogram adherence was significant within nativity subgroup. Figure 4-2 shows how the foreign born-U.S. born probability difference varies with changes in the value of competence score. More specifically, it shows the values at which foreign-born women competence scores and U.S.-born women's competence scores are significantly different (where the blue bar does not cross the red line). The foreign born-U.S. born competence score is significantly different at scores below -0.4. This difference decreases as competence score reaches -0.4. At competence scores between -0.4 and 1.8, the foreign born-U.S. born difference is not significant. As competence score increases again, the difference in scores between the two groups of women becomes significant after 1.8.

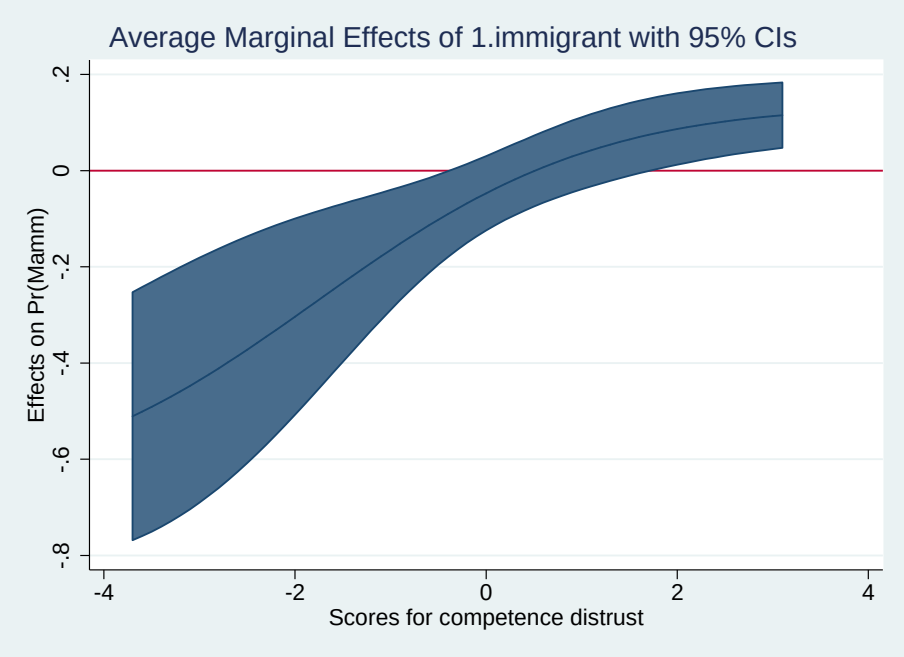
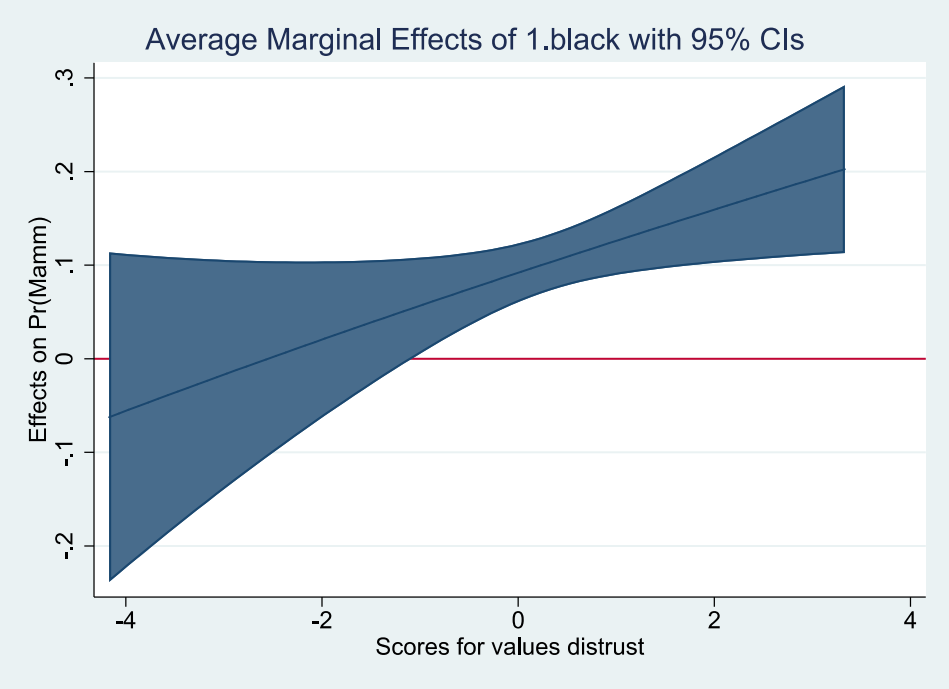


Figure 4-2. Difference in the probability of mammography adherence between foreign-born and U.S. born women with varying values of competence score.

Figures 4-3 and 4-4 show values of distrust scores where significant differences among racial groups occur. The values distrust scores of Black women were significantly different from White women, while competence distrust scores of Hispanic women was significantly different compared to White women. Figure 4-3 focuses on differences in the values distrust score by comparing each Black and Hispanic groups to White women. The graph shows that the Black-White difference in values distrust was insignificant at scores below -1.07 but significant for scores above. In contrast, the Hispanic-White difference in values distrust is insignificant above values of 0.63 and significant for scores below 0.63. Figure 4-4 focuses on differences in the competence distrust score by again comparing Black and Hispanic women to White women. The graph shows that the difference in competence distrust for Black and White women is insignificant above values of 1.8 and significant for scores below. Similarly, the Hispanic-White differences in competence distrust is insignificant above values of 0.3 and significant for scores below.



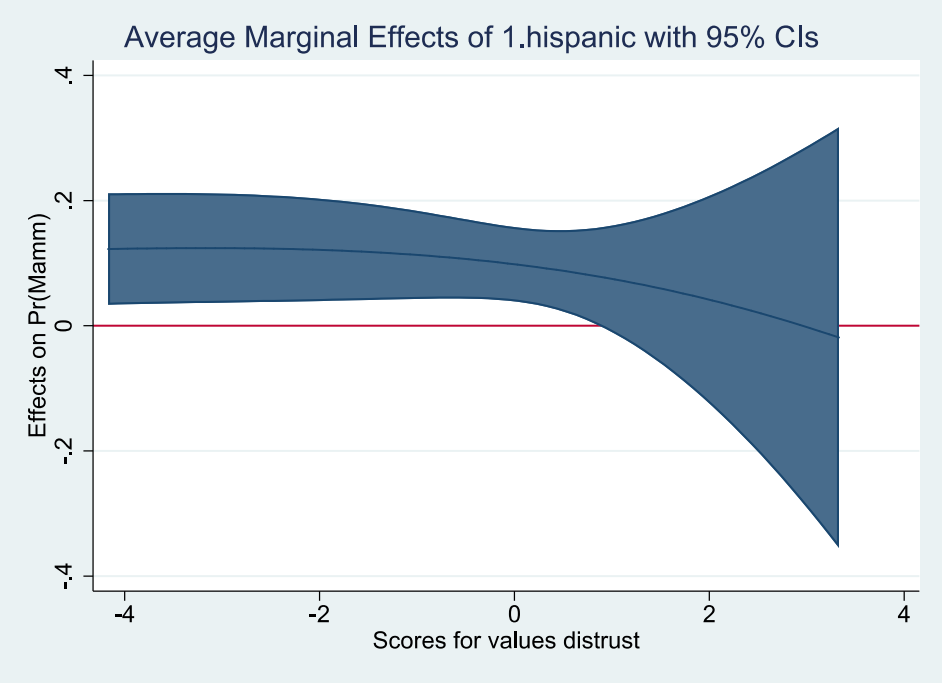
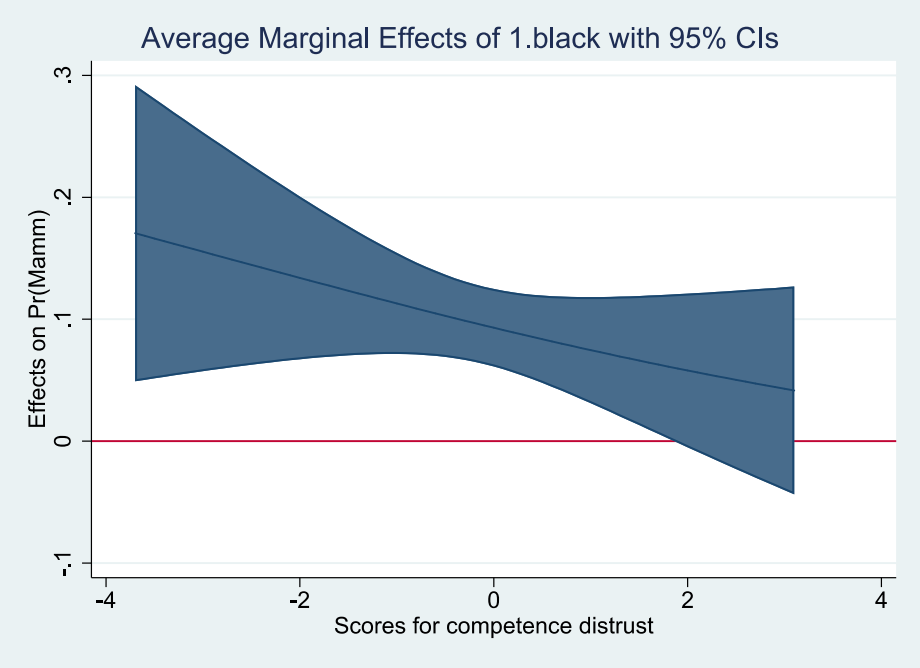


Figure 4-3. Difference in the probability of mammography adherence between racial groups women with varying values scores.



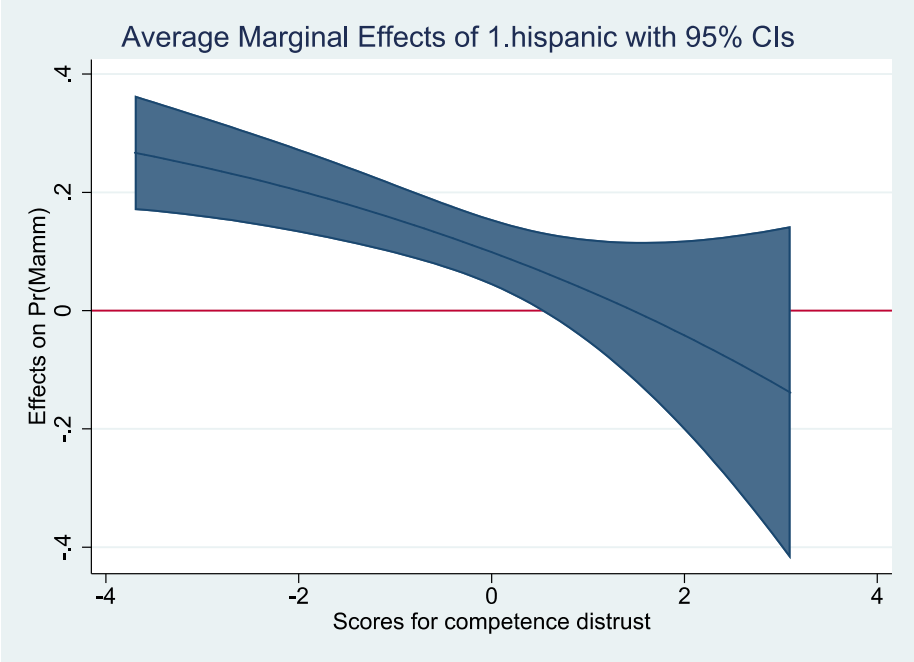


Figure 4-4. Difference in the probability of mammography adherence among racial groups women with varying competence scores.

Discussion

The purpose of this study was to determine whether health care system distrust was associated with breast cancer screening adherence among foreign-born and racial minority women living in southeastern Pennsylvania after controlling for sociodemographic and health resource variables. Differences in health systems distrust exist among population groups and serve as an important barrier to perceived access to health care.[137] Exploring factors that influence predisposition to use health care services regularly might improve the understanding of how to increase the demand for mammography over time.

Several patterns from these results are worth noting. Foreign-born women had higher competence distrust scores but lower values distrust scores compared to U.S.-born women suggesting that the foreign-born women in this study are less likely to believe the health care system can improve patient health but do not dispute its integrity in dispensing services, compared to U.S.-born women. Foreign-born women may have less faith in western medicines ability to heal or prefer traditional sources of medicine or religious practices.[151] Traditional and religious medicine is part of indigenous systems of healing in many parts of the world, and immigrants bring these beliefs with them as has been shown among Caribbean, Asian, and Latin immigrants.[152–154] Black and other women showed higher scores in values distrust but lower scores in competence distrust compared to White women. Distrust has been attributed to expectations of prejudicial treatment and institutional racism.[155] Hence Black and other women may view the health care system as being able to provide good and adequate services to improve health, as demonstrated by lower the competence scores (compared to White women), but question honesty, motives, and equity in providing these services.

Overall, women who received timely mammograms gave lower distrust scores on the two dimensions of distrust compared to women who did not receive timely mammograms. However,

only competence distrust significantly predicted mammography adherence such that women with higher competence distrust scores were less likely to have received a mammogram. Yang et al. (2011) found that values distrust was a significant predictor of clinical breast exams while competence distrust was not. Women who do not have faith in the technical ability of their providers or the health care system may feel less confident about undergoing an evasive procedure such as mammogram, especially if they are not at high risk or screening is optional.

These results provided no evidence that values distrust had an influence on mammography adherence. There are two possible explanations for this. First, mammograms are available for the uninsured at free clinics and covered under Medicare for those over 65 and covered under most private insurance plans.[79,156–158] Even though these results show that the effect of value distrust on adherence was significantly different among Black women, the majority of the sample may believe that mammograms are equally available to all women. Second, due to the objective nature of mammograms assessing competence. Hence, it might be easier a more objective measure of distrust, such as competence, might be a significant predictor versus the more subjective values measure. Also important is that women without a usual source of care gave higher scores on both dimensions of distrust compared to women with a usual source of care. These women were also significantly less likely to have received a timely mammogram. Women who do not have a usual source of care would have less interaction with the health care system and possibly will be less likely to receive recommendation for mammograms.

Although assuming the most distrustful women are those from minority groups is reasonable, this assumption was not confirmed in the study. One possible explanation is that the distrust scale used was not culturally sensitive and, therefore, did not detect differences among racial and nativity groups. Facione and Katapodi (2000) suggested poverty, not cultural differences, accounts for the observed differences in breast cancer screening.[159] This study could not distinguish whether distrust observed was attributed to racial/cultural characteristics or

socioeconomic factors. In addition, previous studies have shown the importance of citizenship status and length of stay on breast cancer screening uptake.[128,160] For those foreign-born, attaining citizenship may be more important in gaining access to health care services or health insurance necessary to undergo a mammogram.[161,162] The PHMC did not give information on the length of time in the U.S. or current citizenship status for foreign-born women, possibly explaining why nativity did not predict mammography adherence in any of the regression models. Future studies with larger, stratified samples might help distinguish different determinants of distrust.

This study has several limitations. The survey was fielded in southeast Pennsylvania, and the results cannot be generalized to the rest of the U.S. In addition, the survey did not have specific information on physician recommendation of breast cancer screening or individual risk of breast cancer. Studies have shown that these two factors are important determinants of women seeking preventive breast screening.[163,164] The PHMC is a cross-sectional study based on self-reported data, and these results may be subject to recall bias. For this study, foreign-born women were aggregated into one category, masking heterogeneity in country of origin within these groups of women. Women migrating from developed countries or countries with universal health coverage will have different perceptions of the health care system and probably varied levels of distrust. Finally, the complex nature of the U.S. health care system means that distrust captured here could extend to one of many facets of the system, such an insurance companies, physicians, and clinics, as well as the impact of patient perception of the entire system. Aggregating health care system distrust into two dimensions prevents the specific aspect of distrust that affects breast cancer screening to be clearly defined and substantial variability may exist in the effects of different health beliefs on screening. Future studies need to consider different aspects of health systems distrust by looking at individual components of the health care system and their relationship to preventive screening use.

Despite these limitations, this study has several important implications. The influence of distrust on mammogram adherence observed in this study suggests that efforts made to improve health care trust among women, could in turn improve breast cancer screening adherence rates. Distrust decreases women's predisposition to use health care services.[165] Therefore, if certain subpopulations are more likely to exhibit higher levels of distrust, then improving trust would be an important intervention point to improve screening rates. One way to improve patient trust is for health care providers to be completely transparent with patients, providing them with adequate information and resources to make informed choices, and providing a welcoming environment in a manner that encourages communication. The significant interaction effects observed in this study also show how the relationship between distrust and mammogram adherence differed within racial and nativity subgroups. For instance, mammogram adherence between Black and White women were significantly different among women with low values distrust scores. This difference highlights the importance of tailoring cancer screening interventions as well as the methods with which they are disseminated, to specific subgroups of women who stand to benefit the most.

Chapter 5

Policy Implications and Conclusion

To increase breast cancer screening rates in any population, relevant factors that influence health decisions need to be identified. A better understanding of these barriers will aid in the design of appropriate cancer prevention strategies that change health behaviors and attitudes of women toward screening. [166]

Macros Level Recommendations

Macro level policy or practice recommendations address barriers at the population and the health care system level.

1) All three studies identified the vital role clinicians and the health care system play in creating and perpetuating a sense of fear or distrust about breast cancer screening. Therefore, health care providers, including physicians, nurses, technicians and other medical staff, must receive training in communication and culturally competent care. Culturally competent care has been defined as "congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals and enable that system, agency, or those professionals to work effectively in cross-cultural situations".[167,168] It essentially helps medical staff develop competencies for interacting with culturally diverse populations. [169] Culturally competent training may help providers understand and consider values, beliefs, and practices of patients,[168] eliminating conscious or unconscious physician biases. [134] Culturally competent training has been shown to improve patient-provider interaction [169] and could enhance positive attitudes regarding the use of breast cancer screening services in order to prompt adherence to

screening guidelines. Educating physicians about women's concerns, lifestyles, and barriers to cancer screening will have positive effects on provider-patient interactions and promote mutual understanding. In addition, community health workers with immigrant, minority, or culturally similar backgrounds to vulnerable women should be trained in breast-screening activities, as these individuals could be used as agents of community change, all of whom share a common language and culture.[170]They will be able to dispel myths and inaccuracies about screening methods and help women navigate the health care system.

2) Breast cancer education and screening programs should be tailored to fit the specific needs of social and cultural groups of women.[171] Breast cancer programs that have been implemented in immigrant home countries can be useful migrant groups in destination countries. For instance, results from the evaluability assessment could be used to develop and implement culturally relevant cancer prevention interventions, strategies, and recommendations to overcome screening barriers among immigrant and refugees in the global north in an effort to increase breast cancer participation and awareness. Numerous studies have observed disparities in breast cancer screening among African refugees and immigrants but have attributed the reduced screening rates and those who are low income and less access to preventive health care.[172] However, a better understanding of the cultural perceptions immigrants bring with them will aid in the development of programs from a culturally grounded perspective. This, in turn, would help increase awareness of the importance of cancer screening and mitigate some of the fear and stigma associated with the disease in immigrant communities. [47,173]

3) In addition to trained community health workers, non-medical facilitators of breast cancer awareness should be promoted.[174] The study conducted in Nigeria showed the role of spirituality in health seeking behavior and similar observations have been made within

immigrant and minority communities in the U.S.[59,175] Educating and involving religious and cultural heads in breast cancer screening and education program may be another avenue to increase breast cancer awareness among women and build trust in the health care system.[176] These facilitators could reinforce physician recommendation, and organize community-based breast cancer screening through mobile mammography programs, and help patients navigate the health care systems from screening through follow-up. They could also add positive stories to community folklore about mammograms and the health care system that can begin to alter perceptions and attitudes and change cultural norms that promote delaying health care and devalue the role of preventive health care.[177]

4) Several organizational measures also could be promoted. First, women in remote or rural areas have difficulty accessing health care services; hence, actual access to breast screening services and provision of these services in an efficient manner is important. The establishment of mobile clinics in difficult to reach, and remote populations could be used as a solution to reduce the cost and time associated with transportation to large health care facilities. In addition, most women need a referral from primary care providers to receive a mammogram. Hence, providers must make timely screening recommendations to their patients by using client and provider reminder systems in clinics. Finally, including traditional healers in the breast cancer programs in communities where their services are frequently sought could serve as another source of accurate information.

Micro Level Recommendations

Micro level policy or practice solutions address barriers at the individual level and specifically targets social and attitudinal barriers to proactive screening behavior.

1) Vulnerable women should be educated about navigating the health systems and identifying what services are available to them, especially for individuals who do not have a regular medical provider. This education should include education on all essential preventive services and timeliness for when services are need to be received. Furthermore, education programs should be implemented to increase awareness about breast cancer, highlighting the importance of regular breast cancer screening and dispel myths about breast cancer being incurable and fatal.
2) Breast cancer screening and awareness programs should target women and men. Husbands are the primary source of income and health insurance for many women. For others, men have a strong influence of the health behaviors they exhibit. Additionally, men need to understand the importance of regular breast screening for their wives, mothers, and daughters.
3) Women should be given a better sense of control over their bodies and health. Health programs should encourage women to take a proactive approach in preventive behaviors. A few women in the Nigerian study mentioned that women's health is low priority in the country and women tend to not use health services at all. This is contrary to the Western ideology in which women have been shown to use preventive services and seek help for medical problems more than men.[178] Interventions should focus on direct appeals to the individual and highlight the importance of screening and early detection as the most effective method of treating breast cancer.

Conclusion

The three studies presented offered a socioecological view of attitudes and perceptions toward uptake of mammograms in three different populations. These attitudes, whether perceived and actual, act as barriers that prevent vulnerable women in multicultural societies from using breast cancer screening services. Some of these barriers reflect a lack of awareness of the benefits of breast cancer screening, distrust in the quality of services being rendered, limited access to preventive services, or the preference of alternative healers. Even when breast cancer screening services were available through Medicare, only half the women in the Appalachian sample had received a preventive mammogram according to guidelines. Women in Nigeria and Appalachia provide evidence that for some women, breast cancer is a remote and unimportant concern compared with more immediate health, such as chronic disease or family concerns, such as competing family needs. Women in their 60s and 70s may believe the consequences of breast cancer at their age is not important. In Nigeria, women rarely had first-hand encounters of breast cancer in other women. Fear, cultural attitudes, and distrust of the medical system or the breast cancer screening process itself were also observed to be barriers reflecting negative experience with components that are both real and perceived. Women may also associate negative health experiences from other encounters with the health care system into their expectations and fears with breast cancer screening.[176]

Individual attitudes and perceptions toward health influence health screening behavior,[146] which are, in turn, influenced by factors acting at the individual, institutional, community, and policy level.[6] A better understanding of women's perceptions and beliefs allows for sustainable approaches to lowering barriers and achieving greater participation in breast cancer screening programs among women from minority or other disadvantaged social groups.

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Appendix A
Program Director Questions

1. Tell be about OCCF
2. What are the goals of the program?
3. Who is the target population of the program?
4. Are you reaching the intended target audience?
5. What problem is the program trying to address?
6. What is your specific role to the program?
7. What challenges do you face fulfilling your role?
8. Do you know of other similar programs?
9. Who (among list of stake holders) is well respected for his/her knowledge/understanding about this program?
10. Has a previous evaluation been conducted?
11. Who are the critics of the program?
12. Who manages the program?
13. How is the program funded?
14. Are there additional individuals with responsibility for the implementation and/or operations of the program?
15. Whom do people look to for information on the program?
16. Who are advocates of this program?
17. How do you measure the program effectiveness or success?
18. As you think about the program, what would success look like?
19. What do you still not know that would be important to know?
20. What questions seem to come up repeatedly, in conversations with others or in your own work, concerning the effectiveness impact, and/or success of this program or initiative?
21. Are you implementing activities as intended?
22. Are key components of the program in place?
23. Are appropriate staff/volunteers who possess necessary skills in place?
24. What are some staff challenges?
25. Do you have the right mix of activities?
26. What are the short-term and/or medium-term outcomes expected in terms of participant reactions to the program, knowledge acquisition, and skill development or change in aspirations?
27. What are the long-term expected outcomes?

Appendix B

Program Staff Questions

Gender:

Education:

Length of time with the program:

Title:

1. What are the goals of the program?
2. Do you know of other similar programs?
3. What is your specific role to the program?
4. What do you still not know that would be important to know about the program?
5. What challenges do you face fulfilling your role?
6. Tell me some successes the program has had
7. What are some personal experience in working with/for the program?

Appendix C

Participant Questionnaires

Pre-Program Survey

Attitude

1) Breast cancer is the most common cancer in women

☐ Yes

☐ No

☐ I don't know

2) Breast cancer is curable when found early

☐ Yes

☐ No

☐ I don't know

3) What is your is your risk of getting breast cancer?

☐ Not at risk

☐ Low risk

☐ High risk

☐ I don't know

Knowledge

4) Breast cancer occur more commonly in old people

☐ Yes

☐ No

☐ I don't know

5) Breast cancer can be inherited

☐ Yes

- ☐ No
- ☐ I don’t know

6) Breast cancer is caused by evil spirits

- ☐ Yes
- ☐ No
- ☐ I don’t know

7) Breast cancer is present as a painless breast lump

- ☐ Yes
- ☐ No
- ☐ I don’t know

8) Breast self-exam is useful in early detection

- ☐ Yes
- ☐ No
- ☐ I don’t know

9) Breast cancer is cured by

- ☐ Removing breast
- ☐ Drugs
- ☐ Other
- ☐ I don’t know

Practice

10) Have you ever been screened for breast cancer

- ☐ Yes
- ☐ No
- ☐ I don’t know

Questions for Patients after OCCF screening

Breast Cancer Practice

1. How did you hear about OCCF?
2. What made you come in for screening?
3. Have you heard of a mammogram?
   (If YES go to 4. If NO got to 5)
4. Have you ever had a breast screening before?
   (If YES go to 6. If NO go to 8)
5. How long ago? Where did it take place?
6. If you have been screened somewhere else, how did this compare to OCCF?
7. What previously prevented you from getting screened?

Breast Cancer Knowledge and Attitudes

8. What do you think causes breast cancer?
9. Do you know anyone who has had breast cancer?
   Ask about friends, family members, etc
10. Do you know how breast cancer can be treated?
11. Do you think it is important for women to talk to each other about breast cancer? Why?
12. What do you do when you are sick?
    Explanation: Do you see a doctor, go to a hospital, see a traditional healer etc?
13. Who makes the health care decisions in your family?
    Explanation: If someone is sick, who decides what happens?
14. Are you married?
    (If yes go to 17. If No, go to 19)
15. Does your husband do anything regarding your health?
16. Can you husband prevent you from getting screened?
17. Do you think it is important for women to talk to men about breast cancer? Why?
18. Why do you think Nigerian women do not go for breast cancer screening?
19. How do your religious beliefs influence breast cancer screening?
20. Is there anything else about beliefs and knowledge pertaining to breast cancer that you think is important for Nigerian women?

Client Exit Interview

21. Are you satisfied with your screening process?
22. When is your next screening?

23. Do you know how often screening should be done?
24. Did someone answer all questions you had?
25. Did you understand everything that was explained to you?
26. Would you recommend OCCF to someone you know?
27. What do you think would prevent you from coming back to OCCF for future screening?

Appendix D
Consent/Recruitment Form

Summary Explanation of Research

The Pennsylvania State University

Title of Project: *Evaluation of a Breast Cancer Screening Program in Nigeria*
Principal Investigator: *Bilikisu Elewonibi*

Telephone Number: *07033447497*

Advisor: *Dr Rhonda BeLue*

Advisor Telephone Number: *+1* 814-865-6898

You are being invited to volunteer to participate in a research study. This summary explains information about this research.

- The purpose of the study is to
    - determine if the breast cancer screening program run by OCCF is achieving its stated objectives and to adjust OCCF activities to improve outcomes.
    - describe culturally relevant factors from interviews that may be influential and deserve consideration in the OCCF breast cancer screening program and
- You will be interviewed before and after the program to assess your hopes and gauge your level of satisfaction with the program. Your screening may also be observed.
- You will be assigned an identification number so the results of your screening will not be linked back to you.
- Your registration fee will be covered

If you have questions or concerns, you should contact Bilikisu Elewonibi at *07033447497*. If you have questions regarding your rights as a research subject or concerns regarding your privacy, you may contact the Office for Research Protections at +1 814-865-1775.

Your participation is voluntary and you may decide to stop at any time. You do not have to answer any questions that you do not want to answer.

Tell the researcher your decision regarding whether or not to participate in the research.

VITA

Bilikisu Reni Elewonibi, MPH

Education

Ph.D, Health Policy and Administration and Demography, Pennsylvania State University 2017
MPH, Health Management and Policy, University of Michigan- School of Public Health 2010
BSc, Biochemistry, University of Lagos 2006

Published Manuscripts

Elewonibi B & BeLue R. The influence of socio-cultural factors on breast cancer screening behaviors in Lagos, Nigeria. *Ethnicity and Health* 0, 1–16 (2017).

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Research Grants and Awards

M.G. Whiting Student Indigenous Knowledge Research Award 2015
Pennsylvania State University Africana Research Center Grant Recipient 2014
Susan G. Komen Breast Cancer Training Fellowship 2013-2015