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# The Impact of False Positive Mammography Results on Breast Cancer Screening Intention Among Black Women

by

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Submitted in Partial Fulfillment of the Requirements

For the Degree of Doctor of Public Health in

Health Promotion, Education, and Behavior

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#### DEDICATION

"If I have seen further it is by standing on the shoulders of giants." – Sir Isaac Newton

I dedicate this to the people who supported my dreams, even when I doubted they would come to fruition. In past two years, I have experienced some of the greatest accomplishments of my professional life and most difficult challenges of my personal life. Were it not for the efforts and "shoulders" of the people listed below (and countless unnamed others); I would not have completed this work.

I dedicate this to my mother, Sondra L. Farr, who passed away during the summer of 2017. Sondra was the type of woman who made up special homework for me to complete during summer vacations and told me to consult a dictionary when I was unsure about the spelling of a word. She continually challenged me, yet her faith in me never wavered. I also want to recognise Sondra's father, my grandfather, Oscar Farr who doted on me as only a grandparent can and was always in my corner. I regret that neither Sondra nor Oscar lived to see this work in print, but I will carry them with me through my future endeavors. Lastly, I want to thank Cathy "Maxine" Farr for all of her love, support, and guidance. I love ya, girl!



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# ABSTRACT

Extensive research indicates that false-positive mammograms (FPM) have been associated with negative psychosocial and cancer-related beliefs, but only a handful of studies examine Black women's reactions to this experience. Additionally, these studies do not investigate how organizational and provider-level factors in concert with individual patient characteristics shape Black women's experiences and reactions to FPM results. The purpose of this study was to determine the impact of organizational, provider, and individual-level factors on the processes and outcomes associated with FPM results in Black women. This study had two specific aims:

1) To describe, using a mixed methods approach, the organizational and providerlevel characteristics of mammography facilities and their impact on Black women's FPM experiences and outcomes.

2) To determine, through quantitative methods, the relationship between receiving a FPM result and future mammography intention among Black women.

Two phases of data collection were conducted as part of this study. Phase I began in March 2016 and concluded October 2016. Observations, key informant interviews, provider surveys, and analyses of screening and diagnostic data were used to describe the facility and provider-level characteristics of five mammography screening centers in the Columbia, South Carolina Metropolitan Statistical Area (MSA). Organizational and provider data collected during Phase I were linked to patient survey data collected during Phase II. The patient survey tool contained items that assessed demographic



characteristics, breast cancer (BrCa) screening history, emotional states, coping behaviors, cancer-related beliefs and attitudes in Black women with FPM and normal results. Black women aged 40+, breast cancer free, who completed screening mammograms from January to August 2016 at one of the previously mentioned screening centers were eligible to participate. Women who received a FPM result were selected as cases, matched controls were selected from women screened on the same day and site but had normal mammograms. Patient surveys were administered from July 2016 to January 2017. Of the 132 patient surveys returned, 117 met the criteria for study inclusion.

No facility, provider, or patient factors were associated with two types of satisfaction: general and provider interpersonal style. FPM status was one of several patient characteristics associated with lower levels of satisfaction with convenience and provider information communication. Facility and provider-level factors had negative and positive effects on satisfaction with provider competence. Satisfaction with the clinical environment was also influenced by facility characteristics. FPM status was only associated with a higher perception of barriers to mammography, and perceived barriers were associated with a lower intention to complete mammography. Afrocentric coping behaviors moderated the perception of mammography barriers for women with FPM results, weakening this relationship.

A variety of organizational, provider, and individual-level patient factors were found to influence the processes and outcomes associated with FPM among Black women. Receipt of FPM results appear to have a detrimental effect on mammography satisfaction and intention in in Black women, but culturally-relevant behaviors such as collective coping strategies may reduce the negative effects of FPM status. Study results



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reinforce the need for incorporating culturally-appropriate theoretical influences and the operationalization of those influences to understand the contributions to racial inequities in BrCa burden.



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# CHAPTER 1

#### INTRODUCTION

# **1.1. Breast Cancer Burden**

Despite steady declines in overall cancer mortality during the past three decades, cancer remains the second leading cause of death in the United States.<sup>1</sup> The burden of cancer varies by gender as a result of sex-specific cancers such as BrCa. BrCa is the most commonly diagnosed cancer in American women and the second leading cause of cancer deaths in this population.<sup>1</sup> In 2015, it is estimated that 40,290 American women died of BrCa.<sup>2</sup> BrCa mortality rates have increased by 0.4% per year in the United States until 1989, when BrCa mortality began a steady decline which continues to this day.<sup>2</sup> Advances in the science and adoption of breast conservation surgery, adjuvant chemotherapy, and tumor detection resulted in a 36% decrease in overall BrCa death rates between 1989 and 2012.<sup>2,3</sup> Due to the enduring presence of racial disparities through the breast cancer continuum, BrCa mortality has decreased at a much slower rate among Black women.

#### **1.2 Racial Disparities in Breast Cancer Burden**

Current BrCa mortality rates are 30.0 and 21.2 per 100,000, among Black and White women, respectively.<sup>1</sup> This disparity represents a 42% higher BrCa death rate in Black women and is due to slower declines in BrCa mortality (-1.8% in Whites vs. -1.4% in Blacks).<sup>1</sup> Black-White inequities in BrCa death rates are driven by a plethora



of interconnected biological, economic, social, cultural, and health system factors.<sup>2,4–7</sup>

Racial differences in BrCa incidence trends, disease progression, and treatment are the primary drivers of Black women's increased BrCa mortality.<sup>8–10</sup> Between 1992 and 2012, BrCa incidence rose by 0.4% annually for Black women while remaining constant in White women.<sup>2</sup> In contrast to the historically higher BrCa incidence rates for White women 50 years of age or older, Black and White women in this age group now have similar rates (125.1 and 128.3 per 100,000 women, respectively).<sup>1</sup> These trends in combination with the fact that Black women are more likely to be diagnosed with larger and advanced staged tumors have negative implications for treatment success and subsequent mortality in this population.<sup>11–13</sup>

BrCa treatment-related disparities encompass issues related to Black women's access to appropriate therapies and treatment delays.<sup>8,14–16</sup> Treatment delay consists of two components: delays in initiating treatment post receiving a diagnosis of BrCa and delays in completing diagnostic testing after symptom detection or notification of an abnormal screening test (diagnostic delays).<sup>17,18</sup> Diagnostic delay has emerged as a significant behavioral factor explaining poor BrCa prognosis in Black women through its contribution to advanced tumor stage at diagnosis and the influence on the timeliness of the start of treatment.<sup>15,16,19–21</sup> Black women are less likely to complete diagnostic testing within the desired 60-day window than their White counterparts.<sup>16–18,20,22,23</sup> Much research has been devoted to understanding the causes and mechanisms responsible for this behavioral trend, but no one factor explains this phenomenon.



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#### 1.3 Contributions to BrCa Diagnostic Delay in Black Women

Of the many determinants of diagnostic delay among Black women, individuallevel factors have received the most attention.<sup>24,25</sup> Sociodemographic characteristics that impact healthcare access including: income, health insurance, and employment status, have been most frequently cited as leading to diagnostic delay.<sup>16,20,24,25</sup> Lack of knowledge regarding BrCa screening, attitudes such as fear, and cancer-related beliefs like cancer fatalism, have also been thought to affect Black women's motivation to complete follow-up testing.<sup>20,24,25</sup> Clinical aspects of the BrCa screening population include: non-adherence to mammography screening guidelines and self-detection of tumors as opposed to mammography are also associated with diagnostic delays.<sup>16,19,26–28</sup>

# 1.4 Previous Mammography Screening Experiences and Diagnostic Delay

Prior research on the characteristics associated with follow-up delay in Black women has paid little attention to Black women's previous screening experiences and their potential to influence the completion of diagnostic testing. Outside of studies of racial discrimination and mistrust in the clinical encounter, virtually no efforts have quantitatively linked past mammography experiences to Black women's attitudes towards diagnostic testing.<sup>29–33</sup> Black women's history of FPM results may be an importan,t but understudied aspect of their screening experience.

One qualitative study of Black BrCa survivors presented accounts of women who delayed seeking care for lumps due to past FPM results.<sup>34</sup> Another study by Kerner et al. examined multilevel influences on follow-up delays among Black women. Kerner et al. found that Black women with previous FPMs were 60% more likely to have diagnostic delays than Black women without a history of FPMs.<sup>35</sup> Additionally, study participants



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with higher levels of cancer anxiety were less likely to complete their diagnostic followup within the recommended 90-day window.<sup>35</sup> Both studies indicate a possible connection between prior FPM results and mammography delay in Black women.

# **1.5 False-Positive Mammography Results**

A FPM result is defined in health research literature as a screening mammogram that requires additional follow-up testing, but does not lead to a cancer diagnosis.<sup>36–38</sup> Clinically, FPMs correspond to a Breast Imaging-Reporting and Data System (BI-RADS) classification of 0 (i.e., additional imaging evaluation and/or comparison to prior mammograms in needed), 3 (i.e., probably benign finding), 4 (i.e., suspicious abnormality) or 5 (i.e., highly suggestive of malignancy) that is confirmed as non-malignant through one or more of the following procedures: diagnostic mammogram, ultrasound, breast MRI, or biopsy.<sup>39</sup> Normal mammograms are classified as BI-RADS 1 or 2.<sup>40</sup>

Anywhere from 5-10% of mammograms each year result in a FPM, but cumulatively a woman has a 20-65% chance of receiving a FPM result depending on the age at which she initiates screening (40 or 50 years old), her screening schedule (annual vs. biennial), and her risk for FPM.<sup>41–44</sup> Younger women (age 40-49), women with heterogeneously dense breasts, those with a family history of BrCa, and previous FPM results are at increased risk of receiving a FPM result.<sup>45</sup> FPM rates are generally the same for Black and White women, but facility and provider characteristics have been documented to affect the prevalence of FPM in various racial groups.<sup>45–48</sup> National data indicate the that rates of abnormal mammography results have risen in recent decades.<sup>49</sup>



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Recommended mammography screening intervals have been lengthened in part due to potential harms to women as a result of FPM.<sup>50–52</sup>

# 1.6 Impact of FPM Among Black Women

FPM results may lead to potentially negative patient-level outcomes, such as additional financial costs due to follow-up testing, impaired daily function, negative emotional states, and reduced levels of future BrCa screening intention and behavior.<sup>37,38</sup> What, if any, effects FPM results may have on Black women's satisfaction with their mammography experiences, BrCa related beliefs and attitudes, and/or future screening and follow-up behaviors is largely unknown due to the lack of research on FPM in this population.

Black women in the United States inhabit different social, environmental, economic, and cultural contexts than White women. As such these contexts impact Black women's BrCa risk and knowledge.<sup>53–56</sup> Black women's access to cancer screening services is impacted by the quality of facilities and providers through residential segregation.<sup>48,57,58</sup> Extensive literature exists to describe the communication challenges Black women face while navigating the healthcare system.<sup>59–62</sup> The actions Black women employ in the face of these challenges are shaped by cultural and social norms for behavior within and outside the Black community. Thus, their experiences and outcomes cannot be fully represented by research consisting of predominately White participants.<sup>63</sup> Being that "Black women are not White women plus color, or Black men, plus gender"<sup>64</sup>, research studies centered on Black women's experiences and grounded in relevant cultural frameworks are essential to explain and address racial inequities in BrCa burden.<sup>65</sup>



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# **1.7 Specific Aims**

The purpose of this study was to determine the impact of organizational, provider, and individual-level factors on the processes and outcomes associated with FPM results in Black women. The study was conducted in two phases and had two specific aims:

**Specific Aim 1**: To describe, using a mixed methods approach, the organizational and provider-level characteristics of mammography facilities and their impact on Black women's FPM experiences and outcomes.

<u>Research Question 1.1</u>. What organizational, provider, and patient-level characteristics predict high levels of satisfaction with their clinical encounter among Black women experiencing a FPM result?

**Specific Aim 2:** To determine, through quantitative methods, the relationship between receiving a FPM result and future mammography intention among Black women.

<u>Research Question 2.1</u>. What is the relationship between receiving a FPM result and BrCa behavioral beliefs (perceived benefits of mammography, perceived BrCa susceptibility, and perceived barriers to mammography screening) among Black women?

<u>Research Question 2.1.a</u>. Do Black women's emotional states explain the relationship between a FPM result and BrCa behavioral beliefs (perceived benefits of mammography, perceived BrCa susceptibility, and perceived barriers to mammography screening)?

<u>Research Question 2.1.b</u>. Does the relationship between receipt of FPM results and BrCa behavioral beliefs (perceived benefits of mammography, perceived BrCa



susceptibility, and perceived barriers to mammography screening) vary by the coping strategy employed?

<u>Research Question 2.2</u>. What is the relationship between BrCa behavioral beliefs (perceived benefits of mammography, perceived BrCa susceptibility, and perceived barriers to mammography screening) and the intention to complete future mammography screening?

The next chapter will provide background information on the burden of BrCa among Black women and the role of mammography and follow-up testing in South Carolina. A review of the research to date on the prevalence, influences, and outcomes associated with FPM results will also be presented.



# CHAPTER 2.

## BACKGROUND AND SIGNIFICANCE

This chapter provides background on recent epidemiological and behavioral trends as they relate to BrCa burden among Black women and potential influences on these trends.

#### 2.1 Cancer in Black Women

Cancer is the second leading cause of death among American women.<sup>66</sup> It is estimated that BrCa was responsible for 19% of cancer deaths in 2016, making it the second leading cause of cancer deaths among Black women in that year.<sup>67</sup> BrCa is also the most prevalent cancer among Black women as it represents an estimated 32% of cancer incidence for this group in 2016.<sup>67</sup>

#### 2.2 Epidemiology of Breast Cancer in Black Women

#### 2.2.1 Racial trends in breast cancer burden in the United States

In the United States, Black women have disproportionately higher BrCa mortality rates than any other racial and ethnic group.<sup>2</sup> This trend began in the late 1990's due to a slower decline in Black women's BrCa mortality relative to White women (-1.4% and - 1.8% percent annual change, respectively).<sup>67</sup> Between 2010 and 2014, BrCa mortality rates were 30.0 per 100,000 in Black women and 21.1 per 100,000 among White women which represents a 42% higher death rate for Black women.<sup>1</sup>

In contrast, BrCa incidence has increased by 0.4% annually among Black women between 2008 to 2012, while remaining stable for White women.<sup>2,68</sup> Historically,



BrCa incidence rates were highest in Black women under the age of 40, but higher among White women over the age of 50.<sup>69,70</sup> Recently, BrCa incidence in Black and White women over the age of 50 has converged.<sup>2,7,71</sup> Current five-year incidence rates (2009-2013) are essentially the same for Black and White women (125.1 and 128.3 per 100,000, respectively). Higher BrCa incidence among Black women over 50 has the potential to increase BrCa mortality, thus widening the current racial disparity in BrCa burden. This trend is especially notable in the Southern US, with South Carolina serving as a typical example.<sup>7</sup>

# 2.2.2 Racial Trends in Breast Cancer Burden in South Carolina

South Carolina contains 46 counties which are organized into four regions by the South Carolina Department of Health and Environmental Control (See Figure 2.1). The Columbia, SC MSA includes Richland, Lexington, Saluda, Fairfield, Kershaw, and Calhoun counties and is largely located within South Carolina Department of Health and Environmental Control's Midlands region (See Figure 2.2). The most recent five-year average (2009-2013) of BrCa incidence in the Columbia SC MSA was 132.0 per 100,000 which is above the Midlands region average of 127.8 per 100,000 or the state average of 127.2 per 100,000.<sup>72</sup> BrCa mortality in the Columbia, SC MSA (23.7 per 100,000) was similar to the regional and statewide mortality rates (22.8 and 22.4 per 100,000) during that time period.<sup>72</sup>

In addition to increased BrCa burden, the Columbia, SC MSA displays significant racial inequities in BrCa burden. This disparity has increased since the racial convergence in national BrCa incidence rates. Average BrCa incidence and mortality rates by race and





Figure 2.1 Map of South Carolina Department of Health and Environmental Control Regions and Central Offices





Figure 2.2 Map of Columbia, SC Metropolitan Statistical Area



geographic location for 2012 and 2013 are presented in Table. 2.1. Black women in the Columbia, SC MSA had higher rates of BrCa incidence (139.5 and 130.0 per 100,000) and mortality (31.8 and 20.3 per 100,000) compared to White women.<sup>72</sup> The Columbia, SC MSA will require special attention to ensure that BrCa inequities do not widen.

Location	Incidence (Per 100,000)		Mortality (Per 100,000)	
	White	Black	White	Black
Columbia MSA	130.0	139.5	20.3	31.8
DHEC Midlands	125.2	134.6	20.3	29.4
South Carolina	128.2	127.9	19.3	28.5
United States	124.3	122.1	20.5	28.8

 Table 2.1 2012-2013 Breast Cancer Incidence and Mortality by Race and Location<sup>72-74</sup>

# 2.3 Contributions to Increased Breast Cancer Burden Among Black Women

Differences in BrCa risk factors; comorbid conditions, and tumor characteristics at/prior to diagnosis; as well as the quality, effectiveness, and adoption of treatment modalities are responsible for the elevated BrCa death rates among Black women.<sup>6,67</sup> Prediagnostic differences in BrCa burden among Black women may lead to future increases in BrCa mortality in this group. Mixed evidence suggests that reproductive factors such as age at menarche and age at first pregnancy may increase the risk of different BrCa subtypes in Black women based on age and/or menopausal status.<sup>75–77</sup> Obesity and diabetes also increase BrCa risk and are suspected to be driving forces responsible for increasing BrCa incidence among Black women.<sup>2,68</sup>



Upon diagnosis, differences in disease severity also drive increased BrCa mortality experienced by Black women.<sup>9,15,19,78–81</sup> Black women are more likely to be diagnosed with stage II, III and IV tumors compared to White women.<sup>15,19,78,82</sup> After controlling for socioeconomic and biological factors, delays in breast cancer diagnosis and treatment have been documented as significant contributors to advanced staged breast cancer in Black women.<sup>10,15,16,27,80,83–85</sup>

# 2.4 Racial Inequities in Breast Cancer Screening

Recent data from the 2015 National Health Interview Survey indicated that Black women complete screening mammograms at somewhat higher rates than White women (69.7% and 65.8%, respectively).<sup>66</sup> Behavioral Risk Factors Surveillance System data from 2014 reports similar screening trends in South Carolina with 81.4% of Black women reporting use of screening mammography compared to 74.4% of White women.<sup>86</sup> Despite higher initial screening rates, Black women are less likely to complete follow-up screening tests if their initial mammogram reveals an abnormality.<sup>15,16,27,83,85</sup>

#### 2.5 Addressing Mammography Follow-Up Among Black Women

Delayed mammography follow-up in Black women has been attributed to lower levels of BrCa knowledge, BrCa related attitudes and beliefs, socioeconomic factors, and issues related to healthcare access.<sup>24,87,88</sup> Recommended client-oriented approaches for increasing BrCa screening include: small media, group and one-on-one education programs, such as Black Corals and the Witness Project, which address racial differences in BrCa knowledge and beliefs, and system level interventions like the National Breast and Cervical Cancer Early Detection Program, and patient navigation focus on removing structural barriers.<sup>89–94</sup> All of the previously mentioned programs and strategies have



been implemented in South Carolina and have had positive impacts on BrCa screening among Black women in the state.

# 2.5.1 Evidence-based Strategies to Improve Mammography Follow-Up Among Black Women

The Black Corals program was developed by the St. James-Santee Family Health Center in collaboration with the South Carolina Department of Health and Environmental Control in 2008.<sup>95,96</sup> Community-based group education sessions provided education about BrCa risk factors, symptoms, detection and screening resources.<sup>95,96</sup> Together with a media campaign, client and provider reminders, the program lead to increased screening rates and a reduction in the rates of missed appointments.<sup>95,96</sup>

Around the same time, a statewide lay education program was developed by the National Cancer Institute-funded Community Network Program Center in South Carolina, the South Carolina Cancer Disparities Community Network-II (SCCDCN-II).<sup>97–99</sup> The SCCDCN-II was a partnership between academic researchers and members of a statewide Black faith organization.<sup>100</sup> Together, members of the SCCDCN-II implemented the South Carolina Witness Project, an evidenced-based group education program that is culturally tailored to provide BrCa education to Black women.<sup>101,102</sup> Women in the program demonstrated increased BrCa knowledge, decreased cancer fatalism, and increased screening intentions after participating in the community education sessions.<sup>103</sup>

The National Breast and Cervical Cancer Early Detection Program (NBCCEDP) is one of the largest programs focused on addressing known barriers to mammography follow-up with special attention to racial and ethnic minorities such Black women.<sup>91,104</sup>



The NBCCEDP consists of several activities such as the building of an infrastructure to support the delivery of and reimbursement for BrCa screening and diagnostic services, the provision of education and outreach services to support the recruitment of eligible women, and the delivery of case management services and patient navigation to support women as if they receive abnormal results.<sup>91,104</sup> In South Carolina, the NBCCEDP funds the Best Chance Network (BCN) which is administered by DHEC's Division of Cancer Prevention and Control.<sup>91,105</sup> Since 1991, BCN has provided BrCa and cervical cancer screening services to South Carolina residents aged 40-64 with incomes at or below 200% of the federal poverty level.<sup>91,105</sup>

The NBCCEDP has made significant progress in providing BrCa screening and diagnostic procedures to low income women and women of color, but the program's efforts alone are not enough to reduce the BrCa burden in Black women. A comparison of BrCa burden among NBCCEDP and non-NBCCEDP participants indicate that Black participants were more likely to have late staged disease compared to Black women who did not participate in the program.<sup>106</sup> Across all groups of program participants, Black women and women residing in the South were also more likely to present with late staged disease.<sup>106</sup> While the NBCCEDP has reduced participants' time from initial screening to diagnosis (diagnostic interval) between 1996 to 2005, Black women and other women of color continue to have longer diagnostic intervals than White women.<sup>92</sup>

Patient navigation is another strategy that has been used address disparities in BrCa screening and diagnostic follow up.<sup>93,94</sup> As described by Dr. Harold Freeman, who developed this model to address cancer disparities in Harlem in the 1980s, patient navigators are lay persons from the same cultural and/or local communities as the patient



population they serve.<sup>93,107</sup> These lay persons are trained to assist patients in "navigating" the healthcare system and overcoming the various cultural, social, systemic, and logistical barriers that prevent patients from getting the recommended cancer care.<sup>93,107</sup>

The NBCCEDP is one of many programs which incorporates the use of patient navigation to improve cancer care among Black women.<sup>104,108</sup> While patient navigation has been effective in reducing delays in the resolution of abnormal screening results; Black participants continue to display longer diagnostic follow-up intervals compared to their White counterparts even after controlling for factors such as the number of barriers to diagnostic resolution or health insurance type.<sup>17,109–111</sup>

# 2.6 Influence of Screening History on Black Women's Screening Behaviors

Despite these programs, racial inequities in the time between BrCa detection and diagnosis persist.<sup>15,16,79,83,85,92,109</sup> The enduring nature of BrCa screening inequities points to gaps in understanding how various factors influence BrCa screening behaviors in Black women. Much of the research on this phenomenon examines BrCa screening knowledge, cultural beliefs, structural/logistical barriers to screening, but few studies have examined the role of past screening history.<sup>24,87,88,112</sup> One screening outcome that has received little attention, but may hold the key to explaining delayed follow-up among Black women, is receiving a FPM.

Black women's history of abnormal mammography results may be an important, but understudied aspect of their screening experience. One qualitative study of Black BrCa survivors presented accounts of women who delayed seeking care for lumps due to past abnormal screening mammograms that were found to be non-cancerous.<sup>34</sup> Another study by Kerner et al. examined correlates of delayed follow-up in a sample of Black



women with abnormal screening mammograms.<sup>35</sup> Women who completed mammography follow-up after the 90-day window were more likely to have had an abnormal mammogram in the past, displayed higher levels of anxiety compared to those completed follow-up within the window, or had a screening mammogram designated as incomplete or inconclusive compared to those designated as highly suspicious or potentially malignant (BI-RADS 0 vs 4/5).<sup>35</sup> Both studies indicate a possible connection between prior abnormal mammograms and mammography delay in Black women.

#### 2.7 Definition and Epidemiology of False Positive Mammograms

FPM is the term used in public health research to describe a screening mammogram with an abnormal result that is confirmed as non-malignant through one or more of the following procedures: diagnostic mammogram, ultrasound, breast MRI, or biopsy.<sup>37,113,114</sup> Clinically, FPM results correspond to a BI-RADS classification of 0 (Incomplete - additional imaging evaluation and/or comparison to prior mammograms in needed), 3 (Probably benign finding), 4 (Suspicious abnormality) or 5 (Highly suggestive of malignancy).<sup>39</sup> Normal mammograms are classified as BI-RADS 1 or 2.<sup>39</sup>

Anywhere from 5-10% of mammograms each year result in a FPM, but cumulatively a woman has a 20-65% chance of receiving a FPM result depending on the age at which she initiates screening (anytime between 40 and 50 years of age) and her screening schedule (annual vs. biennial).<sup>37,41–43,114,115</sup> FPM may lead to potentially negative outcomes, such as additional financial costs due to follow-up testing, impaired daily function, negative emotional states, and potentially reduced BrCa screening intention and behavior.<sup>37,38</sup> Patient and system level factors can increase the rate of FPM results.<sup>114,116,117</sup>



#### 2.7.1 Influences on False Positive Mammography Rates

Biological patient characteristics, such as older age, breast density (as measured by BI-RADS density classification), being premenopausal, having a family history of BrCa, and for women in the 40-59 age range a low BMI, have been associated with increased likelihood of receiving FPM results.<sup>45,114,118</sup> Several aspects of a patient's previous screening history also lead to future FPM results: having a FPM result in the past, if this the patient's first or subsequent screening mammogram of her BrCa screening life, the availability of previous mammography images, and shorter screening intervals.<sup>45,114,118,119</sup>

Provider and facility characteristics also drive FPM rates, but is not entirely clear how these factors influence FPM rates at the mammography facilities Black women use.<sup>46,120–125</sup> Radiologists who were older, male, with more clinical experience, or read less than 1,500 scans annually had lower FPM rates.<sup>47,122,123,125</sup> Additionally, completing a breast imaging fellowship and reporting concerns about malpractice was associated with higher FPM rates among radiologists.<sup>47,122</sup> One study documented radiologists recalling Black women for additional testing at higher rates than White women, but it not entirely clear if this is related to variations in screening history between Black and White women.<sup>124</sup> Facility-level characteristics, such as providing radiologists with audit data, the presence of on-site diagnostic, specialized imaging procedures, and interventional services, were also related to higher FPM rates.<sup>120–122</sup>

Many of the factors associated with high FPM appear to be more prevalent among academic medical centers and facilities with National Consortium of Breast Centers accreditation or American College of Radiology's Breast Imaging Center of Excellence



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certification.<sup>126,127</sup> Yet, Black women are less likely to attend facilities with the previously mentioned credentials when compared to White women.<sup>128</sup> Recent studies have demonstrated that mammography facilities that serve higher percentages of women of color have higher FPM rates, even after adjusting for patient characteristics .<sup>46,120</sup> Together, this evidence points to an interplay between Black women's screening history and BrCa screening environments leading to higher levels of FPM results, but the ways in which these dynamics impact Black women's emotions, beliefs, and behaviors around BrCa has been left out of research on FPM results.

#### 2.8 Current Research on False Positive Mammography Outcomes

# 2.8.1 Populations Studied

Studies of this phenomenon begin appearing in the late 1980's after notable rise in mammography screening rates (and preceding a subsequent recommendation for women ages 40-49 not to participate in screening mammography).<sup>129,130</sup> Multiple reviews of FPM studies were published between 1997 and 2010.<sup>37,38,131–133</sup> Research on FPM has been conducted primarily with homogeneous samples of European women.<sup>37,38,43,131,133–144</sup> Research on the impact of FPM among American women includes samples of primarily White, middle to high income, college-educated women.<sup>37,38,43</sup> Only a handful of American studies include Black women and examine the impact of FPM by race.<sup>35,43,115,145–155</sup>

#### 2.8.2 Explanatory Mechanisms

Except for a recent study by DeFrank et al. (2012), none of the previous research on this topic tested mechanisms describing how FPM results influence subsequent screening behavior as the primary focus has been measuring psychosocial outcomes



including anxiety and depression.<sup>43,115,131,147–149,151,153,155–157</sup> DeFrank et al. (2012) prospectively followed women presenting for mammography to determine how/if emotions and BrCa screening beliefs influenced mammography behavior. In this study, women with FPM results were more likely to experience delays in the completion of their next mammogram and that a mammography recommendation from a provider mediated subsequent mammography completion in this group.<sup>43</sup> Women receiving a FPM result were less likely to complete their next scheduled mammogram, but receiving a recommendation from provider reversed this trend.<sup>43</sup>

#### 2.8.3 Study Design

The majority of FPM studies use national or site-based screening cohorts for study, but the rarity of FPM results in a given screening year makes the use of a case-control design a less time and resource intensive option.<sup>37,43,158–171</sup> Of the handful of case-control studies conducted, only one study by Lowe mentions the selection of matching controls to create a sample in which demographic characteristics are comparable in women with FPM and normal mammography results.<sup>115,151,172–177</sup> The lack of unmatched case-control studies presents doubts as to the validity of FPM study outcomes as findings maybe a result of demographic differences between cases and controls.

The body of research on FPM results is not without several strengths. An important strength is the reliance on prospective studies which confirm a temporal relationship between FPM and psychological outcomes.<sup>37,43,115,158–168,170,172,173,175,178–181</sup> Another positive aspect of this work is the vast number of longitudinal studies assessing participants shortly after receipt of results and following participants, in some cases, for two years after their initial FPM result. <sup>37,43,159–162,164–170,175–178,181</sup> Approximately one-



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third of these studies provide information on the longer term impact of FPM results (greater than 6 months after receipt of results) and report differences between women with FPM and normal results.<sup>37,43,165,166,169,170,175,177,178,181</sup>

#### 2.8.4 Outcomes Assessed

#### 2.8.4.1 Emotions

Anxiety was the most commonly assessed outcome across all studies of this phenomenon.<sup>37,38,131–133</sup> General anxiety was consistently measured with one of three standardized measures the Hospital Anxiety and Depression Scale, the Spielberger State-Trait Anxiety Scale-State Subscale, or the General Health Questionnaire.<sup>37,38,182–184</sup> While standardized measures have detected higher levels of anxiety among women with FPM results, these differences were largely not statistically significant.<sup>37,38</sup> On the contrary, a substantial number of studies using ad hoc measures of general anxiety report statistically significant differences.<sup>37,38</sup> BrCa specific-anxiety has been measured by a combination of investigator developed measures and the anxiety subscale of the Psychological Consequences Questionnaire (PCQ).<sup>38,179</sup> The association of elevated levels of BrCa specific-anxiety and FPM results persists no matter what assessment was employed.<sup>37,38</sup>

Emotions similar to anxiety, including worry, fear, and intrusive thoughts have been examined to a much lesser extent and with largely single item questions developed for individual studies.<sup>37,38</sup> As with BrCa anxiety, measures of worry and fear that are specific to breast cancer document higher levels of these emotions among women with FPM results.<sup>37,38</sup>

Depression often co-occurs with anxiety and has frequently been assessed in studies of FPM mammography.<sup>37,38</sup> A wide variety of standardized scales have been used



to measure the potential depression among women with FPM results, including: the Hospital Anxiety and Depression Scale, the Hopkins Symptom Checklist, the Depression subscale of the General Health Questionnaire, the K-6 Questionnaire, the Beck Depression Inventory, and the Short Form of the Center for Epidemiologic Studies Depression Scale.<sup>37,38,183–188</sup> Yet, the literature on this topic displays a lack of association between FPM results and depression.<sup>37,38</sup>

Various aspects of psychological distress and somatization in response to FPM results have been documented with mixed results.<sup>37,38</sup> Physical, emotional, and social distress, as measured by the PCQ, has consistently been associated with FPM status, but other scales have not yielded the same results.<sup>37,38</sup> There is no clear consensus regarding the relationship between physical complaints and FPM status given the different types of complaints assessed by each scale.<sup>37,38</sup>

#### **2.8.4.2 Breast Cancer Beliefs**

Despite the role of BrCa related beliefs and intentions in understanding BrCa screening behavior, less than a third of studies investigate the potential impact of receiving a FPM result on BrCa screening beliefs and attitudes.<sup>43,112,149,153,163,167,168,178,189–191</sup> Components of the health belief model have been assessed in various studies with perceived BrCa susceptibility being the most frequently examined belief.<sup>43,149,151,153,163,167,168,191</sup> The impact of perceived susceptibility is inconclusive with half the studies measuring this belief reporting statistically significant increases in perceived susceptibility among women with FPM results, while the remaining studies report no relationship between these variables.<sup>43,149,151,153,163,167,168</sup> One study by Molina et



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al. (2017) revealed the influence of FPM status on perceived susceptibility varied by race, with higher levels among Latinas and no differences among White women.<sup>191</sup>

Only four studies measured perceived benefits of mammography, but neither used a standardized scale.<sup>37,43,177,178</sup> DeFrank et al.'s (2012) study of FPM results and subsequent mammography behavior found that FPM status was associated with more time thinking about the benefits of mammography.<sup>43</sup> Gram et al. (1990) and Brett et al. (2001) found no association, while Lerman et al. (1991) did not report an analysis of these factors.<sup>151,177,178</sup> Pisano et al. (1998) and DeFrank et al. (2012) were the only studies to examine how the perception of barriers to mammography may vary by mammography outcome, and neither detected a statistically significant relationship.<sup>43,149</sup>

## 2.8.4.3 Breast Cancer Screening Intentions and Behavior

Screening intention is an important precursor to mammography screening, but this concept only been measured in two studies to date.<sup>163,192</sup> Lerman et al. (1991) found that FPM was associated with increased mammogram screening intention, in contrast to Brett et al. (1998) which found no association.<sup>163,192</sup> These mixed findings do not extend to the impact of FPM results on BrCa screening behaviors. FPM status has overwhelmingly been associated with higher rates of breast self-examination rates.<sup>37,166,167,169</sup> The impact of FPM status on subsequent mammography screening varies by region, with FPM status reducing the likelihood of White European women completing mammograms and increasing the likelihood of mammography completion among American women.<sup>37</sup> FPM status did not affect mammography behavior among Canadian women.<sup>37</sup> Regional differences in the influence of mammography outcomes on future mammography



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behavior speaks to the influence of additional factors on this relationship, specifically health system characteristics.

#### 2.8.5 Influences on False Positive Mammography Outcomes

# 2.8.5.1 Mammography Satisfaction and False Positive Mammography

Much of the research on mammography satisfaction has been conducted in international settings and centers on the influence of patient-level characteristics like age, education, and income.<sup>89,193</sup> Facility features, such as the patient volume, payer mix, geographic location, clinical environment, and provider-level factors, including the communication of information about the screening process, and perceived staff competence, are described as having an important effect on satisfaction in several gualitative studies, but quantitative analyses of these characteristics are limited.<sup>194–196</sup> Both Ong et al. (1997) and Brett et al. (2001) examined how the receipt of FPM results relate to mammography satisfaction.<sup>158,178</sup> Ong et al.'s (1997) analysis found relationships between increased anxiety displayed by women with FPM and poor communication, the need for additional information about screening outcomes, and difficulty understanding screening results.<sup>158</sup> In the case of Brett et al. (2001) no information was given about the measure of satisfaction, but incomplete/poor communication about screening results and longer wait times were associated with dissatisfaction with the clinical encounter among women with FPM results.<sup>178</sup>

#### **2.8.5.2** Coping Behaviors and False Positive Mammography

In the case of BrCa, the majority of studies examine coping in the context of BrCa treatment and survivorship, but some research indicates that coping behaviors may also play a role in breast cancer screening.<sup>197,198</sup> In response to a hypothetical BrCa diagnosis,


Black women, White women, and Latinas from multiple countries reported their anticipated coping styles in addition to the number of mammograms completed in the past 10 years.<sup>198</sup> Avoidant coping behaviors were found to be associated with lower mammography rates among Black American women, but the direction of this association differed within racial groups (Blacks from the Caribbean) and between racial groups (Blacks vs Latinas).<sup>198</sup>

A single study by Chen et al. (1996) sought to determine the effect of various coping behaviors on psychological stress experienced by women with FPM results.<sup>180</sup> Coping strategies appear to be assessed using an early version of the Ways of Coping Scale, which measures primary, secondary and tertiary coping responses.<sup>180,199</sup> Chen used stepwise regression to determine what characteristics mediate/explain the connection between FPM results and negative psychosocial outcomes.<sup>180</sup> Problem-focus engagement behaviors (confronting an issue) were related to lower levels of psychological distress, while neuroticism, as measured by Eysenck's Personality Inventory, was associated with higher levels of distress.<sup>180</sup>

Conceptualizations of coping behaviors have their roots in the transactional model of stress and coping.<sup>200</sup> This model stipulates that multiple interdependent processes are generated when an individual encounters a stressor.<sup>200</sup> In the case of FPM result, the characteristics of the event are evaluated during the primary appraisal process, which may generate an initial emotional response such as anxiety.<sup>200,201</sup> Simultaneously, secondary appraisals are employed to determine a course of action, which usually leads to a coping response.<sup>200,201</sup> Coping strategies can generate new emotions and beliefs in and of themselves or through the new appraisals that are generated in response to the coping



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behavior.<sup>200,201</sup> Individual characteristics including personality traits and cultural differences in social contexts and emotional expression can greatly impact this process.<sup>201</sup>

Personality traits have been shown to impact appraisal outcomes with negative traits such as neuroticism leading to potentially less productive avoidant-style coping behaviors.<sup>202</sup> Additionally, the meaning and usage of coping behaviors vary across racial and ethnic groups and in response to different events.<sup>203–205</sup> Black American culture has retained an emphasis on collectivism, religion, and spirituality thus shaping Black women's coping strategies .<sup>203–206</sup> The use of culturally appropriate coping assessments such as the Africultural Coping Systems Inventory (ACSI) may be necessary to accurately describe Black women's coping behaviors in the face of a FPM result.<sup>204,206</sup>

# 2.9 Gaps in Research on False Positive Mammography Results

All of the systematic reviews conducted on this topic have described weakness related to measurement and external validity.<sup>37,38,131,133</sup> Additional challenges present in FPM studies include: a lack of research on explanatory mechanisms and an overemphasis on individual-level factors (to the exclusion of the healthcare environment).

## 2.9.1 Issues with Study Design and Measurement

Of the standardized measures that have been consistently used to examine anxiety, the following are the most commonly used: Psychosocial Consequences Questionnaire (PCQ), Hospital Anxiety and Depression Scale (HADS), General Health Questionnaire (GHQ), and the Spielberger State-Trait Anxiety Instrument (STAI). GHQ, HADS, STAI are clinical measures and may not be sensitive enough to capture the levels of anxiety present during the screening encounter.<sup>133</sup> The commonly used measure of



BrCa anxiety: the PCQ and the revised version of the measure (PCQ-DK33) have been used almost exclusively in European studies, so the psychometric properties of this measure with American women is unknown.<sup>207</sup> Reliance on cohort designs, self-report data, and the small numbers of women with FPM results are methodological limitations of this body of work.<sup>133</sup> Even more recent work while well designed, uses unstandardized measures and/or and has failed to generate mechanisms describing the link between FPM results and BrCa screening behaviors .<sup>43,115</sup>

#### 2.9.2 Issues with External Validity

All of the studies mentioned thus far provide important information regarding the outcomes of receiving a FPM result, but many of them are not generalizable to American populations, including Black women. The impact of FPM on the screening behaviors of Black women has been largely ignored as the majority of research on this topic has been conducted primarily with homogeneous samples of European women.<sup>37,38,43,131,133–144</sup> Research on the impact of FPM results among American women include primarily White, middle to high income, college-educated women.<sup>37,38,43</sup> Only a handful of American studies include Black women and examine the impact of FPM by race.<sup>35,43,115,145–155</sup>

#### 2.9.2.1 False Positive Mammography in Black Women and Other Women of Color

While Black women's experiences with BrCa screening have been explored indepth, only one study has sought to understand how Black women's screening behaviors relate to various screening endpoints such as the receipt of FPM results. Kerner et. al. (2003) examined multilevel influences on diagnostic delays in Black women and found that women with previous FPMs were 60% more likely to have diagnostic delays than



Black women without a history of FPMs.<sup>35</sup> Additionally, Black women in this study with higher levels of cancer anxiety were less likely to complete their diagnostic follow up within the recommended 90 day window.<sup>35</sup>

When comparing the effects of FPM in non-White and White women, Gibson et al. (2009) found no difference in anxiety levels overall, but upon reviewing outcomes by race, non-White women exhibited significantly higher levels of anxiety if they had received a FPM result.<sup>150</sup> Across racial categories, women in the FPM group with higher anxiety scores were more likely to display depressed mood.<sup>150</sup> Black women only comprised 0.20% of the sample, so it is likely that these results were driven by the Latino women in the study.<sup>150</sup>

Alderate et al. (2006) reports that Asians were less likely than Whites and Blacks to be depressed in the 3-7 months post receipt of FPM result.<sup>145</sup> The study also revealed that women who reported weekly attendance at religious services during that time were less likely to experience depression, but this and other factors correlated with increased depression (having a disability) were not examined separately for each racial group.<sup>145</sup> Alderate et al. (2006) also included women whose abnormal results were revealed to be malignant, so it is questionable how well this study describes the effects of FPM across racial and ethnic groups.<sup>145</sup>

While these studies suggest potential negative outcomes of FPM results in Black women, with the exception of Kerner et al. (2003), they do not provide insights as to how the FPM process may contribute to racial inequities in BrCa screening being that they compared the emotional states of Black women to other groups of women as opposed to describing the process of and impact of FPM in Black women. Additionally, these studies



do not describe the mechanisms by which emotional states, knowledge, attitudes, and beliefs influence mammography intention following the receipt of a FPM result in Black women.

# 2.9.3 Inattention to Mechanisms Explaining the Outcomes of False Positive Mammography

Except for Lidbrink et al. (1995) and Molina et al (2014), none of the previous literature on this topic examined what factors mediated psychosocial outcomes of receiving FPM results nor have they empirically tested mechanisms connecting various psychosocial outcomes of FPM results with future mammography intention.<sup>43,115,131,147-149,151,153,155-157</sup> As psychosocial factors such as emotion, personality traits, and stress response are embedded in cultural contexts, it is important to examine the impacts of these factors within a specific cultural group in order to explain their effects on health behaviors.<sup>208</sup> Blacks and members of other more collectivist cultures have been shown to rely more heavily on external resources leading to potentially different reactions and outcomes than Whites in similar situations.<sup>203,206</sup> Incorporating examinations of culturally-specific coping strategies, such as the Africultural Coping Systems Framework, in response to the receipt of FPM results and can provide important insights as to how Black women respond to this phenomenon.<sup>206</sup>

# 2.9.4 Inattention to the Influence of Socioecological Contexts of the Healthcare System

The socioecological model of health describes the influence of intrapersonal, interpersonal and system level factors on health outcomes as well as racial inequities in cancer screening behaviors.<sup>209,210</sup> Patient-level influences on BrCa screening behaviors in



Black women are well documented and include: BrCa knowledge, beliefs and attitudes.<sup>24,211</sup> In FPM research conducted with US women (primarily White), trait anxiety, mood states such as general and BrCa specific anxiety, depression, and coping styles have been found to be associated with FPM status.<sup>43,115,131,147,148,151,153,155,156</sup> Yet, only a handful studies have empirically tested the mechanisms linking psychosocial outcomes to mammography screening behavior.<sup>43,169,178</sup>

Health system factors shape clinical encounters directly through impacting patient experiences and indirectly by shaping provider practice.<sup>212,213</sup> Appointment availability, referral processes, norms of provider and staff behavior, the method and manner that mammography results are communicated, all impact on women's mammography experiences and their satisfaction with these experiences.<sup>156,213–215</sup> Facility-level factors including but not limited to patient volume, payer mix, facility capacity, can impact providers' behaviors such as the duration and type of communication they are able to engage in during a visit.<sup>35,213–220</sup> Despite theoretical and empirical knowledge of the multilevel influences on mammography and mammography satisfaction, few studies have explored these combined influences on mammography or FPM outcomes.<sup>215,221</sup> As with investigations of FPM outcomes, mammography satisfaction among Black American women has received little attention outside of evaluations of patient navigation programs.<sup>195,222,223</sup> This dissertation research is novel as it employs quantitative and qualitative research methods to explore and explain the interaction of various socioecological levels during the FPM process and how these factors influenced Black women's mammography screening intention.



## 2.10 Statement of the Problem

Black women are less likely to complete the entire BrCa screening process, as they are less likely to return when recalled for a mammogram leading to delays in diagnosis and treatment.<sup>15,16,19,27,83–85,224,225</sup> Understanding what factors influence Black women's behavior during the BrCa screening process can make important contributions toward reducing racial inequities in breast cancer burden, yet we do not know how Black women's BrCa screening behaviors are impacted by their experiences with different BrCa screening pathways, such as receiving a FPM result.

The concept of intersectionality along with the frameworks of critical race theory and womanism can be applied to this issue to determine how the unique features of Black women's lives shape their health outcomes via their physical and social environments.<sup>226– <sup>229</sup> Intersectionality highlights the fact that groups such as Black women face multiple intersecting categories of marginalization that shape their life experiences.<sup>229</sup> As a result, Black women face different barriers due to the way that racism impacts the perceptions of their womanhood and vice versa.<sup>229</sup> Womanism offers a balance to the concept of intersectionality by emphasizing the different sources of strength that Black women can tap into as they combat racism, sexism, and other potential sources of disenfranchisement.<sup>226,230</sup> Critical race theory ties these two perspectives together by recommending that studies of health issues in marginalized groups, such as Black women, center their experiences and voices, and accounts of the social and cultural characteristics that are unique to their lives.</sup>

Black women's lives are grounded in different healthcare, social, and cultural environments leading to differential BrCa risk, incidence and mortality.<sup>56</sup> Black women



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are diagnosed with BrCa at younger ages due to accelerated aging as result of exposure to discrimination (the Weathering Hypothesis).<sup>231</sup> Additional evidence also links discrimination with increased BrCa incidence in Black women.<sup>232</sup> Discrimination in the form of institutional racism restricts Black women's access to heath promoting resources through residential segregation.<sup>233,234</sup> Research indicates that Black women are less likely to live near mammography facilities and/or facilities that demonstrate high-quality BrCa screening services, which may also impact tumor stage at diagnosis.<sup>128,233</sup> Racial segregation has also been shown to impact Black women's mammography follow-up times.<sup>235</sup>

These challenges do not end once Black women access healthcare facilities. Due to historical abuses and past experiences with discrimination, Black women may be hesitant to trust providers leading to lower levels of satisfaction and worse healthcare outcomes.<sup>31,222</sup> Studies of healthcare provider behavior demonstrate the persistence of implicit bias and its negative influence on providers' communication and interactions with Black women.<sup>59,61,62,236</sup>

In addition to navigating the larger dominant culture, Black women must also negotiate Black American culture and its accompanying social and cultural norms. Black women's connection to their communities can function as a source of resources and support in times of need, a way to maintain agency during adversity, or a means of avoiding or denying unpleasant realities.<sup>63,237</sup> The archetype of the "Strong Black Woman" allows women to bond through offering help, but it also limits the level to which Black woman engage in self-care as they must "be everything to everybody" leaving little time for physical and mental health maintenance behaviors.<sup>63,237</sup> The strong



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influence of family and community relationships also has potential implications for overcoming the deficits in health promotion resources and knowledge that so many Black women must overcome to improve their health.<sup>63,237,238</sup>

These features of Black women's lives underscore the need for research devoted to the discovery of deep cultural factors that underlie health and lead to the development of culturally competent solutions.<sup>65,239,240</sup> Much health research uses primarily White populations for theory and intervention development, and the cultural assumptions embedded in such work are often not applicable to Blacks.<sup>241,242</sup> Increasing racial equity in cancer control, and specifically BrCa burden, requires conducting research with Black populations to examine the multilevel factors that contribute to racial inequities they experience.<sup>243</sup>

## 2.11 Study Purpose

The purpose of this study was to understand the processes associated with FPM results and their impact on BrCa screening intention in Black women using a mixed methods study design. This study had two specific aims:

1) To describe, using a mixed methods approach, the organizational and provider-level characteristics of mammography facilities and their impact on Black women's FPM experiences and outcomes.

2) To determine, through quantitative methods, the relationship between receiving a FPM result and future mammography intention among Black women.

This research has the potential to make significant contributions to cancer research by enhancing our knowledge of a common BrCa screening pathway, the one ending in a FPM result, and its role in racial inequities in BrCa burden. Several aspects of



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the research design make this study novel in comparison to other examinations of this phenomenon. Empirical data linking organizational, provider, and patient level features to BrCa outcomes was generated and used to contextualize the ways in which these factors can perpetuate or inhibit racial inequities in cancer burden. The integration of relevant behavioral theories such as the transactional model of stress and coping and the health belief model will allow for the understanding of the mechanisms responsible for the influence of FPM results on subsequent BrCa screening intention. A rigorous study design with the use of a case-control study and culturally-appropriate standardized measures was used to determine how FPM results influenced Black women's BrCa screening beliefs and attitudes. Previously unknown contributors to delays in diagnostic resolution among Black women maybe revealed as a result of this investigation. Given the role that diagnostic delay plays in Black women's increased BrCa mortality, the results of this study may yield new insights as to the causes of racial disparities in BrCa screening behaviors.



# CHAPTER 3

# METHODOLOGY

This chapter contains a description of the conceptual model guiding the study. Details of the study design, data collection methods, sources, and measures are all provided in this chapter. The connections between the conceptual model, specific aims, data collected and analyses conducted are also explained in this chapter. The purpose of this study was to determine the impact of organizational, provider, and individual-level factors on the processes and outcomes associated with FPM results in Black women.

## 3.1 Overview of Study Design

This study had two specific aims:

1) To describe, using a mixed methods approach, the organizational and providerlevel characteristics of mammography facilities and their impact on Black women's FPM experiences and outcomes.

2) To determine, through quantitative methods, the relationship between receiving a FPM result and future mammography intention among Black women.

This study consisted of two phases. Phase 1 featured the collection of facility and provider level data. Qualitative (observations, key informant interviews) and quantitative (medical records review) methods were used to collect data about the organizational features of the participating mammography facilities. A quantitative survey tool was created and distributed to mammography facility staff members via paper packets, flyers, and email messages. Provider demographics, perceptions of women's mammography and



FPM experiences, and providers' communication about these topics were assessed using the survey tool.

Phase 2 of the study consisted of the administration of a survey via postal mail to a cohort of Black women completing screening mammograms at one of the five participating mammography facilities. Cases and controls were selected from medical records and sent a packet containing a paper survey and a medical record release form. Patient sociodemographic information, mammography experiences, emotional states, and coping behaviors were assessed via survey. Medical records were requested for women returning a signed release form and used to confirm mammography screening history and final screening results. Phase 2 was linked to Phase 1 data and the resulting dataset was used to answer research questions for both Phases of the study.

#### **3.2 Conceptual Model**

This research study was guided by the conceptual model presented in Figure 1. The model is based on empirical evidence and components of the multilevel context of cancer care model for abnormal mammograms, the transactional model of stress and coping, and the health belief model.<sup>200,244–246</sup> Figure 3.1 depicts how organizational factors directly and indirectly through provider interactions impact women's mammography experiences. Personal characteristics, i.e., race, age, education, shape how women interpret their mammography experience (specifically receiving a FPM result) and influence their beliefs about the BrCa screening. The relationship between Black women's behavioral beliefs about BrCa screening and their FPM status will be explained by their emotional responses to receiving a FPM result. In other words, the distress



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Figure 3.1 Conceptual Model



created by receiving a FPM will shape their beliefs about BrCa screening and subsequently their attitude towards completing screening and follow-up procedures in the future. Coping strategies will also be generated and will have a moderating effect on BrCa behavioral beliefs.

The multilevel context of cancer care model for abnormal mammograms informs the framework by indicating the various levels of influence that impact mammography screening behavior: organization/practice setting, healthcare providers, and individual patients.<sup>244</sup> Study variables are displayed in the conceptual model under their corresponding socioecological level. The model describes the various steps from the completion of the screening test to initiating diagnostic testing and the referral to treatment, if needed. Multiple tasks are required to resolve this process and this model describes how factors at the organizational, provider, and individual level can affect the successful completion of each task in the follow-up process.

Each mammography facility has an organizational structure, resources, and communication pathways which influence its day-to-day operations. A portion of these factors (capacity, patient demographics, patient load, scheduling and notification processes) are included in the "Organization/Practice Setting" section of the conceptual model. Mammography facilities have a direct impact Black women's mammography experiences through system level factors and indirectly through health providers.

Through their training, communication behaviors, attitudes towards mammography, and their perceptions of patient's mammography experiences; healthcare providers impact women's clinical encounters just as healthcare providers are impacted by the organizational structures of their workplaces. Mammography and primary care



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providers influence Black women's mammography experiences through similar factors, but primary care providers also have the responsibility of recommending mammography screening. Healthcare providers' characteristics are listed by provider type under the "Healthcare Provider" heading in the conceptual model.

Relationships between several individual patient characteristics are displayed in the "Individual Patient" section of the conceptual model. A variety of individual level factors interact to shape how women perceive the mammography experience and their responses to that experience. Demographic characteristics, such as age, education, marital status, employment status, income, and health insurance status impact not only where women access BrCa screening services, but how they are treated during the clinical encounter. Other factors such as the presence of an anxious personality and/or levels of social support can shape how women react to the mammography experience. A woman's BrCa screening history and her previous experience with receiving a FPM results are additional factors that will impact her perception of her current mammography experience and thus impact her beliefs about mammography, BrCa screening, and cancer prevention, in general. It is these BrCa related beliefs that impact a woman's intention to complete future screening procedures and/or follow-up on future inconclusive results. A reduction in mammography intention will lead to lower rates of initial mammography screening and mammography follow-up. Delays in diagnosis and detection can lead to increased rates of advanced stage BrCa and BrCa mortality.

The relationship between a woman's perception of the mammography experience and her beliefs about BrCa screening/mammography may vary by her reaction to the mammography experience (receiving a FPM result). The transactional model of stress



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and coping states that people complete primary and secondary appraisals which inform the actions they take when confronted with stressful events.<sup>200,201,245</sup>

Primary appraisal generates emotions, but the types of emotions generated depend on the features of the event.<sup>201</sup> Receiving a FPM result is an external event that is relevant, significant, and uncontrollable, which are characteristics typically lead to fear and/or anxiety.<sup>201</sup> A secondary appraisal takes place where the individual adopts a coping strategy to deal with the event.<sup>200,245</sup> While the appraisal process is described in a linear fashion, in practice is it not.<sup>200,201</sup> As new information is obtained new appraisals are made, new emotions are generated, and new coping behaviors maybe adopted.<sup>200,201</sup> Additionally, coping behaviors can influence new appraisals and beliefs related to the event in question.<sup>200,201</sup> In the context of FPM results, new appraisals maybe be generated at each point in the process, the employment of coping behaviors has the potential to change a women's attitude toward the behavior (benefits and barriers to mammography) and her susceptibility to BrCa. These constructs of the health belief model have been shown to impact future mammography intention in Black women, thus if FPM impacts mammography intention it likely through these beliefs.<sup>88,189,247</sup>

#### 3.3 Specific Aim 1

To describe, using a mixed methods approach, the organizational and providerlevel characteristics of mammography facilities and their impact on Black women's FPM experiences and outcomes.

<u>Research Question 1.1</u>. What organizational, provider, and patient-level characteristics predict high levels of satisfaction with their clinical encounter among Black women experiencing a FPM result?



<u>Hypothesis 1.1</u>. Mammography facilities with lower screening capacities, higher diagnostic capacity, which employ more patient management systems, have fewer "patient friendly features" in their clinical environments, and have more providers reporting low perceptions of women's distress about FPM will lead to higher levels of satisfaction with the clinical encounter among Black women experiencing a FPM result.

# 3.3.1 Setting

This research study was conducted in collaboration a leading provider of mammography services in the Columbia, SC MSA which diagnoses roughly 70% of the total BrCa population in the area.<sup>79</sup> The Columbia, SC MSA consists of the city of Columbia and its surrounding counties with an estimated population of 776,794 (of which 66,358 were Black women over the age of 35) in 2013.<sup>248</sup> Screening mammography is offered in four in ambulatory care centers and via a mobile mammography van servicing communities across the state (See Figure 3.2). Between June 2013 and June 2014, 38,500 women completed screening mammograms in the health system. Across the system, 2,456 (6.3%) women were recalled for additional follow-up testing, and 248 women were diagnosed with cancer. Approximately 30% of women with FPM results were Black, 29% were in the 40-49 age range, 36% were in the 50-64 age range, and 16% were 65 and older. A little over 50% of women completing screening mammograms lived within the city of Columbia, and 90% of them resided in the Columbia MSA.

#### **3.3.2 Data Sources and Collection Methods**

The Palmetto Health Institutional Review Board approved the study protocol on



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Figure 3.2 Locations of Participating Mammography Facilities in Richland County, South Carolina



February 22, 2016 and the Palmetto Health Administrative Review approval was granted on February 26, 2016 (See Appendix A). Participant observations, key information interviews, provider surveys, and screening record reviews were conducted during Phase I. Participant observations and key informant interviews began March 2016 and concluded August 2016. Provider surveys were fielded from April 2016 to August 2016. Screening records were collected from June 2016 through October 2016. Organizational measures and provider survey domains are presented in Figures 3.4 and 3.5. The variables incorporated in Phase I analyses and the methods used to collect this data are described below.

**Observations.** Patient and clinical settings were observed at each mammography facility for one to three hour sessions to capture information about each facility's processes and procedures. Observations were unstructured. Patient-provider, patientpatient, and provider-provider interactions were recorded during observations. Descriptions of the physical surroundings were also captured during observations. Times and locations (waiting rooms vs clinical care areas) were rotated to gain a comprehensive view of site procedures. Observations were recorded via handwritten or electronic notes. Observation notes were manually transcribed and imported along with electronic notes to NVivo 11.

**Key informant interviews.** Interviews were conducted with imaging supervisors and coordinators at each mammography facility to collect information about facility characteristics such as reporting structure, equipment, staffing, notification procedures, hours of operation, and services offered. Responses were recorded on a structured



Construct	Measure	Variable Type
Patient Demographics	% of patients Age 40-49, % of patients age 50-64, % of Patients age 75+, % of non-White patients, % of patients with public insurance, % of patients with private Insurance, % of uninsured patients, % of rural patients	Continuous
Facility Capacity	Patient volume, # of patient visits, # of administrative hours, # of screening hours, # of diagnostic hours, # of radiologists, # of patient care technicians, # nurses, # of imaging technicians/radiologists # of screening mammograms completed, # of diagnostic procedures completed, # of mammography machines, # of ultrasound machines	Continuous
Patient Management and Notification	Patient notification methods, Presence of self referral process, Use of appointment reminder systems, Use of screening mammogram reminders, Type of notification after abnormal mammogram, Type of notification of after diagnostic testing, Walk in patients accepted	Categorical
Clinical Environment	# of waiting rooms, presence of educational materials, presence of patient navigator activities, participation in outreach activities, presence of free parking, characteristics of the social environment	Categorical

Figure 3.3 Organizational Level Measures



Construct	Measure	Source
Demographics	Age, Gender, Race, Provider Type, Education, Years of Training, Years in the Healthcare Field, Facility	Adapted from Nutting et al. 2001
Perceptions of Mammography	How much physical discomfort do women experience during a mammogram? How much psychological distress do women experience during a mammogram?	Adapted from Nutting et al. 2001
Perceptions of FPM	How often do women completing screening mammogram's get called back? How often does follow up testing reveal a woman does not have cancer? How often are women upset by this experience (getting called back for follow up testing)? How often are Black women upset by this experience (getting called back for follow up testing)?	Adapted from Day et al. 2012, Hochhalter et al. 2012 & Butrick et al. 2014
Communication about FPM	During the past 6 months, How often have you spoken to women getting screening mammograms about the possibility of being called back for an abnormal mammogram? During the past 6 months, How would you rate your ability to communicate information about abnormal mammograms to women? During the past 6 months, How would you rate your ability to assess women's emotional responses to receiving an abnormal mammogram? What are the barriers to discussing abnormal mammograms with women? What types of advice do you give women when they are called back for an abnormal mammogram?	Adapted from Day et al. 2012, Hochhalter et al. 2012 & Butrick et al. 2014
Communication about Breast Density	During the past 6 months, How often have you spoken to women about breast density? How do you describe breast density to women? How do you explain to women how breast density affects mammography results? What barriers or challenges prevent you from discussing breast density with women?	Adapted from Day et al. 2012, Hochhalter et al. 2012 & Butrick et al. 2014

Figure 3.4 Provider Survey Measures



interview form (See Appendix B) and the resulting information was recorded in a Microsoft Excel spreadsheet.

**Retrospective mammography screening data.** Demographic information (date of birth, race, health insurance product and zip code) and mammography screening outcomes (procedure, procedure date, procedure type, BI-RADS rating, and facility) for women completing screening mammograms from January 2016 to August 2016 were requested from the Palmetto Health Radiology Department on a monthly basis. Data was imported into STATA 13 for data management and analysis. Visits were matched medical record number to create a visit history for each patient. Data were analyzed in aggregate to generate facility characteristics such as patient volume, and patient demographics.

**Mammography provider surveys.** Physicians and staff members at all 5 facilities (n=46) were asked to complete a survey about their experiences with mammography screening and their perceptions of women's mammography experiences (See Appendix C). All individuals designated as having patient contact and who worked in a Palmetto Health mammography facility for at least six months prior to the start of the study were eligible to participate in the survey. Participants were recruited using e-mail, flyers, word of mouth, and project presentations at staff meetings. Survey participants were entered into a giveaway to receive one of 10 \$25 gift cards after the survey was concluded.

The survey consisted of closed and open-ended items assessing demographic information (age, gender, race, provider type, professional training) and providers' perceptions of patients' physical and psychological comfort used by Nutting et. al. (2001)



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during their evaluation of influences on primary care providers.<sup>213</sup> Items from national surveys of provider communication regarding dementia and aging and studies of genetic counselors' communication with patients of different were adapted to assess communication from the providers' perspectives.<sup>249–251</sup> These items assessed providers' perceptions of the FPM experience and how providers communicate about this experience. Staff members completed surveys online or using paper survey packets that were returned via postal mail. Survey results were imported into STATA 13 and NVivo 11 for interpretation.

#### 3.3.3 Data Management

A data dictionary was developed, and the facility data (observation, key informant interview, medical records, and provider survey data) were entered into a password protected spreadsheet using numeric codes. Data for each site were entered using an identification number. The data file was uploaded into STATA 13 and merged by site with the patient survey data collected in Phase 2. All notebooks and paper surveys were stored in a locked file cabinet in a locked office at the University of South Carolina. All electronic files were stored on password protected laptop in a locked office at the University of South Carolina.

## **3.3.4 Data Analysis**

All organizational and provider variables were numerically coded and entered into spreadsheet and analyzed in STATA 13.<sup>252</sup> Means and frequencies for organizational and provider level measures were calculated and chi-square tests and ANOVA were used to detect any statistically significant differences in organizational and provider characteristics between sites. Mean values for patient volume, the number of privately



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insured patients, non-White patients, hours of operations, screening procedures and diagnostic were calculated and used as a cut point to categorize facilities as high or low for each variable. Features of the clinical environment such as a dedicated waiting room for follow-up patients, the presence of educational materials, screening navigation, outreach activities, and free parking were marked as present or absent. Providers' responses regarding their perceptions of patient's physical discomfort, psychological discomfort, and distress about screening and FPM were averaged for each facility.

Associations between organizational, provider level data, and patient satisfaction data collected in Phase 2 were assessed using linear regression for continuous variables and ANOVA for categorical variables. The primary analysis for Specific Aim 1 consisted of bivariate logistic regression models to determine the influence of facility, provider, and patient characteristics on satisfaction with mammography by mammography outcome (FPM status vs. normal).

#### 3.4 Specific Aim 2

To determine, through quantitative methods, the relationship between receiving a FPM result and future mammography intention among Black women.

<u>Research Question 2.1</u>. What is the relationship between receiving a FPM result and BrCa behavioral beliefs (perceived benefits of mammography, perceived BrCa susceptibility, and perceived barriers to mammography screening) among Black women?

<u>Hypothesis 2.1</u>. Receiving a FPM result will have an overall negative effect on BrCa behavioral beliefs in Black women. Specifically, Black women with a FPM result will report lower levels of perceived mammography benefits, higher levels of perceived mammography barriers, and higher levels of perceived BrCa susceptibility.



<u>Research Question 2.1.a</u>. Do Black women's emotional states explain the relationship between a FPM result and BrCa behavioral beliefs (perceived benefits of mammography, perceived BrCa susceptibility, and perceived barriers to mammography screening)?

<u>Hypothesis 2.1.a.</u> Anxiety and depression will each independently explain the relationship between receipt of FPM results and BrCa behavioral beliefs.

<u>Research Question 2.1.b.</u> Does the relationship between receipt of FPM results and BrCa behavioral beliefs (perceived benefits of mammography, perceived BrCa susceptibility, and perceived barriers to mammography screening) vary by coping strategy employed?

For Black women with FPM results, women engaging in high levels of cognitive/emotional, collective, and spiritual coping behaviors will have a positive effect on BrCa behavioral beliefs. Specifically, Black women with FPM results who engage in high levels of cognitive/emotional, collective, and spiritual coping behaviors will report higher levels of perceived mammography benefits, lower levels of perceived mammography barriers, and lower levels of perceived BrCa susceptibility.

<u>Research Question 2.2</u>. What is the relationship between BrCa behavioral beliefs (perceived benefits of mammography, perceived BrCa susceptibility, and perceived barriers to mammography screening) and intention to complete future mammography screening?

Black women reporting high levels of perceived benefits of mammography, low levels of perceived barriers to mammography, and high levels of perceived BrCa



susceptibility will display increased intention to complete future mammography screening.

## 3.4.1 Study Design

A survey was designed and fielded to collect data from women completing screening mammograms for Phase 2 (See Appendix D). Given the low number of women in the population with the desired characteristic (FPM represented 6% of the screening patients between June 2013 and July 2014) a case-control study design was employed to maximize the number of participants with FPM results. Black women aged 40 and older (evidence indicates that many women were still following the American Cancer Society's pre-2015 BrCa screening guidelines and were completing screening mammograms between the ages of 40-45),<sup>253</sup> BrCa free for 5 years or more, no evidence of serious mental illness, and whose final mammography results were confirmed as benign were eligible to participate. Patient survey participants were entered into a separate giveaway for a chance to win one of 10 \$25 gift cards at the conclusion of Phase 2.

## 3.4.1.1 Sampling

Women whose screening mammograms were classified as BI-RADS Category 0 were selected as cases.<sup>39</sup> A control participant was selected from eligible women whose screening mammogram was classified as BI-RADS Category 1 (Negative) or Category 2 (Benign) and occurred on the same day and at the same facility as her matched case.<sup>39</sup>

#### 3.4.1.2 Sample Size

Only a few US studies have examined the impact of FPM results on future mammography intention/behavior and they reported small (OR Range: 0.42 - 1.50) to medium effect sizes (OR 2.12, CI:1.54 -2.93).<sup>43,115,147,148,155</sup> With  $\alpha$ =0.05, power = 0.80,



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and model with 10 predictors, a sample size of 1,064 would be required to detect a small effect size and 157 (case and control) participants to detect a medium effect size as calculated by G\*Power.<sup>254</sup> Estimating that 20% of surveys will have missing data, a final sample size of 188 will be needed answer Specific Aim 2.

#### 3.4.1.3 Measures

A 177-item survey tool was used to assess patient demographic information, previous BrCa screening history, and psychosocial constructs. Domains and scales included in the patient surveys tool are listed in Figure 3.5. Information describing the index screening mammogram was collected via survey and compared to the medical record to ensure accuracy. Measures analyzed for Phase II are described in detail below.

**Demographics** – Demographic items such as age, education, employment status, income, marital status, and health insurance status were modeled after items used in the National Health Interview Survey and the Behavioral Risk Factor Surveillance Survey.<sup>255,256</sup>

**Breast Cancer Screening History** – Items assessing age at initiation of mammography screening, the receipt of a provider's recommendation for mammography, family history of BrCa, and FPM mammography history were used to collect information about participants' BrCa screening history. These items were modeled after items from the National Health Interview Survey.<sup>255</sup>

Interpersonal Personal Processes of Care Survey: Discrimination and Disrespectful office staff subscales – The scale measures aspects of provider communication that were indicated to be important by various racial groups. Experiences



Construct	Measure	Subscales
Patient Demographics	Age, Race, Employment, Education, Income, Marital Status, Religious Identity, Health Insurance Status, Family History of Breast Cancer, Breast Density (Adapted from National Health Interview Survey)	N/A
Mammography Screening History	Age at First Mammogram, Number of Mammograms Completed in the Past 6 Year, Reasons for Scheduling Index Mammogram, Completed Index Mammogram Alone or with Someone, Follow-Up Testing Notification Methods and Preferences, FPM History (Adapted from National Health Interview Survey)	N/A
Mammography Screening Knowledge	Knowledge of Mammography Screening Guidelines, Awareness of Changes in Mammography Screening Guidelines, Discussions with Primary Care Providers about Mammography Screening Schedule	N/A
Patient Satisfaction	Cockburn's Mammography Satisfaction Scale	General; Convenience/Accessibility; Staff Interpersonal Skills; Staff Communication: Physical Environment; Perceived Staff Competence
Provider Communication	Interpersonal Personal Processes of Care Survey - Short Form	Interpersonal Style; Discrimination and Disrespectful Office Staff Subscales
Social Support	Medical Outcomes Social Support Survey	
General and Trait Anxiety	Spielberger State-Trait Anxiety (STAI)	Short Forms, State and Trait Versions
Breast Cancer Specific Anxiety	Psychological Consequences Questionnaire DK-33	Anxiety
Depression	Center for Epidemiologic Studies-Depression Scale (CES-D) Short Form	N/A
Coping Behaviors	Africultural Coping System Inventory	Cognitive/Emotional; Spiritual Centered; Collective; Ritual Centered
Breast Cancer Screening Beliefs and Attitudes	Champion Attitudes towards Mammography and Breast Cancer Scale	Perceived Susceptibility; Perceived Benefits; Perceived Barriers
Mammography Intention	Screening and Follow Up Intentions	N/A



of discrimination and disrespect during clinical encounters were assessed with the discrimination and disrespectful office staff subscales, respectively. Validation samples included multiple racial and ethnic groups, the reliability coefficients for the Discrimination subscale is 0.79 and for the Disrespectful office staff subscale is 0.90.<sup>257</sup>

# Spielberger State-Trait Anxiety Inventory (STAI): Trait and State Short

**Scales** – A 10-item scale which measures anxiety as a personality trait and another 10item scale that measures the anxious emotional states. The scale has been validated in a variety of populations with good reliability ( $\alpha$ =0.86 to 0.95).<sup>182</sup>

**CES-D Short Form** – This 10-item survey has been validated with many populations around the world and measures subclinical levels of depression. The short form has good internal consistency ( $\alpha$ =0.75).<sup>185</sup>

Africultural Coping System Inventory – An African cultural framework guided this 30-item measure which assesses the use of four coping strategies used by Blacks in response to a stressful event. The reliability coefficients for the four subscales range from 0.76 to 0.82.<sup>206</sup>

# Champion Attitudes Towards Mammography and Breast Cancer Scale:

Mammography Benefits, Susceptibility and Barriers Subscales – The four-item Benefits sub-scale is part of a larger scale that examines Black women's attitudes and beliefs toward BrCa screening. The four item Susceptibility sub-scale measures susceptibility to BrCa and is highly reliable ( $\alpha$ =0.73).<sup>258</sup> The scale's internal consistency is adequate ( $\alpha$ = 0.73).<sup>258</sup> A shortened 10-item version of the original 19 item barriers subscale was used assess various logistical challenges associated with mammography.<sup>258</sup> The original subscale is highly reliable ( $\alpha$ =0.89).<sup>258</sup>



**Cockburn's Mammography Satisfaction Scale** – This 26-item scale was developed in Australia to measure women's satisfaction with their mammography experiences. The scale has six subscales that measure different aspects of satisfaction: general, convenience and accessibility, provider information transfer, staff interpersonal skill, physical surroundings, and perceived technical competence.<sup>179</sup> The reliability coefficients for the original scale were low (0.53-0.68), but a modified version has been used with an American population with good results.<sup>207</sup>

## Psychological Consequences Questionnaire DK-33: Anxiety Subscale (PCQ-

**DK33**) – The revised version of Cockburn's Psychological Consequences Questionnaire contains 33 items which measures women's psychological responses to screening mammograms.<sup>259</sup> One of these domains, anxiety, is measured with a six item subscale that has been found to be highly reliable in Danish women ( $\alpha$ =0.92), but its use in American samples is limited.<sup>259</sup>

**Mammography intention** – This variable was measured using two ad hoc items: 1) How likely are you get your next screening mammogram as scheduled? and 2) If you asked to return for follow-up testing after your next screening mammogram, how likely are you to complete those additional tests? Response categories were 1=Very Unlikely, 2=Unlikely, 3=Likely, and 4=Very Likely.

# 3.4.14 Survey Administration

Packets containing surveys, medical records release forms, pre-addressed postagepaid envelopes were mailed to eligible patients six months after their initial screening mammograms to allow for the completion of follow-up testing (July 2016-January 2017). Reminder letters were sent to participants one month after the mailing of the initial



survey packet and one month prior to the scheduled end date for the patient survey. Participants were provided an option to complete the survey over the phone or to call the principal investigator to recieve get more information about the study. Brief summary sheets with study contact information were distributed to Palmetto Health staff members as a reference if women inquired about the study. Medical records were used to confirm BrCa screening history information and final screening outcomes reported via survey. In total, 909 survey packets were mailed (411 cases, 498 controls), 25 surveys were returned to sender, two were found to be ineligible and did not return surveys. Of the remaining 882 surveys distributed, 133 (15.0%) were returned.

**Pilot Testing**. Surveys were pilot tested in two waves during June 2016. In total, seven Black women aged 35 and older completed the survey. The first wave consisted of three members of the research staff, two of whom had previously completed screening mammograms. After incorporating the feedback from the first wave, the principal investigator recruited 5 Black women who meet the eligibility criteria, but lived outside of the Columbia, SC MSA for the second wave. A full-scale pilot was conducted with survey packets being mailed to participants in the second wave. Additional edits were made to the survey tool based on the data collected during the second wave.

#### **3.4.2 Data Management**

Each survey packet was assigned a participant id which was attached to all survey materials. All surveys, medical record release forms, and medical records were tracked in a password protected Microsoft Excel spreadsheet. Survey responses were coded using a data dictionary and manually entered by participant id into a separate password protected Microsoft Excel spreadsheet. The data file was uploaded into STATA 13. Paper surveys,



medical records, and medical records release forms were stored in a locked file cabinet in a locked office at the University of South Carolina. Medical records were destroyed using secure data handling procedures after the extraction of required data. All electronic files were stored on password protected laptop in a locked office at the University of South Carolina.

# 3.4.3 Data Analysis

All patient level variables were analyzed in STATA 13. Means and frequencies were calculated for all variables. Chi Square tests and ANOVA as appropriate were used determine associations between demographic variables, BrCa screening history, trait anxiety, state anxiety, BrCa-specific anxiety, depression, coping strategies, perceived mammography benefits, perceived mammography barriers, perceived BrCa susceptibility and FPM status. Specific analyses for each research question included in Specific Aim 2 are described below.

<u>Research Question 2.1</u>. What is the relationship between receiving a FPM result and BrCa behavioral beliefs (perceived benefits of mammography, perceived BrCa susceptibility, and perceived barriers to mammography screening) among Black women?

Covariates associated with BrCa behavioral beliefs and FPM were used to guide the construction of ordinary least squares regression (OLS) models developed to address this research question. OLS models assessing the relationship between each BrCa behavioral belief (perceived mammography benefits, perceived mammography barriers, perceived BrCa susceptibility) and FPM status were constructed, and theoretically important variables expected to influence each BrCa behavioral belief were included in the model for that belief (e.g. family history of BrCa was included in the model for



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perceived benefits and susceptibility to BrCa). Mean values of BrCa behavioral beliefs for women with FPM and normal mammography results were calculated using the average values for the sample with the margins command in STATA. Multilevel variables such as age category or health insurance status were tested for significance using the Bonferroni adjustment.

<u>Research Question 2.1.a</u>. Do Black women's emotional states explain the relationship between a FPM result and BrCa behavioral beliefs (perceived benefits of mammography, perceived BrCa susceptibility, and perceived barriers to mammography screening)?

For OLS models constructed in Research Question 2.1 that were statistically significant, state anxiety, BrCa specific anxiety, and depression were tested as mediators using the khb command in STATA. Trait anxiety appeared to function as mediator in preliminary tests; thus it was included in mediation analyses.

<u>Research Question 2.1.b</u>. Does the relationship between receipt of FPM results and BrCa behavioral beliefs (perceived benefits of mammography, perceived BrCa susceptibility, and perceived barriers to mammography screening) vary by coping strategy among Black women?

For OLS models constructed in Research Question 2.1 that were statistically significant, coping behaviors were tested as moderators. Interaction terms were created by centering each variable at the mean value for the sample and incorporating a term into the model containing the coping style and FPM status. Mean values for BrCa behavioral beliefs at each level of coping style were calculated using the margins command in



STATA. These values were plotted and used to determine the presence of effect modification.

<u>Research Question 2.2</u>. What is the relationship between BrCa behavioral beliefs (perceived benefits of mammography, perceived BrCa susceptibility, and perceived barriers to mammography screening) and intention to complete future mammography screening?

Associations between BrCa behavioral beliefs, FPM, mammography screening intention, and follow-up intention were used to guide the construction of ordinary least squares regression (OLS) models developed to address this research question. OLS models assessing the relationship between each BrCa behavioral belief (perceived mammography benefits, perceived mammography barriers, perceived BrCa susceptibility) and mammography intention (screening and follow-up) were constructed. FPM status and theoretically important variables expected to influence each BrCa behavioral belief were included in the model describing the relationship between that belief and mammography intention (screening and follow-up). The mean values for mammography intention (screening and follow-up) for women with FPM and normal mammography results were calculated using the average values for the sample with the margins command in STATA. Multilevel variables such as age category or health insurance status were tested for significance using the Bonferroni adjustment.



# CHAPTER 4.

# RESULTS

This chapter contains the results of the research conducted to examine the influence of multilevel factors on Black women's experiences with FPM results and the impact of that experience on intention to complete future BrCa screening and diagnostic testing. Manuscript 1 addresses Specific Aim 1, by answering Research Question 1, through the analysis of the influence of organizational, provider, and patient-level data on mammography satisfaction among Black women. Manuscript one has been prepared for submission to the journal *Medical Care*. Specific Aim 2 and its composite research questions are described and answered in Manuscript 2. The relationship between FPM status, BrCa behavioral beliefs, and mammography intentions is explored in Manuscript 2, which will be submitted to the *American Journal of Preventive Medicine*.



4.1 Contributions of Mammography Facility, Provider, and Patient Characteristics on Mammography Satisfaction Among Black Women False-Positive Mammography Status<sup>1</sup>

<sup>1</sup>Farr DE, Brandt HM, Friedman DB, Armstead C, Adams SA, Fulton J, Bull D. To be submitted to *Medical Care* 


#### Abstract

**Background.** Black women are less likely to complete mammography screening. Prior screening experiences such as the receipt of false positive mammography (FPM) results may influence Black women's satisfaction with their clinical experience and subsequent desire to complete future screening. **Objectives.** The purpose of the study is to understand which facility (environmental), provider, and patient level factors influenced aspects of satisfaction with the mammography screening experience among Black women and if FPM status altered these relationships. **Research Design.** A case-control study was conducted using observations, medical record data, and surveys. Logistic regression models were developed to determine influences on different aspects of mammography satisfaction. **Subjects.** Participants included mammography facility staff, and Black, cancer-free mammography patients aged 40 and older who completed index mammograms between January and August 2016. Measures. The Cockburn Mammography Satisfaction Scale, which contains six subscales, was the main outcome measure. Results. No facility, provider or patient factors were associated with two types of satisfaction: general and provider interpersonal style. FPM status was one of several patient characteristics associated with lower level of satisfaction with convenience and provider information communication. Facility and provider level factors had negative and positive effects on satisfaction with provider competence. Satisfaction with the clinical environment was also influenced by facility characteristics. Conclusions. Varied aspects of the clinical encounter influenced Black women's satisfaction with their mammography screening experiences. Further research is needed to understand how these clinical encounters contribute to future screening and diagnostic delay in this population.



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Keywords: (3-5) Mammography, False Positive, African American, Patient Satisfaction, Female

# Introduction

Black women have experienced disproportionately high rates of breast cancer (BRCA) mortality for the past three decades.<sup>1</sup> A complex mix of biological, cultural, economic, and healthcare-related factors contribute to this racial inequity.<sup>1</sup> Healthcarerelated factors are critical as they have the potential to impact BRCA stage at diagnosis through their influence on the timely resolution of abnormal mammography results.<sup>2</sup> Delays in mammography follow-up among Black women have been extensively documented and largely attributed to lower levels of BRCA knowledge and healthcare access in this population.<sup>3,4</sup> The role of Black women's past mammography experiences is largely absent from research on screening and diagnostic delays. Some evidence indicates that past false positive mammography results may influence Black women's decisions to complete follow-up testing after receiving abnormal results.<sup>5,6</sup>

False positive mammograms (FPM) are defined as abnormal screening mammograms that are later confirmed as non-cancerous.<sup>7</sup> Studies have link FPM with psychosocial outcomes (e.g. anxiety, depression), BRCA related-beliefs (e.g. BRCA risk, screening effectiveness, screening intention), and screening behaviors, but the relationship between FPM and women's satisfaction with the mammography process has largely been ignored.<sup>7,8</sup> Patient satisfaction has been associated with mammography completion across diverse populations, but it is unclear how (or if) the process of completing diagnostic testing influences women's satisfaction with the screening process.<sup>9–11</sup> Limited evidence indicates that satisfaction with aspects of the screening process, such as patient-provider



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communication and quality of care, may differentially impact women who are asked to return for additional testing.<sup>5,12–14</sup> Satisfaction with prior screening encounters among women with FPM status may influence BRCA screening attitudes and future screening behavior in this group of women.

Much of the research on mammography satisfaction has been conducted mainly in Europe and centers on the influence of patient-level characteristics, such as age, education, and income.<sup>15,16</sup> Facility (or environmental) features, such as the patient volume, payer mix, geographic location, clinical environment, and provider-level factors, including the communication of information about the screening process, and perceived staff competence, are described as having an important effect on satisfaction in several qualitative studies, but quantitative analyses of these characteristics are limited.<sup>17–19</sup> As with investigations of FPM outcomes, mammography satisfaction among Black American women has received little attention outside of evaluations of patient navigation programs which seek to support women in the completion of the BRCA screening process.<sup>18,20,21</sup>

Given the persistence of mammography delays among Black women, the impact of facility features, provider interactions, and patient characteristics on Black women's experiences with FPM and effect on mammography satisfaction warrant exploration. The purpose of this study was to determine what facility, provider, and patient-level characteristics predicted high levels of satisfaction among Black women and whether the factors associated with satisfaction vary by FPM status. Previous studies suggest that characteristics which many enhance patient-communication and reduce logistical barriers to screening will be associated with higher levels of mammography satisfaction.



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Specifically, mammography facilities with low screening capacities, with screening and diagnostic capacity, and more "patient friendly features" in their clinical environments, and mammography providers who are more sensitive to the distress or discomfort of women experiencing a FPM will lead to a higher level of mammography satisfaction. Patients with normal screening results, higher education levels, higher income, and of older age will be more satisfied with their mammography experience.

### Methods

<u>Setting.</u> Study data were collected from five mammography facilities affiliated with a large hospital system located in the Midlands region of South Carolina. Study activities were approved by the Palmetto Health Institutional Review Board.

Data Collection. Data collection began in March 2016 and concluded in January 2017. Information about the physical characteristics of and operating procedures at each facility were collected through key informant interviews and observations. Key informant interviews were conducted with a supervising staff member at each facility A structured interview guide with items assessing organizational structure, services offered, clinical, and notification processes, and the physical environment was used during the interview. Unstructured observations were conducted to examine clinical processes and determine if any processes changed during the study period. Observation and interview data were manually coded by site and entered into a spreadsheet for organization and analysis.

De-identified clinical records were collected for women completing screening mammograms between January and August 2016. Clinical records provided patient demographic information (age, race, health insurance product, and zip code) and mammography screening information (procedure, procedure date, procedure type, BI-



RADS rating, and facility) for patients screened during that timeframe. All women with current or previous breast cancer diagnoses were removed from the analysis to examine influences on satisfaction in the average risk screening population. Patients were grouped by the facility where they completed their index mammogram, and demographic characteristics of the patient population were calculated for each facility.

Provider surveys were distributed to clinical and administrative staff at the mammography facilities via paper packets and online links. Only individuals employed by a mammography facility for at least six months were eligible to complete the survey. Surveys were distributed via paper packet during staff meetings and via e-mail to key staff members. Approximately 40 individuals were eligible for this portion of the study, and 24 staff members returned the survey for a 60% return rate. Staff members' age, gender, race, job title, and education level were collected in addition to questions examining providers' clinical experiences. Items assessing perceptions of women's experiences with mammography and FPM status were modeled after questions used to examine primary care providers ratings of patients physical and psychological comfort.<sup>22</sup> Survey responses were attributed to the facility (or facilities) where each provider practiced.

Patients meeting the following criteria were eligible for participation: Black/African American, aged 40 or older, BRCA free for five years or more, and completed index screening mammograms between January and August 2016. Survey packets were sent to potential study participants approximately six months after their index mammogram. They received reminders one month after the initial mailing and prior to the conclusion of the study. A case-control design was employed to ensure the recruitment of sufficient



numbers of women with FPM results. Women whose index mammogram had a Breast Imaging Reporting and Data System (B-IRADS) classification of 0 were designated as FPM. Each FPM was matched to a woman who completed an index mammogram at the same facility on the same day, but whose final result was BI-RADS 1 or 2. Packets contained medical records release forms and a paper survey tool. Separate gift card giveaways were held for participants completing provider and patient surveys to acknowledge their efforts.

In total, 909 survey packets were mailed to patients with 25 returned due to bad addresses and two did not meet the racial eligibility criteria. Of the remaining 882 surveys distributed, 133 (15.0%) were returned. Of the surveys returned, five were ineligible due to recent BrCa diagnoses or serious mental illness and 11 were excluded from analyses due to missing demographic information or conflicting responses. A final sample of 117 patient surveys were included this analysis.

*Patient Survey Measures.* Questions from the National Health Interview Survey were used to collect information about patient age, education, marital status, and family history of breast cancer.<sup>23</sup> Patient age was calculated using date of birth and collapsed down to three categories 40-49, 50-64, 65 and older. Education was dichotomized into either less than a college degree or a college degree or higher. Marital status was collected as married, living with a partner, widowed, divorced, separated, and single (never married). Married and living with a partner were reclassified as partnered and the remaining categories were named unpartnered. Zip code, health insurance status, and screening facility were obtained from patient medical records. Zip codes were mapped to counties which were subsequently classified as urban or rural.<sup>24</sup> Health insurance



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products were classified as private or public using information from the South Carolina Department of Health and Human Services website and the National Committee for Quality Assurance Health Insurance Plan Ratings 2016-2017.<sup>25,26</sup>

Patient-provider interactions were measured using the discrimination and disrespectful office staff subscales of the Interpersonal Processes of Care Survey.<sup>27</sup> The scale measures provider communication factors that were indicated to be important by Blacks and other people of  $color^{27}$  The Discrimination subscale consists of two items that assess perceptions of discrimination the clinical encounter.<sup>27</sup> Four items such as "How often did office staff talk down to you?" compose the Disrespectful office subscale.<sup>27</sup> Responses for both subscales were measured on a 4-point scale with 1 = Never and 4 = Always.<sup>27</sup> Scores were computed by averaging responses. Both subscale scales demonstrated sufficient reliability in this sample, with  $\alpha$  of 0.63 and 0.71 respectively.

Satisfaction with the mammography experience was measured with the Cockburn Mammography Satisfaction Scale which contains the following subscales: general, convenience and accessibility, provider interpersonal skills, provider information communication, physical surroundings, perceived provider competence.<sup>28</sup> Each subscale contains 4 to 5 items measured on a 4-point scale with 1 = Strongly Disagree and 4 = Strongly Agree.<sup>28</sup> Satisfaction scores were generated by summing all responses after reverse coding negatively worded items. Except for the provider information transfer scale ( $\alpha$ =0.53), all subscales had adequate internal consistency in this survey population with reliability coefficients ranging from 0.62 to 0.73.

<u>Data Analysis.</u> Facility information and provider survey data were linked to patient survey responses by screening site. Descriptive statistics (proportions and means) were



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calculated for facility and provider characteristics by site, entered into a spreadsheet, and merged with patient survey data. Chi-square tests and ANOVA were used to detect site level differences in characteristics. Multivariable models were constructed to examine the impact of multilevel characteristics (facility, provider, and individual) on the domains of mammography satisfaction. As two of the five facilities accounted for the majority of data, the lack of variability in the sample prevented the creation of stable multivariable models containing all three levels of data. Bivariable logistic regression models were used to examine the relationship between factors that would influence the aspect of satisfaction examined taking account FPM status (e.g. provider communication variables were not included in models for satisfaction with convenience or the physical environment). All data analyses were conducted using STATA 13 and statistical significance was evaluated using an alpha of 0.05.<sup>29</sup>

# Results

*Facility Characteristics.* Descriptive information for the patient population of the five mammography facilities is presented in Table 1. Over 25,000 procedures were completed between January and August 2016 at all sites combined, and the majority of these procedures were screening mammograms (89%). Site A was the largest site, and it served a higher percentage of women over the age of 65 and women with public health insurance. While Site A had equal amounts of White and non-White patients, Site B similarly had a higher proportion of Black patients specifically (57.6%) and non-White patients overall (61.8%). In contrast to Sites A and B, Site C is based in a suburban area and has an increased proportion of older (38.2%), White (75.5%), rural (6.7%), and privately insured (53.7%) patients. Both screening and diagnostic services were offered at



Sites A, B, and C, however, Site C offered fewer diagnostic hours per week requiring patients to wait to complete follow-up testing at Site C or seek care at Sites A or B. As larger sites, Sites A and B had separate waiting rooms for diagnostic visits and several exam rooms. Only Site B had internally developed print educational materials about breast cancer screening available in the main waiting room for women to review. The remaining sites only provided screening services, and women who required follow-up were referred to one of the diagnostic sites. Site E represents a mobile mammography unit that provides services to various institutions across the state (mostly worksites and community groups). Thus, a much higher number of women completing screening at Site E were under age 65 (83.4%), White (62.9%), lived in rural areas (15.5%), and had private health insurance (74.5%).

*Provider Characteristics.* Twenty-four staff members completed the provider surveys (demographic data not displayed due having less than 5 observations at some sites). Responses for staff members who worked at more than one facility were included in each of their worksites. Provider characteristics were similar across sites with the majority of respondents being in the 40-60 age range (mean age  $47.9 \pm 8.91$ ), female (91.7%), and White (87.5%). All respondents had some elements of patient contact as part of their responsibilities whether they were radiologists, mammographers or imagining technicians who perform screening procedures, or patient care technicians/coordinators who provide instructions and facilitate many aspects of the clinical encounter. Most respondents had less than a bachelor's degree (70.8%) as imaging and patient care positions require certification provided by a relevant training programs. On average, respondents had worked 23.3 years in the healthcare field.



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Across sites, staff members had similar perceptions of women's mammography encounters (Table 2). Providers reported that women experienced some physical discomfort (sample mean = 2.5) and psychological distress (sample mean = 2.5) during the mammography procedure. When asked specifically about women's reactions to mammography follow-up, most staff responded that Black women were less upset about having to return for follow-up (sample mean = 3.1) compared to all women (sample mean = 3.4). The difference in staff members' ratings of distress in response to follow up approached, but did not reach statistical significance, t(23)=2.01, p=0.05. Site C did report significantly higher rates of distress for all women (3.9, p=0.04) and Black women (3.6, p=0.03) compared to the other sites.

*Patient Characteristics.* Demographic characteristics of the patient survey respondents are displayed in Table 2. Most of the respondents were in the 50-64 age range (53.9%), did not have a partner (67.5), had less than a college education (70.9%), and made less than \$50,000 annually (75.2%). A third of respondents (29.9%) reported a family history of BRCA, and almost half (46.1%) had a FPM result during the study period. Respondents were well distributed across facilities when accounting for the demographics across screening sites. Patient satisfaction and provider communication scores are presented by site in Table 4. There were no statistically significant differences in scores by site. Mean satisfaction scores were in the middle of the range of possible scores for each subscale, while mean ratings of discrimination and disrespect during the clinical counter fell at the low range of scores.

*Influences on Satisfaction*. Odds ratios demonstrating the influence of selected organizational, provider, and patient characteristics on different types of patient



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satisfaction are depicted in Table 5. None of the factors tested influenced the odds that Black women would report high levels of general satisfaction. Respondents who recently experienced a FPM result were 66% less likely to be satisfied with the convenience and accessibility of mammography services. Women with recent FPM results were also 58% less likely to be satisfied with the way providers communicated these results to them. Reduced satisfaction with provider information given was also shared by women with family history of BRCA (64% less) and those experiencing discrimination (68% less) during their most recent mammography encounter. As with general satisfaction, provider interpersonal style was not influenced by any of the characteristics collected.

Multiple factors were found to impact patient perceptions of providers' technical expertise. Facility characteristics such as serving an older population, having more screening hours, and providers reporting a higher perception of patients' physical discomfort were associated with lower levels of satisfaction with providers' skills. Conversely, the presence of educational materials, higher perceptions of patient distress due to mammography, and being asked to complete mammography follow-up was associated with increased satisfaction with providers' expertise. Similar characteristics influenced women's satisfaction with the physical environment, with the presence of educational materials increasing satisfaction.

## Discussion

The experience of receiving a FPM result may have an immediate and long lasting impact on Black women's BRCA screening experiences, especially as it relates to their satisfaction with the clinical encounter. We examined multilevel influences on



mammography satisfaction among Black women receiving FPM results and generated mixed findings. First, we sought to determine if satisfaction levels differed by facility. Despite the varied characteristics of the mammography facilities assessed, no site-level differences in patient satisfaction were detected in this group of Black women. While it is possible that the sample size limited our ability to detect site-level differences, it is much more likely that standardization of patient notification and care procedures in this health system resulted in women having similar experiences across clinical sites.

Next, we investigated the relationship between the various types of satisfaction and facility, provider, and patient characteristics. No influences on general satisfaction or satisfaction with provider interpersonal style were detected in this sample. Survey items in both subscales were very non-specific, (e.g. I was very satisfied with the care I received at the service; The staff had good manners.) thus there was no obvious connection between the domains and the factors tested.

Multiple factors were found to be related to satisfaction with the convenience of mammography. As expected, FPM status was associated with low satisfaction with convenience, which is mostly likely a result of the challenges related to completing additional procedures.<sup>14,17</sup> Surprisingly women with a family history of BRCA were also less likely to be satisfied with the convenience of mammography. The most probable explanation is that these women were asked to complete additional tests due to their increased BRCA risk, thus complicating their screening encounter. Experiencing discrimination also resulted in lower satisfaction with mammography satisfaction in Black women.<sup>20</sup> Evidence demonstrates that experiencing racial discrimination during



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healthcare interactions is strongly associated with postponing/not accessing healthcare.<sup>30</sup> It is not unreasonable to conclude that Black women's perceptions of convenience in accessing health services could be affected by perceived discrimination.

Women's satisfaction with providers' ability to provide information during the screening process was negatively associated with FPM status. Multiple studies have reported that Black women are more likely to have inadequate or incomplete communication around abnormal mammography results.<sup>6,14,17,18,31</sup> Communication needs for this group include: a preference for results delivered over the phone vs. the mail, definitions of terms used to explain results, and a more detailed description of the activities involved in mammography follow up.<sup>6,17,32</sup> Actions to improve communication in addition to implicit biases that may lead to perceptions of racial discrimination.<sup>33–35</sup>

Similar factors appear to be related to perceptions of provider expertise as satisfaction with provider competence was positively associated with providers' reporting higher levels of patient psychological distress and the presence of educational materials. Serving an older patient population, a higher number of weekly screening hours, and providers' perception of a high level of physical discomfort on the part of patients was associated with lower levels of satisfaction with provider competence. Satisfaction with the clinical environment was influenced by the same facility features in the same directions. It is not exactly clear how these factors contribute to reduced satisfaction; one possibility is that both factors may lead to the perception of slower service in the waiting room and/or more hesitation on the part of the provider during the clinical encounter.



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Our study has some limitations. Due to the small sample size, it was not possible to examine relevant characteristics for all three levels in one model. It is possible that some organization level effects may disappear in the presence of patient-level effects and vice versa. Additionally, certain patient-level factors that may influence satisfaction including patient health status and pain/discomfort felt during the clinical exam were not evaluated. Another point of consideration is the data for this study comes from multiple sites within a single hospital system. Examining satisfaction across multiple hospital systems might reveal additional influences on satisfaction due to the lack of standardization in procedures. Lastly, this study examined different categories of factors that affect patient satisfaction, but it did not link satisfaction to mammography follow-up times, follow up intention, or the completion of multilevel influences concurrently, that include additional influences on satisfaction at each level, span multiple health systems, and/or link satisfaction to mammography follow-up outcomes.

Despite these limitations, we concluded that specific domains of Black women's satisfaction with the mammography process are influenced by different categories of factors. Satisfaction with convenience and provider information transfer were largely impacted by individual experiences such as FPM status or family history, while satisfaction with provider competence and the facility environment were shaped by a combination of provider and facility-related factors. More attention needs to be paid to the aspects of the clinical encounter that shape Black women's experiences to determine how to structure healthcare services with the goal of reducing racial inequities in cancer burden.



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Table 4.1 Mammography Facility Characteristics by Site

	Site A		Site B		Site C		Site D		Site E	
	f	%	f	%	F	%	f	%	f	%
Screening Patient Demographics										
Age Range										
40-49	1,951	17.9	1,155	21.8	734	19.9	247	18.1	513	29.4
50-64	4,699	43.2	2,455	46.3	1,548	42.0	605	44.3	942	54.0
65+	4,234	38.9	1,690	31.9	1,408	38.2	513	37.6	291	16.6
Race/Ethnicity										
White	5,881	54.0	2,028	38.3	2,786	75.5	652	47.8	1,099	62.9
Black	4,620	42.5	3,050	57.6	733	19.9	621	45.5	523	30.0
Latina	133	1.2	64	1.2	23	0.6	15	1.1	14	0.8
Other	250	2.3	158	3.0	148	4.0	77	5.7	110	5.7
Geographic Location										
Rural	386	3.6	191	3.7	245	6.7	5	0.4	266	15.5
Urban	10,326	96.4	5,031	96.3	3,409	93.3	1,349	99.6	1,447	84.5
Health Insurance Type										
Private	5,368	49.3	2,561	48.4	1,981	53.7	689	51.4	1,283	73.5
Public	5,269	48.4	2,610	49.3	1,695	45.9	639	47.7	450	25.8
Uninsured	243	2.2	124	2.3	14	0.4	12	0.9	13	0.7
Physical Characteristics										
# of Waiting Rooms	4		3		1		1		1	
# of Exam Rooms	15		14		4		1		3	
Educational materials? Y/N	No		Yes		No		No		No	
Utilization Characteristics										
Procedures										
Screening Visits	10,939	86.0	5,325	87.4	3,700	93.5	1,371	100.0	1,750	100.0
Diagnostic Visits	1,781	14.0	764	27.3	257	9.2	0	0	0	0
Weekly										
Operating Hours										
Screening	47.5		40		50		42		42	
Diagnostic	31.5		35		14		0		0	

\*Bolded values are statistical significant at the p<0.05 level



#### Table 4.2 Provider Perceptions of Patient Screening Experiences by Site n =24\*

Characteristics	Site A		Site B		Site C		Site D	
	f	Mean (Std)	f	Mean (Std)	f	Mean (Std)	f	Mean (Std)
How much physical discomfort do women experience during a mammogram? <sup>a</sup>	10	2.7 (0.95)	12	2.4 (1.00)	8	3.0 (0.93)	2	3.5 (0.71)
How much psychological distress do women experience during a mammogram? <sup>b</sup>	10	2.4 (0.70)	12	2.5 (0.80)	8	2.5 (0.76)	2	2.0 (0.00)
How often are women upset by this experience (getting called back for follow up testing)? <sup>c</sup>	10	3.1 (0.88)	12	3.7 (0.89)	8	3.9 (0.35)	2	3.5 (0.71)
How often are Black women upset by this experience (getting called back for follow up testing)? <sup>c</sup>	10	3.0 (0.82)	12	3.33 (0.89)	8	3.6 (0.52)	2	3 (1.41)

<sup>a</sup> Responses range from 1 = No discomfort to 5 = A great deal of discomfort; <sup>b</sup> Responses range from 1 = No distress to 5 = A great deal of distress; <sup>c</sup> Responses options: 1 = Never, 2 = Seldom, 3 = About half the time, 4 = Usually, 5 = Always; \*Bolded values are statistical significant at the p<0.05 level



	F	% or
		Mean (Std)
Race		
Black/African American	117	100.0
Age Range		
40-49	22	18.8
50-64	63	53.9
65+	32	27.3
Marital Status		
Married	35	29.9
Living with a partner	3	2.6
Widowed	22	18.8
Divorced	33	28.2
Separated	6	5.1
Single/Never Married	18	15.4
Geographic Location		
Urban	114	97.4
Education		
High school or less	83	70.9
College or more	34	29.1
Income		
Less than 50K	82	75.2
50K or more	27	24.8
Health Insurance Type		
Private	53	45.3
Public	60	51.3
Uninsured	4	3.4
Family History of Breast Cancer - Yes	35	29.9
% With False Positive Mammograms	54	46.1
Screening Site		
A	54	46.1
В	35	29.9
С	7	6.0
D	16	13.7
Е	5	4.3

Table 4.3 Demographic and Screening Characteristics of Patient Survey Respondents n =117



Table 4.4 Patient Survey Respondents' Mammography Satisfaction and Communication Scores by Site n =117

	Site A	Site B	Site C	Site D	Site E
	Mean (Std)	Mean	Mean	Mean	Mean
		(Std)	(Std)	(Std)	(Std)
	n = 51	n = 32	n = 7	n = 16	n=5
Mammography Satisfaction					
General	17.7	18.2	18.6	17.9	18.8
(Range: 13-22)	(2.6)	(2.2)	(1.9)	(2.0)	(1.1)
Convenience and Accessibility	14.5	14.6	14.7	13.8	14.6
(Range: 12-18)	(1.4)	(1.7)	(1.5)	(2.4)	(1.5)
Provider Information	14.5	14.2	15.0	13.8	14.2
(Range: 8-17)	(4.5)	(2.1)	(1.7)	(1.9)	(2.0)
Provider Interpersonal Style	14.6	14.9	15.1	14.3	14.4
(Range: 8-17)	(1.5)	(1.6)	(1.5)	(2.1)	(2.2)
Provider Competence	14.2	14.9	15.1	14.1	14.0
(Range: 8-17)	(1.8)	(1.6)	(1.5)	(2.1)	(1.9)
Physical Environment	16.9	18.1	17.6	16.9	17.2
(Range: 13-22)	(2.2)	(2.2)	(2.5)	(2.4)	(2.3)
Provider Communication					
Discrimination	1.1	1.1	1	1.3	1.2
(Range: 1-4)	(0.3)	(0.3)	(0)	(0.5)	(0.3)
Disrespectful Office Staff	1.1	1.1 (0.2)	1	1.1	1
(Range: 1-4)	(0.2)		(0)	(0.3)	(0)



Tuble 1.5. Divanuole Logit Model	General	Convenience	Provider	Provider	Provider	Physical
			Information	Interpersonal Style	Competence	Environment
			n	Style		
	OR (CI)	OR (CI)	OR (CI)	OR (CI)	OR (CI)	OR (CI)
Facility Factors						
Patient age: 50+	0.72 (0.31-1.69)	0.62 (0.27-1.40)	0.63 (0.28-1.41)	0.57 (0.24-1.32)	0.35 (0.15-0.84)	0.39 (0.17-0.89)
Patient age: 40-49	1.00	1.00	1.00	1.00	1.00	1.00
Patient race:						
Majority Non-White	0.34 (0.06-1.80)	0.77 (0.20-2.92)	0.54 (0.13-2.13)	0.68 (0.15-2.98)	0.91 (0.21-3.82)	2.26 (0.60-8.48)
Patient race:						
Majority White	1.00	1.00	1.00	1.00	1.00	1.00
Patient insurance status:						
High % Non-Private	2.57 (0.51-12.70)	1.27 (0.35-4.55)	2.29 (0.61-8.58)	1.87 (0.46-7.57)	1.37 (0.37-4.99)	0.77 (0.22-2.70)
Patient insurance status:						
Low % Non-Private	1.00	1.00	1.00	1.00	1.00	1.00
# of Waiting rooms: High	0.78 (0.30-2.02)	1.22 (0.50-2.97)	0.72 (0.30-1.76)	0.78 (0.31-1.96)	0.92 (0.38-2.22)	0.97 (0.40-2.31)
# of Waiting rooms: Low	1.00	1.00	1.00	1.00	1.00	1.00
# of Exam rooms: High	0.78 (0.30-2.02)	1.22 (0.50-2.97)	0.72 (0.30-1.76)	0.78 (0.31-1.96)	0.92 (0.38-2.22)	0.97 (0.40-2.31)
# of Exam rooms: Low	1.00	1.00	1.00	1.00	1.00	1.00
# of Education materials: Present	1.02 (0.43-2.40)	1.56 (0.67-3.63)	1.49 (0.65-3.41)	1.89 (0.78-4.59)	3.04 (1.22-7.57)	2.95 (1.12-6.93)
# of Education materials: Absent	1.00	1.00	1.00	1.00	1.00	1.00
Patient volume: High	0.78 (0.30-2.02)	1.22 (0.50-2.97)	0.72 (0.30-1.76)	0.78 (0.31-1.96)	0.92 (0.38-2.22)	0.97 (0.40-2.31)
Patient volume: Low	1.00	1.00	1.00	1.00	1.00	1.00
Screening hours: High	0.87 (0.39-1.91)	0.86 (0.40-1.85)	0.71 (0.33-1.51)	0.64 (0.29-1.39)	0.45 (0.20-0.97)	0.38 (0.17-0.82)
Screening hours: Low	1.00	1.00	1.00	1.00	1.00	1.00
Diagnostic hours: High	0.78 (0.30-2.02)	1.22 (0.50-2.97)	0.72 (0.30-1.76)	0.78 (0.31-1.96)	0.92 (0.38-2.22)	0.97 (0.40-2.31)
Diagnostic hours: Low	1.00	1.00	1.00	1.00	1.00	1.00
Provider Factors						
Perception of patient discomfort:						
High	0.88 (0.37-2.08)	N/A	0.64 (0.28-1.48)	0.53 (0.21-1.29)	0.32 (0.12-0.81)	N/A
Perception of patient discomfort:						
Low	1.00	1.00	1.00	1.00	1.00	1.00
Perception of patient distress:						
High	1.07 (0.48-2.38)	N/A	1.74 (0.80-3.79)	2.08 (0.93-4.66)	2.65 (1.19-5.92)	N/A

Table 4.5. Bivariable Logit Models Describing Associations with High Levels of Mammography Satisfaction Among Black Women\*



Perception of patient distress:						
Low	1.00	1.00	1.00	1.00	1.00	1.00
Perception patient upset by follow up: High	1.07 (0.48-2.38)	N/A	1.74 (0.80-3.79)	2.08 (0.93-4.66)	2.65 (1.19-5.92)	N/A
Perception patient upset by follow up: Low	1.00	1.00	1.00	1.00	1.00	1.00
Perception Black patient upset	1 21 (0 52 2 77)	NI/A	1.04 (0.86 4.36)	240(100572)	1 04 (0 86 4 36)	N/A
Dercontion Plack nations uport	1.21 (0.35-2.77)	IN/A	1.94 (0.80-4.50)	2.40 (1.00-3.72)	1.94 (0.80-4.50)	N/A
by follow up: Low	1.00	1.00	1.00	1.00	1.00	1.00
Patient Factors	1.00	1.00	1.00	1.00	1.00	1.00
FPM Results	0.73(0.33-1.60)	0 34 (0 16-0 73)	0 42 (0 20-0 89)	0.62(0.29-1.34)	0.58(0.27-1.22)	0.52(0.24-1.08)
Normal Results	1.00	1.00	1.00	1.00	1.00	1.00
Age Range	1.00	1.00	1.00	1.00	1.00	1.00
40-49	1.00	1.00	1.00	1.00	1.00	1.00
50-64	1.01(0.35-2.91)	1.12 (0.40-3.11)	0.96 (0.35-2.67)	0.88 (0.31-2.48)	0.39(0.13-1.17)	0.77 (0.28-2.12)
65+	0.84 (0.26-2.072)	1.09 (0.72-5.31)	0.54 (0.17-1.69)	1.16 (0.36-1.83)	0.55 (0.16-2.60)	0.64 (0.21-1.98)
Partnered	0.60 (0.26-1.35)	1.17 (0.52-2.64)	1.60 (0.71-3.60)	0.76 (0.34-1.72)	0.52 (0.23-1.17)	1.12 (0.51-2.47)
Unpartnered	1.00	1.00	1.00	1.00	1.00	1.00
High school or less	0.81 (0.33-1.96)	0.84 (0.36-1.96)	0.62 (0.26-1.45)	0.76 (0.32-1.82)	1.01 (0.44-2.32)	0.80 (0.35-1.82)
College graduate or more	1.00	1.00	1.00	1.00	1.00	1.00
Less than 50K	0.67 (0.25-1.78)	0.68 (0.27-1.72)	0.67 (0.27-1.64)	0.90 (0.36-2.28)	1.60 (0.66-3.88)	0.74 (0.30-1.81)
More than 50K	1.00	1.00	1.00	1.00	1.00	1.00
Private health insurance	0.91 (0.08-9.58)	0.88 (0.41-1.90)	0.61 (0.05-6.63)	0.56 (0.05-5.87)	0.48 (0.04-5.10)	0.46 (0.04-4.87)
Public health insurance	1.00	1.00	1.00	1.00	1.00	1.00
Family History of BRCA	0.58 (0.25-1.33)	0.35 (0.15-0.82)	0.72 (0.32-1.63)	0.51 (0.22-1.16)	0.67 (0.30-1.52)	0.51 (0.22-1.15)
No Family History of BRCA	1.00	1.00	1.00	1.00	1.00	1.00
High Discrimination Score	0.59 (0.23-1.51)	0.32 (0.12-0.87)	0.47 (0.18-1.22)	0.38 (0.15-0.96)	0.39 (0.15-1.00)	0.53 (0.20-1.36)
Low Discrimination Score	1.00	1.00	1.00	1.00	1.00	1.00
High Disrespectful Office Staff	056 (019177)	0.00 (0.20.2.10)	0.57 (0.19.1.91)	0.47 (0.15.1.40)	0.92 (0.26.2.59)	0.46(0.14, 1.50)
Score	0.36 (0.18-1.//)	0.99 (0.30-3.19)	0.57 (0.18-1.81)	0.47 (0.15-1.49)	0.82 (0.26-2.58)	0.40 (0.14-1.50)
Score	1.00	1.00	1.00	1.00	1.00	1.00

\*Bolded values are statistical significant at the p<0.05 level



4.2 False-Positive Mammography and Mammography Screening Intentions Among Black Women: The Influence of Emotions and Coping Strategies<sup>1</sup>

<sup>1</sup>Farr DE, Brandt HM, Friedman DB, Armstead C, Adams SA, Fulton J, Bull D. To be submitted to *American Journal of Preventive Medicine* 



#### Abstract

Abnormal mammograms confirmed as benign are known as false-positive mammography (FPM) results. Research indicates that a history of FPM results may be linked to mammography follow-up delays in Black women, yet much of the research on FPM has focused on White women. The purpose of this study was to examine the influence of FPM on breast cancer (BrCa) screening beliefs and intentions in Black women. BrCa-free, Black women, aged 40 and older who completed screening mammograms in 2016 were recruited for a case-control study. Print surveys assessing demographics, anxious personality, general anxiety, BrCa-specific anxiety, depression, BrCa screening history, BrCa beliefs, and Afrocentric coping behaviors were mailed to participants. Women with FPM results were cases, and women with normal results screened on the same day served as matched controls. The final sample consisted of 117 respondents (54 cases, 63 controls). Ordinary least squares (OLS) models were constructed. Personality traits, emotional states, and coping behaviors were tested as mediators and moderators of the relationship between FPM results and BrCa beliefs. FPM status was associated with a higher perception of barriers to mammography and perceived barriers were associated with a lower intention to complete mammography. Afrocentric coping behaviors moderated the perception of mammography barriers for women with FPM results. FPM status had a detrimental impact on BrCa beliefs in Black women, but the use of collective coping behaviors weakened this relationship. Culturally specific research focused on Black women is needed to explore influences on BrCa screening beliefs and mammography completion in this population.



### Introduction

Despite a continuous decrease in breast cancer (BrCa) mortality among American women, racial inequities in BrCa mortality have remained constant.<sup>1</sup> An important driver of these inequities among Black women is their increased rate of advanced staged tumors at diagnosis, which is partially due to delays in mammography screening resolution.<sup>2–6</sup> Delayed mammography follow-up in Black women has been attributed to various social, cultural, and socioeconomic factors, but the influence of Black women's prior healthcare experiences, such as receiving a false-positive mammography (FPM) result has not been fully explored.<sup>7–9</sup>

FPM results are abnormal screening mammograms that are determined to be nonmalignant after diagnostic testing.<sup>10–12</sup> Clinically, FPM results correspond to a Breast Imaging Reporting and Data System (B-IRADS) classification of 0 (Incomplete additional imaging evaluation and/or comparison to prior mammograms in needed), 3 (Probably benign finding), 4 (Suspicious abnormality) or 5 (Highly suggestive of malignancy).<sup>13</sup> Normal mammograms are classified as BI-RADS 1 or 2.<sup>13</sup> Anywhere from 5-10% of mammograms each year result in a FPM, but cumulatively, a woman has a 41.6-61.3% chance of receiving a FPM result during her screening life depending on the age at which she initiates screening (anytime between 40 and 50 years of age) and her screening schedule (annual vs. biennial).<sup>10,14–17</sup> FPM may lead to potentially negative outcomes, such as additional financial costs due to follow-up testing, impaired daily function, negative emotional states, and decreased BrCa screening intentions and behaviors.<sup>10,18</sup>



Recent systematic reviews report that despite experiencing general and BrCa specific anxiety after receiving a FPM, American women are more likely to complete screening mammograms than their European and Canadian counterparts.<sup>10,18</sup> Very few studies of FPM assess BrCa screening beliefs or integrate health behavior theory, so the exact mechanism that links FPM results with increased mammography completion is unknown. Furthermore, these findings may not apply to Black women as they have not be included in sufficient numbers or a part of subgroup analyses in studies of this topic.<sup>10,16,17,19–23</sup>

A handful of studies have examined FPM outcomes in women of color, but these studies mainly compared the emotional states of White women to heterogenous groups of women of color.<sup>24,25</sup> As a result, these studies have produced inconsistent findings regarding the effects of FPM results non-White women.<sup>24,25</sup> The only study to compare Black women with FPM to those with normal results found that FPM status was associated with higher levels of worthlessness and restlessness.<sup>26</sup>

Black women's experiences with and reactions to FPM may be an important aspect of their screening experience. One qualitative study of Black BrCa survivors presented accounts of women who delayed seeking care for lumps due to past FPM.<sup>27</sup> In another study by Kerner et al., Black women who completed mammography follow-up after the 90-day window were more likely to have had an abnormal mammogram in the past and displayed higher levels of anxiety than Black women with normal results.<sup>28</sup> Together these findings imply a potential link between prior FPM and mammography delay in Black women.



Racial differences are not limited to influences on screening behaviors, but also extend to the impact of coping strategies. In general, coping behaviors vary across racial/ethnic groups and in response to different events, necessitating the use of culturally specific assessments to adequately describe these behaviors.<sup>29,30</sup> A study of FPM results and coping behaviors found that Latinas engaged in more avoidant and religious coping which led to higher levels of distress than their White counterparts.<sup>31</sup> Racial variation in screening and coping outcomes of FPM results underscores the need for studies that focus on Black women to develop contextually relevant theories and knowledge about screening influences in this population.<sup>32</sup>

The goal of this study was to examine the influence of FPM results on mammography beliefs among Black women. Components of the transactional model of stress and coping and the health belief model guided the data collection and analysis for this study.<sup>33,34</sup> A FPM result can be conceptualized as a stressful event which leads to concurrent primary and secondary appraisals.<sup>33</sup> Primary appraisals generate emotional responses, while secondary appraisals lead to a course of action which may include coping responses.<sup>33,35</sup> BrCa screening beliefs, specifically influential predictors of mammography behaviors such as the Health Belief Models' perceived benefits and perceived barriers constructs, can be influenced by women's coping responses.<sup>33,35,36</sup> Personality traits, cultural differences in social contexts, and emotional expression can also impact appraisal and the relationship between health beliefs and behaviors.<sup>35–37</sup> The variability of these characteristics across racial/ethnic groups may generate different FPM responses and outcomes by group.



We (the authors) hypothesized that FPM results will adversely effect BrCa screening beliefs. As part of the appraisal process, emotions will mediate the relationship between BrCa beliefs and FPM status. Personality traits and coping behaviors will moderate these relationships. FPM status will have detrimental effects on mammography intention as will high levels of perceived susceptibility to BrCa, high levels of perceived mammography benefits.

## Methods

<u>Setting.</u> This study was conducted in collaboration with a leading provider of mammography services in Richland County, South Carolina.<sup>2</sup> Richland County is an area where 46% of the population was classified as African American/Black.<sup>38</sup> Study activities were approved by the Palmetto Health Institutional Review Board.

Study design. Preliminary estimates indicated FPM results represented 6% of screening mammograms performed at the participating health system during any 12-month period. A case-control study design was implemented given the rarity of FPM results in a single year. Eligible participants were selected from records of women completing screening mammograms at eligible facilities between January and August 2016. Black women aged 40 and older, BrCa free for five years or more, no indication of major mental illness, and whose final mammography results were confirmed as benign were eligible to participate. Women whose screening mammograms were classified as BI-RADS Category 0 were selected as cases.<sup>13</sup> One control participant was selected from eligible women who completed screening on the same day and at the same facility, but had normal results (BI-RADS Category 1 or 2).<sup>13</sup> Packets containing surveys, postage paid return envelopes, and medical records release forms were mailed to potential



participants five to six months after their initial screening mammograms to allow for screening resolution (June 2016-January 2017). Reminder letters were sent to non-responders one month after the initial mailing and prior to the end of the study. Medical records were used to confirm BrCa screening history information reported via survey.

*Measures*. Patient age, zip code, health insurance information, and screening facility were obtained from patient medical records. Patient zip codes were matched to counties, and the National Center for Health Statistics Urban-Rural Classification Scheme for counties was used to classify areas as urban or rural.<sup>39</sup> The South Carolina Department of Health and Human Services website and the National Committee for Quality Assurance Health Insurance Plan Ratings 2016-2017 were used to identify insurance products, which were further collapsed into three categories: private, public, and uninsured.<sup>40,41</sup> Survey questions assessing patient education, family history of BRCA, and age at first mammogram were modeled after items on the National Health Interview Survey.<sup>42</sup>

BrCa beliefs were measured using the Champion Attitudes Towards Mammography and Breast Cancer Scale, an assessment of the health belief model which was developed using Black women.<sup>43</sup> The Perceived Benefits, Perceived Susceptibility, and a shortened 10-item version of the Perceived Barriers subscale were included in this study.<sup>43</sup> All three subscales displayed high internal consistency in this sample with  $\alpha$ = 0.70, 0.84, and 0.85, respectively. Intention to complete future screening mammograms and follow-up tests were each assessed with a single item: 1) How likely are you get your next screening mammogram as scheduled? and 2) If you asked to return for follow-up testing after your next screening mammogram, how likely are you to complete those



additional tests? Response categories were 1=Very Unlikely, 2=Unlikely, 3=Likely, and 4=Very Likely.

Anxious personality and general anxiety were measured using the 10-item short forms of the Spielberger State-Trait Anxiety Inventory (STAI) Trait and State Anxiety Scales.<sup>44</sup> A six-item anxiety subscale of the Psychological Consequences Questionnaire DK-33 (PCQ-DK33) was used to assess BrCa-specific anxiety and displayed high reliability in this population ( $\alpha$ = 0.93).<sup>45</sup> Depression was assessed with the Center for Epidemiologic Studies Depression Scale Short Form (CES-D 10).<sup>46,47</sup>

The Africultural Coping Systems Inventory (ACSI) measures coping behaviors used by Black Americans and contains four subscales: cognitive/emotional debriefing, collective, spiritual-centered, and ritual centered.<sup>48</sup> Reliability coefficients for the four ACSI subscales in the current sample ranged 0.78 to 0.89.

*Statistical analysis*. Analyses were conducted in STATA 13.<sup>49</sup> Chi-square tests were employed to examine demographic differences between case and control participants. T-tests and ANOVA were used to examine differences in BrCa beliefs and psychosocial factors. Study hypotheses were tested using OLS models. Variables with theoretical relationships to the outcome of interest were included in the models. Missing observations were removed from models via case-wise deletion. The 'khb command' in STATA (Sobel test) was used to test for mediation. Continuous variables were centered at the mean value for the overall sample. Separate models with interaction terms combining the main independent variable (FPM status) with anxious personality, anxiety, depression and coping behaviors were created to determine the influence of these



characteristics on the main outcome variables (BrCa beliefs). An alpha of 0.05 was used to determine statistical significance in all models.

### Results

Between January and August 2016, 9,826 Black women completed screening mammograms and were eligible for study participation. In total, 909 survey packets were mailed (411 cases, 498 controls), 25 surveys were returned to sender, and two recipients reported ineligibility and did not return surveys. Of the remaining 882 surveys distributed, 133 (15.0%) were returned. Five survey participants were found to be ineligible due to recent BrCa diagnoses or mental illness. Another 11 were excluded from analyses due to missing information or conflicting responses. The final analytic sample consists of 54 case and 63 control participants for a total of 117 respondents. Most of the survey respondents were aged 50 and older, had at least a high school education, and had health insurance coverage. Table 1 displays demographic, BrCa screening, and psychosocial information for both groups. Case and control respondents were similar on demographic variables, but significant differences were detected in the mammography barriers scores. Women with FPM results reported an increased perception of barriers compared to women with normal results (13.8 vs. 12.2, p=0.04). Additionally, women with FPM results displayed more general and BrCa-specific anxiety compared to women without FPM results. Both groups of women reported using similar coping styles, except for cognitive/emotional coping behaviors which were more prevalent among women with FPM results.

Multiple OLS models were constructed to investigate the influence of FPM results on BrCa screening beliefs (Table 2). Only the models describing perceived



susceptibility to BrCa ( $R^2 = 0.22$ , p=0.00) and the perceived barriers to mammography ( $R^2=0.19$ , p=0.00) were statistically significant. Receipt of FPM results was associated with a higher perceived barriers score. Anxious personality, anxiety, depression, and coping strategies were tested as mediators, but none of these variables explained this relationship. Testing for effect moderation revealed that the use of collective coping behaviors was associated with a lower mean perceived barriers score among women with FPM results (Figure 1.)

Separate models describing the screening and follow-up testing intentions were constructed (Table 3.) Perceived benefits of mammography were not included in BrCa screening and diagnostic intention models being that the base model was not statistically significant. Neither type of intention was influenced by perceived BrCa susceptibility  $(R^2=0.09, p=0.53; R^2=0.10, p=0.40$  for screening and follow up intention respectively). Both intentions to complete screening mammography ( $R^2=0.21, p=0.00$ ) and diagnostic testing ( $R^2=0.31, p=0.00$ ) were inversely associated with the perceived barriers score.

## Discussion

Previously unasked questions about the relationship between FPM, BrCa screening beliefs, and mammography intentions in a sample of Black women were explored in this study. We hypothesized that FPM status would lead to lower levels of perceived mammography benefits, higher levels of perceived susceptibility to BrCa, and perceived barriers to mammography. In our sample, FPM status was not associated with the perception of the benefits of mammography nor perceived susceptibility to BrCa. Previous studies consistently reported elevated mammography benefits and BrCa susceptibility scores among White women with FPM results.<sup>10,18</sup> While the perception of



benefits has not been shown to impact mammography adherence, regardless of race, BrCa susceptibility has been linked to increased motivation to complete mammography among White women.<sup>10</sup> Research on perceived susceptibility to BrCa suggests that Black women perceive lower levels of BrCa risk and that perceived susceptibility has no influence on their BrCa screening behavior.<sup>37,50</sup> Our findings regarding perceived susceptibility corresponds with the literature describing BrCa screening beliefs among Black women in general.

In our study, FPM status was associated with an increased perception of barriers to mammography, which conflict with DeFrank et al.'s findings of no relationship between these factors.<sup>16</sup> This difference is likely due to the fact that we used the Champion barrier items which assessed logistical, psychosocial, and financial concerns, while DeFrank et al. only examined financial barriers to mammography completion.<sup>16,43</sup> It is not surprising that women with FPM status reported more barriers given their experience with the various challenges associated with the completion of follow up testing.

We also hypothesized that anxiety and depression would mediate the relationship between BrCa beliefs and FPM status, and personality traits and coping behaviors would function as moderators of this relationship. We did not uncover any mediators, but the employment of collective coping strategies were found to decrease the perception of mammography barriers.

Collective coping as measured by the ACSI is similar to the social support subscales of other assessments such as the Brief COPE, but the ACSI subscale contains activities that are prevalent in collective cultures and specific to the Black American



experience.<sup>30,48,51</sup> The positive effect of this coping style appears to indicate that collective coping strategies are protective for individuals in more collective cultures. Molina et al. found differences in coping behaviors and negative psychosocial outcomes between White and Latina women, but the impact of collective coping strategies on psychosocial outcomes was not reported due to inadequate reliability of the Brief COPE's social support subscale.<sup>31</sup> Another analysis conducted by the same authors revealed negative psychosocial outcomes among Latina women with FPM results who did not discuss their results with their family or friends.<sup>52</sup> Together, these findings demonstrate the need for investigations of the effect coping behaviors on BrCa screening outcomes among women of color with FPM results.

Lastly, we postulated that the impact of FPM status on BrCa behavioral beliefs would lead to lower mammography intention among the women surveyed. This hypothesis was only supported for the perception of barriers to mammography. In this sample, high levels of perceived mammography barriers were associated with the receipt of FPM results and decreased intentions to complete mammography screening and follow-up testing. In DeFrank et al.'s study, FPM status was connected with the delayed completion (longer than two years) of participants' next screening mammography, and mammography delay was mediated by provider recommendation.<sup>16</sup> Women with FPM results were more likely to experience mammography delays if they did not receive a mammography recommendation.<sup>16</sup>

It will be important to examine whether provider recommendation has similar impact on subsequent mammography behavior among Black women with FPM results, especially as primary care providers are less likely to discuss mammography screening



recommendations with their Black patients.<sup>53,54</sup> In this sample, respondents were asked the reason for their most recent screening mammogram using a multi-select survey item. Twenty-six percent of respondents indicated scheduling their index mammogram due to a recommendation from their provider (there were no differences in cases and controls). Most respondents (82.7%) reported scheduling screening mammograms "because it was time". This finding appears to confirm the lack of provider discussion about mammography reported in other studies.<sup>53,54</sup>

Limitations. The following limitations should be noted when considering the study's findings. Psychosocial measures were collected retrospectively, thus were subject to recall bias. As both groups were subject to recall bias, we believe the impact on our findings is minimal. It is possible that there were small differences in BrCa screening beliefs that could not be detected due to the relatively small sample size. This study examined BrCa screening and follow-up intentions, not actual behavior. Cross-sectional sampling used for analysis makes this study exploratory, but provided information that can guide longitudinal studies of FPM outcomes among Black women.<sup>55</sup>

Additionally, the long-term effect of receiving an FPM result are unclear as respondents were assessed between 6 and 12 months after their index mammogram (mean response time was 199 days). Respondents were asked if they had a FPM before their most recent mammogram and 24% of controls reported a previous FPM result. Sensitivity analyses were run with respondents who ever had a FPM serving as cases and those never receiving a FPM result as controls. Similar trends emerged from this analysis, but many did not achieve statistical significance. These results suggested that effects of a FPM result are time-dependent. This study has many features that strengthen its findings,


specifically the use of: a case-control design, culturally appropriate standardized measures, clinical records to validate FPM status, and a theoretically grounded conceptual model to guide measure selection and data analysis.

#### Conclusions

Influences on BRCA screening beliefs and mammography intentions vary as result of the different social and cultural contexts that shape their healthcare experiences. Black women exist in an environment with lower levels of BrCa knowledge, fewer discussions with healthcare providers about BrCa screening, and high rates of BrCa mortality, thus the use of collective coping strategies improves Black women's response to the potentially negative experience of receiving FPM results.<sup>1,8</sup> Our findings highlight the importance of conducting culturally specific research with groups that experience racial inequalities, as behavioral pathways and solutions may vary by racial/ethnic group. Additional research examining the influence of Black women's previous BrCa screening encounters and responses to those encounters is needed to better understand behavioral factors linked to mammography delay.

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	Cases (False Positives) n= 54		Controls (Normal Mammograms) n=63	
	_	Percentage (%) or	_	Percentage (%) or
	f	Mean (Std)	f	Mean (Std)
Age Range			0	10.5
40-49	14	25.9	8	12.7
50-64	25	46.3	38	60.3
65+	15	27.8	17	27.0
Education				
High school or less	34	63.0	49	77.8
College or more	20	37.0	14	22.2
Health Insurance Type				
Private	26	48.2	27	42.9
Public	27	50.0	33	52.4
Uninsured	1	1.8	3	4.7
Geographic Location				
Urban	52	96.3	62	98.4
Family History of Breast Cancer -	16	29.7	19	30.2
Yes				
Age at First Mammogram				
Less than 30 years old	7	13.5	7	11.5
30-39 years old	26	50.0	23	37.7
40-49 years old	15	28.9	25	41.0
50 years or older	4	7.6	6	9.8
Perceived Suscentibility	43	7.2 (2.7)	55	7 3 (2 7)
(Range: 4.15)	75	1.2 (2.7)	55	1.5 (2.1)
Perceived Renefits (Range: 10-16)	52	14.5 (1.8)	61	14 4 (1.8)
Parcaived Barriars (Range: 10-10)	50	13.8 (4.7)	57	12 2 (3 2)
Intention Screening	50	13.0 (4.7)	51	12.2 (3.2)
Mammagraphy				
	50	02.6	50	02.7
	30	5.6	2	19
	1	1.0	0	4.0
	1	1.8	0	0.0
very Unlikely	0	0.0	1	1.5
Intention – Mammography Follow				
	10	00.7	57	01.0
	49	90.7	5/	91.9
	4	7.4	4	6.5
Unlikely	0	0.0	0	0.0
Very Unlikely	1	1.9	1	1.6
Trait Anxiety (Range: 10-32)	46	17.4 (5.1)	52	17.2 (5.3)
State Anxiety (Range: 10-34)	49	19.4 (4.9)	56	16.4 (4.8)
Breast Cancer Specific Anxiety	53	4.3 (4.7)	57	2.2 (3.5)
(Range: 0-18)				
Depression (Range: 0-22)	44	6.0 (5.8)	56	3.9 (4.9)
Coping Style				
Cognitive/Emotional (Range: 0-31)	45	13.0 (8.9)	54	9.3 (8.8)
Collective (Range: 0-21)	50	6.0 (5.2)	54	6.1 (5.9)
Spiritual (Range: 0-27)	46	14.2 (7.6)	54	12.5 (8.2)
Ritual (Range: 0-9)	53	0.7 (1.5)	57	0.9 (1.9)

# Table 4.6 Demographic, Screening, and Psychosocial Characteristics of BlackWomen Completing Screening Mammography by Outcome n =117\*

\*Bolded values are statistically significant (p<0.05)



C .	Perceived Susceptibility	Perceived Benefits	Perceived Barriers
Model R <sup>2</sup>	0.22	0.09	0.21
Independent Variables			
	Mean (SE)	Mean (SE)	Mean (SE)
Case	6.5 (0.6)	14.8 (0.4)	13.4 (0.9)
(FPM Result)			
Control	6.8 (0.6)	14.5 (0.4)	11.4 (0.9)
Age Range			
40-49	5.6 (0.8)	14.4 (0.5)	11.6 (1.1)
50-64	7.0 (0.6)	14.8 (0.4)	13.1 (0.8)
65+	7.4 (0.8)	14.7 (0.5)	12.5 (1.1)
Education:			
High school or	6.4 (0.6)	14.5 (0.4)	13.2 (0.9)
less			
College or more	6.9 (0.6)	14.8 (0.5)	11.6 (1.0)
Health Insurance:			
Private	7.8 (0.4)	14.3 (0.3)	10.5 (0.7)
Public	7.1 (0.4)	14.4 (0.3)	11.8 (0.8)
Uninsured	5.0 (1.5)	15.2 (1.1)	14.9 (2.0)
Family History of Breast Cancer			
Yes	7.2 (0.7)	14.5 (0.5)	
No	6.1 (0.6)	14.8 (0.4)	
Breast Cancer Specific Anxiety	6.6 (0.6)	14.6 (0.4)	
(Centered at Mean)			
Age at First Mammogram:			
< 30 years old			10.9 (1.2)
> 30 years old			13.9 (0.8)

# Table 4.7 Multiple Regression Models Describing Influences on Breast Cancer Screening Beliefs\*

\*Bolded values are statistically significant at the p<0.05 level.



	Mammography Screening Intention <sup>a</sup>		Mammography FollowUp Intention <sup>a</sup>	
Model R <sup>2</sup>	0.09	0.21	0.10	0.31
Independent Variables				
	Mean (SE)	Mean (SE)	Mean (SE)	Mean (SE)
Case	3.8 (0.1)	3.8 (0.1)	3.7 (0.1)	3.8 (0.1)
(FPM Result)				
Control	3.9 (0.1)	3.8 (0.1)	3.9 (0.1)	3.8 (0.1)
Age Range				
40-49	3.8 (0.1)	3.8 (0.1)	3.9 (0.1)	3.8 (0.1)
50-64	3.8 (0.1)	3.8 (0.1)	3.9 (0.1)	3.8 (0.0)
65+	3.8 (0.1)	3.8 (0.1)	3.7 (0.1)	3.8 (0.1)
Education:				
High school or	3.8 (0.1)	3.8 (0.1)	3.8 (0.1)	3.8 (0.1)
less				
College or more	3.9 (0.1)	3.8 (0.1)	3.8 (0.1)	3.8 (0.1)
Health Insurance:				
Private	4.0 (0.1)	4.0 (0.1)	3.9 (0.1)	4.0 (0.0)
Public	3.9 (0.1)	3.9 (0.1)	3.9 (0.1)	4.0 (0.0)
Uninsured	3.6 (0.2)	3.6 (0.1)	3.6 (0.2)	3.6 (0.1)
Family History of Breast Cancer				
Yes	3.8 (0.1)		3.8 (0.1)	
No	3.8 (0.1)		3.8 (0.1)	
Breast Cancer Specific Anxiety (Centered at Mean)	3.8 (0.1)		3.8 (0.1)	
Age at First Mammogram:				
Less than 30 years old		3.8 (0.1)		3.8 (0.0)
More than 30 years old		3.8 (0.1)		4.0 (0.0)
Perceived Susceptibility (Centered at Mean)	3.8 (0.1)		3.8 (0.1)	
Perceived Barriers (Centered at Mean)		3.8 (0.0)		3.8 (0.0)

### Table 4.8 Multiple Regression Models Describing Influences on Breast Cancer Screening Intentions

\*Bolded values are statistically significant (p<0.05) a=Single item measure with 1= Very Unlikely and 4 = Very Likely





Figure 4.1. Black Women's' Perception of Mammography Barriers by Screening Results Stratified by Coping Strategy Usage



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## CHAPTER 5.

### SUMMARY, IMPLICATIONS, AND RECOMMENDATIONS

This chapter contains an integrated summary of the results presented in Chapter 4. A discussion of the results, study limitations, conclusions, and implications for public health practice and cancer inequities research is presented. Future research directions generated from this work will also be presented.

#### **5.1 Summary of Findings**

This purpose of this dissertation research was to determine the impact of multilevel factors on the processes and outcomes associated with FPM results in Black women. The study had two specific aims.

**Specific Aim 1**: To describe, using a mixed methods approach, the organizational and provider-level characteristics of mammography facilities and their impact on Black women's FPM experiences and outcomes.

<u>Research Question 1.1</u>. What organizational, provider, and patient-level characteristics predict high levels of satisfaction with their clinical encounter among Black women experiencing a FPM result?

Of the six domains of satisfaction examined, general satisfaction and satisfaction with provider's interpersonal style were not influenced by any of the characteristics included in this analysis. Satisfaction with the convenience of mammography was inversely related to patient factors, such as having a FPM result, experiencing discrimination during the screening encounter, and having a family history of BrCa. The



negative influence of FPM status and experiencing discrimination on satisfaction with convenience mirror the findings of previous studies of this relationship.<sup>158,178,194,222,263</sup> Meanwhile, less data were available to describe the relationship between family history and satisfaction with mammography convenience.

Even though FPM rates were higher among women with a family history of BrCa<sup>45</sup>, the proportion of women in this sample who had ever had a FPM result was not significantly different for women with and without a family history of BrCa (62.8% vs 57.3%, p = 0.68). It is possible that some other aspect of the screening experience, potentially additional testing not related to abnormal mammography results, may impact satisfaction for this subgroup of Black women. Yet, it is not entirely clear what mechanism is responsible for the decreased satisfaction among this subpopulation of Black women as so few studies of family history have included Black women or mentioned the race of study participants.<sup>282–284</sup>

Satisfaction with provider's communication of information was solely influenced by FPM status. Women with FPM results were less likely to be satisfied with the information they received during their clinical encounters. Inadequate communication concerning abnormal screening results has been a recurrent theme in studies of BrCa screening follow-up in Black women.<sup>89,154,194,263,269</sup>

Both satisfaction with provider competence and the physical environment were associated with facility and provider-related characteristics. In particular, the presence of educational materials increased women's satisfaction with provider's expertise and the clinical environment. Previous work on satisfaction with the mammography process, in general, has looked only at a few aspects of the facility environment not related to



communication, such as waiting times or ease of scheduling. <sup>158,178,260</sup> We found that higher levels of dissatisfaction were associated with an older patient population, more screening hours, and increased levels of providers' concern with patients' physical discomfort. It is possible that the age of the patient population and a greater number of screening hours may increase women's perception of longer waiting times. Providers' concern about physical discomfort may have served to make them timid and/or less confident with patients during the clinical encounter.

**Specific Aim 2:** To determine, through quantitative methods, the relationship between receiving a FPM result and future mammography intention among Black women.

<u>Research Question 2.1</u>. What is the relationship between receiving a FPM result and BrCa behavioral beliefs (perceived benefits of mammography, perceived BrCa susceptibility, and perceived barriers to mammography screening) among Black women?

Of the three BrCa screening beliefs measured, FPM only had a direct influence on the perception of barriers to mammography screening. The lack of relationship between perceived BrCa susceptibility and FPM status fits with several previous analyses of these variables.<sup>43,151,163,168</sup> Other studies examining the connection between the perceived benefits of mammography and FPM status also failed to find a significant association.<sup>177,178</sup>

Another explanation for null results as it relates to the relationships between FPM status, perceived susceptibility to BrCa, and benefits of mammography may be the timing of the assessment. Given that women were asked to recall their state of mind for an event which occurred 6 months prior, it is possible that women's memories are influenced by



their final results. It is equally likely that topics such as barriers to screening may be more salient and easier to recall compared to concepts such as susceptibility to BrCa or the benefits of screening.

Women with recent FPM results displayed a higher perception of screening barriers. These results are in direct contrast to DeFrank et al. (2012) who reported no association between FPM status and perceived barriers score.<sup>43</sup> Differences in these findings may be attributed to differences in measurement of perceived barriers. DeFrank et al. (2012) used unstandardized items that only assessed financial barriers as opposed to the current study which assessed financial, logistical, and psychosocial barriers using a shortened version of the barrier subscale of the Champion Attitudes Towards Mammography and Breast Cancer Scale.<sup>43,258</sup> It is likely that the barriers assessed by the Champion Attitudes Towards Mammography and Breast Cancer Scale are more representative of the varied outcomes associated with the receipt of FPM and allowing for the detection of the relationship between these two variables.<sup>37,38,258</sup>

<u>Research Question 2.1.a</u>. Do Black women's emotional states explain the relationship between a FPM result and BrCa behavioral beliefs (perceived benefits of mammography, perceived BrCa susceptibility, and perceived barriers to mammography screening)?

Levels of general anxiety, BrCa-specific anxiety, and depression were assessed and tested as mediators of the relationship between perceived barriers and FPM status. Trait anxiety appeared to function as mediator in preliminary tests; thus it was included in mediation analyses. None of these factors explained the relationship between this BrCa screening belief and mammography outcome. The transactional model of stress and



coping conceptualizes that individuals will generate multiple appraisals in response to stressful events.<sup>200,201</sup> Primary appraisals lead to emotional responses while secondary appraisals lead to coping behaviors and/or changes in beliefs. Emotions are theorized to accompany appraisals and not influence appraisals. The independent nature of the primary and secondary appraisals and different states affected would explain the lack of relationship between emotional states and BrCa screening beliefs.<sup>201</sup>

<u>Research Question 2.1.b</u>. Does the relationship between receipt of FPM results and BrCa behavioral beliefs (perceived benefits of mammography, perceived BrCa susceptibility, and perceived barriers to mammography screening) vary by coping strategy employed?

Several coping styles were tested to determine if they had any influence on the relationship between perceived barriers to mammography and FPM status. Of the different coping styles measured (cognitive/emotion debriefing, collective, spiritual-centered, and ritual-centered), collective coping was found to decrease the detrimental influence of FPM results on the perception of barriers to mammography. Black American culture is highly collective due to its origins in African culture and the need to engage in collective behavior to survive various forms of racial oppression and disenfrachisement. These findings along with other studies illustrate how the collective aspects of Black culture can serve as resources that Black women can access to improve their health.<sup>63,237,238</sup> Previous research on coping behaviors in response to a FPM result examined the relationship between coping behaviors and emotional states/distress, as opposed to BrCa beliefs.<sup>157,180</sup> In the current sample, none of the coping strategies



measured were found to alter the relationship between FPM status and anxiety (general nor BrCa-specific).

<u>Research Question 2.2</u>. What is the relationship between BrCa behavioral beliefs (perceived benefits of mammography, perceived BrCa susceptibility, and perceived barriers to mammography screening) and intention to complete future mammography screening?

To establish the potential link between FPM and mammography intention in this small sample, models linking BrCa screening beliefs and mammography intention were created. Mammography intention was found only to be influenced by the perception of barriers to mammography. It is not surprising that the perceived benefits of mammography and the perceived BrCa susceptibility were not related to mammography intention in this sample. Reviews of the health belief model constructs failed to find a relationship between perceived benefits and mammography screening behavior.<sup>189,285</sup> Despite evidence that perceived susceptibility increases mammography screening behavior among White women, this relationship has not been detected among samples of Black women.<sup>189,190,274</sup> Perceived barriers to mammography has been consistently associated with lower levels of mammography intention and screening, and the current study replicates these findings.<sup>189,285</sup>

In summary, multilevel factors were proven to influence the BrCa screening experiences of Black women with FPM. Organizational and provider level characteristics had positive and negative effects on Black women's satisfaction with BrCa screening services in general. FPM status was related to lower levels of satisfaction and increased perceptions of the barriers to completing BrCa screening services. Literature indicates



that mammography satisfaction facilitates and the perception of barriers to mammography inhibit mammography behaviors.<sup>189,260–262,285</sup> The findings of this dissertation research point to a link between FPM status and mammography behaviors through perceptions of the screening experience and subsequent influences on BrCa screening beliefs.

#### 5.2 Strengths and Limitations

Conclusions drawn from the research findings are strengthened by several features of the study. This research includes a dedicated examination of influences in mammography satisfaction among Black women which is an important, but understudied topic. As a result, valuable information about the characteristics of the clinical encounter related to satisfaction for Black women may be used to guide future work on this topic. Additionally, the use of mixed-methods to collect information about features of the physical and social environment of healthcare facilities represents a more comprehensive approach to describing how the clinical environment influences patient experiences compared to quantitative-only or qualitative-only studies. Another asset of this research relates to the designs employed to address both specific aims. Linking characteristics at the organization, provider, and patient levels to women's experiences at a single screening episode is a novel feature of this work as many studies of mammography screening only examine influences at one or two levels at most. Applying a case-control design to the investigation of the relationship between FPM status and BrCa screening beliefs and intentions enhances the internal validity of the results as does the use of culturally appropriate measures of BrCa screening beliefs and coping behaviors. The use of clinical measures to validate self-reported screening data also strengthens our



conclusions. Lastly, the use of a theoretically and empirically grounded conceptual model enhanced the selection of appropriate variables and analytic methods to understand how FPM results affect Black women.

There were several limitations of this work that may impact the interpretation of the results. First is the small sample size. This issue prevented the inclusion of organizational, provider, and patient-level factors in one model for each type of mammography satisfaction. Another challenge associated with small sample size was the inability to collect data from all healthcare providers with patient contact. These limitations make the analyses of influences on mammography satisfaction, BrCa screening beliefs, and mammography intention exploratory in nature. However, these analyses can support the identification of variables to be incorporated in future studies of mammography beliefs and behaviors.

Secondly, data for this study came from a single health system reducing the external validity of the results. Time and financial constraints would not allow for the inclusion of multiple hospital systems to generate a representative sample. A feature of this study linked to the focus on a single hospital system is the opportunity to examine the impact of standardized notification procedures on mammography satisfaction. This characteristic of the system limited our ability to determine how specific communication methods/protocols may impact satisfaction. Yet, the focus on a single system also proved to be a strength of the study as it allowed for the explanation of the lack of site-level differences in mammography satisfaction despite the variation in all of the other characteristics of the participating sites.



Third, the provider and patient surveys did not measure all variables that may influence women's FPM experiences. In the case of the provider survey, factors, such as the volume of images read or the double reading of images, were not assessed. These factors are only relevant for radiologists, which represent 12.5% of the provider survey respondents. Few studies examined how non-physician staff involved in mammography procedures impacted women's clinical encounters and this study provided important information as to how non-physician staff shaped women's experiences.

Medical conditions/issues, such as pain during the mammography procedure, mental health diagnoses, and chronic conditions that limit mobility or ability to complete mammography screening and follow-up procedures, were not assessed as part of the patient survey. Other cancer-related beliefs such as fatalism and medical mistrust have been shown to be salient influences in this population, but they were not included in the patient survey. These factors may impact women's experiences and intention to complete screening; however there is no reason to believe that these factors would vary considerably between cases and controls. Psychosocial outcomes, including worry, fear, and distress, were associated with FPM status in other studies, but these variables were not measured in this study to minimize respondent burden.

Fourth, the primary endpoint of the analyses examining individual FPM outcomes was mammography intention and not behavior (i.e. repeat mammography). Studies are inconsistent as to the links between mammography intention and actual mammography behaviors.<sup>189,285</sup> Given that recommended mammography screening intervals range from one to two years; it was not feasible to collect prospective screening data for this study. The assessment of perceived barriers to mammography, the BrCa screening belief most



consistently associated with mammography behavior, did strengthen the assertion of a link between FPM status and future mammography behavior.

Lastly, the fact that patient survey respondents were asked to retrospectively recall emotions and mammography experiences has to potential to weaken the study findings. Participants were surveyed six months after the initial screening mammogram to allow for the verification of final screening results. On average, diagnostic results were verified in this sample within three months, and future studies should consider a shorter follow-up time to reduce the potential for recall bias. Yet, the case-control design of this study was designed to yield two groups that were similarly affected by recall bias as well as social desirability to indicate intentions to complete future BrCa screening.

#### **5.3 Conclusions**

The goal of this study was to examine how multilevel factors, characteristics of the organizations, healthcare providers, and patients involved in the mammography screening process influence Black women's responses to receiving a FPM result. While no factors were associated with patients' general satisfaction and satisfaction with provider's interpersonal style, organizational level factors related to the patient population, services offered, and the physical environment had an impact on patients' satisfaction with provider's skills and physical environment of the mammography facility. Provider perceptions of patients' comfort were associated with patients' satisfaction with providers' skills. Patient characteristics related to past and current screening experiences including a family history of BrCa, experiencing discrimination during the most recent screening experience, and receiving a FPM result negatively



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impacted mammography satisfaction. These same characteristics had similar negative effects on BrCa screening beliefs and attitudes.

FPM status was associated with increased levels of general and breast cancer anxiety, but subsequently these emotional states did not influence BrCa screening beliefs. Receipt of FPM results did have adverse effects on women's intention to complete mammography screening and follow-up procedures through an increased perception of the barriers to mammography completion. Culturally-specific behavior in the form of collective coping strategies weakened the effect of perceived barriers on screening intention. Together, these findings point to the potential role of past screening experiences on future screening behavior through influences on BrCa screening beliefs and intention. Additionally, these results also underscore the value and necessity of understanding the contextual influences of the group whose health outcomes are being investigated. Knowledge of the historical, social, and cultural factors that surround the health behaviors of groups, such as Black women, can inform the measurement of culturally-appropriate experiences and behaviors and the development of culturallyrelevant health behavior theories. This research has important implications for clinical practice and public health research as a whole, and with specific ramifications for those engaging in activities designed to reduce racial inequities in BrCa burden.



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#### **5.4 Implications and Recommendations**

### 5.4.1 Clinical Care

Insights generated from this research suggest several strategies that can be employed to improve the screening and follow-up process for Black women. One important result of this research is the lack of facility-level differences in mammography satisfaction, which may be attributed to the standardization of notification procedures across facilities. Despite differences in patient populations, services, and clinical environments, women requiring additional testing are contacted via telephone after their initial mammogram is read (often within 24 hours) and by postal mail (regardless of phone contact) at all facilities. Analyses did reveal that providers' communication about screening and perceptions of patients had an impact on Black women's satisfaction with the encounter. It would stand to reason that the standardization of notification procedures may be one strategy that can improve Black women's satisfaction with the mammography encounter.

The development and testing of standardized scripts to guide provider interactions, particularly around follow-up testing may improve satisfaction with the clinical encounter. As part of these scripts, providers can also encourage Black women with FPM results to speak to their family and friends about their screening results to reduce their perception of the challenges of completing follow up-testing. Additionally, study results indicated that the presence of materials with information about the screening process had a positive impact on Black women's screening and follow-up experiences. Making standard patient education materials from Susan G. Komen or the American Cancer Society available in the waiting room and/or including these materials with postal



notifications of abnormal results can address some of the communication issues commonly reported by this population.

Lastly, Black women with FPM results reported less satisfaction with the convenience of mammography and were more aware of the barriers to completing screening. Survey items measuring satisfaction with convenience described logistical challenges related to the time needed for, distance to, and validity of follow up visits. The aforementioned factors can impact whether a woman is able to return for follow-up or the length of time it takes to achieve diagnostic resolution. Changes in the scheduling of screening can reduce some of the negative effects of FPM. Instead of scheduling all women for screening mammograms in time slots reserved for general screening, women who are likely to have FPM results could be given the option of complete screening during diagnostic screening slots.

In the participating hospital system, mammography facilities held blocks of time specifically for women who need to return for follow up procedures. Women are informed that their visit will take longer, because the radiologist performing the procedure will read the images while the woman is waiting. If necessary, the radiologist will perform additional procedures so that the woman can receive a final result in person, unless a biopsy is required. If a woman completes a biopsy as part of her follow up procedures, a pathologist needs to process the tissue sample and prepare a final report. A nurse is scheduled to call the woman and inform her of the pathology results within 24 hours of the biopsy. Women who are likely to have a FPM result could be offered the option of proceeding with their screening as it if was a follow-up visit and schedule their visit during one of the diagnostic testing slots. Providing women with this option has the



potential to address the logistical barriers in addition to communication issues related to follow-up testing. Providing educational materials about mammography follow-up to women suspected of FPM results while waiting for screening and diagnostic testing can reduce fears and other negative psychological outcomes.

Although it is not possible to predict which women will have abnormal screening mammograms, there are several characteristics that increase the likelihood of receiving a FPM result. Women with dense breasts (BI-RADS Breast Density rating of 3 or 4), who are completing their first mammogram, and those with previous FPM results can be identified and offered the choice of completing initial screening during periods reserved for diagnostic follow-up periods. Women with increased risks of FPM who complete mammography during these slots would be asked to stay longer so that their initial mammograms can be read on site. These women would complete diagnostic testing on site if necessary.

#### 5.3.1 Population Level Mammography Screening Behavior

In fall 2015, a few months before the start of data collection for this study, the American Cancer Society changed its mammography screening guidelines and recommended that average risk women began screening at age 45 and continue screening annually until age 54.<sup>51</sup> After age 55, women can choose to screen annually or biennially.<sup>51</sup> These guidelines differ from the American Cancer Society's previous guidelines recommending annual mammography for women starting at age 40, and the United States Preventive Services Task Force's more controversial guidelines recommending biennial mammograms for women between the ages of 50 and 74.<sup>286,287</sup> Negative consequences of FPM results, including additional financial costs and negative



psychosocial outcomes, were an integral factor in recent decisions to increase the age of screening initiation and lengthen screening intervals.<sup>51,287,288</sup> In the case of Black women, these changes have been criticized as the evidence that informed these changes utilized samples (actual and simulated) of White women, thus the evidence did not account for racial differences in the age at BrCa diagnosis, BrCa tumor severity, incidence, or mortality.<sup>289</sup> Additionally, the research forming the basis of these recommendations does not consider the lack of research on FPM outcomes in Black women. As a result, the current study is one of the few that can take up the discussion of the impact of FPM in Black women and the potential implications on population-level screening behaviors for this group. Several studies indicate that Black women continue to commence annual mammography screening at age 40, meaning that FPM rates are unlikely to change for this group.<sup>253,280,290–292</sup> Some researchers speculate that the persistence of screening behavior may be a result of women and/or their provider's lack of knowledge around or skepticism towards the new screening guidelines.<sup>263,280,292</sup> Published data and findings from the current study revealed low rates of provider recommendation for mammography among Black women. These findings appear to support the idea that Black women are skeptical of or unaware of the guideline changes and provide more evidence as to the different healthcare contexts that surround Black women's healthcare experiences.<sup>263</sup> Overall, trends in Black women's mammography screening behaviors underscore the need to develop strategies to mitigate the potentially negative influences of FPM results on Black women's BrCa screening beliefs and behaviors.



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#### 5.3.2 Theory Development and Application in Health Equity Research

Considering the results of this study, future research on the influences on mammography follow-up in Black women should seek to integrate health behavior theories and theories guiding the organization and processes associated with clinical services. Much of the FPM literature focuses on the influence of clinical processes on outcomes without adequate consideration of the factors that drive the adoption of screening behaviors. Specifically, more work needs to be done to find and develop theories that accurately predict mammography behavior in different racial and ethnic groups. Popular health behaviors theories such as the health belief model or the theory of reasoned action and planned behavior have not been consistently related to mammography behaviors across various racial and ethnic groups.<sup>189,274,285</sup> Even considering the theoretical constructs that consistently influence mammography screening outcomes, various operationalizations of these constructs exist, but the vast majority of scales have not been developed with women of color. This study used a culturally-relevant version of health belief model constructs and detected statistically significant relationships between one BrCa belief and mammography intention. Research needs to be conducted to develop reliable and valid measures that conceptualize behavioral constructs in different racial/ethnic groups.

The transactional model of stress and coping has important applications to cancer prevention and health inequities research and should be explored in future studies. Much of the research on FPM focuses on psychosocial outcomes such as emotions in response to a stressful event, but the transactional model of stress and coping describes emotional responses occurring in a separate pathway from behaviors and/or changes in beliefs.<sup>200</sup>



Using the model to classify health-related events and potential responses to these events may improve researchers' ability to understand and incorporate the impact of past experiences on an individual's current cancer prevention beliefs and behaviors. In combination, the use of the previously mentioned theories and models would have the potential to enhance research and interventions devoted to improving the uptake of cancer screening behaviors across racial and ethnic groups.

Lastly, theories and models used in health inequities research would benefit from explicitly focusing on the role of deep cultural factors such as social roles, norms, and behavior and the intersection of cultural factors with characteristics like gender, sexual orientation, and geography (rurality, region). A focus on deep cultural factors requires time spent considering how culture influences behavior along various intersections and how to assess these influences. Increased development and use of culturally-relevant measures of behaviors, beliefs, and attitudes is needed to discern culturally-specific nuances that shape health behaviors in different racial and ethnic groups.

# 5.3.3 Assessment and Application of Multilevel Influences in Health Equity Research

The socioecological model describes how characteristics at multiple levels (intrapersonal, interpersonal, community, organizational, and policy) influence health behavior, with abnormal mammography results serving as the perfect demonstration of how these levels converge for one health behavior (achieving diagnostic resolution).<sup>221,244</sup> Given the role of federal and state level health policy, institutional policies and practices, and physical and social aspects of the environment in creating and maintaining racially driven health inequities, multilevel interventions are needed to enhance health



equity.<sup>293,294</sup> As part of this study, multilevel influences on mammography satisfaction were investigated and many of the challenges associated with multilevel analysis were highlighted in the process. While influences on satisfaction were detected at each of the three levels measured, stable multilevel models could not be created due to the small sample size of patient participants. Sample size was also challenge at the site level as there were only five mammography facilities. The small sample size and limited procedures available to compensate for the lack of variety in the sample prevented a comprehensive analysis of the relative contributions of each level to the behavior studied and/or interactions between levels.<sup>293</sup> Despite the primarily descriptive nature of the analyses conducted, multilevel influences were operationalized and measured in this study. These processes and findings can be used to guide future efforts to examine screening behaviors in different groups using more advanced methods and larger samples.

#### **5.4 Future Research Directions**

Additional data were collected as part of this study, but were not included in the specific aims of this study given the small sample size and the desire to not to overfit regression models. Future research on this topic will take the form of: 1) Secondary analyses of dissertation data and 2) New studies building on the findings of this investigation. Additional analyses include investigations of the relationship between mammography satisfaction and intention. Mammography satisfaction is an understudied topic, but very few studies attempt to link women's satisfaction in the mammography encounter with their intention to complete future mammography behavior. Of the existing research, few have been conducted with Black women. Items from the patient survey will



be used to develop models examining the relationship between various domains of mammography satisfaction and mammography intention in Black women. The explanatory power of culturally relevant influences such as experiencing discrimination during the clinical encounter will also be explored in this analysis.

As a result of the changes in mammography screening guidelines and new research reporting that Black women receive fewer provider recommendations for mammography, items assessing awareness of changes in mammography screening guidelines, and participation in conversations with primary care providers regarding mammography screening intervals were included in the patient survey. Self-reported screening histories were verified with medical records and that information in combination, with the knowledge, awareness, and conversation variables will be used to determine what (if any) mammography screening guidelines were followed by patient participants.

Breast density is another important factor that may influence Black women's BrCa screening behavior, but very few studies examine Black women's knowledge of their own breast density, and/or their understanding as to how breast density impacts their BrCa risk. Even less research is devoted to understanding how mammography providers describe breast density. Open-ended items from the patient and provider surveys will be used to explore patients' perceptions of and reactions to having dense breasts and the ways that providers communicate with women about this issue.

As previously mentioned, mammography screening behavior can be influenced by factors at multiple levels. Community or neighborhood is another factor that has been shown to impact mammography screening behaviors. Screening data used to classify



facilities will be merged with spatial variables to measure the impact of neighborhood and individual characteristics on mammography follow-up times.

New studies will focus on the role of coping behaviors on mammography screening beliefs and behaviors in a racially diverse group of women with FPM results. Data from this and other studies suggest that coping and BrCa screening beliefs are grounded in cultural factors, and their impact on BrCa screening intention may vary by racial/ethnic group. A study is planned to collect qualitative data to explore experiences with and responses to the receipt of FPM results among Black women, White women, and Latinas in rural North Carolina. The analysis of the influence of coping behaviors on BrCa screening beliefs is novel and has the potential to impact the development of intervention strategies to change BrCa screening beliefs and mammography behaviors in women facing increased BrCa mortality such as those in rural North Carolina.



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## APPENDIX A:

# PALMETTO HEALTH INSTITUTIONAL REVIEW BOARD AND ADMINISTRATIVE RESEARCH REVIEW APPROVAL LETTERS



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Institutional Review Board

Approval

February 22, 2016

Deeonna Farr farrde@email.sc.edu

Dear Ms Farr

On February 22, 2016 the following was reviewed by expedited IRB review:

	Type of Review:	Initial						
	Title:	The Impact of False Positive Mamn Breast Cancer Screening Intentio	nography Results on on in Black Women					
	IRB ID:	Pro00049656						
	Sponsor(s):	Currently there are no sponsors. Fur applications/proposals were subn following organization: South Carolina Department of H Environmental Control University of South Carolina American Association of Univer	nding mitted to the cealth and sity Women					
	IND, IDE, HDE:	None						
	Documents Reviewed:	<ul> <li>The Impact of Mammography Recall in Black Women.PH IRB Protocol.DFarr.docx Last n 2/12/2016</li> <li>Provider Survey Flyer.pdf Last modified 12/20/.</li> <li>Survey Postcard Reminder.docx last modified 12/20/2015</li> <li>Provider Email Mail Invitation.docx 12/20/2015</li> <li>The Impact of Mammography Recall in Black Women.Provider Survey.docx Last modified 12/20/2015</li> <li>The Impact of Mammography Recall in Black Women.Patient Survey.docx Last modified 12/20/2015</li> <li>The Impact of Mammography Recall in Black Women.Patient Survey.docx Last modified 12/20/2015</li> <li>The Impact of Mammography Recall in Black Women.Semi Structured Organizational Ass Form.docx Last modified 12/20/2015</li> <li>Scientific Merit and Scholarly Validity Attestati</li> </ul>						
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Institutional Review Board

- The Impact of Mammography Recall in Black Women. Research Financial Disclosure Form.DFarr.pdf Last modified 12/20/2015 Impact of Mammography Recall in Black
- Women Provider Survey Information Letter DFarr.docx Last modified 12/20/2015 The Impact of Mammography Recall in Black
- Women.Patient Survey Information Letter.DFarr.docx Last modified 12/20/2015
- The Impact of Mammography Recall in Black Women. HIPAA Research Authorization.DFarr.doc Last modified 12/20/2015
- The Impact of Mammography Recall in Black Women.Impacted Services Agreement.DFarr.Signed.pdf Last modified 12/20/2015
- PHARR Form.Mammography Recall Study.DFarr Last modified 2/11/2016

#### The IRB approved the protocol from February 22, 2016 to February 21, 2017 inclusive.

The stamped approved consent documents are downloadable through eIRB under the "Stamped ICF" tab. Use copies of these documents to document consent.

# Palmetto Health Administrative Research Review (PHARR) approval is required prior to study initiation.

#### Partial Waiver of HIPAA Authorization

The PH IRB determined that documentation received from you satisfies the three requirements for a waiver of authorization. These requirements are:

- The use or disclosure of the PHI involves no more than minimal risk to the individuals, based on the following elements:
  - a. An adequate plan to protect identifiers from improper use and disclosure;
  - b. An adequate plan to destroy the identifiers at the earliest opportunity consistent with conduct of the research, unless there is a health or research justification for retaining the identifiers, or such retention is otherwise required by law; and
  - c. Adequate written assurances that the PHI will not be reused or redisclosed to any other person or entity, except as required by law, for authorized oversight of the research project, or for other research for which the use or disclosure of PHI would be permitted by HIPAA.
- 2. The research could not practicably be conducted without the waiver or alteration; and
- The research could not be practicably conducted without access to and use of the protected health information.

5 Richland Medical Park Drive Columbia, SC 29203 Page 2 of 3 PHONE: (803) 434-2884 Version Date: March 16, 2015

PalmettoHealth.org



Institutional Review Board



A waiver of authorization requires an accounting for each disclosure as required by Palmetto Health Accounting of Disclosure PGR.

A continuing review submission must be submitted at least one month prior to expiration to allow time for review or within 30 days of study close, whichever is earlier.

If continuing review approval is not granted before the expiration date, the study will be closed.

As the Principal Investigator, you are responsible for conducting this protocol as approved and for reporting study-related activities to the IRB.

In conducting this protocol you are required to follow the requirements listed in the INVESTIGATOR MANUAL available at <u>www.PalmettoHealth.org/IRB.</u>

If you have questions or need additional information, please contact IRB Administration at 803-434-2884.

Sincerely,

Dr. Edward Catalano IRB Chair<sup>†</sup>

cc: Rebecca Marigliano, Ph.D., Director, Research rebecca.marigliano@palmettohealth.org

> Tejal Patel, J.D., Contracts/Compliance Administrator, Research Compliance tejal.patel@palmettohealth.org

<sup>1</sup>Electronic Signature: This document has been electronically signed through the HSSC eIRB Submission System.

5 Richland Medical Park Drive Columbia, SC 29203 Page 3 of 3 PHONE: (803) 434-2884 Version Date: March 16, 2015

PalmettoHealth.org



# PALMETTO

**Research Compliance** 

February 26, 2016

Deeonna Farr University of South Carolina Arnold School of Public Health Health Promotion, Education & Behavior 915 Greene St., 2<sup>nd</sup> floor Columbia, SC 29208

RE: Pro00049656 – The Impact of False Positive Mammography Results on Breast Cancer Screening Intention in Black Women

#### Dear Ms. Farr:

This letter serves as notification of approval from Palmetto Health for the above referenced study as reviewed by the Palmetto Health Administrative Review (PHARR) process. You may begin your study at Palmetto Health.

As the local principal investigator, it is your responsibility for the proper conduct of the research by complying with Good Clinical Practice, applicable regulatory requirements, and Palmetto Health policies and procedures.

You should be aware of the requirements of publication issued by The International Committee of Medical Journal Editors (ICMJE). The requirements can be located at <u>www.icmje.org</u>. Also, a manuscript of each proposed publication or presentation of the research results must be submitted to Research Compliance for routing of administrative review prior to submission to an external entity per the Publication of Research Results Policy.

If there are any modifications to the study in relation to areas at Palmetto Health impacted by the study or aspects of study conduct affecting finances, billing and/or legal review, please notify Research Compliance immediately.

5 Richland Medical Park Drive Columbia, SC 29203

PHONE: (803) 434-2884

PalmettoHealth.org/ResearchCompliance



Please be aware that current versions of Palmetto Health policies and procedures related to research may be found at www.palmettohealth.org/ResearchCompliance. Best wishes with the project, and please do not hesitate to contact me via telephone at 803-434-6365 or email at Rebecca.Marigliano@PalmettoHealth.org, if I can be of any further assistance.

Sincerely, Rebran Mariglia

Rebecca Marigliano, PhD Director, Research

cc: Palmetto Health Institutional Review Board Edward A. Frongillo, Jr., PhD Deborah Tapley Tiffany M. Winslow



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## APPENDIX B:

### SEMI-STRUCTURED ORGANIZATIONAL ASSESSMENT FORM









The impact of false positive mammography results on breast cancer screening intention in Black women – Organizational Assessment

Interviewer: \_\_\_\_\_

Names of Interviewee(s): \_\_\_\_\_

Location of Interview (or by phone): \_\_\_\_\_

Start Time:

End Time:

Note to Interviewer: Complete as much information in advance as possible.

#### Introduction

**READ TO PARTICIPANTS:** "Hello! Thank you so much for agreeing to talk with me today. During our talk I hope to gather more information about your facility. I will use this information to better understand the factors that influence women's experiences obtaining and completing breast cancer screening procedures such as mammography. I will ask questions about the facility in general, the patients that utilize the facility, the services offered by the facility, the staff at the facility, and basic facility procedures. There is no right or wrong answer to any question, so please answer all questions as honestly as possible. During the interview if you have any questions or need clarification please do not hesitate to ask. Your participation in this project is



voluntary, so you may decide not to answer any question or stop this interview at anytime. Let's get started."

#### Section I. General Information

"This first group of questions is about the facility in general."

1) What is the name of the organization?

2) What is your name and contact information?

a	) Name:
b	) Title:
c	) Address:
đ	) Phone:
e	) Email:
3) What	t is the organization's street address?



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Patient Characteristics

"This next set of questions is about the patient population that you serve.

- 4) About how many unique patients per year are served by your facility?
- About how many patient visits per year occur at your facility? It is ok to estimate if actual exact numbers are unavailable.
- 6) What is the percentage of patients who fall into the following age groups?

Age Range	Percent
40 to 49	
50 to 64	
65 and older	

 What is the percentage of patients that are in the following racial categories? It is ok to estimate if actual percentages are unavailable.

Category	Percent
African American/Black	
White	
Native Hawaiian/	
Other Pacific Islander	
Asian	
American Indian/	
Alaska Native	



 What is the percentage of patients who are Hispanic or Latino? It is ok to estimate if actual percentages are unavailable

Category	Percent
Hispanic/Latino	

9) What is the percentage of patients that are insured/uninsured?

What types of health insurance do they have?

Sta	tus	Percent
Uni	nsured	
Inst	ired	
	Private (Employer	
	based)	
	Military health care	
	(TRICARE/VA/CHA	
	MP-VA):	
	Medicaid	
	Medicare	
	ER or Hospital based	
	Other	

10) What is the referral process for a screening mammogram at your facility? Who does a woman have to contact in order to schedule a screening mammogram?



11) Is there a separate/different referral process for women without health insurance? Medicaid? Health Connections? Best Chance Network? Medicare?

12) Is there any additional information that you would like to us to know about your patient population?

Service Area

13) Is your facility region specific?

\_\_\_\_Yes \_\_\_\_No

14) How would you describe the service area of your facility (organization)?

15) What percentage of patients reside in Richland County?

16) What percentage of patients reside in the city of Columbia?



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#### Facility Details

"This next set of questions is about your facility's operating services."

17) What type of breast cancer screening services do you offer on site or for referral?

Type of Service	On	Referral	No	If yes, what is the referral pattern? (What
Offered	Site			are the steps? Only if applicable)



- 1					
_ I					1
_ I					1
_ I					1
_ I					1
_ I					1

18) How many days per week is your facility open?

Service Type	Time	Mon	Tues	Wed	Thur	Fri	Sat	Sun
Administrative	Open							
	Close							
Screening	Open							
Mammography	Close							
Diagnostic	Open							
Manimography	Close							
Ultrasound	Open							
	Close							
Biopsy	Open							
	Close							

19) How are patients notified if their screening mammograms are normal?

Method	Yes or No
In person/After exam	
Phone call	
Direct Letter to Patient -	
Postal mail	
Direct Letter to Patient –	
E-mail	
Direct Letter to Primary	
Care Provider – Postal mail	
Direct Letter to Primary	
Care Provider – E-mail	
Direct Letter to Primary	
Care Provider – Fax	



20) How are patients notified if their diagnostic mammograms are normal?

Method	Yes or
	No
In person/After exam	
Phone call	
Direct Letter to Patient -	
Postal mail	
Direct Letter to Patient -	
E-mail	
Direct Letter to Primary	
Care Provider – Postal mail	
Direct Letter to Primary	
Care Provider – E-mail	
Direct Letter to Primary	
Care Provider – Fax	

21) How are patients notified if other diagnostic procedures are normal? - Ultrasound

22) How are patients notified if other diagnostic procedures are normal? - Biopsy



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- 1					
- 1					
- 1					
- 1					

24) Is there an appointment reminder system in use? Yes No, If yes please describe the reminder procedures.

25) What is the average wait time between the screening mammogram and a recall notice?

26) What steps must occur between the screening mammogram and before a woman is recalled for follow up testing

27) What is the average wait time between the screening mammogram and a diagnostic mammogram

28) What is the average wait time between the diagnostic mammogram and the next diagnostic procedure?



29) What steps must occur after the diagnostic mammogram and before a woman is notified of the need for additional testing?

30) Is there a person who is responsible for contacting patients and managing the follow up screening process (patient navigator)? \_\_\_\_Yes \_\_\_\_No, If Yes please, explain

31) Does your facility participate in any breast cancer education and/outreach activities? Yes No, If yes, please describe the activity, date, location, population served etc

32) How many of the following are available in your facility?

Patient dressing rooms	
Film mammography machines	
Digital mammography machines	
Ultrasound machines	
Surgical rooms	



- <b>г</b>					
- H		 			

33) How many of the following procedures are completed on a weekly basis?

Screening mammograms	
Diagnostic mammograms	
Ultrasounds	
Breast biopsies	

#### Section III. Facility Space

"This next group of questions is about the organization's physical space and equipment."

#### Capacity

34) How many waiting areas does your facility have? 1 2 or more

a) If 2 or more, What types of patients wait in each waiting area?

35) What is the size (x by x) of each waiting area?

36) What is the shape (square, rectangle, round, L-shape irregular) of each waiting area?

37) How many patients can wait in each the waiting area?

38) Please describe the waiting room area. Describe in detail the content and location of any pictures, educational materials, and signs displayed.



1 1				
1 1				

39) Is there a dedicated parking for patients? \_\_\_\_ Yes \_\_\_ No \_\_\_ Other, explain

40) Is patient parking free? \_\_\_\_ Yes \_\_\_ No \_\_\_ Other, explain

#### Section IV. Staff

"This next group of questions is about the facility staff."

- a. How many \_\_\_\_(see below) \_\_\_\_\_work at this organization?
- b. How many only work at this facility? (As opposed to multiple sites)
- c. On average, how long have they been working here?\*
- d. How many of them are paid employees?\*
- e. How many of them work here full time? \*
- f. How many donate their services or volunteer? \*

Type of Staff	a) How many?	b) How many only at this facility?	b) How long?	c) Number of paid employees?	d) Number of fulltime employees?	e) Donated/ Volunteer Services?
41) Radiologists						
42) Nurses						
43) Patient care technician			?			
44) Other medical staff						
45) Other non- medical staff						




#### Section V. Organizational Structure

"This next group of questions is about the organization's structure of the staff."

46) What is the organization's structure? Please specify lines of responsibility and reporting. Try to denote the different levels horizontally. A few examples are listed below:



Organizational Structure Drawing:





- E					
- L					

#### Part VI. Social Characteristics

"This next group of questions is about the facility's social and working environment."

#### Facility Environment

47) Overall, how would you rate the level of service provided by the facility as compared to others in your area?									
Highest Quality	1	2	3	4	5	Lowest Quality			
48) In your view, how does the community (or patient population) perceive the level of service provided by the facility?									
Always Positive	1	2	3	4	5	Always Negative			
49) How would you rate your interactions with the patients at the facility?									
Always Positive	1	2	3	4	5	Always Negative			
50) How would you rate your interactions with the other staff (doctors, nurses, other medical staff, etc.) at the facility?									
Always Positive	1	2	3	4	5	Always Negative			
51) What is the satisfaction level with how orderly or efficient is the c facility?									
Very Organized/	1	2	3	4	5	Not Organized at All			
Efficient						Inefficient			


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i I I		1 1	
i I I	1 1	1 1	

52) Is there anything else that you want us to know about your facility, your staff, or your patients?



### APPENDIX C:

### PROVIDER SURVEY MATERIALS







### The Impact of False Positive Mammography Results on Breast Cancer Screening Intention in Black Women

Dear Participant,

My name is Deeonna Farr and I am doctoral student at the University of South Carolina. I am interested in understand what factors influence Black women to complete breast cancer screening. An average woman has a 50% chance in her life of being asked to return for follow up testing after her screening mammogram. Black women are less likely to complete follow up testing and/or they take longer to complete follow up testing than White women. I am conducting a research project to learn about Black women's experiences with mammography and follow up testing in order to understand what factors encourage/discourage Black women to complete breast cancer screening. As a healthcare provider, your experiences can provide valuable information that will help us understand these factors.

I am asking you to take part in the survey because you live in South Carolina, are age 18 or older, and have been employed by a Palmetto Health mammography facility for at least 6 months.

If you choose to take part in this study, you will have the option to complete a paper-and-pen or online survey. For the **paper-and-pen** survey, you will be asked to fill out the survey and return it in-person or return it by mail in the postage-paid envelope provided with the survey. If you choose to complete the **online** survey, you will be sent an e-mail containing a link to the survey through Qualtrics. This link will allow you to save your progress on the survey and come back to it later. The survey should take you 15-30 minutes to complete. If you would like to participate in this study please contact me Deeonna Farr at 803-777-7641 or farrde@email.sc.edu.

This survey asks for information about you, your experiences working with women who have been recalled for additional testing. You do not have to answer any questions that you do not want to answer. Although you may not benefit directly from taking part in this study, you may learn more about cancer prevention and cancer prevention research. After completing the survey, you will be entered into a giveaway for one of 4 \$25 giftcards. The giftcards will be given away at the conclusion of the study. The study will last for 5 months.

Participation is anonymous and therefore totally private. This means that no one (not even members of the research team) will know your name or specific answers. For the paper-and-pen, please do not write your name on the survey. Taking part in the study is your choice. You do not have to be in this study/complete the survey if you do not want to. You may also quit being in the study at any time or choose not to answer any question you are not comfortable answering. In the event that you do decide to quit this study, the information you have already provided will be kept in a confidential manner.

Palmetto health IRB Number: Pro00049656 Date Approved: 2/22/2016 Version Valid Until: 2/21/2017







Your decision not to take part in the study will not affect your current or future medical care or any benefits to which you are entitled.

If you would like to request a survey, please contact me Deconna Farr at 803-777-7641 or <u>farrde@email.sc.edu</u>. You may contact me, Deconna Farr or Dr. Heather Brandt (USC) 803.576.5649 or <u>hbrandt@sc.edu</u>, if you have study related questions or if you wish to withdraw from the study. If you have any questions, problems, or concerns, desire further information or wish to offer input, you may contact Lisa Johnson, IRB Manager, Office of Research Compliance, University of South Carolina, Columbia, SC 29208, Phone - (803) 777-6670, Fax - (803) 576-5589, lisaj@mailbox.sc.edu This includes any questions about your rights as a research subject in this study.

This research has been reviewed and approved by an Palmetto Health Institutional Review Board. You may talk to them at (803) 434 2884 or email Research-Assist@palmettohealth.org for any of the following:

- o Your questions, concerns, or complaints are not being answered by the research team
- You cannot reach the research team
- o You want to talk to someone besides the research team
- You have questions about your rights as a research subject
- o You want to get information or provide input about this research

Thank you for interest in this study,

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Deeonna Farr, MPH DrPH candidate University of South Carolina Cancer Prevention and Control Program 915 Greene St, 2<sup>nd</sup> Fl Columbia, SC 29201 Phone: 803-777-7095 Email: farrde@email.sc.edu

> Palmetto health IRB Number: Pro00049656 Date Approved: 2/22/2016 Version Valid Until: 2/21/2017









# The impact of false positive mammography results on breast cancer screening intention in Black women

### Provider Survey

"Thank you so much for agreeing to participate in this study. The purpose of this study is gather to better understand the factors that influence Black women's experiences obtaining and completing breast cancer screening procedures such as mammography. This survey will contain questions about you, your thoughts and experiences about various aspects of the mammography screening process. There is no right or wrong answer to any question, so please answer all questions as honestly as possible. This study is voluntary, you may stop participating at anytime."

### Part I: Demographic Information

- 1. Are 18 years of age or older?
- Yes
  - ] No → STOP. You are not eligible to participate in this study
- 2. Have you been employed at a Palmetto Health mammography facility for atleast 6months?

Yes

No STOP. You are not eligible to participate in this study.

3. What is your gender?

Male Female

- 4. How old are you?
- 5. Are you Hispanic, Latino or Spanish?
- Yes
- No



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### Part I: Demographic Information continued

6. What is your race? Please check all that apply.
Black/African American
White
American Indian or Alaskan Native
Asian
Native Hawaiian or other Pacific Islander
Other
7. What is the highest grade or year of school you have completed?
Less than Grade 12
High school graduate
GED
Some college/Trade School
Bachelor's degree (College graduate, for example BS, BA, AB)
Master's or doctoral degree (For example, MS, MA, MPH, MBA, Meng, MSW, PhD,
MD,)
8. What is your job title?
Radiologist
Nurse
Nursing Assistant
Patient Care Technician
Patient Care Coordinator
Nurse Navigator
Office Manager     Administrative Assistant

Other, Please specify



### Part I: Demographic Information continued

### 9. This question is only for Radiologists. What is your current level of medical

training?
Intern
1 <sup>st</sup> Year Resident
2nd Year Resident
3 <sup>rd</sup> Year Resident
4th Year Resident
PGY-1
Attending

. .

10.How many years have you worked in the healthcare field?

### 11. What Palmetto Health facilities do you work at?

- Palmetto Health Baptist Palmetto Health Parkridge Palmetto Health Richland Palmetto Health Northeast
- Mobile Mammography Van

12. How many years have you worked at this Palmetto Health facility?

### Part II: Beliefs About Mammography

Please answer the following questions based on what <u>vou think</u>. Remember there are no right or wrong answers.

### 13. How much physical discomfort do women experience during a mammogram?

- No discomfort
- Little discomfort
- Some discomfort
- A lot of discomfort
- A great deal of discomfort




### Part II: Beliefs About Mammography continued

Please answer the following questions based on what <u>you think</u>. Remember there are no right or wrong answers.

14. How much psychological distress do women experience during a mammogram?

- No distress
- Little distress
- Some distress
- A lot of distress
- A great deal of distress

	Never	Seldom	About half the time	Usually	Always
15. How often do women completing screening mammograms get called back?					
16. How often does follow up testing reveal a woman does not have cancer?					
17. How often are women upset by this experience (getting called back for follow up testing)?					
18. How often are Black women upset by this experience (getting called back for follow up testing)?					
19. During the past 6 months, How often have you spoken to women getting screening mammograms about the possibility of being called back for an abnormal mammogram?					
20. During the past 6 months, How often have you spoken to women about breast density?					



### Part II: Beliefs About Mammography continued

	Poor	Fair	Good	Very	Excellent
				Good	
21. During the past 6 months, How would you rate your					
ability to communicate information about abnormal					
mammograms to women?					
22. During the past 6 months, How would you rate your					
ability to assess women's emotional responses about					
abnormal mammograms?					

23. What types of advice/guidance do you give to women when they are called back for an abnormal mammogram?

24. What are the barriers to discussing issues related to abnormal mammograms with women?

25. How do you describe breast density to women?

PLEASE TURN OVER ->



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26. How do you explain to women how breast density affects mammography results?

27. What barriers or challenges prevent you from discussing breast density with women?

PLEASE TURN OVER ->



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### APPENDIX D:

### PATIENT SURVEY MATERIALS







### The Impact of False Positive Mammography Results on Breast Cancer Screening Intention in Black Women

Dear,

My name is Deeonna Farr and I am doctoral student at the University of South Carolina. For the past four years, I have been working to learn about the causes of and ways to reduce cancer in Black/African American communities in South Carolina. My goal is to understand what factors influence Black women to complete breast cancer screening. The average woman has a 50% chance in her life of being asked to return for follow up testing after her screening mammogram. Black women are less likely to complete follow up testing and/or they take longer to complete follow up testing than White women. I am conducting a research project to learn about Black women's experiences with mammography and follow up testing in order to understand what factors encourage or discourage Black women to complete breast cancer screening.

I am asking you to take part in the survey because you are a woman, identify as Black/African American, live in South Carolina, are age 40 or older, have never been diagnosed with cancer, and had a mammogram in the past 6 months.

If you choose to take part in this study, you will be asked to fill out the attached survey, and medical records release form and research authorization form and return it by mail in the postage-paid envelope provided with the survey. The survey should take you about 45 minutes to complete. If you would like complete this survey by phone or if you have any additional questions, please contact me Deconna Farr at 803-777-7641 or sc.cancer.prevention.study@gmail.com.

This survey asks for information about you, your experiences with mammography, as well as your thoughts about cancer prevention. The medical record release and research authorization form will be used to request information about your previous mammograms such as the dates of your last mammogram, whether you completed follow up testing etc. You do not have to answer any questions that you do not want to answer. Although you may not benefit directly from taking part in this study, you may learn more about cancer prevention and cancer prevention research. After completing the survey, you will be entered into a giveaway for one of 10 \$25 giftcards. The giftcards will be given away at the conclusion of this portion of the study. This portion of the study will last for 6 months. If you complete a survey, you may be asked to participate in a follow up interview during the next portion of the study. Again your participation is voluntary and you may choose not to complete the interview.

Participation is anonymous and therefore totally private. This means that no one (not even members of the research team) will know your name or specific answers. For the paper-and-pen, please do not write your name on the survey. Taking part in the study is your choice. You do not have to be in this study/complete the survey if you do not want to. You may also quit being in the study at any time or choose not to answer any question you are not comfortable answering. In the event that you do decide to quit this study, the information you have already provided will be kept in a confidential manner.

Your decision not to take part in the study will not affect your current or future medical care or any benefits to which you are entitled.

Please keep this letter for your records.









If you would like to request a survey, please contact me Deeonna Farr at 803-777-7641 or <u>sc.cancer.prevention.study@gmail.com</u>. You may contact me, Deeonna Farr or Dr. Heather Brandt (USC) 803.576.5649 or <u>hbrandt@sc.edu</u>, if you have study related questions or if you wish to withdraw from the study. If you have any questions, problems, or concerns, desire further information or wish to offer input, you may contact Lisa Johnson, IRB Manager, Office of Research Compliance, University of South Carolina, Columbia, SC 29208, Phone - (803) 777-6670, Fax - (803) 576-5589, lisaj@mailbox.sc.edu This includes any questions about your rights as a research subject in this study.

This research has been reviewed and approved by the Palmetto Health Institutional Review Board. You may talk to them at (803) 434 2884 or email Research-Assist@palmettohealth.org for any of the following:

- · Your questions, concerns, or complaints are not being answered by the research team
- You cannot reach the research team
- o You want to talk to someone besides the research team
- You have questions about your rights as a research subject
- You want to get information or provide input about this research

Thank you for interest in this study,



Deeonna Farr, MPH DrPH Candidate University of South Carolina Department of Health Promotion, Education, and Behavior 915 Greene St Columbia, SC 29201 Phone: 803-777-7641 Email: sc.cancer.prevention.study@gmail.com

Please keep this letter for your records.









### The impact of false positive mammography results on breast cancer screening intention in Black women - Patient Survey

Thank you so much for agreeing to participate in this study. The purpose of this study is to understand the factors that influence Black women's ability and desire to complete breast cancer screening procedures such as mammography. I hope to use the information provided through this survey to develop programs and strategies to improve Black women's breast cancer screening experiences. This survey contains questions about you, your thoughts, and your experiences concerning the mammography screening process. There is no right or wrong answer to any question, so please answer all questions as honestly as possible.

This study is voluntary, you do not have to complete the survey. If you prefer to complete the survey over the phone, you may call me Deeonna Farr at 803-777-7641 and I will assist you. After completing the survey, you will be entered into a giveaway for one of 10 \$25 giftcards. The giftcards will be given away at the conclusion of the study.

### Part I: Demographic Information

1.	What is your gender? Female
F	Male $\rightarrow$ STOP. You are not eligible to participate in this study.
	Please do not complete this survey. Thank you for your time.
2.	Are you 40 years of age or older?
	Yes
	No ightharpoond STOP. You are not eligible to participate in this study.
	Please do not complete this survey. Thank you for your time.
3.	Have you completed a mammogram after January 1, 2016?
	Yes
	No $\implies$ STOP. You are not eligible to participate in this study.
	Please do not complete this survey. Thank you for your time.
4.	Have you ever been told by a doctor, nurse, or other health professional that you had breast cancer?
$\square$	Yes
	Please do not complete this survey. Thank you for your time.
	No

Page 1 of 17 PLEASE COMPLETE BOTH SIDES



### Part I: Demographic Information continued

5. What is your date of birth?

Year Date Month

6. Please list your home zipcode:

 	-	

If you do not live in South Carolina, you are not eligible to participate in this study. Please do not complete this survey. Thank you for your time.

7. Are you Hispanic, Latino or Spanish?

Yes
No

8. What is your race? (Check All that Apply)

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- White American Indian or Alaskan Native
- Asian
- Native Hawaiian or other Pacific Islander

Other

If you do not identify as Black/African American alone or in combination with another race then you are not eligible to participate. Please do not complete this survey. Thank you for your time.

#### 9. What is your employment status? (Check All that Apply)

- Employed: Full-time, Part-time, or Self-employed Unemployed
- Disabled
- Retired

### 10. What is the highest grade or year of school you have completed?

Less than Grade 12 High school graduate

GED

Some college/Trade School

Bachelor's degree (College graduate, for example BS, BA, AB)

Master's or doctoral degree (For example, MS, MA, MPH, MBA, MEng, MSW, PhD, MD,)

### Page 2 of 17 PLEASE COMPLETE BOTH SIDES



### Part I: Demographic Information continued

### 11. What is your annual household income?

Less than \$19,999
Between \$20,000 and \$49,999
Between \$50,000 and \$74,999
Between \$75,000 and \$99,999
More than \$100,000

	2. What is your marital status? Married Widowed Divorced Separated Never Married Living with a partner
	<ul> <li>Which term bests describes your religious identity?</li> <li>Protestant (For example: Baptist, Methodist, Lutheran, Pentecostal, Seventh Day Adventist, Apostolic etc.) Please list your denomination here</li> <li>Catholic</li> <li>Jewish</li> <li>Muslim</li> <li>Atheist</li> <li>Agnostic</li> <li>Other, Please list here</li> </ul>
14	<ul> <li>What kind of health insurance or health care coverage do you have? (Check All that Apply)</li> <li>Employer provided health insurance</li> <li>Private health insurance</li> </ul>

_	
Γ	Private health insurance
	Medicare
	Medicaid
	Military health care (TRICARE/VA/CHAMP-VA)
	Prescription drug coverage (as part of your insurance or as a separate plan)
Г	Other

No coverage of any type



### Part II: Personal Characteristics

### If you needed it, how often is someone available..

	All of the	Most of	Some of	A little of	None of
	time	the time	the time	the time	the time
15. To help you if you were confined to bed.					
16. To take you to the doctor if you needed it.					
17. To prepare your meals if you were unable to do it yourself.					
<ol> <li>To help with daily chores if you were sick.</li> </ol>					
19. To have a good time with.					
20. To turn to for suggestions about how to deal with a personal problem?					
21. Who understands your problems?					
22. To love and make you feel wanted?					

## A number of statements which people have used to describe themselves are given below. Read each statement and then select response that indicates <u>how you generally feel</u>.

	Almost	Often	Sometimes	Almost
23. I feel nervous and restless.				
24. I feel satisfied with myself.				
25. I wish I could be as happy as others seem to be.				
26. I feel like a failure.				
27. I worry too much over something that really doesn't matter.				
28. I lack self-confidence.				
29. I feel secure.				
30. I feel inadequate.				
31. I am a steady person.				
32. I get in a state of tension or turmoil as I think over my recent concerns and interests.				

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PLEASE COMPLETE BOTH SIDES



Participant ID# Part III: Mammography Beliefs and Experiences

### 33. How old were you when you had your first mammogram?

Under 30 years 30-39 years old

40-49 years old

50-59 years old

60 years or older

34. What year did you have your first mammogram?

### 35. What is the main reason you had your <u>first</u> mammogram?

Because of a breast problem

My healthcare provider told me I was high risk

Family history of breast cancer

Part of a routine exam

I requested it

Other reason, Please list

### 36. Do you have a family history of breast cancer?

Yes No

37. Have you ever been told that you have dense breasts?

Yes

No, Please skip to Question #40

38. How did you react when you were informed that you have dense breasts? What did you think or how did you feel about this information?

39. What specifically did the doctor/staff person tell you about dense breasts and how that affects mammograms?

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Part III: Mammography Beliefs and Experiences continued

40. How many	y mammograms	have you ha	d in the	past 6	years?
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#### 41. What year(s) did you complete those mammograms?

42.	. Why di	d you	schedule	your	most recent	screening	<u>mammogram</u> ?	(Check	All that .	Apply)

- It was time for my regular screening mammogram
- Because of a breast problem
- Because my healthcare provider recommended it
- Family history of breast cancer
- Because I received a reminder letter in the mail
- Because I received a flyer or saw an advertisement
- Other:

### 43. Why did you choose to go the facility where you completed your <u>most recent screening</u> <u>mammogram</u>? (Check All that Apply)

- Because the location was convenient
- Because I like the doctor at that facility
- Because I like the staff at that facility
- Because the facility has a good reputation
- Because I can be seen quickly
- Other:

### 44. Did someone come with you for your most recent screening mammogram?

- No, I went by myself.
- Yes, they came with me because I needed a ride.
- Yes, they came with me for emotional support.
- Yes, they came with me for another reason.
- Please list that reason here:

## 45. After your <u>most recent screening mammogram</u>, were you asked to come back for follow up testing?

- Yes
- No, Please skip to Question #51

### 46. How were you told that you needed to have follow up testing? (Check All that Apply)

- In person (after your initial mammogram)
- Phone call from the mammography facility
- Letter from the mammography facility
- Phone call from your primary care doctor or primary healthcare provider
- Letter from your primary care doctor or primary healthcare provider

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### Part III: Mammography Beliefs and Experiences continued

### 47. Did you complete follow up testing?

Yes
No, Skip to Question #51

Don't know/Not sure

### 48. Where did you complete your follow up test(s)? (Check All that Apply)

- Palmetto Health Baptist
- Palmetto Health Parkridge
- Palmetto Health Richland
- Other:

### 49. What tests did you complete? (Check All that Apply)

- Another mammogram
- An ultrasound
- A biopsy

Another procedure, Please list

Don't know/Not sure

### 50. What was the result of your follow up testing?

- It was normal/It was not cancer.
- Other, Please list

### Now let's think about mammograms that you had in the past.

## 51. Prior to your most recent mammogram, had you ever been asked to come back for follow up testing?

- Yes
- No, Skip to Question #55
- Don't know/Not sure

### 52. How many times have you been asked to come back for follow up testing?

- 1 time
- 2 times
- 3 or more times
- Every time I get a mammogram, the office/doctor asks me to come back for follow up testing

### 53. What tests did you complete? (Check All that Apply)

- Another mammogram
- An ultrasound
- A biopsy
- Another procedure, Please list
- Don't know/Not sure

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### Part III: Mammography Beliefs and Experiences continued

54	What	was	the	result	of	vour	previous	follow	un	testing	2
	••• шач	was	шe	resure	01	your	previous	1011010	up	testing	٠

- It was normal/It was not cancer.
- Other, Please list

## 55. After completing a mammogram and your results are <u>normal</u>, how would you like to be notified of your results? (Check all that apply)

Phone call from the mammography facility
E-mail from the mammography facility
Text message from the mammography facility
Letter from the mammography facility
Phone call from your primary care doctor
Letter from your primary care doctor
E-mail from your primary care doctor
Text message from your primary care doctor
Other, Please list

## 56. After completing a mammogram and your results are <u>not normal</u>, how would you like to be notified of your results? (Check all that apply)

- Phone call from the mammography facility
- E-mail from the mammography facility
- Text message from the mammography facility
- Letter from the mammography facility
- Phone call from your primary care doctor
- Letter from your primary care doctor
- E-mail from your primary care doctor
- Text message from your primary care doctor
- Other, Please list

### 57. How likely are you to get your next screening mammogram as scheduled?

- Very Likely
- Likely
- Unlikely
- Very Unlikely

### 58. If you are asked to return for follow up testing after your next screening mammogram, how likely are you to complete those additional tests?

- Very Likely Likely
- Unlikely Very Unlikely

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### Part III: Mammography Beliefs and Experiences continued

The next questions are about mammography recommendations. Please answer them to the best of your knowledge.

### 59. At what age should most women have their first mammogram?

	35
	40
	45
	50
	55
	Don't know/Not sure
	Other, Please list
60	How often should women have a memory and

#### 60. How often should women have a mammogram?

	Every year
	Every two years
$\Box$	Don't know/Not sure
$\square$	Other, Please list

### 61. As far as you know, have medical recommendations for the age at which a woman has her first mammogram or how often she should have a mammogram changed in the past ten years?

Yes					
No,	Skip	to	Que	stion	#66
-			<b>b</b> -	-	

Don't know/Not sure

62. Please list any changes to mammography recommendations you may have heard about.

63.	Where did	you hear	about these	changes?	(Check All	that Apply)
-----	-----------	----------	-------------	----------	------------	-------------

- From the news (TV, radio, newspaper, internet)
- From a health care provider
- From a friend, family member, or coworker
- From someone else: Please list
- Don't know, not sure

### 64. What do you think about these changes?

- The changes are very good.
- The changes are somewhat good.
- The changes are somewhat bad.
- The changes are very bad.

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Part III: Mammography Beliefs and Experiences continued

65. Have you had a discussion with your healthcare provider about changes to the mammography recommendations?

Yes
No

Don't know/Not sure

- 66. Have you had a discussion with your healthcare provider about how often you should have a mammogram?
- Yes, I discussed this with my healthcare provider and decided to follow his/her advice
- Yes, I discussed this with my healthcare provider and decided not to follow his/her advice
- No, I have not discussed this with my healthcare provider
- Don't know/Not sure
- Other, Please list
- 67. Compared to other women my age, would you say your chances of getting breast cancer are higher, lower, or average?
- Higher Lower Average

How likely is it that	Very Likely	Likely	Unlikely	Very Unlikely
68. I will get breast cancer in five years?				
69. I will get breast cancer in the next 10 years?				
70. I will get breast cancer during my lifetime?				

A number of statements which women have used to describe themselves after completing mammograms and follow up tests are listed below. Read each statement and then select the answer that describes how you feel right now as a result of completing your last mammogram and/or follow up test(s). Remember there are no right or wrong answers.

	Very	Moderately	Somewhat	Not at
	Much So	So		All
71. I feel calm.				
72. I am tense.				
73. I feel at ease				
74. I am presently worrying over possible misfortunes (related to my mammogram or mammography follow up)				
75. I feel frightened.				
76. I am nervous.				
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Part III: Mammography Beliefs and Experiences continued

A number of statements which women have used to describe themselves after completing mammograms and follow up tests are listed below. Read each statement and then select the answer that describes <u>how you feel right now as a result of completing your last</u> <u>mammogram and/or follow up test(s)</u>. Remember there are no right or wrong answers.

	Very	Moderately	Somewhat	Not at
	Much So	So		All
77. I am jittery.				
78. I am relaxed.				
79. I am worried.				
80. I feel steady.				

Thank you for continuing with this survey. You have completed more than half of the survey. Just a few more pages and you will be finished. Remember, after you return the completed survey, you will be entered into a giveaway for one of 10 \$25 giftcards.

Also, if you prefer to complete the survey over the phone, you may call me Deeonna Farr at 803-777-7641 and I will assist you.

The next questions are about your experience during your <u>most recent mammogram</u>. Please indicate on average, how often the doctor/office staff did the following:

	Always	Usually	Rarely	Never
81. How often did doctors really respect you as a person?				
82. How often did doctors treat you as an equal?				
83. How often did doctors/office staff pay less attention to you because of your race?				
84. How often did you feel discriminated against by doctors/office staff because of your race or ethnicity?				
85. How often were office staff rude to you?				
86. How often did office staff talk down to you?				
87. How often did office staff give you a hard time?				
88. How often did office staff have a negative attitude toward you?				

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### Part III: Mammography Beliefs and Experiences continued

### The next questions are about your experience during your <u>most recent mammogram</u>. Please indicate whether you Strongly Agree, Agree, Disagree, or Strongly Disagree with the following statements:

	Strongly Agree	Agree	Disagree	Strongly Disagree
89. I felt free to ask the staff questions I wanted to ask.				
<ol> <li>The person was too rough when doing the mammogram.</li> </ol>				
91. I felt that I had to wait far too long.				
92. I was very satisfied with the care I received at the center.				
93. I feel confident that the mammogram was done properly.				
94. The staff seemed to hurry me through too quickly.				
95. I was told all I wanted to know about what was done.				

The next questions are about your experience during your <u>most recent mammogram</u>. Please indicate whether you Strongly Agree, Agree, Disagree, or Strongly Disagree with the following statements:

	Strongly Agree	Agree	Disagree	Strongly Disagree
96. The staff did everything they could to make me feel comfortable about having the mammogram.				
97. The center/facility is in a place which is easy for me to get to.				
98. The staff had good manners.				
99. I feel I had a chance to speak freely to the staff/doctors.				
100. The staff/doctors used words that were hard to understand.				
101. The temperature in the place was uncomfortable.				

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### Part III: Mammography Beliefs and Experiences continued

### The next questions are about your experience during your <u>most recent mammogram</u>. Please indicate whether you Strongly Agree, Agree, Disagree, or Strongly Disagree with the following statements:

	Strongly Agree	Agree	Disagree	Strongly Disagree
102. I found it <u>hard</u> to find a convenient time to come in.				
103. The service I got was much worse than I expected.				
104. I am sure that the reception staff knew what they were doing.				
105. The hours which the center/facility is open suit me.				
106. I would recommend the center/facility to my friends.				
107. I had enough privacy during the mammogram.				
108. The staff told me all I wanted to know about when I would get results back.				
109. The changing rooms were too small.				
110. Could <u>not find any faults</u> with the service I received.				
111. I found the waiting room very pleasant.				
112. I think the center/facility could be run much more efficiently.				
113. The person who did my mammogram seemed to know what he/she was doing.				
<ol> <li>I had enough privacy while getting changed.</li> </ol>				

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PLEASE COMPLETE BOTH SIDES



### Part III: Mammography Beliefs and Experiences continued

A number of statements which women have used to describe themselves after completing mammograms and follow up tests are listed below. Please indicate how often you have felt this way during the <u>past week due to your last mammogram and/or follow up test(s)</u>.

	All of the time (5-7 days)	Occasionally or a moderate amount of time (3-4 days)	Some or a little of the time (1-2 days)	Rarely or none of the time (less than 1 day)
115. I was bothered by things that usually don't bother me.				
116. I had trouble keeping my mind on what I was doing.				
117. I felt depressed.				
118. I felt that everything I did was an effort.				
119. I felt hopeful about the future.				
120. I felt fearful.				
121. My sleep was restless.				
122. I was happy.				
123. I felt lonely.				
124. I could not "get going".				

Please answer the following questions based on what <u>you think</u>. Remember there are no right or wrong answers.

How likely is it that.	Very Likely	Likely	Unlikely	Very Unlikely
125. If breast cancer was found early, how likely is it that the cancer could be successfully treated?				
126. Having a mammogram would help me find breast cancer when it is just getting started?				
127. Having a mammogram would help me find a breast lump before it is big enough to feel?				
128. Having a mammogram will decrease my chances of dying from breast cancer?				

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### Part III: Mammography Beliefs and Experiences continued

Below is a list of some of the ways you may have felt or behaved after completing your mammogram and/or follow up tests. Please indicate how <u>often you have felt or behaved</u> <u>this way due to your last mammogram and/or follow up test(s)</u>. Remember there are no right or wrong answers.

	Did this a Great Deal	Did this a Lot	Did this a Little	Did Not Do This
129. Prayed that things would work themselves out.				
130. Got a group of family and friends together to help with the problem.				
131. Shared my feelings with a friend or family member.				
132. Remembered what a relative once said about dealing with these kinds of situations.				
133. Tried to forget about the situation.				
134. Went to church or other religious service to get help from the group.				
<ol> <li>Tried to keep from thinking about the situation, I found other things to keep me busy.</li> </ol>				
136. Sought advice about how to handle the situation from an older person in my community.				
137. Read a scripture from the Bible or religious text for comfort and/or guidance.				
138. Asked for suggestions on how to deal with the situation during a meeting of my organization or club.				
<ol> <li>Tried to convince myself that it wasn't that bad.</li> </ol>				
140. Asked someone to pray for me.				
<ol> <li>Spent more time than usual doing group activities.</li> </ol>				
142. Hoped that things would get better with time.				
143. Read passage from a daily meditation book.				
144. Spent more time than usual doing things with friends and family.				
145. Tried to remove myself from the situation.				
<ol> <li>Sought out people I thought would make me laugh.</li> </ol>				
147. Got dressed up in my best clothing.				
148. Attended a social event (dance, party, movie) to reduce stress caused by the situation.				

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### Part III: Mammography Beliefs and Experiences continued

Below is a list of some of the ways you may have felt or behaved after completing your mammogram and/or follow up tests. Please indicate how often you have felt or behaved this way due to your last mammogram and/or follow up test(s). Remember there are no right or wrong answers.

	Did this a Great Deal	Did this a	Did this a Little	Did Not Do This
149. Asked for blessing from a spiritual or religious person.				
150. Helped others with their problems.				
151. Lit a candle for strength or guidance in dealing with the problem.				
152. Sought emotional support from family and friends.				
153. Burned incense for strength or guidance in dealing with the problem.				
154. Used a cross or other object for its special powers in dealing with the problem.				
155. Sung a song to myself to help reduce my stress.				
156. Found myself watching more comedy shows or other entertainment on TV.				
157. Left the matters in the hands of a higher power (God).				
158. Thought of all the struggles Black people have had to endure and this gave me strength to deal with the situation.				

After completing your mammogram and/or follow up test, how often have you experienced the following things because of thoughts and feelings about breast cancer:

		A Lot	Quite a Bit	A Bit	Not at All
159.	Worried about my future.				
160.	Scared.				
161.	Upset				
162.	Restless				
163.	Nervous				
164.	Terrified				

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PLEASE COMPLETE BOTH SIDES



### Part III: Mammography Beliefs and Experiences continued

Please answer the following questions based on what <u>vou think</u>. Remember there are no right or wrong answers.

How likely is it that	Very Likely	Likely	Unlikely	Very Unlikely
<ol> <li>Getting a mammogram would be inconvenient for me.</li> </ol>				
166. Other health problems would keep me from having a mammogram.				
<ol> <li>My age would keep me from having a mammogram.</li> </ol>				
168. The trouble of having a mammogram would keep me from getting one.				
169. Concern about pain with having a mammogram would keep me from having one.				
170. I find it difficult to remember to make an appointment for a mammogram.				
171. Not being able to afford a mammogram would keep me from having one.				
172. Being treated rudely at the mammography center/facility would keep me from having a mammogram.				
173. Not wanting to know would keep me from having a mammogram.				
174. Being embarrassed about my body would keep me from having a mammogram.				

Thank you for answering these questions!

Please complete and return the attached card so that you can be entered in the gift card giveaway. Return the survey and the medical release form using the attached the prepaid envelopes. If you need a new envelope, please contact Deeonna Farr by phone 803-777-7641 or e-mail <u>sc.cancer.prevention.study@gmail.com</u>

The next portion of this study consists of follow up interviews about your mammography experience. If you are selected for an interview, you will receive a \$25 giftcard for each interview you complete. If you <u>do not want to be considered for a follow up interview</u>, please contact Deeonna Farr by phone 803-777-7641 or e-mail <u>sc.cancer.prevention.study@gmail.com</u>

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### Authorization for Access, Use, and Disclosure of Protected Health Information for Research

### Title of research study: The Impact of False Positive Mammography Results on Breast Cancer Screening Intention in Black Women

### Investigator:

Deeonna Farr, MPH, DrPH Candidate University of South Carolina Department of Health Promotion, Education, and Behavior 915 Greene St, Room 531 Columbia, SC 29208

### What about My Confidentiality and Privacy?

We understand that information about you and your health is personal, and we are committed to protecting the privacy of that information. Because of this commitment, we must obtain your special authorization (permission) before we may use or disclose your protected health information for the research purposes described below. This form provides that authorization and helps us make sure that you are properly informed of how this information will be used or disclosed. Please read the information below carefully before signing this form.

Protected Health Information (PHI) means any information that relates to your health, treatment or condition that could reveal your identity such as medical records or test results. Records of your care will be kept in a confidential form at your hospital or doctor's office where you receive treatment. Efforts will be made to keep information about you private, but we cannot guarantee absolute confidentiality.

### Who will Disclose, Receive, and/or Use My Health Information?

The following person(s), class(es) of persons, and/or organization(s) may disclose, use, and receive information about you, but they may only use and disclose information to those listed here, to you/your personal representative, or as required by law.

- The research staff and medical staff for this Institution
- The members and staff of this institution's Institutional Review Board (Palmetto Health)
- · The members and staff of the University of South Carolina' Institutional Review Board
- · Principal Investigator: Deeonna Farr, MPH, DrPH Candidate

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### What Health Information will be Used or Disclosed?

The entire research record and any medical records held by the institution or participating doctors and practices related to your breast cancer screening procedures such as mammography. may be used or disclosed. This includes all medical records, doctor notes, hospitalization records, laboratory results, pathology results, radiological tests, diagnostic tests, specimens and any other protected health information related to breast cancer screening that is needed by the research protocol.

If your records are used or given out for governmental purposes, it will be done under conditions that protect your privacy to the fullest extent possible consistent with laws relating to public disclosure of information and law-enforcement responsibilities of the agency. The Palmetto Health Institutional Review Board may inspect and/or copy your research and medical records for quality assurance and data analysis.

Your medical information may be used or disclosed when necessary to prevent a serious threat to your health and safety or the health and safety of the public or another person. Any disclosure, however would only be to someone able to help prevent the threat.

### What Specific Conditions am I Agreeing to by this Authorization?

By signing this form, you authorize the use and/or disclosure of your protected health information as described in this form. The purpose for the uses and disclosures you are authorizing is to conduct the research project explained to you during the informed consent process and to ensure that the information relating to that research is available to all parties who may need it for research purposes.

This information may be redisclosed if the recipient(s) described on this form is not required by law to protect the privacy of the information.

You have a right to refuse to sign this authorization. While your health care outside the study, the payment for your health care, and your health care benefits will not be affected if you do not sign this form, you will not be able to participate in the research described in this authorization and will not receive treatment as a study participant if you do not sign this form.

If you sign this authorization, you will have the right to revoke it at any time, except to the extent that Palmetto Health has already taken action based upon your authorization or needs the information to complete analysis and reports of data for this research. This authorization will never expire unless and until you revoke it. You may withdraw your authorization for us to use your data, but you must do so in writing. To revoke this authorization, please contact the Office of IRB Administration for Palmetto Health at 803-434-2884. Data that have already been sent to the sponsor of this study cannot be withdrawn.

You will not be allowed to see or copy the research record information described on this form as long as the research is in progress, but you have a right to see and copy the information upon completion of the research in accordance with institutional policies.

Study records that identify you will be kept confidential as required by law. Federal Privacy Regulations provide safeguards for privacy, security, and authorized access. Except when required by law, you will not be identified by name, social security number, address, telephone number, or any other direct personal identifier in study records disclosed outside of Palmetto Health.

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Study results will be retained in your research record for at least six years. Any research information in your medical record will be kept indefinitely.

You authorize the use of health information contained in your records, but any publication which includes such information or data shall not reveal your name, show your picture or contain any other personally identifying information, except as otherwise required by law.

For records disclosed outside of Palmetto Health, you will be assigned a unique code number. The key to the code will be kept in a locked file in your doctor's office separate from study data.

I have read this authorization form or had it read to me. I have discussed it with the investigator and my questions have been answered. I will be given a signed copy of this form. By my signature I agree to the access, use and/or disclosure of my protected health information as described in this form.

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