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# Experiences of Older African American Women With Breast Cancer Screening and Abnormal Mammogram Results

Marshalee George  
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# Walden University

## COLLEGE OF HEALTH SCIENCES

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Marshalee George

has been found to be complete and satisfactory in all respects,  
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Walden University

2011

Abstract

Experiences of Older African American Women with Breast Cancer Screening and  
Abnormal Mammogram Results

by

Marshalee George

Dissertation Submitted in Partial Fulfillment  
of the Requirements for the Degree of  
Doctor of Philosophy  
Public Health

Walden University

November 2011

## Abstract

Even with access to well-known breast cancer treatment centers, older African American women continue to have higher breast cancer mortality compared to their European American counterparts. Researchers have theorized relationships among diagnostic delay, socioeconomic status (SES) factors, beliefs, culture, and breast cancer mortality in African American women ages 40 to 64, but these same relationships among African American women ages 65 to 80 have not been investigated. The purpose of this qualitative study was to describe older African American women's experiences with abnormal mammograms. The quality-caring model and critical race theory were used through narration to show the association of structure and process within the context of race. Purposeful, criterion-based sampling was used to select and interview 12 African American women ages 65 to 80 who had an abnormal mammogram result after breast cancer screening (BCS) within the previous 2 years. Through narrative analysis with triangulation it was demonstrated that clinical and social systems within the process of BCS affected the women's perceptions of providers and outcome. Their independence, motivation, health outlook, and spiritualistic beliefs kept them adherent to BCS and longterm follow-up. Health promotion activities were supported by family, friends, and spirituality. Variations in mammography practices and poor provider communication were obstacles to health maintenance. Positive social change is supported through health care providers' understanding of the barriers that impede older African American women's follow-up of abnormal mammogram results. Removing these barriers may assist in the reduction of breast cancer mortality.



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## Dedication

This dissertation is dedicated to my family. To my husband, thank you for your love, understanding, and support. To my mom "Ina" who have been there for me throughout my academic journey giving unwavering moral and physical support. Thanks for your strong words of encouragement when I felt like giving up.

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## Table of Contents

List of Tables .....	vii
List of Figures .....	viii
Chapter 1: Introduction to the Study.....	1
Introduction.....	1
Background of the Problem .....	3
Statement of the Problem.....	6
Research Questions.....	8
Purpose of the Study .....	9
Theoretical Framework.....	10
Definitions of Terms.....	16
Assumptions, Scope, Delimitations, & Limitations .....	17
Assumptions.....	17
Scope .....	19
Delimitations.....	19
Limitations .....	20
Significance and Implications for Social Change.....	21
Summary.....	21
Chapter 2: Literature Review .....	23
Introduction.....	23
Search Strategy .....	24
Relationship of Literature to the Problem.....	26

Experience.....	26
Abnormal BCS Mammogram Results .....	27
Process .....	28
BCS Trends Among and Recommendations for Older African American Women.....	29
African American Women's BCS Behaviors.....	31
Abnormal Mammography Follow-up Behaviors (African American Women).....	39
Avoidance Behaviors in Older Women .....	49
Comparisons of Outcomes and Points of View .....	51
Relationship of the Study to Prior Research.....	52
Rationale for the Conceptual Framework.....	53
Literature Related to the Methodology.....	55
Use of Stories to Describe and Understand .....	56
Alternative Methodologies .....	58
Summary of the Literature Review.....	58
Conceptual Framework.....	59
Provider Biases With BCS Recommendations.....	59
Competing Priorities .....	60
Personal Experiences .....	61
Poor Communication .....	61
Silence and Societal Contradictions.....	61

Follow-up Behaviors.....	62
Knowledge Deficit to Follow-Up .....	63
Negative Diagnostic Experience.....	63
Gaps in the Literature.....	64
Summary.....	65
Chapter 3: Methodology .....	67
Introduction.....	67
Qualitative Research.....	68
Research Design .....	69
Approaches to Qualitative Research.....	69
Other Qualitative Approaches.....	71
Researcher's Process .....	73
Method .....	74
Sampling Strategy and Participant Selection.....	76
Researcher's Role .....	80
Trust and Rapport .....	81
Respect, Attention, and Interest.....	82
Trustworthiness and Credibility of Inquiry.....	83
Interview Guide .....	84
Length of Interviews.....	85
Interview Setting.....	86
Method of Recording Information.....	87

Preparation for the Interview .....	87
Ethical Considerations and Protection of Participants.....	88
Confidentiality and Data Storage.....	89
Institutional Review Boards.....	90
Consent Process .....	91
Data Collection .....	93
Data Analysis and Interpretation .....	94
Evidence of Quality .....	97
Feasibility and Appropriateness.....	97
Summary.....	98
Chapter 4: Results.....	99
Introduction.....	99
Data Collection .....	101
Narrative Analysis .....	104
Research Findings.....	105
The Story.....	105
Getting Ready for the Mammogram .....	106
Having the Mammogram.....	109
Getting Bad Results.....	115
Who is their Support?.....	119
Going Back for More Tests.....	122
Is it Cancer?.....	125

What's Next?.....	127
Staying Healthy.....	129
Roadblocks.....	132
Application of The Quality-Caring Model and Critical Race Theory.....	140
How to Make Things Better?.....	142
Discrepant Data .....	145
Summary of Findings.....	145
Evidence of Quality .....	148
Summary.....	152
Chapter 5: Summary, Conclusion, and Recommendations .....	153
Evolution of the Study .....	153
Overview of the Study .....	154
Summary of the Findings.....	155
Theoretical Limitations.....	156
Practical Limitations of the Study .....	159
Interpretation of the Findings .....	160
Findings Related to the Literature and Theoretical Framework.....	172
Implications for Social Change.....	176
Recommendations for Action.....	179
Recommendations for Future Studies.....	182
Researcher Reflections .....	183



Conclusion .....	184
References.....	188
Appendix A: Interview Guide.....	205
Appendix B: Table 3. CPTD Baseline Data: Participants' Supplemental Coverage Status.....	206
Curriculum Vitae .....	207

List of Tables

Table 1. U.S. Female Breast Cancer Death Rates Stratified by Race and Age,  
2001-2005 ..... 7

Table 2. CPTD Baseline Data: Demographics of Interview Participants ..... 78

Table 3. CPTD Baseline Data: Participants' Supplemental Coverage Status ..... 206

Table 4. Summary of the Process of Older African American Women's Experiences With  
BCS and Abnormal Mammogram Results ..... 173

## List of Figures

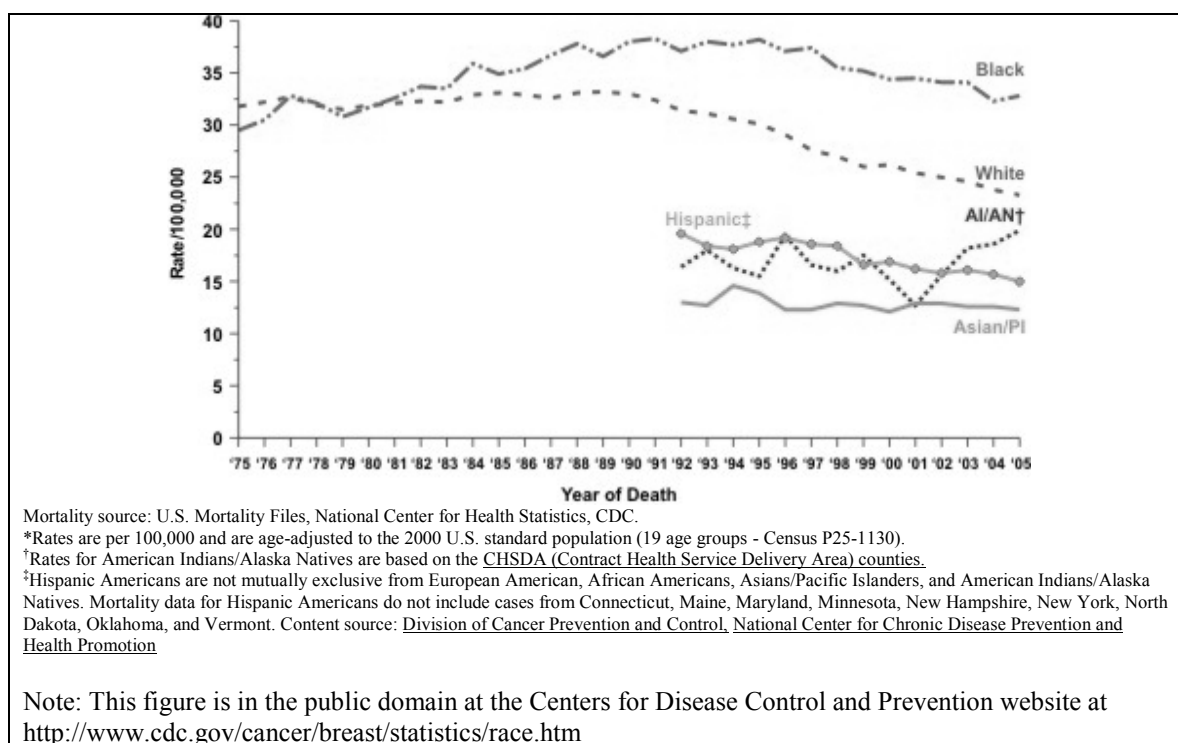
Figure 1. Female breast cancer U.S. death rates* by race and ethnicity, 1975-2005. ....	2
Figure 2. The QCM.....	11
Figure 3. The CRT.....	15
Figure 4. African American women’s (65 and under) experiences with BCS and abnormal mammogram results.....	65
Figure 5. Baltimore coverage area for participants in the CPTD/PHS cohort.....	79
Figure 6. Adaptation of QCM and CRT for older African American women’s experiences with BCS and abnormal mammogram results. ....	176

## Chapter 1: Introduction to the Study

### **Introduction**

An estimated 207,090 women in the United States will be diagnosed with invasive breast cancer in 2010, with an additional 54,010 in situ breast cancer cases (American Cancer Society [ACS], 2010). Approximately 40,230 women with breast cancer died from their disease in 2010 (ACS, 2010). Breast cancer death rates have steadily decreased overall since 1990; however, the breast cancer death rate of women 50 years of age and older increased by 2.0%, whereas the rate for women 50 years of age and younger decreased by 3.3% (ACS, 2008). The Surveillance Epidemiology and End Results ([SEER], 2008) database age-specific breast cancer incidence rates reported that an estimated 42% of breast cancer incidences for a given year occurs in women 65 years and older, with over 20% of these incidences representing women 75 years and older (He, Sungupta, Velkoff, DeBarros, & U.S. Census Bureau, 2005). Approximately two thirds of breast cancer deaths annually occur in women 65 years of age and older (Ries, Reichman, Lewis, Hankey, & Edwards, 2003). The U.S. Census Bureau (2000) predicted that the number of individuals over 65 will double from 35 to 71 million by 2030. This graying of the United States will result in significant increases in breast cancer incidence among older women, especially because the two highest risk factors for breast cancer are being a female and being older than 65 years (Mandelblatt et al., 2005; U.S. Census Bureau, 2000).

Breast cancer is the leading cancer among African American women in the United states, with an estimated 19,010 new cases and 5,830 breast cancer deaths in 2007 (ACS, 2008). African American women are more likely to die from breast cancer than any other ethnic group (see Figure 1.). Distant-stage (metastatic) breast cancer incidence has been persistently 0.5% higher in African American women compared to European American women during the past 3 decades and metastatic breast cancer is directly associated with increased breast cancer mortality (ACS, 2008).



*Figure 1.* Female breast cancer U.S. death rates\* by race and ethnicity, 1975-2005.

The purpose of this study was to understand the issues related to an increase in breast cancer mortality among a sample of older African American women in Baltimore City. Understanding older African American women's breast cancer screening (BCS)

mammograms and follow-up experiences within the social context of the health care delivery systems will provide insight for improved outcomes.

### **Background of the Problem**

The Baltimore City population is 66% African American and includes a collage of foreign-born African Americans as stated in the U.S. Census (2000). Senior citizens represent 13% (82,202) of the African American population and 68% of cancer deaths in all racial and ethnic groups in Baltimore City (Baltimore Metropolitan Council, 2008; U.S. Census Bureau, 2000). The average annual age-adjusted breast cancer incidence of women in Baltimore City is 106.5 cases per 100,000 women, with an incidence of 96.9 per 100,000 among African American women and 120.1 per 100,000 among European American women (Maryland Affiliate of Susan G. Komen for the Cure, 2009). Breast cancer average annual age-adjusted mortality in Baltimore City is 34.2 deaths per 100,000 women, with African American women and European American women mortality rates of 35.4 and 31.8, respectively (Maryland Affiliate of Susan G. Komen for the Cure, 2009). Although breast cancer incidence in Baltimore City is less than the national breast cancer incidence (123.2 per 100.00), Baltimore City surpasses the national breast cancer mortality rate by 7%--national mortality 27% (Maryland Affiliate of Susan G. Komen for the Cure, 2009).

Race may be a contributing factor for the difference in breast cancer mortality between the United States and Baltimore City because Baltimore City has a dominant African American population (Baltimore Metropolitan Council, 2008; Maryland Department of Health & Mental Hygiene, 2008). The 7% breast cancer mortality rate in

Baltimore City over the national rate is high, especially considering that Baltimore City has world-renowned medical institutions and specialty breast centers. The breast specialty centers in Baltimore City provide breast health screening services at low or no cost, breast health education, and breast cancer treatment services, yet women from Baltimore City die from breast cancer more than other localities in Maryland (Johns Hopkins Sidney Kimmel Comprehensive Cancer Center, 2008; Maryland Affiliate of Susan G. Komen for the Cure, 2009; University of Maryland Greenbaum Cancer Center, 2008; Weinberg Center for Women's Health at Mercy Medical Center, 2008).

Maryland also subsidizes BCS and treatment programs through the Cigarette Restitution Fund of Maryland (Maryland Department of Mental Health and Hygiene Community Administration, 2007). It is not clear whether the specialty breast centers located in Baltimore City are meeting the breast care needs of African American women and older African American women in particular.

The increasing mortality rates of African American women may be attributable to diagnostic delay or incomplete follow-up of abnormal breast screening results. Abnormal breast screening results that are not followed up on a timely basis may make the difference between a Stage I and Stage IV breast cancer at diagnosis as well as the possibility of premature death (Facione, 1993; Jones et al., 2005; Richards, Westcombe, Love, Littlejohns, & Ramirez, 1999). A diagnostic delay of 3 months or more from the time of an abnormal screening results means a 12% decrease in 5-year survival compared to women who follow up with abnormal breast results within 90 days (Richards et al., 1999). Sixty-four percent of African American women, in comparison to 13% of

European American women, are more likely to delay surgery for more than 50 days after a diagnosis of breast cancer (Pocock et al., 2007). Diagnosis delay among African American women is associated with methods of detection (Gwyn et al., 2004) as well as sociocultural norms, beliefs, health practices, and complex clinical systems (Caplan, Helzlsouer, Shapiro, Wesley, & Edwards, 1996; Facione, 1993; Facione, Miaskowski, Dodd, & Paul, 2002; Gordon, 2003).

African American women's delay in the follow-up of breast care services has been correlated to knowledge deficits, lack of social support, financial burdens, limited access to care, inefficient clinical systems, and poor provider communication (Caplan, May, & Richardson, 2000; Facione et al., 2002; Gates, Lackey, & Brown, 2001; Goodson & Moore, 2002; Gorin, Heck, Cheng, & Smith, 2006; Harris, Miller, & Davis, 2003; Jenner, Middleton, Webb, Oommen, & Bates, 2000; Lannin et al., 1998). Prejudicial experience in health care delivery is another factor that can delay African American women's follow-up practices. African American women's experiences with prejudice in health care delivery have been mostly associated with perceived access to health care and frequent use of health care services by clinicians (Facione, 1993; Facione et al., 2002).

Carlson et al. (2008) reported that the increase in breast cancer mortality of older women is associated with the limited number of women 65 years and older who participate in clinical trials. The result has been an absence of sound scientific evidence to support individualized breast cancer treatment guidelines for this age group (Carlson et al., 2008).



The next chapter includes in-depth discussions of the experiences of African American women with BCS and abnormal mammogram results. Chapter 2 also highlights gaps in the literature about BCS and abnormal mammogram result experiences of older African American women. New insights into older African American women's BCS and abnormal mammogram result experiences will facilitate a comparison with African American women's experiences (i.e., women < age 65) as they relate to behaviors, demographics, and geography.

### **Statement of the Problem**

In this qualitative study, I interviewed a purposive sample of 12 older African American women ages 65 to 80 living in Baltimore City at the time of the study who had received abnormal results after BCS mammograms within the past 2 years. I explored and described the experiences of older African American women with abnormal mammograms as they decided what to do with those test results. I used the quality-caring model to show how structure and process affect outcome. Interviewing these participants contributed to closing the gap in knowledge about the barriers to additional diagnostic testing and breast cancer treatment that these women experienced.

The disparity between the breast cancer mortality of African American women younger than 50 and those over 50, as well as the difference between the two age groups, is widening in the United States (ACS, 2007; Blackman & Masi, 2006). Older African American women living in Baltimore City have a larger burden of breast cancer mortality. According to the Susan G. Komen Maryland Affiliate's community profile report (2009), women ages 65 and older in Baltimore City have a breast cancer mortality

rate of 138.1 deaths per 100,000 women per year; for women under the age of 50, the mortality rate is 8.8, and for women over the age of 50, it is 100.5. In 2007, approximately 59.9% of new breast cancer cases in Baltimore City were Stage 1, and 6.4% were Stage IV. African American women in Baltimore City are twice as likely to be diagnosed with Stage IV or advanced breast cancer as European American women (Maryland Affiliate of Susan G. Komen for the Cure, 2009).

Table 1 shows the breast cancer death rates and the exceeding breast cancer death rates in Baltimore City compared to Maryland and the United States. From the statistical data known about the demographics (68% of cancer deaths in Baltimore City occur in senior citizens), breast cancer incidence, and death rates of Baltimore City population, it is evident that older African American women are dying more than other groups of women from breast cancer in Baltimore City.

Table 1

*U.S. Female Breast Cancer Death Rates Stratified by Race and Age, 2001-2005*

Age-adjusted annual death rates per 100,000 (95% CI) for U.S., Maryland, & Baltimore City			
	United States	Maryland	Baltimore City
All races**	25.0 (24.9 - 25.1)	27.4 (26.5 - 28.2)	34.2 (31.6 - 36.9)
European American**	24.4 (24.3 - 24.5)	25.8 (24.8 - 26.7)	31.8 (27.8 - 36.4)
African American**	33.5 (33.1 - 33.9)	33.1 (31.2 - 35.0)	35.4 (32.0 - 39.0)
Age (years)			
< 50	5.5 (5.4 - 5.5)	6.4 (6.0 - 6.9)	8.8 (7.2 - 10.7)
50+ (including ≥ 65)	76.1 (75.8 - 76.5)	82.2 (79.4 - 84.9)	100.5 (92.2 - 109.3)
≥ 65	109.1 (108.5 - 109.8)	117.5 (112.7 - 122.6)	138.1 (124.1 - 153.3)

\*\*Includes Hispanic American populations

Addressing the breast cancer mortality of older African American women in Baltimore City requires that clinicians have a better understanding of the scope of the problem. Several researchers (Facione, 1993; Jones et al., 2005; Richards et al., 1999)

have identified a relationship between diagnostic delay and increased breast cancer mortality in African American women between the ages of 40 and 65. Other researchers (Allen, Shelton, Harden, & Goldman, 2008; Arnsberger et al., 2006; Bairati, Jobin, Fillion, Larochelle, & Vincent, 2007; Ell et al., 2002; Facione et al., 2002) have identified a relationship of SES factors, propositional attitudes, provider factors, and complex clinical systems to diagnostic delay among African American women ages 40 and over. I did not find any researchers who have focused on understanding the experiences of older African American women with abnormal mammograms. Most women ages 65 years and over are on Medicare, so access to health care should not be an issue in this age group. However, according to breast cancer data (ACS, 2010), older African American women remain significantly at risk for breast cancer mortality. In this study, I explored and described the experiences of older African American women with abnormal mammograms as they decided what to do with those test results. The accounts of their experiences also helped me to determine whether the factors related to increased breast cancer mortality in the literature apply to older African American women living in Baltimore City.

### **Research Questions**

The study was guided by two research questions:

1. What are the experiences of a group of older African American women with BCS in Baltimore City? (Where did they go, what was their experience like at the diagnostic center, whom did they talk to, what were they told at the end of their screening test, and so on?)

2. What was this group's experience with abnormal mammogram results after BCS? (What did they do: talk with friends and family, keep the results a secret, read information on the web, get additional diagnostic test, and so on?)

To understand the BCS mammogram and follow-up experiences of older African American women, the research questions were framed to solicit informal, open, evolving, and nonjudgmental responses from the participants (Ulin, Robinson, & Tolley, 2005).

The first research question addressed the overall BCS mammogram experiences of the participants, which correlated with the purpose of the study. The second research question was used to address the participants' experience after receiving abnormal results following BCS mammogram. The research questions follow a logical flow and allowed me to probe with follow-up questions to obtain a deeper level of understanding of the participants' experiences. I developed the interview guide from the research questions to ensure comprehensive coverage of the subject matter and to anticipate and close logical gaps in the data (Creswell, 2007; Ulin et al., 2005).

### **Purpose of the Study**

The purpose of this qualitative interview study was to describe the experiences of a group of older African American women in Baltimore City who had received abnormal results following BCS mammograms. Experiences were defined as the older African American women's internal feelings, hopes, dispositions, and behaviors after participating in BCS and receiving abnormal results. I sought to explore and describe the experiences of older African American women with BCS and abnormal mammogram results through the stories of their perceived experiences in an effort to generate thematic

meaning. An interpretive approach guided this qualitative study because the central concept (i.e., their experiences) was reported through the eyes of the participants (Corbin & Strauss, 1990; Creswell, 2007; Rudestam & Newton, 2001).

### **Theoretical Framework**

Two theoretical frameworks were used in this study, namely, the quality-caring model ([QCM]; see Figure 2; J. R. Duffy & Hoskins, 2003) and critical race theory ([CRT]; Delgado & Stefancic, 2001). CRT is a broad philosophical approach in the social sciences that uses race to interpret the lived experiences of individuals. Within the field of public health, the QCM, a middle-range theory, is used to address role-relationships of patients, families, providers, system processes, and outcomes within the scheme of health care management for specific diseases. (see Figure 2). The QCM does not specifically and deliberately address race as CRT, so both theories were used in this study.

The QCM is an adaptation of the Donabedian (1988) model, which emphasizes the unique roles of nurses in improving patient outcomes. The QCM can be used in the field of public health because it has similar application to improving population outcomes. Although the QCM is a nursing model, it provides a framework for understanding the clinical and social systems within the process of BCS and abnormal results that can affect outcomes. The core functions of public health were accomplished in this study through my use of the QCM to assess older African American women's BCS and abnormal mammogram results experiences. The assessment of older African American women's BCS experiences can influence public health officials to develop new

health policies related to breast care and treatment that will provide assurances of health and well-being to this population.

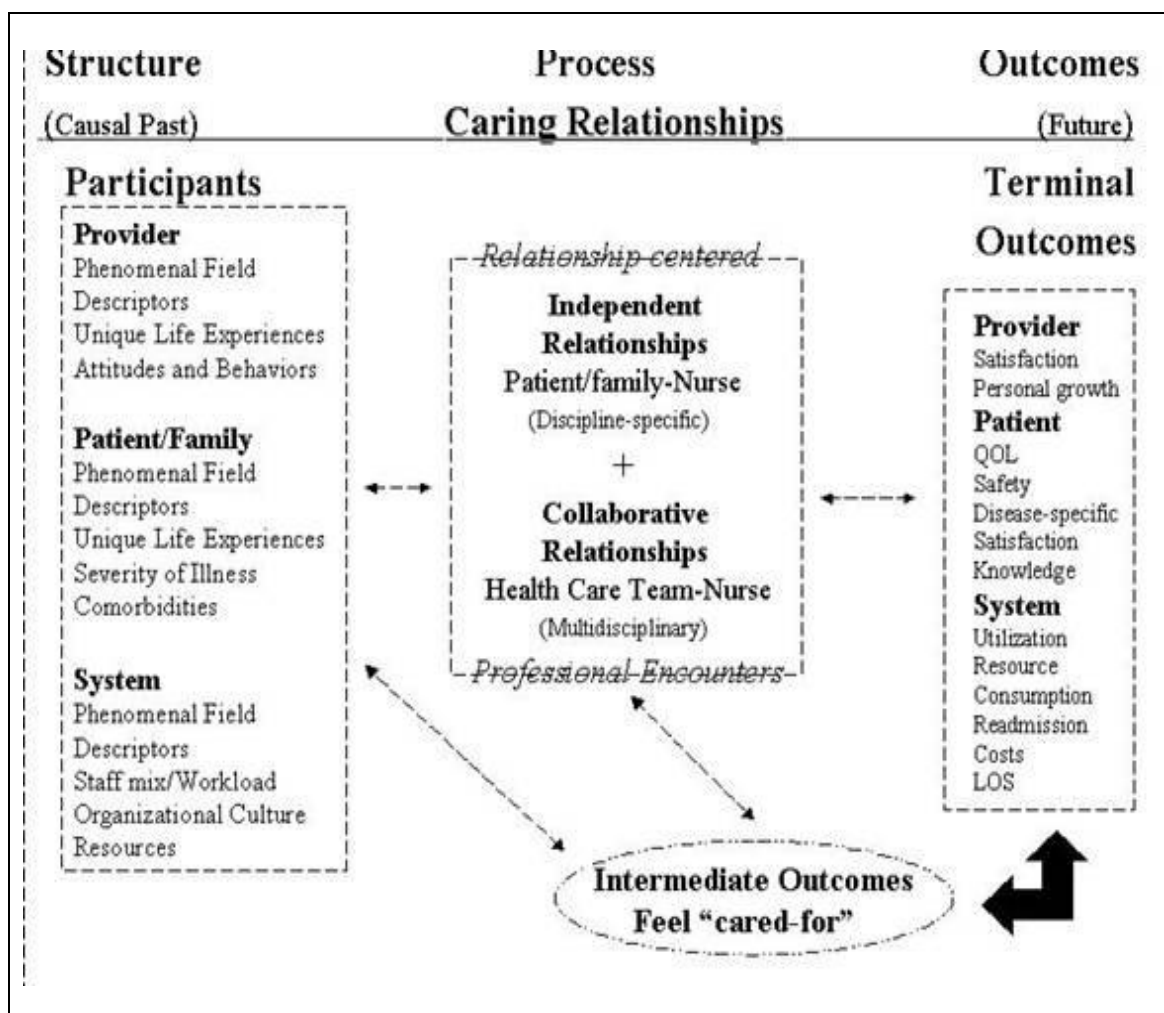


Figure 2. The QCM.

Source. "The Quality-Caring Model: Blending Dual Paradigms," by J. Duffy & L. M. Hoskins, 2003. *Advances in Nursing Science*, 26(1), 81.

The QCM was selected because it can be used to understand the role of relationships of patients, families, health care providers, clinical system process, as well as outcomes within the scheme of health care management and utilization for specific

diseases. The QCM is divided into three domains: structure, process, and outcomes. There is an interdependent relationship among the three domains where structure and process affect outcomes. The structural domain focuses on the attributes of patients, providers, and the health care environment that can affect processes and outcomes (Duffy & Hoskins, 2003). The process domain refers to specific care services that health care providers deliver to patients (Duffy & Hoskins, 2003). The outcomes domain is the endpoint of the health care process (Duffy & Hoskins, 2003). Caring relationships are determined from the patient/family-nurse independent relationship and collaborative relationships with the health care team-nurse in professional encounters. Outcome measures are divided into provider, patient, and system quality indicators (Duffy & Hoskins, 2003; Duffy, Baldwin, & Mastorovich, 2007). I adapted aspects of the QCM to understand the existing structure as it relates to the process of older African American women's experience with BCS and abnormal mammogram results as an outcome.

Yosso (2005) commented,

Critical Race Theory (CRT) is a framework that can be used to theorize, examine and challenge the ways race and racism implicitly and explicitly affect social structures, practices, and discourses. (p. 2) . . . . It addresses the social construct of race by examining the ideology of racism. (p. 6)

Figure 3 shows that racial discourse can be interpreted using ordinariness interest convergence, social construction, differential rationalization, intersectionality and antiessentialism, and the unique voice of color (Delgado & Stefancic, 2001). Racism is difficult to eradicate because it may seem ordinary to discriminate against individuals

because of the color of their skin in settings that support the behavior (Delgado & Stefancic, 2001). In many instances, individuals may find it effortless to adopt prejudicial behaviors toward African Americans that were modeled by parents, relatives, friends, or superiors.

Interest convergence describes the economic advancement of European American that enhances the psyches of working-class people at the expense of African Americans. Supporting racial prejudice may increase the wealth of European American or their acquisition of goods and services, which would have been distributed among African Americans if racial prejudices were nonexistent (Delgado & Stefancic, 2001).

Many ethnic groups have similar physical features and no external markers that determine intelligence, personality, or superior traits (Delgado & Stefancic, 2001). Social construction describes the concept of race as a product of social ideas and relationships. Race does not describe the biological or physical realities of individuals. Race is a category that society created and continues to maintain in order to manipulate various cultures, especially when it is to the advantage of the dominant culture (Delgado & Stefancic, 2001).

Differential racialization is a concept used by the dominant society to rationalize and treat differently various ethnic groups at different times according to the political climate and financial or labor markets (Delgado & Stefancic, 2001). An example of differential racialization is the victimization that Arab Americans or Muslims experienced in the United States after September 11, 2001 because they belonged to the



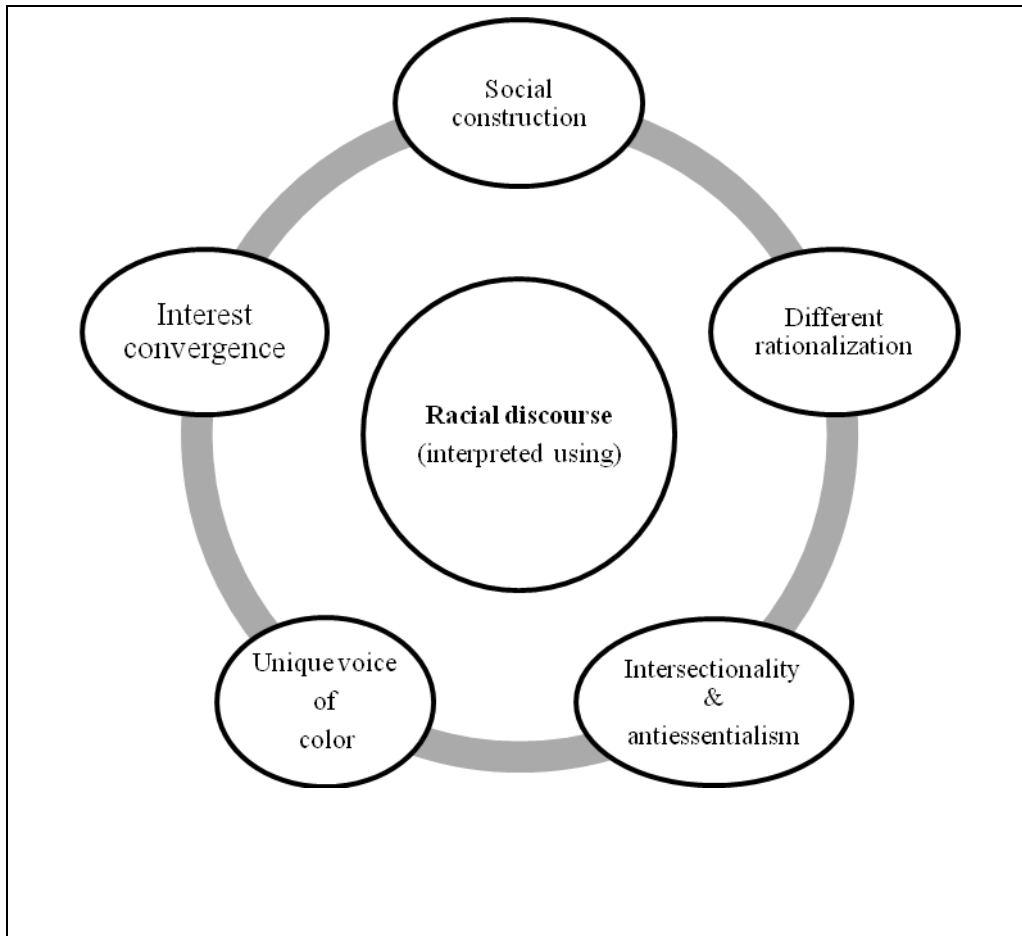
same ethnic or religious group as the terrorists responsible for the destruction of the World Trade Center and other events.

Intersectionality and antiessentialism relate to the various identity categories to which people belong. For example, a woman who is African American, a single parent, and poor may experience discrimination similar to that of a European American woman who is Jewish, a single parent, and poor. However, each woman will be treated differently. Society is made up of individuals who have specific allegiances and loyalties to certain identities or ethnic groups. Therefore, African American women may be more loyal and nonprejudicial to other African American women in various settings because they believe that people like themselves better understand their experiences (Delgado & Stefancic, 2001).

The last tenet of CRT is “unique voice of color” (Delgado & Stephanic, 2001, p. 9) or the unified voice that comes from different ethnic groups with similar experiences. As various ethnic groups experience various forms of prejudices and oppressions at different points in history, they are presumed to be experts about race and racism (Yosso, 2005). Many African American writers are encouraged to write about their experiences with racism and its legal implications (Delgado & Stefancic, 2001).

These six tenets of CRT are influential in the health care setting because health care services are partly determined by a person's culture and racial discourse, factors that influence beliefs, attitudes, and behaviors in various settings. Because the mortality of older African American women with abnormal mammogram results after BCS is higher

than that of other groups, it is important to focus on race to learn whether, and how, that identity category affects their response to abnormal BCS results.



*Figure 3.* The CRT.

Unraveling the experiences of older African American women from the time they participated in BCS to the time they received abnormal mammogram results will help to determine how the process (navigating/accessing breast services, clinical systems, ineffective provider communication, social systems, or economic factors) functioned and whether it was effective for the patient, that is, what the outcomes (such as follow-up with diagnostic center or consultation with breast specialists for abnormal mammogram

results, underwent breast cancer treatment, etc.) were for those women and whether race was a factor in their experiences (Delgado & Stefancic, 2001; Donabedian, 1988; Duffy, 2009; Duffy et al., 2007).

### **Definitions of Terms**

*Chemotherapy:* The use of cytotoxic agents to kill cancer cells. These cytotoxic agents can be given intravenously or orally as a pill (Anderson & Anderson, 1998).

*Core needle biopsy:* The removal of a piece of specimen or tissue from a suspicious mass with a special hollow needle for pathological examination (Willis, 1996).

*Hormone therapy:* The use of synthetic hormones to block estrogen or progesterone (the body's natural hormones) to reduce or stop the growth of breast cancer cells (National Cancer Institute [NCI], 2011).

*Lumpectomy:* A surgical procedure to remove a breast tumor or cancer (with an area of healthy tissue around the tumor) and leaving the remainder of the breast and lymph nodes intact (Willis, 1996). This procedure is usually followed by radiation or chemotherapy (Willis, 1996).

*Mammogram:* A test to detect tumors in the breast that uses low dose X-ray (Willis, 1996).

*Stereotactic breast biopsy:* The incorporation of a computerized frame to precisely locate microcalcifications or small suspicious calcium particles in the breast, under the guidance of X-ray imaging (Willis, 1996).

## **Assumptions, Scope, Delimitations, & Limitations**

### **Assumptions**

The assumption in society and among researchers is that there is a difference in African American and European American women's health care practices and health care delivery (Berz et al., 2009; Keating, Kouri, He et al., 2009). Cancer disparity persists between African Americans and European American in the United States.; however, the disparity in breast cancer mortality has widened between the two races over the past 10 years (Blackman & Masi, 2006). Assuming that African American women's health screening behaviors may contribute to the breast cancer disparity, researchers have used popular theories such as the health belief model, transtheoretical model, theory of planned behavior, theory of social network/social support, precede-proceed model, cultural theory, and even combined models to understand African American women's breast screening behaviors. Overall, these popular theories have yielded inconclusive results because they may not have been appropriate or culturally sensitive to African American women (Armitage & Conner, 2001; Ashing-Giwa, 1999; Baldwin, 1996; Bandura, 1986; Becker, 1978; Janz & Becker, 1984; Kobetz, Vatalaro, Moore, & Earp, 2005; Pasick & Burke, 2008).

One of the theories that has not been popular in breast screening or breast cancer research is the CRT (Pasick & Burke, 2008). During clinical practice, many older African American women attribute their delay to follow-up with abnormal mammogram results

or receiving breast cancer treatment to the following experiences. Some of the experiences that they shared with me include the following:

- “I did not like how the doctor spoke down to me, as if I was not educated.”
- “The doctor told me that I had breast cancer in the waiting room, in front of everyone, and I was so embarrassed.”
- “The doctor told me to have another mammogram in 6 months, if my daughter did not insist that I had a second opinion, I would not have known that I had breast cancer.”
- “I do not trust European American doctors because I remember what happened to the Tuskegee Airmen and I do not want them to use me as a ‘guinea pig’ ” (George, 2010).

In my clinical practice, it seems that many older African American women assume that the delay in follow-up or breast cancer treatment is attributed to the racial prejudices of providers; no available research data have refuted or supported this assumption.

One of the basic assumptions in qualitative research is that researchers have to be interested in others to conduct interviews. There are limits to understanding human behavior; however, researchers seek to comprehend behaviors through the participants’ subjective understanding (Seidman, 2006). The interviewer uses several techniques, such as attentive listening and self-disclosure, to solicit information from the interviewees or the storytellers. The interviewer must try not to let personal opinions and experiences influence data collection or analysis and must view the story of others as important and give individualized attention to the phenomenon being studied. The one-on-one

interaction between interviewer and storyteller yields a plethora of themes that provide insight into understanding new or complex behaviors (Seidman, 2006).

Another basic assumption is that in-depth interviewing in social research can elicit the meanings that individuals make of their experiences that are influenced by behaviors within the experience. In-depth interviewing not only facilitates the recollection of an event but also captures the perceptions and emotions that the interviewees experience when the event occurred (Blumer, 1969). Although the participants in the study were interviewed, I assumed that their detailed accounts flowed from the consciousness of their experiences with abnormal mammogram results.

### **Scope**

The scope of this study was based upon understanding the experiences of older African American women related to BCS mammograms and abnormal results. The study was qualitative, and the sample comprised 12 older African American women living in Baltimore City. The interview method was used to collect the data in order to learn about older African American women's experiences with BCS mammograms and abnormal results. I used an issue-focus analysis to organize data for the ultimate inclusive integration and thematic generation.

### **Delimitations**

The participants had to meet the minimum requirement of having a BCS mammogram within the past 2 years and receiving abnormal results.

**Limitations**

The sample was comprised of 12 older African American women selected from a cohort of 194 older African American women with abnormal results following BCS mammograms who were participating in the Cancer Prevention and Treatment Demonstration (CPTD) among African American older adults, also known as the Baltimore City Community Advisory Committee's Partnership for Healthy Seniors (PHS). The PHS is sponsored by a collaborative relationship between Johns Hopkins School of Public Health (JHSPH) and the Centers for Medicare and Medicaid Services ([CMS]; Johns Hopkins Bloomberg School of Public Health, Department of Epidemiology, 2009). Access to the study population of PHS was requested and granted from the principal investigator of the Johns Hopkins Bloomberg School of Public Health in Baltimore City.

The purposeful sampling of the participants decreased the generalizability of the findings to larger populations. The reason for selecting 12 women was to obtain details of their experiences through open-ended, in-depth interviews for thematic groupings as they related to the problem statement. I understand that my interpretation of themes emerging from the interviews could have been subject to other interpretations. This sample may have had some biases because of their exposure to information on breast care services that may have been more than the information nonparticipants would have received in Baltimore City. Therefore, if the participants' abnormal mammogram results were achieved while they were enrolled in the PHS study, they may have been more motivated

to follow up on abnormal results, regardless of negative encounters during the BCS process.

### **Significance and Implications for Social Change**

This study has significant implications for breast care providers and public health practitioners. The findings will provide a better understanding of the experiences of older African American women and the process of change they undergo from BCS, abnormal results, diagnosis, and beyond. This information will be pivotal for the development of public health initiatives and breast care programs tailored to the holistic needs of older African American women in Baltimore City.

### **Summary**

Although older African American women are at significant risk for breast cancer mortality, they have been understudied in the literature. Baltimore City has experienced a toll of breast cancer deaths in the presence of world-renowned breast specialty centers. Many researchers have associated the high incidence of breast cancer mortality among African Americans with diagnostic delay from abnormal mammograms, but it remains unclear whether the same holds true for older African American women. Uncovering the experiences of older African American women will generate new information that may help to change the processes and procedures used to work with this group of women.

The literature review is focused on concepts from BCS and abnormal mammogram results experiences of African American women. The key concepts from the literature review are discussed, highlighting the research gaps and providing justification for the study. Another concept included in chapter 2 is the application of the



narrative approach in the study. Chapter 3 includes a description of the methodology for the study. This chapter extrapolates information presented in chapters 1 and 2, and incorporates it within the narrative approach. Each process within the method of conducting the study is justified through the review of the literature and the narrative tradition. Chapter 4 includes the results related to the research questions through a rigorous transcript analysis of the participants' interview responses. The data reported in chapter 4 includes figures and tables that aid in visual depiction of variables as well as summarize salient results. Chapter 5 provides a discussion that integrates the significance of the findings with the QCM and CRT and the social implications of public health practice. The limitations of the study and recommendations for further research conclude chapter 5.

## Chapter 2: Literature Review

### **Introduction**

The purpose of this qualitative interview study was to describe the experiences of a group of older African American women in Baltimore City who had received BCS mammograms and abnormal results. The need for this study stemmed from the widening disparity between the breast cancer mortality of older African American women and their European American counterparts nationally (ACS, 2007, 2008). In addition, a large disparity has been seen in breast cancer mortality in Baltimore City, where older women in general have an annual mortality rate of 138.1 deaths per 100,000 women, compared to the statewide rate in Maryland of 117.4 deaths per 100,000 women, despite the availability in Baltimore City of world-renowned medical institutions, breast specialty centers, and free breast screening and treatment programs (Maryland Affiliate of Susan G. Komen for the Cure, 2009). Addressing the breast cancer mortality in Baltimore City requires clinicians and public health officials to have a better understanding of the problem. I used the QCM to facilitate a deeper understand of the role and relationship of patients, families, health care providers, clinical system processes, and outcomes in breast care services (Duffy & Hoskins, 2003). The rich, detailed accounts of the older African American women's experiences through the narrative approach using CRT to attend to issues of race provides an understanding of this problem.

In this chapter, literature relevant to the problem statement that focused on African American women's BCS mammogram guidelines, BCS behaviors, abnormal

mammogram follow-up behaviors, avoidance behaviors in the older women, and the relationship of the variables to the study were reviewed.

### **Search Strategy**

The main topics searched for in this review were African American women's BCS experiences, breast cancer, mammography, abnormal mammogram, follow-up practices, and delay in follow-up. First, the Scopus database, a comprehensive medical database containing over 13,000 peer-reviewed journal titles that can also be sourced from Academic Search Premier, CINAHL Plus with full text, Medline, PsycArticles, PsycINFO, PUBMED, SocINDEX with full text, and so on, was used to search for the following key terms: *Breast cancer, Breast carcinoma, Breast cancer and Breast carcinoma, Breast cancer and carcinoma and screening, BCS, BCS and African American women, BCS and older women, BCS and Older African American women, BCS recommendations, BCS recommendations and older, BCS trends, Mammography and African American women, Mammography and older women, Mammography and abnormal mammogram, Abnormal mammogram and African American women, Abnormal mammogram and older women, Abnormal mammogram and Older African American women, BCS and follow-up, BCS follow-up, BCS follow-up and African American women, BCS follow-up and older, BCS and experiences, BCS experiences, BCS experiences and African American women, BCS experiences and older, BCS experiences and Older African American women, breast cancer diagnosis\*, Breast cancer diagnosis, Breast cancer diagnostic resolution, Breast cancer diagnosis and African American*

women, *Breast cancer diagnosis and older women*, *Breast cancer diagnostic resolution and African American women*, and *Breast cancer diagnostic resolution and older women*.

After receiving these results, the articles were sorted according to the study design and the inclusion of the following additional terms: *story*, *stories*, *storytelling*, *narrative*, *inquiry*, *narrative inquiry*, *interview*, *reflection*, *recollection*, and *perception*. In the reviewed articles, the theme of avoidance behavior figured prominently, even though African American women with abnormal mammogram results were well informed of their breast cancer risk. However, specific avoidance behaviors in older African American women or older were not known. Additional terms searched included *avoidance behavior and BCS*, *avoidance behavior in mammography*, *avoidance behavior in health promotion*, *avoidance behavior in African American women*, *Avoidance behavior in older women*, *Avoidance behavior and the older*, and *Avoidance behavior and cancer screening*.

Other sources of literature were reviewed through snowballing, that is, the references of articles obtained through the primary search were used to locate other relevant articles and books on qualitative methodology, interview study methods, and qualitative data analysis. In addition, committee members, mentors, investigators, and faculty members recommended several relevant articles and books. The results of the search yielded no articles that specifically explored older African American women's experiences with both BCS mammograms and abnormal results.

### **Relationship of Literature to the Problem**

The reviewed literature provided in-depth knowledge of prior research and justified the application of the narrative approach for the purpose of understanding older African American women's experiences with BCS mammogram and abnormal results. Researchers have shown that increased breast cancer mortality in African American women is associated with their underuse of BCS mammography and delay in follow-up of abnormal results. Because the research available on BCS and abnormal results experiences of older African American women has been limited, the reviewed literature that focused on the BCS mammogram and abnormal result experiences of African American women ages 40 to 64 was used to identify key concepts related to the health problem.

### **Experience**

Experience. It has been defined as an "act or process of directly perceiving events or reality" and "conscious events that make up an individual life" (*Merriam-Webster's Online Dictionary*, 2009, n.p.). Experience is a key term in social science inquiry. Experience has no independent voice: rather, experience is understood through the meaning of words and the form in which it is presented. Experience comprises the lived stories of people that are reaffirmed and evolved into new stories during storytelling (Denzin & Lincoln, 1994). When exploring the experiences of others, the researcher establishes the starting and ending points. It is easy to collect information unrelated to the study, so the researcher must keep a firm understanding on the purpose of the study (Denzin & Lincoln, 1994).

The study of personal experience has four domains: (a) inward: the internal feelings, hopes, reactive behaviors, and moral dispositions; (b) outward: the environment; (c) backward; and (d) forward: relating to temporality, past, present, and future (Denzin & Lincoln, 1994). A person simultaneously experiences all four domains within an experience. Personal experience research is a part of public inquiry because it connects human qualities with human experience. I maintained an awareness of the cultural and gender differences that may have influenced the participants' experiences during the interviews (Denzin & Lincoln, 1994). In this study, I defined experience as the conscious recollection of internal feelings, hopes, behaviors, and dispositions that a sample of older African American women in Baltimore City experienced in the past after receiving abnormal BCS mammogram results. It was difficult to minimize recall bias in this study because the line of inquiry during the interviews was open-ended so that the participants could describe their experiences with BCS and abnormal mammogram results through their own perceptions and original voices.

### **Abnormal BCS Mammogram Results**

A normal BCS result occurs when a woman undergoes a bilateral mammogram without a history of breast symptoms and has a Category 1 or 2 finding (American College of Radiology [ACR], 2004; Welch & Fisher, 1998). The Breast Imaging Reporting and Data System (BI-RADS) criteria were developed by the ACR in 1993 to report mammography results using common language (ACR, 2004; Jones et al., 2005). Most screening mammograms are classified as BI-RADS Category 1 (negative) and 2 (benign finding; ACR, 2004). An abnormal mammogram result is defined as

- Category 0 - assessment incomplete: need additional imaging evaluation and/or prior mammograms for comparison;
- Category 3 - probably benign finding: initial short-term follow-up suggested;
- Category 4 - suspicious abnormality: biopsy should be considered;
- Category 5 - highly suggestive of malignancy: appropriate action should be taken (almost certainly malignant; ACR, 2004; Eberl, Fox, Edge, Carter, & Mahoney, 2006; Jones et al., 2005).

### **Process**

Process or a series of stages. Process is “a natural event marked by gradual changes leading to a particular result” (*Merriam-Webster's Online Dictionary*, 2009, n.p.). For the purpose of this study, I defined process as the course or series of events (e.g., social, emotional, physical, etc.) that occurred for the older African American women in this sample who received abnormal BCS mammogram results through to 12 months after this diagnosis.

When little is known about a health problem, a description of the experience is necessary to identify key concepts and provide a framework for understanding all factors relating to the health problem. Therefore, I reviewed literature on BCS guidelines, the BCS mammogram experience, and the receipt of abnormal result experiences of African American women, and the narrative approach for obtaining information on what is known and not known about the health problem. The literature review provided insight into provider practices, reasons for underuse of BCS mammography, delay in follow-up of abnormal results, and recommended future research areas, all of which provided

justification for this study. The review of methodologies used in the literature substantiated the effective approach to inquiry that ultimately answered the research questions.

### **BCS Trends Among and Recommendations for Older African American Women**

BCS mammography on average peaks in African American women ages 55 to 59 and then decreases thereafter, particularly among women ages 70 and older (Jerant, Franks, Jackson, & Doescher, 2004; McFall & Davila, 2008). The decline in BCS mammography in women ages 65 and older can be attributed in part to provider ageism bias and the uncertainty of mammography benefit to older women with estimated life expectancies of less than 5 years (Caplan, 2001; Jerant et al., 2004). Although the U.S. Preventive Services Task Force ([USPSTF], 2002) and the American Geriatrics Society ([AGS], 1999) established guidelines for mammography screening for women 65 to 69 years of age, they have left providers with the responsibility of determining who should have mammography screening at age 70 and above, using a life expectancy of 5 years or more. The provider's dilemma shows a disconnect between BCS guidelines and breast cancer mortality because women ages 75 to 79 years have two times the incidence of breast cancer as women ages 50 to 54 (Department of Health and Human Services, 2010; CDC 2010; NCI, 2010). The ACS (2008) recommended BCS at age 40 and over in women who continue to be healthy; however, conflicting recommendations from the different sets of guidelines have left providers in a quandary when determining who should have BCS mammography.



Benefits, harms, and cost effectiveness of BCS mammograms have been a constant theme in research to provide arguments for screening women ages 70 and older (Kerlikowske, Salzman, Phillips, Cauley, & Cummings, 1999). BCS mammography has proven beneficial for older women because they are diagnosed with more early-stage breast cancers and the treatment is mostly curative. However, BCS mammography seems to be less beneficial for women ages 69 and older because many women have multiple comorbidities and their risk of mortality is already increased outside of their breast cancer diagnosis (Kerlikowske et al., 1999; Kerner et al., 2003).

Cauley et al. (1996) found that BCS mammography in women ages 70 and older (using a multivariate model) has a small increase in life expectancy and is cost effective in women with high bone mineral density (BMD). Bynum, Braunstein, Sharkey, Haddad, and Wu (2005) recommended that providers should factor in other components besides age to predict the life expectancy and mammography benefits for older African American women. In addition, comorbidities, life expectancy, and activity level play important roles in older women's willingness to participate in BCS because they may have other competing priorities (Caplan, 2001). Older women with less distal radius BMD have a low risk for developing breast cancer, which may confirm the use of radiographs to predict breast cancer risk in women ages 70 and older (Cauley et al., 1996; Kerlikowske et al., 1999).

Beck and Pauker (1983) examined the physiologic and age-specific characteristics of older women using the Markov model (a method used for determining one's life expectancy using prognostic factors from an individual's disease states) and found that it

is cost effective to recommend mammograms to older women with at least 9.5 years of life expectancy. However, if BCS guidelines are extended to women ages 70 and older, there is an increased chance of false positive results, which can incur unnecessary cost to health care programs (Elmore et al., 1998; Kerlikowske et al., 1999). The aforementioned researchers identified the gaps in BCS guidelines for women ages 69 and over. There is a need for standard BCS guidelines that are inclusive of older women.

### **African American Women's BCS Behaviors**

Numerous studies on BCS and the screening behaviors of African American women have been conducted. However, the studies included in this review were specific to African American women's reports of BCS mammogram experiences and subsequent follow-up experiences of abnormal results. Little is known from the literature reviewed about older African American women's experiences with BCS mammograms and the receipt of abnormal results. Therefore, the following studies about African American women's (ages 40 to 64) breast care experiences provided insight into older African American women's behaviors and perceptions of social and clinical systems within their BCS and abnormal mammogram result experience.

In a quantitative descriptive study, Powe, Hamilton, and Brooks (2006) examined cancer fatalism, described as participants' acceptance that their cancer diagnosis is fate, and cancer knowledge in African American women ( $N = 714$ ) by using the health belief model and found that African American women with less formal education had higher fatalism scores. Individuals who have witnessed the trajectory of late-stage breast cancer diagnosis and death from a close friend or family may automatically associate cancer

with a death sentence. Fatalistic beliefs are higher in African American women and may influence them not to receive BCS mammograms (Powe, Daniels, Finnie, & Thompson, 2005; Powe et al., 2006). The mean age of the study sample was 29 years, with only 15 women age 60 years and over; therefore, these results were not generalizable to older African American women (Powe et al., 2006). However, these findings provide a platform for determining if cancer fatalism will have a role in the BCS experiences of women in this study, since this population was not adequately represented in Powe et al (2006) study.

Sadler et al (2007) explored the baseline knowledge of breast cancer and screening behaviors in predominantly African American communities in San Diego, California. The sample of African American women ( $N = 1,055$ ) ranged in age from 20 to 94, with 110 women ages 66 and older. Sadler et al (2007) revealed that African American women who believed that they were well informed about breast cancer and screening were the most likely to be compliant with BCS guidelines than African American women who believed that they were not informed about breast cancer (Sadler et al., 2007). The number of African American women who self-reported having a mammogram within 1 year was significantly higher (58%) in women ages 50 to 59 in comparison to women ages 60 and older (48%). There was an association between African American women with personal experience with breast cancer (e.g., family members or friends diagnosed with breast cancer, received treatment, or died from breast cancer, as well as compliance with BSE and mammogram). The findings in Sadler et al (2007) will help to provide insight into the role of direct or indirect knowledge about

breast cancer to be associated with adherence to mammography screening, which will help to understand the experiences of older African American women in this study.

African American women with personal breast cancer experience were more likely to participate in BSE and have a mammogram in the past year than women with no prior personal experience (Sadler et al., 2007). Overall, African American women were aware of the severity of breast cancer, which contradicted the findings of previous studies that African American women were unaware of the risk of breast cancer and its effects (Phillips, Cohen, & Tarzian, 2001; Powe et al., 2005; Sadler et al., 2007). Sadler et al. (2007) implied that the failure of African American women ages 60 and older to participate in BCS mammography may not be attributed to a lack of knowledge of breast cancer risk and effects. More research is needed to identify the other contributing factors to older African American women's underuse of mammography.

In a phenomenological study examining the meaning of BCS (refers to BSE, mammography, and clinical breast exam) among 15 low- and middle-income African American women ages 45 to 81, Phillips et al. (2001) found that the low-income women had problems accessing health care and that BCS was not accessible; therefore, the women has little interest in BCS. By contrast, the middle-income women were more interested in holistic and alternative therapies and perceived BCS as important in promoting their health (Phillips et al., 2001). Some women viewed BCS not only as having a mammogram but viewing BCS as caring for the mind, body, and spirit. Spiritualistic beliefs such as faith in God also influenced some of the women to participate or decline to participate in BCS (Phillips et al., 2001). Lack of confidence in

BCS and BSE techniques influenced some women not to participate in BCS. Women who felt comfortable with themselves and their body image were more likely to participate in BCS than women who had body image disturbance. The findings in Phillip et al (2001) will help to understand access barriers and belief systems that may influence the older African American women in this study to participate in BCS.

Women with a strong support system who were held accountable by their children, family members, friends, and providers for their health maintenance were more likely to have mammograms than women with no or little support systems (Phillips et al., 2001). The mean age of the participants in the Phillip et al (2001) study was 52, and there was no mention of participants ages 65 or older, which was a limitation in generalizing the findings to older African American women (Phillips et al., 2001). Overall, Phillip et al (2001) showed that strong spiritual/religious beliefs, confidence in BCS, positive body image, and accountability to others could influence African American women's willingness to participate in BCS.

Thomas (2006) explored the possible association between African American women's past experiences with their breasts and BCS behaviors examined 12 African American women ages 40 to 64 with a minimum of 2 years of college and health care coverage in Albuquerque, New Mexico. Thomas (2006) found that "silence and societal contradictions' were the two dominant themes that emerged from participants' narratives (p. 360). Silence was related to unspoken messages that African American women experience within the home and community. African American women reported that breasts were viewed as sexual organs and were not discussed in the early years of their

development; therefore, they had feelings of confusion, shame, and imperfection if a breast abnormality were discovered (Thomas, 2006). Societal contradictions pertain to the influence of society's portrayal of an appealing female body to be endowed with large breasts (Koff & Benavage, 1998). The threat of a woman losing a breast or having a breast disfigured threatens her sexual appeal (Andsager, Hust, & Powers, 2000; Koff & Benavage, 1998; Thomas, 2006). Society wants women to participate in health-promoting behaviors such as BCS, but at the same time, society defines female sexuality by the size and contour of the breast (Thomas, 2006).

Thomas (2006) also found that the African American women in the study felt that health care providers did not communicate to them what to expect during a BCS mammogram procedure and did not take the time to explain the results to them. Health care providers' poor communication practices about the BCS procedure perpetuated feelings of shame, confusion, and imperfection among the African American women (Thomas, 2006). Silence and societal contradiction promoted mixed emotions among the African American women that resulted in reluctance and delay in obtaining BCS mammograms (Thomas, 2006).

African American women who had a negative experience at their first BCS mammograms were more likely not to adhere to breast screening guidelines than African American women who had had a positive experience at their first BCS mammograms (Thomas, 2006). Although Thomas (2006) was not able to fully answer her study's objective (i.e., "Is there an association between African American women's past experiences with their breasts and BCS behaviors?"), the findings provided insight into

African American women's experiences about their breasts and breast screening through cognitive reflection.

Thomas (2006) also suggested that researchers have not explored the relationship of African American women's experiences to breast screening behaviors across various age groups. Additional research into African American women's breast screening experiences across the lifespan will help health care providers and policymakers to influence African American women's screening behaviors for positive cancer outcomes. These study findings cannot be generalized to African American women ages 65 and over because the study sample included only African American women ages 42 to 64. However, the findings do offer a platform for identifying themes in African American women's breast care behaviors and providing a framework for comparisons to older African American women.

Bynum et al (2005) conducted a quantitative, retrospective study using a random sample ( $N = 722,310$ ) examined the patterns of mammography use by age, race, and risk of death in female Medicare beneficiaries ages 65 and over from the Standard Analytic File of paid claims between 2000 and 2001. The distribution of the sample was European American ( $n = 639,170$ ), African American ( $n = 57,726$ ), and Other ( $n = 25,414$ ). Overall, 52% of the women age 65 to 69, compared to 11% of women ages 85 and older, had had a BCS mammogram within 2 years. Within the 52% of women ages 65 to 69, the race distribution was 40% European American, 30% African American, and 28% Other. European American women were more likely to receive BCS mammograms than African American women. Age was shown to reduce the likelihood of screening independently of

life expectancy, and nonadherence to BCS mammogram was associated with poor prognosis. Healthy older women ages 70 and over with the fewest comorbidities were 1.61 times less likely to be screened than younger women ages 65 to 69. African American women within the younger and older age groups persisted to have lower BCS mammography rates than European American women within the same age groups (Bynum et al., 2005).

A racial disparity continues to persist in that African American women, in comparison to their European American counterparts, have lower mammography screening rates outside of poorer health status (such as limited health maintenance, and failure to follow up with symptoms, etc.; Bynum et al., 2005). This racial disparity in mammography screening rates has been attributed to access barriers (transportation, copayments, functional impairments); personal preference (beliefs about risk and benefits); biases in provider recommendations (provider referral patterns); or differences in quality of care provided (Bynum et al., 2005; O'Malley, Earp, & Harris, 1997). A potential limitation of the current study was the source of the data, which may have included errors in coding medical conditions affecting propensity (probability) scores of dying (Bynum et al., 2005). The study provided insight into the factors affecting older African American women's BCS practices and highlighted the need for interventions to increase BCS mammography among older African American women.

A retrospective study review was conducted by Levine et al. (2008), the Compressed Mortality File of the National Center for Health Statistics, including 230 counties in the United States, to determine the reasons for disparities of breast cancer



mortality between older African American and European American women. Data for African American and European American women ages 65 to 74 from 1979 to 2003 (12 years prior and 12 years post-Medicare mammogram benefit) were reviewed to determine whether breast cancer mortality rates were the same and where disparities existed. The results of Levine et al (2008) showed that before Medicare coverage for mammography was initiated in 1991, the breast cancer mortality rates for African American and European American older women were 134.2 and 133.5 per 100,000, respectively (Levine et al., 2008). Following Medicare mammography coverage in 1991, the breast cancer mortality rates fell more dramatically for older European American women than for older African American women, with older European American women's mortality rate of 110.6 per 100,000 and older African American women's rate of 129.6 in 2003 (Levine et al., 2008).

Levine et al (2008) also found that older African American women used BCS mammography benefits less than European American counterparts did, which could explain the increased breast cancer mortality rate among older African American women. Older African American women's underutilization of mammography benefits also may be associated with poverty, comorbidities, and social factors. However, more epidemiological studies are needed to identify the social factors that make older African American women more vulnerable than others with available Medicare mammography benefits (Levine et al., 2008). The findings in Levine et al (2008) will also help to understand the utilization of mammography benefits in the group of older African American women in this study.

### **Abnormal Mammography Follow-up Behaviors (African American Women)**

This review was limited to studies that focused on African American women's timely follow-up for diagnostic resolution after abnormal mammogram result and identification of the barriers (e.g. social, financial, etc) to follow-up behaviors. Chang et al. (1996) of 317 women ages 33 to 85 used records from the University of California at San Francisco Mobile Mammography Screening Program to examine whether race or ethnicity was a predictive factor for timely follow-up of abnormal mammography results. Forty-eight percent of the women in the study sample were ages 50 and older and included European American (64%), Latinos (16%), Asians (12%), and African Americans (8%).

Chang et al. (1996) grouped the women into two categories: European American or non-European American. Age was not found to be a predictor of timely follow-up after abnormal mammogram results; therefore, the ages of the women were not associated with their use or underuse of mammography screening. Women who achieved timely diagnostic resolution of abnormal mammography results were more likely to proceed promptly with treatment. Non-European American women were less likely to have a biopsy for diagnostic resolution than European American women. Most of the non-European American women received health care services at community and public health clinics; the European American women were more likely to have primary care providers (Chang et al., 1996). This study did not have an adequate sample of African American women, nor was there pertinent information on the follow-up practices of older women who had received abnormal results. Chang et al. (1996) identified the need for additional

research to explore the reasons for less timely follow-up of abnormal results among non-European American women. The results of Chang et al (1996) can help to provide a baseline for understanding older African American women's follow-up practices of abnormal mammogram in this study.

Jones et al (2005) conducted a prospective study of 1,451 women (who received BCS mammograms between October 1996 and January 1998 in Connecticut) to examine the differences in follow-up of abnormal mammograms by race or ethnicity. The study cohort stratification included African American women ( $n = 635$ ) and European American women ( $n = 816$ ). U.S. census data and survey at mammography facilities were used to identify the facilities that were more likely to provide services to African American women and European American women. Seventy-three women were under the age of 50, and 103 were ages 50 or older (Jones et al., 2005). Of the total sample, 176 women were recommended for follow-up, 146 women (88%) for immediate follow-up and 12% for short-term (3-6 months) follow-up. Over 28% of the women with abnormal results for immediate or short-term follow-up had no recommended follow-up testing within 90 days of the return date. More than 25% of the women with abnormal mammography results did not have additional diagnostic testing within 3 months.

Jones et al.'s (2005) findings were consistent with several other studies. Gwyn et al, (2004) examined the differences between African American women and European American women ages 20 to 54 who had newly diagnosed breast cancer. The findings in Gwyn et al (2004) showed that African American women had longer diagnostic delay ( $\geq 3$  months) and treatment delay than European American women. Poor communication of

screening results on the part of radiologists and providers was noted more frequently with African American women in comparison to European American women (Gwyn et al., 2004). The findings of Gwyn et al (2004) and Jones et al (2005) showed that diagnostic delay is a reality among African American women BCS experiences. Therefore, this study will determine if diagnostic delay is present among older African American women and the contributing factors associated to the delay.

Another study by Yabroff et al (2004) of 1,901 women retrospectively selected from the National Health Interview Survey of 2000 also found younger women to be less likely to follow up abnormal mammography results. Many physicians perceive the risk of breast cancer to be lower in women under the age of 50, so they fail to recommend aggressive follow-up of abnormal breast findings (Yabroff et al., 2004). In Jones et al.'s (2005) study, African American women had lower SES related to employment, education, and occupational status in comparison to European American women. African American women depended more than European American women on public transportation or transportation by someone else to attend follow-up appointments. Forty percent of African American women, in comparison to 19% of European American women, did not receive adequate follow-up of abnormal mammogram results. There was a significant association of lower SES, not being married, no regular primary care provider, and painful mammogram procedure with inadequate follow-up (Jones et al., 2005).

One of the limitations of Yabroff et al.'s (2004) study was the absence of age stratification among African American women (e.g., 65 years of age and over), nor were

there any hints to differences in follow-up behaviors between older and younger women. Therefore, the results of this study cannot be generalized to older African American women's follow-up behaviors after receipt of abnormal mammogram results. Although the results were not specific to older African American women, the findings suggested that improved patient tracking by health care providers is necessary to ensure African American women's adherence to timely follow-up of abnormal BCS mammogram results. Yabroff et al (2004) findings will also help to understand the role that providers play in tracking older African American women's follow up practices in this study after receiving abnormal mammogram results. Inadequate follow-up after abnormal mammograms is a contributing factor to African American women being diagnosed with late-stage breast cancer and having more aggressive tumors. Yabroff et al. recommended additional research to understand patient and clinical factors that contribute to delay or lack of follow-up of African American women (across the life span) with abnormal mammogram results.

Welch & Fisher (1998) conducted a quantitative retrospective study to examine the Medicare National Claims History System of women ( $N = 23,172$ ) ages 65 and older from January 1, 1995, until April 30, 1995, and to determine the frequency and timing of diagnostic testing after an abnormal BCS mammogram. The participants were tracked for 8 months after their initial screening mammograms to determine their follow-up behaviors. Follow-up behaviors for women were categorized as breast imaging procedures, including diagnostic mammogram and breast ultrasound, and biopsy

procedures, that is, methods of obtaining tissue samples such as fine-needle aspiration, core-needle biopsy, and excisional biopsy.

BCS mammography was highest in the age group 65 to 69 (13.9%), with results in the other age groups as follows: 70 to 74 (11.7%), 75 to 79 (9.4%), and 80 to 84 (6.4%), respectively (Welch & Fisher, 1998). Of the 1,395 women who received diagnostic mammograms, approximately 55% of the women had a diagnostic mammogram within 30 days of the screening mammogram, and 40% had a diagnostic mammogram within 91 to 240 days, which can be inclusive of 6-month follow-up X-rays. A total of 573 women underwent breast biopsies, with approximately 55% receiving a biopsy within 30 days; 50% of the women waited at least 21 days before having their biopsies (Welch & Fisher, 1998).

The limitation of this study was that Welch and Fisher (1998) failed to describe sample characteristics according to racial classification and other demographics. The researchers implied that older women between the ages of 65 and 69 are more likely to be compliant with BCS mammography, but they could not explain why. Overall, the study provided information about the general follow-up practices of Medicare beneficiaries in 1995; however, it failed to provide data on older African American women's follow-up practices.

Welch and Fisher's (1998) study has been the only one to examine the BCS behaviors and abnormal mammogram follow-up practices of older women who are Medicare beneficiaries. This study supported the need for additional inquiry into older African American women's (i.e., women enrolled in Medicare insurance plan) BCS and

follow-up practices of abnormal mammogram results. Welch and Fisher's (1998) findings suggested that enrollment in the Medicare program will increase access to health services or guarantee older African American women's participation in BCS and abnormal mammogram follow-up.

Kerner et al (2003) conducted a study with 184 African American women ages 44 to 55 from screening clinic sites in New York after an abnormal BCS mammograms looked at the role of SES, breast cancer risk, system barriers, and cognitive-attitudinal factors in time to diagnostic resolution. The sample included all English-speaking African American, non-Hispanic American women, with complete interview and medical record review requiring follow-up within 3 months (main outcome measure) between July 1996 and June 1998 (Kerner et al., 2003).

Of the 184 African American women, 73% were born in the United States; 71% were never married, were separated, were divorced, or were widowed; and approximately 39% had family incomes at or below the 1997 U.S. census-defined poverty level. Thirty-nine percent of the women did not have a diagnostic resolution within 90 days of their abnormal mammogram results. African American women with highly suspicious abnormal findings for breast cancer were more likely to be diagnosed within 90 days than African American women with low, suspicious abnormal mammogram results. African American women with a history of prior abnormal mammogram and benign breast findings were 60% less likely to be diagnosed within 90 days than African American women with no prior history of breast abnormalities (Kerner et al., 2003).

African American women who had open communication with their health care providers or diagnostic technicians about mammography results and next steps to follow-up were more likely to achieve a diagnosis within 90 days than African American women with poor communication with their health care providers (Kerner et al., 2003). African American women who had fatalistic beliefs or high levels of anxiety were more likely to achieve a diagnostic resolution over 90 days than African American women with no fatalistic beliefs or low levels of anxiety (Kerner et al., 2003). Approximately 39% of the women did not have a diagnostic resolution within 90 days; 28% had no diagnostic resolution past 180 days (Kerner et al., 2003). Women with a delay of 3 to 6 months in diagnosis and treatment had a 12% lower 5-year survival than women diagnosed and treated within 90 days (Kerner et al., 2003; Richards et al., 1999). There was no relationship between SES and timely diagnostic resolution after an abnormal mammogram.

Predictive factors for delay in diagnostic resolution were identified as the extent of abnormality on mammogram and the women's history of prior breast abnormality (Kerner et al., 2003). Kerner et al. (2003) recommended that more effective communication between health care providers and diagnostic technicians could result in African American women achieving a timely diagnostic resolution after abnormal mammography results. The study sample did not represent African American women ages 65 and older, so the findings may or may not be true for older African American women. This study will help to determine if Kerner et al (2003) findings on predictive



factors for delay in diagnostic resolution for women under 65 years is true for older African American women.

A qualitative interview study was conducted with 64 women ages 40 and older to determine the barriers to receiving diagnostic resolution following abnormal BCS mammograms (Allen et al., 2008). The participants were selected from three breast care service sites in Boston, MA (i.e., community health center, mammography mobile-van, and a breast center at an urban hospital) through purposeful sampling. The racial classification of the sample was 40 Hispanic Americans, 42 African Americans, two European American, and one other. The age ranges of the participants were 40 to 49 ( $n = 34$ ), 50 to 59 ( $n = 21$ ), 60 to 69 ( $n = 7$ ), and 70 and older ( $n = 2$ ). Timely follow-up was defined using BI-RADS classification: Category 3 - diagnostic procedure within 6 months plus 60 days of abnormal mammogram; Categories 4 and 5 - having a repeat mammogram, ultrasound, and biopsy within 60 days of the abnormal mammogram (Allen et al., 2008). Allen et al (2008) findings showed that most of the participants had a delay in follow-up attributed to (a) dissatisfaction with how providers and clinic staff communicated to them about their abnormal mammogram results and recommended diagnostic testing; (b) disrespect and mistreatment from health care providers and clinic staff; (c) logistical barriers to diagnostic testing (e.g., complaints of lengthy clinic wait times, limited appointment times, transportation problems, and follow-up of diagnostic procedures at unfamiliar locations); (d) anxiety and fear of dying from breast cancer; and (e) few or no support systems (Allen et al., 2008).

One limitation of the study was the inability of Allen et al. (2008) to corroborate the participants' self-reported follow-up behaviors with medical records. Corroboration of the data would have controlled recall bias and ensured that self-reported follow-up times were reflected in the medical records. Further research was recommended to address and understand the beliefs and attitudes of women, health provider practices, and patient-provider communication with abnormal results and follow-up diagnostic testing (Allen et al., 2008). The study is relevant to the current study because it highlighted the need for understanding the factors relating to delay in timely follow-up in women at risk for increase breast cancer mortality.

A longitudinal study of 483 African American women ages 40 to 75 was conducted to meet the goals of the Boston Racial and Ethnic Approaches to Community Health (REACH) 2010 Breast and Cervical Cancer Coalition case management intervention program (Clark et al., 2009). The study had several objectives, but the two objectives pertinent to this study were to assess social determinants to baseline mammography screening patterns, and determine whether women with increased medical and social risks who completed standardized health questionnaires and received case management services can participate in screening mammography and obtain timely follow-up of abnormal mammogram results (Clark et al., 2009).

Clark et al. (2009) found that a social determinant for women obtaining a recent BCS mammogram (within 2 years) was whether they had regular health providers or housing concerns. Seventy-nine percent of the women without housing concerns obtained BCS mammograms within 2 years, versus 64% of women with housing concerns

( $p < .05$ ; Clark et al., 2009). The researchers also found that self-rated comorbidities and the locations where the women received care were predictors of timely follow-up of abnormal BCS mammograms. Assessments of social determinants for BCS mammography were better identified in primary care settings at academic hospital clinics and hospital-licensed community health centers than at freestanding community health centers (Clark et al., 2009).

Several limitations of the study meant that the findings were not generalizable to older African American women (Clark et al., 2009). The first limitation was that the study had a small sample of participants under the age of 50 ( $N = 233$ ) and made no mention of the number of women ages 65 and older. The mean age of the participants was 51; therefore, the sample was not representative of older African American women. The second limitation was that the study used standardized assessment tools that did not allow the participants to respond openly about other barriers to BCS mammography and follow-up of abnormal results. The third limitation was that Clark et al. (2009) did not assess the participants' beliefs or perceptions about BCS mammography or their overall experience, which would have been helpful in assessing their health-screening behaviors.

Clark et al. (2009) recommended that social assessments of African American women are needed for effective navigation to initiate BCS mammography and follow-up of African American women and that further research be conducted to discover building points for improving clinical systems to increase mammography use by African American women. However, the experiences of African American women or older African American women with BCS mammography and abnormal results must be

understood prior to making improvements in social and clinical systems for increasing mammography use and follow-up. The current study provided better insight and generated meaning into the experiences of older African American women with BCS mammograms and abnormal results.

### **Avoidance Behaviors in Older Women**

One of the constant themes observed in several articles reviewed about BCS mammograms and the follow-up behaviors of African American women or older African American women regarding abnormal results was avoidance behavior. The literature discussed in the previous sections (Allen et al., 2008; Kerner et al., 2003; Jones et al., 2005; Welch & Fisher, 1998; and Yabroff et al., 2004) indicated that although some African American women or older African American women may be knowledgeable about BCS and the process for follow-up after abnormal results, they delayed follow-up or showed a lack of interest in regular BCS mammography. Therefore, the following articles were reviewed to identify specific avoidance behaviors of older women.

A longitudinal study conducted by Bundek, Marks, & Richardson (1993) examined 270 older Hispanic American women's locus of control beliefs in cancer screening of older Hispanic American women. Study participants were ages 55 and older, with 83% of the participants ages 65 and older from the Project to Your Health Los Angeles program (Bundek, Marks, & Richardson, 1993). Internal control relevant to these women was defined as the belief that health outcomes are determined by health behaviors and decisions to seek health care. Women were influenced to have positive internal control when they paid attention to health-related information such as pamphlets,

brochures, and media. Women with a positive belief about cancer screening with strong internal control were more engaged in cancer screening practices.

Bundek et al. (1993) also found that women who had external control exerted by powerful others (i.e., physicians, support systems, etc.) were more likely to engage in cancer screening practices. Women without internal control or external control by powerful others were more likely to avoid cancer screening practices completely (Bundek et al., 1993). Bundek et al. (1993) findings suggested that older women who have ongoing appointments with their regular physicians and have strong support systems, such as family and friends, are more inclined to participate in cancer screening.

Abdulraheem (2007) conducted a qualitative study of 1,125 older Nigerians, used survey and interview methods to assess the health needs and determinants of health-seeking behaviors. Of the total sample, 608 were women, and 454 (76%) of the 608 were older women ages 65 and over (Abdulraheem, 2007). Older women with polymorbidity, such as joint pain, generalized weakness, poor sight, and fatigue, were more likely to avoid health-seeking practices. Older women were more likely to have comorbidities than males, and they were more dependent on others and societal systems to maintain quality of life, factors that increased their vulnerability. Despite having many comorbidities, the older women underutilized health care services. Abdulraheem (2007) postulated that underutilization of health care services by older women could be related to their dependent care-giving roles. In addition, SES was paramount in determining the health-seeking behavior of the older women.

Abdulraheem (2007) and Bundek et al. (1993) studies identified possible determinants for older women's underutilization of health care services. Abdulraheem (2007) and Bundek et al. (1993) findings will help to provide insight into the themes of older African American women's BCS and followup experiences in this study.

### **Comparisons of Outcomes and Points of View**

Social constructivism philosophy has been used by researchers to identify different points of view of individuals in scientific inquiry (Crotty, 1998; Patton, 2002). Social constructivism highlights the unique experience of each individual and calls for respect for different viewpoints of similar events or experiences (Crotty, 1998).

Researches in the area of BCS mammograms and the follow-up of abnormal results have targeted ethnic or racial groups to identify differences in mammography utilization, follow-up behaviors, and perceptions of experience.

The health belief model, social cognitive theory, transtheoretical model, and many others were used as a framework for researchers to develop interventional studies that may improve mammography screening or lead to positive change in African American women's health behaviors. Some researchers have attributed the underuse of mammography screening and delays in the follow-up of abnormal results to social system barriers, such as propositional attitudes (e.g., belief, hope, or desires), lack of knowledge, comorbidities, competing priorities, lack of confidence in clinical system, and age. Other researchers have associated the underuse of BCS mammography and delays in the follow-up of abnormal results to failed clinical systems such as the lack of BCS

guidelines for women ages 70 and over, poor provider communication, provider bias, and negative diagnostic experiences.

Thomas (2006) identified the BCS experience of African American women ages 42 to 64 by effectively demonstrating the use of the narrative approach to obtain baseline data in the participants' original voice. These participants came from a large Midwestern city. By interviewing them, Thomas was able to capture their stories about the development of and changes to their breasts across the life span. Overall, the literature provided concepts associated with African American women's poor breast cancer outcomes. Some of the findings from quantitative studies were not generalizable because of several limitations, including small sample size; source of data; lack of descriptive characteristics (e.g., age, racial/ethnic classification) of sample; and noncorroborated data. The findings from Thomas (2006) identified the gaps in information about older African American women's experiences with BCS mammography and abnormal results, which may provide insight into the high breast cancer mortality and provide validation for this study.

### **Relationship of the Study to Prior Research**

There are two structures to the application of the narrative approach. In the first structure, the researcher requests stories from the participants about their experiences to understand the setting, interactions, circumstances, and perceptions. In the second structure, the researcher constructs a story of the participants' experiences collectively with interpretations of how, when, and why using a theoretical model to generate meaning (Creswell, 2007).

I am aware that to understand the factors that contribute to a health problem, I must have an understanding of what is already known about the problem. Therefore, I retrieved literature that embodied key terms related to the research question and the problem statement to understand the breadth and depth of the utilization of BCS mammography and the receipt of abnormal results. I analyzed and evaluated the findings of each study, limitations, recommendations, and future research areas related to BCS mammography and follow-up of abnormal results. From the literature reviewed on experiences, attitudes, and behaviors of African American women with BCS mammograms and abnormal follow-up results, it was evident that to understand an experience of an event required the participants' perceptions and descriptions of the event.

I identified the narrative approach as the most applicable framework to understand the experiences of older African American women with BCS mammography and the receipt of abnormal results, guide the description of events, and provide details through open-ended questioning. The application of the narrative approach not only provided information about the experiences of older African American women related to BCS mammography and abnormal results but also identified implications for change to promote positive breast cancer outcomes among older African American women.

### **Rationale for the Conceptual Framework**

The conceptual framework is used to explain the relationship among the key variables or concepts, theories, and beliefs guiding the development of the research questions (Maxwell, 2005; Miles & Huberman, 1994). That framework may include one



or more theories that work synergistically to identify the research problem, generate research questions, conduct narrative inquiry and narrative analysis, and theorize about the data. In the literature, conceptual framework and theoretical framework have been used interchangeably with similar applications (Miles & Huberman, 1994).

The QCM (Duffy et al., 2007) was the key midrange theory used to understand the role of social and clinical systems in the breast cancer mortality rates of older African American women. According to McKenna (1997),

Mid-range theories are more focused than grand theories . . . have fewer concepts and variables within their structure are presented in a more testable form, have a more limited scope and have a stronger relationship with research and practice.

(p. 144)

The QCM is inclusive of the theory of human caring (Watson, 1988), and the quality model (Donabedian, 1988, 1992). The CRT works with the QCM because of its focus on race, which was of great importance in this study. When used together, the theories provide a more comprehensive framework for conducting assessments into health problems to protect and promote quality care in individuals, especially when race matters (Donabedian, 1988, 1992).

In one study, a cross-sectional sample of 236 inpatients was interviewed to explore the structure and processes that influenced patients' perceptions of quality nursing care (Wagoro, Othieno, Musandu, & Karani, 2008). Using the QCM, Wagoro et al. (2008) identified the physical setting, personality, and positive interpersonal relationships of nurses as the structural and process factors that influenced patients'

perception of nursing care. Duffy et al. (2007) used the QCM to assess and provide solutions to poor nursing care delivery at a Maryland hospital. A team of staff members, specialist, and administrators were formed into a group to provide solutions to the poor delivery of nursing care. Using the QCM, the group organized patient care into categories according to resource allocation, environment, nursing roles and responsibilities, communication, and caring practices. The group made recommendations for improvements in patient care delivery based upon the categories and were able to justify hospital expansion to possible profitable units (Duffy et al., 2007). Duffy et al. (2007) and Wagoro et al. (2008) demonstrated the application of the QCM to explore the perceptions or experiences of individuals to events as well as provide a framework to develop solutions and intervention programs.

### **Literature Related to the Methodology**

Qualitative research inquiry can take many approaches. Studies that measure the illnesses and determinants of diseases in populations, evaluate health intervention programs, and assess the impact of diseases on specific populations have used qualitative methodology. However, some of these studies were based upon what was known about a specific problem, whereas others sought to describe the unknown. In this study, I sought to understand older African American women's experiences with BCS mammogram and abnormal results; therefore, the narrative approach was selected to best solicit the participants' stories of their lived experiences.

The narrative approach draws from the traditions of drama, oral history, sociology, psychology, and philosophy to understand the storytellers' experiences

through the emotional, physical, and social context of that time (Connelly & Yoder, 2000; Marshall & Rossman, 1995). The holistic understanding of experiences through narration addresses the intersectionality of individuals, cultures, and environments that highlights the complexity and variation of the stories (Connelly & Yoder, 2000; Marshall & Rossman, 1995).

Although this approach is useful, it can have drawbacks. One of the main downsides to the narrative approach is its time-consuming nature and the laborious efforts to maintain rigor in transcript analysis to ensure that the participants' voices are preserved. The voice of the researcher in the findings should be inherently sparse to decrease subjectivity (Czarniawska, 2004). Frequent problem areas for researchers new to narrative approach include a lack of understanding that there is no generalization (because findings are specific to the sample, context, and environment at that time), but that transferability to another setting is possible, and a small study sample size because it is determined by data saturation, not strength of analysis consistent with quantitative studies (Connelly & Yoder, 2000).

### **Use of Stories to Describe and Understand**

Eide (2006) described the experiences of 11 native Hawaiian women ages 44 to 82 diagnosed with breast cancer to understand factors associated with increased breast cancer mortality. A narrative approach was adopted because little was known about native Hawaiian culture and the health beliefs that may have affect the women's health behaviors (Eide, 2006). Participants were interviewed using open-ended question for 45 to 60 minutes and asked to share their breast cancer stories. Three general themes were

generated from the interviews using interpretive phenomenology: (a) context of discovery, that is silence or ignorance of cancer history; (b) context of transformation, namely, physical, spiritual and emotional; and (c) context of life realignment, or the regaining of balance (Eide, 2006). Eide was successful in answering the research question through the narrative approach, and the results revealed the increased breast cancer mortality of Native Hawaiian.

Thomas (2004) described the association of emotions to the experiences of 12 African American women ages 42 to 63 and their BCS behaviors. The themes that arose from the analysis of the interview transcripts included (a) seasons of breast awareness: recollection of breast development and changes during childhood; (b) womanhood: personal meaning of being a woman; (c) self-portraits: how women view their or mothers' or peers breasts, and the media's depiction of breast; (d) breast cancer and cancer beliefs; (e) breast cancer experiences; and (f) recommendations for change (Thomas, 2004). Through the narrative approach, Thomas was able to obtain in-depth understanding about women's recollections and emotions about experiences with BCS and other health behaviors in an area that had not been the subject of prior research.

A narrative feminist methodology was used to understand the experiences of nine women living through breast cancer in a rural town. These women were ages 44 to 75 who were living 5 and 32 years after breast cancer diagnosis and had received mastectomy for breast cancer (Rogers-Clark, 2002). In-depth, face-to-face interviews were conducted, with each interview lasting between 1 and 4 hours; follow-up telephone interviews were conducted at a later interval. The postmodern feminist theoretical

framework was used to guide and maintain rigor in the analysis of transcripts. Rogers-Clark (2002) results showed that 90% of the women felt that rural living benefited them during and after their breast cancer diagnosis. Overall, Rogers-Clark (2002) recommended that cancer resources to support rural cancer survivors be incorporated into the current strengths of the rural community.

These three researchers (Eide, 2006; Rogers-Clark, 2002; Thomas, 2004) demonstrated the effective use of the narrative approach to obtain information about a health problem within a specific population. I employed a similar application of the narrative approach described above to obtain the recollections, feelings, perceptions of BCS and receiving abnormal mammogram results from a sample of older African American women. The goal of this study was to describe the BCS and abnormal result experiences of older African American women to understand the factors that contribute to increase breast cancer mortality in this population.

### **Alternative Methodologies**

No other methodology besides the narrative approach can broadly address the unknown human experience about an event that will produce rich descriptive data about individual experiences (Boyd, 1993; Connelly & Yoder, 2000). Therefore, I conducted an in-depth review of the literature about narrative inquiry, interview techniques, and data analysis methods to be true to the tradition of narrative inquiry.

### **Summary of the Literature Review**

The studies that were reviewed covered four main topics: BCS trends and recommendations, BCS behaviors of African American women, abnormal mammography

follow-up behaviors of African American women, and avoidance behavior of older African American women. African American women are at risk for breast cancer mortality because of their underuse of mammography screening and their delay in follow-up. The literature showed that African American women's underuse of mammography screening and delay in follow-up is associated with the following variables: provider biases with BCS recommendations, competing priorities, personal experiences, poor communication, silence and societal contradictions, follow-up behaviors, and negative diagnostic experience. A conceptual framework was used to summarize and graphically depict the findings of the study.

### **Conceptual Framework**

A conceptual framework provides a visual depiction of a group of related variables behind the study design (Ulin et al., 2005). It can be used to show associations or relationships of variables related to identifying gaps in the literature. It also helps to formulate research questions and a context for others to understand the problem (Ulin et al., 2005). The following discussion is a summary of variables or concepts derived from the literature reviewed and is used to construct the conceptual framework as it relates to African American women's underuse of mammography screening and delay in follow-up of abnormal mammogram results.

#### **Provider Biases With BCS Recommendations**

BCS mammography for older women has been proven to decrease the incidence of late-stage breast cancer and breast cancer mortality. Controversial findings remain regarding the benefits, harms, and cost effectiveness of BCS in women ages 70 and older.

The USPSTF (2002) made recommendations for timely screening in women ages 50 to 69, but it handed the responsibility for providers to recommend screening for women ages 70 and older according to predicted life expectancy. However, the USPSTF did not establish a standard guideline for providers to predict life expectancy (U. S. Preventive Services Task Force (USPSTF), 2002) The AGS (1999) was more liberal than the USPSTF, recommending BCS mammograms until age 75, but it still left life expectancy to be determined by providers for women over 75 (Bynum et al, 2005). Bias is evident when provider recommendations for BCS mammograms for women over the age of 70 are made haphazardly based upon age, race, SES, appearance, support systems, or patient request. The lack of consistency among providers for BCS mammograms has contributed to a significant decline in the number of older African American women receiving BCS after age 70, which is a predictor for increased breast cancer mortality in that age group.

### **Competing Priorities**

Older African American women are challenged with health care activities to maintain their health to guard against such illnesses as diabetes mellitus, heart disease, respiratory disorders, and general debilitation. These women may view BCS mammograms as a competing factor with their daily battle to manage their comorbidities. Older African American women also serve as primary caregivers for their children, grandchildren, or other relatives and they are not inclined to go for BCS mammograms because it is a threat to their availability to care for loved ones. Therefore, older African American women may choose not to participate in BCS mammograms despite recommendations from health care providers because of their competing priorities.

**Personal Experiences**

Older African American women may be influenced not to participate in BCS mammograms because of fatalistic beliefs resulting from personal experiences of family members or close friends dying from breast cancer (Powe, Daniels, Finnie, & Thompson, 2005; Powe et al., 2006; Sadler et al, 2007). On the other hand, older African American women are motivated to have BCS mammograms when they have personal experience with BCS mammograms BCS, diagnosis, treatment, or the death of family members or friends (Sadler et al, 2007). Older African American women are influenced to have BCS mammograms when they are accountable to family, friends, and providers for their health maintenance.

**Poor Communication**

Poor communication from radiologists and health care providers during BCS mammograms and after receiving abnormal results create mistrust, feelings of shame or confusion, and feminine imperfection among African American women, leading to delays in follow-up and future BCS practices (Gwyn et al., 2004). Some African American women attribute their racial and ethnic origin as the reason for provider poor communication and disrespectful treatment during BCS mammograms or follow-up diagnostic testing.

**Silence and Societal Contradictions**

Unspoken messages that African American women experience as youth within the home and community lead to silence about the breast because it is viewed as a sexual organ (Thomas, 2004). Contradictory media messages in society about health promotion



and female beauty, defined as having full or large breasts, create a threat to African American women's sexual appeal, which influences them not to participate in BCS mammograms (Thomas, 2004; Thomas, 2006).

### **Follow-up Behaviors**

African American women are more likely to receive prompt treatment if they follow up in a timely manner after receiving abnormal BCS mammogram results (Kerner et al., 2003b). Predictive factors for delay in diagnosis of abnormal results in African American women include extent of breast abnormality and past history of abnormal breast findings (Kerner et al., 2003b). Some African American women with a history of abnormal mammograms or abnormal breast findings are reluctant to complete additional diagnostic testing because they take for granted that the findings will be benign.

African American women without consistent primary care providers rely mostly on community clinics for health care needs and are more inclined to delay follow-up of abnormal BCS mammogram results (Allen et al., 2008b). When African American women have primary care providers who communicate openly with them about BCS mammograms, abnormal findings, and breast treatment, they are more motivated to reach diagnostic resolution as soon as possible (Clark et al., 2009). African American women ages 65 to 69 are more engaged in BCS mammograms than women ages 70 and older, and they will undergo diagnostic mammograms and breast biopsies immediately after receiving abnormal mammogram results (Welch & Fisher, 1998a). African American women who view breast cancer as a death sentence and experience high anxiety about BCS mammograms are more likely to delay follow-up after receiving abnormal results.

Younger women delay follow-up more than women ages 50 and over because they perceive their risk for breast cancer as low see themselves as healthy otherwise (Yabroff et al., 2004). Inadequate follow-up or delay in diagnostic resolution after an abnormal mammogram contributes to late-stage breast cancer diagnosis and an increase in breast cancer deaths.

### **Knowledge Deficit to Follow-Up**

Some African American women are lost to follow-up because they have no knowledge that they should follow up (Sadler et al., 2007). Radiology centers may fail to give women their results of abnormal mammogram testing, and providers may fail to discuss the need for follow-up diagnostic testing (Thomas, 2006; Sadler et al., 2007). This lack of knowledge can be detrimental to African American women because they may have a breast cancer that is untreated. Thus, when they later present with breast symptoms, they are diagnosed with late-stage breast cancer.

### **Negative Diagnostic Experience**

African American women who have experienced pain during a mammography procedure or who have had a negative experience (i.e., poor communication from diagnostic technicians, etc.) are more likely not to participate in BCS mammograms or even seek follow-up treatment after receiving abnormal results (Jones et al., 2005).

The conceptual framework (see Figure 4) provides a visual display of the variables (Maxwell, 2005; Miles & Huberman, 1994) discussed in the literature that were associated with the experiences of African American women under the age of 65 with BCS mammograms and abnormal results. The conceptual framework shows that many of

the variables influencing African American women's BCS behaviors are the same ones that lead to delays in follow-up after receiving abnormal mammogram results. Therefore, if African American women under the age of 65 are reluctant to participate in BCS mammograms, they are more likely to delay in follow-up because the variables are constant. This overtone of persistent avoidance behavior of African American women toward BCS mammograms and abnormal results creates a need for further inquiry into typical avoidance behaviors among older African American women.

### **Gaps in the Literature**

The reviewed literature did not provide any standardized recommendations for BCS of older women 70 years and older. There were no studies or comparative data on the BCS behaviors and follow-up of abnormal mammogram results among older African American women. This gap in the literature was surprising, especially because older women (i.e., 65 and over) have the highest risk for breast cancer and breast cancer mortality. Describing the experiences of older African American women with BCS and abnormal results will help providers and health policymakers to tailor breast care programs and establish BCS mammograms guidelines for women ages 70 and over to have a positive effect on breast cancer outcomes.

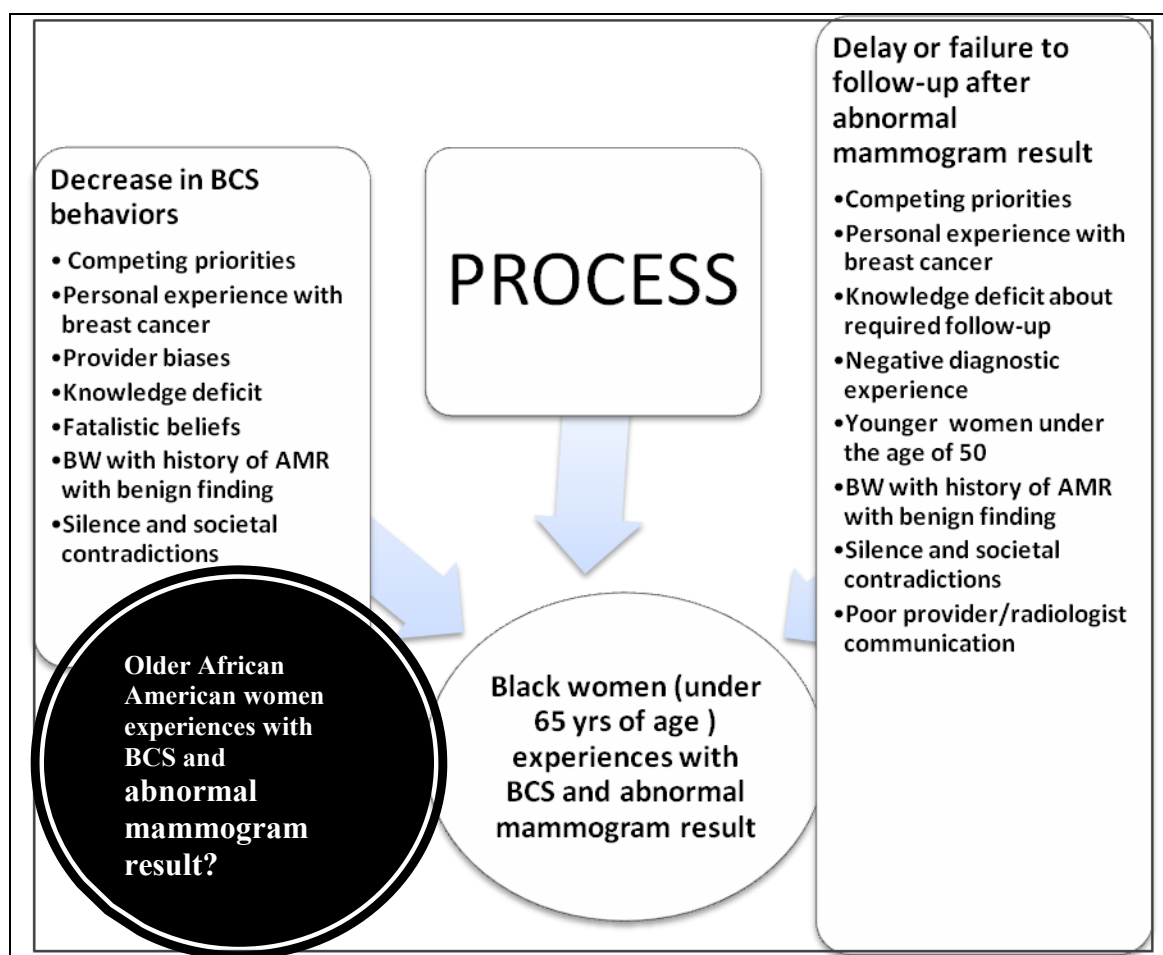


Figure 4. African American women's (65 and under) experiences with BCS and abnormal mammogram results.

### Summary

This chapter was divided into three sections to show the process, application and deductive meaning of literature reviewed. The first section was an account of the rigor in seeking literature related to the purpose of the study. The second section included a discussion of the literature related to BCS trends and recommendations, BCS behaviors in African American women, abnormal mammogram follow-up behaviors, avoidance behaviors, and relational viewpoints of the study. A conceptual framework showed the themes identified in the literature that dominated African American women women's

BCS and abnormal mammogram result experiences. The third section focused on literature relevant to the application of narrative inquiry that was used to obtain information about an unknown topic. This review provided overwhelming support for addressing the BCS mammogram and abnormal result experiences of older African American women as one way to decrease breast cancer mortality rates. Chapter 3 describes the methodology used to understand older African American women BCS experiences and their follow up behaviors of abnormal results. Chapter 3 begins with an introduction of the problem, followed by the research design, methods, sampling strategy and participant selection, researcher's role, consent process, data collection and data analysis procedures, and methods for evaluating the quality of evidence, feasibility and appropriateness.

## Chapter 3: Methodology

### **Introduction**

The projected graying of the United States should place breast cancer incidence, treatment, and mortality high on the agenda of public health officials. In the next 2 decades, the number of individuals age 65 and older will double from 35 million to 71 million, and women will outnumber the men by 30% (Department of Health and Human Services, 2010; CDC, 2010; NCI, 2010; Ries et al., 2008; SEER, 2008). Researchers have found a relationship between diagnostic delay, SES factors, beliefs, and culture, and an increase in breast cancer mortality among African American women ages 40 to 64; however, they have failed to research the same variables in the age group 65 and older (Caplan et al., 1996; Facione, 1993; Facione et al., 2002; Gordon, 2003; Pocock et al., 2007; Richards et al., 1999). The lack of standard recommendations for BCS among women ages 70 and older has created an open threshold for provider biases.

Currently, providers have to project the life expectancy of older women to 5 years or more to determine who should be referred for BCS (American Geriatrics Society, 1999; USPSTF, 2002). A gap in the research literature has existed on BCS behaviors and follow-up practices of older African American women with abnormal BCS mammogram results, despite high breast cancer mortality rates for more than 20 years (Ries et al., 2003; SEER, 2008). The narrative approach is one qualitative inquiry that can be used to unfold the stories of the lived experiences of older African American women who receive negative BCS mammogram results. Therefore, I employed a narrative approach (i.e.,

storytelling) to convey the lived experiences of the participants regarding their BCS mammogram experience and the receipt of positive results.

### **Qualitative Research**

Qualitative research is based upon the methodological use of theory to focus on complex relationships among individuals, cultural practices, social meanings, and the environment (Ulin et al., 2005). It begins with theoretical assumptions of the world in order to uncover meanings about a human problem and society. Qualitative researchers use the natural setting of individuals to collect data that are sensitive to the individuals' cultural and social settings (Creswell, 2007; Ulin et al., 2005). The findings of qualitative studies are multifaceted through systematic discovery (Ulin et al., 2005). Qualitative researchers rely upon the individual voices of the participants; observational descriptions of events, people activities, and behaviors; interpretation of the problem; the researcher's reflections; and interpersonal interactions that add to the body of literature and provide saliency or reason for action (Creswell, 2007; Patton, 2002; Ulin et al., 2005).

Observations facilitate direct and unequivocal findings of overt human behavior that the researcher uses to evaluate the feelings, attitudes, and experiences of the individuals observed (Singleton & Straits, 2005). The researcher takes field notes on human interactions, with a focus on individual behaviors and attitudes in specific settings. Information obtained from observations includes descriptions of people's behaviors, actions, activities, and interactions through human experiences (Patton, 2002). The advantage of observation is that it provides the researcher with firsthand knowledge about the participants' actions and explores topics that the participants might not talk about

while being interviewed (Creswell, 2003). The disadvantage of observations is that the researcher may seem to be intrusive into a participant's space or environment, and the researcher may lack effective observational skills (Creswell, 2003).

Written document reviews include the synthesis and analysis of specific excerpts, speeches, publications, reports, quotations, e-mail discussions, clinical documentation, and responses to surveys and questionnaires (Creswell, 2003, 2007). The advantage of document reviews is that they provide the researcher with information in the natural language of the participants and they are accessible multiple times and unobtrusive to the participants (Creswell, 2003; Patton, 2002). The disadvantages of document review are that the researcher may have difficulty accessing private or protected information and may have to retrieve documents that are incomplete and inaccurate (Patton, 2002; Trochim, 2005). If the researcher is interested in a secondary analysis of existing data (i.e., U.S. Census Bureau data, CDC data, minutes of a meeting, etc.) to retrieve information on systems, organizations, structures, processes, and outcomes, then document review (content analysis) is the most appropriate (Patton, 2002; Trochim, 2005).

## **Research Design**

### **Approaches to Qualitative Research**

Several approaches for qualitative research dictate how data are collected and the analysis strategies used to report the data. These approaches include, but are not limited to, narrative (descriptive), phenomenology, ethnography, and grounded theory (Creswell, 2007). After reviewing the variety of qualitative methods, the most appropriate method to



describe the experiences of older African American women with BCS and abnormal mammogram results is the narrative approach. The narrative approach was best suited for this study because it allowed me to obtain information from the participants to understand the chronicle of events ranging from their BCS mammograms to abnormal results and then to possible follow-up behaviors for treatment. The narrative approach is fundamental in understanding the what, when, why of the participants' experiences at the diagnostic centers after they had received abnormal mammogram results and the factors that could have contributed to a delay in follow-up and treatment and possible death.

The first step in understanding an experience is knowing what events occurred within the experience (Creswell, 2007). The description of the participants' experience provided detailed accounts of the internal and external processes that affected the participants' experiences with BCS mammograms and abnormal results. The most appropriate method of inquiry to solicit information from the participants was the interview because that method can provide a historical, narrative account of the women's breast care experiences in their original language and voices (Creswell, 2007; Seidman, 2006). Therefore, this study was defined as a descriptive interview study using narrative.

I used the narrative approach in this study because it can solicit rich, detailed information from individuals about the meaning they ascribed to their lived experiences (Creswell, 2007). Sometimes, researchers collect descriptions of events and behaviors and configure them in a chronological form using line plots (Creswell, 2007). The narrator's story may provide the researcher with information on interactions, setting, circumstances, and continuity of a specific experience (Creswell, 2007). The essence of a

narrative study is to provide descriptions of events that the participants had not yet previously considered and organized into a coherent story (Andrews, 2000; Creswell, 2007). The narrative approach is different from other qualitative approaches because it can be used to not only interpret information from the participants about their experiences but also to bring meaning to those experiences within the participants' social and environmental context (Clandinin & Connelly, 1994; Denzin & Lincoln, 1994). For the researcher to understand the experiences of the participants, a collaborative relationship between the participants and the researcher must be established (Clandinin & Connelly, 1994). The challenge of narrative research is that the researcher has to collect extensive data about an experience within an individual's life through active collaboration.

### **Other Qualitative Approaches**

The following discussion provides descriptions of other approaches used in qualitative research (such as phenomenology, grounded theory, ethnography) and their inapplicability to this study.

**Phenomenology.** A phenomenological qualitative study provides descriptions of the lived experiences of the individuals about a phenomenon, an event, or a concept to generate meaning (Creswell, 2007). In hermeneutical phenomenology, the researcher is focused on the interpretation and meaning of the lived experiences of individuals (Creswell, 2007; Moustakas, 1994). Phenomenology was not an appropriate approach for this study because the goal of the study was not to reduce and condense the participants' BCS and abnormal mammogram results experiences into a singular universal meaning, but to understand a possible multiplicity of experiences.

**Grounded theory.** Grounded theory research is different from phenomenological research because it extends beyond the descriptions of individuals' lived experiences to generate meaning and discover new theories (Creswell, 2007; Denzin & Lincoln, 1994; Strauss & Corbin, 1990, 1994). In grounded theory, the individuals provide an account of their experiences that contributes to the development of new theory. In the development of new theory, the researcher provides a general explanation of the process, behaviors, and interactions of the participants' experiences. By using grounded theory, the researcher is able to step back, recognize personal bias, think abstractly, remain open to criticism, be sensitive to the participants' experiences, and stay devoted to the study (Patton, 2002; Strauss & Corbin, 1990). Grounded theory was not appropriate for this study because I would have needed information about an experience before theories of that experience could have been formed. I sought to acquire information about an experience that was unknown; therefore, grounded theory would have been a premature approach.

**Ethnography.** Ethnography is based upon extensive field research and extended time in the field during which the researcher engages in direct observations of human behaviors and repeated interviewing of members of a particular cultural group in various social environments (Creswell, 2007; Moustakas, 1994). Ethnography requires the researcher to be immersed completely in the daily lives of the individuals to understand the meaning they ascribe to their behaviors, cultural practices, and group interactions (Creswell, 2007). The qualitative tradition of ethnography was not applicable to this study because I did not have access to a particular culture but only to particular

individuals. Thus, observation of a culture was not the purpose of this study, nor was it necessary to answer the research questions. The research questions of the study could be answered only by talking with the participants themselves in order to understand their experiences with abnormal BCS mammogram results.

### **Researcher's Process**

I conducted interviews to solicit detailed descriptions of the unknown processes or events during older African American women's experiences with BCS mammograms and abnormal results. Descriptions of the participants' BCS mammograms and follow-up procedures after receiving abnormal results provided information that can improve the structure, process, and outcome of breast care services among older African American women. Descriptions of the participants' experiences also provided a window into the BCS mammogram behaviors of older African American women, follow-up of abnormal results, provider practices, and diagnostic services, as well as a framework for future research (Creswell, 2007; Strauss & Corbin, 1994). Face-to-face, unstructured interviews were conducted with the participants to obtain in-depth descriptions and to capture the emotions of their BCS mammogram and abnormal result experiences.

Storytelling is basically a meaning-making process that allows individuals to select specific details from experiences that flow from their consciousness (Seidman, 2006). Great storytelling stirs the individual's soul and consciousness, which ultimately provides new insights into human problems and conditions (Reason & Rowan, 1981). I was able to experience the participants' BCS mammograms and abnormal results through their verbal and nonverbal responses to the interview questions.

The following research questions guided this study:

1. What are the experiences of a group of older African American women with BCS in Baltimore City? (That is, where did they go, what was their experience like at the diagnostic center, who did they talk to, what were they told at the end of their screening test, and so on?)
2. What is this group's experience with abnormal mammogram results after BCS? (That is, what do they do—talk with friends and family, keep the results a secret, read information on the web, get additional diagnostic test, and so on?)

The research questions were answered from the information obtained from the interview questions. The following sections of this chapter include a discussion of qualitative research, methods used in qualitative data collection, approaches for qualitative research, and an overview of the research design.

### **Method**

The purpose of any study dictates the data collection process (Weiss, 1994). Qualitative interview studies provide the researcher with rich, thick data that answer the research question or questions (Seidman, 2006). Qualitative interview studies can be conducted for a variety of reasons: (a) solicit detailed descriptions about events that the researcher could not experience, (b) integrate multiple perspectives, (c) describe processes of human behaviors within the context of various events, (d) develop holistic descriptions by pooling reports of individuals and interrelated behaviors about events,

(e) learn how to interpret events, (f) describe intersubjectivities so that the reader can understand the internal processes of events similar to the participants' perceptions, and (g) identify variables and frame research questions for quantitative research (Seidman, 2006; Weiss, 1994). I selected a descriptive interview study as the research design for this study because it provided detailed descriptions of unknown processes or events within older African American women's experience with BCS mammograms and abnormal results. Several researchers who have studied this topic have used descriptive interviews to successfully elicit detailed information on African American women's BCS mammogram practices (Phillips et al., 2001; Powe et al., 2006; E. Thomas, 2006).

Descriptions of older African American women's experiences provided information that can improve the structure, process, and outcome of breast care services among older African American women. Descriptions of older African American women's experiences also provided a window into the behaviors of older African American women to BCS mammogram, abnormal results, provider practices, and diagnostic services, as well as a framework for future research (Creswell, 2007; Strauss & Corbin, 1994). The interview method allowed me to solicit descriptions of older African American women's experiences after receiving abnormal mammogram results. The interview guide provided me with a systematic way to conduct interviews to ensure delimitation of the subject matter to be explored (Seidman, 2006).

I asked the participants questions listed on the interview guide that were focused on the BCS mammogram experience (central) and the receipt of abnormal results (subquestions) during the interviews. I listened attentively and only used probing

questions to obtain more information from the participants about their experiences. I did inform the participants during the interviews that the goals for conducting the interview are being met by offering words of praise, support, and gratitude (Patton, 2002). The participants' verbal and nonverbal cues indicated whether the questions asked were difficult; if they were, I simplified the questions and praised the participants for answering the question. During the interviews, I asked and documented additional questions that stemmed from the participants' responses so that I could request additional interviews (if needed) to answer those questions from prior interviewees (Patton, 2002; Seidman, 2006). I documented field notes about the participants' responses, new lines of questioning, and setting while ensuring that the documentation did not decrease my attention to the participants' responses.

### **Sampling Strategy and Participant Selection**

I used purposeful, criterion-based sampling to select the participants (Creswell, 2007; Maxwell, 2005). Purposeful sampling is a common strategy used in qualitative research because it allows the researcher to deliberately select participants for the study that can best inform and provide an understanding of the research problem. Criterion-based sampling is used to ensure that the selected participants have experienced the phenomenon (Creswell, 2003, 2007). The combination of purposeful, criterion-based sampling helped to ensure that the group of older African American women selected to participate in the study had had abnormal results after BCS mammogram and could provide detailed accounts of their experiences. The number of participants selected for the study was small because the goal of this study was not to generalize to a larger

sample, but to collect extensive information that can add knowledge and significance to the field of public health (Creswell, 2007).

The participants were older African American women living in Baltimore City, Maryland. The participant selection was purposive from a convenience sample of 10 or more participants, recruited from a cohort of 194 from the ongoing research project, CPTD, among African American older adults, also known as the PHS, sponsored by a collaborative relationship between JHSPH and CMS (Johns Hopkins Bloomberg School of Public Health, Department of Epidemiology, 2009). Table 2 includes baseline data from the CPTD/PHS study about the 12 participants in this study—a 7-digit S0 number (S0 represents the control group of the CPTD/PHS study) and the women's ages, educational level, combined family income, and marital status. The 12 participants were between the ages of 68 and 76 years of age and most had some education, were widowed, married, or divorced. Participants had an average income of \$10,000 – 29,000 annually and they lived in various zipcodes in Baltimore City.



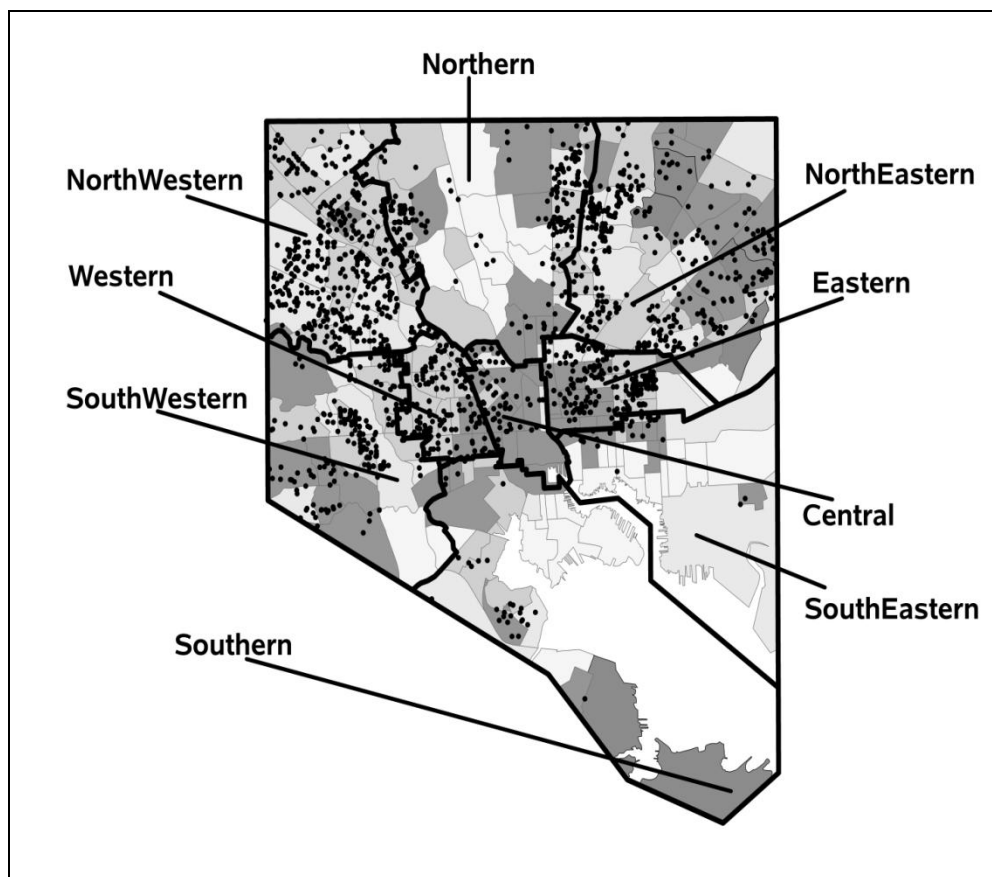
Table 2

*CPTD Baseline Data: Demographics of Interview Participants*

Participant	Age	Education	Combined family income	Marital status
00-00001	71	High school grad/GED	\$10,000-\$19,999	Divorced
00-00002	75	Some college	\$10,000-\$19,999	Divorced
00-00003	68	High school grad/GED	\$20,000-\$29,000	Married
00-00004	73	Some college	Less than \$5,000.	Divorced
00-00005	68	Bachelors degree	\$20,000-\$29,000	Married
00-00006	70	High school grad/GED	\$20,000-\$29,000	Widowed
00-00007	74	High school grad/GED	\$20,000-\$29,000	Married
00-00008	76	Some college	\$40,000-\$49,000	Widowed
00-00009	76	Master's or PhD	Refused	Never married
00-00010	69	Grade 9-Grade 12	\$10,000-\$19,999	Separated
00-00011	72	High school grad/GED	\$10,000-\$19,999	Never married
00-00012	68	High school grad/GED	Less than \$5,000	Widowed

\*Note: These data were abstracted from CPTD baseline data in 2010

The purpose of the PHS study is to address disparities in breast, cervix, colon, and prostate cancer screening and outcomes among African American seniors in Baltimore City by comparing two interventions, namely, access to media information/educational materials, and navigation of health care services. The PHS cohort includes African Americans ages 65 and older living in Baltimore City and currently enrolled in Medicare Parts A and B (Johns Hopkins Bloomberg School of Public Health, Department of Epidemiology, 2009). Figure 5 shows the distribution of participants in the PHS cohort using African American dotted markings to show the density of the population throughout Baltimore City. Potential participants from this cohort included women who have had abnormal BCS mammograms within the past 2 years and who indicated during the informed consent process that they could be contacted to participate in future studies.



*Figure 5.* Baltimore coverage area for participants in the CPTD/PHS cohort.

Other inclusion criteria for this study included the following: (a) women ages 65 to 80; (b) women who were African American (African American, African, Afro-Caribbean, non-Afro-Hispanic American); (c) women currently enrolled in Medicare Parts A and B; (d) women who could communicate effectively in English (able to read, write, and comprehend English); and (e) women in the PHS who did not receive navigation services after BCS mammogram (i.e., the control group).

After receiving Walden University's Institutional Review Board (IRB) approval (IRB approval #11-30-10-0324311) to conduct the study, I obtained up-to-date records from the PHS data management team of eligible participants who had had abnormal BCS

mammograms in the past 2 years. The PHS study has two arms. The first arm of the study includes participants who received navigation services after BCS, and the other arm (i.e., the control group) includes participants who did not receive navigation services after BCS. The participants in this study were selected from the control group; they also met the other inclusion criteria for the study. The CPTD/PHS data team confirmed approximately 44 participants who met the inclusion criteria. Potential participants from the PHS team's list were contacted in alphabetical order and invited to participate in this study.

I contacted the potential participants by telephone to inform them about the study, its objectives, and enrollment information, and to request their participation in a face-to-face, 60-minute audio-recorded interview. Telephone calls to specific participants were possible because of a signed waiver that they completed at the inception of the PHS study that gave permission for them to be contacted for future studies. The first 15 participants who agreed to participate in the study were interviewed at a mutually agreed upon time at the East Baltimore Medical Center (EBMC). I used a field log to document the number of participants recruited, the number of potential participants who declined to participate in the study, and barriers to recruitment. Participants received a \$25.00 gift card (as per the study's protocol) at the completion of the interview, and those who attended the end-of-study meeting received an additional \$15.00 gift card.

### **Researcher's Role**

I brought to this study clinical experience in BCS, treatment, research, patient education, attitudes, and biases. I place a high value on BCS mammograms and consider

the timely follow-up of abnormal results paramount in the detection of early-stage breast cancer. My clinical experience was beneficial in understanding the clinical systems of BCS, follow-up care, and breast cancer treatment that the participants described in their recollection of their BCS mammograms and abnormal results. In a sense, I was an insider in this study in that I understood the processes and procedures used at Johns Hopkins. Of course, this status meant that I had to be diligent in attending to the assumptions that I brought to the study.

### **Trust and Rapport**

In the narrative approach, gaining trust and establishing rapport are pivotal steps in the collaborative relationship between the researcher and the participants (Denzin & Lincoln, 1994; Seidman, 2006). To establish a close rapport, the researcher has to have a harmonious relationship with the interviewees (participants) to ensure their conformity to the inquiry (Glesne & Peshkin, 1992; Seidman, 2006). The overall goal of unstructured interviews is to find meaning; therefore, establishing a close rapport with participants during interviews helps researchers to understand their experiences more clearly (Denzin & Lincoln, 1994; Seidman, 2006).

I was aware that by establishing a close rapport with the interviewees, I may have been able to discover new themes or variables within the participants' BCS mammogram and abnormal result experiences that I did not anticipate. I also was aware that too close a rapport could have transformed the interviews into conversations, with the result being that the descriptions of the interviewee' experiences were overshadowed (Seidman, 2006). In this study, I adopted common strategies to establish a rapport during the

interviews, such as sharing personal experiences, if and when appropriate, and asking the participants to tell their stories (Seidman, 2006). Other strategies that I used to build rapport included showing respect, attention, and interest in the participants during the interview process (Seidman, 2006). I attempted to understand the experiences of the participants from their perspectives and did not make assumptions based upon my own ideas and experiences (Denzin & Lincoln, 1994a).

### **Respect, Attention, and Interest**

I addressed the potential participants formally during the recruitment process via the telephone and during the interviews by asking whether they would like to be called by their first or last names (Seidman, 2006). Other gestures that I used to show respect included providing another introduction and brief discussion of the importance of the study at the beginning of the interview, holding doors open for the interviewees, and not sitting until they had been seated. In addition, I maintained respect for the participants, even though the interviewees may have made remarks that were biased, prejudiced, or racist (Glesne & Peshkin, 1992; Seidman, 2006). During the interviews, I discussed the details of the study, and obtained the participants' written consent. I have received documented training in human research and HIPAA, which ensured that the participants' human rights would be protected and their privacy/confidentiality maintained.

I demonstrated attention and interest by listening intently to the participants' stories during the interviews. I kept the participants focused on the concrete details of their experiences first and then explored additional details about their beliefs or opinions about their BCS experiences (Glesne & Peshkin, 1992; Seidman, 2006). I tolerated any

silence that preceded the responses and did not interrupt the reconstruction of the participants' experiences. Storytelling can evoke emotional responses such as purging, relief, and distress (Munhall, 2007). I gave the participants my undivided attention throughout the interviews, even though I was not comfortable with some of their responses. I employed sensitivity and respect throughout the dialogue and contact with the participants to develop a trusting relationship (Munhall, 2007).

Participant laughter or distress during the interview process must be explored because it may uncover relevant information that adds meaning to the experiences (Seidman, 2006). Therefore, I followed hunches or instincts during the interviews that generated questioning that deviated from the interview guide. This technique of probing is the mark of rigorous interviewing and involves listening well and asking the next appropriate question, even if it is not in the interview guide. Sometimes, asking probing questions may give a researcher a completely different understanding of a participant's experience (Seidman, 2006).

### **Trustworthiness and Credibility of Inquiry**

Trustworthiness and credibility are maintained by engaging the participants completely in the research process (Munhall, 2007). I provided the participants with interview transcripts as well as my subjective interpretations of the exchange to ensure the authenticity of their voices (Munhall, 2007). I met with participants individually at an end-of-study meeting to discuss the results of the study. All participants who attended that meeting received their \$15.00 gift card, as per the study's protocol.

### **Interview Guide**

I constructed an interview guide with questions that were meant to solicit responses from the participants that would answer the research questions (see Appendix). Prior to constructing the interview guide, I had developed a substantive body of questions based upon the research questions and the literature reviewed (Weiss, 1994). In this study, each of the questions in the interview guide emerged from the original research questions: (a) What are the experiences of a group of older African American women with BCS in Baltimore City? (b) What are the group's experiences with abnormal mammogram results after BCS? Each question represented a specific line of inquiry that was pursued with the participants during the interviews.

The research questions were used to address the various lines of inquiry that informed the structure and body of the interview guide (Seidman, 2006; Weiss, 1994). Examples of lines of inquiry include questions that address past thoughts and feelings, current thoughts and feelings, history of events, plans and activities, and self-image and self-representation (Weiss, 1994). Seidman also suggested that researchers narrow issues and topics from various lines of inquiry and focus on specific questions and subquestions. Although a researcher may sometimes have command of the interview and may not have to use the interview guide as a prompter (Weiss, 1994), it is recommended that the researcher review the guide at the end of the interview to ensure that all topic areas were discussed (Seidman, 2006). An effective interview guide lists the questions so that the researcher can identify them at a glance. An interview guide densely populated with

questions may influence the researcher to shift from unstructured interviews to survey-style interviews (Weiss, 1994).

When using an interview guide, the researcher should let the participants speak freely and without mandating compliance with the interview guide (Seidman, 2006; Weiss, 1994). A standard interview guide should be constructed for all participants; however, the interview guide should be abandoned if the interview takes the participant in another direction. In this study, I took notes during the interviews to record the participants' emotions, gestures, body language, unanswered questions, and potential questions for probing. I constructed an interview guide and was aware that I may have had to make revisions after several interviews because of the unexpected direction of previous participants' interviews (Weiss, 1994).

Even though qualitative studies require an initial purpose for the study, qualitative research is emergent, so the focus of the study can shift over time. Therefore, I took advantage of ongoing analysis and continued revising the lines of inquiry as the study progressed. This kind of qualitative research cannot easily be described before the study begins. It is well defined only at the end of the study (Seidman, 2006; Weiss, 1994).

### **Length of Interviews**

To avoid preconceived expectations, I informed the potential participants during the recruitment process that although each interview was scheduled to be 60 minutes long, there was the possibility that the interview could end earlier or go beyond the 60 minutes (Seidman, 2006; Weiss, 1994). I was prepared to support a comprehensive response from the participants by continuing the interviews as long as appropriate



information was divulged (Weiss, 1994). I would have requested follow-up interviews with the participants if additional lines of inquiry had been identified after analysis of the initial interviews. Second or subsequent interviews can help researchers to clarify information and gain a better understanding of the participants' events or experiences (Seidman, 2006; Weiss, 1994).

### **Interview Setting**

Participants can be interviewed in various settings; however, the choice of setting depends upon the preferences or ease of access to the participants (Weiss, 1994). Seidman (2006) noted that researchers should take every step to ease the logistics of the interview process so that the focus can be on the interview and any safety issues. Seidman also suggested that researchers should determine the best dates, times, and places for the interviews with potential participants at the time of initial contact. In this study, I conducted the interviews at the EBMC in a conference room on the third floor as well as at the homes of some participants. The EBMC is a location that is not only community oriented but also is safe for the participants to freely discuss information and for me to conduct the interviews. Although all of the interviews were to be completed at the EBMC, some participants were interviewed at their homes upon their requests and IRB approval.

I made the initial telephone contact with individuals from the PHS study who agreed to be contacted for future studies. I made every effort for the potential participants to choose the most appropriate times for the interviews (Seidman, 2006). At the initial contact with the potential participants, I offered possible windows of time for conducting

interviews between the hours of 8:30 a.m. and 4:30 p.m. Monday through Friday. I scheduled interviews when I could devote several hours after each interview to the immediate transcription and analysis of the responses (Glesne & Peshkin, 1992; Seidman, 2006). Therefore, I did not schedule more than two interviews per day to ensure that 4 or more hours were available so that I could transcribe the taped interviews.

### **Method of Recording Information**

It is common practice in qualitative research to preserve the original words and tone of the participants. Therefore, in this study, the participants' interviews were audiotaped to capture their authentic voices. Tape recording the interviews also allowed me to be attentive to the participants' verbal and nonverbal cues during the interview rather than take notes, an activity that can be distracting (Glesne & Peshkin, 1992). Interview tapes can also be used by researchers to evaluate their interviewing techniques and identify areas for improvement. When conducting tape-recorded interviews, researcher must ensure that the recording equipment is of high quality to avoid muffled recordings that may impede the transcription process (Glesne & Peshkin, 1992). A transcribing machine with foot controls also can be useful when transcribing multiple tape-recorded interviews (Glesne & Peshkin, 1992). I collaborated with other qualitative researchers in this field to obtain their recommendations for high-quality recording and transcription equipment for the interviews (Glesne & Peshkin, 1992).

### **Preparation for the Interview**

After the time and place of each interview was arranged, I adhered to the following rules: (a) I arrived early or on time; (b) if I arrived early, I waited in the car or

another location several minutes prior to the time of the interview; (c) I dressed professionally (e.g. skirt, blouse, slacks, etc.), but did not dress to appear superior to the participants. As I introduced myself to the participant and was seated, I established a good interviewing relationship with the participant (Weiss, 1994) by working together to obtain information pertinent to the study.

### **Ethical Considerations and Protection of Participants**

Three basic ethical principles outlined in the Belmont Report govern research that involves human participants: (a) respect for the person (i.e., respect the individual's autonomy); (b) beneficence (i.e., do no harm and minimize risk); and (c) justice (i.e., equitable selection of participants; Seidman, 2006; U.S. National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1978). The Code of Federal Regulations, Title 45, Part 46, (Protection of Human Subjects) includes a mandate for universities and other research institutions that receive federal funding to establish IRBs as gatekeepers of the basic ethical principles in research with human participants (Seidman, 2006).

Researchers must guarantee the confidentiality of the participants' identifiers and information obtained during the interviews. They must establish a commitment to the participants that no harm will come their way from the information shared throughout the interviews or overall participation in the study (Weiss, 1994). The only time that researchers are obliged to break the confidentiality commitment is if a participant is homicidal, suicidal, or harming others. I followed all of these procedures in this study.

### **Confidentiality and Data Storage**

Confidentiality was maintained throughout the data collection process by conducting the interviews in a private setting, either at the EBMC or in the participants' homes. I developed a master list of all information collected from the participants. To guard the privacy of the participants, I used deidentifiers on all written and audio-based information to ensure their anonymity (Creswell, 2007b). I stored the audiotapes and written transcripts of the interviews in a locked drawer in a locked room where data for the PHS are stored. In the electronic database, no personal identifiers were included; however, linkable identifiers exist separately, and the data are so sensitive in nature (e.g., substance use, mental health, genetic propensities, sexual practices or activities) that disclosure could present a risk to the individuals.

Codes were stored on a password-protected computer with a secure server. Backup copies of NVivo 9 data management computer files of the participants' transcript analysis were made and stored in the locked drawer. Any transfer or storage of data files was done on encrypted portable devices (e.g., laptops, flash drives). The devices on which the data were stored were accessible only to the individuals who needed access to the data, such as the PHS principal investigator and research assistant. Any data stored on a portable or a desktop computer were protected by two passwords. When possible, redacted (i.e., deidentified) versions of the data collection sheets were used for coding and analysis. When the results of the study are presented or published, no names will be used, and I will make every effort to keep the facts (e.g., demographics, names, etc.) of

the participants confidential. It is unlikely that anyone outside of the study could find out about this private information.

Under U. S. federal guidelines, research materials must be stored for a minimum of 3 years from the time of project completion. When the PHS project is completed, research materials will be stored at a secure facility. In the event that the principal investigator of the PHS study does not store the study materials beyond 3 years, I will make arrangements to transfer the research materials to CMS to fulfill its required storage period.

### **Institutional Review Boards**

The IRB is a board in an academic institution comprised of faculty members and others who have expertise in different processes of research (Creswell, 2007b; Seidman, 2006). IRBs require researchers to submit proposals for review prior to the collection of data. Through this review process, IRBs ensure that three basic ethical principles (respect for the person, beneficence, and justice) are met in proposed studies. IRBs also review the consent form and the consent process in detail and request revisions, if needed, prior to approving studies (Creswell, 2007b; Patton, 2002; Seidman, 2006).

Because this study was conducted with the cohort of the CPTD among African American Older Adults, also known as the PHS study, an IRB application was submitted to the IRB at JHSPH for approval. This study was submitted as Ancillary Study IV of the CPTD among African American Older Adults. An IRB application was submitted to Walden University, along with attachments verifying the JHSPH IRB approval of CPTD (PHS study) and Ancillary Study IV.

### **Consent Process**

Although qualitative interviewing does not have a high risk associated with it, as do some biomedical studies, it does have some risk (Seidman, 2006; Weiss, 1994). The consent form for qualitative interviewing should be divided into eight parts:

1. An invitation to the study including what, when, why, how, and for whom.
2. Risks or potential risks or discomfort to participants in the study.
3. Rights of participants and a statement that participation is voluntary and refusal to participate are without consequence.
4. Potential benefits.
5. Confidentiality of documents.
6. Dissemination of information.
7. Special considerations for vulnerable populations, i.e., children, older, etc.
8. Contact information for the researcher and copies of the consent form.

(Seidman, 2006)

This process was followed in this study. During the consent process, I discussed the study in detail and solicited questions from the participants about the study (Creswell, 2007b). As Creswell (2007b), Seidman (2006), and Weiss (1994) advised, I was honest and open with the participants, explaining the sampling procedure, how information would be stored during the study, and what deidentifiers would be used in the data analysis. There were three signed copies of the consent form, one for the participant, one for PHS, and one for my records. Once signed consent was obtained, I asked the participants whether they were ready to proceed with the interviews.

I obtained verbal informed consent from the participants at the time of enrollment and written informed consent prior to administration of each interview. I signed agreements of confidentiality and completed training in human subject research ethics and HIPAA-specified training. Documentation of such training, as per the requirements of Johns Hopkins University's IRB and Walden University's IRB, was kept on file.

At the beginning of the interviews, I reviewed the purpose of the study and carefully discussed the consent form, explaining anything that the participants had concerns about. I ensured that the participants understood that (a) their participation was completely voluntary; (b) they had the right to withdraw at any time and would continue to receive the same quality of medical care available through their providers; (c) they had the right to privacy; and (d) their receipt of Medicare Insurance services would not be jeopardized, regardless of their decision to participate or decline to be in the study. I respected the integrity of all of the participants and encouraged them to speak freely.

Although I requested permission to tape record the interviews when scheduling the interviews with the participants, I requested permission again at the onset of the interview to ensure informed consent (Feldman, 1981). I answered all questions before each participant decided whether to sign the consent form. The consent form was structured to represent the required Grade 8 comprehension level. Where it was not possible to reword or substitute a word to create Grade 8 comprehension, a phrase was added to the consent form to clarify the meaning of the word. Once a participant signed the consent form, the interview began.

### **Data Collection**

In this study, the participants were interviewed for approximately 60 minutes using an unstructured interview guide describing their experiences with BCS mammogram and abnormal results in Baltimore City. The interview guide was developed using the theoretical framework of the QCM, which has been proven effective in measuring the domains of structure, process, and outcome in health care services (Duffy & Hoskins, 2003; Duffy et al., 2007) and the CRT. Use of the QCM and CRT in this study produced findings that will help providers to understand the role relationships of patients, families, health care providers, clinical system processes, and outcomes within the scheme of health care management; utilization of resources; and how race affects the entire process.

Questions in the interview guide were tailored to address the research questions of the study using a standardized open-ended interview method (Patton, 2002). Several studies (Balneaves, Truant, Kelly, Verhoef, & Davison, 2007; Frost, Venne, Cunningham, & Gerritsen-McKane, 2004; López, Eng, Randall-David, & Robinson, 2005) with small sample sizes of 10 to 20 participants have used the interview method to examine the quality of life and explore decision making and the personal social processes of African American women with breast cancer have yielded in-depth responses to their research questions. Therefore, this study sample comprised 10 to 15 participants to describe the participants' experiences with BCS mammogram and abnormal results. The interview method selected for this study was consistent with the qualitative rigor that is expected within the theoretical framework.



At the end of each interview, I communicated gratitude to each participant for participating in the study and solicited any additional comments or responses to questions that had been neglected (Feldman, 1981; Patton, 2002). Some extra time was designated for informal conversation at the end of each interview (Feldman, 1981; Glesne & Peshkin, 1992; Patton, 2002; Seidman, 2006). I was aware that the participants may have been affected emotionally by personal experiences shared during the interviews and may have discovered new things about themselves (Glesne & Peshkin, 1992). I summarized the participants' responses at the end of the interview so that the participants could clarify their responses and provide additional feedback if they chose to do so. I also asked the participants whether I could contact them for an additional interview or to answer some questions that might have arisen during the data analysis (Feldman, 1981; Glesne & Peshkin, 1992).

### **Data Analysis and Interpretation**

As Feldman (1981) and Seidman (2006) advised, after the interview, the researcher should immediately find a place to reflect on the interview and interpret the data in three dimensions, such as inward and outward (social and personal interactions), forward and backward (relation to time) and place (setting of the event). I reflected on each interview and purged any thoughts or concerns about each interview immediately after completing it. This was the best time to take notes about the interview because the exchange had just occurred. Transcription began, and I listened to the audiorecording intently, noted follow-up questions, and made revisions, if needed, to the interview guide for future interviews with other participants (Feldman, 1981; Patton, 2002; Seidman,

2006). Staying true to the qualitative tradition, I used an inductive process in which transcripts, field notes, and demographic data obtained from PHS team formed foundational categories, patterns, and themes about the participants' experiences (Creswell, 2007a).

In this study, the data analysis was issue focused, and I was concerned about what could be learned about the experience or the process through the experiences of the participants with BCS mammogram and abnormal results. Using the QCM, CRT, and narrative methodology, I interpreted the interview transcripts and field notes. The narrative approach can open many interpretations of the same data. It is for this reason that I logged a step-by-step approach to show how the interpretation of the data was derived (Creswell, 2007a; Patton, 2002; Seidman, 2006).

The four analytical strategies involved in issue focus analysis were coding, sorting, local integration, and inclusive integration (Weiss, 1994). I coded the data at the beginning and used sorting, local integration, and inclusive integration later in the process. Local integration is the summarizing of observations and understanding with coded data. Inclusive integration combines local integration and all other file excerpts for meaning. Thematic sampling was applied to emerging concepts. Range of variability was tested through sampling concepts for diversity.

I ensured that all data were critically examined, and I categorized the data in units to ease triangulation. Critical examination of the data was accomplished through member checking, that is, the participants met with me at the end-of-study meeting to discuss the major findings and choose whether they wanted to add information that could be

incorporated into the findings (Strauss & Corbin, 1990). I used data and theory triangulation to strengthen the validity of the study. Data triangulation was accomplished by the various sources of data that I had used, such as transcripts, field notes, demographic data from the PHS team, and medical record reviews from the PHS team to interpret the data. The medical records were reviewed and verified the participants' self-reported data.

I used the CRT and the QCM to provide multiple perspectives to interpret the data, also known as theory triangulation. I had no limits on the number of interviews and comparisons of data, as long as the information added depth to the participants' experiences and meaning emerged. Relational statements hypothesized the textural descriptions, clustered themes, and meanings of older African American women's experiences with BCS mammogram and abnormal results (Creswell, 2007b; Patton, 2002; Strauss & Corbin, 1990). I kept an audit trail of all discussions with the participants, mentors, and committee members that reflected the evolving analysis of data. I also documented any personal biases, thoughts, and feelings about the study (Patton, 2002). I used a visual display of the findings to highlight the local and inclusive integration, and thematic generation (Weiss, 1994).

NVivo v.9 data management software was used to facilitate data storage, coding, retrieval, local integration, and inclusive integration of transcripts. With the NVivo v.9 software, I could upload the interview transcripts and query the frequency of words, patterns, and various themes before organizing the data into various formats. I also could upload field notes into NVivo to create linkages to various themes or patterns and then

graphically depict codes and patterns (Creswell, 2007a; QSR International, 2010; Seidman, 2006)

### **Evidence of Quality**

Researchers must ensure that the evidence is of good quality so that the findings can be accepted in the field. Many researchers have established standards for evaluating good-quality evidence. In this study, I was aware that the results could have had several interpretations. Therefore, I paid specific attention to providing details about how the findings addressed the research questions and the use of the QCM, CRT, and narrative tradition. In this study, I maintained rigor in the data collection procedures within the framework of the study by maintaining documentation of recruitment, data collection procedures, step-by-step data analysis, and other data relevant to the study (Creswell, 2003, 2007a; Patton, 2002; Seidman, 2006).

### **Feasibility and Appropriateness**

I developed the study design and research plan consistent with the qualitative tradition and narrative inquiry. The participant pool was available from the CPTD/PHS study. The JHSPH IRB has already given approval for Ancillary Study IV of the CPTD/PHS study during the preparation of the proposal. The CPTD/PHS team gave their commitment to support my creation of deidentifiers, participant pool selection, data storage, escort services for in-home interviews, costs for participants' transportation, and gift card. I paid for other services and costs.

### **Summary**

I used a narrative inquiry to effectively obtain information about older African American women's BCS mammograms and abnormal result experiences. The in-depth audio-recorded interviews with the participants allowed me to capture their perceptions and emotions about their BCS mammograms and abnormal results in their own voices. Data were analyzed using the QCM and CRT to respond to the research questions. Chapter 4 presents the findings that derived from the data collection and the narrative analysis as it relates to the research questions and theoretical framework. It also provides a description of participants' perception of the events that occurred within their BCS and health maintenance experiences. Chapter 4 also provides a summary of salient results and the significance of the study at the end of the chapter.

## Chapter 4: Results

### **Introduction**

This chapter includes the results of the study that answered the research questions through careful analysis of data collected during face-to-face interviews with participants. The purpose of this qualitative interview study was to learn the experiences of a group of older African American women with BCS mammogram and abnormal mammogram results in Baltimore City and stemmed from an increase in breast cancer mortality of older African American women in comparison to their European American counterparts in Baltimore City and in the United States overall (ACS, 2007, 2008). A gap in the literature confirmed the need for additional studies to understand the behavior of the participants once they were given reports of abnormal results. This narrative inquiry was guided by two research questions:

1. What are the experiences of a group of older African American women with BCS in Baltimore City?
2. What are the group's experiences with abnormal mammogram results after BCS?

The significance of this study is that it provides an in-depth understanding of the BCS experiences of one group of older African American women that can help breast care providers, public health practitioners, and the development of public health initiatives and policies improve their breast cancer outcomes.

I used a narrative research design and interviewed 12 older African American women in Baltimore City who met the inclusion criteria from the CPTD or the PHS. I was interested in the stories these women told about their experiences during and after their BCS mammograms. As Marshall and Rossman (1995) explained, there is value in participants' language in the form of symbols, signs, and emotional expressions as key attributes for the construction of meaning from their stories.

After transcribing the audio-taped interviews, I used the QCM and CRT as well as NVivo 9 software to analyze the interview data. The women's stories can be used to illuminate the clinical and social processes (i.e., navigating/accessing breast services, clinical systems, provider communication, social systems, and/or economic factors) that accompanied their receipt of abnormal mammogram results after BCS and other health care related experiences.

I examined the clinical and social systems throughout their BCS experience to understand how effective their processes, such as follow-up with diagnostic centers or consultation with breast specialists for abnormal mammogram results, breast cancer treatment, and so on, were in improving the women's BCS outcomes and whether racial discourses, as noted in CRT, were a factor in their experiences (Delgado & Stefancic, 2001; Donabedian, 1988; Duffy, 2009; Duffy, Baldwin, & Mastorovich, 2007). This chapter is organized into four sections: data collection (including the IRB procedures, recruitment process, etc.); the narrative analysis (empirical data collection and analysis for thematic generation according to the narrative design of the study); research findings; and summary (of outcomes).

## **Data Collection**

### **IRB Procedures**

After receiving approval to conduct the study from the CPTD/PHS investigators at JHSPH, I submitted an official IRB application to the JHSPH IRB for approval to conduct the study under the parent study CPTD. Approval was granted, and this study was approved as Ancillary IV Study under CPTD J0678 IRB: 063. A formal IRB application also was submitted to Walden University along with copies of the JHSPH IRB's approval documents. The data collection process commenced when I received permission on November, 30, 2010 from Walden University's IRB to proceed with the study.

### **Overview of the Study**

I used a narrative inquiry design to learn the experiences of a group of older African American women with BCS mammograms and abnormal mammogram results who lived in Baltimore City. A purposeful, criterion-based sampling technique was used to select the participants who had received abnormal mammograms within the past 2 years to answer the research questions because they were the expert witnesses of their own BCS experiences.

The CPTD data team generated a list of 44 participants from their cohort who met the inclusion criteria for the study. I contacted the 44 potential participants via telephone using the approved phone script and documented the potential participants' interactions on the recruitment log. Thirteen participants agreed to participate in the study, so I proceeded to schedule interviews with them. I used Microsoft Outlook to manage the



interview schedule with participants. I conducted in-depth face-to-face interviews as the primary mode of data collection with the older African American women in the study.

During the recruitment phase, six participants requested in-home interviews because of the cold winter weather, exacerbation of arthritic conditions or other illnesses, and opposition to traveling to the east side of Baltimore City to the East Baltimore Medical Center (EBMC). An amendment application to the JHSPH's IRB was submitted to permit in-home interviews with the participants, and it was granted on December 17, 2010. Walden's University IRB was notified and accepted the approved amendment application from JHSPH's IRB. Twelve participants total were interviewed; one participant was not at home for the interview. I made several attempts to contact her by telephone to reschedule the interview, but she did not respond, and I was unable to interview her.

Six participants were interviewed at their homes and six were interviewed at the EBMC. The PHS team provided an escort to accompany me to participants' in-home interviews. Four of the six participants who were interviewed at EBMC arrived via taxicab service (prepaid by the researcher) and two drove. I asked participants to sign the transportation logs that verified their arrival by taxicab service to account for funds budgeted for this service.

Data were collected through audio taped, face-to-face interviews conducted at participants' homes and at EBMC. I also collected observational data in the form of field notes about each interview. Before beginning the interviews, I introduced myself; introduced the study; explained my academic and clinical affiliations; and provided an

overview of the interview questions, consent process, and asked for participants' questions or concerns. I gave each participant a signed copy of the consent form after she had verbalized her understanding of the study and had signed the consent form.

The original voices of the participants were maintained through electronic audio tape recording. To solicit rich data, I used an informal conversational strategy and an interview guide approach, as recommended by Patton (2002). I used the interview guide at the beginning of each interview to ensure that the dialogue remained focused on the subject matter. Toward the end of the interviews, I encouraged participants to discuss compelling issues or to follow unanticipated lines of questioning. At the end of each interview, I informally member checked the data by summarizing the participants' statements and seeking their verbal validation. At that point, participants were able to provide clarification of prior statements and additional information about their experiences. Each interview was 1 to 1 1/2 hours long. Participants received a \$25.00 gift card to the store of their choice at the end of the interview.

To maintain the original voices of the participants, I captured their stories on an Olympus DM-520 Digital Voice Recorder. Audio files were immediately uploaded after the interviews into NVivo v.9 software for transcription and saved in an encrypted, password-protected file. Data were transcribed word for word immediately after the interviews in Microsoft Word file formats into templates that were created to align with the salient questions on the interview guide and imported into NVivo v.9 for analysis. Both the audio files and transcripts of participants were labeled with a 7-digit deidentified

number, provided by the CPTD data team, to protect participants' identity and insure anonymity.

### **Narrative Analysis**

I analyzed the data in the following stages: (a) listened to the audiotapes prior to transcription, (b) transcribed the audiotapes, (c) formed linkages of existing and new data, and (d) categorized by coding and identifying common themes. NVivo v.9 facilitated central data storage, coding, retrieval, local integration, and inclusive integration of rich data. I uploaded the transcripts and field notes into the software and queried the data for frequency of words, patterns, and various themes before organizing the data into various formats. I inserted field notes (e.g., observations during interview, etc) from participants' interviews into their interview transcripts so they could be included in the analysis. The templates created in the transcripts were used to organize the data into tree nodes and free nodes for analysis. The baseline data received from the CPTD team were used to create classifications (e.g., age, zip code, education level, etc.) for the participants that were linked to specific sources (or participants) in the software. The organization of the data facilitated thematic generation for participants within the context of the research questions (Creswell, 2007; QSR International, 2010; Seidman, 2006). All electronic or written data derived from the study were stored according to the data storage procedure discussed in chapter 3.

## **Research Findings**

### **The Story**

A narrative analysis was used to analyze the data. In this section, the research questions are answered in the form of a composite story about what happened to this group of older African American women when they went for BCS mammograms and received abnormal results. The narrative analysis includes attending to the conceptual framework informing the study, namely, the QCM and CRT. Data were collected in face-to-face interviews with the participants and in field notes about those interviews.

Participants were asked to respond to the following interview questions:

1. Why did you decide to have a mammogram?
2. Tell me about the mammogram procedure.
3. Tell me about the delivery of mammography results.
4. What process of experiences followed abnormal mammogram results?
5. Tell me about your support systems.
6. Tell me about your health promotion and health-seeking behaviors.
7. Name one thing that you would change about your mammography experience.

Because the participants' stories had many similarities, the data are presented in the form of a story, common in narrative analysis, in which participants' experiences are organized into their common sequential experiences. I then interpret those experiences throughout the larger story. The story begins with the participant's perception of events prior and during and after the mammogram procedure, then progresses to the

participants' health promotion and health-seeking behaviors, and culminates in their recommendations for improving their mammogram experiences.

### **Getting Ready for the Mammogram**

Most of the women felt apprehensive both about having the mammography done and about going to the mammography center to do so. These emotions arose from their past experiences with abnormal breast findings and family members' terminal illness from breast cancer. One of the women described this experience as follows:

When I was about 30 years old, I went to Sinai Hospital and he examined me and he told me that I have a lump in my breasts. And I always wondered when I go have a mammogram what are they going to say. Um..., in February when I went in, I was a little afraid that they'll find something. I'm 71 years old and you always hear about cancer, breast cancer and from the experience that I have had, I never know when they are going to tell me that I really do. (00-00001, 2010)

Many of the women in the study had mothers, aunts, sisters, or nieces who had been diagnosed with breast cancer, and they had journeyed with their relatives through the trajectory of treatment and even death. "My mother had cancer of the breast-- she died with cancer of the breasts, my sister had cancer of the breasts, and well she suffered the damn... I have two nieces that have had breast re-construction for breast cancer" (00-00009). The thought that the upcoming mammogram could be "the one" to diagnose their first breast cancer made them focus on their spiritual connection with God.

Spirituality was a dominant theme throughout the women's stories. The women drew on spirituality when their initial concerns about having a mammogram seemed

emotionally overwhelming. Their spiritual connection to God was paramount in bringing the women back to a place of peace, comfort, and strength to overcome feelings of fear about having a mammogram. This strength to overcome came from their ongoing relationship with God through worship and prayer. “Um, you know I have faith in God so really nothing; I uh just put it on the back burner” (00-00002). One woman recalled the words (“Why worry when you can pray”) of her deceased mother (00-00002) through fearful times in her life. These women drew on their fundamental belief in the Bible, their worship experience, and faith in God to calm their fears and anxiety about having a mammogram.

And I was out of church for a while, I was just terribly weak, and all I could do when I get back in here was crash and sleep, a lot of sleep. And then I would sit up in the corner and listen to testimonies and Christian music and you know teaching and all that, you know the spirit of GOD would just come all over me. (00-00003)

Some women proclaimed the healing power of God and that God knows “the beginning and the end.” They also believed that they will leave this earth only when God says that it is their time to leave.

Many of the women understood the importance of having a BCS mammogram so that if they did have breast cancer, it could be diagnosed early, and they would have the possibility of being cured. It is important to note that all of the women in this study participated in annual BCS mammograms and they did not discuss any difficulties with getting transportation to and from their mammography appointments. Their motivation

came from their desire to maintain their health and avoid the breast cancer morbidity and mortality that their family members had experienced.

Well my mother died from cancer and at first... well I started getting a mammogram say about 50... and um my mom died in 1998 from cancer and my doctor at that time said that me and my other sister, siblings should have these tests done every year. So I started getting my test done every year . . .so that if something was to come up maybe we would be able to catch in time. (00-00006)

Some of the women had regular BCS mammograms because their health care providers encouraged them to have the procedure, as stated by 00-1364, "Well, I would go yearly anyway because of my GYN doctor would have me go for ultrasounds and mammograms so that was something that I would do." Other women looked forward to receiving an annual reminder letter from the mammography center.

Well I always go every year. I'm trying to think what year I started, but anyway it's been a long time, but I usually go every year. They usually get in contact with me in August, they always send me a letter-- this is at Mercy Hospital. They always send me a letter and let me know when to come in. So, I just go. (00-00007)

In summary, the women are filled with emotional concerns as they get ready for their annual mammogram. Their family member's experiences with breast cancer have a strong influence on their perception of their upcoming BCS experience. Even though most of the women were fearful, they did not allow their emotions to impede their adherence to BCS. The women inferred that transportation was not a barrier to their BCS

because they did not discuss any transportation problems in getting to their mammogram appointments. The women understood the risk of breast cancer and were empowered to maintain optimum health through BCS.

### **Having the Mammogram**

There are two types of mammography diagnostic centers: same-day and multiple-day centers. Same-day mammography diagnostic centers complete a BCS mammogram, give the abnormal mammogram results, and complete additional diagnostic tests (mammograms, ultrasound, biopsy, etc.) on the same-day as the BCS mammogram. Multiple-day mammography diagnostic centers complete a screening BCS mammogram, send the results of the mammogram to the patient in the mail, schedule a diagnostic mammogram and or ultrasound, and perform an ultrasound-guided breast biopsy on at least three different days.

Nine of the women had their BCS mammograms at multiple-day diagnostic mammography centers and three women had their BCS mammograms at same-day diagnostic mammography centers. One of the women that had her mammogram at a same-day diagnostic mammography center described having multiple mammogram X-rays at her first sitting. She then had to wait in the dressing room before being called back for more mammogram X-rays without an explanation for the repeat mammograms until she shared her frustration with the technician (00-00009). Another woman went to another same-day diagnostic mammography center had a BCS mammogram, an ultrasound, and a biopsy on the same day and then, also on that day, received thorough explanations about her abnormal breast findings from the radiologist and technician (00-



00003). The women who had BCS mammograms at same-day mammography centers saw the technicians as the conduit to communicate the radiologists' findings or plans of care for them. Although most of the women did not mind receiving communication from the radiologist through the technician, some of them wanted the radiologist to directly speak to them about the abnormal findings on the screening mammogram.

One of the women described the following experience at a multiple-day diagnostic mammography center as the kind of experience she has had for the past 15 years or more:

Nothing unusual. I just went in; they...enroll you in and no problem there. And uh ...they take you back, they tell you to undress from the top, and put on a gown and then they call you in. You sit and wait until they get to you, and then they call you in, which probably be like 5, 10 minutes. (00-00002)

She also described what happened after she completed the mammogram procedure:

Um, they tell you to wait and see for a few minutes if the picture is good. And then they tell you ok you can go. So you just go in and put your clothes on and leave. And then I got a letter maybe a week later asking me to come in and make an appointment for another mammogram because a side wasn't clear, or normal, or something. I set up another appointment and I went back and they just took the breast that they thought wasn't clear. And then they said everything was okay. And the same thing . . . I went home. And then I got a letter saying everything was okay. (00-00002)

This letter came “about a week to 10 days” (00-00002) after the diagnostic mammogram.

Although the women went to mammography diagnostic centers that they were used to going for many years, it seems that the women that went to multiple-day diagnostic centers were unaware of the operations of same-day diagnostic centers.

Because the women have had mammograms for many years at the same diagnostic centers, they were used to the routine, process, and procedures. Some of the women noted that they had been going to the same mammography diagnostic centers for the past 10, 15, or even 20 years, so they could anticipate the clinical processes at the centers. Eleven of the women went for their BCS mammograms alone, and one woman went with her spouse and to the same mammography diagnostic center that they have gone to for many years. Besides the administrative staff registering the women for the mammography procedure and directing them to the waiting room, the women anticipated the routine interaction with the technicians and or radiologists as well as the administrative process.

The operations of multiple-day diagnostic mammography centers may create unnecessary emotional, and physical burden for the women as they wait long times for their results. The women's' emotional burden caused by long wait times was evident when they discussed the anxiety and fears they experienced as they wait for their mammogram results and additional tests results. The physical burden was implied because of the women having to make adjustments to their daily routine to go to the diagnostic mammography centers on multiple visits for follow up testing because of abnormal mammogram results.

*Mammography providers.* As expected, the women reported that the technician at the mammography diagnostic center met them in the waiting room and ushered them back to the dressing room in preparation for the mammography procedure. Before the technicians did the mammogram procedure, they provided the women with instructions on their body positioning for the procedure. Some of the women felt that the technicians were not sensitive to the pain and discomfort they experienced during the procedure. For example, one woman said, “I say, ‘Don’t push so hard because it hurt’; [She said], ‘I got to get a picture.’ I say, ‘But it hurts, I had a lump removed from my left bust’ ” (00-00008). This woman expected the technician to adjust her technique to reduce the pain caused by the procedure; however, the technician did not make any comments or gestures to acknowledge her pain. Another woman give an account of her experience with an insensitive mammogram technician as follows:

It was a young girl there, and when she pressed down on me it hurt so bad I cried, and she told me oh, you must have drank some Pepsi or something cause that’s the only reason why it hurt; and I never went back. (00-00001).

Another woman discussed her worst experience with having a mammogram as follows:

My worst experience with a mammogram was when, . . .you can see I’m not a very big woman and my little breasts they kill’em for a week I’m walking around caved in because I’m so sore. By the time they finish with me I’m really hurting. But I understand that in order to get a good picture that they have to do it.

Most of the women reported that after their mammogram procedure, the technician told them to wait in the procedure room while they spoke with the radiologist. Then the technicians would return and tell them that the picture was good and that they could leave the mammography center. Some of the women recollected the following comments by their technicians:

“They tell you to wait and see for a few minutes if the picture is good. And then they tell you, ‘OK, you can go.’ They really didn’t give me any dialogue. They just tell you, ‘OK’ ” (00-00002).

“But meanwhile I went to sit and she said everything was fine and sent me home” (00-00010).

“They told me I was fine. I was fine. They told me that I was fine and everything was alright” (00-00001).

”And then they said everything was okay” (00-00002).

One of the woman reported that after her BCS mammogram, the technician took the films immediately to the radiologist to review and later reported back to her that the radiologist wanted her to follow up in six months, but without an explanation of why (00-00011). In general, the women indicated that they wanted more dialogue or explanation from the technicians about the mammogram X-rays that they had taken. Without clear directives from the technicians about the process to receive their mammogram results, the women felt a false sense of assurance that their mammograms were normal.

The women had very limited interaction with the radiologists. They knew that the radiologists provided the technicians with directions to pass along to the women, but some of the women wondered why the radiologists would not talk to them directly.

Well, I think um, if is someone else that, the person that reads the mammograms could be there to assure you that the mammogram is okay. No. No the one who reads the. . . um, I don't see. I never met him. (00-00002)

Sometimes, the technicians consulted with the radiologists and informed the women that additional films were needed.

“To me, I think they are just there to take the picture. I don't think they, for what I can see how the handle other women, also they wasn't really there to diagnose your case or tell you anything” (00-00002).

“I didn't have, yeah, much breast tissue and she kept, you know, mentioning that. Then I had the mammogram done and in fact she had to do it twice and they didn't say anything about any cancer or anything” (00-00005).

The women explained during their interviews that they wished the radiologists had been more willing to discuss abnormal findings on the mammogram X-rays and inform them of the next steps.

Overall, the women knew what to expect during their mammogram procedure; however, the women expected the technician to be more sensitive to their concerns about breast pain during the procedure. In most cases, the women were not given an opportunity to ask the radiologist questions about their abnormal screening mammogram when the radiologist conferred the results through the technicians. The women viewed

the radiologists as the experts in reading the mammogram x-rays, and most of them desired an explanation from the radiologist about their x-rays because they could explain the abnormal calcifications or mass seen on the x-rays.

### **Getting Bad Results**

The women received their abnormal BCS mammogram reports in various ways. The results sent to the providers were different from the reports given to the participants. Participants received a generic report that the mammogram results were abnormal and were instructed to call the office to schedule additional testing within the next 10 days. Some women were given no time frame to return for additional testing. The results that the providers (i.e., primary care providers or gynecologists) received were detailed reports that referenced specific details of the characteristics, dimensions, and location(s) of suspicious masses, micro calcifications, and final impressions.

Most of the women received their abnormal mammogram results in the mail one to two weeks after the initial BCS mammograms. As 00-00007 (2010) stated,

I guess . . . about two weeks or a week and a half later I got a letter saying they want me to come back and take another one because they saw something. They wanted to find out what it was all about.

Another woman received her results in the mail and immediately called her primary care provider to help her make sense of the results. The primary care provider offered her an explanation of the results and gave assurance that was helpful in decreasing her anxiety and fear. She explained as follows:

They just sent me this letter to come back in for an ultrasound. And when I went

in, well I of course called the doctor and he said they found a lot of cyst so it's nothing to worry about but we want to do an ultra sound just to be sure. (00-00004)

One of the women described a different event. She had a conversation with the radiologist and was told that everything was fine and that the report would be sent to her primary care physician.

The day that I went for my original mammogram and they did the mammogram, the doctor herself came in. She held me there and then she came in and she did an exam of my breasts and I said, "Is everything OK?" . . .and she oh I think so. Everything is pretty good. I'll send a report to your doctor . . .And then I guess maybe a week or so later I got a letter and an appointment to come back for an ultra sound. (00-00004)

When the doctor told the woman that "Everything is pretty good. I'll send a report to your doctor" the radiologist shifted the responsibility of explaining the results to the primary care doctor (who would have received the written report). However, the primary care provider's knowledge base is limited because they are not radiologists and may not be able to address all of the questions that a woman might have about the radiographic findings of an abnormal mammogram.

One of the women who had a history of multiple abnormal mammograms always received her abnormal results in the mail and had no verbal interaction with the radiologist during the screening mammogram procedure:

Ok...they let me know that I can leave and then in a couple of days I get a letter

that states we have... seen some slight of abnormality on your x-ray mammogram and we'd like for you to return for a second examination. Oh, whenever I got the results or the questionable results it was always by letter . . . an official letter from the women's center . . . The letter always said during your recent mammogram we've discovered or we've noticed some abnormalities and for that reason we would like to exam you again. Please call this number as soon as you get this letter. And um, it's always been like that. (00-2811)

Another woman remembered her history of multiple follow-ups with the mammography center after the BCS mammogram. She stated that the follow up diagnostic mammograms were sometimes scheduled "one week, two weeks, or 6 months later." She was not told the reason for her follow-up diagnostic mammogram or that she had an abnormal mass at those subsequent mammography center visits. The technician had always told her at the end of the BCS mammogram procedure that everything was fine. "And I'm thinking that everything is OK, you know. I didn't know it was abnormal. Well, I guess it was abnormal if I keep having to go back for the same procedure" (00-00005).

Throughout the women's stories of receiving their mammogram results, the process of communication with their provider was always perceived as inadequate. Many of the women's misconceptions or questions about their abnormal mammogram results could have been clarified if the providers had communicated effectively with them.

***Emotional responses to the report.*** Many of the women did not experience increased anxiety or worry from the time of the BCS mammogram to receiving their results in the mail because they believed that when the technicians told them that



everything was fine that their mammograms were normal. Two of the women stated that they believed the letter they received about abnormal results had nothing to do with their breasts and everything to do with a malfunctioning machine or the diagnostic center's attempt to bill the insurance company for more services because they had been told at the screening center that everything was fine. Some of the women who expected to receive their results in the mail verbalized some concern about the results but quickly found resolution through prayer and their faith that God has everything in his hands. "Jesus, I immediately prayed. Father I'm not accepting this. This is not mine. This is yours; you take care of it because I know I can't have nothing wrong with me" (00-00004).

One of the women recalled the emotions she felt when she had her first three abnormal mammograms, describing them as mentally and emotionally traumatic events. "The first time... I broke out in a cold sweat, I got weak in the knees... had to sit down because my head started hurting. I lost weight.... I was having complications of the heart." She bore these emotions alone because she did not want to burden her family members and did not know whether she should communicate her concerns to her primary care doctor. "I just went through a full range of emotions—tears, fears, secrecy, privacy, do I tell somebody, who can I ask, who do I talk to about this, should I call my doctor?" Even though the radiologist told her about her results and assured her that the abnormal finding was benign, she still worried. Most of her worry came from her anticipation of the worst outcome of abnormal mammogram results. She commented:

Began to think things like do I have my things in order, should I start thinking seriously on some other issues that I hadn't even thought of...I mean I thought of

a lot of things, and my only experience or knowledge that I have of people with cancer was always such a devastating thing, so of course I considered all of that. But suffering and death...that was such a major impact suffer first and then die.  
(00-00012)

In summary, when the women received negative results, they were often surprised because they had been told at the mammography center that everything was fine. Such conflicting information was common and caused anxiety and frustration. Some women interpreted the request for follow-up mammograms as simply a strategy for the mammography center to make more money. In addition, the women often did not know how to interpret the negative results they were given. Some consulted their primary care physicians, but most did not. The women's responses to the results were coupled with false assurance and disbelief. The technicians failed to communicate accurate discharge instructions to the women, and some of them left the mammography diagnostic center with a false assurance that their results were negative for cancer. When the women received their results in the mail reporting abnormal results, they were in disbelief and perceived the request for additional tests to be of benefit to the diagnostic center.

### **Who is Their Support?**

The women viewed their support system during the process to include spouses, children, family/ relatives, friends, church members (or church family), community members, and their faith in God. Most of the women lived with their spouses, children, or other relatives. One of the women shared the abnormal mammogram results with her spouse:

Then after I sat down... and I told my husband that they had found some abnormalities and that I had to go back for more tests. He went off, but we all got it together and everything worked out perfectly but it was... that day was not a good day. (00-00004)

Another woman shared her abnormal mammogram results with her children prior to completing the follow-up for additional diagnostic tests. “When I come home, I talk to them about it. It’s just because my husband didn’t talk to us about his illness, and I need to let the children know what is going on with me” (00-00006).

Most of the women wanted to keep abnormal mammogram results between them and God until they received the results of their follow-up diagnostic tests. Only if the follow-up diagnostic tests revealed cancer or serious diagnoses of any kind did most of the women feel compelled to share the results with their spouses, children, siblings, and friends. “I would have talked to them because . . . I would need them to baby me ,you know, I’m just saying truthfully, you know, or pamper me or do things, you know, and they would do it anyway” (00-00010).

Some of the women were more inclined to share their abnormal mammogram results with church members rather than family members. The women saw the church family as a medium to strengthen their faith in God as well as their prayer line to God, especially because the church members could collectively pray to God on their behalf.

Many of the women’s family and friends were very supportive in regard to their general health promotion experiences. Some women talked about the strong support they received from their children and grandchildren who ensured that they took their

medications and obtained their prescription refills for medication on time.

My, uh, oldest granddaughter she's ah, a, pharmacy tech. And as far as my medicine is concerned, I got medicine bags upstairs; she keeps me filled up with medicine. Yeah . . . I don't have to worry about no medicine or nothing like that. (00-00007)

Even when they had acute medical conditions or accidents, their children and grandchildren were always there to support them. "I fell and couldn't get up. I wiggled my way over to the phone and called my granddaughter both of . . . my granddaughters came they got me up off the floor [laughter]" (00-00007).

Even though they had strong support systems, the women often did not take advantage of them until they felt that it was necessary. They wanted to maintain their independence in dealing with personal matters as much as possible and wanted to decide when they needed to share those matters with their support system. The women had a close relationship with their spouses, children, siblings, and relatives. One woman described her relationship with her family as close. Because of that closeness, they live near to each other so they can continue meal-time family traditions.

Yeah, my daughter lives three blocks away so when she comes from work at 5, the food is usually fixed. You know my aunt, her aunt fixes it, my sister cooks it or I cook it, and then we have the food; and then my brother in law doesn't mind eating leftovers. (00-00010)

Another woman described having a close relationship with her children and sometimes having to be supportive of them by allowing them to live with her in times of stress or financial hardship.

My oldest daughter just left here. I have three daughters, they are all right here, and my youngest daughter is here with me right now temporarily.

Um, I have a great support system; they get on my nerves. I have a great support system, and my son is in California. (00-00011)

The QCM shows the structure of the health care experience to include the provider, patient, and family. However, the women in this study described their family as a nuclear structure that also included church members. To the older African American women in this study, family included any individual who played a supportive role in their lives: spouses, family members, relatives, friends, pastors, church members, and community leaders. The key to understanding the concept of family for these older African American women was the level of communication and interaction they had with individuals and the formation of relationships. The women indicated that positive relationships with their family and other supportive networks such as their churches were a resource for maintaining their adherence to screening and followup activities.

### **Going Back for More Tests**

Four of the women who had to have diagnostic mammograms (i.e., repeated mammograms with additional compression views) reported that their anxiety was brief because they received the results the same day. "I spoke to a doctor. After they finished, they had me to wait and um uh the doctor came in and talked to me and told me that I had

nothing to worry about, everything's okay" (00-00007). Six women had to wait one to two weeks to receive their results in the mail.

One of the women (0-01364) had a BCS mammogram and a diagnostic mammogram and was told to return in 6 months for another diagnostic mammogram because of some concerns about calcifications in one of her breasts. She returned for the diagnostic mammogram 6 months later and was informed by the radiologist that because the calcifications were increasing, he wanted her to return in six months for another follow-up diagnostic mammogram. She became so afraid that she went back sooner for the follow-up mammogram. "And I went back in 6 months and things were progressing more, and then the next thing I know when it was schedule for the six months . . . I went back in four months, and things had really progressed" (00-00003).

Besides receiving diagnostic mammograms, three of the women received ultrasounds on the same day. Two of the women received their results after the ultrasound, and one woman had to wait for the results in the mail. When Participant 00-00004 received the ultrasound results in the mail, the letter stated that she should go back to the mammography diagnostic center to have a mammogram and ultrasound every 6 months. The results did not include a description of the abnormal findings in the breast, but the letter did indicate that a copy of the results had been sent to her gynecologist. She then called the gynecologist for an explanation of the results.

So when I called my gynecologist and I talked to him and he said well there are little cysts all over. He said but none of them looked malignant. So we're not going to do anything but watch you and he suggested that I see a surgeon. And I

choose my own which was ... And he said that he didn't think it was anything that he should do a biopsy on or anything because it was multiple ones and they didn't look suspicious. (00-00004)

She continued to have mammograms and ultrasounds for every six months for follow-up.

Participant 00-0134 (2010) was referred by the radiologist for an MRI prior to having a stereotactic biopsy on that day. She was able to complete the MRI and stereotactic biopsy on the same day because the mammography center was part of a comprehensive cancer center. One of the women who had an ultrasound at a same-day mammography center would have received a core biopsy the same day, but because she became hyperglycemic in the waiting room, she was rescheduled for the next week. Another woman who had the ultrasound then had the breast mass aspirated (00-00005).

Going back for more tests was an emotional ordeal for the women. Emotions of fear and anxiety were short lived in the women who had their mammograms at same-day diagnostic mammography centers; however, they were longer lived in the women at multiple-day diagnostic mammography centers. The process that the women went through for additional tests included the completion of diagnostic mammograms, ultrasounds, breast biopsies, and breast MRIs. Although the women experienced anxiety as they go back for more tests, in the end they received diagnostic resolution for the breast abnormality that was seen on the screening mammogram.

**Is it Cancer?**

Many of the women were apprehensive and anxious about the results of additional diagnostic tests that they had to undergo. Nine of the women were diagnosed with benign breast masses; one woman was diagnosed with a simple cyst and had it aspirated; and two of the women were diagnosed with breast cancer. One of the women diagnosed with breast cancer was first followed for progressing calcifications in the breast, but the stereotactic breast biopsy produced a pathology report that was positive for cancer.

“And when I went back to him the following week for the results, he had his head down, and I said, ‘I have cancer.’ And he said, ‘How do you know?’ ...I Just pointed up” (00-1363).

The other woman diagnosed with breast cancer was found to have a suspicious breast mass. The core breast biopsy produced a positive pathology report for cancer.

For many of the women, the final results from the additional diagnostic tests (i.e., diagnostic mammograms and ultrasounds) from their abnormal mammogram results were a sigh of relief. Even though they had some emotional distress while waiting for the results, it was brief.

Oh, I say, oh my goodness! Don’t tell me that I have cancer and they are going to have to remove my breasts! And then I say Oh well, if that’s what has to happen I’d have to have it done. (00-00001)

Because they no longer had to worry about having breast cancer, they felt a sense of comfort in sharing the good news with family and friends at that time. These women look ahead to their next mammograms in the hope that there would be no abnormal breast



findings. A few of the women still had some fear that the results could have been inaccurate and that they could have breast cancer. These women were more prone to lacking trust in the results of their abnormal mammograms because they had a strong family history of breast cancer and had experienced the trajectory of breast cancer treatments among friends of family members:

So of course they can say it's nothing to worry about but as a female I had every right to worry about it. You know I've had several relatives to die. Only one are an immediate family member and she was my father's sister and then some of my cousins on my father's side have had breast cancer and have since died from it.

But they say it's nothing going on. (00-00004)

However for the other women who had to have additional procedures, they experienced conflicting emotions of fear, anxiety, and faith. They began to reach out to family members, friends, and church family for emotional and spiritual support. One of the woman diagnosed with breast cancer even requested that the church members pray and fast for her recovery.

Going back for more tests increased fear and anxiety in the women. They did not want to be bearers of bad news so they told their support systems of their abnormal mammogram results when they had confirmation that they did not have breast cancer. Although this study did not formally explore the physical burdens that the women endured to make follow up visits to the mammography diagnostic center, some mentioned during the recruitment phase of the study that they are only available on specific days because on other days they are caring for their grandchildren, provide in

home day care services, have to attend church, etc. Rearranging their schedules to make follow-up appointments after abnormal mammogram can take up some of their time, and physical energy which could have been avoided if they had their mammogram at a same-day diagnostic center.

In general, the women anticipated their next annual mammogram after an abnormal mammogram hoping that there would be no abnormal results. A few of the women still had some concerns that their negative diagnostic mammogram could have been a false negative result because of their strong family history of breast cancer and personal experience with the trajectory of breast cancer and treatment with family members.

### **What's Next?**

Most of the women were diagnosed with benign breast masses, so they required no further intervention and were told to return in a year for routine mammograms. One woman who had had a breast cyst aspirated found out several months later that her breast cyst experience was not over:

They aspirated the mass and that was it. And I found another one last week... and I mentioned to my doctor again what was happening. So I have another appointment for a mammogram and a possible ultrasound or a biopsy on Monday. They were going to give me a biopsy the last time [when I had the abnormal mammogram result] I had the appointment for the mammogram and all and then they decided not to do it. They did the aspiration instead. (00-00005)

One of the women diagnosed with right breast cancer received a right lumpectomy and sentinel lymph node biopsy of the right axilla (armpit) that was negative for cancer. A sentinel lymph node biopsy is a surgical procedure to remove the first lymph node (under the armpit) that uptakes drainage from a breast with a known breast tumor. The lymph node is identified by the injection of a radioactive material near the tumor. The surgeon uses a Geiger counter or probe to locate the lymph node that contains the radioactive material and then removes the lymph node for pathological examination (NCI, 2011). At her postoperative visit with the surgical oncologist, she was told that she had Stage I breast cancer. She then was referred to a radiation and medical oncologist and received 6 weeks of radiation to the right breast and was subsequently placed on hormonal therapy (antiestrogenic therapy that decreases the availability of estrogen in the body) by the medical oncologist for 5 years.

The other woman diagnosed with right breast cancer also had a right lumpectomy and sentinel lymph node biopsy of the right axilla, but the lymph node was positive for cancer. The surgical oncologist completed an axillary dissection (i.e., removal of several lymph nodes under the armpit) on the right armpit. "I think it was 15 they removed." All of the lymph nodes were positive for cancer. "Uh, I think... it was all, because it had progressed. I have pictures and everything" (00-00003).

The literature as well as the data from this study report that women who go through breast cancer treatment can be overwhelmed when seeing the surgical, radiation, and medical oncologist to determine the treatment plan. In addition, the treatment intervention can negatively impact the woman's physical activity, bodily functions, and

self-image. The increased fatigue resulting from multiple treatments and clinic visits is not an excuse to prematurely terminate treatment but a reason to continue their pursuit of cure.

I had 8 weeks of radiation, 5 days a week after the chemo, they had to stop the chemo because I had horrible side effects from the chemo less than 24 hours, I had very long hair and my hair just fell out just like that and uh, like there're different types of kinds of chemo and there're, just, it was hard to make a lot of decisions. They were in conference, the doctors and everyone, so they started on that and the first time they gave me chemo I almost went out, and they tried to bring me back. (00-1364)

Although some of the women had some negative mammogram experiences, their motivation to continue mammograms was not shattered. However, they did indicate that they wanted to see some improvements within the clinical and social systems to provide more support throughout their BCS experiences and follow-up procedures.

### **Staying Healthy**

As the women discussed their healthcare provider experiences during BCS, they commented on other health care provider experiences during their health promotion activities and I have included this information below.

Most of the women had a positive outlook on life. They reminisced about their working lives, retirement, and their independent lives. “You know, I don’t want to be just sitting around waiting for somebody to do something for me” (00-00002). Sometimes these women became caregivers for their spouses and still maintained their health and

positive attitude.

But um so far I'm doing well . . . I view it . . . right now I think that I'm thankful. I'm seventy-three, and I just stopped working three years ago, and the only reason I stopped was because of my husband. But call myself, right there, moderate. Just keep going. . . keep moving. Keep pissing off, the little man. (00-00004)

Several of these women drive themselves to medical appointments, food markets, and other retail stores. "Yeah, yeah, I 'm still driving. Thank God I don't need a cane . . . A lot of my friends had hip operations, knee operations, and stuff you know. But I haven't had any of those problems yet" (00-00002).

The women were actively engaged in health promotion and health-seeking activities (see Table 6). Some of them independently sought screening activities (e.g. BCS, colonoscopy, etc); others engaged in screening based on the recommendations of their providers. Some of the women who relied on their providers to recommend screening may not have engaged in specific screenings because their providers had failed to recommend them.

I go to a cardiologist and every time I go to him if something's wrong I tells him what it is and I don't know he sends me to everywhere, I mean I've been to so many doctors it's not funny... I haven't been to my primary care doctor in a long time, cause I just figure he's my primary care doctor now. (00-00007)

When one woman was asked during the interview whether she had ever had a colonoscopy, she responded, "What is a colonoscopy?" After I explained to her that a

colonoscopy is the test to check the colon for colon cancer, she then said, “No. I don’t think so. But when I go back to my doctor, I will have, I will tell him.”

Although the women have reported going for various health screenings, I wanted to know how they were getting there and some of their other daily activities. Most of the women took a combination of public transportation and taxi service to travel to their medical appointments, and do other retail shopping. Many of the women buy their groceries and prepare their own meals and sometimes cook for other family members. “I cook for myself. I market for myself” (00-00005).

The women desired to maintain their optimum health and were willing to engage in health-promoting and health maintenance behaviors. They also displayed great strength of character as they made decisions about their healthy behaviors.

“I am really blessed because I am really basically healthy” (00-00010).

”I take care of me. It’s my body” (00-00011).

”I maintain my health. Well, I try to walk, and I try to do everything that I’m supposed to do” (00-00001).

“Yeah, I listen to my body. When I get tired, I just lay down, and then I get up and go... Because I am 75 years old. I have problems, but none of them that keep me down” (00-00002).

Overall, the women trusted their health care providers and relied on them to recommend health-promoting activities such as BCS, etc and medical treatment for their acute and or chronic illnesses. Some of the women described their health care providers as doing a great job according to their standards. Several perceived the role of the

primary care provider as managing their health care needs and ensuring that they are referred to specialists for consultation when needed; whereas, others perceive their specialists as their primary care provider and want them to manage all of their health needs. Some of the women did not see the necessity of having a primary care doctor (i.e., an internal medicine physician) to manage all their health care needs on the frontline if they had a specialist managing a medical condition.

Maintaining optimum health was a priority for the women as demonstrated in their adherence to various screening activities such as colonoscopy, glaucoma screening, etc. Some of the women viewed the primary care physician or the provider they see most often as the gatekeepers of their health. The women's adherence to health promotion activities described above are driven by the health care provider's communication to them about screening tests needed to maintain their health. When the primary care provider was not engaged in the women's care, they lacked essential screening tests because the specialist providers that they see for chronic illnesses are not within the scope to be gatekeepers of their health. The women showed discipline and dedication with managing their chronic illnesses with the resources they had and endured multiple clinic visits and procedures. The management of their chronic illnesses was not a deterrent for their maintaining their independence and positive outlook on life and their health.

### **Roadblocks**

Even though the women were motivated to participate in screening activities, there were two roadblocks identified. The first roadblock was discussed within the previous section and described the lack of provider recommendation for screening when

the provider is not a primary care physician. For example, one of the women did not know what a colonoscopy was because she her cardiologist instead of a primary care physician managed all of her medical needs. When she was asked if she had ever had a colonoscopy she replied, “What is...colonoscopy?” After explaining to her that it is a test to screen for colon cancer, she said, “No. I don’t think so . . . . I haven’t been to my primary care doctor in a long time . . . (00-00007). The second road block is lack of supplemental coverage ((Medicare Part B (or Medigap) insurance) and a fixed income, making the women unable to have insurance coverage or afford the consultation fees for specialist providers. One of the women wanted to have a colonoscopy, but she could not afford the supplemental cost for specialist visits. She did not have Medicare Part B (or Medigap) insurance, which would have supplemented the cost of the gastroenterologist.

And then the reason that I am not keeping up with my heart doctor and podiatrist ..... I go to the primary care, but I don’t go to the others because I was cut off of Medicaid. I read according to your income, and I was in that range where they were supposed to keep me on Medicaid but I’m not . . . My access in care is only to my primary care doctor. . . . You know, I know they can’t work for nothing. But since I don’t have the insurance I try to take care of myself. (00-00008)

Table 3 describes the women’s health care coverage status for supplemental insurance and shows that several of the women did not have Medicare Part B or any other supplemental insurance. When they have made attempts to contact representatives from social services to obtain Medicaid coverage, many of those representatives failed to



return their telephone calls or provide them with the information promised. As a result, some of the women did not get to have a consult with specialist providers because of lack of health care coverage and or could not afford the co-payments because of their limited (fixed) incomes. Many of the women (as shown in Table 3) lacked Medicare Part B, yet only two women had Medicaid coverage. Medicaid is a state health insurance program for those whose income isn't sufficient for them to purchase of their own supplemental insurance plan. Thus, they should be automatically enrolled in the Medicaid program.

The road blocks described above are health care system barriers that must be reduced to ensure the health of older African American women like those in this study. Two of the very serious problems identified in this study are that some of the women did not have primary care physicians and that some did not have supplemental insurance coverage. Both problems were barriers to their health care. These road blocks can directly affect breast care services. The primary care provider is the gatekeeper of the referrals to specialist providers and coordinator of care of women's health maintenance during BCS, diagnostic resolution, and breast cancer treatment (if needed). If the primary care provider is absent during the women's breast care services then the women may have poor coordination of care and health maintenance. Also, the women with no supplemental insurance coverage may not be able to have additional diagnostic tests (such as breast MRI, etc) to make a definitive breast diagnosis or they may not be able to receive standard breast cancer treatment (such as chemotherapy, or targeted therapy, etc).

***Healthcare providers.*** In the course of answering questions about their mammography experiences, the women commented on their general concerns with

healthcare services which are part of the analysis within the QCM. These general concerns were included in the narrative analysis because it describes the attributes of providers and health care settings that can influence the women's perception of services and their care outcomes.

***Poor communication.*** Some of the women complained about the poor communication between and among health care providers about their medical conditions and treatment plans. Too often, the women had to inform their primary care physicians of medical treatments received from specialists. Several of the women had to constantly remind the specialists to send copies of their test results or clinic notes to their primary care providers or to the doctors who referred them to the specialist.

Other women experienced poor communication with providers who spoke English as a second language. The women described their inability to understand the providers' treatment recommendations and the reasons for prescribing specific medications for their illnesses. "I have a problem hearing. The foreign doctors bother me because I don't know what they are saying" (00-00011).

Some of the women also perceived foreign doctors as lacking knowledge about their medical conditions because of their experiences of being prescribed the wrong medications by these doctors. As a result, the women were noncompliant in taking medications or following up on visits as they looked for new providers to manage their medical conditions. "Trust and believe that I do not stay with them. They cannot help me if I don't know what they are saying. It's no need for me to go; it's like me going and not taking the medicine" (00-00011).

When health care providers communicate poorly to the women, they lose trust in them and perceive them as not being knowledgeable to manage their medical conditions. As a result, the women discredit their medical management for their health conditions and fail to follow up with clinical visits as they seek to find more skilled providers that can communicate effectively. A serious consequence of failed communication is that the women's treatment is suspended as they find other providers.

*Ageism.* The women also observed that the medical needs of their friends and others in the community were ignored by health care providers and social services. Some women perceived society as a whole to be intolerant of their decrease in physical functioning, as manifested in the impatience of retailers, public transportation operators, and medical practitioners.

Yes, I've experienced that. I've experienced it. Yes, a lot of times if you're older you're taken for granted or I won't say disregarded, but they deal with you when they get to you. They seem to be more interested in what's going on with the younger person. When a person who is senior talks about what's going on, to the person who's listening...the older person is talking too slow. It's like come on with your story. (00-00012)

Sometimes, the women felt rushed when they were making complaints to medical providers, social service representatives, or retailers.

I'm trying to tell you what's wrong and you're rushing me. So, I find impatience in a lot of the places dealing with seniors. They want them to hurry up and say whatever it is you're trying to say or not take them serious or not take the

complaints as serious. (00-00012)

Some of the women observed that health care providers spent more time in the examination rooms with younger patients for the same medical conditions that they had. Younger patients discussed their medical conditions in the waiting rooms at doctors' offices, which provided the women with insight into the temporality of their visit.

You sit in the office right and you see a younger lady go back. And she's back there for... you know...I watched one day. Three girls went back, one I knew she had had surgery because of the way she was holding herself. Now I don't know what she had had done. I don't know what her problem was and one lady I knew she had had a mastectomy because she sat there and told everybody everything about it. And then there was a young girl that had had a cyst removed. But these three people went back. When the first one came...the first one they called came, she had been back there approximately 20 minutes. Each one of them, you know...And I'm going hum, and I go back there and I'm out in 5 seconds. That's the way I felt you know. (00-00004)

Ageism was demonstrated in the women's descriptions of health care providers' intolerance to their needs because of their age and normal process of aging. The women felt that the health care providers' neglect sends a message to them that they are simply too old. But that idea isn't supported by statistics that show that by the year 2030 approximately 1 in 5 adults will be 65 years and older (U.S. Census Bureau, 2000).

***Racial discourse.*** Some of the women perceived that older European American women were treated differently from the way they were treated. "I was the only African

American person there, they put me in a room and I lay there so long that I really got angry” (00-00006).

She further described the GI specialist doctor (that the ER referred her to see for removal of her inflamed gallbladder) as entering the examination room and dismissing her shortly without conducting a physical exam.

He never examined me in anyway so when I left there I had made up in my mind that I wasn't going back and I kept that gallbladder I don't know for about a year and a half, but every time that I would have to have something done to take that x-ray it would show up so I said, well I told my doctor I said well it doesn't bother me so I'm not going to bother it. . . but I never went back to that particular doctor again. He was prejudice as far as I am concerned. And I didn't want to see him anymore. He just talked to me and left. (00-00006).

Clinic support staff were intolerant of their questions and concerns about their appointments, waiting times to be seen by providers, and office location changes.

And nobody had told me that the office moved and then she comes out and she's one of those people that look down on you. And I had to let her feel the wrath. And then I left there and I went back over and I got the little girl behind the desk. I said how could you call my house and tell me not to forget my appointment and not tell me that the office has moved? And she's going, I didn't call... I said yes it was sweetheart. It was you. I said it was you. And she went well I'm so sorry. (00-00004)

A woman described the neglect in medical management that her niece received by an HMO insurance company to be attributed to her being African American or from another ethnic group.

And they are bad not only for the ages but for the nationality. Whether you are African American, European American, whatever you know you can see a difference in the way African Americans are treated. I have a niece that was going to them for almost six months with pain in her back and finally I told her go to the emergency room. She had multiple myeloma. She's dead in a year. You see what I'm saying. Those kinds of things... they kept telling her she just sprained her back but by the time they got to her they were everywhere. They were in her spine, her rib cage, her pelvic, everything. So I don't know. I don't understand... I understand some of it but some of it I don't. (00-00004)

One of the women described her doctor's visit as an experience where the provider was making stereotypical judgments about her health status based on her age and race without regards to her actual health status.

I've found that a lot of times that they just don't believe you, that's why I say don't compare me to what your textbooks say, I'm not your normal. I'm not your normal 69 year old African American female uh, widowed, you know what I mean. I won't fit your normal pattern. (00- 02811)

This woman demonstrated antiessentialism as explained in critical race theory because she refused to be stereotyped and wanted to be judged on her unique characteristics that are indigenous to her as an individual. In fact, the women's demonstrated

intersectionality in that they explained that they lived at the intersection of age and race, both of which influenced how they were treated by health care providers who should understand that not all older African American women have the same voice, experiences, or health conditions. Health care providers should avoid grouping older African American women into one category, be more culturally sensitive to their needs, and deliver patient-centered care that looks at the patient with “fresh eyes” regardless of the health care services that are delivered.

### **Application of the Quality-Caring Model and Critical Race Theory**

The QCM says that the quality of health care is determined by human caring; therefore, the individuals within the healthcare system should demonstrate care and compassion at every process level (Duffy & Hoskins, 2003). Within the structure of the QCM the focus is on the attributes of the women (patients), providers, and the health care settings. It also focuses on the process of care during interventions that the providers delivered to the women and the outcomes of those processes (Duffy & Hoskins, 2003).

The analysis of the women's stories within the QCM showed that the structure consisted of the women, support system, and health care providers within the various health care settings where the patient-provider encounters took place. The process through the women's BCS experiences was relationship centered and based on their communication with providers, office staff, support system, and the providers' communication among each other. The outcomes for the women BCS experiences are as follows:

- Provider-most of the women were satisfied with their provider during

their BCS experiences; however, some of them were not satisfy with their providers during other health care experiences (external to BCS).

- Patient-the women were knowledgeable about breast cancer screening and the importance of annual mammograms; however some of the women were not knowledgeable about other health care screenings (outside of BCS). Overall, the women were satisfied with their breast cancer BCS but some of them were dissatisfied with the delay in obtaining results and additional testing from multiple-day diagnostic centers.
- System- the women accessed same-day and multiple-day diagnostic mammography center for their BCS and the same-day diagnostic mammography center showed to be more efficient and well appreciated by the women. Lack of supplemental Medicare Part B insurance is a significant barrier to women receiving specialty services such as specific cancer treatments, etc.

The integrity of the communication among the health care providers, family members, etc with the women can influence the women's perception of their BCS and other health care experiences. Therefore, the quality of communication through the women's BCS experiences is the process that can impact their breast care or health care outcomes.

The CRT has six tenets (ordinariness, interest convergence, social construction, differential rationalization, intersectionality and antiessentialism, and the unique voice of color) that were used to help determine if race matters and how or whether identity



affects the women's response to abnormal BCS results (Delgado & Stefancic, 2001). Intersectionality and antiessentialism was the only tenet present within the women's stories. Intersectionality was evident when some of the women described their race and or age as having an impact on how society treats them. Some of the women perceive their age and or race to be associated with the neglect they experienced from office staff, providers, and supplemental insurance representatives. The women refused to be essentialized and wanted providers to judge them on their own unique characteristics and health profile. Although most of the experiences that the women described that supported intersectionality and antiessentialism were outside of their BCS experience it is paramount to understanding some of the psychological barriers to an older African American women participating in health promotion activities.

The next section discusses the recommendations or improvements that this group of older African American women would like to see during their mammogram experiences in Baltimore City.

### **How to Make Things Better?**

The women made several recommendations that could have a positive impact on their mammography experience and the delivery of abnormal mammogram results.

**The mammography experience.** The recommendations addressing the older African American women's concerns about their mammography experiences described below focused on the clinical and communication processes of the radiologists and technicians. Most of the women wanted their radiologists to be more personable with them by speaking to them directly about the abnormal findings on the mammograms and

discussing the reasons for follow-up mammograms and or additional diagnostic tests. Even though the technicians were the conduit for the radiologists' instructions, some of the women were bothered about the radiologist not speaking directly to them about their results while others wanted clearer communication about when the radiologists would review the X-rays and how they would get their results. Some of them wanted the invention of a new mammogram machine that would not cause breast pain or discomfort. For example, one of the women stated:

And I was just trying to figure, what they could do to get another machine, you know, and some other kind of machine they got, maybe you could put your breasts in, like it was round or something and then take it like that, . . . then to flap down on top of you, . . . it is so inhumane. (00-00001)

### **Recommendations to Improve Mammography Experience with Abnormal Results**

- Radiologist to discuss the results with patients.
- Radiologist to give the results of the screening mammogram on the same day.
- Primary care providers to explain the mammogram results to patients over the phone or at their next visit.
- Primary care providers to provide explanation of any changes to on-going followup of abnormal breast findings.
- Radiologists and primary care providers to provide more explanation of abnormal breast findings.
- Same-day service mammogram diagnostic centers as standard practice.
- Privacy should be maintained in dressing rooms prior to mammogram procedure.

- Technicians should be trained to be sensitive to patients during mammogram procedure.
- Technicians should be trained on what information to communicate to patients after mammogram procedure.

The following are the women's recommendations that will help to improve their health screening and health-seeking activities.

### **Recommendations to improve general Health Promotion and Health-Seeking**

#### **Behaviors**

- Primary care providers to be better gatekeepers of health promotion and health care activities for patients.
- Primary care providers to communicate results and coordinate care for patients.
- Primary care providers to educate patients on the necessity for various health promotion activities.
- Foreign-speaking providers should overcome language barriers to improve communication with patients.
- Health care providers should practice cultural sensitive care to patients regardless of their age, race, or health status.
- Primary care providers to ensure office support staff or clinic staff are trained in cultural sensitivity and customer service.
- Specialist providers should communicate to the patient's primary care providers about their findings.

- Specialist providers to ensure that patients have a primary care provider overseeing their health care management.

### **Discrepant Data**

There were no discrepant data received from participants when cross referenced from the recruitment phase and or during the interview. However, data obtained for participant's medical record review was incomplete and some of the data received were labeled in-correctly when compared to the record of service. This hindered the triangulation process of analysis because I was not able to confirm some of the women's medical encounters or diagnostic testings.

### **Summary of Findings**

In summary, the participants described similar BCS experiences with some variances in the care they received from their health care providers. Overall, the women had many initial concerns and reservations about their mammography experiences, including their prior history of abnormal breast findings, a strong family history of breast cancer, fear of being diagnosed with breast cancer, and the discomfort from the mammogram procedure. To address the first research question, (What are the experiences of a group of older African American women with BCS in Baltimore City?) the results suggested that the participants understood the importance of having BCS mammography for early detection of breast cancer. Most of the women experienced emotional difficulty, as they prepared for their annual screening mammogram and waited for their results (screening mammogram and diagnostic mammogram) from multi-day diagnostic mammogram centers. Their positive outlook on health and mostly their faith in God

helped them deal with emotional distress. Their family members' experiences with breast cancer served as a motivator for them to engage in BCS, other health screening activities, and follow up exams. Technicians were viewed as being insensitive to the concerns or needs of the women during the mammogram procedure and did not effectively communicate discharge instructions after screening mammogram. The women had a strong support system that encompassed their meaning of family to be the nuclear/extended family members, as well as the church family (or church members). The women sought after spiritual support through prayer and their faith in God primarily before sharing their health status with their nuclear and extended family members. The women pride themselves on their independence and ability to make decisions about their health and maintain a good quality of life. Throughout most of the women's stories of receiving their mammogram or other results the process of communication among and with their providers were perceived as suboptimum. They have made recommendations that are comprehensive in nature and will serve as a platform for improving not only their mammogram and abnormal mammogram result experience but also their health screening and other health maintenance activities.

To address the second research question, (What are the group's experiences with abnormal mammogram results after BCS?) some of the women did not believe the abnormal results that were mailed to them 1 to 2 weeks later because they understood the technicians' parting comment that "Everything is OK" to mean that their mammograms were normal. Other women received abnormal mammogram results and additional diagnostic tests on the same day of the BCS mammograms. Emotional responses were

imminent in the period after receiving abnormal mammogram to resolving abnormal breast findings. Some women experienced prolonged emotional discourse because they were diagnosed with breast cancer and had to undergo treatment. However, when the women were diagnosed with breast cancer they sought out their nuclear and extended family members for support. All the women have followup timely with abnormal results with respect to the method or time that they have received the results.

The women's followup behaviors for health seeking and health promotion activities are similar to their breast care followup behaviors. However, some of the women did not engage in health screening and health maintenance activities because of poor provider communication. The women's health promotion and health-seeking experiences were centered on the type of communication they had with their primary care providers or specialists. Most of the primary care providers were involved in coordinating health care and maintaining communication with other specialists for the women. Other primary care providers were not communicating with the specialists or were failing to relay information to the women about their medical conditions at their next appointment. Women with no primary care providers to coordinate health care activities were lagging in their health promotion activities. The women were motivated to maintain their health and wellness through health promotion activities and health maintenance. However, most of the women relied on their primary care providers or specialists to give them instructions and make recommendations for their health screening. The women also perceived elements of ageism and racial bias in the concept of intersectionality and antiessentialism during their health-seeking experiences.

## Evidence of Quality

### Researcher's Subjectivity

Although social scientists have stressed that researchers must maintain their objectivity, in the narrative tradition, researcher subjectivity is inevitable (Patton, 2002). I was aware that being detached from the storytellers' emotional expressions could have limited my understanding of and advancement into the meaning-making process. Therefore, I sought to understand participants' stories and maintain an awareness of my personal biases, values, and assumptions that could have influenced the outcomes in a positive way. Through Clandinin and Connelly's (2000) "nesting" (p.144) process (researcher and participants' stories), I was able to intertwine opinions, beliefs, and subjectivities throughout the data interpretation, which was conducted within the framework of a three-dimensional narration, where I could look at the forward and backward, and inward and outward meanings of the participants' stories within the context of their environment. My subjectivities not only included the emotional attachment to the participants' stories but also my personal experience, views on health promotion, and professional experience as a health care provider in the field of breast cancer management.

### Validity of the Study

**Validity of the study.** Maxwell (2005) discussed two major threats to the validity of a study: "reactivity and researcher bias" (p. 108). I maintained an awareness of my preconceptions or personal biases and remained transparent about my personal biases. I avoided the selection of data that supported my personal biases, and I maintained

objectivity in the data analysis process (Maxwell, 2005). I also evaluated the data in an open-minded manner and looked for different ways to understand the data or form different themes. Although social scientists view reactivity as a major problem in qualitative studies, it is unavoidable in interview studies.

Sometimes interview studies refer to reactivity as a form of reflexivity (Hammersley & Alkinson, 1995). Reflexivity supports the concept that the researcher's presence can have a powerful influence over what the participants say and how the data are interpreted (Maxwell, 2005). Sometimes, the participants will react to the researcher's nonverbal responses by conveying what they think the researcher wants to hear. I did not attempt to eliminate reflexivity or reactivity during the interviews; instead, I maintained a uniform style of interviewing by using an interview guide. There is no doubt that reflexivity requires a bartering of information between the researcher and the participant. Reflexivity was a valuable process in this study because it facilitated collaboration with the participants and promotes a deeper understanding of their experiences (Czarniawska, 2004).

### **Reciprocity**

Issues of reciprocity have been controversial in the areas of ethics and quality of evidence when addressing questions of compensation for participants (Patton, 2002). It may be idealistic to think that individuals will participate in a study that may be a burden to them and for which they will receive no compensation when the researcher often is compensated for the time spent conducting the study. What is the most important for the researcher to consider in determining reciprocity is how much or what type of



compensation should be given to participants. The compensation has to be adequate for the participants' willingness to join the study, but financial compensation that is too generous can influence the participants to embellish the accounts of their experiences, and too little compensation may jeopardize the accrual of participants.

I provided the participants with two forms of reciprocity: financial compensation and intellectual capital. Participants were compensated with a \$25.00 gift card for being interviewed and a \$15.00 gift card for attending the end-of-study meeting. I also provided the participants with my intellectual capital to address their various health concerns that may have been unrelated to the study objectives. Participants had an awareness of my background as a health care provider in the field of breast cancer management, as was revealed through the consent process. They sought my expertise or knowledge on health promotion activities and other areas of health maintenance that were of concern to them. I also am keenly aware that I can give something back to the participants that help to address their health concerns. Therefore, during the interviews, I addressed the questions on the interview guide first before asking the participants questions about other health concerns.

### **Member Checks**

Member checks are another measurement of quality of evidence (Creswell, 2002) that were accomplished in various ways. Results of the study were disseminated to participants at an end-of-study meeting. All 12 participants were contacted about the end-of-study meeting. Two participants were unable to be reached via the previous contact information provided during the initial recruitment; therefore, I met with 10 participants

at the end of study meeting. At this meeting, I discussed the results of the study and gave the participants an opportunity to validate the results of the study and provide additional feedback. All 10 participants agreed with the findings of the study and were pleased with their contribution to addressing the increase in breast cancer mortality in their population.

Other experts in the field of cancer disparity research, breast cancer research, and qualitative research were consulted to test or challenge the results of the study. These experts included the dissertation committee members, the principal and coinvestigators of the CPTD/PHS study, and breast cancer and qualitative researchers at Johns Hopkins University. No discrepant data were identified during the data analysis and from the data obtained from CPTD/PHS team in the study. I anticipated discrepant data to be present from E-Global Health; however, but with incomplete medical record reviews of participants, discrepancy could not be determined.

### **Data Triangulation**

The data were triangulated by collecting information from different sources. I cross-validated the participants' transcripts with their audio-recordings and captured their emotional nuances for deeper understanding of the data. I reviewed the CPTD baseline data on participants' demographic information and reviewed medical records obtained from CPTD and abstracted by E-Global Health, a subcontractor for obtaining medical records from health care providers. However, E-Global Health submitted only supportive medical records that confirmed the recollection of screening and health maintenance for Participants 00-00002, 00-00005, 00-00006, 00-00010, and 00-00011. Two of the record of service data from 00-00006 and 00-00011 were labeled in-correctly. Maxwell (2005)

promoted data triangulation to ensure comparison and contrasting of participants' data to decrease the probability of systemic biases and poor associations.

### **Summary**

This chapter presented the stories of older African American women experiences with BCS, follow-up of abnormal results, as well as their health promotion/health-seeking behaviors and recommendations. The data collection process (highlighting IRB procedures, participants' recruitment, and equipment used to preserve the original voice of participants) and the narrative analysis process were described. The stories of participants' were told in sequential order of events throughout their BCS experiences. Discrepant data was not present during participants' interviews or recruitment but it was present in some of medical records reviewed. The findings of this study are significant for understanding older African American women's BCS and abnormal results experiences which can have a great impact on reducing their breast cancer mortality. These results also describe the process that the women go through their BCS experience and the factors that can impact their outcome. The next chapter will present a detailed discussion about the results of this study as it relates to the research questions, significance, social change implications for public health practice, and future research.

## Chapter 5: Summary, Conclusion, and Recommendations

### **Evolution of the Study**

Included in this chapter is an explanation of my quest to understand older African American women's experiences with abnormal mammogram results. As a breast care clinician in Baltimore City, I am passionate about reducing breast cancer disparities among minority women by focusing on the individual patient, the community, and providers. I have anecdotal experiences of African American women not following up for a consultation after an abnormal mammogram, which sometimes results in a late-stage breast cancer diagnosis. The stories from the African American women ages 40 to 64 at the initial consultation seemed to be different from the stories of older African American women ages 65 years and over related to follow-up practices with abnormal mammogram results; beliefs (e.g., feminist); past experiences; and family dynamics.

In my clinical practice at an academic medical center in Baltimore City, I noticed that many of the factors associated with African American women's delay in diagnosis or treatment are independent of their health insurance status. It would make sense for women not to follow up if they could not afford to, but it is unclear why they would not follow up if they had insurance that would cover their expenses. I completed a review of empirical studies on breast screening experiences of African American women and found the majority of studies to be focused on African American women under the age of 65. Access to care was used in many of these studies as a reason for diagnostic delay and higher mortality among minority women, but I did not agree with that consensus. Many

of the older African American women who sought initial consultation after an abnormal mammogram had health insurance or access to special breast care programs, yet some older African American women in my clinical practice voiced a plethora of reasons for their delay in following up abnormal mammogram results.

From my clinical practice and the review of empirical studies, it is evident that there are many questions remain unanswered: Why do older African American women have later stage breast cancer at the time of diagnosis? What is the length of time from older African American women receiving an abnormal mammogram to the time of follow-up with a breast specialist? Therefore, the two research questions in this study are what are the experiences of a group of older African American women (65 and over) with BCS in Baltimore City? and what was this group's experience with abnormal mammogram results after BCS?

This study was focused on unraveling the experiences of older African American women with abnormal mammogram results in Baltimore City because this group has been understudied in the literature and at high risk for breast cancer mortality. In this chapter, I discuss and integrate the significance of the findings with the QCM and CRT, and I also address the social implications of the findings to public health practice. The limitations of the study and recommendations for further research are included in the discussions.

### **Overview of the Study**

The purpose of this qualitative interview study was to describe the experiences of a group of older African American women with BCS and abnormal mammogram results

in Baltimore City. The impetus for this study stemmed from the widening disparity between the breast cancer mortality of older African American women and their European American counterparts nationally (ACS, 2007, 2008). The two research questions that guided this study were used to address the gap in knowledge about older African American women's BCS and abnormal mammogram results. Answering these questions will provide a better understanding into the possible barriers in older African American women's BCS experiences that can impact their breast cancer mortality.

### **Summary of the Findings**

**Experiences of a group of older African American women with BCS in Baltimore City.** The women had a plethora of events in their BCS experience, including mammography screening, receipt of abnormal results, additional diagnostic tests, diagnostic resolution, and breast cancer treatment. The women had expectations about the care that they should have received from health care providers in their mammography experience, which the providers may not have been aware of. Timely and detailed communication from providers could have reduced the emotional distress that the women faced. The women had a strong support system through spouses, family, relatives, friends, and church family or church members. However, their main support was their faith in God and communication with God through individual or collective prayer.

**The group's experiences with abnormal mammogram results after BCS.** The women experienced variances among their receipt of abnormal mammogram results, including time to delivery of the results, how the results were delivered, and misinterpretation of results. The women who went to the same-day mammography center

received their results in person and a letter in the mail; the women who went to multiple-day mammography centers received their results 1 to 2 weeks later. Technicians lacked clarity in communicating with women after the mammogram procedure and led the women to believe that their mammogram results were benign, even though they had not yet been reviewed by the radiologist. The women who were misled by the technician's communication maintained their disbelief upon receipt of their abnormal mammogram results in the mail and perceived that the controversial results were for the benefit of the mammography center. The women who understood that they truly had abnormal mammograms were emotionally distressed and concerned about the possibility of having breast cancer.

### **Theoretical Limitations**

The paramount goal of narrative inquiry is to understand the stories of the lived experiences of the participants' mammography experiences (Clandinin & Connelly, 2000; Patton, 2002). The purpose of an in-depth interview study is to obtain answers to questions that will help to understand the lived experiences of individuals within the narrative tradition using the framework of the QCM and CRT (Seidman, 2006). Therefore, this narrative study focused on older African American women's mammography and abnormal mammogram result experiences in Baltimore City.

This study had seven ingrained limitations. First, my subjectivity may have impeded an unbiased interpretation of the participants' mammography experiences. I may have had preconceived expectations of the study outcomes that influenced my selection of data to report in the findings. To decrease subjectivity, I used the following strategies

previously described in chapter 3: (a) maintained uniformity in interview style in the presence of reflexivity, (b) conducted member checks through the end-of-study meeting with participants and consultation of experts in the field, and used (c) data triangulation so various sources of participant information could be cross-referenced and compared for congruency.

Second, I was unable to verify all of the participants' medical records because E-Global Health did not submit them to the CPTD/PHS team. The unavailability of the medical records from E-Global Health was an unexpected outcome, especially because it had been subcontracted by the CPTD/PHS with the promise to deliver the complete medical records of the participants in the study. Therefore, participants' medical encounters and diagnostic testings were not able to be verified which can compromise the validity of their stories.

Third, the results of this study may be applicable within the context of a similar target population in a different locality, but the results were not intended to have universal applications. I chose purposeful sampling to obtain information about an unknown phenomenon from participants who were experts about their mammography experiences. Experience is a concept of variation that is personal to the individual; therefore, the participants' stories arose out of the context of their social and cultural environment.

Fourth, I may have had a professional bias toward health care systems because of my knowledge of and practice within them. Therefore, in an attempt to decrease bias, I maintained the line of questioning according to the interview guide. Although I answered



additional, unrelated health information for participants, this was done at the end of the interview and was not included in the narrative analysis.

Fifth, I was the main instrument for data collection, so I knew that the quality of the information collected depended on how I conducted the interview. To solicit high-quality data, I followed the interview guideline and probed with follow-up questions for a deeper level of understanding of the participants' mammography experiences. I observed the participants' gestures and responses with emotional undertones to empathize with their depicted experiences.

Sixth, structure, process, and outcome are the three stages within the QCM and they are not linear events occurring within the patient→provider, patient →family, or provider→provider relationships. Those three stages are dependent on the circumstances surrounding the event (e.g., going for the mammogram, etc), and the timing of the event. The interactions between human beings are dynamic and can vary at any given time and circumstance. An individual may have an experience or outcome that is different from another person who had been exposed to the same provider, or setting (e.g., similar diagnostic mammography center). Therefore, I was unable to determine what the causes for variations within the human interactions that may contribute to older African American women's negative perceptions of providers or health care services.

Seventh, CRT is impacted by the social environments of individuals. An individual interpretation of racial discourse can be related to ones perception of their social status, ethnicity, and their acceptance into mainstream society. Therefore, different older African American women may encounter similar experiences with providers or

healthcare settings and walk away with positive or negative perceptions of their experiences. CRT is not generalizable to a group of older African American women because of the inherent variations (such as age, socioeconomic status, social environment, etc) within this group of women.

### **Practical Limitations of the Study**

The open-ended format of the interview protocol solicited rich data from the participants about their mammography use, abnormal mammogram results, health promotion, and health-seeking behaviors. It was evident from the review of the interview transcriptions that the participants wanted to explore additional subject areas, but the interview guide prohibited that exploration. The overarching theme of this study was rooted in the mammography and abnormal mammogram results, but participants may have had more to say about observed health care clinical processes.

Participants delved into additional experiences of their first mammogram or other mammogram experiences. Prior mammogram experiences could have framed their perceptions or interpretations of current or future mammogram experiences. Some women had difficulty responding to the question, “If there is one thing that you can change about your mammogram experience what would it be? Why?” This question limited their response to one recommendation for change, and during the interview some of the women had difficulty limiting their response to one recommendation.

## **Interpretation of the Findings**

### **Data Corresponding With Research Questions**

The BCS experience of older African American women in Baltimore City was multifaceted. Some of the positive experiences depicted the women as being motivated to obtain an annual BCS mammogram, as recommended. Older African American women's behaviors toward health care services are influenced by beliefs, culture, environment, and lived experiences. Therefore, older African American women's health maintenance practices are likely to be similar to their BCS mammography practices. The following discussion provides insight into the findings related to the research questions and provides a deeper understanding of older African American women's BCS mammogram and receipt of abnormal results experiences. Similarities and differences among the women's experiences in the mammography and health promotion /maintenance settings are discussed in conjunction with identified barriers that impeded them from receiving screening services.

### **Mammogram Procedure**

Many of the women expressed disdain for the mammogram procedure. The compression of their breasts between two flat surfaces almost seemed inhumane or barbaric to them. The women understood the importance of having a mammogram for early detection of breast cancer and that is why they did it every year, but they did express the desire for a new invention or an invention that is more sensitive to the female breast (00-00001) As discussed in chapter 2, Phillips et al. (2001) found that the lack of confidence in BCS techniques can influence African American women to not participate

in BCS. Although the discomfort that the women in this study experienced during the mammogram did not deter them from BCS, it may not be the same outcome for other older African American women since this study's sample is not generalizable and the literature have documented poor mammography screening behaviors of African American women in comparison to European American counterparts.

### **Mammography Behaviors**

The older African American women were motivated to have an annual BCS mammogram. This motivation came from their strong family history of breast cancer or from having abnormal mammogram results or breast findings in the past. As discussed in chapter 2, Thomas (2006) reported that African American women who have a negative experience at their first BCS mammogram are more likely not to adhere to BCS guidelines than African American women who have a positive experience at their first BCS mammogram. Thomas's sample comprised African American women ages 40 to 64; in this study, the women were ages 65 and older and their negative experience had no effect on their adherence to BCS mammography because they did not allow the negative experiences they had with mammography providers to influence them not to participate in BCS. On the other hand, Welch and Fisher (1998a) found that older women ages 65 to 69 who are Medicare beneficiaries are more adherent with BCS mammography than women ages 70 and over. I refute this claim because all of the women in this study were Medicare beneficiaries and were adherent with BCS mammography.

The women in this study were aware of the breast cancer risk and were engaged in continual mammography use. Powe et al. (2006) reported that African American

women who have witnessed the trajectory of late-stage breast cancer diagnosis and death among friends or family members have strong fatalistic beliefs. I contradict Powe et al.'s findings, arguing that even though some of the women in this study experienced the death of a loved one to breast cancer, they exhibited faith in God rather than fatalism. The women also wanted to understand the reasons for additional diagnostic tests or follow-up generated from their BCS mammogram. Sadler et al. (2007) reported that the failure of African American women ages 60 and older to participate in mammography screening had nothing to do with their lack of knowledge about breast cancer risk. The findings of this study supported Sadler et al.'s findings.

As discussed in chapter 2, Bynum et al. (2005) related the lack of BCS among older African American women to such access barriers as transportation, copayments, functional impairments, and beliefs about risk and benefits of BCS. However, older African American women in this study lived independent lives and were willing to take public transportation to get to and from medical appointments. The women also had the support of their family members to drive them to medical appointments. Therefore, transportation was not a barrier for older African American women to get BCS in this study. Copayments would have been a barrier beyond BCS mammography if the women had to see specialists and did not have supplemental insurance or Medicare Part B coverage. Based upon the findings, the conclusion may be drawn that the barriers to older African American women engaging in BCS should be addressed on an individual basis and that women ages 65 years and older can and do live independently.

### **Delivery of Abnormal Mammogram Results**

Most of the abnormal mammogram results from multiple-day mammography centers were delivered to the women 1 to 2 weeks after the BCS mammography. It is difficult to understand why radiologists have to prolong the delivery of abnormal results to patients that may have already been known at the time of the mammogram. I understand that radiologists have to dictate official reads on mammograms, but there is a process called preliminary results which is the results that the radiologist confer verbally to the patient prior to the written report. This practice of the radiologist giving preliminary results to patients have already been in practice at same-day diagnostic mammography centers and may not be a difficult practice for other mammography centers to adopt. The women viewed the technicians as the conduit for the radiologists at every level of the mammogram process. Some women had hoped to meet with their radiologists to discuss their mammography results, but they also understood that the radiologists' busy schedule did not give them the time to meet with them one on one; therefore, they accepted the radiologists' need to send messages through the technicians.

### **Abnormal Mammography Follow-up Behaviors**

After many of the women received their abnormal mammogram results in the mail, they had to call to schedule appointments for follow-up BCS mammograms. Some women recounted that their follow-up mammograms were 2 to 10 days later. Most of the women relied on public transportation or family members to take them to appointments. The women who had to schedule follow-up mammograms had a delay of 1 to 2 week for additional tests and the inconvenience of having to return to their respective

mammography diagnostic centers. All of the women followed up after their abnormal mammograms.

As described in chapter 2, Jones et al. (2005) found that African American women ages 40 to 64 years with lower SES who were not married and had no regular primary care provider, and who also had painful mammogram procedures, had inadequate follow-up to abnormal mammogram. However, despite these factors, the women followed up abnormal mammogram results adequately. The findings of this study supported Chang et al.'s (1996) finding that a woman's age is not a predictor of timely follow-up of abnormal mammogram results.

Most of the radiologists failed to communicate with the women who participated in my study about their BCS mammogram or abnormal results. The lack of communication from the radiologists contributed to the vague communication from the technicians and the women's misinterpretation of their mammogram results. This finding also supported Gwyn et al.'s (2004) finding about poor communication of mammography screening results noted with African American women. The results of this study showed that older African American women's timely follow-up of abnormal BCS mammogram results was not influenced significantly by their misinterpretation of the technicians' communication. However, Kerner et al. (2003b) recommended that effective communication between mammography providers can influence African American women to follow up abnormal mammogram results in a timely manner to achieve timely diagnostic resolution.

Two of the women in the current study sample were diagnosed and treated for breast cancer. Their breast cancer diagnostic resolution and treatment processes were expedited through the clinical process of comprehensive cancer centers. The women reported that the technicians communicated clearly to them about the next step in the process and the radiologists spoke directly to them about the abnormal mammograms and the need to do additional tests that same day. They received breast cancer treatment immediately after their breast cancer was biopsy proven. Even though the women's descriptions of the events leading up to their breast cancer treatment may have been without deficits (e.g. in clinical processes, etc), the literature has shown that delays between diagnostic resolution and breast cancer treatment are a reality for African American women. The women in this study were from the PHS study and were exposed to information on breast care services which could have motivated them to follow up immediately for additional testing after abnormal mammogram results.

Kerner et al. (2003b) found that African American women with a history of prior abnormal mammogram are 60% less likely to be diagnosed within 90 days. Allen et al. (2008b) found that the delay in time between diagnostic resolution or follow-up of the participants in their study was related to (a) dissatisfaction with how providers and staff communicated; (b) disrespect and mistreatment from health care providers and clinic staff; (c) logistical barriers to diagnostic testing (e.g., complaints of lengthy clinic wait times, limited appointment times, transportation problems, and follow-up of diagnostic procedures at unfamiliar locations); (d) anxiety and fear of dying from breast cancer; and (e) few or no support systems. Although the women in this study expressed



dissatisfaction with communication from staff and primary care providers, long waiting times for abnormal mammogram results, and additional diagnostic tests, they did not delay their diagnostic resolution. Perhaps their strong faith in God, other strong support systems combined with their participation in the PHS study was the motivation for their timely follow-up practices. This assumption may be the focus of future research.

### **Communication**

**Communication among providers.** Overall, primary care providers and specialist providers communicated poorly among themselves about the women's medical conditions. Some of the women had to inform their primary care providers of the changes in their medical management from specialist providers and often forced communication among their providers by demanding that providers send reports to each other or by taking their reports to the providers at their next clinic visit. The specialist providers who were part of a breast cancer center or institute showed superior communication strategies among each other than did the primary care and specialist providers who were managing or treating other medical conditions. This was evident when some of the women commented on the free flow of communication among specialist providers in cancer institutions that facilitated rapid treatment of their breast cancer. The difference in communication practices among providers at a breast cancer center or at a standalone diagnostic mammography center was not present in prior research noted in Chapter 2. However, Pruthi, Brandt, Degnim, Goetz, Perez, Reynolds et al. (2007) conducted a review on the practices surrounding the diagnosis and treatment of breast cancer and found that a multidisciplinary team approach of breast experts have a positive impact on

the timely care that the patient receives. Many of the breast cancer centers or cancer institutions in the US utilize a multidisciplinary team approach. Pruthi et al. (2007) provided understanding into the multidisciplinary team approach that can be inferred as the reason for the women in this study positive experience with providers at cancer institutions.

**Providers' communication to patients.** Poor communication among providers and between providers and the women was noted in the results. The woman expected their primary care physicians or specialist doctors to provide them with guidance about what screening examinations to take, when to take them, and what the results meant. The women's expectation of good communication was not only during their mammogram experiences but also through health promotion and health -seeking activities. Most of the women's expectations about the roles of their health care providers were not being met, as was evident across their stories. This is similar to the findings of Thomas (2006) discussed in chapter 2, where providers communicated poorly to women about the mammogram procedure and the results of the procedure.

### **Emotional Discourse**

Emotion is a feeling or a subjective reaction that is prompted from a physiological change before or after an emotional response to the causing event (Lefton, 1997). The women had to deal with the emotional distress of having BCS mammography, waiting for the results, and then waiting for additional diagnostic tests to be scheduled because the mammogram results were abnormal. I am not dismissing the notion that the women who received same-day mammography results did not experience some emotional distress, but

their anxiety or fear was brief. They received their abnormal results the same day and had additional diagnostic test that negated any abnormal findings the very same day. For the women who were diagnosed with breast cancer, their emotional distress was different from the women who had a benign resolution of breast findings. These women did not have prolonged wait times for abnormal results and additional diagnostic testing because their screening mammograms had been done at a comprehensive cancer center. Their emotional distress was in the result of the time that they had to wait to know whether the surgery, radiation, or chemotherapy that they had undergone had cured their breast cancer. Thomas (2004), one of the few studies discussed in chapter 2 that examined the associations of emotions to African American women BCS experiences, found that women diagnosed and treated for breast cancer process their experiences differently (e.g. their seasons of breast awareness, womanhood, self-portraits, view of their mothers', breast cancer beliefs, etc) than women undergoing BCS with no history of abnormal results.

Other emotional distress was the result of the additional responsibility that the women took on to ensure that their medical reports or treatment plans were shared among their health care providers. The women's insistence about that their providers communicate place not only an emotional burden on them but also a physical burden because they had to request copies of documents and take the reports with them to their appointments with other providers. Emotional distress was described throughout the women's mammography and health promotion and health-seeking experiences in this study. The women's account of their emotional distress was able to be brought out

through the narrative approach used in this study. As discussed in chapter 2, Eide (2006) used the narrative approach to understand the Native Hawaiian culture because little was known. The stories of participants generated themes within the context of emotional transformation which is similar to the findings of this study. Emotional discourse transforms the experiences of the women into positives and negatives which can influence future BCS behaviors.

### **Health Promotion and Health-Seeking Behaviors**

One of the themes mentioned in the literature review was avoidance behavior. Therefore, older African American women's (in this study) avoidance behaviors in health promotion or health-seeking activities will provide more information about their BCS practices. Older African American women were mostly adherent to the screening recommendations for colonoscopy, glaucoma screening, bone density scan, and hemoglobin A1C monitoring for diabetic control. However, most of the women relied on their primary care providers, gynecologists, or other specialists to recommend these additional screening examinations, besides mammography. This finding was consistent with Bundek et al.'s (1993) conclusion that the women who had external control by powerful others such as a physician also were more likely to engage in cancer screening practices. Therefore, the findings of the current study suggested that when primary care providers and specialists recommend health promotion activities to older African American women, the women are more likely to be adherent.

Older African American women's compliance with health promotion and health-seeking behaviors was evident in their dependent care-giving roles. Some of the women

had to assume the primary caregiver role to family members because of illness or disability. However, this role did not deter them from engaging in health promotion activities or following up with abnormal results. The women seemed knowledgeable about their health status and were attentive to the due date of their next screening tests and annual physical exams which could have been because of their participation in the PHS. This finding was in contrast to Abdulraheem's (2007) finding that underutilization of health care services by older women is related to their dependent care-giving roles. There may be an association between older African American women's primary care-giving roles and compliance with health promotion and health-seeking activities to their compliance with family members' medical treatment plan.

### **Spirituality**

Older African American women's spirituality was highlighted throughout their BCS stories. Receiving support from members of their church congregation or church family through their mammography experience was vital to the women's faith and optimism. Many of the women mentioned that their faith in God got them through the fear and anxiety of having a mammogram or waiting for the results. The women who underwent breast cancer treatment had a strong and unwavering faith in God, and they gave credit to their faith as the power source that sustained them through their experiences. This finding was similar to Phillips et al.'s (2001) assertion that African American women ages 40 to 64 years have strong spiritual or religious beliefs that could have a powerful influence on their participation in BCS activities.

### **Supplemental Insurance Coverage**

In regard to other health promotion and health-seeking experiences, the women described experiencing emotional distress when they were not able to consult with specialists for medical conditions because of no supplemental or Medicare Part B insurance. When one of the women telephoned the social service office to apply for Medicaid for which she qualified, she had to wait 30 minutes before she could speak to a representative. The representative told her that he would call her back, but he did not. Medicare (Part A) covers the cost of long-term hospitals, in-patient hospital care, home health care services, hospice care while Medicare Part B (supplemental coverage) covers medically necessary services such as doctor visits, outpatient care, annual physicals, and preventive services (Medicare.gov, 2011). Therefore, if a person does not have Medicare Part B they will not have coverage for medically necessary services such as ultrasound, MRI and breast biopsy; however, in the state of Maryland they will still have coverage for medically necessary services through the Maryland State Cigarette Restitution Fund (Breast Cancer Screening Program (discussed in Chapter 1). There is a need to streamline the process in an effort to increase the accessibility of supplemental coverage for women on a fixed income.

### **Role of Participants in PHS Study**

Although this study yielded various themes, the participants' knowledge of BCS and importance of timely follow up with abnormal mammogram may have been influenced from their participation in the PHS study. These participants were in the non-navigated arm of the PHS study and received minimal information on breast cancer

screening. However, the impact of PHS study on participants was not able to be determined.

### **Findings Related to the Literature and Theoretical Framework**

As I examined the results of this study within the theoretical framework, I found that the results were relational to the structure of the QCM. Table 4 depicts the women's mammography and health promotion and health-seeking trajectory within the QCM structure (providers, patient or family, and system). The first column includes the findings of the study that relates to providers. The second column is divided into two columns showing the findings as it relate to the patients, severity of illness, comorbidities include providers and family descriptors. The third column shows the descriptors organizational, culture and resources within the health care system. These findings show that the women's BCS and abnormal mammogram experience is multifaceted and a holistic approach should be used in health care delivery for older African American women.

Table 4

*Summary of the Process of Older African American Women's Experiences With BCS and Abnormal Mammogram Results*

Structure			
Providers	Patient or family		System
	Patient Severity of illness Comorbidities	Family descriptors	Descriptors Organizational culture Resources
1. Poor communication - All providers 2. Poor gatekeepers - Primary care providers 3. Ageism -All providers	1. Multiple doctors' appointments 2. Seeking knowledge of medical status 3. Competing priorities 4. Delay in follow-up or screening exams 5. Role of faith/spirituality	1. Strong support system: -Immediate (spouse, children and siblings) - Relatives - Friends - Church family	<u>Mammography</u> 1. Delayed abnormal mammogram results 2. Lack of privacy in waiting rooms 3. Painful mammography procedure 3. Lack of sensitivity among technicians  <u>Health promotion &amp; health seeking</u> 1. Long wait times 2. Abbreviated physical exams 3. Complaints of symptoms not addressed at visit 4. Role of faith/spirituality

*Note.* All providers refer to radiologists, technicians, primary care providers, specialists, and clinic support staff.

The process of the older African American women's BCS and abnormal mammogram result experiences were relationship centered: providers →patients, providers →providers, and patients →God. The stories of the older African American women focused on the communication they had with providers; support systems; and, most of all, with God through prayer and their faith. The women also discussed their



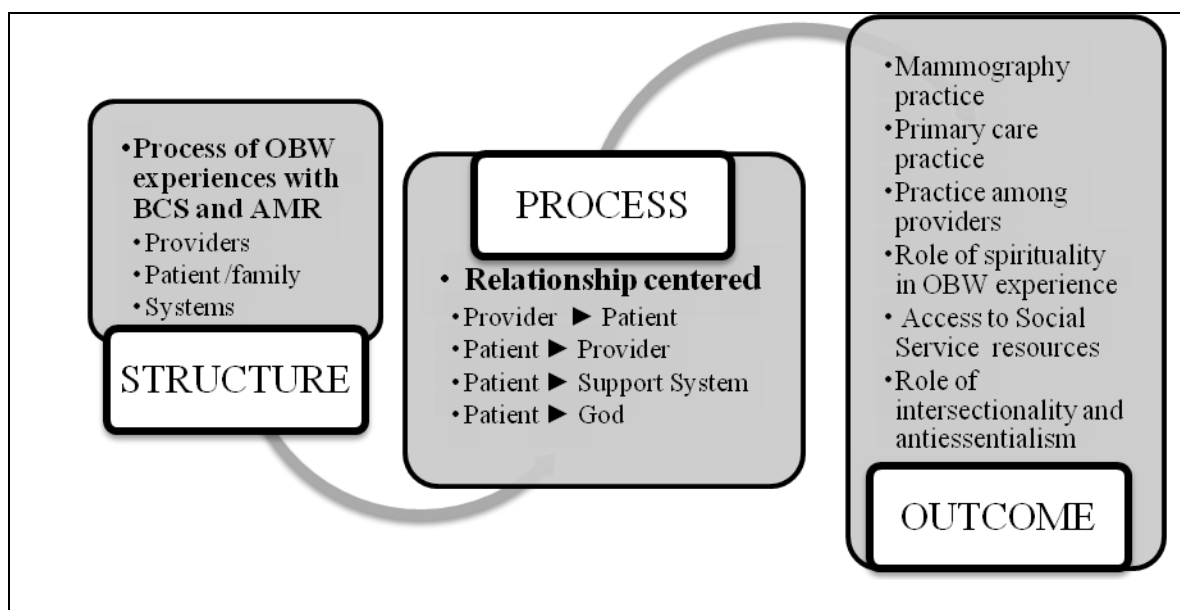
disappointment with providers' failure to communicate with them about their medical status and treatment plan.

Racial discourse was present in the women's accounts of their health promotion experiences and was not present in their BCS experiences. When the data were analyzed according to the CRT, some of the women experienced intersectionality and antiessentialism because they perceived themselves as being treated differently from younger patients or patients from another ethnic group by health care providers and office clinic staff. Some of the women perceived providers and clinic staff as talking down to them and passively neglecting them (e.g., by having them wait longer times for the provider's encounter) because they were older and African American. As described in chapter 1, within the concept of intersectionality and antiessentialism, providers may manifest behaviors that influence them to behave a specific way toward certain ethnic groups because of their allegiances and loyalties to another group. For example, European American providers of African American women may be more loyal and nonprejudiced to other individuals from their ethnic group because they believe that people like themselves will better understand their experiences. Therefore, older African American women may perceive health care providers with similar ethnocultural background as providing more impartial services to them.

Figure 6 addresses the process of older African American women's experiences with BCS and abnormal mammogram results as being relationship centered using an adaptation from the QCM and CRT. The first box represents the structure of older African American women's experiences with BCS and Abnormal Mammogram Results.

This structure includes providers, patients, family and systems (both clinical and social). The second box is describing the process through the women's experiences as relationship centered among patient, provider, support system, and God. The third box described the outcome of understanding the process of the women's experiences to include factors within mammography and primary care practice, among other providers, the role of spirituality, access to social service resources and the role of intersectionality and antiessentialism. The type of relationships formed among providers and patients can affect patients' outcomes physically, emotionally, and socially after receipt of an abnormal mammogram result.

Most of the results in this study are different from the findings of African American women's (40-64 years) experiences with BCS and abnormal mammogram results as synthesized in Chapter 2 and described in Figure 4. The only common theme within the study findings of younger African American women (40 to 64 years) and this study (older African American women), is that there is poor provider communication within the process of their BCS and abnormal mammogram experiences. Younger African American women had a decrease in BCS behaviors because of various factors, however; this study did not find any reduction in BCS behaviors among older African American women. Younger African American women had a delay or failure to follow-up after abnormal mammogram results for many reasons listed in Figure 4; however, older African American women's delay was mainly because of poor provider communication.



*Figure 6.* Adaptation of QCM and CRT for older African American women's experiences with BCS and abnormal mammogram results.

### **Implications for Social Change**

Chronic diseases pose heightened threats to the public's health because of such contributing factors as unhealthy behaviors, poor lifestyles, deplorable social and living conditions, and limited accessibility of healthcare on various levels (Siegel & Lotenberg, 2007). There is a need for public health practices to focus on modifying unhealthy behaviors, and increasing the accessibility of health care services within the social context of the individual's environment (Siegel & Lotenberg, 2007). The social change implications of this study address how to change behavior, social conditions, and develop policies to reduce the burden of breast cancer among older African American women in Baltimore City (Siegel & Lotenberg, 2007). As discussed in chapter 1, seven implications for positive social change were identified in this study.

The first implication is directed toward breast care providers, including radiologists, technicians, breast surgeons, medical oncologists, radiation oncologists, primary care providers, and gynecologists. The poor communication or complete lack of communication that the women experienced with providers highlighted the need for educational programs focused on improving providers' communication with patients. These educational programs should include a component that develops providers' communication skills among each other as well as with their patients. All providers, regardless of first language or country of origin, should ensure that their patients can understand their treatment plans. Health care providers are the primary gateway to health services, so it is essential that they communicate clearly with patients and colleagues.

The second implication is the need for providers to discuss mammography studies or results with older African American women instead of having technician deliver the findings. The type of personable or intimate care received from providers can impact older African American women's interpretations of their BCS experiences or motivation to engage in follow-up care.

The third implication is the need for mammography centers to change from multiple-day to same-day centers to reduce older African American women's emotional distress resulting from long wait times for abnormal mammogram results. Same-day diagnostic mammography centers would help to reduce the physical burden (e.g., comorbidities, transportation issues, etc.) on older African American women of having to return for additional diagnostic tests for abnormal mammogram results. Same-day mammography centers offer quick resolution of abnormal findings. Public policies can

support the development of same-day mammography centers by establishing guidelines for the centers' operational protocols. Older African American women want radiologists to speak directly to them about their mammogram x-rays and results, and they also want results on the same day.

The fourth implication is the establishment of guidelines for mammography centers' internal clinical processes. These guidelines will provide a framework for the way in which mammograms are to be administered, the layout of dressing rooms, communication strategies for technicians, and the delivery of abnormal mammogram results. Improving the clinical process so that it addresses the organizational culture as well as the cultural diversity of patients will create a nonthreatening environment for older African American women and encourage compliance with mammography screening and follow-up.

The fifth implication is the provision of support to improve communication between primary care providers and other specialists about older African American women's medical conditions and treatments. Recent technological advancements such as electronic medical records have demonstrated that patient data can be uploaded in one location and accessible in many locations by different providers. Public health policymakers and health care providers should strive to identify ways to improve providers' communication with each other through electronic media.

The sixth implication supports the development of educational programs to increase older African American women's support systems' knowledge of their health promotion needs. Family, friends, and church family and church members have played an

important role in supporting older African American women through their mammography and health promotion experiences; therefore, educating them about the women's health promotion needs will help to maintain compliance.

The seventh implication calls for the development of public health programs to increase providers' understanding of the spiritual beliefs of older African American women. Public health officials should find ways to collaborate with religious organizations to facilitate health promotion and health-seeking activities of older African American women.

### **Recommendations for Action**

As discussed in chapter 2, there are no established BCS mammography guidelines for women as 70 and older; the recommendation for screening women in this age group is determined solely by the providers. In this study, the eight women over the age of 70 were engaged in annual mammography screening. Their motivation to engage in annual mammography came from their strong family history or recommendations from their health care providers. The older African American women who participated in this study were living full, high-functioning lives and were independently involved in their own health maintenance, and should be allowed to continue with mammography screening beyond age 70.

Kerlikowske et al. (1999) and Kerner et al. (2003a) argued that BCS mammography is less beneficial for women ages 69 and older because of multiple comorbidities that increase their risk of mortality. Many of the women in this study had comorbidities, including diabetes mellitus, hypertension, emphysema, coronary artery

disease, and so on, that were well controlled, while they continued to live independent lives. Thus, a lack of mammography guidelines that support screening for women ages 70 and over could result in these older African American women dying from breast cancer rather than complications of diabetes or hypertension. Public health policies need to support an extension of mammography screening guidelines for women ages 70 and older. More studies are needed to determine the maximum age for BCS mammography guidelines.

Same-day mammography centers should be the standard practice of all mammography centers in Baltimore City to reduce the emotional distress that women face while waiting for screening mammography results, the burden on their support systems, and our national health care costs. The women in this study were Medicare beneficiaries, and Medicare reimburses mammography centers at the same rate for the screening, diagnostic mammogram, and ultrasound that they perform on the same day or on different days. However, multiple-day mammography centers can capture an additional facility fees from Medicare when the women have to return for additional diagnostic tests.

Same-day mammography centers schedule fewer patients per day for screening than multiple-day mammography centers, which schedule additional diagnostic tests on other days. Therefore, it is evident that mammography centers that do not provide same-day service can schedule higher volumes of patients daily and may yield higher profit margins. However, the burden still remains on the older African American women to rearrange their schedules as caregivers or request family members to take time off work

to accompany them to follow up mammography appointments. Public health providers should strive to improve the health of the community and identify strategies to increase compliance with BCS mammography and follow-up protocols while reducing the burden on patients. Public health policymakers should look at same-day mammography centers as supporting public health goals within the social context of the individual and the community.

Academic institutions that support the training of radiologists and technicians should include effective communication strategies into their education curriculum. The radiology curriculum should encourage students to provide patient-centered care through a provider-patient relationship. Radiologists can establish standard verbal scripts for technicians to use when communicating with patients after a mammogram procedure. Scripting will provide clear directives so that patients do not receive mixed messages about mammogram results. Radiologists and technicians also should be trained in providing culturally sensitive care to address the geriatric needs of women to avoid ageism.

The women who participated in this study complained about the pain and discomfort they experienced during the mammogram procedure. No technological advancements of a new, more comfortable design for a mammography machine to detect a mass or a microcalcification are yet available.

Poor communication was a dominant theme in the findings; therefore, public health programs or mechanisms should be in place to facilitate communication among providers and with their patients. Providers have to learn to communicate with their



patients on a level that they can understand. Providers also must make time to address patients' questions and validate their symptoms or complaints. Electronic systems can support communication among providers; however, there is a need for an electronic system that can facilitate effective communication among providers.

### **Recommendations for Future Studies**

Many unanswered questions regarding what is unknown about a process or experience within older African American women's mammography or health promotion activities arose throughout this study. The following four areas were identified in this study for future research:

1. An extension of the BCS mammography guidelines for women ages 70 and older will help to save the lives of older African American women who have well-controlled chronic diseases. However, future studies are needed to determine the maximum age for the extension of the mammography guidelines for older women.
2. There is a strong association between older African American women's faith in God and their coping mechanisms when dealing with mammography and health promotion experiences. However, more studies are needed to address the spiritual needs of older African American women during health promotion and health-seeking activities. The merging of spirituality and health care delivery may be a mechanism to ensure older African American women's compliance to BCS and follow-up of abnormal results.

3. Although this study highlighted the benefit of same-day mammography centers, more studies are needed to identify and develop incentive programs that would encourage multiple-day mammography centers to change their practice to same-day mammography centers in Baltimore City. Even though the women in this study supported same-day mammography centers, the sample was not generalizable to other older African American women. Therefore, additional studies are needed to determine the benefit of same-day centers for older African American women from various jurisdictions.
4. Additional studies are needed to determine an effective curriculum for training mammography providers such as radiologist and technicians in providing culturally sensitive care to older African American women. Culturally sensitive training for mammography providers will help to address the different ethnocultural and geriatric needs of African American woman and avoid the perception of providers' ageism.

### **Researcher Reflections**

As I reflect on the development of this study, the process of identifying a problem, observing its impact on the community, and seeking answers to address the problem, I found the experience filled with discovery. I began to conduct this study with assumptions that older African American women may have similar barriers to BCS or timely follow-up as younger African American women; however, these assumptions were discredited by the findings of this study that show the participants' motivation to participate in BCS and follow up in a timely way with their abnormal mammogram

results. Through this research experience, I now have more respect for the research process, especially the qualitative design. The rigor of staying true to the narrative tradition by maintaining patience, diligence, and perseverance throughout the research process allowed me have a deeper understanding into older African American women's breast care practices that can impact their breast cancer outcomes.

No researcher can conduct exceptional research without passion for the topic. The many articles that I reviewed, the books on qualitative design and narrative inquiry that I read, the discussions that I engaged in with experts in the field, and the multiple drafts of the research proposal have allowed me to become more knowledgeable of the experiences of older African American women with BCS and abnormal results. The most compelling experience for me was the process of interviewing the participants. I felt a connection to the participants' stories and empathized with their emotions about the events related to their mammography experiences. I also understood the participants' frustration with the clinical systems and processes throughout their health promotion experiences. This research experience has increased my desire to continue research practice into the areas of minority cancer disparities and gerontology.

### **Conclusion**

The experiences of BCS and abnormal mammogram results of older African American women yielded a plethora of themes related to their independence, motivation, and spiritualistic beliefs, as well as the negative outcomes of their health promotion experiences. This chapter began with a discussion on the evolution of the study that was followed by an overview of the study that addressed the purpose and salient research

questions, and provided a brief summary of the findings. This chapter also included a comprehensive analysis and interpretation of the data that interwove the main points with the literature reviewed in chapter 2. The findings provided support, refuted previous researchers' claims about African American women, or provided answers to the gaps in the literature identified in chapter 2. Theoretical limitations of the study, including my subjectivity, data triangulation, purposeful sampling method, professional bias, and my role as the main instrument for data collection, were discussed. The practical limitation of this study was the use of the interview guide which prohibited the participants from freely exploring additional subject areas.

The conclusion for this study had implications not only for breast care providers and public health practitioners but also primary care providers, gynecologists, and other specialists. The findings implied that providers should give older African American women personable care and communicate directly and in a timely fashion with them about their health status. The establishment of same-day mammography centers to improve clinical processes, address organizational culture, and promote cultural diversity was viewed as one way to facilitate a nonthreatening environment for older African American women to maintain compliance to BCS. The development of educational programs on health promotion activities for older African American women's support systems will increase compliance with health promotion activities. The development of spiritual educational programs should be considered to help providers understand the health beliefs of older women related to their spirituality.

This chapter also included discussions on recommendations for action. One of the recommendations was for the change in BCS mammography guidelines to include women ages 70 and older. Providers should effectively communicate among themselves as well as with their patients to improve patient satisfaction and promote compliance with treatment plans. Scripted communication should be considered one way to resolve technician' unclear communication to patients after the mammogram procedure. Technicians should be more sensitive to older African American women during the mammogram procedure, and primary care providers should strive to be better gatekeepers of older African American women's health promotion and health maintenance.

The BCS and abnormal mammogram result experiences of this sample of older African American women in Baltimore City were unique. The mammogram experiences of older African American women cannot be compared to African American women ages 40 to 64 because there are different characteristics between African American women ages 40 to 64 years and those ages 65 and older. One factor is that access to health care or the lack of health care insurance can be a reality in the group of women ages 40 to 64; however, in the older age group, the women are Medicare beneficiaries, so there is no cost to them associated with a BCS mammogram. Researchers need to put more emphasis on understanding the experiences of older African American women with BCS mammography.

Public health practitioners should not only be about the business of reducing cancer disparity and mortality in susceptible populations. Based upon the findings of this

study, public health practitioners should promote breast health services tailored to meet the needs of older African American women in Baltimore City.

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## Appendix A

1. PARTICIPATING IN SCREENING MAMMOGRAM
  - a. Why did you decide to have a mammogram?
2. THE DAY AT MAMMOGRAPHY DIAGNOSTIC CENTER
  - a. Tell me about the day you went to the clinic for your mammogram. Tell me what happened. How did you get there? Did anyone go with you? How did you feel during the exam and after?
3. THE MAMMOGRAM PROCEDURE
  - a. Had you had a mammogram before? If so, was this one like the others? If not, did you know what the procedure was like? How were you treated? Who did the test? How long did it take?
4. DELIVERY OF MAMMOGRAPHY RESULTS
  - a. When did you get the results of the mammogram? How long did you have to wait? Did you get a letter in the mail or did someone call you? Who called? What did they tell you? How did you feel about the process of notifying you about the results?
  - b. How did you feel after you found out you had an abnormal mammogram? Had this happened before?
5. PROCESS OF EXPERIENCES AFTER ABNORMAL MAMMOGRAM RESULTS
  - a. What did you do after you receive your mammogram results? What did you do first, second, third...? Did you experience any problems or roadblocks? If so, describe? Were there any solutions available? If so, describe? What did you do to solve the problem? How did you feel about this process?
6. SUPPORT SYSTEMS
  - a. Did you have any support system (or person) during this experience? Who they were? How did they support or help you? How did you feel about your support system?
7. HEALTH PROMOTION & HEALTH SEEKING BEHAVIORS
  - a. What activities do you normally do to maintain your health outside of breast screening? Did you ever have an abnormal result? What was the recommended follow-up? Did you do what was recommended? Why?
  - b. How do you feel about health promotion? How do you feel about your health?
8. PARTICIPANT'S RECOMMENDATIONS
  - a. If there is one thing that you can change about your mammogram experience what would it be? Why?



## Appendix B

Table 3. *CPTD Baseline Data: Participants' Supplemental Coverage Status*

Participant's S0 no.	Medicaid beneficiary	Medicare Part B or Medigap	Recipient of VA services	Tricare insurance
00-00001	Yes	No	No	No
00-00002	No	Yes	No	No
00-00003	No	Yes	No	No
00-00004	No	No	No	No
00-00005	No	No	No	No
00-00006	No	Yes	No	No
00-00007	No	No	No	Yes
00-00008	No	Yes	No	No
00-00009	No	Yes	No	No
00-00010	No	Yes	No	No
00-00011	Yes	No	No	No
00-00012	No	Yes	No	No

## Curriculum Vitae

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**Education**

- 2011 PhD Candidate, Public Health, Walden University, Minneapolis, MN.
- 2008-2011 Research Trainee at Johns Hopkins Sydney Kimmel Cancer Center, Johns Hopkins University Bloomberg School of Public Health & Johns Hopkins University School of Medicine; Baltimore, MD
- 2008 MSPH, Walden University, Minneapolis, MN
- 2004 MSN, Adult Oncology Nurse Practitioner & Clinical Nurse Specialist Program, University of Pennsylvania, School of Nursing, Philadelphia, PA
- 1998-2002 BSN, Coppin State University, Helene Fuld School of Nursing, Baltimore, MD
- 1995-1998 LPN Certification, Hunter College of the City University of New York; New York
- 1996 CNA Certification, Allen's School for Physicians Assistant, New York

**Experience****Clinical Internships**

- 2004 Surgical Oncology and Medical Oncology, Hospital of the University of Pennsylvania, Rena Rowan Breast Center of Abramson Cancer Centers, Philadelphia, PA

2003 Primary Care/Internal Medicine, Hospital of the University of Pennsylvania, Penn Care Internal Medicine, Philadelphia, PA

**Professional Health Care Experience**

2007-Present Surgical Oncology Nurse Practitioner/Clinical Nurse Specialist  
Johns Hopkins University School of Medicine; Baltimore, MD

2009-Present External Examiner for Oncology Nursing Programme,  
University of the West Indies, School of Advanced Nursing  
Education, St. Augustine, Trinidad & Tobago

2004-2006 Oncology Nurse Practitioner/Clinical Nurse Specialist,  
Weinberg Cancer Institute at Franklin Square Hospital, Baltimore,  
MD

2006-2010 Advisory Board Member (Maryland Chapter), Lymphoma,  
Leukemia & Myeloma Society, Baltimore, MD

2006-2007 Rituxen Nurse Speakers Bureau for Genentech,  
GENENTECH/Biogen Idec, San Francisco, CA

2002-2006 Registered Nurse, Oncology - Medical Surgical, Oncology  
Certified, Chemotherapy Certified,  
St Agnes Medical Center; Baltimore, MD

1998-2006 Registered Nurse, Licensed Practical Nurse, Certified Nursing  
Assistant,  
Access Nursing Services, Towson, MD

### **Health Care Licensure & Certifications**

- CRNP-Adult Maryland license
- Registered Nurse – Maryland license
- American Academy of Nurse Practitioner Certification (NP-C) – National Certification
- Advanced Oncology Nurse Practitioner Certification (AOCNP) - National Certification
- Cardiopulmonary Resuscitation (CPR)
- Advance Cardiac Life Support (ACLS)

### **Health Care Memberships**

- American Academy of Nurse Practitioners
- American Public Health Association
- Greater Baltimore Community Oncology NP/PA Society
- Oncology Nursing Society
- Mary Mahoney Honor Society
- Sisters Enduring Cancer Support Group
- Lymphoma Leukemia Society

### **Honors and Awards**

- 2002 Deans Award & Honors Upper Division Student of the year
- 2002 Honors Program Graduate Medallion
- 2002 Ronald McNair Scholar Program Graduate

- 2002 Certificate of Recognition for Mentoring in “Sisters Enduring Cancer Support Group”
- 2002 Mary Mahoney Honor Society Doris N. Starks Leadership Award
- 2000-2001 Ronald E. McNair Outstanding Mentee Award
- 2000 Thurgood Marshall Scholarship Fund Leadership Institute: Coppin State University Scholar for Leadership Training