

AFRICAN AMERICAN WOMEN'S PERCEPTIONS, EXPERIENCES, AND MEANING
ASSOCIATED WITH BREAST CANCER SCREENING IN RURAL EASTERN NORTH
CAROLINA

by

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This qualitative study addressed the research question, what are the perspectives and experiences related to breast cancer and breast cancer screening of African American women residing in rural eastern North Carolina? A literature review indicated little research related to the perceptions and experiences of rural African American women about breast cancer and breast cancer screening. In a previously conducted unpublished larger study (Burke, Barrett, & Cherry, 2009), the perspectives of women from rural North Carolina about breast cancer and breast cancer screening were collected by means of focus group interviews. The researcher in the present study conducted a qualitative analysis of data from a sub-set of focus group interviews that involved African American women.

A qualitative approach in this study afforded an opportunity to gain insight into African American women's experiences and views regarding breast cancer and breast cancer screening. The researcher analyzed transcripts from three focus group interviews that involved 17 African American women residing in rural eastern North Carolina. Five themes that emerged from the data were: knowledge and beliefs about breast cancer, influences on breast cancer screening behaviors, personal experience with screening, emotional reactions to discussing breast cancer and breast cancer screening, and promoting breast cancer screening.

Key findings related to these emergent themes included a self-perceived low level of knowledge about breast cancer, cultural views about various causes of breast cancer,

perspectives about mammograms, perceived barriers to breast cancer screening, the influence of faith on breast cancer and breast cancer screening, personal experiences with breast cancer screening, fear as a commonly shared reaction to breast cancer and breast cancer screening, and best practices for promoting breast cancer awareness and education. The researcher identified a need for future research on the topic of minority health in rural populations, specifically around breast cancer screenings and preventive health. An analysis of a sub-set of qualitative data provided by African American women and a comparison of findings with the research literature led the researcher to recommend that tailored health education be provided African American women on the topic of breast cancer and breast cancer screening.

African American women's perceptions, experiences, and meaning associated with breast
cancer screening in rural eastern North Carolina

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CHAPTER 1: INTRODUCTION

Breast cancer is the leading type of cancer that is diagnosed in women of all races and ethnicities and is the second leading cause of cancer death among African American, Caucasian, Asian/Pacific Islander, and American Indian/Alaska Native women (Centers for Disease Control and Prevention (CDC), 2013). Although Caucasian women are more likely to be diagnosed with breast cancer and have higher rates of breast cancer, African American women are more likely to die from the disease (Office of Minority Health (OMH), 2011). Barriers to screening and access to care can inhibit some African American women from being screened for breast cancer, which may impact disparities in breast cancer mortality within this population (Susan G. Komen for the Cure, 2007). This qualitative study aimed to explore the perceptions and experiences regarding breast cancer and breast cancer screening, including facilitators of and barriers to breast cancer screening, from the perspective of African American women living in rural eastern North Carolina.

Statement of the Problem

Major racial and ethnic disparities in breast cancer mortality exist in the United States. The risk for African American women being diagnosed with breast cancer is lower than that for Caucasian women, but mortality rates for African American women diagnosed with breast cancer are higher than those for Caucasian women (Martin & Wingfield, 2012; OMH, 2011). African American women are 10% less likely to be diagnosed with breast cancer but have a 40% higher mortality rate compared to their Caucasian counterparts (OMH, 2011). The mortality rates associated with breast cancer are some of the highest cancer mortality rates within the African American population (CDC, 2011d; OMH, 2011). When African American women are diagnosed with breast cancer, the disease tends to be in a more advanced stage, which may

impact the observed racial disparity in breast cancer mortality (Lannin, Matthews, Mitchell, & Swanson, 2002; Martin & Wingfield, 2012).

In order to reduce the risk of breast cancer, the CDC (2011b, 2011c) has recommended physical activity, maintaining healthy weight, avoiding hormone replacement therapy, limiting alcohol intake, knowing individuals' family history of breast cancer, and regular screening for breast cancer. Lifestyle modification and screening have been shown to reduce women's risk and mortality associated with breast cancer (CDC, 2011e). In accordance with the American Cancer Society recommendations at the time of this study, women aged 40 and in good health should receive a yearly mammogram (ACS, 2013c). Women in their 20s and 30s should receive a clinical breast exam (CBE) every 3 years. A CBE should be conducted annually for women over 40.

Breast cancer screening rates among African American women have been consistently irregular and remain low in comparison to other racial and ethnic groups (Breen, Gentleman, & Schiller, 2011; Chapgar & McMasters, 2007; Martin & Wingfield, 2012). Numerous studies have shown that African American women younger than 50 years of age have lower screening rates, higher mortality rates, more aggressive types of breast cancer, and more advanced stages of breast cancer at diagnosis (Breen et al., 2011; Chapgar & McMasters, 2007; Martin & Wingfield, 2012). The American Cancer Society (ACS) reported in 2010 that 65.9% of African American women over the age of 40 years received a mammogram within the prior two years and 50.6% of African American women reported having a mammogram in the previous year. In 2003, 70.4% of African American women 40 years of age and older received a mammogram within the prior two years and 54.2% received a mammogram within the previous year (ACS, 2011c; ACS, 2006). Mammogram screening for African American women has thus declined

from 2003 to 2010, yet mammograms are the most effective screening tool in the early detection of breast cancer (Institute of Medicine, 2003).

Researchers have identified major barriers to breast cancer screening, including a lack of understanding about who should be screened and the underlying purpose of screening, health care providers' failure to recommend screening, and failure to be screened in a timely manner (Husaini, Emerson, Hull, & Sherkat, 2005). The same study also indicated differences in screening rates between urban and rural African American populations. Rural populations were less likely to get screened than urban populations. A negative community perspective about screening can discourage women from obtaining mammograms. Rural African American women have reported more perceived barriers to mammography screening than urban African American women. Husani et al. (2005), for example, examined the breast screening perspectives of African American women aged 40 years and older residing in rural Tennessee. The women indicated that they did not think about needing a mammogram or thought that their breasts were healthy.

Gaining knowledge and understanding about African American women regarding breast cancer screening, including their perspectives and experiences about barriers, challenges, attitudes, and cultural beliefs may be an important first step in reducing racial and ethnic disparities in the area of breast cancer mortality. In this qualitative study, the researcher analyzed a sub-set of data from a larger qualitative study in order to explore theories about the facilitators and barriers perceived by rural African American women, a population with disproportionately higher breast cancer mortality rates. In addition, the researcher sought to describe the perspectives and behaviors of the population of interest (Corti & Thompson, 1995; Heaton, 1998). The researcher sought to uncover how African American study participants

viewed breast cancer and breast cancer screening in the geographical and cultural context of rural eastern North Carolina, including barriers that prevented them from being screened for breast cancer, facilitators that promoted breast cancer screening, and their experiences with breast cancer and breast cancer screening in general. The qualitative nature of this study gave voice to study participants and enabled the researcher to document an emic or insider's view of breast cancer and screening for breast cancer (Patton, 2002).

Statement of Purpose

The purpose of this qualitative study was to understand and explore breast cancer and breast cancer screening from the perspective of African American women residing in rural eastern North Carolina.

Research Question

The researcher addressed the following research question: What are the perspectives and experiences related to breast cancer and breast cancer screening of African American women residing in rural eastern North Carolina?

Significance of Study

This study focused on the perspectives about breast cancer and breast cancer screening of African American women living in rural areas, a setting that has received limited attention in the research literature. The lived experiences and opinions of the study participants, including their attitudes, challenges and cultural beliefs, have provided firsthand insight into and understanding of breast cancer and breast cancer screening among African American women in a rural area. By understanding what rural African American women perceive and experience related to breast cancer and breast cancer screening, it may be possible to apply the findings from this study to improving screening rates and thus potentially decrease the racial and ethnic

disparities in breast cancer mortality within this population. Furthermore, findings from this study can enable health educators to use insight gleaned from the study to more effectively address challenges and tailor interventions when designing breast cancer screening programs or interventions in the future.

Limitations of Study

1. Due to the use of a small sample size and the inclusion and exclusion criteria used, it was unlikely that study findings pertained to all rural African American women regarding breast cancer and breast cancer screening. However, these study participants' experiences can provide further insight into the subject of breast cancer screening among minority populations and allow for a better understanding of barriers, facilitators, attitudes and cultural influences faced by rural African American women. In addition, the findings from this study may be transferable to other similar settings depending on readers' assessment of the similarity of the sample and setting to their own circumstances.
2. Because qualitative research strategies document participant's voices and experiences, findings may be interpreted in other ways. In this study, the researcher used multiple strategies to increase the rigor of the study, including providing evidence for data interpretation using participants' quotations.
3. The use of secondary data by an independent analyst can create ethical issues regarding participant consent. The inclusion of a clause in the written consent form associated with the larger study from which this sub-set of data was taken, however, stated that data may be used for future research and thus addressed this issue.

Delimitations of Study

This study was delimited to participants who met the following criteria:

- African American women over 18 years of age who participated in focus group interviews as a part of a larger qualitative study on breast cancer and breast cancer screening.
- Residents of rural eastern North Carolina
- Willingness to voluntarily share personal perspectives and experiences regarding breast cancer and breast cancer screening.

Summary

Breast cancer incidence rates among African American women are lower than their Caucasian counterparts, yet mortality rates are higher among African American women (OMH, 2011). This can be attributed to low screening rates, lack of access to care, socioeconomic status, religious belief, and geographical location. Compliance with recommendations offered by the ACS and CDC can potentially reduce the risk of breast cancer in women. Breast cancer screening rates among African American women are lower than those of Caucasian women and African American women have been found to have more aggressive types of breast cancer or more advanced stages of breast cancer at the time of diagnosis. Racial and ethnic differences between African American and Caucasian women contribute to different screening practices, perceptions about and attitudes towards breast cancer and breast cancer screening (Lannin et al., 2002).

In the following chapters, the researcher will present a review of the research literature focused on breast cancer and breast cancer screening; an overview of the research methods, including the rationale for a qualitative approach, the data collection processes used in the initial,

larger study, and the data analysis associated with the current study; and the findings that emerged from the analysis of data. Finally, the researcher will present a discussion of the findings, with implications for the discipline of health education and promotion and for further research.

CHAPTER 2: LITERATURE REVIEW

According to the National Cancer Institute ([NCI]; n.d.), breast cancer is defined as a cancer that originates in tissues of the breast and occurs in both men and women. In 2012, this specific type of cancer affected approximately 227,000 women and claimed the lives of approximately 40,000 women (NCI, n.d.; Siegel, Naishadham, & Jemal, 2012). Breast cancer is most commonly diagnosed in middle-aged women 55-64 years of age according to the Surveillance Epidemiology and End Results (SEER), 2013). It is estimated that 1 in 8 women in the United States will be diagnosed with breast cancer at some point during their lifetime (Stuckey, 2011). Age-adjusted probabilities of developing invasive breast cancer in the U.S. between 2005 and 2007 were as follows: 0.48 (1 in 207) among women birth to 39 years old, 3.75 (1 in 27) among women 40 to 59 years, 3.45 (1 in 29) among women 60 to 69 years and 6.53 (1 in 15) among women 70 and older (Siegel et al., 2011).

Breast cancer rates in the United States have continued to increase among women. According to the American Cancer Society (2013), it is estimated that in 2013 there will be approximately 230,340 newly diagnosed cases of invasive breast cancer among women (ACS, 2013; National Cancer Institute, 2013). In 2009, 211,731 American women were diagnosed with breast cancer, reflecting a rate of 123.1 per 100,000 women (U.S. Cancer Statistics Working Group, 2013). Between 2006 and 2010, the average breast cancer incidence rate among all races was 123.8 per 100,000 women (Surveillance Epidemiology and End Results (SEER), 2013). Incidence rates increased by a 4.0 annual percent change (APC) between the years 1980 to 1987, 1.8 APC in 1994 to 1999 and 0.1 APC in 2004 to 2010. Currently, over 2.8 million women residing in the United States are living with breast cancer.

Currently, breast cancer is the second leading cause of mortality among women in the United States (U.S Cancer Statistics Working Group, 2013). It is estimated that approximately 40,000 women will die from breast cancer in 2013 (ACS, 2013). Although incidence rates of breast cancer have been increasing, breast cancer mortality rates for females have been decreasing. From 1991 to 2007 mortality rates decreased from 32.69 per 100,000 women to 22.84 per 100,000 women, an absolute change of -9.85 and a percentage change of -30.13% (Siegel, Ward, Brawley, & Jemal, 2011). The age-adjusted death rate between the years 2006 and 2010 was 22.6 per 100,000 women (SEER, 2013). As of January 1, 2012, there were 2,971,610 female breast cancer survivors in the United States; it is estimated that by January 1, 2022 there will be 3,786,610 female breast cancer survivors (ACS, 2012).

Mortality rates vary by race. Between the years 2006 and 2010, the mortality rate for Caucasian women was 22.1 per 100,000 women, 30.8 per 100,000 African American women, 11.5 per 100,000 for Asian/Pacific Islander women, 15.5 per 100,000 American Indian/Native American women and 14.8 per 100,000 Hispanic women (SEER, 2013). Just over a quarter (26.4%) of American women diagnosed with breast cancer will die from the disease (CDC, 2008; NCI, 2007; Susan G. Komen NC Triangle Affiliate, 2009b).

High rates of breast cancer mortality can be attributed to the poor rates of early detection and early treatment, specifically for priority populations such as rural African American women (Susan G. Komen for the Cure, 2007). Breast cancer incidence rates among Caucasian women were 127.4 per 100,000 women versus 121.4 per 100,000 African American women (SEER, 2013). However, breast cancer mortality rates among Caucasian women were 22.1 per 100,000 women compared to 30.8 per 100,000 African American women (SEER, 2013). Breast cancer incidence rates are lower among African American women than their Caucasian counterparts,

but higher in African American women younger than 40 years old (Baquet, Mishra, Commiskey, Ellison, & DeSheilds, 2008). African American women have a 77% higher mortality rate once diagnosed, an observation that has been attributed to a lack of access to care (ACS, 2010). Breast cancer death rates among minorities are 1.5 times higher than for their white counterparts, compared to the incidence rates among Caucasian women, which is 1.1 times higher than incidence rates among African American women (ACS, 2008; CDC, 2008; North Carolina Department of Health and Human Services, 2007; Susan G. Komen for the Cure, 2007).

The exact cause of breast cancer is unknown and currently there is no cure for the disease (Susan G. Komen NC Triangle Affiliate, 2009a). Common risk factors that can lead to the development of breast cancer include a genetic mutation in the BRCA1 and BRCA2 genes, having a family history of breast or prostate cancer, and lifestyle factors such as obesity or weight gain (specifically after menopause), drinking alcohol, lack of physical activity and higher socioeconomic status (ACS, 2011a; Stuckey, 2011; Susan G. Komen for the Cure, 2010b). Research continues to provide a better understanding of the disease and the risk factors with which it is associated.

North Carolina

Cancer rates in North Carolina have decreased over the years. In 2010, over 49,000 North Carolina residents were diagnosed with cancer and approximately 18,000 died from cancer (NC Central Cancer Registry, 2013a; 2013b). These rates led cancer to be the leading cause of death in North Carolina, surpassing cardiovascular disease (NC Central Cancer Registry, 2013d). Although North Carolina was ranked as the 45th lowest state for cancer incidence rates, it was ranked 16th in cancer mortality (ACS, 2008).

In North Carolina, breast cancer was the most frequently diagnosed type of cancer and was the third leading cause of cancer death between the years 2007 to 2011 (NC Central Cancer Registry, 2013). In 2010, 8,526 women were newly diagnosed with breast cancer, reflecting a rate of 152.3 per 100,000 general population (NC Central Cancer Registry, 2013a). In 2011, 1,309 women in North Carolina died from breast cancer (NC Central Cancer Registry, 2013b).

In 2011, African Americans made up 21.9% of the total population in North Carolina (North Carolina Department of Health and Human Services, Division of Public Health & State Center for Health Statistics, 2012). Cancer was the second leading cause of death among the African American population in North Carolina, accounting for 3,459 deaths out of 15,764 total deaths (SCHS & OMH, 2010). The cancer death rate for African Americans in North Carolina (211.3 per 100,000 population) was higher than the cancer death rates among their Caucasian counterparts (176.8 per 100,000 population) (NC DHHS DPH & SCHS, 2012). Between the years 2006 to 2010, the cancer incidence rate for African Americans in North Carolina was 517.5 per 100,000 population, a rate that was higher than the cancer incidence rate for their Caucasian counterparts (501.2 per 100,000 population) (NC Central Cancer Registry, 2012).

Similar to national trends, a disparity exists between African Americans and Caucasian women in incidence and mortality of breast cancer in North Carolina. The age-adjusted incidence rates for breast cancer among African American women were 143 per 100,000 compared to 149.5 per 100,000 Caucasian women in North Carolina between the years 2002 and 2006 (SCHS & OMH, 2010). Between 2007 and 2010, African American women residing in North Carolina died from breast cancer at a rate of 30 per 100,000, whereas the rate of Caucasian women residing in North Carolina who died from breast cancer was 21.4 per 100,000 (NC Central Registry, 2013).

Risk County, North Carolina

One county in North Carolina has one of the highest breast cancer incidence and mortality rates in the state (Susan G. Komen NC Triangle Affiliate, 2009b). It also has the 16th highest rate of breast cancer mortality rate in the nation (CDC, 2008; NCI, 2008; Susan G. Komen for the Cure, 2007; Susan G. Komen NC Triangle Affiliate, 2009b). The county, herein referred to as “Risk County” in order to protect the identity of study participants, is located in rural eastern North Carolina and has a population of approximately 56,000, with females making up 53.5% of the population (Susan G. Komen NC Triangle Affiliate, 2009b; U.S. Census, 2013). The average age of the population in Risk County is 40.63 years, with a majority of the County population (58%) being African American (N.C. Office of State Budget and Management, 2008; U.S. Census, 2013). At the time of this study, County data indicated that 19.6% of the population lived below the poverty line, 34.4% of the population had less than a high school education (age 25 years and over), and 15.3% of the population was unemployed (U.S. Census, 2005).

The breast cancer incidence rates in Risk County between the years 2006 and 2010 were 162.6 per 100,000 persons (North Carolina Division of Public Health and State Center for Health Statistics, 2013; Risk County Health Department, 2010). Between the years 2007 and 2011, the average death rate from breast cancer in this County was 34.5 per 100,000 persons (NC Central Cancer Registry, 2013c), in comparison to a national average breast cancer mortality of 22.6 per 100,000 persons between the years 2006 and 2010 (SEER, 2013). Although breast cancer mortality rates were considered to be stable in this County, the County continued to be considered a priority by Susan G. Komen due to its above average breast cancer mortality rates (NCI, 2007).

Beliefs and Attitudes about Cancer and Breast Cancer

Women and cancer

Women's beliefs and attitudes about breast cancer vary. Some women believe cancer is a "death sentence" once someone is diagnosed with it, while others believe it has something to do with personal attitude, such as choosing to be optimistic or pessimistic after a diagnosis (Swinney & Dobal, 2011). In line with fatalism, some women believe that a "medical intervention" would not make any difference in their diagnosis or outcome (Lannin, Mathews, Mitchell, & Swanson, 2002). Many women choose not to find out if they have cancer, preferring instead to "be ignorant" (Lannin et al., 2002; Swinney & Dobal, 2011). In a study that examined participant's views of cancer fatalism, 80% of the participants in the study had at least one belief of fatalism regarding a cancer diagnosis (Sheppard, Davis, Boisvert, Jennings, & Montalvo, 2011).

African American women and cancer

Lannin et al. (2002) identified that cultural factors, such as beliefs, attitudes and knowledge about cancer, significantly varied by race. African American women's beliefs and attitudes related to cancer included viewing cancer as fatalistic, lacking spousal support upon diagnosis, and prioritizing taking care of their families before taking care of themselves. In a study examining African Americans' perceptions of top health threats, 80.9% of participants listed one or more types of cancer as a health threat (Sadler et al., 2005). One study found that the majority of those who held fatalistic views of cancer were African Americans of lower socioeconomic status who were over the age of 50 years and less educated (Gullatte, Brawley, Kinney, Powey, & Mooney, 2010). Another study focusing on fatalism found that African

American women were more susceptible to fatalistic views than Caucasian women (Gullatte et al., 2010).

Women in some African American communities have heavily weighted spousal support in the face of cancer. Women tend to fear that their spouse will leave them if they receive a cancer diagnosis. Some women may be reluctant to discuss a potential cancer diagnosis with their male partners because of a perceived lack of support from him (Lannin et al., 2002; Lopez et al., 2005; Swinney & Dobal, 2011). In addition to spousal support, supporting and taking care of one's family has been viewed as equally important for women in African American communities (Lopez et al., 2005; Swinney & Dobal, 2011). The majority of African American women's time and energy has been observed to focus on placing the needs of their families before their own needs and on their service as caregivers for their families (Lopez et al., 2005; Swinney & Dobal, 2011). The aforementioned studies identified supporting one's family and receiving support from their spouses as significant attitudes and beliefs regarding cancer for some African American women. The researchers in these studies also observed that a fatalistic view related to a cancer diagnosis was common among African American women.

Women and breast cancer

Women, particularly American women, fear losing their breast to a mastectomy more than dying from breast cancer (Thomas, 2006). According to Thomas (2006), although many women believed it was inappropriate to talk about breast cancer and their breast, they acknowledged that mammography screening was appropriate. Some women, in general, believed that talking about breast cancer and about one's breasts was unacceptable. However, in a different study, more than 91% of women believed women over 50 years of age should have a mammogram (Lannin et al., 2002). When asked about their relationship with men and breast

cancer, women believed that most men would want to know if the women in their lives developed breast cancer (Lannin et al., 2002).

African American women and breast cancer

There are significant differences between Caucasian women and African American women when examining their beliefs about breast cancer (Lannin et al., 2002). According to Lannin et al. (2002), these significant differences included: a) attitudes toward doctors and health professionals, b) African American women's belief that men would leave their significant others because of breast cancer, c) African American's belief that cancer spreads when it is exposed to air or cut into (as in the case of surgery), and d) spiritual beliefs. Lannin et al. (2002) surveyed about 1,500 African American and Caucasian women in a population-based study. The researchers examined influential factors related to the diagnosis, treatment, and outcome in African American and Caucasian women. Researchers found in their survey that 58% of African American compared to 80% of Caucasian women believed doctors and health professionals should be the most trusted of people to decide how to treat one's cancer (Lannin et al., 2002).

In a qualitative study utilizing focus group interviews, Masi and Gehlert (2008) examined perceptions of breast cancer treatment among 280 African American women. Participants said that they did not trust physicians and medical establishments. Participants in this study expressed concern that African American's did not receive as high quality of care in general as their Caucasian counterparts, with quality of care thought to be affected by patients' type of insurance (Masi & Gehlert, 2008).

Another cultural belief that differed between African American and Caucasian women related to women's relationships with their husbands or male partners. Lannin et al. (2002) found a high percentage of both groups of women who thought that most men would want to

know if the women in their lives developed breast cancer. Yet, 27% of African American women compared to 6% of Caucasian women believed that a man would not be likely to stay with a woman if she was diagnosed with breast cancer. Study findings also revealed that 30% of African American women versus 9% of Caucasian women thought that a man would leave a woman if she had to undergo a mastectomy.

African American women viewed a diagnosis of breast cancer as something that they feared and believed should remain private rather than shared (Lopez, Eng, Randall-David, & Robinson, 2005; Swinney & Dobal, 2011). The women study participants indicated a fear of disfigurement or loss of a spouse due to a partial or total mastectomy. They believed that cancer could rapidly spread if it was incised or the incision was exposed to air (Lannin et al., 2002; Lopez et al., 2005; Masi & Gehlert, 2008; Swinney & Dobal, 2011). About 8% compared to 34% of Caucasian and African American women respectively believed cancer would be lethal if air entered a physician's incision (Lannin et al., 2002). In addition, 31% of Caucasian women versus 48% of African American women believed that cancer could spread if air touched it during surgery. In the study, 86% of African American women interviewed believed that, although a breast lump was not painful, it could still be a serious health concern.

Breast Cancer Detection – Mammograms

Traditional methods used for breast cancer detection consist of mammograms, breast self-examinations, estrogen/progesterone receptor test, MRI, and biopsy (ACS, 2013b). A mammogram is essentially an x-ray taken of the breast and then examined for abnormalities. The American Cancer Society (2013c) recommendations, at the time of this study, were that women aged 40 years and in good health should receive a yearly mammogram. The most recent guidelines for mammography use recommended by the American College of Physicians were for

women who were 40 to 49 years of age to receive screening mammograms after consulting with their physician (Qaseem et al., 2007). Women were advised to seek physician referral for mammograms and determinations about the need for yearly scheduled mammograms (Armstrong, Moye, Williams, Berlin, & Reynolds, 2007; Qaseem et al., 2007; Susan G. Komen for the Cure, 2010a). Chagpar and McMasters (2007) found that the majority of large medical organizations that provided the public with breast cancer screening recommendations, including the American Medical Association, National Alliance of Breast Cancer Organizations, Susan G. Komen Foundation, and National Cancer Institute, recommended women 40 years of age and older have an annual mammogram (Susan G. Komen for the Cure, 2010a).

The percentage of women 40 years of age and older who received a mammogram within the previous two years steadily increased from 1993 to 2010 (National Center for Health Statistics, 2012). In 1993, 59.7% of women over age 40 received mammograms compared to 66.5% of women who received mammograms in 2010. In 2010 and 72.7% of non-Hispanic women (aged 50 to 74 years) in the United States received a mammogram in the prior two years (CDC, 2012). Approximately 73% of African American and Caucasian women had a mammogram in 2010.

Until recently, African American women had lower rates of mammography screening compared to their Caucasian peers. In 1990, the screening rate among African American women was 46.4% compared to 52.2% of Caucasian women (National Center for Health Statistics, 2012). In 2000, 67.8% of African American women received a mammogram in the prior 2 years, whereas 71.4% of their Caucasian counterparts were screened by means of mammography. Mammography use percentages among African American women in 2010 were 67.9% compared to 67.4% of Caucasian women in 2010. From the year 2000 to the time of this study,

mammography screening rates among African American women have remained consistent at about 68%. According to the National Center for Health Statistics (2012), the trends of mammography rates among African American women have fluctuated since 2003, when the rate was 70.4%, to 64.9% in 2005, 68.0% in 2008 and 67.9% in 2010. Rates also varied among different age groups of African American women in 2010. African American women 40 to 49 years of age had a screening rate of 63.5% in 2010. The screening rate of those aged 50-64 years was 74.0% and, for those 65 years of age and older, the screening rate was 60.9%. A study conducted by Miller, King, Joseph, and Richardson (2012) used data from the BRFSS to examine mammography adherence rates among more than 220,000 adult women of different races and ethnicities. About 79% of African American women reported having a mammogram within the past two years compared to 75% of Caucasian women, 75.4% of Hispanic women, 63.9% of American Indian and 73.7% of Asian/Pacific Islander.

Mammography screening is a critical step in the early detection and treatment of breast cancer. Many factors influence women's decision to seek a screening mammogram. Rahman, Mohamed, and Dignan (2003a) distributed a questionnaire to 285 uninsured and underinsured women in Ohio. The researchers used the constructs of the Health Belief Model to form a basis for perceived factors that affected women's adherence to mammography recommendations. Consistent with the Health Belief Model, personal factors such as age, race, and education were considered predisposing factors or factors over which people had no control. Enabling factors included socioeconomic status and having health insurance. Influencing factors or cues to action included a) knowing someone with breast cancer, having a family history of breast cancer, or having current breast problems; b) hormone use and compliance with follow-up recommendations regarding breast health; and c) the role of the aforementioned factors in

adherence to recommendations for mammography. It was found that there was a low adherence to early detection and prevention among the study population and they did not perceive themselves as being at risk for breast cancer (72.2%), yet they did believe breast cancer is a serious disease (89.4%). In relation to viewing mammography screening as beneficial, there was a difference of level of significance among study participants and 87.5% are afraid to have a mammogram because of the fear of something being found from the screening. Nekhlyudov, Ross-Degnan, Fletcher (2003) found that women acknowledged that the positives associated with getting screened far outweighed the negative influencing factors of mammograms. The authors suggested that women seek mammography screening due to its effectiveness in detecting breast cancer and thus preventing death caused by breast cancer.

When identifying factors that influenced women under 50 years of age to be screened for breast cancer, Nekhlyudov et al. (2003) found that many of the decisions that women made in regard to receiving a mammogram were influenced by four major factors: media-driven information, physician recommendation, a woman's own intuition, and having known someone who was diagnosed with breast cancer. Researchers revealed that the women's intentions to be screened, the factors that motivated them, their attitudes towards screening mammography and their attitudes toward breast cancer were recurring trends during the mammogram-related decision-making process of the participants. A case-controlled study of 553 African American and Caucasian women found greater support among women 40 to 65 years of age regarding the perceived benefit of mammography in order to reduce the risk of breast cancer deaths (Norman et al., 2007). The same study also showed that observed efficacy in reducing the breast cancer mortality rate after diagnosis was found to be greater among the older women (aged 50 to 64

years), as compared to their younger counterparts (women aged 40 to 49 years), and among postmenopausal women compared to premenopausal women (Norman et al., 2007).

Women who were 38 to 40 years of age were found to have different motivations for receiving a mammogram compared to their older-age counterparts (ages 41 to 45 years) (Nekhlyudov et al., 2003). The younger women's motivations included knowing someone with breast cancer, feeling responsible for the maintenance of their health, and wanting to be adherent with the screening guidelines since they were aware of the recommendation to begin screening at age 40. In terms of adherence to breast cancer screening guidelines, Rahman, Dignan, & Shelton (2003b) concluded that approximately 40% of 27,778 participants were adherent to breast screening guidelines. The study recruited women of varying races, ages, education and socioeconomic status who completed the Colorado Mammography Project (CMAP). The breast cancer screening guidelines used in this study were that women 50 years of age and older received a biannual mammogram, as well as women 40-49 years of age with a history of breast cancer. Women 40-49 years old with no history of breast cancer received at least two mammograms within a two year period. Study findings revealed that African American women were 24% less likely to adhere to breast cancer screening guidelines and more likely to underutilize screening mammography compared to their Caucasian counterparts (Rahman et al., 2003b). The researchers also identified socioeconomic status, educational attainment, insurance status, age, and family history as predictors of adherence to mammography screening guidelines, none of which were cross-examined with race.

Preexisting knowledge about screening and prevention can be influential in breast cancer screening behaviors, as indicated by findings from a study of 321 African American women conducted by Sung, Blumenthal, Coates, and Alema-Mensah (1997). Study participants were

recruited through a variety of sources in Georgia and were asked to take part in face-to-face interviews. Sung et al. (1997) examined participants' knowledge about breast cancer screening and screening adherence behavior. Study findings revealed that 32% of African American women older than 45 years of age who had little knowledge of screening had received a clinical breast examination compared to 60% of those who had more knowledge. About 13% of women aged 35 to 54 years who had little breast cancer knowledge complied with mammography screening recommendations, while 37% of women older than 55 years of age evidenced compliance by receiving a mammogram (Sung et al., 1997).

Chapgar & McMasters (2007) conducted a study examining the recommended guidelines, trends and use of mammograms and clinical breast exams between the years 2000 to 2005. Using National Health Interview Survey (NHIS) data, the study revealed a decrease in the number of women forty years of age and older who had received a mammogram. The researchers noted a trend among younger age women for their first mammogram (Chapgar & McMasters, 2007; Martin & Wingfield, 2005). Participants who said they received their first mammogram between 30 and 39 years old increased from 26.8% in 2000 to 30.9% in 2005 (Chapgar & McMasters, 2007). In 2000, 40.7% versus 42.1% of women in 2005 said they were 40 to 49 years old when they had their first mammogram. The percentage of women who received a mammogram as part of clinical breast cancer screening increased between 2000 and 2005, but a decrease occurred in the number of women receiving clinical breast exams (Chapgar & McMasters, 2007).

Perceived Barriers

Barriers perceived by women that prevented them from seeking breast cancer screening included a number of influential factors. In a 2009 Community Profile, the Susan G. Komen NC

Triangle Affiliate (2009b) identified a number of barriers and gaps to women receiving breast health screening services in North Carolina. These barriers included: religious beliefs, stigma associated with having breast cancer and being sick, family priorities that relegated women's health to less of a priority, lack of effective health message communication, particularly for ethnic minorities, and pain and discomfort from the screening (Kalsen et al., 2008; Kinney et al., 2002; Susan G. Komen NC Triangle Affiliate, 2009b; Smedley et al., 2003). Davis et al. (2012) interviewed 1,189 female patients in Louisiana who had not been screened for breast cancer in the prior two years. This study revealed similar findings relating to barriers to breast cancer screening.

As identified in the Community Profile, gaps or problem areas in screening adherence included: inadequate availability and knowledge of services, access to transportation, concentration of rural breast health services in one geographical area, and negative community perceptions of providers in these areas, including feeling a lack of respect from providers (Susan G. Komen NC Triangle Affiliate, 2009b). Similar gaps were also identified in research studies conducted by Kinney et al. (2002), Kalsen et al. (2008), and Smedley et al. (2003).

Risk County, North Carolina was seen as priority county in the United States as stated in the national Komen Breast Cancer Mortality Report (Susan G. Komen for the Cure, 2007). The perceived barriers within the Risk County were listed in the report as: “a) inability to afford doctors office and medical co-pays, b) limited access to primary health providers, c) lack of reliable and easily accessible and affordable means of transportation, d) limited resources for childcare, e) inability to take time off work for doctor's appointments, and f) if diagnosed, an added burden of psychological strain and financial stress associated with treatment” (p.3).

According to the University of Maryland Medical Center (2011), spirituality is viewed by many people as, “a belief in a power operating in the universe that is greater than oneself” (p.1). Swinney and Dobal (2011) conducted a study examining beliefs and attitudes of 57 older African American women through the use of focus groups. They observed that some African Americans value spirituality and faith as an important component of life. Many African Americans turn to prayer, especially in hard times, sickness, or when “blessed by God either for recovery from a serious illness or for having good health” (Swinney & Dobal, 2011, p. 13). Some African American women believed that prayer would aid them in resolving negative life circumstances (Swinney & Dobal, 2011).

A reliance on God to cure cancer, including breast cancer, reflects a cultural belief that a cure of disease is possible without medical treatment (Lannin et al, 2002). Findings from a study that examined the religious beliefs of African American breast cancer survivors revealed that 96% of the women interviewed said that they believed God would work through the medical staff to cure their cancer. Sixty-five percent of African American women in the study believed that the strength of their faith determined if their breast cancer would be cured. The women typically turned to God and to prayer to ask God for direction (Swinney & Dobal, 2011). In another study, African American women understood that a breast cancer diagnosis was a “test or demonstration from God that they were on the right spiritual path” and, “God would take care of them” (Lopez et al, 2002, p.109). Believing that everything related to God or God’s plan were other examples of African American women’s beliefs about a breast cancer diagnosis, screening, and treatment.

Rural Settings and Breast Cancer

According to the Committee of the Future of Rural Health Care (2005), compared to urban populations, those who lived in rural areas exhibited poorer health behaviors. Populations that resided in rural areas faced many challenges when it came to accessing health care. These challenges included: transportation, lack of access to care, lack of providers in rural settings, and low-levels of health literacy (Green-Hernandez, 2006; Committee of the Future of Rural Health Care, 2005). Rural residents were challenged to have access to their own transportation or find an alternative means of transportation to medical appointments (Green-Hernandez, 2006). Health professionals located in rural areas are often in short supply, thus resulting in a lack of access to health care for rural populations (Committee of the Future Rural Health Care, 2005). Rural populations often had low levels of health literacy and health behavior understanding, and engaged in practices that reduced their practice of positive health behaviors (Committee of the Future of Rural Health Care, 2005).

In the study conducted by Davis et al. (2012), researchers assessed the women's knowledge, beliefs, experiences, and barriers regarding mammograms. Rural women identified more with knowing someone who had breast cancer compared to their urban counterparts. Approximately 13.0% of rural participants compared to 20.1% of urban participants said they had no knowledge about any type of test to detect breast cancer, but 93.1% knew what a mammogram was. Almost two thirds of rural women (63.3%) perceived that getting a mammogram was uncomfortable; approximately 4% of rural women believed it was a painful procedure (Davis et al., 2012).

African American women living in a rural setting had lower mammography rates (63.0%) compared to their urban counterparts (71.6%) (Husani et al., 2005). Husani et al. (2005) showed

that participants in a rural church-based educational program about breast cancer increased their mammography rates from a baseline of 63.0% to 68.5% three months post intervention and 74.1% in six months post intervention.

Husaini et al. (2005) detected differences in mammography screening beliefs of rural African American women compared to African American women living in urban areas. Rural African American women believed that because their breasts were healthy, they did not need a mammogram. Rural residents also believed that mammograms were embarrassing and medical tests like mammograms could not be trusted. Husani et al. (2005) also identified a barrier to screening for rural participants in that the women said that they did not want to get a mammogram because of their religious beliefs.

As observed in the reviewed literature, there were differences between the reported incidence and death rates of breast cancer among Caucasian women and African American women at a national, state, and county level. There were also differences in beliefs related to cancer and breast cancer among women in general and Caucasian women and African American women in particular. The literature also revealed differences relating to perceived barriers to screening among Caucasian women, African American women, and women residing in rural areas versus urban areas.

Significance of Study

African American women experience significantly high mortality due to breast cancer compared to other racial or ethnic groups. In an effort to address this important disparity, a need existed to examine African American women's attitudes, beliefs, barriers and challenges regarding breast cancer screening. A particular need existed to explore the perspectives and experiences of African American women who lived in or near a geographical area that had one

of the highest breast cancer incidence and mortality rates in the State of North Carolina. Through what was learned from the women who participated in the study, health educators will be able to design and implement breast cancer-related health promotion and prevention programs that are tailored to this priority population. Women's perceived barriers, attitudes, and beliefs regarding breast cancer and breast cancer screening has been explored in the peer-reviewed literature, but such issues have not been investigated from the perspective of rural African American women, a population recognized as high-risk for breast cancer mortality. This study thus aimed to explore the breast cancer and breast cancer screening perceptions and experiences of African American women, particularly those residing in a rural area characterized by a markedly elevated breast cancer incidence and mortality.

The following chapter will present the research methods associated with this study. The researcher will address the rationale for a qualitative approach and the processes employed in this study to address the research question.

CHAPTER 3: METHODOLOGY

This study aimed to explore breast cancer and breast cancer screening from the perspective of rural African American women who resided in rural eastern North Carolina. The researcher addressed the following research question: What are the perspectives and experiences related to breast cancer and breast cancer screening of African American women residing in rural eastern North Carolina? She sought to gain insight into breast cancer and breast cancer screening by inviting an emic or insider's perspective and thus used a qualitative approach that included the analysis of focus group interview data drawn from three focus group interviews that involved 17 African American women.

Qualitative Design

Rationale for Selecting Qualitative Methods

A qualitative approach in this study was selected for several reasons. Qualitative data provides insight into individuals and their personal experiences (Patton, 2002; Glaser & Strauss, 1966). Qualitative research methods yield deeper understanding, depth, detail, and meaning related to these experiences (Glaser & Strauss, 1966; Patton, 2002). A need existed to learn more about the factors that impacted rural African American women's decisions regarding breast cancer screening, particularly screening by means of a mammogram. Qualitative research that focused on women's experiences of breast cancer screening existed but many of these studies focused on the perceived barriers, attitudes, and beliefs of women in general, not necessarily African American women or African American women who resided in rural areas. Because African American women have the highest breast cancer mortality rates in the U.S. and because rural residence is associated with health care access barriers and other issues, a need existed to explore the perceptions and experiences of African American women who lived in rural areas.

Insights gained from this research study could be used to inform and tailor future breast cancer screening interventions to this high-risk population.

The research literature indicates that qualitative research is suitable and effectively used when the researcher was interested in describing context and the settings in which, in this case, breast cancer screening decisions took place (Creswell, 2007; Glaser & Strauss, 1966). Much of the literature has explored adherence to mammogram recommendations among African American women by asking them if and how often they received mammograms and then comparing these data to recommendations offered by national health organizations. Also, some peer reviewed literature examined cultural attitudes and beliefs about lowering breast cancer mortality rates or breast cancer rates in general, but have not specifically explored the breast cancer screening perspectives of those at high-risk for breast cancer such as rural African American women.

This study explored the breast cancer knowledge and screening practices of African American women in rural eastern North Carolina. At the time of this study, African American women had the highest mortality associated with breast cancer in the U.S. and second highest breast cancer incidence in the United States, thus providing further evidence for the need of the present study.

Rationale for Secondary Data

The researcher used a sub-set of data in this study that was drawn from a larger unpublished study (Burke et al., 2009). No analysis of this sub-set of data had been previously conducted. The research question addressed in the present study differed from that of the original research study primarily in terms of participants' race and ethnicity (Long-Suthehall, Sque, & Addington-Hall, 2011; Heaton, 1998). A concerted effort by the researcher to recruit

rural African American women living in eastern North Carolina as the population of interest for an IRB-approved qualitative study on the topic of breast cancer and breast cancer screening proved unfruitful. The difficulty the researcher had in accessing this population (Long-Sutchall et al., 2011; Heaton, 1998) thus gave impetus to a secondary analysis of data that were contributed by this population during a larger qualitative study that involved a wider range of races and ethnicities. The use of secondary research could, as Glaser was quoted, ‘lend new strength to the body of fundamental social knowledge’ (Long-Sutehall et al., 2011, p. 336). The current study thus provided in-depth findings related to a specific sub-set of the population who participated in the primary study (Long-Sutehall et al., 2011; Heaton, 1998).

While there are numerous benefits associated with using secondary data analysis, there are also concerns related to theoretical and ethical issues. Researcher biases can be intensified due to the use of secondary data analysis, making it important for the researcher to reflect on the process and analysis and to be reflexive in terms of the researcher’s personal biases, assumptions, beliefs, and values (Thorne, 1998; Glaser & Strauss, 1966). No problems arose in this secondary analysis related to the theoretical approach, research design, or research question addressed in the initial study (Thorne, 1998; Long-Sutehall et al., 2011), since the research question was similar to that used by the researcher in the analysis of the sub-set of data.

Researcher’s Qualifications

As the principal investigator in this study, the researcher was responsible for all research study activities, particularly in the area of data analysis and reporting findings. The researcher is a Master of Arts in Health Education candidate in the Department of Health Education and Promotion at East Carolina University. Through her graduate program, she received formal training in conducting qualitative research. Her formal training consisted of engaging in research

projects with a faculty mentor, completing a graduate-level qualitative research methods course, certification with the University and Medical Center Institutional Review Board (UMCIRB) using CITI training modules, and receiving approval from the UMCIRB to conduct this study. In addition, the researcher has experience conducting qualitative research. In addition, her thesis committee provided oversight and guidance for this study.

Researcher's Expectations, Assumptions and Biases

Because this study involved qualitative inquiry, the researcher recognized the possibility that her biases, assumptions, values, and beliefs might influence her analysis and interpretation of the data. She thus engaged continuously in reflection and reflexivity during the course of this study. The researcher believed that, based on preliminary unpublished data, prior published research, and direct observation of the population, many African American women were not aware of the need for breast cancer screening or, because they lived in rural areas, faced important health care access barriers. Prior to the initiation of the study, the researcher assumed that the main barrier to mammography that rural African American women from rural eastern North Carolina experienced was a lack of access to health care. The researcher also assumed that access problems were due to transportation issues, a lack of financial means, no proximity to clinics, women prioritizing caretaking of their families above themselves, or a lack of childcare. In addition, the researcher believed that some potential participants may have been unwilling to participate in the study due to their personal desire for privacy and their reluctance to share their personal concerns or experiences related to breast cancer and breast cancer screening.

Population and Sample

Participants were recruited with the help of a community gatekeeper. The gatekeeper served as a leader on the breast cancer taskforce for the area and worked with women in the

geographical location of the study to promote breast cancer awareness and screening. The gatekeeper served as one of the facilitators of the focus group interviews from which the researcher drew the sub-set of data used in this study. Participants in this study were recruited via the Risk County Breast Cancer Taskforce listserv, the Risk County Chamber of Commerce, a social service childcare agency, and a regional Partnership for Children and a Housing Authority via flyers and email. A faculty member at East Carolina University served as a trained and experienced co-facilitator for the focus group interviews.

According to Crosby et al. (2006), the recommended sample size for focus group interviews range from 6 to 15 participants. Data from a sample of 17 African American women residing in rural eastern North Carolina and ranging in age from 35 to 87 years contributed to the current study. The co-facilitators conducted three focus groups that were collectively comprised of 17 African American women. Ten female participants comprised the first focus group interview, three women engaged in the second focus group interview, and four women participated in the third focus group interview.

The facilitators employed purposeful, homogeneous sampling in the original study. Purposeful sampling “focuses on selecting information-rich cases whose study will illuminate the research questions under study” (Patton, 2002, p. 230). These information-rich participants provided insights and a deeper understanding compared to what might have been possible in quantitative studies (Patton, 2002). Homogenous sampling provided in-depth descriptions of participants whose characteristics proved important to the research topic (Patton, 2002).

Ethical Issues

Prior to beginning the study, the researcher successfully completed an IRB training course. The successful completion of the training course allowed the researcher to work with

human subjects, while properly protecting their identities. Consistent with Anthony's (2010) recommendation, the researcher sought approval from the university institutional review board to use the sub-set of data from the original research study after receiving permission to use the data set by the original focus group interview facilitator (Dr. Sloane Burke). The researcher received IRB approval to conduct the study (Appendix A).

Data Collection Methods

This study is an analysis of secondary qualitative data that explored the perspectives and experiences of African American women residing in eastern rural North Carolina about breast cancer and breast cancer screening, with a particular focus on mammogram screening. Dr. Sloane Burke and Ms. Michele Cherry originally facilitated data collection in association with a study sponsored by the Susan G. Komen for the Cure.

Two trained, experienced co-facilitators conducted all focus group interviews, including the three focus group interviews involving African American women that comprised the sub-set of data analyzed in this study. The facilitators used an interview guide and a similar process to conduct each focus group interview. Participants in at least one focus group knew each other and one of the facilitators, but it was uncertain if participants knew the women who participated in any of the other focus group interviews. Those who participated in the audio-recorded (with permission of participants) focus group interviews included African American women participants and two facilitators. One of the facilitators served as the primary moderator for the interview and the other co-facilitator took notes during the interviews and interjected comments and questions when appropriate. The second facilitator was a gatekeeper of the community and thus was known to those who chose to participate in the study, an attribute that may have encouraged participation. The interview guide that the facilitators used served as a memory tool

and aided them in ensuring the continuity of questions asked of all interview participants (Appendix A).

Each focus group interview that involved African American women took place at a different site: a community center meeting room, a hospital meeting room, and a private room at a county housing authority. Prior to conducting the focus groups, the facilitators engaged in an informed consent process that culminated in each participant signing written consent to participate in the study.

According to Grudens-Schuck, Allen, and Larson (2004), focus group interviews are a data collection tool that can be used to “generate valid information important to the advancement of programs, communities, and organizations” (p. 9). The primary facilitator initiated each of the focus group interviews by explaining the purpose and procedures associated with the study and inviting participants to pose questions or express any concerns they might have had. Once participants were satisfied with the information provided and responses to their questions, they gave their voluntary written consent to participate in the study. The primary researcher also reiterated the participant’s ability to withdraw from the interview at any time.

In order to protect their identities, the primary facilitator assigned letters to each of the participants and referred to them thereafter by their letters. The focus group was conducted in a “round robin” fashion where each participant was asked to respond to the same question. The facilitator took field notes, including making notations about such things as participants’ gestures, facial expressions, attentiveness, and general notes about what the participants were saying. The facilitator responsible for note taking maintained a running list of who was speaking to ensure accuracy in data collection. The duration of each of the three focus group interviews ranged from about one to three hours.

The primary facilitator met with three participants for the first focus group interview held at a community center conference room. The facilitators and participants met in a conference room that was equipped with a conference table and chairs. The second focus group interview was conducted in a similar manner to the first focus group. The second interview consisted of 10 participants and was conducted in a private room in a Housing Authority setting. Two facilitators and the participants met in a recreation room that contained one long fold out conference table and enough folding chairs to accommodate participants and facilitators. The third interview, conducted in a conference room at a local hospital, involved four African American participants and the two facilitators and was conducted in a manner similar to the preceding focus group interviews.

During the interviews, the participants shared their knowledge of breast cancer, breast cancer screening (BSE, clinical exam and mammograms), breast cancer screening guidelines, and their views about how breast cancer screening affected the communities where they resided. They also addressed perceived facilitators and barriers to breast cancer screening.

Study Credibility

The researcher used several strategies to ensure research design credibility. The researcher identified and bracketed her beliefs, biases, and preconceptions before and while conducting the data analysis. She engaged in bracketing, a technique in qualitative research where the researcher sets aside her experiences and beliefs to prevent compromising the analysis and interpretation of data.

No detrimental environmental issues were identified during the three interviews. At the initiation of data collection the facilitators reassured participants that they could leave the discussion at any time or discontinue their participation in the study entirely without negative

consequences. Threats to confirmability and credibility were addressed through the creation and maintenance of an audit trail that consisted of data transcriptions, field notes and observations, informed consent documents, artifacts, and articles that contributed to the literature review. The researcher maintained a reflexivity journal in which she wrote weekly. Her entries consisted of reflections on the process of researching and analyzing data and chronicled her engagement in reflexivity during the process of analyzing data and writing findings (Appendix D). She maintained a research log in order to document the process of searching for literature related to the topic of the study (Appendix E). Analysis and interpretation memos and a codebook were also created and updated by the researcher (Appendix F & Appendix G). The audit trail provided evidence of the systematic approach she used in this study, enabling anyone external to the study to follow the process the researcher took to conduct the analysis and interpretation of the data. According to Glaser and Strauss (1966), reflection during the analysis of data is important. The researcher thought holistically about the data, her analytical experiences, the coding process, and writing findings.

The researcher maintained the following documents as a part of the audit trail for the secondary analysis of data. The audit trail included her reflections on the process of the study and personal reflexivity (Appendix D), a chronological research log of actions and events associated with the study (Appendix E), a codebook used during the data analysis process, (Appendix G) and reflective insights and interpretation regarding the analysis of data (Appendix F).

Data Analysis

One of the facilitators for the interviews included previously recorded field notes of the participant's responses, expressions, and tone as part of the sub-set of data analyzed for this

study. The focus group facilitators transcribed the recordings verbatim. The researcher repeatedly read the transcripts of the three focus group interviews with the African American women participants. Rereading the transcriptions enabled the researcher to identify initial “coding categor[ies]” (Patton, 2002). It was during this process that the researcher began to indicate codes in the margins of the transcripts. The purpose of coding data during the analysis process, was to simplify the complexity of translating fieldnotes, verbatim transcripts, and other observations noted during the study (Patton, 2002). After applying initial codes to segments of data that ranged from parts of sentences to paragraphs, with the possibility of coding the same data segment with more than code, she then collected all similarly coded material and read through the narrative excerpts within each code.

After multiple times of reading the narrative excerpts within each code, the researcher combined related codes or recategorized some codes and initiated the development of a codebook (Appendix G). The codebook contained abbreviations and explanations of finalized codes as well as the inclusion and exclusion criteria for each code. She recoded the transcribed data referring to the codebook as a guide for each code. After segmenting and rereading the data according to each code, she began to identify themes that emerged from the data. After finalizing themes, the process of data analysis continued as the researcher wrote and revised study findings. In Chapter four, the researcher described the research sample and setting and presented findings associated with this study.

CHAPTER 4: FINDINGS

The researcher used a qualitative approach to conduct a secondary analysis of qualitative data related to rural eastern North Carolina African American women's perceptions of and experiences with breast cancer screening, with a particular focus on mammogram screening. The study aimed to address the following research question: What are the perspectives and experiences related to breast cancer and breast cancer screening of African American women residing in rural eastern North Carolina?

The researcher coded and analyzed a subset of focus group interviews that involved African American women. The data were drawn from a larger study of breast cancer screening. The analysis of data specifically related to African American women's perspectives and experiences was original to this thesis. In this chapter the researcher will describe the study participants, settings, and findings associated with this study.

Study Participants

Seventeen African American women aged 35 to 87 years residing in rural eastern North Carolina voluntarily agreed to participate in one of three focus group interviews, each of which lasted from one to three hours. All of the participants (100%) contributed to the focus group interview at least once. The majority of participants (71%) had received at least one mammogram prior to study participation. One participant was a breast cancer survivor and 83% of the women had some form of health insurance. Although educational attainment varied, almost half of participants' reported having a high school education (47%) and income level varied. A summary of the participants' demographic information is included in the following table:

Table 1: Participant Demographics

Characteristic	N	Percentage
Age		
30 – 40	3	18%
41 – 50	2	12%
51 – 60	2	12%
61 – 70	5	29%
71 – 80	0	0%
81 – 90	2	12%
None Listed	3	18%
Marital Status		
Single	3	18%
Married	3	18%
Divorced	3	18%
Widowed	4	24%
Other	1	6%
None Listed	3	18%
Employment		
Part Time	2	12%
Full Time	6	35%
Retired	7	41%
Not Employed	2	12%
Education		
> High School	2	12%
High School	8	47%
Some College	1	6%
College	3	18%
None Listed	3	18%
Health Insurance Status		
Yes	14	83%
Gov't	8	47%
Private	3	18%
None Listed	3	18%
No	3	18%
Mammogram		
Yes	12	70%
No	1	6%
None Listed	4	24%

Thematic Findings

The qualitative analysis of the interview data revealed several themes that emerged in relation to the participants' perceptions and experiences of breast cancer and breast cancer screening. These themes included knowledge and beliefs about breast cancer, influences on breast cancer screening behaviors, personal experience with screening, emotional reactions to discussing breast cancer and breast cancer screening, and promoting breast cancer screening. In the following section the researcher examines these themes in greater detail.

Focus Group Observances Summary

Participants of the first focus group expressed that they were knowledgeable about the breast cancer screening guidelines, were influenced by a diversity of factors in engaging in breast cancer screening, and identified personal health insurance as the primary barrier to obtaining breast-related health care. All of the participants in the second focus group shared during the course of the interview. Some participants in the second interview indicated a lack of knowledge about breast cancer and breast cancer screening or believed that breast cancer screening guidelines didn't apply to them. They identified numerous factors prohibiting them from receiving regular mammograms, but were aware of mammogram resources available to them in the county where they resided. The participants of the third focus group disclosed a lot of information about their personal experience with breast cancer screening and their knowledge regarding breast cancer. They also mentioned time being a factor for not going to the doctor, possibly geographical indicators as to why they think the Risk County has higher rates of breast cancer, and suggested health fairs and employee health fairs as ways to increase knowledge about breast cancer and breast cancer screening among women.

Knowledge and Beliefs about Breast Cancer

The focus group participants shared their knowledge and a wide range of beliefs about breast cancer and breast cancer screening. The beliefs they shared included self-perceived level of knowledge about breast cancer, people who they believed were at risk for breast cancer, screening for breast cancer, discussing breast cancer with others, and the cause of breast cancer, each of which will be discussed below.

Self-perceived level of knowledge. Several focus group interview participants offered self-perceived low levels of knowledge about breast cancer or breast cancer risks during the course of the interviews. Four participants, for instance, revealed that they had little or no knowledge about breast cancer through comments such as, *“I don’t know about breast cancer,”* or *“I don’t know that much about breast cancer.”* Study participants openly recognized breast cancer as a *“serious”* or *“deadly disease”* or implied such perceptions by expressing concern for other women who had experienced breast cancer or for themselves related to the results of breast cancer screening.

Beliefs about at-risk populations. The women who participated in the study shared insights about the individuals they believed were at risk for developing breast cancer. The categories of risk that they spontaneously addressed included age, heredity, race, and gender, with some participants acknowledging that men as well as women could experience breast cancer.

Age. When considering risk, many participants said that age was a factor in developing breast cancer, with most indicating that middle or older age women experienced greater risks. One participant said, for example, *“I think women, older women’s usually get it earlier than the young.”* In contrast, however, one participant contended that, *“any age and any woman can get*

sick [with breast cancer]. It's not based on a certain age or time... It can happen anytime." This same person also clarified that, in her opinion, there was *"no particular person who's more susceptible to [breast cancer] than anybody else."*

Heredity. Participants generally recognized that the risk of breast cancer could be hereditary or, in one participant's words, could *"run in families."* One woman said she knew it was in *"your genes"* but then inquired, *"What about someone [who] because they have the gene they have to have their breast removed? Is that necessary?"* Although the inherited risk for breast cancer was acknowledged, some women attributed a lack of family history to a lack of risk. One woman in particular believed that, since breast cancer did not run in her family, she was not at risk and, in any case, she believed that her *"positive attitude keeps [her] healthy."*

Race. Participants who acknowledged that race might play a role in breast cancer risk identified primarily Caucasian or African American women as potentially vulnerable. No one specifically mentioned women of other races or ethnicities in the context of risk and not all participants agreed that distinctive differences in risk existed between African American and Caucasian women.

One participant identified African American women as individuals at particular risk for breast cancer; another participant wondered aloud if *"black minority people"* were more at risk. A participant shared that she had initially thought middle-aged white women were the only ones who got breast cancer until a girl she knew was diagnosed with breast cancer and, *"once she had it, [the participant] started to see all kinds of women with breast cancer."* One woman's observation of, *"no distinction between black women and white women,"* regarding risk was echoed by that of another woman who participated in the interview. The second woman raised the possibility of factors other than race playing a role in increased breast cancer risk. She said,

One of the things that shocked me...because someone made the comment to me is Black women are the candidates for everything. Because low income Black women ... Black women are candidates for everything. We go through everything. When the research came out there was nothing to support that. There is no difference between black women and white women, even no difference between women who have insurance and women who don't. So it's gotta be something else.

Gender: Men's risk. During the focus group interviews, some women questioned the group about the possibility of breast cancer in males. One participant, after contending that *"anybody, anyone [can have breast cancer],"* went on to ask if men could have breast cancer as well. Three women confidently acknowledged that it was possible for men to experience breast cancer. As one of these participants said, *"anyone is capable of getting it and even in rare cases in men."*

One woman mentioned that her source of information about breast cancer in men was a television program and information she received about different types of medical problems offered at a hospital she visited. She heard that men as well as women were at risk for breast cancer based on a medical program that she had seen. She also said she had been to the hospital and seen different types of *"medicine [medical information] and stuff that they show, that mens have breast cancer like womens."*

Beliefs about breast cancer screening. Although individual focus group participants mentioned breast cancer detection by using of one or more strategies, including breast self-examination, clinical breast examinations, and mammography, they were most familiar with breast self-examination as a means of detecting breast cancer. The rationale for screening was

shared by one participant who commented that, “*an ounce of prevention is worth a pound of treatment.*”

Breast self-exam. Participants in two of the focus group interviews mentioned breast self-examination as a means of detecting breast cancer. Some of them said that they knew how to perform a breast self-examination (BSE) and reported that women should examine themselves on a monthly basis. A few women proclaimed that BSE was the extent of their knowledge about breast cancer and breast cancer detection. Others went on to explain that they were checking their breasts not only for the presence of lumps, but also for evidence of “*soreness.*” Breast soreness was mentioned more than once during the focus group interviews as a symptom of possible breast cancer. One woman, for example, proclaimed that detecting breast soreness would serve as an impetus for her to visit a doctor to have her breasts checked.

The women in this study generally understood the importance of breast cancer screening and measures such as BSE so that, in the words of one participant, “*[they] can be on top of things and catch it [breast cancer] early.*” One participant challenged the necessity of mammograms and clinical breast exams since a woman she knew who regularly received negative mammogram and clinical breast exam reports found her breast lump herself and the lump proved to be malignant.

They never found nothing until one particular day she had decided when she took a bath she would check herself and that’s where she found the lump. But the lump was never found while she was doing the mammogram and the clinical exam...only when she did it herself. And she said they found it and both of her breasts had to be removed.

Clinical breast exam. In terms of breast cancer detection, a few participants affirmed the importance of breast examinations performed by health care providers. One woman, for

example, said that she would go to a physician only if she had “*soreness or... coating around the breast.*” Others contended that they would seek assistance from a health care provider if they believed they were “*at risk*” for breast cancer. One participant, who experienced no clinical exam on physician’s visits, reported her experience as follows: “*When you go to the doctor, they don’t self exam you, they just send you for your mammogram.*”

Mammography. About one quarter of the focus group interview participants shared insights about mammography screening as a means of breast cancer detection. These participants acknowledged the importance of mammograms when speaking with the other women in the interview and shared their awareness that women should receive them “*often*” or “*every year.*” Two of the six participants who spoke about mammograms indicated a recommended age for mammography screening that was “*between 40 and 50*” years of age.

A participant observed that women who were over childbearing age believed that, “*they do not need to get mammograms.*” She based this comment on knowing women who had not received a mammogram in 20 years because they were beyond the age when childbearing was possible. The women to whom she referred believed that women older than childbearing age had a decreased risk for breast cancer and thus did not need mammograms. She linked a lack of awareness about the need for mammography among older age women with a tendency for women to have advanced stage cancer when they were eventually screened. She said,

As a result of a lump or some kind of discharge or something in the breast, [women get screened and find that] they’re in stage IV or stage III or one of the later stages of breast cancer.

One participant associated women's failure to engage in clinical exams and mammograms to their denial that something significant may be wrong and their disinclination to hear that a problem exists. She said,

I believe if we would get checked more at an early stage ... I have these checkups and mammograms, I have them every year... You may just be saving yourself from a lot of things if you just get checked often enough. You know sometimes we don't do it because we are afraid to [go to] the doctor, but we might be hurting a bit, but we don't want to go to the doctor because we feel like the doctor is gonna say, 'yes,' and we don't want to hear it. And then you mess around a long time, it's almost too late to get in there.

A participant who was a breast cancer survivor at age 37 recounted her experience with mammograms. She was the first person in her family to have breast cancer and knew the guidelines were to wait until age 40 to have a mammogram. Based on her experience, she believed that *'they need to do away with that [age-specific guideline].'* She goes on to explain,

I feel that, being a woman, if you are 20 and you desire to go have a mammogram, then I feel that you should have one. Just argue with your doctor because he's gonna say or she's gonna say, 'No you're too young'. But go anyway because, like me, if I had waited 'til I was 40...I was 37... If I had waited 'til I was 40 I wouldn't be with y'all here today.

For one older age participant, personal beliefs about her own life expectancy influenced her disinclination to be screened for breast cancer. She said, *"I don't [need] to [be screened] at the age I am now. I feel like it's not too very long that I go home [die] anyway ... I feel like why should I worry?"*

Beliefs about discussing breast cancer. Participants shared that conversing about breast cancer was not something that commonly occurred in their communities. In fact, one participant

said that her community viewed such a topic of discussion as “*taboo.*” The same participant explained that the word, “*breast is an ugly word ... You’re talking [about] under your clothes...It’s a no no.*” She said that she has lived in the same geographical area for many years yet had never heard the topic of breast cancer mentioned. She said,

I’ve never sat around and ... talked about breast cancer...Nobody talks about it. In this neighborhood – I’ve been here 33 years, I’ve never heard anyone mention breast cancer.

Another participant echoed the experience of silence regarding breast cancer. She said that, in contrast to her personal experience, breast cancer was something that should be more openly discussed at all ages, especially during the early teen years.

Direct experience with breast cancer may change individuals’ inclination to talk about their experience. One participant shared the story of her sister being diagnosed with breast cancer and then going through treatment. She said that her sister initially did not want to talk about her diagnosis but then found that sharing her experience was helpful in coping with the experience. She said,

She found out that the more that she talked about it, the better she got along with it and went through everything. And so now you can’t stop her from talking about it ... She just talks about it, talks about it with anybody.

Beliefs about the cause of breast cancer. Some focus group interview participants shared their knowledge and beliefs about what they perceived to be the causes of breast cancer. The causes they mentioned included breast injury, cancer as an infectious agent, cancer as a “root” that keeps “sprouting,” and cancer due to milk that clogged the breast. For men, they speculated that chest muscle size might increase their risk of breast cancer.

According to one participant, the origin of cancer could be, *“sleeping in the bed the wrong way and bruise[ing] your breast or whatever and get cancer.”* Another participant asked if cancer had a root that, *“when it spreads, sometimes doesn’t it kill and the root is left and it’s never been got out because it’s sprouting all the time?”* One woman believed that since women had milk in their breasts, they could experience breast cancer when the milk was not completely extracted and the breast became clogged. This participant’s sister had breast cancer and had informed her about this possibility.

Two women raised the possibility that cancer could be communicable during the interviews though, for a woman who learned that her biopsied lump was not, in her words, *‘contagious,’* it might have been an issue of misunderstood terminology. Another woman, however, inquired if breast cancer was *“something that can be caught?”* An additional area of concern for one participant related to cancer recurrence in an area of the body that differed from the original site. Seemingly alluding to the possibility of metastasis, this participant asked the group, *“Does it hit one spot and hit something else?”*

Conjecture about why men experience breast cancer occurred to a limited degree during one focus group interview. A participant in that interview, for instance, wondered if men who had larger *“pecs”* (pectoralis muscles) were at greater risk, *“because some larger men, they actually look like they have little boobs.”*

In summary, the women who participated in the focus group interviews discussed wide-ranging beliefs and knowledge about breast cancer, breast cancer risk, breast cancer screening, the appropriateness of discussing breast cancer in their faith communities, and their beliefs about possible causes of breast cancer. In the following section, participants’ perspectives about what influences breast cancer screening behaviors will be addressed.

Influences on Breast Cancer Screening Behaviors

The participants in the focus group interviews identified several influences on their breast cancer screening behaviors: direct or indirect personal experience, media messages, incentives, health care providers, faith and faith communities, time considerations, and geographical context. Each of these influences will be addressed in the section that follows.

Personal experience. The personal influences they mentioned included direct personal experience with breast cancer, experiences with screening or breast cancer by close family members, or stories about breast cancer told to them by friends or more distant family. A majority of participants identified direct or indirect personal experience as influential in being screened for breast cancer, with a personal connection to someone with breast cancer accounting for about half of the comments regarding who or what influenced them to be screened. One participant said that her own early experience with a breast lump impacted her breast cancer screening behavior, including mammography screening,

Because I was in the 10th grade when I went through having a biopsy on my breast and they thought I had cancer, so it's me [that influences her screening behavior].

Other participants shared that having known someone with breast cancer influenced them to be screened. One participant said she tried to “*keep a check on [herself]*” because breast cancer ran in her family. Another participant shared that her sister-in-law had breast cancer and that she had learned from her sister-in-law’s experience about the need for screening.

Media messages. Participants explained that messages from various media sources influenced them to be screened for breast cancer by means of a mammogram. They shared that they received information about breast cancer and mammograms from sources such as magazines, television, the Internet, the radio, informational mailings, and pamphlets or

brochures. A few participants said that they received information that influenced them to be screened from posters, documents, and pamphlets from their doctor's office.

Other participants reported that information they had obtained from health-related information booths influenced them to get screened. One participant had received a visual reminder of screening from a booth that was a *"string of balls that go from small to big...and if [she] saw it every month maybe it would remind [her] to do breast self examination,"* because every time she saw the size of the balls that illustrated breast tumor sizes, it "shocked" her. Another participant described, *"a thing in [her] bathroom on [the] shower, that hangs on [the] shower hook, with your breast...and it reminds [her] to check [her] breast."*

Health care providers. Few participants relayed that their physicians influenced them to be screened for breast cancer. One participant said, *"I get [mammograms] every two years because my doctor reminds me to get them."*

Incentives. The women who participated in the focus group interviews acknowledged that incentives might influence them to be screened. Two of the participants believed that people, including themselves, would be more likely to *"check [their] breasts"* if someone would give them a gift card. Another participant agreed with this suggestion. Another participant suggested holding a class to educate young girls in the community about breast health and using it as an incentive for community service hours. She believed it would expand the breadth of knowledge about breast cancer and breast cancer screening among different age groups.

Faith, faith communities, and personal prayer. A few women who participated in the focus groups mentioned the influence of their personal faith, prayer, and their faith communities regarding breast cancer and breast cancer screening. A handful of women in the interviews spoke about the role that their faith communities had played in breast cancer education. Some of

these women recalled that their faith communities offered the congregation opportunities to increase their awareness of cancer in general and breast cancer in particular. One of these participants, for example, knew that the pastor's wife was a breast cancer survivor because that information had been shared with church members. Another woman said that her church had held an event about cancer. A different participant said that she had a 'sister' at church that spoke about breast cancer, but did so in the context of declaring that she would not get screened for breast cancer because she was afraid of what screening might reveal.

Not all faith communities, however, openly shared information about breast cancer among its members. As one participant revealed, "*We are church oriented and they don't talk about it at church. Another said, "I've never been to church and they've talked about [breast cancer]."*"

Three participants discussed prayer and praying to God about breast cancer. One participant talked about people's fear of visiting doctors. She said that these individuals who were fearful about a doctor's visit did not want to know about the problem they had if the doctor was going to say that something was wrong. She said, "*You just rather walk on with it and just don't know. Pray to God it's not [breast cancer], but you know.*" Another participant shared her reliance on her faith saying,

I am a person that don't ask too many questions about disease and nothin' like that ... I always wait and let the Holy Spirit speak to me if I have a concern. I always will ask God to tell me and explain it to me and what it is about and then I don't have no troubles.

One woman discussed the need for more education about breast cancer and for people to be willing to learn about breast cancer. She shared, "*I would truly hope and pray that some other attendants would take the time to come out [and learn more about breast cancer]."*

In summary, participants spoke about the role of their faith communities and prayer in facing breast cancer and screening for breast cancer. Some participants relied on their faith regarding health issues in general and breast health specifically. Others took initiative and played an active role in health promotion, including participating in breast screening. Some faith communities increased women's awareness of breast cancer and breast cancer, while others remained silent on topics related to the breast and breast-related health issues. Expressions of fear related to breast cancer or the seriousness of what might be found on screening were a part of the discussion of breast cancer and breast cancer screening in the context of faith, faith communities, and prayer.

Time considerations. Some women in the focus group interviews discussed the issue of time being a barrier to their participation in breast screening, particularly for clinical breast exams and mammograms. They were particularly concerned about taking time off from work for appointments or the amount of time they had to wait to be seen by a health care provider or have a mammogram performed.

A handful of women conversed about taking time off for a doctor's appointment. One woman explained that she would have to take the whole day off for the appointment. Another responded that some women don't have "*that kind of time,*" and, even if they did have time, they did not want to use the time off that they had earned for a doctor's appointment.

Seven of 10 women who discussed time as an impediment to breast screening, expressed frustration in arriving for an appointment and having to wait to be seen by a physician. As one participant said, "*They'll put you back there and forget you ... [If] they won't see you, then why do you make an appointment 'til 12:00 or 1:00?*" Another spoke about how her doctor did not allow enough time for her when she was finally seen. Others shared that they would just sit in

the examination room for a long time. Women who found themselves sitting in examination rooms for hours before they were seen for their appointment or experiencing long wait times in general, became frustrated by not being seen by a health care provider in a timely way. Their experience increased their reticence to devote time to appointments with health care providers where clinical breast exams could be performed or appointments made for mammograms.

Geographical context. Study participants identified a number of factors contributing to the widely recognized high rates of breast cancer in the geographical area of North Carolina where the focus group interviews had been conducted. These factors included socioeconomic factors such as the cost of screening tests costs, health insurance, unemployment and underemployment that contributed to a lack of health insurance, and transportation access, and environmental factors such as water and diet. The researcher will address each of these factors individually in the section of the chapter that follows.

Socioeconomic factors. Women who discussed factors that contributed to higher rates of breast cancer in the geographical area where data were collected mentioned the cost of mammograms and a lack of health insurance as barriers to breast cancer screening. The expense of mammograms was illustrated by one woman's story about someone she knew who paid \$300 for her mammogram. This study participant said, *"If I know that my insurance is not going to pay for it, why am I going to get a \$300 mammogram if I know I don't need to."* Another woman said that her health insurance was not applicable in the state where she currently resided. She had to travel back and forth to another state in order to receive health coverage.

A study participant suggested that current socioeconomic issues contributed to a lack of health insurance or being underinsured, including unemployment, part-time employment, or jobs

that required no education and were without health insurance benefits. A lack of income or no insurance, in turn, affected women's engagement in breast cancer screening.

All these factories in ... [name of] County have lost their jobs and [the] only jobs here now are for people with no education. With no education, it's jobs ... and no health insurance. And part-time jobs. And other people are underinsured or they're on unemployment.

Two women stated that failure to engage in breast cancer screening was unrelated to having health insurance. They contended that other issues such as county transportation access were key to facilitating screening.

Environmental factors. A few of the women mentioned environmental factors such as water that influenced the high rates of breast cancer in the geographical area where data were collected. Three women posed the possibility of there being something in the water that increased their risk for breast cancer, with one person expressing the concern that, *"I hope it ain't our water."*

Other contributing factors. During the discussions of influential factors in breast cancer and breast cancer screening, some of the women mentioned a health clinic in their geographical area that did not effectively support them. One woman said, *"it's a business."* Another contended that the *"clinic is a bad [place]... That place shouldn't be sitting there."* Other participants shared that, *"I despise it,"* and, *"I don't care nothin' for none of them."*

In summary, participants declared that several factors influenced their motivation to be screened for breast cancer. Some of the women in the interviews shared their personal experiences with breast cancer, including those with family members or an acquaintance who had been affected by the disease. At least one woman indicated that her health care provider

influenced her to be screened for breast cancer by reminding her about the need for screening. Other women were influenced by various media messages to engage in breast cancer screening. Some participants proposed offering incentives as a means of encouraging women to participate in breast cancer screening.

The women shared conflicting views of faith-based breast cancer awareness, with some sharing that their faith communities openly addressed breast cancer, while others remained silent about anything having to do with breasts, including breast cancer. Time, especially wait time, played a role in the women's willingness to be screened. They acknowledged feeling particularly frustrated with prolonged waiting times associated with health care provider visits. Socioeconomic factors, environmental factors, and other contributing factors, such as a lack of perceived support by a particular local health clinic, were also influential in breast cancer screening behaviors.

Personal Experience with Screening

The participants shared their personal experiences with three types of breast cancer screening: breast self-examination, clinical breast exams conducted by a health care provider, and mammograms. In the chapter segment that follows, the researcher will address the women's experiences with each of these screening strategies.

Breast self-exam. Some participants mentioned that they performed breast self-exams (BSE) monthly or "regularly," while others did not do BSE or shared impediments to doing the self-assessment. When examining their breasts, the women who engaged in BSE sought evidence of "*soreness*," lumps or "*knots*," or the presence of anything that should "*not be there*." In terms of performing BSE, they spoke in terms of "*feeling*" or "*mashing*" their breast tissue with their fingers. One woman, for example, said that she knew, "*how to mash and feel*

with the fingers,” while another participant shared a lack of confidence in self-examination due to the size of her breasts. She said, *“I be feelin’ but they’re so big and don’t know what I am feelin.’ All I know, I just be mashing.”* As another participant shared,

I can mash on them and squeeze them but I can’t feel everything. I’ve got some big boobs, so I don’t know the difference between a lump or a...They tried to show me, but I don’t know how to do a self-exam.

Although some participants were confident in their knowledge of BSE, they did not necessarily perform the self-examination. One participant said, for example, that she did not regularly perform BSE because, though she was comfortable touching herself, she just did not do it, even though *“[she] knows better.”* A reticence to touch one’s breasts proved to be a barrier to performing BSE for some of the other women. As one participant stated, *“It’s like playing with your boobs- I mean who plays with their own boobs? That just ain’t cool.”*

Other women, however, examined their breasts regularly because they believed they were at risk for cancer or in order to detect, *“soreness,” “lumps,” “knots”* or anything that seemed abnormal. Expanding on why she regularly checked her breasts, for example, one participant said, *“I am constantly checking myself to see if I can find a knot or anything that’s not supposed to be there.”* Someone else explained that she checked herself if her breasts were *“sore,”* but did not check her breasts every time she bathed or she would *“be checkin’ them all day long.”*

Clinical breast exam. Participants infrequently mentioned their clinical breast exam experiences, compared to their experiences with BSEs and mammograms. The study participants were asked if they received clinical breast exams from their health care provider or from a doctor, and at least six participants said they did. One participant mentioned that she felt fearful when she *“climbed up on the table”* to be examined. Another participant mentioned the

outcome of a clinical exam by sharing that, “*They felt this knot and [I] had to have a biopsy twice.*” As previously mentioned, another participant indicated that, rather than experiencing a clinical breast exam, a health care provider referred her for a mammogram. One participant correctly identified that a clinical breast exam was “*when the doctors do it.*” She proceeded to share about a nurse who worked at the health department, would get her mammogram every year and do her clinical check up until one day she decided to give herself a BSE and she found a lump. A different participant shared her experience with her health care provider at a women’s center after giving birth to her baby. She was given a clinical breast exam and the health care provider found a lump which led her to get a mammogram and was diagnosed with breast cancer, but credits her health care provider for checking her.

Participants infrequently mentioned their clinical breast exam experiences. A participant mentioned that she felt fearful when she “*climbed up on the table*” to be examined. Another participant mentioned the outcome of a clinical exam by sharing that, “*They felt this knot and [I] had to have a biopsy twice.*” As previously mentioned, another participant indicated that, rather than experiencing a clinical breast exam, a health care provider referred her for a mammogram.

Mammography. The women in the focus groups shared varying personal experiences with mammography screenings. Those who spoke about having mammograms indicated that the X-ray procedure could be uncomfortable or painful but, as one woman understood it, “*They said to me that the reason they do that [squeeze the breast between the X-ray plates] [was] to spread the tissues out*”.

Several women described the discomfort they experienced during a mammogram by stating, “*They squeezed my titty and it hurts,*” and “*This girl squeezed me so bad, for a whole week I walked around with bruises ... I was really black.*” One study participant explained that

her friend told her, *“It was like putting it [her breast] in a refrigerator door and having it mashed real hard.”*

Some study participants were philosophical about the discomfort they experienced in terms of the screening test being worthwhile. A woman shared her perspective regarding the discomfort by stating, *“It [mammogram] used to hurt but it doesn’t anymore ... and I’d rather it hurt a little bit and to know what is going on in my body.”* Another one shared a similar view by stating, *“[It] hurts for a few minutes ... [but that] is better than hurt for a lifetime.”*

The technique used by the technician who performed the X-rays could make a difference in the level of discomfort a woman experienced. As one participant recounted, *“Some of those younger women in there can do them so you can barely feel it, but some of them just jerk down on them [her breasts] so hard that it actually hurts.”*

One of the women offered advice about preparing for a mammogram:

I had a scare ... last year ... I had taken a shower and went to the mammogram and evidently I probably didn’t rinse all of the soap off and so they called me back in to do a retest. It was like 3 months later. And so if you are going to the doctor, if you have any soap or shower gel or whatever you use, make sure you rinse real well because it can show up on that.

Some of the women shared their experience with mammography regarding the detection of breast lumps, or having *“lumpy boobs”* or *“raised area[s]”* in their breasts. Others recounted their experiences with mammography results that led to the need for a biopsy or additional mammograms. Regardless of the nature of the problem, the women experienced fear or anxiety regarding the need for further follow-up, with two women sharing that the mammography screening process left them feeling uneasy. A participant who had fibrocystic breast disease, for

example, had to receive an ultrasound in addition to a mammogram. She said that the process made her “*very antsy about it [breast screening].*”

A few other women spoke about receiving a positive screening result that proved to be positive for a problem in the breast. One participant recounted an experience with repeated mammograms that raised her concerns about having mammograms in general:

I do take my yearly [mammogram] ... I always have my mammograms. This time I had to come back from my mammogram because they had a mass ... I had to come back [to] do my mammogram and I think [I] probably stood on that floor for 45 minutes where they took all the needles... But it was still fine. Then they took me to. . . [a city] where I had to hang on that table where she could see it from one angle, but she couldn't see it from this angle. So I had to climb all the way down from that table and had to get another mammogram in another room. But then she didn't like that one so she took me to another room for a mammogram ... It will be so that now when I take my mammogram, I'll be kind of skittish.

Emotional Reactions to Discussing Breast Cancer and Breast Cancer Screening

Speaking about experiences with breast cancer screening elicited remembered feelings among the study participants related to the screening such as fear, a sense of encouragement, uncertainty, or anger. Fear was the most commonly recalled emotion among the women.

Fear. The participants in the focus group interviews believed that fear was a common emotional reaction that women in general felt when discussing breast cancer and breast cancer screening. Some participants said that they had friends that were reluctant to go to the doctor to get their clinical breast exams or mammograms because, according to one woman, “*I think it's just fear.*” Another participant suggested that fear was the reason why women were not getting

screened for breast cancer. As another woman pointed out, *“the thought of having breast cancer is scary.”* The latter participant went on to explain that knowing people who had passed away from breast cancer and a many people who were affected by breast cancer was *“an eye opener”* for her and the thought of breast cancer scared her. A different participant explained that a lot of people were scared to go to the doctor, including herself, and that she did not want to know the outcome of her illness if she were to go. One participant offered an explanation to someone else in the interview who had shared a story in which her mother explained to her why she (the mother) would not get screened for breast cancer. The participant said to the other interviewee, *“your mom was just telling you, she’s scared.”* While recounting her experience with getting a clinical breast examination, another participant disclosed that she was scared when she climbed up on the table for her exam.

In addition to being fearful about what a screening test might reveal in terms of breast cancer, it was also breast cancer treatment, particularly mastectomy that posed concerns for study participants. One woman explained that her friend’s situation of having a mastectomy and *“having a flat spot there [where the breast had once been present]”* was a source of fear for some women. Women not only had to face a diagnosis of breast cancer, but also a disfiguring surgical procedure that was necessary to treat it.

Some of the women who participated in the interviews shared stories of encouragement about women with breast cancer and urged women to be screened regularly. One woman shared a story about how her mother had waited until it was too late to be treated for breast cancer and went on to address a participant in the group in this way:

So, stop being afraid... You are the smartest person we have been around for quite some time, and I would appreciate it if you would go, like I said to the older lady, at least one time. You'd make me feel better.

Another participant disclosed that she felt comfortable going to the hospital or clinic to get a mammogram or a breast exam. A third participant felt “*optimistic*” about spreading the word about breast cancer and encouraging people, especially young women, to be screened for breast cancer.

Anger. Women in the focus group interviews expressed anger and distain when discussing access to breast cancer screening in their community. During one of the interviews, a particular location for people to be screened was a for-profit clinic about which one participant said, “*They're so centered on you guys paying and getting the money they can out of you.*” Another participant angrily shared a story about a woman she knew whose husband had died, she had lost her job, and then she went to the clinic and was told she had to pay \$65 in order to be seen. She did not have that amount of money, so they refused to see her. Other participants chimed in with their thoughts about this particular clinic, saying that it was “*a bad [place]. That place shouldn't be sitting there*” or “*I despise it*” or “*I don't care nothin' for none of them.*”

During the discussion about breast cancer and breast cancer screening, women disclosed feelings regarding the topic of breast cancer and breast cancer screening that ranged from anger and fear to encouragement and optimism. One source of anger regarding screening was a particular for-profit health clinic that failed to treat clients in a supportive way. A few women sought advice from other interview participants or questioned the need for breast cancer screening. One woman, for example, sought advice from her group about what to do about screening, asking whether she should, “*change doctors or something?*” Another woman said

that not knowing many women who had been affected by breast cancer left her with questions about whether or not she should be screened.

Promoting Breast Cancer Screening

In response to a query about breast cancer screening promotion, participants offered different ways they could promote breast cancer screening in their communities. Some of the ideas that they offered involved the dissemination of promotional materials; holding health fairs; talking openly about breast cancer and breast cancer screening, especially to youth; and having groups or offering classes to promote screening.

Promotional materials. Several participants said that the dissemination of materials would help promote breast cancer screening in their community. Three women indicated that they had received information from their physicians about breast cancer, breast cancer screening, or breast cancer treatment. Other women who participated in the interviews shared that providing tangible objects or articles would help promote screening, including such items such as *“a string of balls...going from small to big”* to remind them of how small or how large a lump could be or a BSE card that could be hung in their shower to remind them to check their breasts.

Health fairs and educational classes. Participants suggested that holding health fairs and educational classes could assist in promoting breast cancer screening. One participant suggested that companies should have health fairs that have health professionals on location to do clinical screenings and even mammograms. She explained that her company enabled its employees to take the time off without penalty to attend health fairs and, by doing that, communicated to employees that, *“my company actually cares for me.”* She said that it also saved the company money and could possibly save someone’s life.

Two other participants suggested that offering informational classes would promote breast cancer screening. They suggested that these classes would allow people to come and talk about topics of importance to them freely and confidentially and they would “*encourage each and everyone that they need to get a mammogram.*” The participants also suggested that having visual items would be beneficial, “*like bras what show ways, you know how you can get bras with the pad, without the pads, if you had the mastectomy.*”

Discussing breast cancer. Many participants suggested the promotion of breast cancer screening by talking more openly and often about breast cancer and breast cancer screening. One participant said, “*I think that if you would talk to one of your friends and tell them you were going to the doctor to take one of these tests and you’d be supportive of them, then they’d probably go...alone.*” Another woman perceived she could get out in the community and talk to more people about breast cancer and breast cancer screening, though that was something she had not been doing. A different participant suggested giving her own testimony about what she had gone through could help promote screening, especially “*with breast cancer being an issue since it’s so prevalent here in ... [name of] County.*”

Discussing breast cancer screening with youth. Three participants felt strongly that promoting screening should start with the youth in the community. One woman inquired, “*Is there a special age that we’re supposed to start taking with the children about [breast cancer and breast cancer screening]?*” Another explained that she thought promoting breast cancer screening should start in school in order to introduce youth to the problems of breast cancer at a young age and include providing them with literature more readily available at booths. The same participant added,

I just really feel like it should be started at a younger age because a lot of girls... maybe their grandparents or parents had it and they are not even aware they are at risk so I would just like to see at an earlier age ... discuss[ion].

A participant shared her thoughts in response to the above comment:

Maybe when they first start going to have their first pap smear ... not only the first pap smear, but being taught how to check their breasts at that time.

Breast cancer awareness. One participant told her fellow interview participants that having a breast cancer awareness month at church and the minister's wife talking about her personal experience with breast cancer had promoted breast cancer screening in her faith community. Another participant said that breast cancer items like a little pink pen that you can buy with a \$1 donation promotes screening because "*knowledge is power*" and such a pen would get people thinking about breast cancer.

In summary, the women discussed different ways to promote breast cancer screening in the community, particularly among women and youth. They shared that promotional items, which could serve as a visual reminder of the need for screening, health fairs, and speaking to their physicians were helpful strategies. They also suggested that having women openly discuss breast cancer and promote breast cancer screening among young women could be helpful.

Summary

The researcher was able to identify several themes that emerged from the data in this study. The themes included self-perceived knowledge and beliefs about breast cancer and breast cancer screening, influences on breast cancer screening behaviors, personal experience with screening, emotional reactions to discussing breast cancer and breast cancer screening, and promoting breast cancer screening. Study findings suggested varying levels of breast cancer

knowledge among the participants, with several reporting a lack of knowledge. Older women were believed to be at higher risk for experiencing breast cancer but some men were able to develop breast cancer. They perceived that breast cancer could run in families. Some participants disclosed no distinction between African American and Caucasian's risk developing breast cancer, though others recognized the increased risk status of African American women. Findings also indicated that some women understood how to perform a BSE, though many expressed uncertainty about their ability to perform and interpret their self-examination. Participants tended to be knowledgeable about current mammography recommendations, though some older women indicated they did not need to be screened due to their self-perceived life expectancy. One woman who was an early age breast cancer survivor suggested that women obtain a mammogram when they believed they needed one. Their discussion of breast cancer led to participants acknowledging fear and anger related to the health problem. The participants talked about promoting breast cancer and breast cancer screening to women of all ages, young and old, through promotional items, health fairs and education classes and getting people to talk about breast cancer were of great importance. A discussion of the study findings with implications for health education and further research will be presented in Chapter 5.

CHAPTER 5: CONCLUSIONS AND DISCUSSION

Although attention and research has focused on breast cancer and breast cancer screening for women in general, a need continues to exist for promoting breast cancer screening, especially by means of mammography (NCI, 2013) among African American women as a whole. Screening for the purpose of breast cancer detection, especially in circumstances when early detection is possible, offers a possible strategy to reduce breast cancer mortality among African American women (Susan G. Komen for the Cure, 2007). Unlike the uncertain advantages associated with breast cancer screening strategies such as clinical breast exam and breast self-exam, mammography has been identified as the strategy that benefits women from 40 to 74 years of age (NCI, 2013). The effective promotion and regular adoption of mammography screening, however, must consider the cultural attitudes and beliefs of the target population (Ochoa-Frongia, Thompson, Lewis, & Deans-McFarlane, 2012; Swinney & Dobal, 2011). The purpose of this qualitative study was to investigate the perceptions and experiences of breast cancer and breast cancer screening from the perspective of African American women residing in rural eastern North Carolina.

In order to accomplish this aim, the researcher analyzed a sub-set of data collected during an unpublished larger qualitative study that investigated the perspectives of 19- to 87-year-old African American, Caucasian, and Latina women living in eastern North Carolina about breast cancer and breast cancer screening (Burke et al., 2009). The purpose of the original study was to learn from participants about what was happening in their community in the area of breast health, breast cancer, and breast cancer screening. Data analyzed in the present study were collected in the original study by two facilitators who conducted focus group interviews, three of which were with 35- to 87-year-old African American women residing in rural eastern North Carolina.

This exploration of rural African American women's views about breast cancer and breast cancer screening led to cultural insights and understandings that will potentially enable health educators and other health professionals to develop more effective breast cancer screening awareness interventions that are tailored to this population. In addition, the applicability of these findings to other similar populations may be considered, given readers' assessment of the transferability of the context, sample, and setting associated with this study.

Discussion of Research Findings

The African American women from rural eastern North Carolina who participated in one of three focus group interviews expressed their views and shared their experiences specifically related to breast cancer and breast cancer screening. In this chapter, the researcher will discuss the major findings that emerged from the analysis of data in the context of the research literature. Study findings have been organized according to the following themes: knowledge and beliefs about breast cancer, influences on breast cancer screening behaviors, personal experience with screening, emotional reactions to discussing breast cancer and breast cancer screening, and promoting breast cancer screening.

Key findings associated with these themes included a self-perceived low level of knowledge about breast cancer by some of the women, views about various causes of breast cancer, perceived barriers to breast cancer screening, the influence of personal faith related to breast cancer and breast cancer screening, and the cultural context of talk related to breast cancer and breasts in general. Additional key findings included personal views and experiences with three breast cancer screening strategies, fear as a common response to the possibility of breast cancer, relationship issues raised in response to the possibility of breast cancer, and ideas about promoting breast cancer awareness and education within communities.

Knowledge and Beliefs about Breast Cancer

Many of the African American women who participated in this study shared their knowledge and beliefs about breast cancer and screening for breast cancer. A key finding from this study revealed some women's self-perceived low level of knowledge regarding breast cancer and breast cancer screening, though the women generally recognized breast cancer as a serious or "deadly" disease. The thought of cancer as a deadly disease was congruent with a Chicago-based study of African American women (Kaiser, Cameron, Curry, & Stolley, 2013). Consistent with previous research (Sadler et al., 2007), some of the women in the present study lacked basic knowledge about breast cancer. Prior research suggested that women who were less knowledgeable about breast cancer screening and prevention were also less likely to adhere to screening guidelines (Sung et al., 1997).

Participants shared their views and beliefs about the causes of breast cancer in the focus group interviews. They identified these causes as having had a breast injury, cancer as an infectious agent that is able to spread, cancer as a root that is able to sprout, and milk that clogged the breast. Beliefs about the association between breast injury and breast cancer have been addressed in the literature, though to a limited degree. One study of women 50-65 years old revealed a possible link between breast cancer and physical trauma, but alluded to the need for more research (Rigby, Morris, Lavelle, Stewart, & Gatrell, 2002). A study examining physically abused African American women and their risk of breast cancer due to physical trauma resulted in a possible relationship, as the previously mentioned study, but further research is necessary (Wise, Palmer, Boggs, Adams-Campbell, & Rosenberg, 2011). In a qualitative study of breast cancer beliefs held by urban African American women aged 65 years and older (Swinney & Dobal, 2011), the participants affirmed the views of women in the present study in

terms of mentioning two causes of breast cancer: breast injury and milk clogging the breast the latter of which participants in the Swinney and Dobal study (2011) attributed to not breastfeeding. Perspectives about roots within the African American community have been addressed in the literature (Eiser & Ellis, 2007); however, not about cancer having roots, but rather roots being a method of healing or causing illness. Lannin et al. (2002) discussed the belief among African American women for cancer to spread or become fatal if cut into or exposed to air. This perspective shared by Lannin et al. was similar to what was found in this study.

Influences on Breast Cancer Screening Behaviors

Another theme that emerged from the current study was influences on breast cancer screening behaviors. Participants frequently mentioned a number of different issues related to screening such as incentives, personal experience, media, health care providers, faith community and prayer, time considerations, and geographical context. Participants discussed their faith and faith communities as influences on breast cancer screening behaviors. As was also found in other studies (Swinney & Dobal, 2011; Lannin et al., 2002), participants in this study disclosed a reliance on God for trust and explanation regarding one's health. A correlation was found between an increased chance of a breast cancer diagnosis at a later stage and religious beliefs, supporting the findings of the current study in which some women relied on God rather than going to a doctor (Eiser & Ellis, 2007).

Findings from this study also revealed the varying beliefs of different faith communities, some actively supporting breast cancer and breast cancer screening, while others never talking about breast cancer or screening. While the participants in this study held varying views about their churches promoting breast cancer screening, Eiser and Ellis (2007) contended that religious

leaders and community members in African American communities had the opportunity to encourage medical care utilization while acknowledging their the religious beliefs that served as a foundation of their faith.

Study findings confirmed that time was an identified barrier for women to be screened for breast cancer (Susan G. Komen for the Cure, 2007). A number of women in the current study revealed they did not have the time to take off work and wait to be seen by a physician during their appointment to be screened. Women also shared their thoughts about socioeconomic status as being a factor affecting women's engagement in breast cancer screening. This finding was supported in Komen Breast Cancer Mortality Report (Susan G. Komen for the Cure, 2007), which identified poverty and the inability to afford medical visits or transportation. Other factors, environmental and a local screening facility, identified by participants in this study were specific to their location and could negatively impact their community to be screened for breast cancer.

Personal Experience with Screening

Participants' personal experiences with screening emerged from the data. This theme garnered new insights into perspectives about screening. Participants provided the researcher with rich data related to their personal accounts of being screened for breast cancer. Findings suggested that participants understood and conducted breast self-examinations to varying degrees, though they expressed concerns about their self-examination knowledge and skill and, thus, the effectiveness of their exam. Participants also shared their experiences with clinical breast examinations, but such experiences were not mentioned often and clearly not as frequently as breast self-examination and mammography. The women's personal experiences of receiving a mammogram varied. Many participants identified with what the literature reported in that

mammograms were painful or caused discomfort (Davis et al., 2012; Kalsen et al., 2008; Kinney et al., 2002; Smedley et al., 2003; Susan G. Komen NC Triangle Affiliate, 2009b).

Emotional Reactions to Discussing Breast Cancer and Breast Cancer Screening

A theme that emerged from this study related to participants' emotional reactions to discussing breast cancer and breast cancer screening. Participants spoke of fear and anger relating to breast cancer and screening. Similar to previous research, some women in this study did not want to know the outcome of their screening results because of fear that the diagnosis might be cancer (Lopez et al., 2005; Swinney & Dobal, 2011). A review of the literature revealed fear relating to cancer to be seen as a barrier to screening for African American women (Consedine, Magai, Krivoshekova, Ryzewicz, & Neugut, 2004). A qualitative study examining beliefs, attitudes, and practices related to breast cancer screening among African American women of low to middle income found that fear of a cancer diagnosis was the primary emotion felt by study participants (Phillips, Cohon, & Tarzian, 2001). Previous studies have also revealed a fear of disfigurement after having a mastectomy performed (Lopez et al., 2005; Swinney & Dobal, 2011).

Consistent with the women in this study, women in other studies have acknowledged fear that a spouse would leave a women diagnosed with breast cancer or one who had had a mastectomy performed (Lannin et al., 2002; Lopez et al., 2005; Masi & Gehlert, 2008; Swinney & Dobal, 2011). Although not addressed by the women in the current study, Thomas (2006) revealed women had less fear of dying from breast cancer than from losing a breast due to a mastectomy as a treatment for breast cancer.

Promoting Breast Cancer Screening

Ways to promote breast cancer screening were frequently discussed among study participants. Some women believed that promotional and education materials would prove beneficial for reminding women to be screened for breast cancer. In this study, participants shared that they received some breast cancer screening information through media messages. Similarly, Nekhlyudov et al. (2003) found that women viewed the media as a source of information regarding screening recommendations and information related to breast cancer screening. Print media was also noted by women in one study to be the best source of breast cancer information (Sadler et al., 2007).

Participants also believed that health fairs at employment sites and educational classes would be another effective way to promote breast cancer screening. One participant, for example, shared that the company she works for allowed employees to attend health fairs without penalizing them for the time it took in order to promote their health and possibly saving a life.

Some of the women in the present study acknowledged that silence surrounds and curtails discussions about women's breasts, breast health, breast cancer, and breast cancer screening strategies. They recommended that women be able to talk about breast cancer openly. Sharing personal stories and talking to young women about breast cancer would help to promote breast cancer screening.

Limitations

This study had both strengths and limitations. Qualitative data use provided rich and detailed information about African American women residing in rural areas of rural eastern North Carolina. The collected data defined participants' knowledge of breast cancer and

perceived barriers of breast cancer screening. The qualitative study design used a small purposeful sampling of African American women residing in a rural area. The findings are not generalizable to all African American women residing in rural areas, but they may be applicable to a similar population and setting. Also, because of the use of qualitative research, the approach to the data and consequent interpretation can differ depending on the theoretical lens that the researcher uses to inform the data analysis.

Ethical issues regarding participant consent can arise from the use of secondary data that is interpreted by an independent analyst. A written clause that was included in the participant's signed consent form provided participants' approval of the use of the data in future research. The researcher also addressed the ethical issue of protecting the identity of those who participated in the study by masking their identities, the location of their residence, and the sites where data collection took place.

Implications for Health Education and Promotion

Findings from this study have implications for health education and promotion professionals. The population studied was underrepresented in the research literature at the time of the study and clearly at risk for breast cancer mortality. The results from the study may help health educators and other health-related professionals better serve African American women in rural settings. For example, these qualitative findings underscore the need to gain insight into the cultural perspectives and culturally appropriate intervention strategies. Cultural appropriateness reflected in interventions that are tailored to the population of interest can potentially result in increased rates of breast cancer screening and ultimately, reduced breast cancer mortality. Health educators can use qualitative strategies, similar to those practiced in the original study, to gain insight into community culture. Such strategies enable health educators to

plan programs that effectively address gaps and barriers to breast cancer screening and other services across a continuum of care.

Involving the community is key to successfully lowering the breast cancer mortality rate among African American women living in rural areas like Risk County (Susan G. Komen for the Cure, 2007). Participants in the present study suggested involving the community in ways that ranged from presenting information, to involving youth, to the promotion of breast cancer screening in faith based communities. Facilitating collaboration among all aspects of the community such as healthcare providers, community health organizations, grassroots organizations, social services, governmental officials and members of academia will aid in this approach (Susan G. Komen NC Triangle Affiliate, 2009b). The promotion of mammography screening could be organized and conducted by community health care workers known to member of the community in order to increase mammography rates among women within the community (West et al., 2004; Masi & Gehlert, 2008). Creating a community-based taskforce to lead the initiative is another possible approach (Susan G. Komen NC Triangle Affiliate, 2009b; Kaiser et al., 2013). The taskforce could focus on breast cancer screening recommendations from national organizations to conduct provider assessments that investigate the breast health services that are working well and what can be improved for more effective delivery of care. A need exists to address the gap in the knowledge related to breast cancer and breast cancer screening within this population and community.

Other examples of interventions for health education and promotion include initiatives in the workplace, educational roundtables, Lay Health Advisor Programs, publicizing the stories of breast cancer survivors who agree to serve as a role model for other women in the community, and establishing African American cancer survivor groups (Masi & Gehlert, 2008; Susan G.

Komen NC Triangle Affiliate, 2009b). The initiative in the workplace might entail the implementation of an evidence-based multifaceted worksite health promotion program that included breast health assessment, “Well Women” hours, or eight hours off from work to go to appointments, health fairs, or engage in other approved health promotion activities. The educational roundtables would enable women to speak freely about their concerns and questions regarding breast health and breast cancer. Breast health materials can be provided and the meeting could be facilitated by a health educator and refreshments, with giveaways provided to participants as an incentive.

During the focus groups participants identified a gap in the knowledge related to breast cancer and breast cancer screening within their population and community. Participants believed that there were many barriers preventing them from getting screened. Study results suggested that a need exists for educational interventions focused on increasing breast cancer screening and breast cancer awareness, with ample opportunity to address women’s questions and concerns. Study participants suggested that providing incentives would positively influence women to be screened for breast cancer. This influential factor had not been previously reported in the literature. It would be advantageous for the health-related programming to be held outside of medical facilities and in community settings, such as faith communities.

The participants in the study recognized that there were cultural and religious or spiritual beliefs that served as barriers to screening. That is also why it is important to hold programming in a faith community setting since it indicates support within the church for getting screened for breast cancer. The opportunity to encourage women to get screened and talk openly about BSEs, CBEs, and mammograms may allow for the cultural and social norms of breast cancer to be

changed. Participants suggested examples of programs that could be held in churches including Witness Programs or Pink Sundays (Susan G. Komen NC Triangle Affiliate, 2009b).

Implications for Future Research

The findings from this qualitative study suggest opportunities for future research. Although qualitative research is a common research approach used to conduct exploratory studies that examine study participants' beliefs and experiences related to breast cancer and breast cancer screening, researchers may consider other research approaches, particularly those that use quantitative methods to assess the scope and frequency of African American women's perspectives that have been identified in the present and other studies. Due to persistent health disparities, more research is needed that focuses on the perspectives and experiences of African American women who live in rural areas. Since the majority of participants in the present study received mammograms regularly, a need exists to examine the perspectives of rural African American women who have not been screened or whose screening schedule does not fall within recommended guidelines.

The women in this study revealed various causes of breast cancer that warrant further investigation in order to better understand the origin of these ideas, particularly since such beliefs have also appeared in other studies. Their ideas included beliefs about the origin and spread of cancer such as cancer spreading due to exposure to the air, cancer as a root that spouts, or cancer that arises from obstructed milk ducts. Participants believed that an important influence in getting screened by means of mammography was knowing someone who had breast cancer, whether it was themselves, friends, or family members. It may be beneficial for researchers to delve into this topic further in an effort to obtain more insight from women about this issue. Due to participants' mixed responses to questions about their knowledge of breast cancer health,

further examination of rural African American individuals knowledge and attitudes about breast cancer and screening may be beneficial.

Participants in the present study were unaware or uncertain about the high rates of breast cancer mortality in Risk County, North Carolina. Researchers could consider conducting studies to further examine factors contributing to the high ranking of breast cancer mortality in this and other rural counties with similar breast cancer mortality rates. Further examination of the impact of disseminating information about breast cancer risks within a particular region is also warranted since the women in this study voiced fear of being diagnosed with breast cancer and thus may be more likely to ignore such efforts to increase awareness of risk or may experience increased anxiety as a result.

Another topic that warrants further research is the impact of faith on cancer screening in general and breast cancer in particular. Participants in this study offered many reasons for why screening for breast cancer was not widely accepted by the targeted population. It may be important to understand why people become screened despite cultural or faith community messages to the contrary.

Conclusion

In this study, African American women residing in rural eastern North Carolina shared their experiences and beliefs related to breast cancer and breast cancer screening. They addressed possible barriers and facilitators that influenced breast cancer screening among themselves and the women in their communities. Findings revealed that some of the women had a self-perceived low level of knowledge regarding breast cancer and breast cancer risks, which might contribute to low levels of screening at least among some of the women. Low levels of breast cancer screening can potentially contribute to high rates of breast cancer mortality. The

women identified perceived barriers to screening as time, socioeconomic factors, and environmental factors.

Findings also revealed that one woman, an early-age breast cancer survivor, believed that women should be allowed to have a mammogram at any age, raising the need to tailor screening opportunities to individual women's needs. The final major finding was best practices for promoting breast cancer awareness and education. This finding encompassed suggestions from the participants for approaches they believed would work to promote breast cancer. Based on this research study, a need continues to exist to educate rural African American women about the importance of breast cancer screening and to expand the knowledge held by women about breast cancer in general. Health educator's efforts should focus on the educational needs of African American women in rural areas, addressing the barriers perceived by the population. Their efforts to dispel breast cancer myths must be based on a clear understanding of the underlying understandings that inform the myths. In addition, since African Americans hold their faith to be of great importance, health educators should consider implementing interventions in collaboration with faith-based communities and programs. In the end, health educators must continue their work that addresses health disparities, particularly in the area of breast cancer mortality and breast cancer screening within at risk populations.

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APPENDIX A: UMCIRB LETTER OF APPROVAL

EAST CAROLINA UNIVERSITY

University & Medical Center Institutional Review Board Office

4N-70 Brody Medical Sciences Building · Mail Stop 682

600 Moye Boulevard · Greenville, NC 27834

Office 252-744-2914 · Fax 252-744-2284 · www.ecu.edu/irb

Notification of Exempt Certification

From: Biomedical IRB

To: [Catherine Royal](#)

CC: [Sharon Knight](#)

Date: 4/1/2013

Re: [UMCIRB 13-000620](#)

African American women's perceptions, experiences, and meaning associated with breast cancer screening in rural eastern North Carolina

I am pleased to inform you that your research submission has been certified as exempt on 4/1/2013. This study is eligible for Exempt Certification under category #4.

It is your responsibility to ensure that this research is conducted in the manner reported in your application and/or protocol, as well as being consistent with the ethical principles of the Belmont Report and your profession.

This research study does not require any additional interaction with the UMCIRB unless there are proposed changes to this study. Any change, prior to implementing that change, must be submitted to the UMCIRB for review and approval. The UMCIRB will determine if the change impacts the eligibility of the research for exempt status. If more substantive review is required, you will be notified within five business days.

The UMCIRB office will hold your exemption application for a period of five years from the date of this letter. If you wish to continue this protocol beyond this period, you will need to submit an Exemption Certification request at least 30 days before the end of the five year period.

The Chairperson (or designee) does not have a potential for conflict of interest on this study.

APPENDIX B: RISK COUNTY BREAST HEALTH FOCUS GROUP PROTOCOL

Research Questions to be Addressed

- 1) What is the degree of knowledge about breast health practices among women in Risk County?
- 2) To what extent are women in Risk County aware of local breast cancer screening services available to them?
- 3) What are the motivators and barriers that women in Risk Co. experience in practicing breast cancer prevention?
- 4) What are motivators and barriers that women in Risk Co. experience in using breast cancer screening and services?
- 5) What strategies should be implemented to increase breast health screening and prevention participation in Risk Co.?

Hello Everyone. My name is _____ and this is my colleague _____. We represent the Risk County Breast Cancer Taskforce and Susan G Komen for the Cure. We are here today to learn from you about what is happening in your community in the area of breast health. Thank you for coming. Our goal is to have a relaxed discussion on various topics related to your community, breast cancer in your community and breast health programs and services.

We are here today to talk about breast health issues in your community. The purpose is to get your ideas on breast cancer, breast health programs and services, and what ideas you have on how we can help make a difference in your community when it comes to breast health. We are not here to share information, or to give you opinions. Your thoughts, experiences and ideas are what matter. There is no right or wrong answers. You can disagree with each other, and you can change your mind. I would like you all to feel comfortable saying what you really think and how you feel and I ask that everyone be respectful of each other.

My colleague will be taking notes and tape recording the discussion so that I do not miss anything you have to say. Everything you say in this room is confidential – no names will be used outside this room and no one who reads our report will ever know who said what. All the information gathered today will be studied and reviewed for common themes. These themes will help us set priorities for targeted breast health programs for residents in Risk Co.

I would like this to be a group discussion, so feel free to respond to me and to other members in the group without waiting to be called on. Having said that, I would appreciate it if only one person talks at a time and that we are all respectful of what each person says. The discussion will last about an hour. There is a lot we need to discuss, so at times, I may move us along if we seem to be stuck on one topic.

Thank you very much for coming. Your time is very much appreciated and your comments will be very helpful to us. Just a reminder that your answers will be part of a final report that will be available in March, 2009 for your review.

Questions for Participants

Format: Semi-Structured

- 1) What do you know about breast cancer?
- 2) Where do you get your information on breast cancer?
- 3) Who do you think is more likely to get breast cancer?
- 4) Do you feel you are at risk for breast cancer?
 - a. If “yes,” why?
 - b. If “no,” why not?
- 5) What do you know about the recommended screening guidelines for breast self-exams, clinical breast exams, and mammography?
- 6) Do you perform breast self-exams?
 - a) If “yes,” why and how often?
 - b) If “no,” why not?
- 7) Do you get clinical breast exams from your health care provider?
 - a) If “yes,” why and how often?
 - b) If “no,” why not?
- 8) Do you get mammograms?
 - a) If “yes,” why and how often?
 - b) If “no,” why not?
- 9) What do you feel would encourage you to use these methods?
- 10) What do you feel would encourage your friends/family members to use these methods?
- 11) What support or motivation do you receive from family members/friends for your use of breast cancer screening?
- 12) What are the barriers to your access to healthcare facilities for obtaining breast cancer screening and services in Risk Co.?
- 13) Where can you obtain free or low-cost breast cancer screening services in Risk Co.?

- 14) How do you prefer to receive educational information about breast cancer (and other health) information?
- 15) Who has the strongest influence on your use of breast cancer screening?
- 16) What are the best ways to get women in Risk Co. to participate in breast cancer screening and prevention practices?
- 17) What could you do to promote breast cancer screening and prevention in your community?
- 18) Are there any other thoughts you would like to share about these topics?

Demographics

Age

Employment

- Full-time
- Part-time
- Not Employed
- Retired

If employed, occupation:

Marital Status:

- Single
- Married
- Divorced
- Widowed
- Living with Significant Other/Life Partner

No. of Children

City of residence

Ethnicity

- African American
- Latina
- Caucasian
- Asian/Pacific Islander
- Middle Eastern
- Other:

Education

- Less than high school

High School
Some College
College – Undergraduate Degree
Some Graduate School
Graduate Degree
Professional Degree (MD, JD)

Primary Language
English
Spanish
Other:

Household Income Level
Less than \$20,000
\$20-30,000
\$31 – 40,000
\$41 – 50,000
\$51 – 60,000
\$61 – 70,000
\$71 – 80,000
Over \$80,000

Health Insurance
Yes No

Type of Health Insurance
Private
Government

Do you have a primary healthcare provider?
Yes No

Have you ever had a mammogram? If so, age at first mammogram:

Are you a breast cancer survivor? If so, age at diagnosis:

Have you ever had a family member (mother, sister, daughter, etc.) diagnosed with breast cancer? Yes No

APPENDIX C: FOCUS GROUP DISCUSSION SCRIPT

An introduction serves several purposes:

- Helps establish the nature of the relationship between the interviewer and respondents.
- Establishes a context for the questions and respondents' answers.
- Establishes credibility. This is important in order to receive respondent cooperation and high quality data. If the process or interviewer lacks credibility, the respondents may not provide complete or thoughtful answers.
- Provides an incentive for respondents. The incentive is often the feeling respondents have in cooperating and knowing that their contribution will help lead to a better community.

A focus group introduction should include:

- An introduction to the moderators
- A statement of gratitude
- A statement of purpose
- An explanation addressing why community input is important
- Discusses procedures

Sample Introduction

Good morning. My name is _____ and this is my colleague _____. We are from Susan G Komen for the Cure and we are here today to learn from you about what is happening in your community in the area of breast health. Thank you for coming. Our goal is to have a relaxed discussion on various topics related to your community, breast cancer in your community and breast health programs and services.

We are here today to talk about breast health issues in your community. The purpose is to get your ideas on breast cancer, breast health programs and services, and what ideas you have on how we can help make a difference in your community when it comes to breast health. We are not here to share information, or to give you opinions. Your thoughts, experiences and ideas are what matter. There is no right or wrong answers. You can disagree with each other, and you can change your mind. I would like you all to feel comfortable saying what you really think and how you feel and I ask that everyone be respectful of each other.

My colleague will be taking notes and tape recording the discussion so that I do not miss anything you have to say. Everything you say in this room is confidential – no names will be used outside this room and no one who reads our report will ever know who said what. All the information gathered today will be studied and reviewed for common themes. These themes will help us set priorities in terms of the work Susan G Komen for the Cure will do in your community. Your answers will be part of a report that will be completed by _____ and will be available on our website for your review.

I would like this to be a group discussion, so feel free to respond to me and to other members in the group without waiting to be called on. Having said that, I would appreciate it if only one person talks at a time and that we are all respectful of what each person says. The discussion will last about an hour. There is a lot we need to discuss, so at times, I may move us along if we seem to be stuck on one topic.

Participant Introduction

Ice Breaker

Come up with a short activity that will allow the participants to introduce themselves and briefly discuss their interest/experience with breast cancer. The activity should help build trust and comfort levels among the group.

Question Format

- First question can introduce the topic.
 - For example: What do you know about breast cancer?
- Second question can transition to what you need to know in a general sense.
 - For example: Where do you go for breast health information?
- The next set of questions should ask in detail what you really want to know.
 - For example: What barriers do African American women face in seeking mammography services?
- The last question should be an ending question.
 - For example: Is there any other information regarding your experience that you think would be useful for us to know?

Sample Closing Statement

Thank you very much for coming this afternoon. Your time is very much appreciated and your comments have been very helpful. Just a reminder that your answers will be part of a report that will be completed by _____ and will be available on our website for your review.

APPENDIX D: SAMPLE OF RESEARCHER'S JOURNAL
Researcher maintained handwritten journal

1/16/13 Spoke with Dr. Knight to review approach of study and addressing suggested edits. Focus of secondary data analysis is necessary for the study since that is the qualitative approach used. Need to email Dr. Knight all study transcripts.

Search terms used today –
Secondary analysis
Secondary data
Secondary data + qualitative research

2/6/13 Beginning data analysis. Reading and re-reading transcripts

Search terms used today
African American women AND breast cancer
Breast cancer + African Americans + qualitative research
Breast cancer + qualitative research
Breast cancer

2/15/13 Needing to keep track of which transcripts belong to what focus group, but also ensuring to protect the identity and not identifying focus groups in paper. Transcript log:

- #1 Location 1 – Housing Authority
- #2 Location 2 – Partnership for Children
- #3 Location 3 – Hospital

2/18/13 Need more support for beliefs. Literature review: cover the spectrum of beliefs relating to cancer and/or cancer among women in general and African American women.

Search terms used today:
Breast cancer + fatalism
Breast cancer + fatalism + African American women
Breast cancer + religious beliefs
Breast cancer + religious + African American women

3/6/13 Updating breast cancer incidence and mortality rates to current time is challenging. When is data considered outdated?

Search terms used today
Breast cancer beliefs
Beliefs + Breast Cancer + qualitative research
Breast Cancer + Barriers
African American + Breast Cancer + Beliefs

APPENDIX E: SAMPLE OF RESEARCH LOG

Researcher maintained handwritten log

Date Time Action/Decision Comment Plan

1/16/13	<p>Qualitative Project underway. Topic about African American women's perceptions, experiences and barriers with breast cancer and breast cancer screening in eastern rural North Carolina.</p> <p>Search terms used today – Secondary analysis Secondary data Secondary data + qualitative research</p>
2/6/13	<p>Continuing Literature Review Terms I searched: Search terms I used today – PubMed African American women AND breast cancer Breast cancer + African Americans + qualitative research Breast cancer + qualitative research Breast cancer</p>
3/3/13	<p>Continue Literature Review Search terms used today: Breast cancer + fatalism Breast cancer + fatalism + African American women Breast cancer + religious beliefs Breast cancer + religious + African American women</p>
6/13/13	<p>Strengthening literature so someone with no medical or health background would have a clear understanding of what is being said. Search terms used today: Rural health Rural health + African Americans Rural health + African American + breast cancer Breast cancer in African Americans residing in rural areas Screening behaviors + Rural</p>
9/6/13	<p>Focus on qualitative sources. Search terms used today: Qualitative research Qualitative research + purpose Qualitative research + methods</p>

APPENDIX F: SAMPLE ANALYSIS & INTERPRETATION MEMOS

Date & Time Analysis & Interpretation Memos

2/8/13 Realized electronic file names for the transcripts of the original focus groups were mislabeled. Need to revisit and correct. It's important during data analysis not to assume anything about study participants or findings.

2/15/13 Not optimal focus group with facilitators asking questions and sharing information (possibly disrupting the rawness of the data). Also giving participants letters to ensure confidentiality is not best protocol since it could provide participants with negative feelings from the facilitator. Leave the option up to the participants.

-Transcript log:

#1 Location 1 – Housing Authority

#2 Location 2 – Partnership for Children

#3 Location 3 – Hospital

2/26/13 Reading and rereading transcripts take a lot of focus. Themes are beginning to emerge. By the end of this I'll have this data memorized!

4/14/13 Think about screening behavior broadly as opposed to specifically BSE, CBE, and mammography. Even consider looking at screening behavior among women in general and cervical cancer screening.

5/20/13 Interesting that some participants have little knowledge of screening guidelines and recommendations and what breast cancer is.

7/1/13 Clarifying and present whole story for findings, for example, expanding more about a participant's personal experience with breast cancer screening.

9/6/13 Participant shares personal story with the group about being screened at such a young age. I couldn't even imagine. She seems like a huge advocate for screening and to share her story.

10/12/13 Add CBE findings to Chapter 4 thematic findings.

APPENDIX G: CODEBOOK

CODE name or abbreviation	Explanation of code	Inclusion	Exclusion
Acc	Access to health care	Any reference to access relating to risks for breast cancer	
Beliefs	beliefs of participants	Sharing beliefs about cancer, breast cancer and screening	
BSE	Breast Self Exam	Any reference to BSEs	Any reference to Mammogram and CBE
CBE	Clinical Breast Exam	Any reference to CBEs	Any reference to Mammogram and BSE
EmoReac	Emotional reactions such as fear, frustration, excitement	In response to breast cancer in self or others and breast cancer screening	
Faith		Any reference to religion, church, church community and spirituality	
Incent.	Incentive – something to encourage an action	Sharing what would encourage participants/people to get screened	
Infl.	Influences – people or messages that influence their beliefs of breast cancer screening; self responsibility	Sharing who or what influences participants; self-responsibility	
Know	Screening guidelines	Participants share their knowledge of screening	
Loc	Geographical contributor to rates of breast cancer	Any geographical reference to breast cancer risks	
Mammo	Mammograms	Any reference to mammograms	Any reference to BSE and CBE

PersExp	Personal experience	Participants share personal experience of breast cancer	Participants speaking of experience with screening
PersExpScr	Personal experience (screening)	Participants sharing personal experience with breast cancers screening	Participants speaking of experiences with breast cancer (i.e.: diagnosis)
Promot.	Promotion – something to encourage a certain behavior	Sharing what would influence to get screened more	
Prev	Prevention	Participants share thoughts, experiences of prevention (either themselves or someone else) for breast cancer	
Scr	Screening	Consequences of not screening and/or screening	
Time	Time	Sharing why time is an issue	

