2009

A Phenomenological Inquiry of the Experiences of African American Women with Mammography Screening

Gwendolynn D. Randall

A PHENOMENOLOGICAL INQUIRY OF THE EXPERIENCES OF AFRICAN AMERICAN WOMEN WITH MAMMOGRAPHY SCREENING

DISSERTATION

Presented in Partial Fulfillment of the
Requirements for the Degree of
Doctor of Philosophy in Nursing

Barry University

Gwendolynn D. Randall, CRNA, MSN, MS, ARNP

2009

SIGNATURE PAGE

COPYRIGHT PAGE

ABSTRACT

Background: Breast cancer is the second leading cause of cancer deaths among African American women. The incidence rate of breast cancer is 17% lower in African American women in comparison to White women; however, the mortality rate is 34% higher. Screening for breast cancer among African American women is underutilized, yet breast cancer screening can significantly reduce morbidity and mortality numbers of African American women.

Purpose: The purpose of this study was to explore the lived experiences of African American women with mammography screening and to gain an understanding about their motivators for and/or barriers to seeking mammography.

Methods: A qualitative research design following van Manen's hermeneutic phenomenological tradition was used to explore the lived experiences of 13 purposively-selected African-American women with mammography screening. Face-to- face interviews, demographic data, and six open-ended questions were used for data collection. Data analysis was conducted using verbatim transcription and content coding.

Results: Five themes were identified: (a) fear of fear, (b) avoiding, (c) unknowing, (d) discriminating, and (e) communicating. Thematic poems describing the participants' experiences were constructed from the interviews. Persily and Hildebrandt's (1996) middle range theory of Community Empowerment was identified as a framework for research to develop interventions to promote increased mammography screening among African American women.

Conclusions: The utilization of community partners and lay workers in research interventions may help to increase participation in mammography screening.

ACKNOWLEDGEMENTS

First and foremost, I would like to thank God for all the many opportunities, blessings, and provisions he has endowed upon me in my lifetime. Mattew: 6:33 says "seek ye first the kingdom of God and his righteousness, and all things will be added unto you." That is truly my testimony. The road leading to the PhD was very arduous. I am so grateful for the maintenance of good health during this journey despite many nights of inadequate sleep. There were many people along the way who helped support my efforts and to them I am deeply grateful.

Dr. Jessie Colin

I want to publicly and personally thank her for agreeing to be my dissertation chair. In the midst of my overzealousness, she always had a calm, gentle way of directing me back to reality. Although she wore many hats, both on and off campus, she always made herself available via cell phone and that was very comforting during this process. It was both a privilege and honor working with her. She has enhanced both my academic and professional growth.

Dr. Teri Melton

In spite of the untimely death of her husband, she maintained vigilance over my dissertation studies and that is truly commendable. My second course in the PhD program was qualitative research taught by Dr. Melton. Early on, in the program, we discussed completion time lines which she never let me forgot and always kept me on task towards degree completion. She was such a motivator and encourager and her words were resonant "Come on honey, let's just get this done." She was the APA queen and did a "fabulous" job of editing all my documents. She had such a unique way of making words come to life. I do not think anyone will be asking “so what” when they read this dissertation study. I am so thankful she agreed to remain on the committee after leaving Barry.

Dr. Rosario-Medina Shepherd

It was a pleasure having her as a member of my dissertation committee. Her enthusiasm towards my study was both encouraging and inspiring. Our research interests were very similar, so it was easy to discuss the content and make comparisons between her findings in Hispanic females and my findings in African American females. Many thanks go out to her for agreeing to remain a part of my committee despite a new opportunity elsewhere.

Anesthesia Staff at St.Mary’s Hospital

I wish to express many thanks to all my anesthesia colleagues for allowing me to disappear to read and write when the operating room schedule was no busy. I really appreciate their understanding and encouragement through this PhD process.

Dr. Juan Gonzalez

To my good friend, colleague, and brother in Christ, thank you so much for your love, encouragement, and steadfastness throughout our Doctoral studies. We were joined at the hip pocket from beginning to end. We held each other to task: looked after one another, ensured we were keeping up with the assignments, and performing at the highest academic level possible. A PhD program is palatable with a buddy. Juan was an awesome buddy! We complimented each other nicely, in that, he worked the numbers and I did the talking. It was such a blessing that when tasks seemed insurmountable, we were on the same page and could solicit prayers from each other. To God be the glory, for all the things he has done.

Dr. Howard Merson

To my very dearest friend, thank you so much for listening to the tales and woes of the PhD process. The insight you offered me about the Jewish way of “always seeing the flip side of the coin” was invaluable during the research process. Your analytical mind and previous exposure to research caused you great asperity when you were exposed to the concept of qualitative research, but praise be to God, you now have some comprehension about the meaning and technique involved. I can’t thank you enough for all your support, suggestions, and recommendations along the way. I know the dissertation process “drove him nuts,” but we made it. I now bestow upon him an honorary PhD degree, because he certainly progressed through chapters’ I-V and dissertation with me. Todah.

Donald Randall, Jr.

To my one and only child, it is my hope, dream, and desire that you will soon realize the importance of an education. Any educational goal is attainable if you stay focused and remain steadfast, as I have demonstrated here. I hope you will view this dissertation as a source of strength and inspiration as to what one can achieve and accomplish with hard work and determination. I love you and wish the best for you always.

DEDICATION

This dissertation is dedicated to my parents, LeRoy Thelma and Johnson. God truly blessed me with the greatest parents in the world. Their love, encouragement, and support (financial, emotional, and spiritual) throughout the years, from birth until now, are just indescribable. They have been a powerful source of strength for me in all my endeavors. I am so thankful that God has allowed my dad, of 87 years, “to finally witness my last graduation.”To daddy, thank you for the many jobs you worked, at one time, and the sacrifices you made to ensure I got a good education. To mommy, thank you for being such a “prayer warrior” and projecting so much positivity in our family. I have been successful because of both of you.

TABLE OF CONTENTS

LIST OF FIGURES

CHAPTER I

INTRODUCTION

Cancers are a group of diseases characterized by excessive growth and spread of abnormal cells. Most type of cancer cells form a lump or mass called a tumor and are named after the part of the body where the tumor originates (American Cancer Society [ACS], 2005).

Cancer affects all populations and is the second leading cause of death in the United States and in Florida. In 2005, approximately 1.4 million cases of invasive cancer were diagnosed in the United States (National Cancer Institute [NCI], 2003). Currently, the African American population bears a disproportionate burden of cancer. African Americans have the highest mortality of any racial and ethnic group for all cancers and for most major cancers. African Americans have experienced high mortality rates from cancer for many years (Ries, Eisner, & Kosary, 2004).

Breast cancer is one of the most preventable causes of cancer morbidity if it is detected early and treated appropriately (Sharp et al., 2003). Breast cancer is the most common malignancy and the second most lethal form of cancer among American women in the United States (Blackman & Masi, 2006). It accounts for one of every three cancer diagnoses (ACS, 2005). Breast cancer is the second leading cause of cancer deaths among African American women, exceeded only by lung cancer. In 2008, The American Cancer Society estimated 19,010 African American women would be newly diagnosed with breast cancer resulting in 5,830 deaths. A general consensus exists that screening for breast cancer is underutilized (NCI Breast Cancer Screening Consortium, 1990).

The incidence rate of breast cancer is 17% lower in African American women in comparison to White women; however, among younger African American women (under age 40), the mortality rate is 32% higher than among White women. African American women, particularly young ones, are typically diagnosed with more aggressive suffer more often by more aggressive forms of breast cancer that are invulnerable to many of the latest treatments (Stein, 2007). The lower incidence of breast cancer and the higher mortality rate in African American women are phenomena largely unexplained (Chlebowski, Chen, & Anderson, 2005). Some researchers suspect the higher rate among African Americans might stem from a genetic disposition and have begun studying women in parts of Africa (Carey, 2006).

The expansion of federal research efforts has influenced the scientific understanding of cancer resulting in significant improvements in its control, prevention, detection, and treatment. It is now understood, more than ever before, how breast cancer cells become cancerous, how the disease metastasizes, why some types of cancer are more aggressive than others, and why some women suffer more and are less likely to survive (Jones & Chilton, 2002). Despite all the significant advancements and improvements in the area of breast cancer research, not all segments of the U.S. population have benefited to the fullest based on outcome studies (Institute of Medicine, 2005). In fact, the 5-year survival rate for African American women diagnosed with breast cancer is only 63% compared to 90% among White non-Hispanic women (ACS, 2008).

According to the American Cancer Society (2008), the key to surviving breast cancer is early detection and treatment. In the absence of prevention, early detection by regular screening is the best means to reduce disparities in breast cancer survival (Mitchell, Mathews, & Mayne, 2005). Both the stage of the disease at diagnosis and the availability of timely treatment influence survival rates. Factors that may contribute to the survival differential include lower quality of health care accessibility, higher prevalence of coexisting conditions, and differences in tumor biology (ACS, 2008).

When coupled with appropriate treatment, mammography is the single most effective method of early detection, since it can identify cancer several years before physical symptoms develop (Michaelson, Santija, & Moore, 2002). Early detection could significantly reduce morbidity and mortality numbers of African American women (Frisby, 2002). The underlying premise for breast cancer screening is that it allows for the detection of breast cancers before they become palpable. Breast cancer tumors can exist for 6 to 10 years before they grow large enough to be detected by palpitation (ACS, 2008).

Knowledge and awareness are essential elements to impact the morbidity rates of breast cancer in African American women. In the United States, mortality from breast cancer has been on the decline since the late 1980s; perhaps secondary to increased knowledge and awareness, but this decline has been steeper among White women compared to Black women. As a result the Black: White mortality rate ratio has increased over the last two decades (Blackman & Masi, 2006).

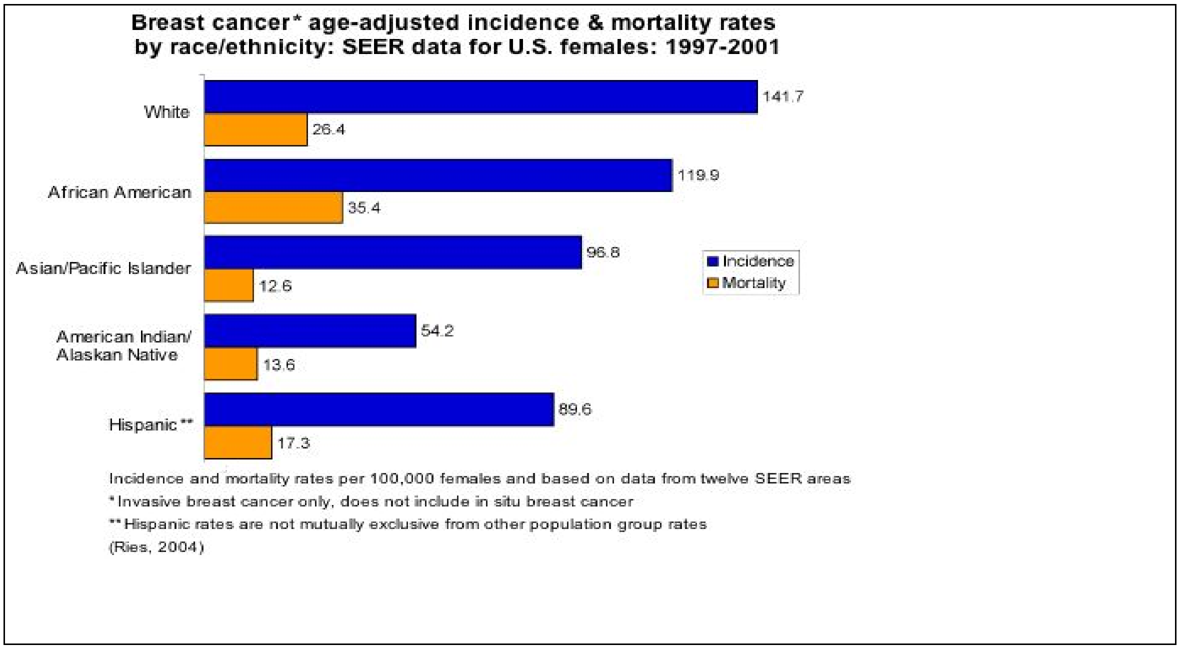
The knowledge and understanding African American women have about mammography screening as it affects them, needs to be explored and clearly defined. Breast cancer screening can greatly improve the chances for cure, extended life, reduction in the extent of treatment needed, and improvement in the quality of life for cancer patients (ACS, 2008).

Statement of the Problem

Breast cancer survival rates among African American women remains stagnant despite a growing public awareness and the introduction of new treatment and diagnostic techniques (NCI, 2003). Recent breast cancer research efforts have not produced results to affect the necessary benefits for African American women (Jones & Chilton, 2002). Reasons for this lack of progress are not clearly defined. However, this phenomenon has long been identified by authorities in the public, private, and professional sector as a national health care concern (Underwood, 2007). Disparities in cancer care among minority populations are the subject of increasing concern for policy makers (Klausner, 2000).

African American women suffer disproportionately from the effects of breast cancer disease (Chu, Lamar, & Freeman, 2003). Breast cancer is not just a medical issue; it is a psychological, social, economic and political issue (ACS, 2008). The disparity in the rate of breast cancer survival between African American and White women has been documented since the 1980s (Long, 1995). This poorly understood disparity has been consistently documented in population-based data from the Surveillance, Epidemiology, and End Results (SEER) program since its inception in 1976 (Ries et al., 2003). The higher mortality rates are partially explained by the more advanced stage cancer distribution that is seen among African-American breast cancer patients due to late presentations (Newman, 2005).

Each year the American Cancer Society, the National Cancer Institute, and the Center for Disease Control and Prevention, including the National Center for Health Statistics, collaborate to produce a “report card” to explain the nation’s progress in preventing and controlling cancer in the United States (Jones & Chilton, 2002). The initial report card, issued in 1998, reported the nation’s first continuing decline in cancer mortality since national research record keeping was instituted in the 1930s (Wingo, Ries, Rosenberg, Miller, & Edwards, 1998). The 1998 report also noted, however, the disproportionate breast cancer incidence and rates of mortality of African American women compared with White women. The incidence of breast cancer in African American women was continuously increasing with no decrease in mortality trends. African American women also tended to present with a later stage at diagnosis (Howe, Wingo, & Thun, 2001). (See Figure 1).



Breast cancer* age-adjusted incidence & mortality rates by race/ethnicity: SEER data for U.S. females: 1997-2001

Incidence and mortality rates per 100,000 females and based on data from twelve SEER areas
*Invasive breast cancer only, does not include in situ breast cancer
**Hispanic rates are not mutually exclusive from other population group rates
(Ries, 2004)

Figure 1. Breast cancer incidence and mortality in African and Caucasian American women. Source: SEER Cancer Statistics Report 1973-2000.

The 2001 report card documented similar trends and indicated that African American women have the highest breast cancer death rates (Howe et al., 2001). Increasing mortality appears to be strong and most consistent for African American women (ACS, 2007; Chlebowski et al., 2005; Li, Malone, & Daling, 2003). African American women are clearly not winning the battle against breast cancer (Jones & Chilton, 2002). There is evidence to suggest that African American women continue to be disproportionately affected by this disease because they seek and/or receive suboptimal breast cancer surveillance (Newman, 2005).

One of the greatest barriers to addressing cancer within minority populations is the lack of adequate and consistent cancer data. Without such data, it is difficult to assess the current systems, contribute to the development of a plan to address problems, and better allocate resources (Jones & Chilton, 2002). While focused research holds the promise of playing a role in improving breast cancer rates and outcomes in African American women, it should be pointed out that there is extensive documentation of this existent health disparity. There continues to be collection of data and identification of issues, with little progress being made towards decreasing the morbidity and mortality statistics for the at-risk African American female population. Research has not yet provided answers for the question of why this phenomenon still exists.

Strategies for successful conduct of research with African American women are necessary (Underwood et al., 2005), however, there is little direction for successful strategies for recruiting African Americans for participation in breast cancer research (Adderly-Kelly & Green, 2005). Quantitative studies have clearly demonstrated the problem of breast cancer in African American women, but have not offered sufficient remedy (Champion & Skinner, 2005).

Current health screening behaviors among women of diverse cultural groups have been reported to be deficient (Thomas, 2004). The literature suggests that cancer prevention programs have failed in minority or underserved communities as demonstrated by the increasing mortality trends (Byrne, 2001). According to Ashing-Giwa (2000), researchers have not adequately addressed the influence of cultural behaviors of African American women, including those related to breast cancer screening. Research has shown that fewer African American women are having mammograms (Breen, et al., 2007). Understanding what influences and motivates women to obtain mammograms is critical in trying to achieve the highest compliance rates (Brem, 2007).

Purpose of the Study

The purpose of this study was to explore the lived experiences of African American women with mammography screening, provide an inductive description of the lived experience and gain an understanding of the motivators and/or barriers to seeking mammography as perceived and comprehended by them. A phenomenological approach was used to describe and interpret the participants' experiences pre-reflectively (van Manen, 1990). For this researcher, the goal for conducting phenomenological inquiry was to "involve the voice [of participants] in an original singing of the world" (van Manen, 1990, p. 13).

Significance of the Study

After an exhaustive literature search, only one study was located with the explicit purpose of exploring the experience of mammography screening among African American women who have not been diagnosed with breast cancer. The literature is lacking in studies that address the influence of past events on current health behaviors among women of diverse cultural groups (Thomas, 2004).

The documentation of under-utilization of breast cancer screening tests among the African American population warrants further research efforts to increase the number of women who get a first mammogram as well as encourage repeat screening. This study was designed to gain a better understanding of the meaning of mammography screening for African American women. It may provide some scientific information which is much needed to bridge the gap between detection and screening of breast cancer in African American women. Eliminating health disparities among racial and ethnic groups is a crucial step toward improving overall health in a community (Carmona, 2003).

Significance to Nursing

Significance to Nursing Education

The average African American woman underestimates her risk of breast cancer (Hall, 2005). The educative role of nurses and other health care professionals in breast cancer detection and prevention is vital (Consedine, 2004).

In 2001, the American Cancer Society reported that the higher mortality in African Americans compared to Whites could be attributed partly to cultural beliefs and practices. Kagawa-Singer (2002) added that a woman's culture influences how she will respond to the fact and meaning of cancer (for screening, early detection, or diagnosis) and how emotions will be expressed. Thus, education and interventions for African American women must be culturally sensitive for them to engage in breast cancer screening, and further should indicate the importance of spreading the word about breast cancer screening (Philips, Cohen, & Tarzian, 2001). The attempt to educate African American women about the importance of breast cancer screening tests, when fundamental knowledge about their experiences is clearly lacking, results in futile efforts to impact outcomes.

The results of this study may reinforce the need for breast health education of minority women, with the message of breast cancer screening. Tailored interventions based on the participants' voices may be a promising strategy for increasing mammography use among African American women (Rawl, Champion, & Menon, 2000). The relationship between culture and psychosocial issues is integral to understanding how this population responds to cancer prevention (Guidry, Matthews-Juarez, & Copeland, 2003).

Data gathered from this study may lead to the development of culturally competent models of care that may assist in reducing and/or eliminating cancer disparities in African American women. These cultural models may be included in nursing curriculum to assist nursing students in gaining a more in-depth understanding about the African American women's experience with mammography screening tests.

Significance to Nursing Practice

Nurses can potentially impact mortality outcomes of African American women by increasing their investment in educational efforts to influence variables related to compliance with early detection behaviors (Rutledge, Barsevick, Knobf, & Bookbinder, 2001). Recognition of the need to focus on culture-specific models for delivering health care to diverse populations is gaining momentum in the health care industry.

Many psychological theories have ignored the important role of culture in explaining and understanding the behavior of diverse groups. Most conceptual models describing African American women's participation in breast and cervical screening services have used psychological variables that were referenced on White middle-class groups (Champion, 1994). Conducting studies that utilize culture-specific models may provide a more accurate picture of the experience of African American women.

This study may add to the body of nursing knowledge with the exploration of the lived experience of African American women’s experiences with breast cancer screening tests. This study may provide nurses and practitioners with an increased understanding about African American women’s experiences with breast cancer screening tests and may assist the health care provider in designing strategies to engage African American women in improved decision-making behaviors with regards to breast cancer screening tests to decrease their current mortality rates. Additionally, nursing care practices that are culturally based may be developed to address the unique needs of African American women as expressed by them.

Community-based models for coordinated outreach and case management may be necessary to encourage African American women’s participation in breast cancer screening tests to help reduce the disparity in the early detection of breast cancer. Dr. Adams at the University of Texas at Austin School of Nursing developed The African American Breast Cancer Outreach (AABCO) program in 1998. During its 3-year implementation phase, mammography screenings for 8,459 African American women were facilitated. In addition, more than 114, 386 people received one or more direct services including cancer related information and materials as well as prevention, risk assessment and/or screening services.

The findings of this study may indirectly impact the mortality and morbidity rates among African American female participants, in this study, by increasing their knowledge and awareness of the importance of participation in breast cancer screening tests.

Significance to Nursing Research

Despite the documentation of the higher breast cancer morbidity and mortality among African American women, there is limited information published on effective interventions to increase breast cancer screening among this population. While many reasons are suggested for this phenomenon, empirical research is limited (Williams, 2001). Research examining the efficacy of health promotion appeals, content, and channels of delivery regarding breast cancer has also been very limited in public health research (Williams, 2001). Research that includes defining the variable of cultural sensitivity is also very limited regarding interventions that target diverse populations (Williams, 2001). Furthermore, there is little direction for successful strategies for recruiting African American women for participation in breast cancer research (Adderly-Kelly & Green, 2005).

New nurse investigators are critical to nursing/clinical research as they seed it with new ideas and approaches. The nursing role has evolved to one that is a much more proactive part of the health care team, and nursing research has been the catalyst for many new advances. As indicated above, there continues to be data collection and identification of disparity issues with little progress being made toward actually improving the statistics for the at-risk African American female with breast cancer. The reduction of the incidence of breast cancer in African American women may benefit from new and non-traditional research initiatives using culturally competent and participatory action methodologies.

Nurses exhibit caring qualities and are best suited for scientific inquiry to make a significant impact in outcomes among the African American population regarding breast cancer and screening tests. The important research that nursing does is underscored by scientifically valid findings (Carmona, 2003).

Given the limited number of qualitative studies about breast cancer screening and prevention in African American women, this study may serve as a foundation upon which other qualitative studies about this phenomenon may build upon. Qualitative research is well suited for understanding phenomena within their context, uncovering links among concepts, behaviors, and generating and refining theory (Campbell & Gregor, 2004; Patton, 2002). Qualitative inquiry strategically, philosophically, and methodologically aims to minimize the imposition of predetermined responses when gathering data (Patton, 2002). A paucity of clinical research on minority groups presently contributes to inadequate knowledge of clinicians (Prothow-Stith, Gibbs, & Allen, 2003). Nursing research might facilitate the provision of quality care by increasing nursing knowledge and understanding relevant to problem of the African American women not participating in mammography screening.

Significance to Public Policy

President George W. Bush and Health and Human Services Secretary Tommy Thompson asked the Surgeon General to focus on three priorities: prevention, public health preparedness, and elimination of health care disparities. Nursing research can address all of these things using imaginative and critical thinking initiatives (Carmona, 2003). In recent years, cultural competency has been recognized as a key component of patient-centered care—and may help reduce disparities. Cultural competency is particularly critical in the realm of healthcare, as the potential impact on quality of health and life is at stake (Beal, 2007).

The National Health Interview Survey (2004) indicated that women with less than a high school education, without health insurance coverage, or who are recent immigrants to the United States are the least likely to have had a mammogram. This study may influence nurses about the urgency to develop social policies relative to preventive health behaviors for minorities, racial disparities in heath care, and quality of care (Beal, 2007).

Research Questions

The overarching research question that guided this study is: What is the lived experience of African American women with mammography screening? The subquestions are:

1. What are the barriers that preclude continued participation in mammography screening?
2. What are some strategies or interventions that can be used to increase continued participation in mammography screening?

Philosophical Underpinnings

An examination of the philosophical basis of knowledge development is an essential component of nursing scholarship (Packard & Polifoni, 2002). The philosophical underpinning of this study is that of social constructionism.

Social constructionism stems from an epistemological position. It is an approach to psychology and other bodies of knowledge that focuses on meanin*g* and power. The epistemological position dictates that meaning and power are all that can really be claimed to know about. It is called *social constructionism* because it aims to account for the ways in which phenomena are socially constructed (Burr, 1995). Social constructionism uncovers ways in which individuals and groups participate in the creation of their perceived reality. It also involves looking at the ways social phenomena are created, institutionalized, and made into traditions (Berger & Luckman, 1966). Through qualitative inquiry, the researcher intended to uncover the realities of African American women's experiences with breast cancer screening tests.

Qualitative researchers approach their studies with a particular paradigm or worldview, a basic set of beliefs or assumptions that guide their inquiries. These assumptions are related to the nature of reality (the ontological issue), the relationship of the researcher to that being researched (the epistemological issue), the role of values in a study (the axiological issue), and the process of research (the methodological issue) (Creswell, 1998).

Lincoln and Guba (2000) described questions of ontology (what is the form and nature of reality and what can be known about it, epistemology (what is the nature of the relationship between the knower and what can be known), and methodology (how can the inquirer go about finding out whatever he or she believes can be known) as essential in critiquing and conducting research.

Constructivism is considered an interpretivist tradition. The interpretivist framework of inquiry supports the ontological perspective of a belief in the existence of not just one reality, but of multiple realities that are constructed and can be altered by the knower. Reality is not something “out there,” but rather something that is local and specifically constructed. Realities are not more or less true, rather they are simply more or less informed (Denzin & Lincoln, 2000).

Epistemologically, this framework sees a relationship between the knower and the known. The notion of value-free research has been challenged as questionable. Denzin and Lincoln (2000) viewed the investigator and the investigated as interactively linked in the creation of findings, with the investigator as a passionate participant. The interpretivist perspective may evolve, for example, in a process of interpretation and interaction between the investigator and research participants.

In this study, the researcher addressed the embedded assumptions of social constructionism epistemologically through the following: by asking questions framed in such a manner as to facilitate responses that allowed her to gain insider knowledge of how and why participants make the choices they make regarding screening tests; ontologically, by examining the reality of breast cancer as it relates to the community of participants; axiologically, by acknowledging and reporting the value-laden nature of information gathered from the field and identifying the biases of the researcher; rhetorically, by identifying how social and cultural groups consume information about health and illness and by using specific terms, words, or themes that evolved from the study; and methodically, by approaching the investigation inductively (Creswell, 1998).

An inductive research methodology is best suited for this study, which necessitated the use of a phenomenological qualitative approach. This philosophical and methodological approach to inquiry facilitated identification of the uniqueness of African American women's experience with mammography screening tests.

Phenomenology

Phenomenology has become a dominant method in the pursuit of knowledge development in nursing, as it presents "credible displays of living knowledge for nursing" (Jones & Borbasi, 2004, p. 99). Phenomenology is a human science (rather than a natural science) since the subject matter of phenomenological research is always the structures of meaning of the lived human world. Human science operates with its own criteria for precision, exactness, and rigor (van Manen, 1997). It differs from almost every other science in that it attempts to gain insightful descriptions of the way individuals experience the world pre-reflectively, without taxonomizing, classifying, or abstracting it (van Manen, 1990).

The term *phenomenology*, although used frequently in nursing scholarship, is accompanied by confusion surrounding its nature. First, it is not only a research method employed frequently by qualitative researchers; it is also a philosophy. Second, there are as many styles of phenomenology as there are phenomenologists (Spiegelberg, 1982). There are a number of schools of phenomenology, and even though they all have some commonalities, they also have distinct features (Dowling, 2005). Furthermore, the many perspectives of phenomenology locate its various forms in the positivist (Husserl), postpositivist (Merleau–Ponty), interpretivist (Heidegger) and constructivist (Gadamer) paradigms (Racher & Robinson, 2003). Finally, a type of phenomenology as a research method, which has evolved in the United States and is known as new phenomenology (Crotty, 1996), is evident of a transformation that has occurred in phenomenology as a research method utilized by nurses (Dowling, 2005).

The historical movement of phenomenology as a tradition was launched in the first half of the twentieth century by Edmund Husserl (Stroker, 1993). Phenomenology is the study of structures of consciousness as experienced from the first-person point of view and is committed to descriptions of experiences, not explanations or analyses (Moustaskas, 1994). The domain of phenomenology is the range of experiences including perception, imagination, thought, emotion, desire, volition, and action. Conscious experiences have unique features: they are experienced, lived through, and performed.

Phenomenology can describe in detail an issue, problem, situation, or experience, using qualities and properties from specific contexts or perspectives, so that the events or experiences take on vivid and essential meanings, a clear portrait of what is (Moustaskas, 1994). Phenomenological research aims to illuminate the nature and nuances of life experiences and to suggest plausible insights about the lifeworld-- the world as it is experienced pre-reflectively rather than as being conceptualized, categorized, or reflected upon. (Husserl, 1970).

Some phenomenologists, like Husserl, say that bracketing is essential in descriptive phenomenology. On the other hand, Heidegger (1962) argued that it was not possible to bracket because phenomenology views people as being in the world. This notion of being-in-the-world allows researchers to bring their experiences and understanding of the phenomenon under study to the research.

There are two ubiquitous terms within phenomenology that need clarification. The first is *essence* and its cognates, such as essential and essentiality. In everyday life, human beings strive toward some ideal or perfection that could legitimately be called "essential" to their mode of being-in-the-world, and yet the term "essence" can be troublesome (Kleiman, 2004).

Merleau-Ponty (1964) pointed out that phenomenology is the study of essences. Accordingly, all problems amount to finding definitions of essences, such as the essence of an experience. Essence makes a thing what it is; without it, the thing would not be what it is. The phenomenological approach is most appropriate when little is known about a phenomenon or when a fresh look at a phenomenon is indicated (Creswell, 2005; Fitzpatrick, 1998; Patton, 2002). In descriptive phenomenology, a researcher is interested in discovering meanings of phenomena from lived experiences rather than from universal principles. Therefore, essence is taken to mean the most essential meaning for a particular context (Giorgi 1997, 2000).

The second term is *lived experience*. Lived experiences are those experiences that reveal the immediate, pre-reflective consciousness one has regarding events in which one has participated. One uses such lived experiences as the basis for recalling how one lived through the event, thereby transforming the experiences into objects of consciousness. Recollection implies that what can be recalled must have already been constituted as meaningful (Burch, 1989).

During the past decade, nurse researchers have increasingly used hermeneutic phenomenology as a basis for scientific inquiry. Nursing is an interpersonal practice. It embraces the dimensions of emotion and cognition as well as the cultural, historical and political contexts of individuals. Thus the value of interpretive methodologies is argued on the grounds that nursing is a situated, dynamic and intersubjective phenomenon (Spence, 2001). Phenomenology provides a close fit conceptually with clinical nursing and with the kinds of research questions that emerge from clinical practice.

Phenomenology tries to discover meanings as persons live them in their everyday world. This qualitative approach will provide the researcher with data to explicate the essence or nature of the experiences of African American women with mammography screening tests through their voices, since the literature appears to be lacking on this phenomenon (van Manen, 1990).

The phenomenological approach to the research question helped the researcher gain an understanding of the actual experiences of African American women who have engaged in mammography screening. This is because a phenomenological approach facilitates the description of an experience, as perceived by those who have lived it. It can make visible the essence of that experience, and thus, enrich the understanding of the taken-for-granted dimensions of everyday life (van Manen, 1990).

van Manen’s hermeneutic approach to phenomenological inquiry was used to guide this study. "Phenomenological research, unlike any other kind of research, makes a distinction between appearance and essence, between the things of our experience and that which grounds the things of our experience" (van Manen, 1990, p. 32). The focus in this approach is toward illuminating details and seemingly trivial aspects within experience that may be taken for granted in our lives, with a goal of creating meaning and achieving a sense of understanding that allows capture of what is retained and what is given in terms of lived experiences. It is these very descriptions that “keep a phenomenon alive, illuminate its presence, accentuate its underlying meanings and enable the phenomenon to linger, retain its spirit, as near to its actual nature as possible” (Moustakas, 1994, p. 59), even though the event has passed. The researcher has used the words of the participating African American women when describing their experiences with mammography screening, as a means of interpreting a deeper understanding of the everyday experiences that may go otherwise unnoticed.

According to van Manen (1990), phenomenology as a type of research is a poetizing activity in that "it tries an incantative, evocative speaking, a primal telling, wherein we aim to involve the voice in an original singing of the world" (p. 13). He further states: "a good phenomenological description is collected by lived experience and recollects lived experience; is validated by lived experience and it validates lived experience" (p. 27). “Creating a phenomenological text is the object of the research process" (van Manen, 1990, p. 111).The data generated in the form of phenomenological text will provide rich and thick descriptions of the participant’s experiences as they lived it.

van Manen (1990) believes that human science is a critically oriented action research and a philosophy of action in three ways:

> Hermeneutic phenomenological reflection deepens thought and therefore radicalizes thinking and the acting that flows from it. Second, phenomenology is a philosophy of actions especially in a pedagogic context. Pedagogy itself is a mode

> of life that always and by definition deals with practical action. Finally, phenomenology is a philosophy of action always in a personal and situated sense. A person who turns to phenomenological reflection does so out of personal engagement. (p. 154)

van Manen (1990) subscribes to “warding off any tendency toward constructing a predetermined set of fixed procedures, techniques and concepts that would rule-govern the research project" (p. 29). For van Manen, human science research writing is an original activity where "there is no systematic argument, no sequence of propositions that we must follow in order to arrive at a conclusion, a generalization, or a truth method" (1990, p. 173). While there is not a set of fixed procedures, van Manen (1990) understands hermeneutic phenomenological research in the human sciences as an interplay of six research activities

1. turning to a phenomenon which seriously interests us and commits us to the world;
2. investigating experience as we live it rather than as we conceptualize it;
3. reflecting on the essential themes which characterize the phenomenon;
4. describing the phenomenon through the art of writing and rewriting;
5. manipulating a strong and oriented pedagogical relation to the phenomenon;
6. balancing the research context by considering parts and whole. (pp. 30-31)

To produce lived-experience descriptions, van Manen further suggests that the researcher:

1. Describe the experience as you live(d) through it avoiding as much as possible causal explanations, generalizations, or abstract interpretations.

2. Describe the experience from the inside as it were; almost like a state of mind: the feelings, the mood, the emotions, etc.
3. Focus on a particular example or incident of the object of the experience: describe specific events, an adventure, a happening, a particular experience.
4. Try to focus on an example of the experience which stands out for its vividness, or as it was the first time.
5. Attend to how the body feels, how things smell(ed), how they sound(ed), etc.
6. Avoid trying to beautify your account with fancy phrases or flowery terminology. (1990, pp. 66-67)

van Manen (1990, p. 101) suggests four existential life-world themes as guides for the reflective research process: "lived space (spatiality), lived body (corporeality), lived time (temporality), and lived human relation (relationality or communality)."

Lived space is felt space. Recent breast cancer research efforts have not produced significant results to affect the necessary benefits for decreasing mortality in African American women (Jones & Chilton, 2002). For the African American woman, touching her breast to do a breast self examination or the thought of scheduling a mammogram could result in restricted spatiality. If a lump is detected, then their lived space may become increasingly smaller. The detection of a tumor and diagnosis of breast cancer could imply radical changes or even end of life, so perhaps it is best not dealt with. In the Black community there is a saying, “What you don’t know can’t hurt you” and that really may be taken to the extreme in the cases of non-participation in breast cancer screening tests.

Lived body refers to the phenomenological fact that we are always bodily in the world. A woman's physical or bodily appearance reveals something about her, but other things like consciousness are concealed. Western values and traditions have oppressed women with the message that without breasts, women are not whole (Mackel, 2000). Western society appears to be breast obsessed, and many American women fear losing their breasts from breast cancer more than dying from it (Ferguson & Kasper , 2000). The female breasts are often seen as symbols of sexuality, femininity, and motherhood. Contradictory messages women receive from society, both voiced and unvoiced, can have a long-term effect on how some women perceive their bodies, and how they value early detection related to breast cancer screening (Thomas, 2006).

Lived time is subjective time. Participation in mammography screening for some African American women may elicit worry, fear, and anxieties at the thought of what could be found during, and what could come after the procedure; therefore, making it easier to just not participate.

Lived relationality is the lived relation that is maintained with others in the interpersonal space that is shared with them. A well documented distrust exists among African Americans and the medical community. For African American women, the thought of having to entrust their breasts to a mammography or a radiologists for the purposes of examination and evaluation may contribute to lack of participation. Articulation of feelings of ambivalence about entrusting the body into the hands of a mistrusted professional (i.e., mammography technician) as valued sources of trust and security are important (Moene, Bergbom & Skott, 2006).

While these four themes can be identified they cannot be separated in the lived world of experience. These four exisentials may prove helpful as a guide for reflection in the research process. van Manen (1990) tells us that the ultimate aim of phenomenological research is “the fulfillment or our human nature; to become more fully who we are” (p. 12). He encourages the concurrent activities of describing, interpreting, and textual writing, and poetry to support the goal of becoming fully human. (See Figure 2).

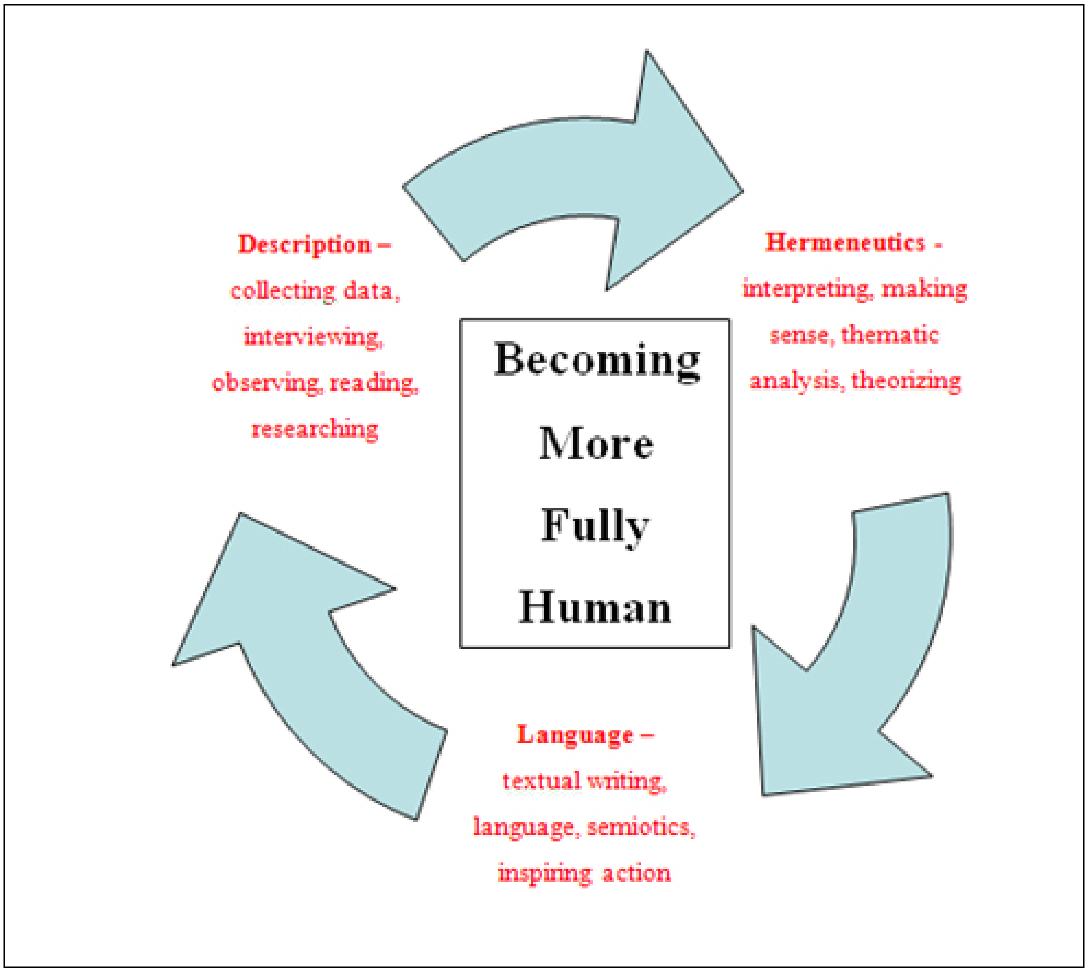


Figure 2. Process of phenomenological exploration (adapted with permission from McFadden [2008] as he adapted it from van Manen, 1990, pp.2-8).

Sharing the understanding the researcher has gained of the lived experiences of African American women's experience with breast cancer screening tests may help students, primary health care providers, and nurses identify their needs and increase awareness.

Scope and Limitations of the Study

The researcher employed purposive sampling to identify and recruit pre-menopausal women who self-identify as African American, who are between the ages of 25 and 55, who have not been diagnosed with breast cancer, and who were willing to participate in this study for the purpose of exploring African American women's lived experience with mammography screening tests. The women all had to be able to read, write, and speak English, and to have had only one mammogram and no more. Women were recruited with the use of a flyer, from local African churches, primary care physician offices, ob-gyn offices, and housing developments within Palm Beach County, Florida, to participate in a one-on-one one hour long interview and a subsequent follow-up one hour meeting. Following the advice of Creswell (2005), originally a maximum number of 20 participants were proposed.

Therefore, the findings of this study may be limited due to self selection, self reporting bias, and time constraints for this project. This means that transferability of this study may be impacted by the small population sample of African American women in Palm Beach County; the fact that volunteers may not be the best candidates to fully articulate their stories; and the use of time-limited interviews, which may have prevented thorough discussions of all the experiences of the participants. Finally, the credibility of this novice researcher may be a threat to the trustworthiness of the study. Some of these potential limitations of this study were addressed by strict adherence to the inclusion and exclusion criteria set by the researcher.

Chapter Summary

African American women underutilize mammography screening tests and experience higher mortality rates from breast cancer than White women despite a growing public awareness and the introduction of new treatment and diagnostic techniques. Regular screening mammograms for asymptomatic women are the most effective method of detection of breast cancer.

This phenomenological inquiry was undertaken to achieve a greater understanding of African American women's experience with mammography screening tests. The findings of this study may have implications for nursing education, nursing practice, nursing research, and influence policy development to help address a national health disparity that is presently negatively affecting African American women.

CHAPTER II

REVIEW OF LITERATURE

Introduction

This chapter provides the context for the basis of this qualitative research study and explicates the meaning of African American women's lived experiences with mammography screening tests. The researcher conducted a search of the literature that addresses the phenomenon under investigation. Using the search engine provided by accessing the Barry University on-line library, the following computerized databases were used for this study: Ovid, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Plus databases, Pub Med, ProQuest, Medline, EBSCO, and Dissertation Abstracts. The key words used in the search were mammography, health disparities, breast cancer, breast cancer screening, African American, breast self examinations, cultural sensitivity, and women. Citations were limited to English and to literature published since 1995. This limitation was imposed to find relevant and current information, with classics sought by reviewing citations in published works.

Cancer Clinical Epidemiology

In 2005, there were 1.3 million new cancers diagnosed in the United States, resulting in 570,000 deaths (National Cancer Institute [NCI], 2008). Nationwide about 63,100 African- Americans die from cancer annually. The leading killer for both African American men and women is lung cancer, followed by prostate cancer in men and breast cancer in women.

Death rates for all major causes of death are higher for African Americans than for Caucasians, contributing to a lower life expectancy for both African American men

(68.6 years versus 75.0) and African American women (75.5 years versus 80.2) (American Cancer Society [ACS] , 2007). Currently, the African American population in the United States bears a disproportionate burden of cancer and has experienced high mortality rates from cancer for many years (Ries et al., 2003).

Florida Cancer Statistics

Florida ranks second in the nation for cancer incidence and cancer mortality and first in overall cancer burden, yet it ranks 21st in the receipt of research grant funding from the National Cancer Institute. Among Floridians, cancer ranks first in terms of potential years of life lost, which is estimated to be 259,901 years (Florida Annual Cancer Report, 2003). The uninsured population of Florida is 19.2%, which is higher than the national average of 15.5%, resulting in higher cancer morbidity and mortality due to an inability to access the medical system (Goldberg, 2002). In 2002, healthcare practitioners diagnosed 94,630 cancers among Floridians, which averages at 259 new cancers per day (Florida Annual Cancer Report, 2003).

More than 7,000 African American Floridians are diagnosed with cancer annually according to the National Cancer Institute (2003). Cancer kills more than 3,000 African American Floridians each year, the National Cancer Institute reports (2003). In Florida, African Americans succumb to cancer at the rate of 213.1 persons per 100,000 deaths compared to 158.9 persons per 100,000 deaths for Caucasians. This is a fact that is not likely to change, considering the state’s demographics and increasing medically underserved populations.

Breast Cancer

Breast Cancer Statistics

The American Cancer Society estimates that a woman in the United States has a 1 in 8 chance of developing invasive breast cancer during her lifetime (ACS, 2007). In 2007, there were 1.3 million newly diagnosed cases of breast cancer globally resulting in the deaths of 465,000 women. Approximately 3 million women in the United States are living with breast cancer; 2 million who have been diagnosed and an estimated 1 million who do not yet know they have the disease. In 2007, 212,920 new cases of invasive breast cancer and 61,980 new cases of in situ breast cancer were detected among women in the U. S. resulting in 41,000 deaths (Florida Breast Cancer Coalition Research Foundation [FBCCRF], 2008).

One woman is diagnosed with breast cancer every 3 minutes, and one woman will die of breast cancer every 13 minutes in the United States. The seriousness of invasive breast cancer is strongly influenced by the stage of the disease, that is, the extent or spread of the cancer when it is first diagnosed (ACS, 2005). The importance of breast cancer screening cannot be stressed enough because non-participation among African American women may result in them presenting with advanced stages of the disease.

In Florida, in 2007, an estimated 13,430 new cases of breast cancer in women was diagnosed and 2,570 died from the disease. This represents an average of 109 deaths per day (Florida Breast Cancer Coalition Research Foundation, 2008).

Breast cancer and its treatments result in physical, economic and employment problems, familial and marital relationship challenges, and concerns with body image and sexuality. The financial costs of cancer treatment are a burden to people diagnosed with cancer, their families, and society as a whole (ACS, 2007).

Breast Cancer in African American Women

Breast cancer is the second most prevalent cancer among African American women, surpassed only by lung cancer (ACS, 2007). In 2007, there were 19,010 newly diagnosed cases of breast cancer among African American women resulting in 5,830 deaths (ACS, 2008). Of all breast cancers diagnosed among African American women, 53% are diagnosed at a localized stage, compared to 64% among Caucasian women. The mortality rate is 32% higher for African-Americans than for Caucasians. The reasons for this survival differential have been studied extensively. Between 1990 and 2002, the mortality rate for women of all races combined declined by 2.3% annually. In White women, breast cancer mortality declined by 2.4% annually. In Black women, mortality declined by 1.0% annually during the same period (Jemal et al., 2005).

Over the past 25 years, trends in breast cancer incidence among African American women have shown four distinct phases: a period of stable rates from 1975 to 1978, followed by a rapid increase between 1978 and 1986, and a less rapid increase from 1986 to 1999, and a leveling off in 1999 to 2001 (Institute of Medicine, 2005).

Hirschman, Whitman, and Ansell (2007) examined trends in Black versus White female breast cancer mortality, incidence, stage at diagnosis, and mammography screening in Chicago for the years 1999-2003. They used data from the Illinois State Cancer Registry, Illinois Department of Public Health Vital Records, and the Illinois Behavioral Risk Factor Surveillance System. The breast cancer mortality rate for Black women in Chicago for 1999–2003 was 49% higher than that of White women, and the disparity is increasing rapidly. In 2003, the Black rate was 68% higher than the White rate. There has been no improvement in mortality from breast cancer for Black women in Chicago in 23 years.

Schootman, Jeffe, Baker, and Walker (2006) reported that the area poverty rate was independently associated with never having been screened for breast and colorectal cancer, but not cervical cancer. A cross sectional survey using data from the 2005 Behavioral Risk Factor Surveillance System was used for 118,000 persons residing in 98 areas. After adjustment for individual level factors, increasing area level poverty rate (per 5%) remained associated with never having had a mammogram (odds ratio (OR) = 1.28, 95% confidence interval (CI): 1.03 to 1.37); clinical breast examination (OR = 1.28, 95% CI: 1.11 to 1.48).

Chlebowski et al. (2005) conducted a large longitudinal study of postmenopausal women to examine whether known and/or presumptive breast cancer risk factors would explain the difference in breast cancer incidence between White women and women of minority groups. Women were recruited at 40 clinical centers across the United States, largely through direct mailings. They were eligible to participate if they were premenopausal, aged 50-70 years, and unlikely to move or die within 3 years; participants were provided with written informed consent. In addition, all clinical trials excluded women with a breast cancer history and required that the baseline mammogram and clinical breast exam not be suspicious for breast cancer.

A total of 161,809 participants enrolled in either the observational study (N=93,676) or clinical trial (N=68,133) components between October 1, 1993 and December 31, 1998. Descriptive analyses were conducted for breast cancer risk factors and other covariates by racial/ethnic groups and by breast cancer status in each group. Baseline self-administered questionnaires were used to collect information on demographics, medical, reproductive, and family history; personal habits such as smoking and alcohol use; and physical activity as metabolic equivalents. Food intakes were assessed using a semi-quantitative food frequency questionnaire. Body mass indeed (BMI) was calculated as weight (kg)/height (m)^2. Information on mammography use was collected prospectively and incorporated.

The results of that study indicated differences in breast cancer incidence rates between most racial/ethnic groups can be largely explained by difference in risk factors except for African American women. Mammography frequency screening rates were significantly lower for African American women than for Whites (HR=0.75, P -.006). The results also provided a unifying concept for the unfavorable breast cancer outcomes seen in African American women despite a lower incidence. That large quantitative study documented the disparity in mammography participation and survival of African American women. However, the study still left many unanswered questions about why African American women lack participation in breast cancer screening. Qualitative research techniques are needed to answer some of those questions and to explore the meaning that participants ascribe to their experience with mammography screening.

Chu, Lamar, and Freeman (2003) conducted a meta-analysis of population-based data collected by the Surveillance, Epidemiology, and End Results (SEER) Program of the National Cancer Institute for the period from January 1992 to December 1999. The invasive breast carcinomas (i.e., in situ carcinomas were excluded) used in this study were diagnosed among residents of 11 geographic areas: Connecticut, Hawaii, Iowa, New

Mexico, Utah, Atlanta, Detroit, Seattle-Puget Sound, San Francisco-Oakland, San Jose-Monterey, and Los Angeles. The variables analyzed were estrogen receptor(ER) status, disease stage at diagnosis, and patient age.

The ER status was coded by the SEER Program data collectors based on laboratory results in the medical records at the time of data collection since 1992 for the 11 cancer registries. Women of all ages combined, women younger than age 50 years, women ages 50-64 years, and women age 65 years and older were examined. The older age group was chosen to represent possible Medicare-eligible patients. The estrogen receptor (ER) status data were reported for ER-positive tumors and ER-negative breast tumors. Tumors with unknown ER status (this group includes not done, borderline/undetermined, ordered but results not in chart, or unknown for ER status) were excluded. The ER status was used because there are different beneficial cancer treatments for women with ER-positive tumors and women with ER-negative tumors.

The stage at diagnosis used in that report was based on the American Joint Committee on Cancer's classification of tumors (Stages I-IV). A Z test was performed to determine whether the stage specific survival rates for white females and black females were equal; a Z test was also used to determine whether the fraction of patients with Stage I disease was the same for Black females and White females The reported results of this study indicate the presence of less early stage of breast cancer and more late stage breast cancer in Black females as a major contributor to their lower survival rates. The greater amount of late-stage disease in African American women may reflect the great difficulty in getting underserved minority populations to participate in screening activities and/or racial differences in the utilization of cancer treatment. Adams and Joski (2007) and Adderley and Kelly (2005) reported that more early interventions, such as participation is screening activities and early diagnosis is needed among black females. This validated the need for the researcher to do a qualitative study to gain an understanding of the experiences of African American women with mammography screening in an effort to increase participation.

In 2002, the proportion of African American women aged 40 and older who reported receiving a mammogram within the past year was 62.9% versus 89% for White women (ACS, 2005). The National Health Interview Survey indicated that women with less than a high school education, without health insurance coverage, or who are recent immigrants to the U.S. are the least likely to have had a mammogram. The Centers for Disease Control and Prevention's National Breast and Cervical Cancer early Detection Program (NBCCEDP) was begun in 1990 to improve access to breast cancer screening and diagnostic services for low-income women. While the utilization in general has been increasing, African- American women below the poverty level are still less likely to have had a mammogram within the past 2 years than women at or above poverty levels (National Health Institute, 2003).

Breast Cancer in African American Women in Florida

The Florida Cancer Data System (FCDS) is Florida's legislatively mandated, population-based, statewide cancer registry. The FCDS is the single largest population-based, cancer incidence registry in the nation. Over 150,000 cases are collected from patient medical records annually. Cancer cases are submitted by hospitals, freestanding ambulatory surgical facilities, radiation therapy facilities, and private physicians and are identified from death certificates. The FCDS database contains approximately 2.3 million cancer records, 3.5 million discharge records and 3.1 million mortality records.

The current Florida Cancer Data System shows the highest percentage of advanced stage breast cancer occurs among African American females age 20 to 44 years of age (see Figure 3).The age-adjusted incidence rates increased 16% among Black females and 2% among White females between 1981 and 2003 (see Figure 4). The prevalence of receiving a mammogram among both Black and White females increased by 57%, and 115% respectively from 1987 to 2004.

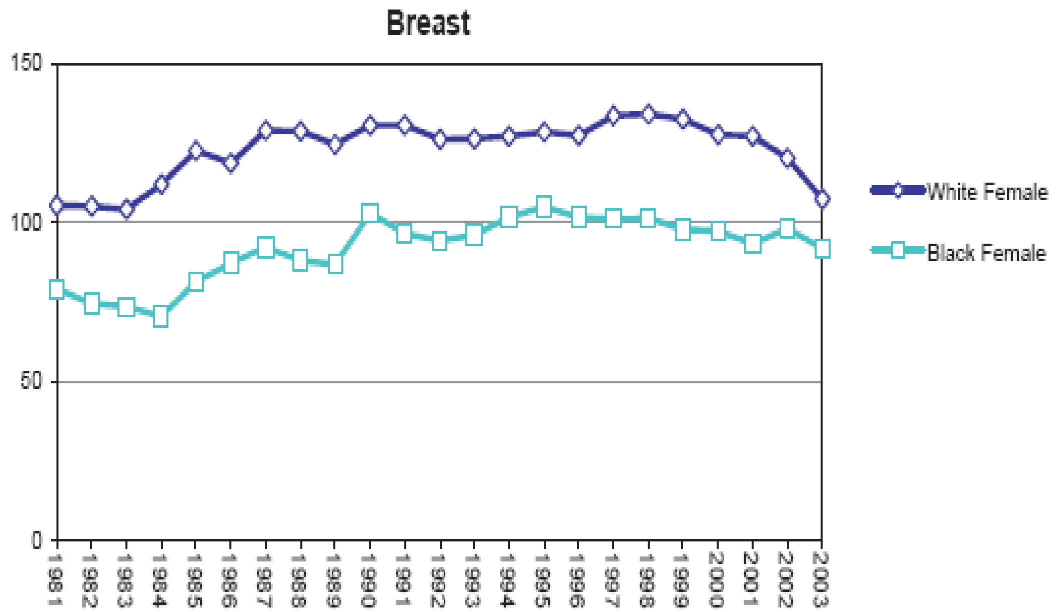


Figure 3. Age-adjusted incidence rates by sex and race, Florida, 1981-2002. Data Retrieved June 12, 2008, from www.doh.state.fl.us/disease_ctrl/epi/brfss/index.htm

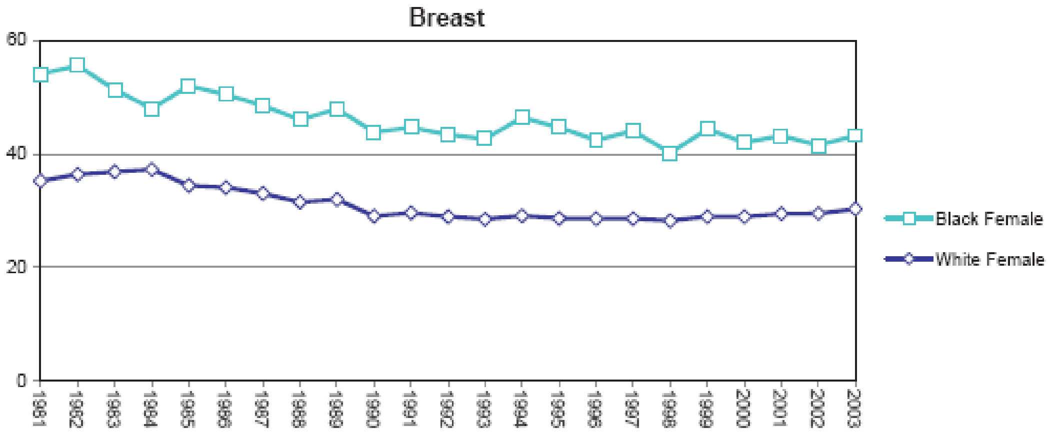


Figure 4. Percentage of advanced stage cancer at diagnosis by sex and race, Florida, 1981-2003. Data Retrieved June 12, 2008, from www.doh.state.fl.us/disease_ctrl/epi/brfss/index.htm

Deaths from breast cancer for Black women of all ethnicities are reported by the Florida Department of Health, Office of Vital Statistics (see Figure 5). There is some doubt the data from Figure 5 present a true reflection of statistics for African American women and breast cancer. Currently, there is no mechanism in place to tease out specific statistics for African American females. The Florida Office of Planning, Evaluation and Data Analysis reports that the sample size for Black females who have had a mammogram is too small to yield a statistically significant result, thus those data are not included.

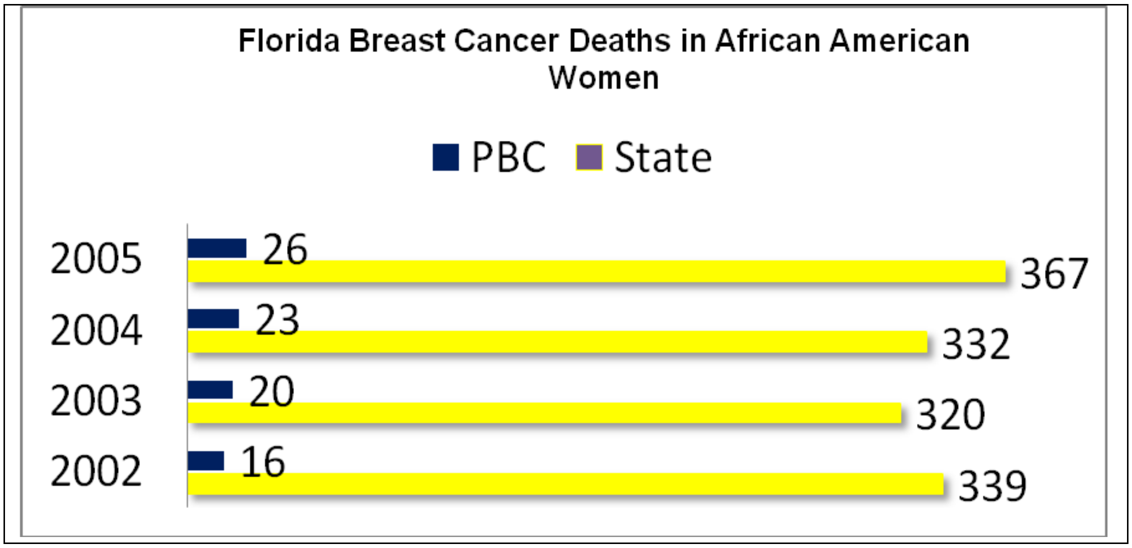


Figure 5. Death from breast cancer of Black women in Florida. Created from data retrieved from the Florida Department of Health, Office of Vital Statistics (2007).

Breast Cancer Screening

Screening tests are used to detect some cancers at stages when they are still highly curable. For some cancers, early detection tests can lead to the prevention of cancer through the identification and removal of precancerous lesions. Early detection means the application of a technique or strategy that results in earlier diagnosis of nonpalpable, as well as palpable breast cancers that otherwise would have occurred (Smith, 2003). The underlying premise for breast cancer screening is that it allows for the detection of breast cancers before they become palpable. Screening can also greatly improve the chances for cure, extend life, reduce the extent of treatment needed, and improve quality of life for cancer patients (ACS, 2005). The main forms of screening consist of breast self examinations and mammography.

Breast Self-Examination (BSE)

Although BSE has been widely promoted, researchers have been unable to find evidence that it reduces mortality from breast cancer (Lerner, 2002). In 2003, the American Cancer Society dropped its recommendation that all women perform BSE monthly. The reason for this change was fueled by results from the Canadian National Breast Cancer Screening Study (CNBCSS) reported in the September 3 issue of the *Annals of Internal Medicine*. The CNBCSS is the only trial to date specifically designed to evaluate breast screening among women aged 40 to 49. In this controlled trial, 50,430 volunteers recruited from 1980 to 1985 at 15 Canadian screening centers were randomized to receive four or five annual mammography screenings and breast physical examinations, or a single breast physical examination followed by usual care from their personal physician. At enrollment, subjects ranged in age from 40 to 49 years, were not pregnant, had no previous breast cancer diagnosis, and had not had a mammogram in the previous 12 months. Both groups received instruction on breast self-examination. At the first screening examination, mammography detected 87 cancers compared with 58 cases detected by breast self-examination alone. After 13 years of follow-up, invasive breast cancer was diagnosed in 592 women in the mammography group and in 552 women in the usual-care group.

Mammography detected 71 cases of in situ breast cancer compared with 29 cases in the usual-care group. By the end of 1996, 105 women in the mammography group and 108 in the usual-care group had died from breast cancer. The difference between annual screenings compared to the control group was not statistically significant. Breast cancer mortality was not reduced with screening alone. This study showed that mammography coupled with self examination of women in their 40s did not reduce the death rate from breast cancer compared with self-examination and physician examination.

While the American Cancer Society no longer recommends BSE women should continue to do them. All women should become familiar with both the appearance and feel of their breasts so they are able to notice any changes. Often, a woman who detects her own breast cancer finds it outside of a structured breast self-exam; she may detect a lump while bathing or getting dressed (Weiss, 2007). Bloom, Glazier, Hodge, and Hayes (1999) reported the single most important predictor of African American women having a mammogram was the regular practice of breast self-examination; the group of women who practiced self-examination was almost twice as likely to have a mammogram.

In view of the fact that the ACS no longer recommends monthly BSE, it now more urgent to explore African American women's experiences with mammography screening. The researcher must take a pro-active approach to identification of the problems in order to devise educational strategies to impact the morbidity and mortality associated with breast cancer in African American women. It is imperative for practitioners to counsel women about the risks of solely relying on breast self-examination for a cancer diagnosis while at the same time respecting their beliefs and expectations (Rosolowich, 2006).

Mammography

Historically, ethnic minority women in the USA are less likely than Whites to undergo recommended mammography screening (Smith-Bindman et al., 2006). Mammography plays a critical part in diagnosing breast cancer. It is one of the most powerful breast cancer detection tools and the single most effective method of early detection, since it can identify cancer several years before physical symptoms develop. Mammography is a low dose-x-ray procedure that allows visualization of the internal structure of the breast and its purpose is to detect cancer before it becomes symptomatic and to change the course of the disease by treating the cancer early (National Cancer Institute, 2008).

Mammography is highly accurate, but like most medical tests, it is not perfect. On average mammography will detect about 80-90% of breast cancers in women without symptoms (Kerilikowske, 1999). It is especially important that women receive regular mammograms (Michaelson, Satija, & Moore, 2002). Other important tools—such as breast self-exam, clinical breast examination, ultrasound, and MRI—can and should be used as complementary tools, but there are no substitutes or replacements for a mammogram (Weiss, 2007). There are currently two types of mammograms:

1. Film mammograms: A skilled technologist positions and compresses the breast between two plates. Then a highly specialized camera takes two pictures of each breast from two directions. This technique has been used successfully since the 1960s.
2. Digital mammograms: Digital mammography uses the same technique as film screen mammography, except that the image is recorded directly into a computer. The image can then be enlarged or highlighted. This new technology is more expensive than film mammography and not as widely available. About 8% of breast imaging centers in the United States offer digital mammograms.

In 2000, *Healthy People 2010* first set out its objectives of eliminating health disparities and increasing the proportion of women aged 40 and older who have received a mammogram within the previous 2 years to 70%. Although progress has been made since 1987 in increasing mammography screening among low-income and uninsured women, the increases for low-income women are less than those for higher-income women, and screening among the uninsured lags far behind screening among women with private or public health insurance (Swan, 2003). The greatest disparities in breast cancer screening were for women who had no health insurance, those who had no usual source of care, and recent immigrants. Recent data from the 2000 Health Interview Survey (NHIS) reports only 39.3% of women living in the U.S. for less than 10 years reported having a mammogram within the prior 2 years, in comparison with 64.7% of women living in the U.S longer than that.

Stephenson and Gorey (2008) performed a meta-analysis review of 33 studies identified from interdisciplinary research databases (1980 to 2006). The purpose of that study was to investigate the association between ethnic minority status and receiving a screening mammogram within the past 2 years among American women over 50. Using the random effects model, results showed that African Americans were less screened than non-Hispanics. The results of that study solidified the researcher’s decision to explore African American women’s experiences with mammography screening tests in an effort to bump up the number of African American women who will participate.

Tangka, Alaker, and Sajal (2006) reported approximately 4 million (8.5%) of U.S. women aged 40-64, had no health insurance and had a family income below 250% of the federal poverty level. More than 2.3 million uninsured, low-income, women age 40-64 did not receive recommended mammograms in 2003. When U.S. women who are living in poverty develop breast cancer, they are more likely to be diagnosed at advanced stages, are less likely to be treated with breast-conserving surgery and radiation when they have early-stage disease, and are less likely to survive their disease than more affluent women. Certainly, this is important because there are a higher proportion of ethnic minority and immigrant women than Caucasian women living in poverty in the U.S. (Karliner & Kerlikowske, 2007).

Most experts agree that randomized controlled trials are the best way to determine the effectiveness of an intervention. There have been eight major randomized controlled trials regarding mammographic screening for breast cancer conducted over the past 30 years from the United States, Sweden, Canada, and Great Britain (Jackson, 2002). The meta-analysis of these clinical trials, involving more than 180,000 women, demonstrated statistical significance of a 15% reduction in mortality. If 30,000 women in their forties are diagnosed with breast cancer in any given year, then a 15 % reduction would mean over 1600 lives saved with mammographic screening (Klausner, 2000).

Tabar et al. (2000) conducted a study to compare deaths from breast cancer diagnosed in the 20 years before screening was introduced (1958-77) with those from breast cancer diagnosed in the 20 years after the introduction of screening (1978-97) in two Swedish counties. The study population was 210,000 women aged 20-69 years. In the analysis, data were stratified into age-groups invited for screening (40-69 years) and not invited (20-39 years), and by whether or not the women had actually received screening. The mortality for the age-group 40-49-years was analyzed separately. The unadjusted risk of death from breast cancer dropped significantly in the second screening period compared with the first in women aged 40-69 years (relative risk [RR] 0.77 [95% CI 0.7-0.85]; $p<0.0001$). No such decline was seen in 20-39 year olds. After adjustment for age, self-selection bias, and changes in breast-cancer incidence in the 40-69 years age-group, breast-cancer mortality was reduced in women who were screened (0.56; 0.49-0.64 $p<0.0001$) versus those who were not screened (0.84 [0.71-0.99]; $p=0.03$). After adjustment for age, self-selection bias, and changes in incidence in the 40-49-year age-group, deaths from breast cancer fell significantly in those who were screened (0.52 [0.4-0.67]; $p<0.0001$); but not in unscreened women ($p=0.2$). In the 40-69-year and 40-49-year age-groups, reductions in deaths from all cancers and from all-causes in women with breast cancer were consistent with these results. The results of this study concluded when taking into account potential biases, changes in clinical practice and changes in the incidence of breast cancer, mammography screening is contributing to a 32% reduction in breast cancer mortality in these two Swedish counties.

Breast cancer mortality reductions associated with screening have been reported from the Florence, Italy screening program comparing attenders and nonattenders to screening, and the introduction of screening between 1990 and 1996. The incidence-based mortality ratio (i.e., the rate of fatal incident breast cancer cases) comparing 1990 to 1996 with 1985 to 1986 showed a 50% reduction in the rate of breast cancer death. The investigators concluded that breast cancer mortality reductions were attributable to improvements in therapy and the introduction of a breast cancer screening program. Although mammogram use increased substantially during the 1990s results from a recent cohort study of health maintenance organization members revealed declining screening rates during 1999-2002 (Blackman, Bennett, & Miller, 1999). That report describes the Behavioral Risk Factor Surveillance System (BRFSS) state-based telephone survey of the civilian, noninstitutionalized adult population (i.e., persons aged greater than or equal to

18 years). In this report, responses for women aged greater than or equal to 40 years were included for measures of breast cancer screening, and responses for women aged greater than or equal to 18 years with an intact uterine cervix were included for measures of cervical cancer screening. In all 62,278 participated in the survey in 1997. From 1990 through 1995, the proportion of women aged greater than or equal to 40 years who reported regular breast cancer screening as recommended by the American Cancer Society increased from 31% to 47%.

Despite these substantial gains in use of breast cancer screening, its use continues to be low among several subgroups, including women with low income, less education, and no health-care insurance. Feldstein, Vogtt, Aickin, and Hu, (2006) reported a decreasing trend in self-reported use of mammograms among women aged 40 years and older during 2000-2005. A continued decline in mammography use might result in increased breast cancer mortality, especially among the African American community.

Routine breast cancer screening is key to meeting national goals for the elimination of death and suffering due to cancer (Adams, Breen, & Joski, 2007). Timely screening with mammography can prevent a substantial number of deaths from breast cancer (Breen et al., 2007).

There seems to be a lot of confusion about when and how often to get a mammogram. Currently, The American Cancer Society recommends that women 40 years and older get an annual mammogram and an annual clinical breast examination by a health care professional. Women ages 20-39 should have a clinical breast examination (CBE) by a health professional every 3 years (ACS, 2007). If women are at high risk for breast cancer with a strong family history of breast or ovarian cancer, or have had radiation treatment to the chest in the past, it is recommended to start having annual mammograms at age 30 (Weiss, 2007).

In February 2002, The United States Preventive Services Task Force released recommendations for breast cancer screening mammography every 1 to 2 years for women beginning at age 40 and negated the use of breast self-examinations. An accompanying editorial, however, suggests that screening mammograms cause harm from increased rates of mastectomy and lumpectomy.

As a researcher, discovering the information about the decreasing use of mammography was quite distressing. A decrease in use of mammography means that even more African American women are likely to die from breast cancer because of non-participation in mammography screening. The researcher, through the use of face-to-face interviews undertook the present study to gain insight into the experiences of mammography screening in African American women.

Experiential Context

As an anesthesia provider, I am frequently faced with many young African American women, presenting to the operating room for breast biopsies. Often times they have huge, hard, breast masses and/or disfigured breasts. When frozen sections of the excised tissue are performed, a diagnosis of second or third stage breast cancer is made. I am always amazed and distressed by the mere fact they have allowed this to happen to them. Some of the questions that come to my mind are: Didn’t they know something was wrong? Didn’t they know about breast screening tests? Why didn’t they seek help sooner? Why didn’t they do monthly breast examinations? Why didn’t they just look in a mirror? Why didn’t they confirm or discuss with a family member or friend? Why didn’t they have a mammogram since there is a free mobile service in the area? How could anyone walk around with their breast looking like that? Even if they thought it was an infection, why didn’t they seek medical care for antibiotics? When the surgical procedures are over and the patients are in the recovery room, the very first question to the staff and surgeon is: Was it cancer? When affirmed by the surgeon, they are devastated and appear to be in a state of disbelief. I immediately start thinking, what did you think that grossness on your breast was? Time and again I thought, “There is no way possible they could not have known something was wrong with their breast.”

In many forms of qualitative research, it is expected that researchers will make sincere efforts to put aside their values in order to more accurately describe respondents’ life experiences. The means by which researchers endeavor not to allow their assumptions to shape the data collection process and the persistent effort not to impose their own understanding and constructions on the data are known as bracketing (Crotty, 1996).

The researcher entering the research arena should have no ax to grind, no theory to prove or test, and no predetermined results to support (Patton, 2002). Personal biases of the researcher take on the epoche perspective. Epoche is an ongoing analytical process (Patton, 2002). In the epoche, the everyday understandings, judgments, and knowing are deliberately set aside and phenomena are revisited, freshly, naively, and in a wide open sense. (Moustakas, 1994).

Bracketing and reflexivity are fruit from the same tree. One must be reflexive in order to bracket, and both activities require time to reflect, an environment of support, and reflective skill In reflexive bracketing, the focus is to make transparent, overt, and apparent the researcher’s personal values, background, and cultural suppositions (Ahern, 1999). This potentially allows him or her to reduce the influence of his or her lived experience on the phenomenon under investigation. Reflexive bracketing demands the researcher to develop a “thoughtful, conscious self-awareness” (Finlay, 2002, p. 532). van Manen (1990) describes bracketing as suspending one’s experiences and preconceived ideas about the phenomenon, under study, to better understand the experiences of the participants.

As an African American female researcher who is passionate about the phenomenon of breast cancer in African American women, and who really wants to make a difference, throughout this study I had to be cognizant of my feelings about the phenomenon under study in order to gain insight as to what are/were African American women’s experiences with breast cancer screening tests?

I had to practice conscious reflexivity and bracketing of my pre-conceived ideas in order to fully explore the lived-experience of the participants, consequent meanings and behaviors derived from these experiences, and an understanding of their uniqueness. I used journaling as a means of addressing personal assumptions and on-going self reflection. I recognized that I have health insurance, do monthly breast exams, have yearly mammograms and clinical breast exams, and go to the doctor immediately when something is not right with my body, inside or outside, but that my task as a researcher was to identify the lived experiences of my participants.

The literature review of this chapter has clearly demonstrated under-utilization of breast cancer screening tests by African American women. My professional duty as a researcher was to be open-minded, understanding, respectful humble, flexible, and compassionate towards the participants as I explored this phenomenon (Nystrom & Dahlberg, 2001). I could not allow my operating room encounters and recovery room experiences to influence my research endeavors.

Chapter Summary

The literature suggests participation in regular screening mammography is an important factor in increasing survival rates. Breast cancer screening measures saves lives. Screening mammograms diagnose breast cancer at non-palpable and palpable stages when they are still highly curable. The strongest predictor of breast cancer survival is the stage of the disease at diagnosis. Women whose breast cancer is diagnosed by screening mammography have better long-term survival rates than those with tumors of the same stage found in other ways. (Joensu, Lehtimaki, & Holli, 2004).

The disparity in mammography participation and survival rates of African American women has been clearly documented by large quantitative studies. Mammography utilization has been increasing among other ethnic groups, but not among African Americans. The frequency of mammography screening is statistically lower in African American women than White women and there are still many unanswered questions as to why African American women lack participation in mammography screening. An exploration of the experiences of African American women with mammography, through their voices, may provide answers to some of the unanswered questions and served as the foundation for this study. There is a validated urgency for increased investments in nursing research to increase participation in mammography screening and hopefully decrease morbidity and mortality. Winning the fight against breast cancer in African American women is not possible without increased investments in research.

CHAPTER III

METHODS

Introduction

This chapter is of fundamental importance to the study because it describes the research design and methodology applied to the study. It discusses the method of inquiry, the methodology of data collection and processing procedures, data analysis, standards of quality and verification, ethical considerations, and ends with a chapter summary.

The purpose of this study was to explore the lived experiences of African American women with mammography screening and to provide an inductive description of their everyday lived experience of the motivators and barriers to seeking mammography as perceived and comprehended by them.

A qualitative research design following van Manen’s (1990) hermeneutic phenomenological tradition was used to explore, identify, describe, and uncover the meaning of the lived experiences of African-American women with mammography screening. The experiences of African American women with mammography screening are vitally important to the quest of decreasing the mortality associated with the disease. This study followed the interpretivist perspective since information was shared and interpreted between the researcher and the participants.

Research Design

Creswell (2005) described a research design as an overall framework which is developed by assessing knowledge claims brought to the study, considering the strategy of inquiry that should be used, and identifying specific methods.

This study utilized a qualitative exploratory research design that used a phenomenological approach. Exploratory research helps determine the best research design, data collection method, and selection of subjects for problems that have not been clearly defined. It begins with a phenomenon of interest and is aimed at investigating the nature of the phenomenon, the manner in which it is manifested, and the other factors with which it is related. Exploratory research is undertaken to explore the full nature of a little understood phenomenon (Creswell & Clark, 2003).

Rationale for a Phenomenological Study

Phenomenology is the study of structures of consciousness as experienced from the first-person point of view. The naturalistic phenomenological paradigm guided this research study because it aims at a faithful, authentic reproduction or representation of others’ ways of life. This approach seeks to explain the structure and essence of the experiences of a group of people. This paradigm is not contrived, manipulated, or artificially fashioned by the inquirer; hence the setting is said to be naturally occurring (Guba & Lincoln, 1995).

Phenomenological research originates in practice, and through careful descriptive and interpretive scholarship, enlightens practice. Because of its focus on the detailed description of an individual’s experience in the world, phenomenology is a type of inquiry that can meet the needs of nurse researchers who wish to focus their research to a greater degree on aesthetics, on personal ways of knowing, on questions of being, and on multiple realities (Van der Zalm & Bergum, 2000).

Context of Hermeneutic Phenomenology

The main difference between hermeneutic phenomenology and other qualitative approaches lies in the fact that hermeneutic phenomenologist's believe that humans are self-determining beings. "The hermeneutic phenomenologist tries to move towards an essential understanding of being in the world through embodied understanding and interest lies in how awareness of new meanings in lived experience is developed (Holloway, 2005, p. 136)". Central to analyzing data in a hermeneutic study is the notion of the hermeneutic circle, which signifies a methodological process in which there is continual movement between the parts and the whole of the text under analysis (Polit & Beck, 2005).

Hermeneutic phenomenology is a method of inquiry rather than a theoretical standpoint, through which a researcher can effectively "funnel" his or her research findings. While it is readily acknowledged that there is much diversity within the separate "hermeneutic" and "phenomenological" forms of social inquiry, there exist within these diversities some fundamental and shared principles (Spiegelberg 1982, pp.1-19; Zaner & Ihde 1973, pp. 333-374). These principles include an interest in understanding the phenomena at hand from the "inside," in the study of the lifeworld, in comprehending the meaning of everyday experiences in providing credible insights of our "social" world. By "partnering" hermeneutics and phenomenology, a researcher tries to be attentive to both in terms of its method: it is a descriptive (phenomenological) method because it wants to be attentive to how things appear, it wants to let things speak for themselves; it is an interpretive (hermeneutic) methodology because it claims that there are no such things as uninterpreted phenomena (van Manen, 1991).

> A rigorous human science is prepared to be *soft, soulful, subtle*, and *sensitive* in its effort to bring the range of meanings of life's phenomena to our reflective awareness… [but it] is to attempt to accomplish the impossible: to construct a full interpretive description of some aspect of the lifeworld, and yet to remain aware that lived life is always more complex than any explication of meaning can reveal. Full or final descriptions are unattainable. (Van Manen, 1990, p.18)

Hermeneutic phenomenology is particularly interested in the complexities and diversities of our societies. The determining factors in the decision to utilize van Manen's approach was, however, his specific concern for the articulation and importance of context, his pointing out the need for the development of creative approaches and procedures when carrying out research studies (which he argues should be uniquely suited to both project and individual researcher), and his emphasis on researchers' understanding and awareness of "self" within the context of the study boundaries. The researcher, through the eyes of the participants sought to document the need for more creative strategies to encourage African American women's participation in mammography screening.

van Manen (1990) states, hermeneutic phenomenological research is concerned with "a search for the fullness of living (p. 12) and providing an approach which allows the study of the lifeworld. This approach, or method of inquiry, attempts to describe and interpret the relevant meanings of the research, to a "certain degree of depth and richness" (van Manen, 1990, p. 11). It does not focus upon statistical relationships, but attempts to resolve "meanings" as we live them in our everyday existence, our "lifeworld" (van Manen, 1990, p. 11).

In seeking meaning, van Manen asserts that “any lived-experience description is an appropriate source for uncovering thematic aspects of the phenomenon it describes” (1990, p. 92). However, he also concedes that some descriptions may be a richer source of information than others, and that different people will contribute more to our understanding of life, than others. Nevertheless, he argues, “when a person shares with us a certain experience then there will always be something there for us to gather” (van Manen, 1990, p. 92).

van Manen's conceptualization of hermeneutic phenomenology was used to guide this research study. The method provided a more detailed and explicit description of the actual experiences of engaging in BSE, mammography and PBE, as described by African-American women. The description, by African American women, of their experience with mammography screening enlightened the researcher and produced data that will be published and shared with other health care providers.

van Manen (1990) asserts that the researcher can take three approaches toward uncovering or isolating the thematic aspects of a phenomenon in some texts: (a) the holistic or sententious approach (viewing the text as a whole); (b) the selective or highlighting approach (pulling out key statements and phrases) and; (c) the detailed or line-by-line approach (analyzing every sentence). The researcher employed the selective approach to this study to identify statements that are particularly revealing.

The researcher used van Manen’s (1990) phenomenological method, which promotes six activities to help explore the phenomenon:

> 1. Ensure a sense of commitment and passionate concern about the lived experience under exploration. Engage in the investigation from a specific orientation of interest.
> 2. Return to the phenomenon so that the study of the specific experience is through living it, not conceptualizing it. Enter the lifeworld of the person under study by participating in it.
> 3. Contemplate the essential meaning of the experience. Determine the essence of its uniqueness against the complexity of the lifeworld.
> 4. Construct a phenomenological text that describes and explains the phenomenon being aware of the power and limits of language.
> 5. Avoid speculation and wandering into other concepts by remaining faithful to the original orientation in both reflection and writing. Ultimately, this may lead to a change in practice or even political action.
> 6. Balance the importance of the phenomenon against the greater whole of human experience. Recognizing the complexity of life, consider the significance of the inquiry with the goal of becoming more fully human. (pp.30-31)

The hermeneutic circle (see Figure 5) addresses the ways in which the researcher and the participants engaged in conversation and mutually transformed each other’s ideas through continuing interaction. The researcher and the participants worked together to bring life to the experience explored through the hermeneutic circle and attention to language and writing (Laverty, 2003).

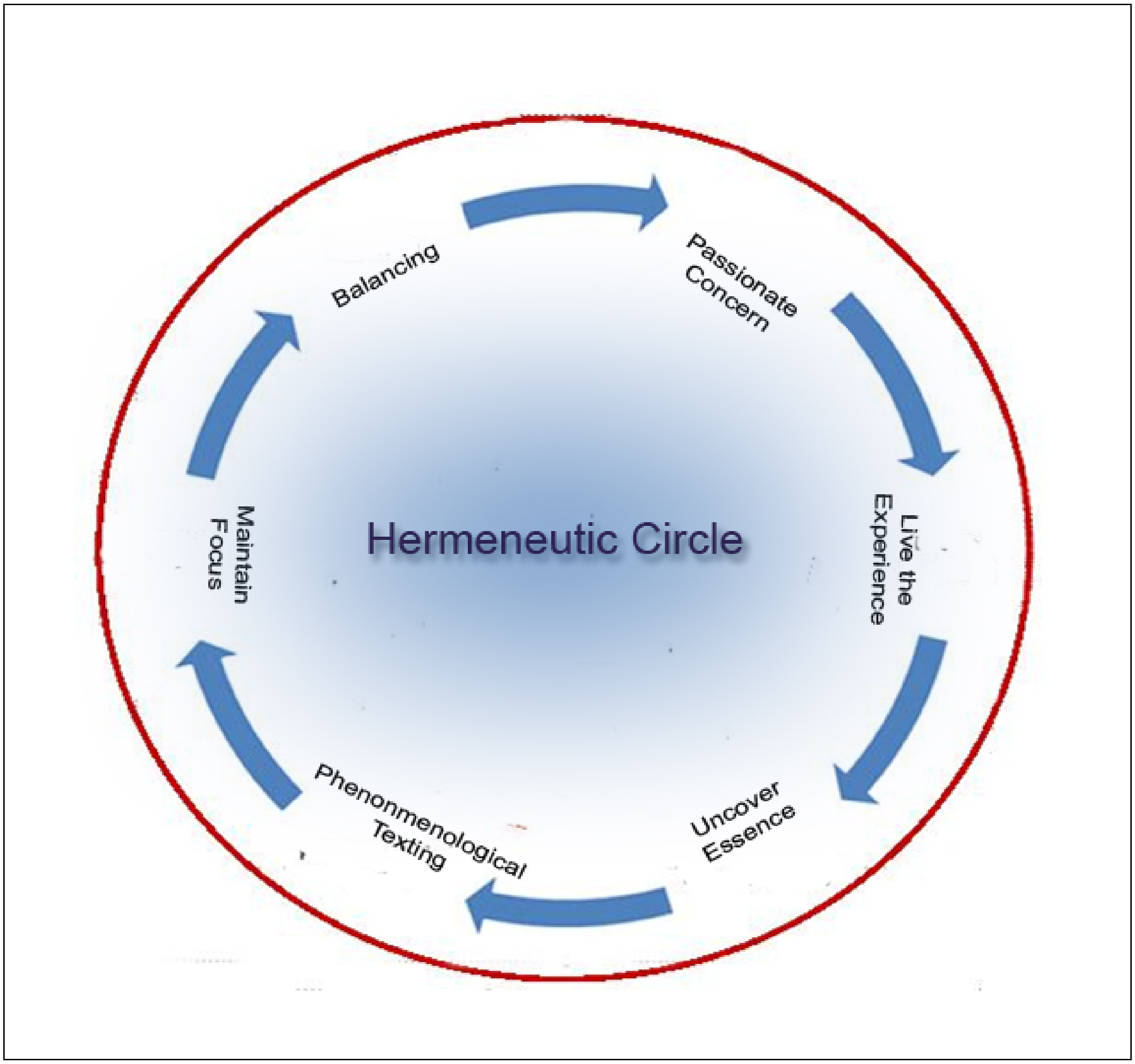


Figure 5. Randall adaptation of the phenomenological method. Adapted with permission from McFadden (2008).

This study adhered to van Manen's investigative activities to explore this phenomenon. These activities were not conducted sequentially, but rather "intermittently or simultaneously," as van Manen suggests (1990, p.34).

Research Questions

This study was guided by the following research question. What is the lived experience of African-American women with breast cancer screening tests? The subquestions that contributed to this study are:

1. What are the barriers that preclude continued participation in mammography screening?
2. What are some strategies or interventions that can be used to increase continued participation in mammography screening?

Sampling

Sample size is dependent on what you want to know, the purpose of the inquiry, what is at stake, what will be useful, what will have credibility, and what can be done with available time and resources. Purposive sampling is the dominant strategy in qualitative research. Purposive sampling seeks information-rich cases to illuminate the question under study (Patton, 2002). An ample sample size in qualitative research is one that permits - by virtue of not being too large - the deep, case-oriented analysis that is a hallmark of all qualitative inquiry, and that results in - by virtue of not being too small - a new and richly textured understanding of experience (Sandelowski, 1995). Since the qualitative tradition of phenomenology was used to guide this study, determining an adequate sample size was ultimately a matter of judgment (Patton, 2002). The researcher used 13 participants.

According to Lincoln and Guba (1985), the most useful strategy for the naturalistic approach is maximum variation sampling. This strategy aims at capturing and describing the central themes or principal outcomes that cut across a great deal of participant or program variation. For small samples, a great deal of heterogeneity can be a problem because individual cases are so different from each other. The maximum variation sampling strategy turns that apparent weakness into strength by applying the following logic: any common patterns that emerge from great variation are of particular interest and value in capturing the core experiences and central, shared aspects or impacts of a program (Patton, 2002).

The researcher employed purposive sampling to identify and recruit 13 African-American women; the number that turned out to be enough to reach saturation, which is the point when no new information was uncovered (Creswell, 2005).

Inclusion Criteria

The participants included women:between the ages of 25 and 55, with no previous or current diagnosis of breast cancer, who had only one mammogram, self-identified as African American, lived in Palm Beach County, and were willing to participate in this study. African American premenopausal women under the age of 50 have a high mortality rate from breast cancer, almost twice that of younger White women. The current Florida Cancer Data System shows the highest percentage of advanced stage breast cancer occurs among African American females age 20 to 44 years of age, which is why this age population was targeted.

Exclusion Criteria

Any female who does not self identify as African American, who has a history of breast cancer, is less than 25 or older than 55 years in age, and who has not has a previous experience with a mammogram.

Ethical Considerations

In qualitative research, the researcher is the primary research instrument, which generates specific ethical problems because of the high level of rapport that develops between the researcher and the participants. Although it is often assumed that involvement in qualitative research is relatively harmless, the actual risk to participants is unknown (Richards & Schwartz, 2002). Therefore, the utmost of care needs to be taken to minimize any risk of harm to the participant.

Human science researchers are guided by ethical principles of research with human subjects. Informed consent is seen to be one of the most critical issues in qualitative research. The participants were informed both verbally and in writing about the purpose of the study, the scope of the study, types of questions they were likely to be asked, how the results of the study will be used in reports, and the method of confidentiality that would be employed (see Appendix A). During the process of qualitative research, unexpected themes and topics may be generated and the participants were informed they could withdraw their consent to participate at any time without penalty (Berg, 2004). Participants who demonstrate emotional distress during or after the interview process would have been referred to Grace Fellowship Counseling Services, in West Palm Beach, Florida, for services. No study participants required this service.

Demographics and Interview Questions

The researcher used a demographic data sheet at the beginning or the end of the interviews to collect data for the purpose of describing the participants. Demographic information included: age, education, with what racial group they self-identified, sources where they obtained health information, how many mammograms they have had, how long since last mammogram, frequency of performance of self breast examinations and routine clinical breast examinations, family history of breast cancer, and awareness of breast cancer risk factors (see Appendix D). This information assisted the researcher to understand each participant’s perception and identify commonalities that transcended the group.

The interview questions for this study sought to illuminate the experiences of African-American women with breast cancer screening tests and the reasoning behind non-participation with recurrent tests. The researcher used broad standardized questions to start the interview with the intent of facilitating free flowing dialogue and minimal prodding (see Appendix F). An example of one of the questions was, “Can you please describe for me, in your own words, the definition of breast health?”

Data Collection Procedures

Approval to conduct this study was obtained from the IRB at Barry University. Institutional Review Board guidelines were stringently followed. Informed consent was obtained from the participants. The original intent for recruitment was the use of posters placed in African American churches, primary care physician offices, ob-gyn physician offices, and housing developments within Palm Beach County, Florida. The recruitment handouts clearly identified the researcher as an African American doctoral student. The research objectives of the study and factual documentation of the problem of breast cancer in African American women were clearly communicated A period of 2 weeks went by with no responses. A second set of posters were distributed which included the $25.00 compensation for participation. This proved futile as well. Finally, the women were recruited by snowball sampling with the first participant recruiting two family members, the second participant recruiting another co-worker, and a social worker recruiting her colleagues, acquaintances, and family members.

Qualitative interviewing can be both rewarding and challenging (Patton, 2002). The interview is the most widely used method of generating data in qualitative social research. It is seen as a tool for collecting data in an effort to create and construct stories. An interview may help the participant to reflect on her situation. The interview requires linguistic transactions and relationships between at least two persons. The interview invites and persuades individuals to think and talk to discourse their needs, wants, expectations, experiences, and understandings at both the conscious and unconscious levels (Nunkoosing, 2005).

Qualitative interviewing offers the participant the opportunity to define problems and to challenge the researcher's pre-conception about what is important or significant about the matter at hand. The skillful use of qualitative interviewing is aimed at the researcher avoiding imposition of his/her own structures and assumptions upon the respondent's view of the world (Berg, 2004). The focus of the researcher should be to gather information that is useful, relevant, and appropriate (Patton, 2002).

Beck (2005) identifies three major interview categories: the standardized (formal or structured) interview, the semi standardized (semi-structured) interview, and the unstandardized (unstructured) interview. The main difference among these interview structures is their degree of rigidity with regard to presentation structure (Berg, 2004).

Hermeneutic interviews encourage the development of conversational relationships between the interviewer and the interviewee through in-depth discovery and intimacy and intend to build trust within the relationship by offering interviewees space to translate knowing into telling. They tend to turn the interviewees into collaborators. (van Manen, 1990).

When interviewing is the method of choice, when a number of interviews are analyzed together, the variety of constructions that exist around the phenomenon may be brought into consensus to reveal the "essential" quality of that phenomenon. This process includes "fusing horizons" to compare and contrast a variety of ideas expressed and to arrive at a definitive understanding of the text (Holloway, 2005, p.135).

The hermeneutic researcher uses interviews to uncover meaning by

1. Gathering experiential narrative data;
2. Conducting face-to face interaction that captures mantic and semantic levels of understanding;
3. Engaging in conversational development;
4 Gathering experience as immediately lived;
5. Incorporating the views of the participant with those of the researcher;
6. Concentrating on the immediacy of data collection. (Holloway, 2005)

The researcher met with each participant for 1 hour initially for a one-on-one semi-structured interview using open-ended questions and following the hermeneutic interview process. This method of data collection allows the world to be seen through the eyes of the participants, hear their voices and explanations, and view their daily lives in their natural setting (van Manen, 1990).

The interviews were sequenced so that each question flowed from general to specific (see Appendix E). All initial interview sessions were tape-recorded with the recorder openly in view and transcribed verbatim. The interviews took place in a mutually agreed upon time and location where there were no distractions.

Participants were asked to sign the Informed Consent Form (see Appendix B) and complete the demographic data survey (see Appendix D) prior to the onset of the interview. Participants were informed they did not have to respond to any question that made them feel uncomfortable or were case sensitive, and they could request the tape recorder to be turned off at any time. Participants who demonstrated emotional distress during or after the interview process would have been referred to Grace Fellowship mental health counseling, in West Palm Beach, Florida, which offered free services. None of the participants demonstrated a need for this free service. A follow-up meeting was planned for an additional 1 hour once the data had been transcribed and analyzed. The participants were exposed to the information and engaged in member checking by being given opportunity to identify responses and to make recommendations or clarifications with regards to their lived experiences and responsibility for their care (Creswell, 2005).

Prior to transcription, the tapes were reviewed to validate the ability to understand and hear the participant’s words. The audio taped interview, when completed, was transcribed verbatim by the researcher. The transcripts were reviewed, by the researcher, with the tapes to assure accuracy. They were also peer reviewed by another qualitative researcher to guard against bias. Through journaling of personal assumptions and bracketing, biases were recognized and managed. Overarching themes were identified. The findings were correlated to the literature and implications for nurses and health care providers identified. A narrative report of the findings was developed and reported in the aggregate.

The issue of confidentially is one which underpins all qualitative research. Confidentiality is a vital requirement for credible research. More importantly, mere anonymity is insufficient for confidentiality to be safeguarded (Berg, 2004). To enhance confidentiality, the researcher employed the following strategies for the secure storage of tapes and transcripts. The transcripts were kept in a locked file box, in a locked cabinet, in the researcher's locked home office. The signed Informed Consent Forms (see Appendix B) were kept separate from transcripts and demographic data.

Confidentiality of the participants was maintained in the dissertation by disguising demographic identifiers with pseudonyms; additionally data were disseminated in aggregate**.** Identifiers and data were kept separate.

The audio-tapes were destroyed within 2 weeks after transcription and verification of accuracy by the participants. Transcripts, demographic data sheets and signed Informed Consent form will be disposed of after 5 years (see Appendix C).

The reflexive mode is particularly pertinent to the hermeneutic study, where data collection will be dependent on the recognition of historical connections linking researcher interpretation to the participant's story (vanManen, 1990).The researcher actively listened to the stories being told and the meanings being put across.

Data Analysis

Unquestionably, data analysis is the most complex and mysterious of all of the phases of a qualitative project, and the one that receives the least thoughtful discussion in the literature (Thorne, 2000). There are numerous forms of phenomenological research;

however, many of the most popular approaches used by nurses derive from the philosophical work of Husserl on modes of awareness (epistemology) and the hermeneutic tradition of Heidegger, which emphasizes modes of being (ontology; Thorne, 2000). Hermeneutical analysis allows the researcher to make sense of the written text. This approach typically challenges researchers to set aside or "bracket" all such preconceptions so that they can work inductively with the data to generate entirely new descriptions and conceptualizations (van Manen, 1990).

In the hermeneutic, phenomenological method, the process of storytelling is a sacred and confidential process (Lane, 2005). The key to Van Manen’s hermeneutic, phenomenological research is for the researcher to rewrite the stories over and over to grasp the essence of revealed themes (Lane, 2005). In this study, the researcher retold the stories in detailed ways through the lens of the participants.

There is no singularly appropriate way to conduct qualitative data analysis, although there is general agreement that analysis is an ongoing, iterative process that begins in the early stages of data collection and continues throughout the study. Immersion in the data to comprehend its meaning in its entirety is an important first step in the analysis (Pope, Ziebland, & Mays, 2000).

Data analysis began once each interview was completed. The taped interviews were transcribed verbatim. Content analysis was conducted and themes were identified and tabulated. The researcher used the “selective or highlighting approach” for analytic thematic analysis (van Manen, 1990, p.79). This approach consists of four stages

1. Searching for “structures of experience” (van Manen, 1990, p.79)
2. Describing how structures are thematic of the phenomenon

3. Searching for essential and incidental themes
4. Explaining and interpreting essential and incidental themes

Each stage is rigorously selective and it is important to move slowly through the data as not to overlook essential detail. Structures of experience, or sentences of great relevance to the research question, that stand out for the manner in which they are thematic of the phenomenon, are selected to help throw light on recurring themes, incongruities or puzzles within the data. Once they are revealed, they are described in the order in which they were discovered to show not only how each one is thematic of the phenomenon, but to present a decision trail through the data that illustrates the process of revelation. Analysis leads to focusing-in-on essential and incidental themes. An essential theme helps give shape to the data, and as a cognitive response, it encourages a thoughtful and controlled response to participant stories.

The researcher melded personal knowledge with emergent understanding, in effect taking part in “the hermeneutic conversation” with the text, to reveal new understanding of underlying words. Individual analysis was enhanced by collaborative analysis, informally, with participants at time of second interview. “Collaborative analysis” leads to a common orientation to the phenomenon that one is studying” (van Manen, 1990, p.100), offering new insights or corroboration with researcher perspectives.

Once data had been reviewed and there was a general understanding of the scope and contexts of the key experiences under study, coding began. Coding provided the researcher with a formal system to organize the data, uncovering and documenting additional links within and between concepts and experiences described in the data. The coding process included development, finalization, and application of the code structure.

A single researcher conducting all the coding is both sufficient and preferred. This is particularly true in studies where being embedded in ongoing relationships with research participants is critical for the quality of the data collected. (Janesick, 2003).

There are several approaches to coding in the literature. Miles and Huberman (1994) describe a deductive approach to coding, which starts with an organizing framework for the codes They suggested analytic techniques such as rearranging the arrays, placing the evidence in a matrix of categories, creating flowcharts or data displays, tabulating the frequency of different events, using means, variances and cross tabulations to examine the relationships between variables, and other such techniques to facilitate analysis.

Denzin and Lincoln (2000) suggested that a good codebook should include: a detailed description of each code, inclusion and exclusion criteria; exemplars of real text for each theme, and exemplars of the theme's boundaries. For the purpose of this study the researcher employed Miles and Huberman' method of coding

Research Rigor

Rigor is the means by which integrity and competence are demonstrated, and a way of demonstrating the legitimacy of the research process (Aroni et al, 1999). Researchers such as Lincoln and Guba (2000), Denzin and Lincoln (2000) and Flick (2002) have pointed to the need for qualitative researchers to be as vigilant as positivist researchers about ensuring the validity and reliability of their studies.

Researchers working in hermeneutic phenomenology regard the study as a complete process. It must be holistic and integrated, with no part of the study design more important than another (Holloway, 2005),

The major issue in qualitative research is trustworthiness and authenticity. According to Lincoln and Guba (2000) a study is for naught if its trustworthiness is questionable. Activities such as maintaining field journals, mounting safeguards against common distortions, doing debriefings, triangulating data, and developing an audit trail are all directed either to increasing the probability that trustworthiness will result or to making it possible to assess the degree of trustworthiness after the fact. Lincoln and Guba (2000) established four criteria for establishing trustworthiness of quality data: credibility, dependability, confirmability, and transferability.

Authenticity is the degree to which the researcher fairly represents different viewpoints from the social setting under research. Ontological authenticity represents the degree to which the research helps members of a social setting to better understand their own environment (Guba & Lincoln, 1989). The researcher demonstrated this by leaving an audit trail and member checking. The results of this study will be readily available to be shared with other African American women in the form of lectures and publications.

Credibility corresponds roughly with the positivist concept of internal validity. Credibility was established by in-depth investigation of the topic of breast cancer in African-American women, prolonged engagement with the participants, peer debriefing, and member checks. Member checking is a vital part of a constructivist inquiry in order 'to check with the actors who are the subject of (the research) focus how they interpret (the researcher’s) interpretations (Rolfe, 2006).The researcher engaged in continuous journaling to establish authenticity and credibility and depict a true picture of the phenomenon under investigation. Journaling helped the researcher to bracket preconceived ideas or feelings and report data through the eyes of the participants.

Dependability relates more to reliability and may be supported by an audit trail. This was established by keeping accurate records of the study materials such as raw data, field notes, summaries, formulated meanings, and themes (Rolfe, 2006). This enhances the chance that “proceedings and developments in the process of the research can be revealed and assessed” (Flick, 2002, p. 229). Bracketing is a very important part of this process to contain preconceived ideas and feelings on the part of the researcher. To enhance dependability the researcher adhered to the recommendations of Gadamer (1996) and kept a diary. The diary helped the researcher note information about the participants themselves, such as their reactions to events and comments they make. A diary also helped to contextualize personal actions and behaviors to help create rich data congruent with the phenomenological philosophy (Holloway, 2005).

Confirmability is vital in order to demonstrate that investigator bias has not unduly influenced the research outcome. It is accepted that in constructivist research the knowledge and experience of the investigator will impact on the findings, but it is important to demonstrate that tacit knowledge has not been transferred from the researcher to the findings to such an extent that meaning has been changed (Graneheim & Lundman, 2004). Confirmability was established by linking the data of the words of the participants and the findings. The researcher took all the steps necessary to clearly demonstrate the data that emerged from the study were not her own predispositions

(Shenton, 2004). Published results will be evaluated by the participants, members of the research committee, and other experts in the field.

Transferability, in constructivist inquiry, allows for transferability of the findings rather than wholesale generalization of those findings. Here the researcher provides “rich pictures” on an individual level, and the readers then gather, or already have, empirical evidence concerning the cases to which they wish to apply the findings. Transferability is a form of external validity (Rolfe, 2006). If sufficient similarities between the two contexts are identified by the reader, and then it is reasonable for that reader to apply the research findings to his/her own context (Lincoln, 1992). Transferability is the responsibility of the researcher since he or she is the one accountable for the generalization. This was established by collecting detailed description of the data and the sample (Morgan, Mock, Rose, & Fogel, 2005). The researcher provided sufficient detail of the context of fieldwork for the reader to be able to decide whether the prevailing environment can be justifiably applied to another setting (Shenton, 2004).

In qualitative research, the term confidentiality is often confused with privacy and/or anonymity. Privacy refers to individuals and to their interest in controlling others' access to themselves. Confidentiality refers to data and to limiting the access to private data about a person. Anonymity means that names and unique identifiers of participants are never attached to the data or known to the researcher. In most qualitative research, the participants are known to the investigators, so anonymity is virtually nonexistent (Berg, 2004). The issue of confidentiality is one that underpins all qualitative research. Confidentiality is a vital requirement for credible research. Maintaining confidentiality of private information entrusted to them by their participants is a way that researchers protect the participants from harm. Ensuring confidentiality is critical if the researcher expects to get truthful and free-flowing discussions (Berg, 2004).

Exploitation

The importance of power relationships and the potential for research to exploit the vulnerable populations is an issue. When a researcher is also a health professional, this power imbalance can be exaggerated. The researcher ensured that the interview process was not overshadowed by her role as a health care professional by asking inappropriately sensitive questions requiring the participants to divulge more information than they had anticipated when consenting to the study (Richards & Schwartz, 2002).

Reciprocity

The issue of whether to compensate and how to compensate interviewees involve questions of both ethics and data quality. Researchers can offer participation incentives in the form of a modest gift certificate to compensate the participants for their time and participation, while at the same time praising them for their contribution to research efforts (Patton, 2002). The researcher offered each participant a $25.00 gift certificate.

Generating Results

There are three types of output from qualitative studies: taxonomy, theory and themes. Taxonomy is a formal system for classifying multifaceted, complex phenomena according to a set of common conceptual domains and dimensions. Taxonomies promote increased clarity in defining and hence comparing diverse, complex interventions which are common in health policy and management (Patton 2002).

Theory is a set of general, modifiable propositions that help explain, predict, and interpret events or phenomena of interest (Patton 2002). Theory is important for understanding potential causal links and confounding variables, for understanding the context within which a phenomenon occurs, and for providing a potential framework for guiding subsequent empirical research (Bradley, Curry, & Devers, 2007).

Themes are recurrent unifying concepts or statements about the subject of inquiry. Themes are fundamental concepts that characterize specific experiences of individual participants by the more general insights that are apparent from the whole of the data (Ryan & Bernard 2003). Themes and theory guide researchers to explain and predict various outcomes within diverse contexts of the health care system (Bradley et al., 2007).

According to van Manen (1990), a theme is the experience of meaning, a simplification of the summary of the significant factor. It is not an object one encounters at certain points or moments in a text but is a way of capturing the phenomenon one is trying to understand. Also important is the understanding of how themes come to be, which van Manen (1990) explains as being the needfulness or desire to make sense, the sense we are able to make of something, the openness to do something, and, finally, the process of insightful invention, discovery and disclosure. In terms of how a theme relates to the notion of what is being studied, the theme is the means to get at the notion, gives shape to the shapeless, describes the content of the notion, and is always a reduction of a notion.

Phenomenological themes “ are not objects or generalizations; metaphorically speaking they are more like knots in the webs of our experiences, around which certain lived experiences are spun and thus lived through as meaningful wholes” (van Manen 1990, p. 90). In utilizing these themes to guide explorations, the researcher can attain a deeper, more comprehensive insight into the participant’s lifeworld (van Manen 1990, p. 90).

In seeking meaning, van Manen asserts that “any lived-experience description is an appropriate source for uncovering thematic aspects of the phenomenon it describes” (1990, p. 92). However, he also conceded that some descriptions may be a richer source of information than others, and that different people will contribute more to our understanding of life, than others. Nevertheless, he argued, “when a person shares with us a certain experience then there will always be something there for us to gather” (van Manen 1990, p. 92).

Chapter Summary

This chapter described the method applied to this study. The methodological framework, rationale for a phenomenological method, data collection and processing procedures, data analysis, standards of rigor, quality and verification, ethical considerations have been discussed.

Hermeneutic phenomenology, by which this study was guided, allowed the researcher to investigate the lived experience of the participants and illuminate what it is to be human in the lifeworld - the world as it is immediately experienced - in order to offer a deeper meaning to the experience. This tradition also allowed the researcher to understand the nature of human beings and gave meaning to the way language is interpreted

The research information obtained in this study added to the body of nursing knowledge by the exploration of African-American women’s experiences with breast cancer screening tests. The voices of the participants, may guide the researcher and other nursing professionals towards developing culturally sensitive teaching strategies to decrease the morbidity associated with the disease among this population.

CHAPTER IV

FINDINGS OF THE INQUIRY

Introduction

This chapter details the significant findings of this phenomenological inquiry into the lived experiences of African American women with mammography screening. Characteristics of the participants are presented in aggregate. The interviews were sincere, thought-provoking, and intense at times, and depicted the essence of participants' lived experiences. Feelings, emotions, and the essence of their experiences are detailed. The themes that evolved through the exploratory interviews are elucidated.

The purpose of this phenomenological study was to explore the lived experiences of African American women with mammography screening and to gain an understanding about their motivators for and/or barriers to seeking mammography as perceived and comprehended by them. "Phenomenological research, unlike any other kind of research, makes a distinction between appearance and essence, between the things of the experience and that which grounds the things of the experience" (van Manen, 1990, p. 32).

van Manen's six activities of hermeneutic phenomenological inquiry were used to explore, identify, describe, and uncover the meaning of the lived experiences of African American women with mammography screening. These experiences with mammography screening are vitally important to the quest of decreasing the mortality associated with the disease. Through the eyes of the participants more creative strategies can be documented to encourage African American women's participation in mammography screening. Presently, little is known about the cultural beliefs of African American women with no personal history of breast cancer regarding the meaning of the mammography screening experience (Russell, Swenson, Skelton, & Steele, 2003).

Purposive sampling was employed to identify and recruit participants. This type of sampling is warranted when the researcher seeks information-rich cases for in-depth study (Patton, 1990). Although flyers were posted in exam rooms of physicians' offices, local malls, hospital bulletin boards, church bulletin boards, and a housing development, no participants were recruited in that manner. Snowball sampling was the mainstay of recruitment efforts. The first participant recruited three family members, the second participant recruited two coworkers, and the third participant recruited five coworkers, family members, and/or work clients for this study. The recruiting participants expressed excitement and a sense of duty to help with the study. Thirteen African American women who met inclusion criteria of: self-identification as African American, could read, speak, and understand English, no previous history of breast cancer, age 25-55, only had one mammogram, and willingness to participate in this study were interviewed for this study African American premenopausal women under the age of 50 have a high mortality rate from breast cancer, almost twice that of younger White women. The current Florida Cancer Data System shows the highest percentage of advanced stage breast cancer occurs among African American females age 20 to 44 years of age, which is why this age population was targeted.

By the 10th interview/re-interview, saturation of data had been reached, but an additional three participants were interviewed to confirm saturation. The participants chose their pseudonyms for the purpose of maintaining confidentiality.

The instrument used to explore the lived experience of participants with mammography screening was face-to-face audio-taped interviews. The interview, as described by Gadamer (1996), is a specific kind of conversation. Genuine conversation was characterized by a stance of openness to the meanings offered by the other, by the awareness that the other may assist participants in the dialogue to revise their own partial understandings, and by a willingness to be transformed through the revised understanding of the topic that emerges from the encounter.

All procedures for this study followed institutional review board guidelines as set forth by Barry University. Demographic data sheets were completed at the beginning of the interviews to collect data for the purpose of describing the participants (see Appendix D). Prior to the start of the interview, the researcher explained the interview process, answered any questions, thanked the participants for allotting an hour of their valuable time to participate, and required participants to sign the Informed Consent Form. The researcher proposed five broad standardized questions to start the interview with the intent of free flowing dialogue and minimal prodding (see Appendix F). Initially, the participants were interviewed between 45 and 60 minutes. The researcher collected data using open-ended, semi-structured interviews that began by asking the participants to describe their experiences with mammography screening. The interviews were transcribed personally and verbatim by the researcher in an attempt to assign meaning to the descriptions of their experiences, to contemplate the essence of the experiences of the participants, and to maintain trustworthiness of the study. During the second interview the transcribed data were shared with the participants to clarify meaning and to validate the essence of their experiences with mammography screening. The themes were shared and compared among all participants and they agreed the phenomenological process was effective in uncovering their experience with mammography screening.

The overall context of the interviews was guided by Gadmer’s (1996) levels of conversation. The first is openness to the other’s position. In order to be open to the other's positions, researchers must be aware of, and take into account, their own preconceptions and prejudices which include their past history, culture, and personal experiences culminating in the personhood and understanding they bring to the conversation. This position of awareness orients the researcher to the potential differences and similarities between themselves and others. This means that the researchers are open to learn something from their participants, even if it is something they would rather not learn. Openness allows for accessibility to the other's point of view, so that the researcher no longer sees only his or her own point of view. For the purpose of this study, the researcher demonstrated openness by engaging in conscious bracketing and reflexivity of pre-conceived ideas in order to fully explore the lived-experience of the participants, consequent meanings and behaviors derived from these experiences, and an understanding of their uniqueness.

The second is the essence of the question. The stance is one in which researchers recognize they are in the position of not knowing, which is a position that opens them up to be ready to ask a question. The researcher asked probing questions for the purpose of knowing and clarification. The third is the concept of possibilities. The conversation leads to new possibilities and new levels of understanding that were not present before the conversation took place. The researcher seized the opportunity to provide teaching in response to questions asked by the participants. The fourth is the art of listening.

Research participants need a listener who is attentive but also able to keep silent in wisdom and deference to the experience being related. The researcher asked the questions, kept silent, and allowed the participants to ponder their responses and answer in their own time.

The discussions permitted the researcher to enter the *life world* of the participants. In seeking meaning, van Manen asserts that “any lived-experience description is an appropriate source for uncovering thematic aspects of the phenomenon it describes” (1990, p. 92).

Contemplation involved multiple, concurrent activities: mentally highlighting expressions of meaning while listening to the audiotapes and performing holistic and selective readings of the transcripts; identifying common words, metaphors, or statements; or poetic phrases tending to the meaning of words through the use of internet searches, etymologic sources and a thesaurus; writing and re-writing; and accessing literary works associated with the participants’ stories (McFadden, 2008). The contemplation period occurred over a 2 month period. The hermeneutical task was to interpret writing, a kind of alienated speech, back into meaning (Gadamer, 1996).

This study was based on interpretive phenomenology focusing on how people make meaning of their experience Phenomenologists often use literary sources (e.g., poetry, novels, stories, play) as case material and as textual resources for phenomenological writing to convey findings or create dramatic interpretation of the experience (van Manen, 1990). For the purpose of this interpretation, poetry was used as a technique through which to present findings to better hear and understand the experiences of African American women with mammography screening. Poems were constructed that emerged easily and flowed freely from the words of the participants (Kooken, Haase, & Russell, 2007).

Poetry reveals how persons make sense of and are influenced by their experiences (Hansen, 2004). Poetry draws the reader into the data and engages them emotionally to see the world in new ways (Richardson, 2000). Expressing emotions in research is compatible with African American cultural practices. Personal expressiveness, emotion, and empathy are highly valued qualities for conveying African American experiences (Banks-Wallace, 2000).

The data obtained from the interviews were transcribed, coded, and disseminated into classification tables. The data generated in the form of phenomenological text and poetry provided rich and thick descriptions of participants' experiences as they lived them. It is these very descriptions that "keep a phenomenon alive, illuminate its presence, accentuate its underlying meanings and enable the phenomenon to linger, retain its spirit, as near to its actual nature as possible" (Moustakas, 1994, p. 59), even though the event has passed. Journaling was used as a means of addressing personal assumptions and on-going self reflection by the researcher.

The words of African American women, when describing their experiences with mammography screening, were used as a means of interpreting a deeper understanding of the everyday experiences that may go otherwise unnoticed. Through contrived analysis of the interviews, which required listening to the tapes repeatedly and writing and rewriting the interview statements, content themes of: fear of fear, avoiding, unknowing, discriminating, and communicating emerged. It should be noted, that some of the words and or sentences are not grammatically correct, but are reported as spoken by the participants.

Characteristics of the Participants

The following is a description of the characteristics of the participants. All 13 of the participants (100%) met inclusion criteria of: self-identified as an African American woman, only had one mammogram, was between the ages of 25 and 55, had no previous or current diagnosis of breast cancer, could read, speak, and understand English, lived in Palm Beach County, and was willing to participate in this study.

The women all lived in West Palm Beach, Florida or the surrounding suburbs. The ages of the participants were as follows: seven women aged 41-50 (55%), four women aged 51-55 (30%), and two women aged 31-40 years (15%). Six of the participants were high school graduates (46%), three had some college (23%), three had some high school (23%), and one had a Master’s degree in Social Work (8%). Nine of the participants had health care coverage (69%).

The time elapsed since their last mammogram was greater than 3 years for ten of the participants (77%), 2 years for two participants (15%), and 1 year for one participant (8%). Seven of the participants performed monthly breast self examinations (54%) and six did not (46%). Of the participants who performed breast self examinations, six (46%) could not articulate or demonstrate the proper technique as outlined by the American Cancer Society. The response of the participants to having routine clinical breast exams, resulted in four of the participants having them (31%), while the other nine participants did not (69%).

Four of the participants had family members die of breast cancer (31%), while the other nine participants did not (69%).Nine of the participants were unfamiliar with the incidence of breast cancer in their families (69%), three were familiar (23%), and one was somewhat familiar (8%). Nine of the participants were unfamiliar with breast cancer risk factors (69%).

The participants identified sources they obtained health information as: television (15%), radio (4%), newspaper (8%), magazines (23%), and friend or relative (50%). Twelve of the participants (92%) were concerned about getting breast cancer and one participant (8%) only thinks about it.

Themes

The 13 participants provided rich descriptions of the feelings, emotions, frustrations, and the experiences with mammography screening. The overarching theme of this study was fear of fear. The common themes that emerged from this study were: avoiding, unknowing, discriminating and communicating. These themes illuminated the essence of the lived experience of the African American woman with mammography screening. The statements from the various participants illustrate and provide understanding for the themes identified in this study.

Fear of Fear

The participants in this study were candid, open and honest about their experiences with mammography screening. The fear of fear was a very profound theme. Fear is described as an unpleasant emotional state that occurs as a response to a real threat or danger (Anderzen-Carlsson, Kihlgren, Skeppner & Sorlie, 2007). Fear is considered a strong survival instinct, is particularly potent, and has a powerful effect on the mind. Fear does not have to be experienced, it can be imagined (Fiske, 2002).

Franklin D. Roosevelt in his first inaugural address (in 1933) said "So, first of all, let me assert my firm belief that the only thing we have to fear is fear itself—nameless, unreasoning, unjustified terror which paralyzes needed efforts to convert retreat into advance" (Roosevelt, 1938). The fear of being diagnosed with breast cancer was a paralyzing factor in the decision not to participate in continued mammography screening. The fears expressed could not be explained by the participants.

Amy expressed "I was called back two times for a repeat mammogram because they thought they saw something and that really scared me because I didn't want to lose my breasts." Dawn said, "Although my sister died of breast cancer at 47 years of age and I watched her pain and suffering, I just didn't have the courage to get another mammogram. I was just afraid." Evelyn expressed "being frightened by the experience." "Breast cancer is a death sentence and I haven't had any more mammograms because I was really afraid to find out," said Naomi.

Beth said, "I guess you can say that I have made a conscious decision to not participate---call it fear of fear." Georgie expressed, "Both my grand mom and mom had breast cancer and they both died."

Charlie said, "My sister was diagnosed with breast cancer and died 3 months later at 47 years old. I watched her die and I know that could be me too." Harriett expressed, "I haven't had any more mammograms because I am really afraid to find out. I don't think I could handle it and have a normal, healthy life." Joyce expressed, "My mother, cousin and aunt died of some type of cancer and my brother died of HIV. I’m scared to know that I have it too.”

Melinda stated,

> I have very large dense breasts. I was called back two times for a repeat mammogram because they thought they saw something. Each time no one ever shared with me exactly what they saw. I was so scared because I didn’t develop my breasts fully until I was 21 years old and I didn’t want to lose one or none.

Oprah expressed.

Avoiding

African American women may defer decisions regarding their own health to tend to the needs of other family members, especially their children. The role of perception is an important intervening psychosocial barrier for cancer prevention and control that affects decision-making (Guidry, Matthews-Juarez, & Copeland, 2003). The decision to participate in any type of health care program rests on the role of risk and how it will affect the family (Hopwood, 2000; Lawrence, Steiner, & Hazuda, et al., 2000). Some African American women experience the “Superwoman” syndrome (Wallace, 1978), giving little focus to their own health needs.

Naomi said, “What if I did have breast cancer, like my mom; would I have to fight the disease like she did to live? It’s probably best not to know rather than have to go through that kind of frustration.”

Harriett expressed, “Most of the black people at church or at my job that have had breast cancer have all died from it. I just want to live freely right now, so that’s why I haven’t had another mammogram.”

Fran said, “Why should I go looking for trouble? Sometimes it’s better to leave well enough alone, honey. My last mammogram was 5 years ago and it was negative.” Despite Amy expressing, “I’ve had a co-worker and a close friend that had breast cancer” She did not have a repeat mammogram but thanked the researcher for the reminder and information about the death rates.

Charlie expressed, “I had a mammogram at 40 years old and after my sister died. I just knew I had it too and surely didn’t want to confirm it with a mammogram.”

Dawn said,

> My mammogram experience was painful. As you can see I have small breasts and they were really squashed in that machine. I can’t really say that is the reason that I have not gone back. I have not had a repeat mammogram because I just haven’t made the time to do it. I have a very busy life with the kids so I would have to take time off from work. I know that African American women need to step up to the plate and take better care of themselves and I realize that I am not taking care of myself properly by not having yearly mammograms.

> Evelyn expressed the thought of having a mammogram was frightening because you hear so much talk about the pain and discomfort. It really wasn’t that bad, certainly not enough to say that’s what has kept me away all this time. In all honesty, I would have to say I have just been too lazy and too busy to pick up the phone and schedule it. I work two jobs. When I’m not working, I’m sleeping or in church. I guess I should do better, huh?

Fran said, “I didn’t feel getting another mammogram was necessary. I wasn’t feeling any lumps or having any problem or anything.”

Georgie expressed,

> When I went for my mammogram, I expected the worst but got the best. Why haven’t I been back for a repeat? Procrastination. Procrastination. Unfortunately, it’s not something I think about. I always take my kids to the doctor for yearly physicals and other visits in between. I take my animals to the vet, but yet I can sit here and say I don’t put myself in the mix. I prioritize everyone else’s schedules except my own. I guess I need to take some time out for me. When you are single mom, who is working every day, you don’t tend to put yourself first.

Joyce expressed the following,

> When I was 34 years old my doctor ordered a mammogram and I had a heck of a time getting approval from my insurance company because of my age. I fought with them so much and had to wind up paying for it myself. It was a horrible experience and I never wanted to go through that again. I know this may sound very silly.

Lilly decided “not to put herself through that again because the worst part of the experience was waiting and stressing for an extended time for the results.”

”Sometimes I think about cancer, but I think it’s okay to let it find me. I don’t think I really want to know if I have breast cancer” said Oprah.

Unknowing

Women in the United States are not properly informed about the benefits and risks of mammography and therefore are not able to make an educated decision about whether or not to have the breast cancer screening performed (Schwartz, 2000). Women participating in this study were no different, as reflected in the following statements.

Harriett stated,

> I had a mammogram at age 40 but was never told I needed to come back every year. I don’t have nobody in my family with breast cancer as I know of, so I didn’t think it was that big of a deal. No one has ever sat me down and told the information you told me today. Now I really don’t have an excuse since I got new information from you.

When I was told “you have very dense breasts and the pictures are sometimes hard to read I kept thinking to myself, she knows something and is just not telling me” Evelyn expressed.

Fran expressed, “I had a mammogram at 40 just because my doctor told me to. I wasn’t having any issues with my breasts.”

> Melinda said, I only had one mammogram because it was a requirement prior to me having breast implants three years ago. I haven’t had a repeat because I didn’t think I could get breast cancer with implants. I really haven’t given it much thought. My implant doctor never talked to me about continuing mammograms and I hardly ever go to other doctors. I would like to add that waiting for the mammogram results was more painful than the mammogram itself.

Lilly stated “I wasn’t provided with any information about the test, what to expect either during or after the mammogram.”

Naomi said,

> I was told I had dense breasts tissue and required to have a second

> exam. I really didn't understand what that meant but it didn't sound good. My older sister had breast cancer and I watched her suffer and her qualities of life deteriorate.

"I had to be called back for a second dose of radiation because some doctor didn't know how to read the x-rays properly. I'm sure I'm not the only person with large, thick breasts" expressed Oprah.

Discriminating

Discrimination has been shown as a major causal factor in health disparities, yet little is known about the relationship between perceived medical discrimination and cancer screening behaviors. In the context of this study, discriminating will be addressed as perceived discrimination. In health care today, the term "disparities" is seemingly being substituted or interchangeably used for the word discrimination.

The recent Institute of Medicine (IOM) report, Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care (IOM, 2002) defines a disparity as a difference in treatment provided to members of different racial (or ethnic) groups that is not justified by the underlying health conditions or treatment preferences of patients. Discrimination, when a provider supplies less to a member of a racial/ethnic minority than to an otherwise similar white patient, is part of a disparity. The motives behind discrimination could include prejudice, stereotypes, or, "rational" decisions by the provider to take the race/ethnicity of a patient into account in treatment decisions because of a different underlying disease prevalence or communication problems with minorities (IOM, 2002; Balsa & McGuire, 2003).

African American women have reported many encounters with insensitive health care providers (Kooken et al, 2008).) Many African American women perceive they are being treated with disrespect and receive inadequate explanations about screenings when they go to healthcare facilities. These experiences influence their decisions to skip mammograms. The issue is not whether these feelings are founded or unfounded, but they are perceptions that impact participation in breast cancer screening decisions (Peek, Sayad, & Markwardt, 2008).Some of the women in this study perceived "they were being treated differently."

Evelyn expressed watching the expression on the face of the girl who was doing the mammogram and how she seemed disturbed "because my breasts wouldn't stay up on the table. When the test was done, she made me sit in a cold room, still undressed, and then came back out to tell me we needed to repeat it."

Harriett said, "I had a very cold and callous person that did my exam. She put me in a cold waiting room and it seemed like I was treated as just one of the herd. It seemed unfair."

Lilly said,

> The nurse who did the exam was very mean and uncaring. She didn't talk to me and barely responded to the questions I asked her. I felt like an animal going to slaughter. I was told "just have a seat" with no further explanation. I really felt mistreated.

Beth stated,

> It seemed as if she banged my boobs around like crazy. I never wanted to experience anything like that again. I've talked to several friends who say they

> had similar experiences. Aren't there any nurses out there, who do mammograms, who look like us and would be more sensitive?

"The person, who did it, treated me differently. The facility was cold and so was she" Oprah expressed.

Communicating

One of the questions in this study asked participants if they were ever prompted by their primary care physician to have a mammogram. Only one of the 13 (92%) participants in this study was ever prompted by her primary care physician to have breast cancer screening and none of the participants indicated that there had been any discussion of breast cancer with their primary care physicians. A typical comment was, "When I go into his office, we barely have time to talk about the problem I came in there for let alone about breast cancer."

Doctor-patient communication is the primary process by which medical decision-making occurs and numerous studies have shown that the communicative features of the consultation (e.g., information exchange, shared decision-making) can influence outcomes. My primary care doctor told me to get a mammogram prescription from my gyn doctor even though I was in his office" said Amy. Provider recommendation is an important reason many women receive screening (O'Malley et al., 2001). "My implant doctor never told me anything about continuing mammograms" stated Melinda.

Lilly and Melinda attempted to ask questions of the mammography technician about the procedure, since it was their "first time," but they did not feel they received appropriate responses. "You have to sit in the waiting room so long before you are seen and then it’s as if he comes in ready to leave” said Harriett. Amy expressed that “No one told me how long I had to wait for the results, and the wait took years off my life.”

Chapter Summary

This phenomenological inquiry sought to describe the experiences of African American women with mammography screening and to provide an inductive description of the lived experience of the motivators and barriers to seeking mammography as perceived and comprehended by them. Utilizing van Manen’s interpretive inquiry interviews, transcription, journaling, and follow-up dialogue were considered in the hermeneutic process to explicate the essence of their lived experience to provide illuminated landscapes.

The overarching theme that evolved from the phenomenological process was fear of fear. The other themes were: avoiding, unknowing, discriminating, and communicating. The participants had the opportunity to review the transcripts and were in agreement that the phenomenological process was effective in uncovering their experience with mammography screening.

The barriers which precluded the participants, in this study, from continued participation in mammography screening were identified as recollection of previous experiences, family responsibilities, just not making time for self care, perceived mistreatment and/or discrimination, misinformation and/or lack of information, lack of knowledge, and overwhelming fear.

The potential motivators to increased participation in mammography screening were identified as: suggestions by family members to get screened, loss of family members to breast cancer, dissemination of culturally appropriate breast cancer information within the community, health care professionals who look like them, health care professionals who are culturally sensitive, and actually seeing African American breast cancer survivors in Palm Beach County.

The fear expressed, in this study, must be further evaluated and identified from an existential perspective. It must be understood that health beliefs of African Americans differ from those of Whites. These beliefs suggest a lower perceived susceptibility to cancer and a higher degree of perceived barriers for engaging in preventative health behaviors to reduce the risk of cancer (Lyna, McBride, Samsa & Pollack, 2002). It is important for the researcher to understand that the Health Belief Model, which is cited extensively in the breast cancer literature, was not designed and has not been adequately tested with African American women.

The cultural myth that breast cancer is a death sentence must be dispelled in the African American community. This can be by attacked by extensive community centered educational outreach programs featuring breast cancer survivors. Interventions and strategies for increased participation must include community groups like *Sojourner Truth,* a group of African American breast cancer survivors, located in Palm Beach County; and lectures and/or workshops in community churches, block parties, community barbeques; and community health fairs hosted by people who look like them, perhaps collaborative campaigns of the local chapters of the Black Nurses Association or the Negro Medical Association.

One strategy that has proven effective for this researcher has been to host Purple Teas during Breast Cancer Awareness month. This is a signature event of the American Cancer Society to stimulate awareness about breast cancer. This event is in conjunction with the Black Nurses Association of Palm Beach County. The event incorporates lectures/slide about breast cancer developed by the researcher, nutrition, talks by women who have survived breast cancer and those currently in treatment, dissemination of breast cancer information, and a question and answer session. The turnout has averaged 15 participants per event. If each person who attended the event would tell one other person about the importance of mammography screening then perhaps we can effect some change in morbidity outcomes.

It is the hope of the researcher this phenomenological inquiry will contribute to the advances in education of the health care community and stimulate researchers to develop some interventional strategies, based on the experiences of African American women with mammography screening, to increase screening behaviors.

CHAPTER V

DISCUSSION OF THE FINDINGS

A discussion of the findings of the phenomenological inquiry into the lived experience of African American women with mammography screening is presented in this chapter. This study was guided by the following research question. What is the lived experience of African-American women with mammography screening? The subquestions that contributed to this study were:

1. What are the barriers that preclude continued participation in mammography screening?
2. What are some strategies or interventions that can be used to increase continued participation in mammography screening?

The purpose of this study was to explore the lived experiences of African American women with mammography screening and to gain an understanding about their motivators for and/or barriers to seeking mammography as perceived and comprehended by them. van Manen’s (1990) six activities of hermeneutic phenomenological inquiry were used to guide this study, which aims towards illuminating details and seemingly trivial aspects within the experience that may be taken for granted with a goal of creating meaning and achieving a sense of understanding.

The philosophical underpinning of this study was that of social constructionism which uncovers ways in which individuals and groups participate in the creation of their perceived reality. This interpretivist framework of inquiry supports the ontological perspective of the belief in the existence of not just one reality, but of multiple realities that are constructed and can be altered by the knower. The words of African American women, when describing their experiences with mammography screening, have been depicted with the intent of health care professionals gaining a deeper understanding of their everyday experiences and developing appropriate plans of care.

This interpretive analysis is presented in three sections. The first section explores and integrates the themes that emerged from the interviews, correlates these themes with the published literature, and explicates the meanings uncovered through poetic expressions. The second section establishes a connection between the findings of this study and the theory of community empowerment as it relates to nursing. Finally, the third section discusses the strengths and limitations of the study, and nursing implications for education, practice, research, and public policy.

Interpretative Analysis of the Findings

Interpretive phenomenologists may use a variety of techniques to convey findings, such as metaphor, production of art, or a creation of a dramatic interpretation of the experience such as poetry. Phenomenologists often use literary sources (poetry, novels, stories, plays, etc.) as case material and as textual resources for phenomenological writing to convey findings or create dramatic interpretation of the experience (van Manen, 1990). The researcher used poetry as an interpretative means to convey the findings of the study to better hear and understand the experiences of African American women with mammography. Poems were constructed using the words extracted from interviews describing their experiences. Through the process of writing and rewriting the transcripts thematic poems emerged. The poems were free flowing and easy to construct from the dialogue. Poetry is an expressive way to examine meanings in life (Kooken, Haase, & Russell, 2007).

Poetry can be viewed as a vehicle through which to communicate powerful and multiple truths about the human experience. While poetry may not commonly be thought of as a source of knowledge, poems are powerful documents that possess the capacity to capture the contextual and psychological worlds of both poet and subject (Furman, Langer, Davis, Gallardo, & Shantif, 2007). Stein (2004) argued that poetry used in research, while not generalizable in a traditional sense, may be "metaphorically generalizable". While poems typically address the experience of one person, they have the capacity to sensitize readers to existential themes that are often shared by many people.

Richardson (1993) presents wonderfully crafted research poems utilizing the exact words of her participants, derived from traditional qualitative interviews as a means of exploring the lived experience of women in various life cycle transitions. Furman (2006) demonstrates how using different poetic forms in conjunction with traditional data analysis methods can lead to the development of data that are both highly consumable and emotionally evocative.

Expressing emotions in research is compatible with African American cultural practices. Personal expressiveness, emotion, and empathy are highly valued qualities for conveying African American life experiences. These qualities are closely linked with well-being, credibility, and concern (Banks-Wallace, 2000). African American literature has long been the venue for expression of both joy and sorrow. It is, as Gates (1988) described, "the textual outlet for the unnaturally suppressed inner lives" (p. xv) that African Americans have had to lead.

Fear of Fear

Fear is described as an unpleasant emotional state that occurs as a response to a real threat or danger (Anderzen-Carlsson, Kihlgren, Skeppner, & Sorlie, 2007). Fear is considered a strong survival instinct, is particularly potent, and has a powerful effect on the mind. Fear does not have to be experienced, it can be imagined (Fiske, 2002).

The fear expressed, by the participants seemed very real although they could not explain it. In an attempt to identify and more fully explore the theme of fear, as expressed by some of the participants, the researcher noted some visible facial expressive discomfort among the participants. In humans, facial fear is a reliable unconditioned stimulus whereby emotional response can be observed (Olsson & Phelps, 2007). With probing questions the participants expressed the following; “I’d just rather not talk about that, or “Nobody wants to think of dying or even know that you are” and “the thought of dying and leaving my kids was just overwhelming.”

There have been numerous studies in the nursing literature (Holt, Lukwago, & Kreuter, 2003; Kooken, Haase, & Russell, 2007; Matthews, Lannin, & Mitchell, 1994; Peek, Markwadt, & Sayad, 2008; Phillips et. al., 2001; Rojas et al., 1996; Russell, Swenson, & Skelton, 2003; Sadler et al., 2007), where fear is often identified as one of the continual barriers to mammography screening for African American women. However, the literature is deficient on its existential meaning. After an exhaustive search, using the key words fear, African American, African American women, breast cancer, mammography, and screening, the researcher was unable to locate a definition of fear as expressed in these studies.

One 2007 study found in the *International Journal of Pediatrics* described and addressed fear in the children with cancer. Anderzen-Carlsson, Kihlgren, Skeppner and Sorlie (2007) conducted a study to research fear in children with cancer. The main focus was to gain experience-based knowledge on how children with cancer express their fear and how nurse and physicians handle it and methods for alleviating fear in children with cancer.

The phenomenological hermeneutic study was conducted at a pediatric clinic of a university hospital in Sweden. The sample included 7 nurses and 3 physicians with more than 10 years of experience in pediatric oncology. Open interviews, which were audio taped and then transcribed verbatim, by an experienced secretary, were used to collect data. The themes of handling existential fear within the relationship and handling fear related to medical procedures emerged, which illuminated the underlying meaning. The participants discussed persuading children to enter a conversation about what frightens them in a gentle way. Being emotionally present and committed was expressed as a way for professionals to alleviate fear. Handling children's existential fear in the right way was described as listening to one's inner feelings. Naming the fears and expressions of those fears were identified as a way to confirm and legitimize them for the children. Making the unknown known by thoroughly informing the children about what is going to happen, how it is going to happen, and how it might feel fosters adherence to treatment plans for the children and their parents.

The authors conclude, in the case of the children's fear it is important to establish a good relationship and initiate a communication bond. The fear related to medical procedures is often intertwined with the pain, or the fear of pain, and that is not easy to separate these expressions. It is difficult for a child to explain what causes the fear, in a situation that could be frightening in itself. It is interesting to note the study recommends identifying, confirming, and legitimizing fears in order to confront them. The results reported from Anderzen-Carlsson et al.'s (2007) pediatric study have significant relevance and applicability to the adult population in this research study as well. The issues addressed in that study are the same as those that were raised in the researcher's study and have application to other groups. In the present study,

> Harriett expressed, "If you don't get a mammogram and get cancer you are going to die, and if you do get a mammogram and have cancer you are going to die anyway, so what's the point?"

Similarly, Evelyn was frightened to have her first mammogram because of the pain and discomfort she heard about. Further, in an attempt to confront the fears expressed during the interviews, two of the participants became very uncomfortable and asked that "we not talk about that."

Cultural attitudes and beliefs, such as cancer fear and the concept of cancer fatalism have been identified as barriers to participation in mammogram utilization and treatment among African Americans (Gates, Lackey, & Brown, 2001; Guidry, Matthews-Juarez, & Copeland 2003; Phillips, Cohen, & Moses, 1999).

Cancer fatalism is the belief that death is inevitable when cancer is present. It is viewed as a situational manifestation of fatalism in which individuals may feel powerless in the face of cancer and may view a diagnosis of cancer as a struggle against insurmountable odds (Powe & Finnie, 2003).

In 1980, the exemplar study sponsored by the American Cancer Society and conducted by EVAXX, Inc., a Black-owned evaluation organization, was critical in documenting the view of cancer as a death sentence. The study was based on personal, in- home interviews, conducted by African American interviewers. The nationwide sample consisted of 750 African American men and women, 18 years old and older. Interviewing for this study was carried out between June 2 and July 4, 1980. This study further highlighted many of the glaring disparities between African Americans and Caucasians with regard to cancer knowledge and health behaviors. For example, the report found that African Americans underestimated the prevalence of cancer and think of it an illness of Caucasian people; were pessimistic about its cure and believed that even with early detection, there is not much chance or no chance at all of surviving cancer; were less knowledgeable about cancer and 77% felt that cancer was a death sentence. Sixty nine percent of the participants thought they were not likely to get cancer compared to Caucasians. Only 30% of the women participants heard of mammographic examinations for breast cancer. Forty one percent were less knowledgeable about cancer’s warning signals and are less apt to see a doctor if they experience symptoms. Fifty-one percent believed that surgery can expose cancer to the air and cause the spread of cancer. The participants in this study reported they belonged to various groups and organizations where they would welcome cancer education programs. Sadly, many of these same factors continue to highlight the disparities in cancer care for some African Americans in 2009.

There is a paucity of research investigating the root causes of this fear and exploring which phenomena contribute to the sense of cancer fatalism in this population

(Peek, Sayad, & Markwardt, 2008). Cancer fatalism may be modified through culturally relevant interventions (Powe & Finnie, 2003).

This fear or sense of fatalism was demonstrated in the following statements by the participants: “the fear of having breast cancer was overwhelming,” “even though my baby sister died of breast cancer, I guess you can say I have made a conscious decision not to have another mammogram, call it fear of fear,” “the whole experience was frightening,” most of the Black people, at church or on my job, that have had breast cancer have died from it,” and “it’s very scary.”

The following poem written by the researcher uses the participants’ own voices to illustrate the deep sense of fear expressed by the study participants.

Fear

My sister had breast cancer yes I know
That’s all the more reason, I just didn’t go.
Pain, suffering, and loss of autonomy
I didn’t want to deal with it truthfully.
My sister died and I should know better
But fear of fear is really what matters.
The fear is intense; it takes my breath away,
It’s felt deep in my soul, I can truly say.

The intense fear of knowing the outcome of breast health activities still pervades the African American community (Underwood et al., 2005). The participants’ voices about fear are resonant in the quote of

> You gain strength, courage, and confidence by every experience in which you really stop to look fear in the face. The danger lies in refusing to face the fear, in not daring to come to grips with it. If you fail anywhere along the line, it will take away your confidence. You must do the thing which you think you cannot do.
>
> Eleanor Roosevelt (1961, p. 67).

Avoiding

The natural world gives human beings many reasons to undertake certain activities and avoid others. People want to avoid pain and suffering (Bromberg, 2004). Avoidance is a simple way of avoiding having to face uncomfortable situations, things or activities. Avoidance may include removing oneself physically from as situation or finding ways not to discuss or even think about the topic in question. Procrastination is a form of avoidance where things are put off until tomorrow or another day. Avoidance behaviors are difficult to get rid of (Straker, 2002).

African American women may defer decisions regarding their own health to tend to the needs of other family members, especially their children. The role of perception is an important intervening psychosocial barrier for cancer prevention and control that affects decision-making (Guidry, Matthews-Juarez, & Copeland, 2003). The decision to participate in any type of health care program rests on the role of risk and how it will affect the family (Hopwood, 2000; Lawrence et al., 2000). Beth said “I guess you can say that I have made a conscious decision to not participate in mammography screening.” It is also important to note the initiation of health-seeking behaviors for prevention and illness is related to the individual’s cultural belief system. The cultural milieu from which these psychosocial issues arise affects the choices that African American women make and their level of participation in breast cancer screening programs (Matthews, 2000).

Gates, Lackey, and Brown (2001) were intrigued with the contribution of caring for others behaviors that influenced the delay of African American women to seek prompt diagnosis and treatment for breast cancer. They engaged in an ethnographic research study to investigate these caring behaviors. Caring behaviors were described as demands and responsibilities related to caring for others in the family or extended social network.

Thirteen African American women were purposefully selected from two oncology clinics in the mid-South. Audio-taped ethnographic interviews, observations at informant-selected sites, field notes, and snapshots of caring taken by the women where caring occurred were analyzed using Leininger’s phases of ethnographic analysis. The inclusion criteria included: age 30-75 years, able to speak and understand English, and first-time diagnosis of breast cancer. Within 3 to 6 months of that diagnosis, participants received at least one of the following treatments: surgery, chemotherapy, or radiation. Two consent forms were used: one for participation and one for use of snapshots. The mean age of the participants was 45.2 years. The participants were given a $50.00 stipend. The participants described caring for others as a way of being; a philosophy based on spiritual upbringing, a tradition in the family one was expected to do. Ironically a theme of noncaring emerged. Their responses demonstrated that it was “not caring” behaviors of self and others, especially healthcare providers, which were more likely to contribute to delay in seeking treatment. Some of the women were apologetic for not caring enough about themselves to have disregarded something as important as follow-up care.

Some of the same sentiments documented in the Gates et al. (2001) study were documented in this research study by the following words of the participants. “I just haven’t had a mammogram because I just haven’t made the time to do it. I’m very busy with my kids and I really can’t take time off from work,” expressed Dawn.

Georgie said,

> Having a mammogram is not something I think about. I always take my kids to the doctors for yearly physicals and other visits in between. I take my animals to the vet, but yet I can sit here and say that I don’t put myself in the mix.

African American women juggle a host of responsibilities. They manage careers, raise children, contribute to society, but more importantly, take care of extended family members (Coker, 2004). In order to understand the cultural context of African American women, researchers must recognize that extended families are ones in which mothers, fathers, aunts, uncles, grandmothers, grandfathers, brothers, sisters, cousins, godmothers, godfathers, and church family play an important role when defining family and taking care of one’s own personal health. This intergenerational living and responsibility is not prevalent in White families. Beginning in the 1960s, White families experienced significant declines in intergenerational living and associations (Brown University, 2004).

Some African American women experience the “Superwoman “syndrome (Wallace, 1978), giving little focus to their own health needs. The stereotype of being a Superwoman has been a controlling image (Collins, 1991) many African American women have been socialized to perpetuate. African American women are often expected (by others and by themselves) to endure all, manage all, and be strong without complaint.

There are legitimate historical reasons that many African American women possess “Superwoman” attitudes and behaviors. The effects of slavery were particularly brutal for African American women and they had to develop strong survival skills in order to endure unspeakable trauma. The image of the self-sacrificing family matriarch is still embedded in the minds and hearts of many African American women who see their role as keepers of culture, community, and family (Coker, 2002). There is the myth of the “strong, Black woman” (Beauboeuf-Lafontantant, 2005) that has been reinforced within the African American culture. This myth portrays the Black woman as a superhuman being who can overcome any encounter and survive any emotion, all without the support of anyone. The strong Black woman never needs assistance of any kind. The following poem reflects the sense of avoidance.

BUSY BEE

I care for the kids, but not for me
Make time for a mammogram that I just can’t see;
There’s dinner, homework and lots of sports
By the time I finish all that I’m all out of sorts.
I should schedule a mammogram I’m 5 yrs late
When I finish this interview I promise to schedule a date.

Thomas (2006) ascertained, in her study, socioeconomic factors, cultural barriers, and access to care contribute only partially to the avoidance of breast cancer screening by African American women. The purpose of that study was to gain insight and a better understanding of barriers to breast cancer screening that have not been previously identified in the literature. A qualitative, exploratory study was used to generate data. Twelve professional African American women participated in that study. Inclusion criteria were: 40-64 years of age, with at least an associate’s degree in any discipline, health insurance, and no history of breast cancer. A diverse sample of middle income women was obtained by mailing and personally delivering recruitment flyers to local hospitals, secondary and post-secondary schools, and through word-of-mouth referrals. The median age of the participants was 56 years. One participant had an associate’s degree, 7 had bachelor’s degrees, 2 had master’s degrees, and 2 had doctoral degrees. Face to-face interviews and individual narratives provided the data for that study. Establishing qualitative rigor involved member checking and peer debriefing.

Two core themes emerged from Thomas’s data analysis: *silence* and *societal contradictions*. Silence and secrecy were threads woven throughout all of the women’s stories about their breast and breast cancer screening experiences. One woman described her experience of unintentionally “discovering a family secret that was very frightening” to her. She was 7 years old when she saw her grandmother washing up at the sink and saw that she only had one breast.

> I started screaming because I was so afraid of her breasts. It looked like someone had tore off her breast and it had started to grow back. It was all jagged and raw looking. It was so scary. I woke everyone up with my crying and screaming. I could not talk and all the adults were whispering to each other. I really became afraid to go to my grandmother’s house after that experience. No one in my

> family ever talked about my grandmother’s cancer or her breast surgery. No one explained to me what had happened to her until I was in my 20.

Societal contradictions was used to describe the spoken, tacit, and underlying mixed messages that are sent to women from a variety of sources such as the media, parents, peers, male partners, the health care system, and Western society in general. One participant shared, “This society is so focused on youth and that [youth] being equated with beauty and all the rest of that. The sagging breasts are just kind of like the last straw; everything is going south.” In addition, another participant shared, “Society tells us that the bigger the breast, the sexier you are.” The participants agreed that the messages from society play a significant role in women’s self-identity. “Breast cancer threatens this self-perception” (Wilmont, 2001, p.283).

Twentieth century anthropologist, Margaret Mead’s study of various cultures led her to conclude, “Breasts are so idealized in American society that they are the primary source of female identity” (Mead, 1949 in U.S. DHHS, 1984, p.108).

Many women who have survived breast cancer admitted to avoiding mammograms and follow-up examinations for fear of losing their breasts. The message about women’s breasts in advertising and culture has been extremely powerful. Many women who lose a breast feel a loss of identity and self-worth because of these societal expectations (Rosenbaum & Ross, 2000). The participants recognized that society, through messages communicated in the media and advertising industry, have conditioned women to believe that having large breasts is a sign of womanhood (Thomas, 2006). These findings were validated in the researcher’s study when Joyce said “I didn’t develop my breasts fully until I was 21 years old and I didn’t want to lose one or none.”

Unknowing

During the second interview when the theme of unknowing emerged, participants were asked if their church had a wellness ministry. Nine out of the 13 said “no.” Many of the larger African American churches have wellness ministries to nurture the physical and financial health of the church community. Many health-related topics are presented on a continuum. Unfortunately, the smaller, local community churches do not have the membership, leadership, or resources to support such efforts.

Women in the United States are not properly informed about the benefits and risks of mammography and therefore are not able to make an educated decision about whether or not to have the breast cancer screening performed. The authors concluded that most women are unaware that screening can detect cancers that may never progress but think that such information would be relevant (Schwartz, 2000). Women participating in this study were no different, stating the following: “I just didn’t know about the breast cancer problem with Black women because nobody ever talked to me about it, or do I ever hear other people talking about it.” “The only time I really hear a lot about breast cancer is during Breast Cancer Month and I never see Black women.” “How are you supposed to find out this information?” “I only had a mammogram because my older sister told me I should get one.”

There is much more misinformation about mammography in the minority community and it is important for researchers to undo current knowledge and teach/re-teach accepted truths. Naomi said, “breast cancer was a death sentence.” Three participants were called back for repeat mammograms and “feared that too much radiation would cause breast cancer if it wasn’t already there or make it worse.” In the

African American culture pain is often times associated with illness. When you are ill you then seek medical care or advice. Charlie expressed that she “wasn’t having any pain or discomfort or anything” as a reason for no repeat mammogram. Despite the availability of credible, factual information about breast cancer, there continues to be an abundance of misperceptions about the disease that may potentially influence a woman’s decisions about breast cancer screening and treatment.

Powe et al. (2005) conducted a study to evaluate the perceptions of African American women (N=179) about breast cancer at primary care centers. The study was guided by the Patient/Provider/System Model for cancer screening. Data were collected using Breast Cancer Perceptions and Knowledge Survey and a demographic questionnaire. The average age of the women was 34 years with an average educational level of 12 years. Breast cancer pamphlets were evaluated for readability and the extent they challenged misperceptions. They reported African American women’s perception that cancerous lumps in the breast would be painful. Reasons for this perception are unclear but could be rooted in the fact that breast cancer is often diagnosed in advanced stages of the disease and pain is more likely to occur in the later stages of the disease. So it could be over time as women view others in their family and community with cancer experience pain, they begin to subconsciously associate the disease with pain, regardless of the stage.

There was recurrent mention of “dense breasts” in this study. For example, one participant commented, “I had to go back two times for repeat mammograms and all they kept telling me was I have dense breasts and this is what happens sometimes, but nobody bothered to explain to me what dense breasts meant.”

Boyd et al.(2007) published a study in the New England Journal of Medicine examined the association of the measured percentage of breast density in the baseline mammogram with risk of breast cancer, according to method of cancer detection, time since the initiation of screening, and age. They carried out three nested case-control studied in screened populations with 1112 matched case-control pairs. The selected characteristic of the case patients and control subjects were: earlier age at menarche, later age at first birth, nulliparity, a smaller number of live births, later age at menopause, a family history of breast cancer, and use of hormone therapy They reported that women with extensive breast density are about five times more likely to develop breast cancer than those with more lucent, fattier breasts. Two-thirds of pre-menopausal women and a quarter of women 50 and over have dense breasts, defined as 75 % cloudiness on a mammogram. In addition to being harder to image, dense breast tissue also appears to be more biologically active and susceptible to malignancy. Density may mask nonpalpable cancers presenting on mammography as a mass or architectural distortion, or calcifications, which are present in 40% of cancers.

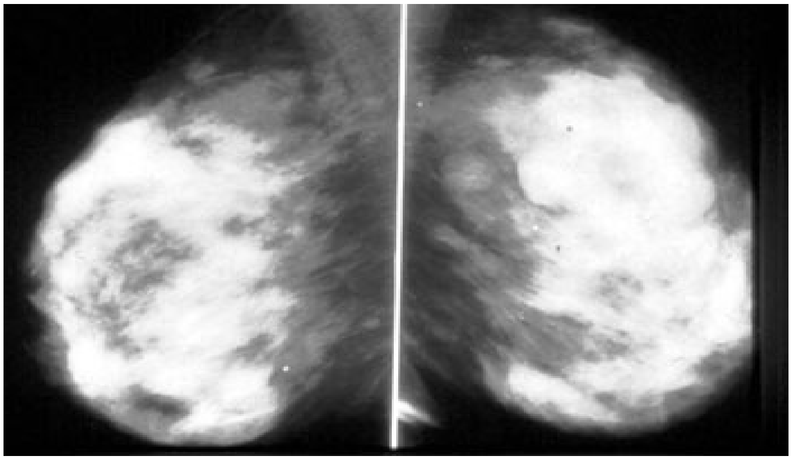
These results further suggest that annual screening examinations in women with extensive mammographic density are not likely to increase the rate of detection of cancers; attention should be directed to the development and evaluation of alternative imaging techniques for such women. Digital mammography, ultrasonography, and magnetic resonance imaging may increase the detection of cancer in women who have extensive mammographic density and in whom the risk of breast cancer, detected at screening and between screening examinations, is greatest. Woodward (2004) reports

African American women had a 40% increase in breast density compared to White or Asian women.

delCarmenet al. (2007) reported differences in mammographic breast density among African American women appeared to be differences in body mass index (BMI), bra size, or cup size. The National Institutes of Health (NIH) definitions of BMI and weight categories were used. According to the NIH (2005) underweight is defined as a BMI of 18.5 kg/m2 or less; normal, as 18.6–24.9 kg/m2; overweight, as 25–29.9 kg/m2; and obesity, as 30 kg/m2 or greater. Women who have mammographic densities in 60%-75% of their breast tissue have a four-to six-fold increase in breast cancer risk compared with women with low density readings, as documented in a number of reviews (Boyd,et al., 1998; Byrne, 1997; Oza & Boyd, 1993).

Mandelson et al. (2000) have recently reported that the sensitivity of mammography screening was significantly compromised (30% vs. 80%) in women with extremely dense breasts compared with women whose breasts were predominantly fatty. They further demonstrated that the risk of a diagnosis of an interval cancer (cancer occurring between regular screenings) was more than six times higher (odds ratio [OR] 6.14, 95% confidence interval [CI] 1.95-19.4) in women with extremely dense breasts than in women with low density breasts. Results from this study in which a large number of African American women were included (n = 883) showed a race difference in breast density among women aged 65 years and younger after controlling for potential confounders. If the greater prevalence of high risk patterns among younger African American compared with younger White women is confirmed in other investigations using standardized methodology and controlling for potential confounders (likely negative confounders), breast density may play a role in the higher incidence of breast cancer observed in young African American women. Furthermore, a higher prevalence of very dense breasts in young African American women could also complicate the reading of their mammograms, contributing to a delay in diagnosis and more advanced stage at diagnosis (El-Bastawissi , White , Mandelson , & Taplin., 2001). None of the participants, in this study who were told they had dense breasts, were offered alternatives to regular mammography.

Digital mammography is more sensitive in women younger than 50 years, pre- or perimenopausal women, and women with radiographically dense breasts according to an article published in the American Family Physician (2007). Because mammography is less sensitive and breast tissue is more dense in younger women, ultrasonography has been considered as a screening tool for younger women who are at high risk for breast cancer (Knutson & Steiner, 2007).



Dense breast tissue appears white on digitized mammography, while fatty tissue appears as black. Photo Courtesy of Dr. Connie Lehman (2004) Fred Hutchinson Cancer Research Center

Figure 6. Digitized mammography of dense breast tissue.

Is that something I should know or see?
I had to come back for repeat mammograms times three
All because of this breast density.

Some women in this study, particularly, Charlie and Naomi discussed knowing family members and friends who died of breast cancer, but unfortunately were not aware of any African American breast cancer survivors. In Palm Beach County there is an African American breast cancer survivor group called *Sojourner Truth*. This group formed independently of the American Cancer Society due to perceived injustices towards African American women with breast cancer. The founders of this group cited non-adherence, by the American Cancer Society, to their own policies and procedures for women of color newly diagnosed with breast cancer. The group is very active, highly visible in the community, and nationally known.

Cancer is “family business” and “kept a secret” in most African American families, as eloquently expressed by Beth. Many Americans of color are reluctant to reveal information about their family health histories, even to their closest loved ones (Shabazz, 2002). A city council member in Houston, Texas was almost on his death bed before he admitted that he had cancer. It was said that he did not want people to vote him out of office so he never told them. When he died from the disease; the perception, within the African American community was that he was recently diagnosed and succumbed quickly, leaving a negative impact (Jones, 2008).

Silence about cancer is an issue in the African American community. Several studies have noted silence about cancer as a factor the lack of early cancer screening behaviors and lack of social support within the African American community (Ashing-

Giwa etal., 2004; Lopez et al., 2005; Phillips et al., 2001; Thomas, 2004). The poet Audre Lorde (1985) who lost her life to metastasis of her breast cancer to the liver, wrote, "Your silence will not protect you and silence is a tool for separation and powerlessness" (p.10). Perhaps most crucially, Lorde realized through the experience of her breast cancer diagnosis, surgery, and remission, the necessity of visibility and voice. Seeing silence as a tool for separation and powerlessness, she understood the important function of her writing not only to free herself of the burden of the experience but also to share her experiences so that others might learn. Survival, she wrote, is only part of the task; the other part is teaching. The unknowing expressed, by the participants was captured in their voices in the following poem.

Just didn't know
All I can say is that I just didn't know
Trust me if I did, do you think I just wouldn't go?
No, my church doesn't have a wellness ministry
I definitely would attend, especially if it were free.
Secrets in our family
We keep a lot of secrets in our family Yea that I see
Grandmom, Mommy, and my uncle make three
Who probably checked out of this life prematurely?
Without Breast Self Exam and mammography,
Breast cancer could really be the death of me.

Discriminating

Discrimination has been shown as a major causal factor in health disparities, yet little is known about the relationship between perceived medical discrimination and cancer screening behaviors. In the context of this study, discriminating will be addressed as perceived discrimination.

African American women have reported many encounters with insensitive health care providers (Kooken et al, 2008). Peek, Sayad, and Markwardt, (2008) reported many African American women perceive they are being treated with disrespect and receive inadequate explanations about screenings when they go to healthcare facilities. These experiences influence their decisions to skip mammograms. The findings were based on feedback gathered during focus groups that included 29 low-income African American women who were at least 40 years of age. The women were asked about their perception of mammograms and whether they would undergo one to screen for breast cancer. Despite recommendations for women to have annual mammograms, only 55% of the women reported having a mammogram within the last 2 years.

Crawley, Ahn, and Winkleby (2008) examined whether perceived medical discrimination was associated with lowered screening rates for breast cancer among racial and ethnic minority adults Californians. The respondents were 40-75 years of age. More than half had at least some college education, about 85% had health insurance, and more than 90% reported a usual source of care. About 60% of the women reported having a mammogram within the past year. Pooled cross-sectional data from the 2003 and 2005 California Health Interview Survey were examined for screening trends among African American, American Indian/Alaskan Native, Asian, and Latino adults reporting perceived medical discrimination compared with those not reporting discrimination (n=8,051). The responses showed that 9% of the women perceived medical discrimination. The findings suggests, based on racial or ethnic based experiences, 48% of the women perceiving medical discrimination were less likely to be screened for breast cancer compared with women not perceiving discrimination. The study reported a significant association between perceived racial or ethnic-based medical discrimination and cancer screening behaviors; findings that have serious implications for cancer health disparities.

In his classic study of the role of race in American life, Gunnar Myrdal (1944, p.21) noted, “area for area, class for class, Negroes cannot get the same advantages in the way of prevention and care of disease that whites can” (p.10). The 1985 Report of the Secretary’s Task Force on Black and Minority Health concluded that “despite the unprecedented explosion of scientific knowledge and the phenomenal capacity of medicine to diagnose, treat and cure disease, Blacks, Hispanics, native American, and those of Asian/Pacific Islander heritage have not benefited fully from the fruits of science or from systems responsible for translating and using health sciences technology” (p.22).

Smedley, Stith and Nelson (2003) in a report titled *Unequal Treatment in American Health Care*, expressed concern that racial and ethnic discrimination may play a major role in health-care disparities. They reported health care provider bias - conscious or unconscious, individual or institutional and that research indicated that U.S. racial and ethnic minorities are less likely to receive even routine medical procedures and experience a lower quality of health services. The findings suggest that "some persons may delay or avoid getting screened for cancers and that this delay may be associated with racial or ethnic-based experiences they encounter within the medical settings” (p.

722). As contributors to the Institute of Medicine report, Smedley et al. (2003) showed credible evidence that physicians made fewer referrals for clinical services for individuals in racial, ethnic, and minority groups.

Participants in this study expressed *“I never wanted to experience anything like that again, the nurse was very mean.”* “I told her this was my first time and she didn’t seem to care.” “Sit down, get undressed, stand here, wait here, get dressed, were almost like commands you would give a dog.” “She treated me differently.”

Understanding cultural perspectives is important to decrease the possibility of unintentional discrimination, also known as *disparate impact*, where there appears to be no intent of discrimination, but nonetheless the results of behavior are similar to intentions of discrimination (Institute of Medicine, 2003) and may contribute to refusal to participate in preventative screening measures. Culture is a very important variable to consider in rendering care and advisement to African American women and must be strongly considered to increase participation in and adherence to mammography screening.

Medical Mistreatment

She handed me a gown, instructed me to get undressed and sit down,
All of this with such a frown.
The room was very cold, I felt scared and alone,
Although there were others there talking on their phones.
I was sitting there thinking how soon, how soon,
when finally she came out and escorted me to the mammogram room.
This is my first time with mammography, so why isn’t she talking to me?

My breast were flipped and flopped just like a fish, and I kept saying “I can’t even
believe this.”
OK we’re done, now go sit back in that room,
I knew I had cancer by her look of gloom.
You can get dressed now we’ll be in touch, you doctor will call.
Thank you very much.

Communicating

One of the questions in this study asked participants if they were ever prompted by their primary care physician to have a mammogram. Only one of the 13 (7.6%) participants in this study was ever prompted by her primary care physician to have breast cancer screening nor did any participant indicate that there had been any discussion of breast cancer with her primary care physician. “When I go into his office, we barely have time to talk about the problem I came in there for let alone talk about breast cancer.”

Doctor-patient communication is the primary process by which medical decision-making occurs and numerous studies have shown that the communicative features of the consultation (e.g., information exchange, shared decision-making) can influence outcomes. Provider recommendation is an important reason many women receive screening (O’Malley et al., 2001). Nutting et al. (2002) reported multiple competing demands of the busy office visit have been shown to interfere with delivery of preventive services. One hundred eighty physicians in the Ambulatory Sentinel Practice Network (ASPN) completed a questionnaire describing their knowledge, attitudes, and beliefs about screening mammography. They also described the content of a series of nonacute care visits with women aged 40 to 75 years with regard to making a recommendation when the patient was due for screening mammography. The data were linked, and univariate and multivariate logistic regression methods were used to examine the relative importance of physician, patient, and visit characteristics on making a recommendation for mammography. Ninety-three physicians reported making a recommendation for screening mammography on 53.1% of nonacute visits. The authors concluded effective strategies must consider the multiple competing demands faced by patients and physicians during each office visit and seek ways for assisting them in setting rational priorities for services.

Sabatino et al. (2006) examined the association between breast cancer risk factors and provider recommendation for mammography. A cross-sectional study was conducted using the 2000 National Health Interview Survey. In all, 1673 women ages 40 to 75 years without cancer who had seen a health care provider in the prior year and had no mammograms within 2 years were included in study. Breast cancer risk was assessed by Gail score and risk factors. These scores estimate risk of developing breast cancer within 5 years based on age, age at menarche, age at first birth, number of benign breast biopsies, and number of first-degree relatives with breast cancer. Multivariable logistic regression adjusted for age, race and illness burden examined the association between risk and reported recommendation for mammography within 1 year for all women. Approximately 70% of recently unscreened women seen by a health care provider in the prior year reported no recommendation for mammography, regardless of breast cancer risk. They also detected increased reported recommendations among northeastern women compared with southern women. Increasing reported recommendation rates may represent an opportunity to increase screening participation among recently unscreened women, especially for African American women.

Fowler (2006) conducted a qualitative, grounded theory study to investigate how African American women aged 50 years and older of different socioeconomic status make decisions about mammography screening. Sixteen African American women were recruited from two large Baptist churches. Participants were included if they met the following criteria: aged 50 years or older with no prior diagnosis of breast cancer, no mammography screening in the previous 2 years, willingness to participate in two audio taped interviews, and a total household income based on 100% of the federal poverty level. Women received a $40 gift certificate to local stores to participate. Data were obtained from a semi-structured interview guide. The median household income was $14,260 for four people. Half of the group was retired or on medical disability. Some women reported completion of college credits. The theme "claiming health" emerged. The purpose of claiming health was to control the right to make one's own decisions about health and mammography screening. Claiming health was embedded in the social contexts of cultural heritage and learned kinship values and prior negative experiences with healthcare professionals and systems. More than half (60%) of the women stated that negative attributes of male physicians had influenced their use of healthcare services. The attributes such as aloofness, arrogance, a hurried manner, impatience, and lack of cultural sensitivity had a negative impact on how women interpreted information. Claiming health was ground in skepticism, and some women declined mammography screening because they needed additional information and felt powerless when interacting with healthcare professionals.

Provider recommendation for mammography is an important reason many women undergo screening.”My implant doctor never talked to me about continuing mammograms” stated Melinda. Physicians are perceived as less informative and use less supportive communication when interacting with nonWhite than with White patients. Harriett stated, “I had a mammogram at age 40 but was never told I needed to come back every year.” Racial disparities in health care may stem, in part, from problems in doctor-patient communication (Gordon, Street, Sharf, & Souchek, 2006).

African American breast cancer survivors have historically received less information and fewer opportunities to participate in decision making during medical appointments. Royak-Schaler et al. (2002) investigated patient-physician communication from the patient’s perspective in a study about guidelines and sources of information used in developing survivorship care and preferred avenues for information delivery to African American breast cancer survivors. Thirty nine African American breast cancer survivors with a mean age of 55 were recruited for that study. More than 90% reported a lack of specific recommendations from healthcare providers for reducing their risk of cancer recurrence, highlighting a missed opportunity to develop feasible plans of ongoing care and promote long-term health. The gap in scientific understanding about the patient-physician communication process and the limited dissemination of evidence-based guidelines by health care providers has been identified by the Institute of Medicine (IOM) in its report, *From Cancer Patient to Cancer Survivor: Lost in Transition* (Hewitt, Greenfield, & Stovall, 2006).

According to Katz, Jacobson, Veledar, and Kripalani (2007) patients with lower literacy levels tend to ask fewer questions and make fewer requests for information or additional services and, therefore, may understand less about their medical conditions and treatments. The participants in this study were not documented to be of lower literacy levels, but yet felt intimidated and rushed in physician offices. Lilly and Melinda attempted to ask questions of the mammography technician about the procedure, since it was their “first time,” but they did not feel they received appropriate responses. Many of them were unaware that their primary doctor knew anything about mammograms making statements such as, “I had no idea that he even knew anything about mammograms.” Amy said “My primary care doctor told me I would have to get the mammogram prescription from my gynecologist when I discussed it with him.”

African Americans are more likely to face difficulties other than communication difficulties that affect their health care (e.g., limited health literacy, and perceived discrimination in medical settings). African Americans also reported shorter office visits and lower visit satisfaction with physicians who are of other races (Cooper et al., 2003). “I feel so rushed when I go to see my doctor.” “You have to sit in the waiting room so long before you are seen and then it‘s as if he comes in ready to leave.” said Harriett. The following poem expresses the sentiment of the participants regarding primary care visits.

Primary Care Visit

When I go to the Doctor, it’s not me he sees
All he wants is my brief history.
He’s in and out with no time to spare
Sometimes I wonder if he really does care.
It’s like wham, bam, Thank you Maam.

The poems written in this study are representative expressions of the fears, frustrations, and barriers experienced by the African American women participants with mammography screening. The non-verbal communications witnessed during the interview process, even though they cannot be captured in writing, were influential in the transcription of the expression of their experiences. There was a tremendous amount of dialogue that went forth between the researcher and participants in such a short amount of time (an hour or less). The conversations were bi-directional and respondents often asked questions of the researcher for things they “just didn’t know.” During the process of listening to the tapes over and over again, writing and re-writing the data, and visualizing expressions and gestures during the interview process, there was a resonance of *powerlessness.* “I just didn’t know” was a theme identified from the participants in this study, but “knowledge is power” as expressed by Sir Francis Bacon (1597; as cited in Kurtz, 2009). The phrase implies that with knowledge or education one's potential or abilities in life will certainly increase. Bacon, saw himself, as the inventor of a method which would kindle of light in nature- “a light that would eventually disclose and bring into sight all that is most hidden and secret in the universe.” This method involved the collection of data, their judicious interpretation, primarily through the carrying out of an experiment, thus learning the secrets of nature by organized observations of its regularities.

Fear results in powerlessness and can cause psychological distress, which in turn affects health outcomes (Burns, 2008). In the mammography environment, the participants were told “to sit down, get undressed, get dressed, and wait here” resulting in a loss of personal control secondary to uncaring and perceived medical discrimination.

This too is an expression of powerlessness. The “professional power” (Parsons, 1985) exerted by the “rushed” physician at time of office visits results in powerlessness of the patient. Talcott Parsons was the first social scientist to theorize the doctor-patient relationship, and his functionalist, role-based approach defined analysis of the doctor-patient relationship for the next two decades. He developed a conceptual model that attempted to organize the individual’s experience of the sick role. The participants in this study expressed how rushed their primary care physician was at the time of their evaluation and indicated that they were unaware that he knew anything about mammograms. In one instance, Amy was referred to her gynecology doctor for a mammogram prescription by her primary care physician. The participants go in seeking care and are placed in vulnerable situations by the role of the physician, therefore, perceive themselves to be intimidated or powerless over the situation. The fact that some of the participants expressed “I just don’t make time for me” demonstrates a loss of autonomy in caring for one’s self to render care to others, resulting in feelings of powerlessness. “What you don’t know can’t hurt you” is tied into the power of fear, which in turn manifests as powerlessness.

Powerlessness is a social phenomenon that is deeply rooted in social systems and the disempowering practices that originate in that system (Perkins & Zimmerman, 1995). It is the social systems, which are intended to solve social problems that produce the powerlessness of the people in need of their services. What all situations of powerlessness have in common is the personal psychological experience of loss of control, which every human can identify with emotionally. Powerless people expect a lack of connection between their behavior and desirable outcomes, and defend themselves by means of extreme fatalism, self contempt, and indifference (Sadan, 1994).

The strong echo of powerlessness, in this study, brought the researcher to the theory of community empowerment. In order to take control of their health situation, the participants in this study need to be empowered with knowledge, information, self-efficacy, confidence, and autonomy. The theory of community empowerment seems to be a theoretical lens through which one could gain a better understanding of African American women regarding breast cancer screening.

Theory of Community Empowerment

The community empowerment middle range theory of Persily and Hildebrandt (1996) and modified by Randall (2009; see Figure 7) was developed to promote health by building relationships both at individual and community levels. It seeks to provide a framework for research and practice through development of effective interventions at individual and community levels. It was designed to structure a community involvement approach that enables community people to increase their knowledge and health care decision-making capabilities. The middle range theory of community empowerment is based on the concepts of involvement, lay workers, and reciprocal health.

The Randall Model of Community Empowerment addresses the themes of: avoiding, communicating, discriminating, fear, and unknowing that emerged from the African American women in this study, regarding their experiences with breast cancer screening from a cultural perspective. The African American culture is intertwined with the high value placed on human relationships, community, unity, and interdependence. The African American culture places considerable emphasis on social and affective ways of obtaining knowledge (Schiele, 2000). Axiologically, African American culture significantly underscores the value of interpersonal relationships; it is one of the most important cultural values. In comparison to the linear reasoning of the Eurocentric culture, the African American culture reveals a more holistic and circular kind of reasoning that recognizes interconnectedness in all things. Interconnectedness and interdependence are closely related. The structure of reality in African American culture is a perspective of interdependency. All of the elements of the universe are viewed as interconnected, and all human beings are dependent upon one another. This is closely related to spirituality. The cultural view is that of Ntuology, which refers to the interrelation of all things through human and spiritual networks (Nocotera, Clinkscales & Walker, 2003).

In the model, the circular enclosure depicts the interconnectedness that is required to ensure success with implementation of the theory. Community and interconnectedness are the foundation of identity development within the African American community (Freeman, 1998). It is imperative for researchers to heavily engage community lay workers and churches in intervention projects geared towards decreasing breast cancer mortality in the African American women and stimulating reciprocal health.

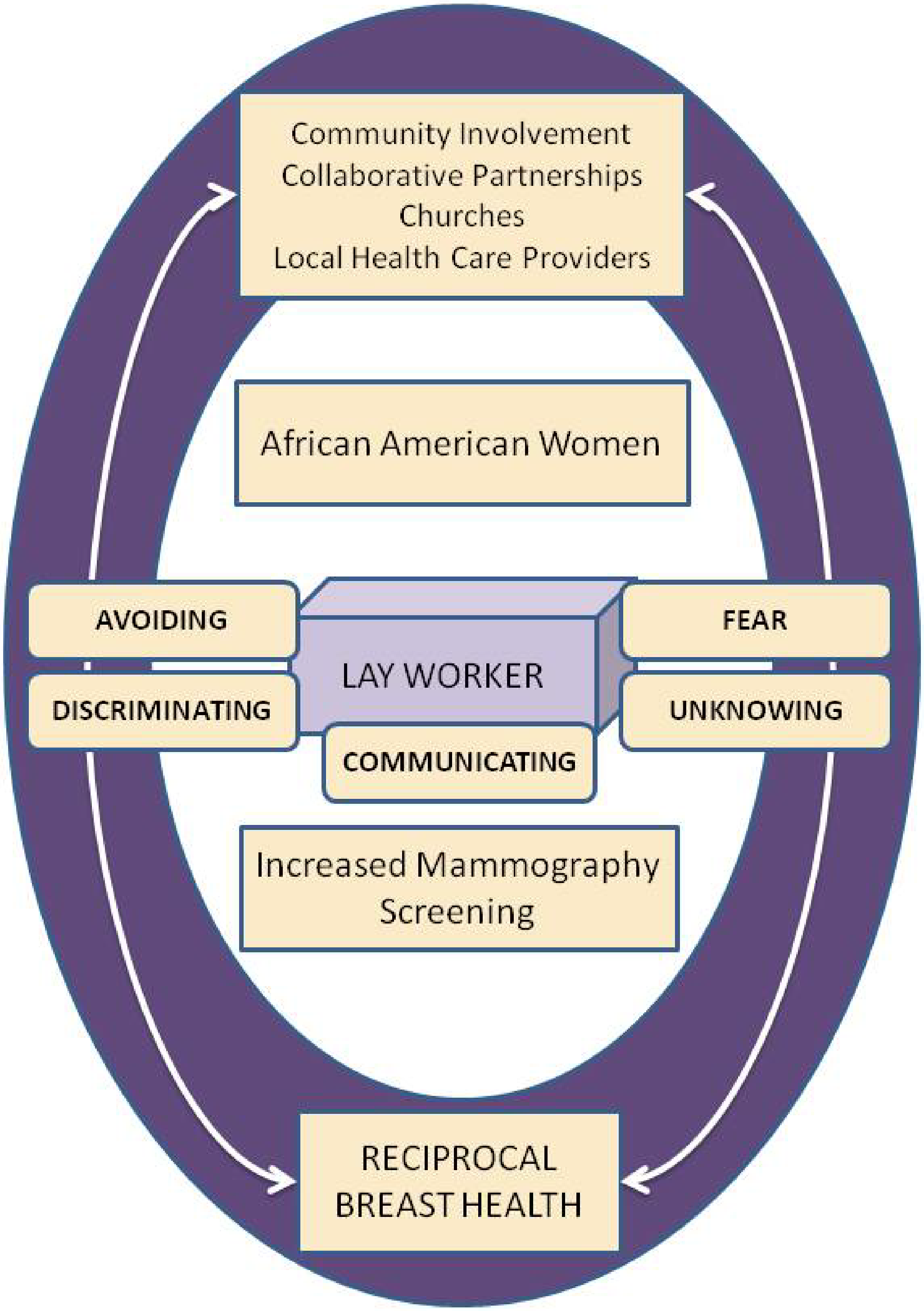


Figure 7. Randall Community Empowerment Model

Involvement is linking a group of community people to identify their common ground of needs, resources, and barriers, and to build a strong coalition to mounting problems by maintaining intervention.

In the nursing literature, individual empowerment has been defined relative to the nurse-client dyad and as related to changes in health behaviors (Persily & Hildebrandt, 2003). Clifford (1992) believes individual empowerment is a process closely linked to caring and that caring for clients is intrinsic to the profession and important for the process to be successful. Rafael (1995) links empowerment to the process of participation, defining it as a “process in which clients participate with nurse facilitators, with the desired outcome client control toward authentic self determination” (p.25). Empowerment is more than the traditional psychological constructs with which it is sometimes compared or confused (e.g., self-esteem, self-efficacy, competency, locus of control). It is simply a process by which people gain control over their lives, democratic participation in the life of their community (Rappaport, 1987).

In utilizing the theory of community empowerment lay workers are trained persons who share backgrounds with the families they visit. Their knowledge of the community enables them to reach out to families not easily accessible to outsiders. Reciprocal health is defined as the actualization of inherent and acquired human potential (Pender, Murdaugh, & Parsons, 2002) and is a desired outcome of community empowerment where the community and professionals engage to promote proactive healthy behaviors. The desired outcome was for the researcher to gain insight into the experiences of African American women with mammography in an effort to identify research based strategies to increase participation in screening practices. It is evident that cultural beliefs and practices remains a big obstacle to participation. If the cultural community takes ownership of the problem and becomes actively involved than perhaps mammography screening will be increased and mortality decreased. The increased visibility of African American breast cancer survivors may also impact participation.

A good example of a community empowerment program is The Witness Project. as reported by Bailey(2000). It is an educational and outreach program of the Winthrop P. Rockefeller Cancer Institute’s Cancer Education Department. It is a culturally competent, community-based, breast and cervical cancer education, outreach program, through which cancer survivors and lay health advisors increase awareness, knowledge, access to screening, and early detection in the African American population in an effort to reduce mortality and morbidity from cancer. In spite of living in the information age, cancer is still a fearful, stigmatized disease in many rural and minority communities, and people simply don't talk about it. But thanks to The Witness Project, more and more African American women are talking about cancer. Witness Project programs are presented in churches and community centers by Witness Role Models and Lay Health Advisors. Witness Role Models are African American women who are breast or cervical cancer survivors. Their presence as survivors is seen as a blessing and proof that cancer is not a death sentence. Lay Health Advisors are not cancer survivors themselves, but are women who want to work with the project to organize and publicize programs, network with community people, give facts about breast and cervical cancer, answer questions about available services, and teach Breast Self Examination. The Witness Project currently has programs in 22 states at 33 different sites. In 2003, The Witness Project was established at the Moffitt Cancer Center in Tampa, Florida.

Empowerment can refer to values, processes, or outcomes, as well as to activities at the level of the individual, the organization, or the community (Zimmerman 1995). Empowerment is a construct that links individual strengths and competencies, natural helping systems, and proactive behaviors to social policy and social change (Rappaport, 1981, 1984). There are three processes of empowerment, individual, community, and professional practice (Sadan, 1994).

Empowerment theorists and researchers have argued that empowerment assumes divergent forms and meanings across people, is contextually determined, and changes over time (Rappaport, 1984; Zimmerman, 1995).The contextual theory of empowerment presents the transition from powerlessness to more control in life as a change in both human activity and the social structures.

Empowerment theory, research, and intervention link individual well-being with the larger social and political environment. Theoretically, the construct connects mental health to mutual help and the struggle to create a responsive community. It compels communities to think in terms of wellness versus illness, competence versus deficits, and strength versus weaknesses. Similarly community empowerment research focuses on identifying capabilities instead of cataloging risk factors and exploring environmental influences of social problems instead of blaming victims. Community empowerment-oriented interventions enhance wellness while they also aim to ameliorate problems, provide opportunities for participants to develop knowledge and skills, and engage professionals as collaborators instead of authoritative experts (Douglas & Zimmerman, 1995). Empowerment, as a personal enhancement, can assist and underscore the attributes of African American women in regards to social support. Social support provides role modeling and the kinship needed to confront fear associated with breast cancer control. In addition, empowerment, along with culturally sensitive information, may assist African American women in the decision-making process, which can increase their participation in breast cancer screening (Guidry, Matthews-Juarez, & Copeland, 2002).

The constructivist paradigm, one of several post positivist epistemologies provides an interpretive framework and incorporates research methodologies that correspond with the critical assumptions of empowerment theory. (Foster-Fishman, et al., 1998) . Constructivists emphasize the importance of capturing individuals' unique realities and understanding local meanings (van Manen, 1990). These realities emerge from the individuals' lived experiences and personal histories (Swigonski, 1994). This emphasis on capturing each individual's personal reality, and recognizing that this reality is embedded within a particular context, makes constructivism particularly compatible with the multiplicity assumption of empowerment. The underlying assumptions of constructivism are also compatible with empowerment's dynamism. Constructivists believe that because knowledge is contextually and historically bound by space and time, the reality seen or understood at one particular point may shift significantly across settings and across time (Gergen, 1985; Hare-Mustin & Marecek, 1988; van Manen, 1990). This perspective calls for researchers and informants to continually revisit the meanings previously constructed and reshape their understandings. Constructivists naturally assume that the dynamic nature of social phenomena will shift the realities seen and understood (Foster-Fishman et al., 1998).

In constructivism, an active collaborative relationship between scientist and informant, in which the participants are viewed as experts on their own lives, becomes the context in which the process of discovery takes place (Kingry-Westergaard & Kelly, 1990). The interaction between researcher and stakeholder becomes the vehicle for understanding, constructing, and reconstructing knowledge (Guba & Lincoln, 1989).

In regard to the scientific legitimacy of their endeavors, constructivists are less concerned about objectivity and more focused on issues of trustworthiness and authenticity (Lincoln & Guba, 1986). Through a strong partnership between the researcher and the researched, a constructivist approach ensures not only that multiple social realities are considered but also that the conclusions drawn are legitimate and credible.

The exemplary study of McMillan et al. (1995) helped to enlarge the theoretical understanding of empowerment. The study was a broad-based community coalition approach to the public health and primary prevention literature, certain empowerment principles, and an effort to comprehensively engage multiple social systems (e.g., families, schools, workplaces, media, civic organizations) in solving seemingly intractable social, psychological, and health problems. They then evaluated the individual and community organizational level empowerment effects of a statewide coalition of task forces organized for the prevention of alcohol and other drug problems. They used response data from 35 community coalitions, comprising 850 members, organized for the prevention of alcohol and other drug problems, to answer these questions: (a) What factors are associated with psychological empowerment among members participating in a community coalition? (b) What characteristics of a community coalition are related to its being an empowering organization, that is, successful in the collective empowering of its members? (c) What characteristics of a community coalition are related to its being organizationally empowered, that is, successful in influencing its environment? The response rate was 41% with 350 surveys being returned. They ascertained that community coalitions, can promote a community development process that builds confidence, competencies, and social connections among participants. They can engage broad participation, which increase local ownership, thereby expanding resources and increasing commitment to sustaining activities long term. Finally, community coalitions can expand health promotion and prevention activities beyond individual life-style change by collectively influencing key decision makers and social policy within the community. Although funding of community coalitions is ahead of clear scientific evidence of their utility, commitment to collaborative problem solving and to local ownership of solutions put this movement squarely at the cutting edge of empowerment praxis, or the practice of translating ideas and theories about empowerment into action and results. Their study provided evidence of the utility of a multidimensional approach to conceptualizing empowerment.

Constructivist research methods, such as the one employed in this study, are particularly well suited to empowerment research because they are epistemologically compatible with empowerment theory. By including this paradigm in their repertoire of investigative approaches, researchers will be better equipped to develop research methods and interventions that effectively give voice to the participant's empowerment experiences and provide meaningful opportunities for increased control (Fishman et al., 1998).

There is an ancient African proverb that says “it takes a village to raise a child.” Another African proverb says the following, “If you educate a man, you educate an individual, if you educate a woman you educate a community.” The researcher would like to equate that to a new concept development of “it takes a community to decrease mortality of breast cancer in African American women.” The community initiatives could be operational in the form of partnerships or coalitions. Community partnerships serve as catalysts. Members take action to effect changes in programs, policies, and practices throughout the community. These changes reshape community agencies, institutions, and citizen organizations, and may enable them to better address the issues of concern. Collaborations may be more effective since partners share responsibilities, risks, and resources (Himmelman, 1992).

Implications of the Study for Nursing Knowledge

In 1985, Secretary of the Department of Health and Human Services (HHS) Margaret Heckler (1983-1985) issued a landmark report called *Perspectives in Disease Prevention and Health Promotion*, which revealed large and persistent gaps in health status among Americans of different racial and ethnic groups. That report served as an impetus for addressing health inequalities for racial and ethnic minorities in the U.S. In response to that report the Office of Minority Health and Health Disparities (OMHD) was created. The Centers for Disease Control and Prevention (CDC) created its own Office of Minority Health (OMH) in response to that same report. In 1999 Racial and Ethnic Approaches to Community Health (REACH) 2010 was designed and launched in an effort to eliminate disparities in at least some of the health priority areas, breast cancer being one of them. In January 2000, The Healthy People 2010 initiative was launched to achieve two overarching goals:

Goal 1: Increase Quality and Years of Healthy Life: The first goal of Healthy People 2010 is to help individuals of all ages increase life expectancy *and* improve their quality of life.

Goal 2: Eliminate Health Disparities: The second goal of Healthy People 2010 is to eliminate health disparities among different segments of the population.

The American Cancer Society (2008) has reported that African American women and women of other racial and ethnic groups have benefited less than White women from the advances that have led to gains in cancer research, and that a recent drop in cancer incidence is due in part to fewer women getting mammograms. In 2005, mammography rates for women overall had dropped to about 66%, which was nearly 4% lower than the peak rate of 70%. The decline was not just across the board but also in many subgroups of women, including some who have traditionally had the highest rates of mammography use. It is speculated that today fewer women have insurance coverage, co-pays for mammograms have increased, fewer radiologists are available to read mammograms due to reimbursement cuts, and that there are longer appointment delays. This information is very alarming because African American participation rate was already documented as deficient and mortality rates high despite formation of the two Offices of Minority Health and the goals set forth by Healthy People 2010.

The African American women who participated in this study have demonstrated compelling evidence of the persistent gap in participation in mammography screening for breast cancer. According to the U.S. Department of Health and Human Services (2000) breast cancer continues as a major health problem in African American communities.

Unprecedented advances in translating research findings into public health practices to reduce cancer risks have been observed over the past decade; however, such advances have not been realized by all members of society regardless of race, ethnic and socioeconomic group membership and have not been well disseminated at the community level. The mortality rates for African American women with breast cancer have remained unchanged despite a decrease in mortality for other racial/ethnic groups. The American Cancer Society continues to generate yearly statistical data depicting better outcomes inclusive of African American women when in fact their lack of participation has generated higher mortality rates.

Significance to Nursing

Implications for Nursing Education

The African American participants in this study underestimated their risk of breast cancer as evidenced by the following emergent themes of: fear of fear, unknowing, avoiding, discriminating, and ignoring. They only had one mammogram and chose to not continue participating in screening as recommended by the American Cancer Society despite having family members, friends, coworkers and church members succumb to the disease.

The Essentials of Baccalaureate Education for Professional Nursing Practice (2008) developed by the American Association of Colleges of Nursing (AACN) define the professional nursing role as threefold: caring for the sick in and across all environments, health promotion, and population-based health care. Inherent in each of these three components is the commonality of diverse populations. In order for nurses to care for diverse populations they must have enhanced knowledge and sensitivity to such variables as age, gender, culture, race, religion, socioeconomic status, and lifestyle choice. Health promotion, risk reduction, and disease prevention require cultural knowledge and cultural sensitivity towards the populations they service. Porter and Barbee (2004) revealed that there is little to no content that addresses issues of racism and discrimination in nursing education (AACN, 2008).

The relationship between culture and psychosocial issues is integral to understanding how this population responds to cancer prevention (Guidry, Matthews-Juarez, & Copeland, 2003). Culture is core considerations in how people behave, interpret, and perceive their illnesses, and cultural knowledge is essential for nurses regardless of healthcare setting. Effective teaching, meaningful interventions, or appropriate assessments cannot be made without understanding of the patient's perception of illness framed in a cultural context (American Nurses Association [ANA], 1991)

The educative role of nurses and other health care professionals in breast cancer detection and prevention is vital (Consedine, 2004). It is imperative for schools of nursing to develop and mandate cultural diversity as a core that is essential in their curriculum. In order to improve the health care mortality outcomes of African American women's participation in mammography screening, nurses are obliged to provide culturally appropriate materials and interventions. Nursing education must provide a foundation of intellectual skills and capacities for learning and working with diverse populations and must include the five key elements essential for baccalaureate nursing graduate to provide culturally competent care. Those essentials are: (1) apply knowledge of social and cultural factors that affect nursing and health care; (2) use relevant data sources and best practice in providing culturally competent care; (3) promote achievement of safe and quality outcomes of care for diverse populations; (4) advocate for social justice, including commitment to health of vulnerable populations and the elimination of health disparities; and (5) participate in continuous cultural competence development (AACN, 2008, p.12).

The findings in this study elucidate the thoughts, communications, beliefs and actions of the participants and validate the need for culturally sensitive breast health education. An understanding of culture and its impact on the lived experiences of African American women with breast cancer screening may provide some insight into the role of culture and health prevention. Culturally appropriate interventions, based on the participants' voices may be influential for increasing mammography usage. Data gathered from this study may lead to the development of culturally competent models of care which could result in reducing and/or eliminating cancer disparities in African American women. An integrated culture curriculum must be incorporated into the curriculum of every nursing program. One "culture course" is not sufficient to tackle the health disparities that are presently documented in the African American community. Nurses must seize every available opportunity to undo current knowledge and re-teach accepted truths about breast cancer and breast cancer screening f or African American women.

Implications for Nursing Practice

Culturally appropriate, community driven programs are critical for increasing African American women's participation in mammography screening. Community initiatives often operate as partnerships or coalitions. Representatives of different community sectors, organizations, or constituencies create alliances to work toward a common purpose or mission. Community members take action to effect changes in programs, policies, and practices throughout the community. These changes reshape community agencies, institutions, and citizen organizations, and may enable them to better address the issues of concern. Collaborations may be more effective since partners share responsibilities, risks, and resources (Himmelman, 1992).

The findings of this study may indirectly impact the mortality and morbidity rates among African American female participants in this study by increasing their knowledge and awareness of the importance of participation in breast cancer screening tests through collaborative partnerships. A community partnership should be developed between a school of nursing, a community church, the Susan Komen Foundation, a mammography center, and lay community workers to effect some change in the health disparity in Palm Beach County. Collaborative partnerships for community health and development provide an opportunity for studying and contributing to empowerment. (Fawcett et al., 1995). This would be an awesome opportunity to promote reciprocal health which is the ultimate goal of the community empowerment theory identified in this study. Theory, practice and research are essential components of the empowerment theory.

This study will provide nurses and practitioners with an increased understanding about African American women’s experiences with breast cancer screening tests and may assist the health care provider in designing strategies to engage African American women in improved decision-making behaviors with regards to breast cancer screening tests to decrease the group’s mortality.

Implications for Nursing Research

Despite all the gains that have been made in the area of breast cancer research, African American women continue to suffer disproportionately from the effects of the disease (Jones & Chilton, 2002). One of the greatest barriers to addressing cancer within minority populations is the lack of adequate and consistent cancer data. Without such data, it is difficult to assess the current systems, contribute to the development of a plan to address problems, and better allocate resources (Ries et al., 2000).

Breast cancer is firmly entrenched in the national cancer research agenda because of its enormous impact on our society, claiming 62,000 lives annually among African American women. A new study from the American Cancer Society (2008) found that while breast cancer death rates are decreasing for White women in every U.S. state, for African American women, death rates are either flat or rising in at least half the states. DeSantis (2008) analyzed data from the National Center for Health Statistics for the years 1975 through 2004 and reported breast cancer death rates among African American women are decreasing in only 11 of 37 states with sufficient numbers for analysis and in the District of Columbia. In the remaining states, death rates are either flat (24 states) or actually increasing (2 states; Arkansas and Mississippi). Florida is listed as one of the states where the numbers are flat.

Researchers must close the gap on this health disparity by generating research funding to develop culturally appropriate models of intervention since culture is a known factor in health-seeking behaviors. This is the only way to encourage African American women to be more participatory in their health issues is by using culturally appropriate information and models. Research based on the variable of cultural sensitivity is also very limited regarding interventions that target diverse population. The researcher cautions that cultural congruency needs to be a very important part of the research endeavor.

The themes that emerged from this study lead the researcher to the theory of community empowerment. Currently, there are no studies documented in the literature that apply this theory to African American women and breast cancer screening. This would be pioneer research. Empowering research methods thus deserve further attention Current literature is deficient of research exploring African American with no prior history of breast cancer. The researcher would recommend this study be replicated using focus groups which may generate some more rich data. Phenomenological studies using focus groups have been successfully conducted in the context of women's health issues and health disparities research, specifically with African American women (Baldwin, 1996; Cote & Beedy, 2001; Ruff, Alexander, & McKie, 2005). There is an urgent need to produce practical, usable, and culturally appropriate cancer information from prevention to survivorship. A reduction of the incidence of breast cancer in African American women may result from new and non-traditional research initiatives using culturally competent and participatory action methodologies.

Implications for Public Policy

The Carolina Breast Cancer Study (2006) identified so-called “triple negative” breast cancers, tumors that do not contain any of three significant tumor markers (estrogen receptors [ER], progesterone receptors [PR], and human epidermal growth factor receptor-2 [HER2]) are aggressive, deadly cancers that affect young, poor minority women. They found that premenopausal Black breast cancer patients have the highest prevalence of a subtype of breast cancer called “basal like” cancer. These tumors are more common among women who are African American and Hispanic, under 40 years old, and who have lower socioeconomic status (SES). The cause of clustering among certain ethnic groups is an inherited genetic mutation called BRCA1.The study found triple negative tumors are also associated with later diagnosis and shorter survival.

Year after year reports are generated validating the continual problem of breast cancer in the African American population and year after year the statistics do not change. Records have been published dating as far back as 1978 regarding this health disparity. For women 40 years and older who are at average risk, most major health organizations endorse mammographic screening every 1 to 2 years, and every year after age 50 as long as the woman is healthy based on the recommendations of the U.S. Preventive Services Task Force. However, cancer is being diagnosed at as early as 25 years of age among African American women; so the established guidelines need to be changed. Black women under the age of 50 have a high mortality rate from breast cancer, almost twice that of younger White women. The insurance companies should be mandated to pay for early screening mammograms in this population. These extensive, highly funded research efforts must be translated into positive and measurable outcomes for African American women.

Because African American women can have an earlier onset of breast cancer; mammography screening at an age younger than 40 is needed to decrease mortality rates. The researcher postulates that the established guidelines by the American Cancer Society and the established payment policies mandated by insurance companies regarding breast cancer screening must be changed. As patient advocates, nurse researchers must keep abreast of the current literature regarding health disparities and have a seat at the policy making tables. Nurses must be active in their professional organizations, sit on boards of hospitals, the American Cancer Society, Komen Foundation, and insurance companies. Legislative visits to address health care policies must become a part of the professional practice of nurses to effect health care policy changes. Nurses must challenge state and government officials to adopt policies to address this health disparity. The federal initiatives to eliminate racial and ethnic disparities in health by the year 2010 are not on target. The U.S. Preventive Services Task Force should be challenged to revisit their recommendation concerning breast cancer screening. Nurses need to become legislative advocates for their patients by being members of their professional organizations and making time for an audience with legislators. Nurse must be versed in health care policies and act as champions for change.

Strengths and Limitations

The strength of this study was the participants were excited and enthusiastic to participate in this study. The information they provided gave new insight into the development of culturally relevant and empowering mammography screening interventions. The literature is flooded with research information depicting African American women, who do not adhere to the recommended mammography screening guidelines, as more likely to be uninsured or underinsured, lack a usual source of care, have lower levels of education and lower income, and have lower levels of literacy (Hiatt, Pasick, & Stewart, et al., 2001; Mandeblatt, Gold & O'Malley, 1999; Selvin & Brett, 2003; U.S. Department of Health and Human Service, 2001). Contrary to what is consistently published regarding characteristics of non-adherent African American women with mammography screening, the participants in this study were not of lower socioeconomic status, lower levels of literacy, did had access to care, and all but one were insured.

The African American women who agreed to participate in this study were representatives of a small sample of Palm Beach County residents, not of the general population, therefore transferability may be limited. The sample included those who met inclusion criteria, although there were many others who wished to participate but were excluded. The researcher used self-reported data to identify eligible women, and therefore some misclassification may have occurred. The snowball sampling technique may have led to a biased sample of women who were working and had health insurance, and may have been better educated than the original targeted population of Palm Beach County. Some women may have participated because of the remuneration for the interviews. In addition, there exists the threat of trustworthiness from the responses given by the participants during the interview process. Perhaps, more data could have recovered from the participants, if the researcher did not have familiarity with them. Lastly, the inexperience of the researcher may have hindered some responses by the participants when teachable moments were seized during the interview process.

Future Studies

The researcher encourages action research using collaborative community partnerships, and employing lay health care workers, who are African American community residents, to reduce the traditional barriers, that is, access to the community as an outsider. The development of professional-community based partnerships that integrate community and public views may be what are needed to inspire, empower, and mobilize the community of African American women towards breast cancer screening participation and affect mortality outcomes. The training and orientation of community lay workers is imperative in order to empower African American women to attain reciprocal health.

Theoretical models explaining the mammography experiences of African American women who have not been diagnosed with breast cancer need to be developed and implemented. In the literature, there is much discussion of and reference to the development of culturally sensitive models and intervention strategies for African American women with breast cancer but, to date, no publication are referenced with documentation of successful interventions in the nursing literature.

Little is known about the cultural beliefs of African American women with no previous history of breast cancer regarding the meaning of the mammography screening experience. The extensive literature review required to complete this study demonstrated some very deep-rooted cultural beliefs that need to be further investigated. The concept of fear defined from an existential perspective warrants further investigation.

All 13 participants in this study had difficulty identifying breast health and what that meant to them; therefore further research is needed to explore the meaning of health and breast health among African American women.

Conclusions

The African American women who participated in this study gave rich descriptions of their experiences with mammography screening. The themes that emerged from this study may have uniqueness to the African American culture from a historical perspective. The literature consistently identifies low socioeconomic status, poor education, and limited access to care as the primary barriers and cause of health disparities in ethnic/minority populations. Contrary to the published literature, 12 of the 13 participants, in this study, did have insurance, were gainfully employed, and were not poverty stricken, yet participation in mammography screening was still low. Cultural and health beliefs that differ from mainstream society are reported to be factors contributing to the low rates of breast screening participation (Forte, 1995).

The discussions of their experiences highlighted the misconceptions, misinformation, fears, and lack of knowledge towards this topic. It became evident that all the large number of breast cancer awareness campaigns, such as *Race for the Cure* and February being designated as Breast Cancer Awareness month, have not impacted the knowledge or level of participation of these participants. There is an urgent need to tailor breast cancer screening campaigns and promotions that are reflective of the African American culture.

If African American women are not educated about the importance of mammography screening, then their chances for survival are greatly diminished before and after a diagnosis of breast cancer. Perhaps, African American women need to see people who look like them in order to fathom the possibility this disease really affects them.

The fear of death upon diagnosis must be dispelled among the African American women. Breast cancer is not a death sentence and that can be eloquently communicated, to African American women, by the words, songs, and dance of African American breast cancer survivors. In Palm Beach County, there is a very vibrant and active group of African American breast cancer survivors called *Sojourner Truth*, and the key is for them to gain more visibility in the area African American communities. The researcher will solicit the support of this group during the development and implementation of The Birthday Club Project, a community empowerment intervention research program. The researcher plans to pilot the study using local churches, mammography centers, local hospitals, the Susan G. Komen Foundation, The Palm Healthcare Corporation, and lay community members to foster adherence to mammography screening for African American women in Palm Beach County. A monthly birthday party is planned with mammography screening, breast health information, and refreshments. Funding is currently being sought for this project.

The researcher has gained insight into the development of some culturally appropriate strategies to increase participation in mammography screening. Breast cancer screening is an important component of health maintenance and must be discussed during primary care physician visits. The development of professional-community based partnerships that integrate community and public views is needed to inspire, empower, and mobilize the community of African American women towards breast cancer screening participation and effect better mortality outcomes. Health disparities translate into earlier death, lower quality of life, loss of economic opportunities, and perceptions of societal injustice for culturally diverse populations (Centers for Disease Control, 2005).

The themes identified in this study present complex problems for the researcher because they seem to be culturally driven. To remove cultural beliefs and practices requires a progression towards cultural competency by the healthcare provider. Brandt (1985) notes there are no “magic bullets” that will resolve the racial and ethnic problem quickly and easily. Winning the fight against breast cancer in African American women is not possible without increased investments in research.

The barriers and contributors to mammography screening in the African American women, in this sample population, have been identified. Finally, this researcher is calling future researchers to ACTION:

A	**C**	**T**	**I**	**O**	**N**
W	U	I	N	P	E
A	L	M	N	T	C
R	T	E	O	I	E
E	U	L	V	O	S
N	R	Y	A	N	S
E	A		T	S	A
S	L		I		R
S	L		V		Y
	Y		E		

Clearly, while some of the participant's experiences may not differ significantly from experiences of other groups/individuals, it is the African American culture that adds dimensions to the implications of these findings. There is an urgent need for researchers to develop culturally stimulating awareness campaigns that address the issue of breast cancer in African American women on a continuum, not just a breast cancer awareness month. Health care providers must be culturally competent to care for the clients they service. Any strategies or interventions implemented must be timely and relevant. Innovative programs must be developed to appeal to African American females for increased participation in mammography screening. African American women must be educated regarding options to maintaining breast health, that is, mammogram, versus digital mammogram, versus ultrasonography.

Finally, a comprehensive approach to achieving reciprocal breast health for African American women is needed. The utilization of community partners (healthcare providers), lay workers, nursing students, and local churches in the quest to decrease the mortality statics and increase participation in mammography screening among African American women is imperative.

REFERENCES

Adams, M. (2007). The African American breast cancer outreach project: Partnering with communities. *Community Health, 30*(15), 585-594.

Adams, E., Breen, N., & Joski, P. (2007). The impact of the National Breast and Cancer Cervical Early Detection Program on mammography and Pap test utilization among White, Hispanic, and African American women. *Cancer, 31*(3), 220-224.

Adams-Campbell, L., Makambi, K., Palmer.J., & Rosenberg, L. (2007) Diagnostic accuracy of the Gail Model in the Black Women's Health Study *The Breast Journal, 13*(4) , 332–336.

Adderley-Kelly, B., & Green, P. (2005). Strategies for successful conduct of research with low-income African American populations. *Nursing Outlook 53*(3), 147-152.

Ahern, K. (1999). Ten tips for reflexive bracketing. *Qualitative Health Research, 9*(2), 407-411.

American Association of Colleges of Nursing. (2008). Essentials *of baccalaureate education for professional nursing practice.* Retrieved December 12, 2008, fromhttp://www.aacn.nche.edu/Education/pdf/BEdraft.pdf

American Cancer Society (2005). *Cancer facts & figures 2005-2006*. Atlanta, GA: Author.

American Cancer Society (2007). *Cancer facts & figures for African Americans 2007-2008*. Atlanta, GA: Author.

American Nurses Association. (1991). *A position paper.* New York: Author.

Anderzen-Carlsson,A., Kihlgren, M., Skeppner, G., & Sorlie, V. (2007). How physicians and nurses handle fear in children with cancer. *International Pediatric Nursing, 22*(1), 71-80.

Aroni, R., Goeman, D., Stewart, K., Sawuyer, S. Abramson, M., & Thein, F. (1999). Concepts of rigour: When methodological, clinical, and ethical issues intersect. *British Medical Journal, 31*(9), 780-782.

Ashing-Giwa, K. (2000). Health behavior change models and their socio-cultural relevance for breast cancer screening in African American women. *Women's Health, 28,* 53-56.

Ashing-Giwa, K., Padilla, G., Kraemer, K., Coscorelli, A., Clayton, S.,Williams, I., et al. (2004). Understanding the breast cancer experiences of women: A qualitative study of African American, Asian American, Latina, and Caucasian cancer survivors. *Psycho-oncology 13,* 408-428.

Bach, P., Schrag, D., Brawley, O., Galaznik, A., Yakren, S., & Begg, C. (2002). Survival of Blacks and Whites after cancer diagnosis. *Journal of the American Medical Association, 287,* 2138-2139.

Bailey, E.J., Erwin, D.O., & Belin, P. (2000). Using cultural beliefs and patterns to improve mammography utilization among African American women: The Witness Project. *Journal of the National Medical Association, 92*(3), 136-142.

Baldwin, D. (1996). A model for describing low-income African American women's participation in breast and cervical cancer early detection and screening. *Advances in Nursing Science, 19*(2), 27-42.

Balsa A.I., & McGuire T.G. (2003). Prejudice, clinical uncertainty and stereotyping as sources of health disparities. *Journal of Health Economics,* 22(1), 89-116.

Banks-Wallace, J.A. (2000). Womanist ways of knowing: Theoretical considerations for research with African American women. *Advances in Nursing Science, 22,* 33-45.

Beal, A. (2007, September). *Program on quality of care for underserved populations. Addressing barriers to quality improvement adoptions that would benefit the underserved.* Presented at a meeting of the New York State Minority Health Council.

Beauboeuf-Lafontant, T. (2005). Keeping up appearances, getting fed up: The embodiment of strength among African American women. *Meridians: Feminism, Race, and Transnationalism, 5,* 104-123.

Beck, C. (2005). Benefits of participating in internet interviews: Women helping women. *Qualitative Health Research, 15*(3), 411-422.

Berg, B. (2004). *Qualitative research methods for the social sciences* (5th ed.). Boston: Pearson.

Berger, P., & Luckman, T. (1966). *The social construction of reality: A treatise in the sociology of knowledge.* Garden City, NY: Doubleday.

Bickell, N., Wang, J., Oluwole, S., Schrag, D., Godfrey, N., Hiotis, K., et al. (2006). Missed opportunities: Racial disparities in adjuvant breast cancer treatment. *Journal of Clinical Oncology, 24,* 1357-1362.

Blackman, D., Bennett, E., & Miller, D. (1999). Trends in self-reported use of mammograms (1989–1997) and Papanicolaou tests (1991–1997): Behavioral risk factor surveillance system, 1997. *CDC Surveillance Summary, 48,* 1–22.

Blackman, D., & Masi, C. (2006). Racial and ethnic disparities in breast cancer mortality: Are we doing enough to address the root causes? *Journal of Clinical Oncology, 24*(14), 2170-2178.

Bloom, J., Grazier, K., Hodge, F., & Hayes, W. (1999). Factors affecting the use of screening mammography among African American women. *Cancer Epidemiology Biomarkers and Prevention, 1*(1), 75-82.

Boyd, N. F. Guo H., Martin, L. J., Sun, L., Stonr, J., Fishell, E., et al. (2007). Mammographic density and the risk and detection of breast cancer. *New England Journal of Medicine, 356,* 227- 36.

Bradley, E., Curry, A., & Devers, K. (2007). Qualitative data analysis for health services research: developing taxonomy, themes, and theory. *Health Service Research, 42*(4), p.1758-772.

Bradley,C., Given,C., & Roberts, C. (2002). Disparities in cancer diagnosis and survival. *Cancer, 91*, 178-188.

Bradley, E., Holmboe, E., Mattera, J., Roumanis, M., Radford, M., & Krumholz, H. (2001). A qualitative study of increasing beta-blocker use after myocardial infarction: Why do some hospitals succeed? *Journal of the American Medical Association, 28(20),* 2604-2611.

Brandt, A.M. (1985). *No magic bullet: A social history of veneral disease in the United States since 1880*. New York: Oxford University Press.

Bray, F., McCarron, P., & Parkin, D. (2004). The changing global patterns of female breast cancer incidence and mortality. *Breast Cancer Research, 6*, 229-239.

Breen. N., Cronin, K., Meissner, H., Taplin, S. , Tangka, F. , Tiro, J., & McNeel, T (2007). Reported drop in mammography: Is this cause for concern? *Cancer, 109*(12), 2405-2409.

Breen, N., Wesley, M., & Merrill, R. (1999). The relationship of socio-economic status and access to minimum expected therapy among female breast cancer patients in the National Cancer Institute Black-White cancer survival study. *Ethnic Diversity, 9*, 111–125.

Brem, R. (2007). Mammography screening of women in their forties. *Cancer, 112*(3), 458-460.

Bromberg, S. E. (2004). *The evolution of ethics*. Retrieved February 10, 2009, from Strakerhttp://changingminds.org/books/changingminds_book.htm

Brown University. *Whites less likely than blacks to live with extended family: A dramatic half century change.* Retrieved March 20, 2009, from http://www.scienceblog.com/community

Burch, R. (1989). On phenomenology and its practices. *Phenomenology & Pedagogy, 7*, 187-217.

Burns, P. J. (2008). The links between neighborhood disadvantage and anger: Perceived disorder, fear of victimization, and psychological distress. *Paper presented at the annual meeting of the American Sociological Association,* Boston, MA. *Retrieved March 13, 2009 from* http://www.allacademic.com/meta/p241201_index.html

Burr, V. (1995**).** *An introduction to social constructionism*. London: Routledge.

Byrd, W., & Clayton L. (2000). *An American health dilemma, Volume II. A medical history of African Americans and the problem of race: Beginnings to 1900*. New York: Routledge.

Byrd, M., & Clayton, L. (2001). Race, medicine, and health care in the United States: A historical survey. *Journal of the National Medical Association, 93*(Suppl. 3), 11S-34S.

Byrne, M. (2001). African American Women and breast cancer: Notes from a study of narrative research reviews - brief article. *Association of Operating Room Nurses, 24*, 35-42.

Campbell, M., & Gregor, F. (2004). Mapping social relations: A primer in doing institutional ethnography. Walnut Creek, CA: AltaMira Press.

Carey, L., Perou, C. M., Livasy, C. A., Dressler, L. G., Cowan, D., Conway, K., et al. (2006). Race, breast cancer, subtypes and survival in the Carolina Breast Cancer Study. *Journal of the American Medical Association, 295,* 2492-2502.

Carmona, R. (2003). Nursing research: A key to the nation's health. *Friends of the National Institute of Nursing Research Conference* (pp. 1-5). Washington, DC: U.S. Department of Health and Human Services.

Centers for Disease Control. (2005). *Use of mammography for women 40 years of age and older, according to selected characteristics: Selected years, 1987-2000.* Atlanta, GA: National Cancer Institute.

Champion V. (1994). Beliefs about breast cancer and mammography by behavioral stage. *Oncology Nursing Forum, 21,* 1009-1014.

Champion, V., & Skinner, C. (2005). Development of a self-efficacy scale for mammography. *Research in Nursing and Health, 28*, 329-336.

Chlebowski, R., Chen, Z., Aragaki, A., Lane, D., Paskett, R., Hubbell, R., et al. (2005). Ethnicity and breast cancer: Factors influencing differences in incidence and outcome. *Journal of the National Cancer Institute, 97*(6), 439-448.

Chu, K., Lamar, C., & Freeman, H. (2003). Racial disparities in breast carcinoma survival rates: Separating factors that affect diagnosis from factors that affect treatment. *Journal of the American Medical Association, 97*, 2853-2860.

Clifford, P.G. (1992). The myth of empowerment. *Nursing Administration Quarterly, 16*(3), 1-5.

Coker, A.D. (2002, April). *Counseling African American women: Issues, challenges, and interventions.* Paper presented at the 36th Annual Conference, Alabama Counseling Association, Mobile, Alabama.

Collins, P. H. (1991). *Black feminist thought*. Boston: Unwin Hyman

Consedine, N. S. (2004). Breast cancer knowledge and beliefs in subpopulations of African American and Caribbean women. *American Journal of Health Behaviors, 28*(3), 260-271.

Consedine, N. S., Magai, C &, Neugut, A.I. (2004). The contribution of emotional characteristics to breast cancer screening among women from six ethnic groups. *Preventive Medicine, 38*(1), 64-77.

Cooper, L.A., Roter, D.L., Johnson, R.L., Ford, D.E., Steinwachs, D.M., & Powe, N.R. (2003). Patient-centered communication, ratings of care, and concordance of patient and physician race. *Annals of Internal Medicine, 139*(11), 907–915.

Consedine, N.S., Horton, D., Magai, C. & Kukafka, R. (2007). Breast screening in response to gain, loss, and empowerment framed messages among diverse, low-income women. *Journal of Health Care for the Poor and Underserved, 18(3), 550-566.*

Crawley, L. M., Ahn, D. K., & Winkleby M. A. (2008). Perceived medical discrimination and cancer screening behaviors of racial and ethnic minority adults. *Cancer Epidemiology Biomarkers & Prevention, 10,* 1055-1099.

Creswell, J.W. (2005). *Educational research: Planning, conducting, and evaluating quantitative and qualitative research* (2nd ed.) Upper Saddle River, NJ: Pearson.

Creswell, J.W. (2003). *Research design: Qualitative, quantitative, and mixed methods approaches. (2nd. ed.).* Thousand Oaks, CA: Sage.

Creswell, J.W. (1998). *Qualitative inquiry and research design: Choosing among five traditions.* Thousand Oaks, CA: Sage.

Creswell, J.W., & Clark, P.V. (2003). *Advanced mixed methods research designs.* Thousand Oaks, CA: Sage

Crotty, M. (1996). *Phenomenology and nursing research.* Melbourne: Churchill Livingstone.

del Carmen, M.G., Hughes, K.S., Halpern, E., Rafferty, E., Kopans, D., Parisky, Y.R., et al. (2007). Racial differences in mammographic breast density. *Cancer, 98,* 590-596.

Denzin, N., & Lincoln, Y. (2000). *Handbook of qualitative research* (2nd ed.). Thousand Oaks, CA: Sage.

Dowling, M. (2005). From Husserl to van Manen. A review of different phenomenological approaches. *International Journal of Nursing Studies 44*, 131-142.

El-Bastawissi, A. Y., White, E., Mandelson, M. T. & Taplin, S. (2001). Variation in mammographic breast density by race. *Annuals of Epidemiology, 11,* 257-263.

Fawcett, S. B., Paine-Andrews, A., Francisco, V. T., Shcultz, J., Richter, K. P., Lewis, R. K., et al. (1995). Using empowerment theory in collaborative partnerships for community health and development.. *American Journal of Community Psychology, 23*(5), 677-697.

Feldstein, A., Vogt, T., Aickin, M., & Hu, W.(2006). Mammography screening rates decline: A person-time approach to evaluation. *Preventive Medicine*, *43*, 178-82.

Ferguson**,** S., & Kasper, A. (2000). Introduction: Living with breast cancer. In A.S. Kasper & S. J. Ferguson (Eds.), *Society shapes an epidemic: Women, their bodies, and the illness experience* (pp. 1-24). New York: St. Martin Press.

Finlay, L. (2002). “Outing” the researcher: The provenance, process, and practice of reflexivity. *Qualitative Health Research*, *12*(4), 531-545.

Fischhoff, B. (1999). Why cancer risk communication can be hard. *Journal of the National Cancer Institute, 199*(25) 14-15.

Fishman, B., Marx, R.W., Blumenfeld, P., & Krajcik, J. (2004). Creating a framework for research on systematic technology innovations. *The Journal of the Learning Sciences, 13*(1), 43-76.

Fiske, S. (2002). Where fear lives. *Psychology Today, 35*(5), 74.

Fitzpatrick, J. (1998). *Encyclopedia of nursing research.* New York: Springer.

Flick, U. (2002). *An introduction to qualitative research* (2nd ed.). London: Sage Florida Annual Cancer Report (2003). Retrieved April 8, 2005, from http://www.fbccrf.org/statictics/

Florida Breast Cancer Coalition Research Foundation. (2007). *Florida Breast Cancer Statistics.* Retrieved April 8, 2008, from http://www.fbccrf.org/statictics/

Forte, D. A. (1995). Community-based breast cancer intervention program for older African American women in beauty salons. *Public Health Reports, 110*(2), 179-183.

Foster-Fishman, P. G., Salem, D. A., Chibnall, S., Legler, R., & Yapchai, C. (1998). *Empirical support for the critical assumptions of empowerment theory. American Journal of Community Psychology, 26*(4), 507-537.

Fowler, B. A. (2006). Claiming health: Mammography screening decision making of African American women. *Oncology Nursing Forum, 33*(5), 969-975.

Frankford, D. M. (1997). The Normative Constitution of Professional Power. *Journal of Health Politics and Law, 22*(1), 185-224.

Freeman, K. (1998). *African American culture and heritage in higher education research and practice.* Santa Barbara, CA: Greenwood Publishing Group.

Frisby, C. (2002). Messages of hope: Health communication strategies that address barriers preventing black women from screening for breast cancer. *Journal of Black Studies, 32*(5), 489-505.

Furman, R. (2006). Poetic forms and structures in qualitative health research. *Qualitative Health Research 16(*4), 560–566.

Furman, R., Langer, C. L., Davis, C. S., Gallardo, H. P., & Shantif, K. (2007). Expressive research and reflective poerty as qualitiative inquiry: A study of adolescent identity. *Qualitiative Research, 7,* 301-311.

Gadamer, H. (1996). *Truth and method*. London: Sheed and Ward.

Gates, H., Jr. (Ed). (1988). *Collected black women's narratives.* New York: Oxford University Press.

Gates, M., Lackey, N., & Brown, G. (2001). Caring demands and delay in seeking care in African American women newly diagnosed with breast cancer: An ethnographic, photographic study. *Oncology Nursing Forum, 28,* 529-637.

Gergen, K. (1985). The social constructionist movement in modern psychology. *American Psychologist, 40*(3), 266-275.

Giorgi, A. (2000). The status of Hussedian phenomenology in caring research *Scandinavian Journal of Caring Sciences, 14*(1), 3-10.Glaser, B., & Strauss, A. (1967). *The discovery of grounded theory*. Chicago, IL:Aldine.

Giorgi, A. (1997). The theory, practice, and evaluation of the phenomenological method as a qualitative research procedure. *Journal of Phenomenological Psychology, 28*(2), *235.*

Goldberg, J. (2002). *Florida facts and figures 2001-2002.* Atlanta, GA: American Cancer Society.

Gordon, H., Street, R. L., Sharf, B. F., & Souchek, J. (2006). Racial differences in doctor's information-giving and patient's participation. *Cancer*, *107*(6), 1313-1320.

Graneheim, U., & Lundman, B. (2004). Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today, 24*(2), 105-112.

Guba, E.G., Lincoln, Y.S. (2000), "Paradigmatic controversies, contradictions, and emerging confluences", in Denzin, N.K., Lincoln, Y.S. (Eds),*Handbook of Qualitative Research*, Sage, Thousand Oaks, CA, pp.163-88.

Guba, E. G., & Lincoln, Y. S. (1989). *Fourth generation evaluation*. Newbury Park, CA: Sage.

Guba, E.G., & Lincoln, Y.S. (1995). Naturalistic Inquiry. Newbury Park, CA: Sage

Guidry, J., Matthews-Juarez, P., & Copeland, V. (2003). Barriers to cancer control for African American women: The interdependence of culture and psychosocial issues. *Cancer, 97*(1), 318-323.

Halcomb, E., Ghozlizafeh, L., DiGiacomo, B., Phillips, J., & Davidson, P. (2007). Literature review: Considerations in undertaking focus group research with culturally and linguistically diverse populations. *Journal of Clinical Nursing, 16*(6), 1000-1011.

Hall, M. (2005). Confronting genetic testing disparities: Knowledge is power. *Journal of the American Medical Association, 293*(14), 1783-1785.

Hansen, D. (2004). A poetics of teaching. *Educational Theory, 54*(2), 119-142.

Hare-Mustin, R. T., & Marecek, J. (1988). The meaning of difference: Gender theory, postmodernism, and psychology. *American Psychologist, 43(*6), 455-464.

Heidegger, M. (1962). *Being and time.* New York: Harpers & Rowe. (Original work published 1927).

Hewitt, M., Greenfield, S., & Stovall, E. (Eds). (2006). *From cancer patient to cancer survivor: Lost in transition.* Washington, DC: National Academies Press.

Himmelman, A. T. (1992). Communities working collaboratively for a change. Monograph available from author.

Hirschman, J., Whitman, S., & Ansell, D. (2007). The Black:White disparity in breast cancer mortality: The example of Chicago. *Cancer Causes and Control, 18*(3), 323-333.

Holloway, I. (2005) (Ed.). *Qualitative research in health care*. Berkshire, England: McGraw-Hill International.

Holt, D., Lukwago, S., & Kreuter M. (2003). Achieving cultural appropriateness in health promotion programs: Targeted and tailored approaches. *Health Education Behavior, 30,*133-146.

Hopwood, P. (2000). Breast cancer risk perception: What do we know and understand? *Breast Cancer Research, 387,* 387-391.

Howe, H., Wingo, P., & Thun, M. (2001). Annual report to the nation on the status of cancer (1973 through 1998) featuring cancers with recent increasing trends. *Journal of the National Cancer Institute, 93*, 824-842.

Husserl, E. (1970). *The idea of phenomenology*. The Hague, The Netherlands: Nijhoff.

Institute of Medicine. (2003). *The future of the public's health in the 21st Century*. Washington,DC: National Academies Press.

Institute Of Medicine. (2005). *Saving women's lives: Strategies for improving breast cancer detection and diagnosis.* Washington, DC: National Academies Press.

Jackson, V. (2002). Screening mammography: Controversies and headlines. *Radiology, 225*, 323-326.

Janesick, D. (2003). The choreography of qualitative research: Minuets, improvisations, and crystallization. In N. Denzin & Y. Lincoln (Eds.), *Strategies of qualitative inquiry* (pp. 46-79). Thousand Oaks, CA: Sage.

Jemal, A., Murray, T., & Ward, E, Samules, A., Tiwari, R. C., Ghafoor, E. J., et al. (2005). Cancer Statistics, 2005. *Canadian Cancer Journal for Clinicians, 1,* 10-30.

Joensuu, H., Lehtimaki, Y., & Holli, K. (2004), Risk for distant recurrence of breast cancer detected by mammography screening or other methods. *Journal of the American Medical Association, 292*(4), 1064-1073.

Jones, A., & Chilton, J. (2002). Impact of breast cancer on African American women: Priority areas for research in the next decade. *American Journal of Public Health, 92*(4*)*, 539-541.

Jones, J., & Borbasi, S. (2004). Interpretive research: weaving a phenomenological text. In Clare, J. & Hamilton, H. (Eds.), *Writing research: Transforming data into text* (pp. 85–101). Churchill Livingstone: Edinburgh.

Jones, L. A. (2008). The African American cancer burden. Retrieved January 20, 2009, from http://www.cancer.org/docroot/SPC/content/SPC_1_Jones_Lovell_On-African_American_Cancer_Rates.asp

Jules-Rosette, B. (1980). Talcott Parsons and the phenomenological tradition in Sociology: An unresolved debate. *Human Studies, 3*, 311-330.

Kagawa-Singer, M. (2002). Health literacy and cancer communication. *Canadian Cancer Journal*, *52*,134.

Karliner, L., Napoles-Springer, A., Kerlikowske, K., Haas, J., Gregorich, S., & Kaplan, C. (2007). Missed opportunities: Family history and behavioral risk factors in breast cancer risk assessment among a multiethnic group of women. *Annals of Internal Medicine, 22*, 308-314.

Katz, M. G., Veledar, T.A., & Kripalani, S. (2007). Patient literacy and question-asking behavior during the medical encounter: A mixed methods analysis. *Journal of General Internal Medicine, 22*(6), 782-786.

Kerlikowske, K. & Barclay, J. (1997). Outcomes of modern screening mammography. *Journal of National Cancer Institute, 22,* 105-111.

Kingry-Westergard, C., & Kelly, J. (1990). A contextualist epistemology for ecological research. In P. Tolan, F. Chertok, C. Keys, & L. Jason (Eds.), *Researching community psychology* (pp. 23-31). Washington, DC: American Psychological Association.

Klausner, R. (2000). Statement on the unequal burden of cancer. *National Institute of Health.* Retrieved November 12, 2007, from http://www/gov/asl/testify/t9990121a.html

Kleiman, S. (2004). Phenomenology: To wonder and search for meanings. *Nurse Researcher*, *11*, 7-19.

Kluwer Academics (1997). Special issues in Phenomenology. *Center for Advanced Research in Phenomenology.* Retrieved January, 10, 2007, from www.phenomenologycenter.org

Knutson, D., & Steiner, E. (2007). Screeing for breast cancer: Current recommendations and future directions. *American Family Physician, 57*(11), 1660-1670.

Kooken, W. C., Haase, J. E., & Russell, K. M. (2007). " I've been through something": Poetic explorations of African American women's cancer survivorship. *Western Journal of Nursing Research*, *29*, 896-919.

Kreuter, M. W. & McClure, M. S. (2004). The role of culture in health communication. *Annual Review of Public Health*, *25*, 439–455.

Kurtz, P.E. (2009). Knowledge is power. *Journal of Hand Surgery, 22*(1), 99-101.

Lane**,** M.R. (2005). Spirit body healing: A hermeneutic phenomenological study examining the lived experience of art and healing. *Cancer Nursing, 28*(4), 285-291.

LaVera, M., Crawley, L. M., Ahn, D.K., & Winkleby, M. A.(2008). Perceived medical discrimination and cancer screening behaviors of racial and ethnic minority adults. *Cancer Epidemiology Biomarkers Prevention, 17*(8), 1-8.

Laverty, S. (2003). Hermeneutic phenomenology and phenomenology: A comparison of historical and methodological considerations. *International Journal of Qualitative Methods, 2*(3). Retrieved August 12, 2007, from http://www.ualberta.ca/~iiqm/backissues/2_3final/html/laverty.html

Lawrence ,V. A., Streiner, D., Hazuda, H. P., Naylor, R., Levine, M., & Gafni, A. (2000). A cross-cultural consumer- based decision aid for screening mammography. *Preventive Medicine, 30*, 200-208.

Lerner, B. (2002). When statistics provide unsatisfying answers: Revisiting the breast self-examination controversy. *Journal of the Canadian Medical Association, 166*(2), 477-484.

Li, C., Malone, K., & Daling J. (2003). Differences in breast cancer stage, treatment, and survival by race and ethnicity. *Archives of Internal Medicine, 163,* 49-56.

Lincoln, Y. (1992). The making of a constructivist. In E. Guba. (Ed.) *The alternative paradigm* (pp.67-87). London: Sage.

Lincoln, Y., & Guba, E. (2000). *Naturalistic inquiry*. Beverly Hills, CA: Sage

Long, F. (1995). Breast cancer in African American women. *Cancer Nursing, 16*, 1-24.

Lopez, E., Eng, E., Randall-David, E., & Robinson, N. (2005). Quality-of-life concerns of African American breast cancer survivors within rural North Carolina: Blending the techniques of photovoice and grounded theory. *Qualitative Health Research, 15*, 99-115.

Lorde, A (1985). *The cancer journals*. London, UK: Sheba Feminist Press.

Lyna, P., McBride, C.M., Samsa, G.P., & Pollack, K. (2002). Psychological and behavioural impact of genetic testing smokers for lung cancer risk. *Journal of Health Psychology, 13*(4), 481-494.

Mackel, L. (2000). Taking the breasts out. *Arizona Daily Wildcat.* Retrieved March 15, 2005, from http://wc.arizona.edu/papers/93/91/opinions.html

Mandelson, M. T., Oestreicher, N., Porter, P., White, D., Finder, C. A., Taplin, S. H., et al. (2000). Breast density as a predictor of mammographic detection: Comparison of interval- and screen-detected cancers. *Journal of the National Cancer Institute, 92*, 1081-1087.

Mathews, H. F. (2000) Negotiating cultural consensus in a breast cancer self-help group. *Medical Anthropology Quarterly, 14,* 394-413.

Mathews, H. F., Lannin, D. R., & Mitchell, J. P. (1994). Coming to terms with advanced breast cancer: Black women's narratives from eastern North Carolina. *Social Sciences and Medicine*, *38,* 789–800.

McFadden, J. (2008) *Coming out.* Unpublished doctoral dissertation. Barry University, Miami Shores, Florida.

McMillan, B., Florin, P., Stevenson, J., Kerman, B., & Mitchell, R. (1995). Empowerment praxis in community coalitions. *American Journal of Community Psychology, 23*(5), 699-727.http://web.ebscohost.com.ezproxy.barry.edu/ehost/delivery?vid=5&hid=103&sid=6261793d-5652-4baa-b66b-1ca26a7dcd14%40sessionmgr103 - bib11up#bib11up

Merleau-Ponty, M. (1964). *Phenomenology of perception.* New York: Routledge & Kegan Paul.

Michaelson, J., Satija, S., & Moore, R. (2002). The pattern of breast cancer screening and utilization and its consequences. *Cancer*, *94,* 37-43.

Miles, M., & Huberman, M. (1994). *Qualitative data analysis: A sourcebook of new Methods*, (2nd ed.) Beverly Hills, CA: Sage.

Mitchell, J., Mathews, H. F., & Mayne, L. (2005). Differences in breast self-examination techniques between Caucasian and African American elderly women. *Journal of Women's Health, 14*(6), 476-484.

Moene, M., Bergbom, I., & Skott, C. (2006). Patients' existential situation prior to colorectal surgery. *Journal of Advanced Nursing, 54*(2), 199–207.

Morgan, P., Mock, V., Rose, L., & Fogel, J. (2005). African American women's emotional responses to breast cancer. *Women's Health and Urban Life, 3,* 56-73.

Morrison-Beedy, D., Cote-Arsenault, D., & Feinstein, N. (2001). Maximizing results with focus groups: Moderator and analysis issues. *Applied Nursing Research, 14*(1), 48-53.

Morse, J. (1999). Myth 93: Reliability and validity are not relevant to qualitative inquiry. *Qualitative Inquiry, 9,* 717-718.

Moustakas, C. (1994). *Phenomenological research method.* Thousand Oaks, CA: Sage.

Munhall, P. (2007). *Nursing research: A qualitative perspective* (4th ed.). Boston: Jones & Bartlett. (Original work published 2001).

Myrdal, G. (1944). *An American dilemma: The negro problem and modern democracy*. New York: Harper & Bros.

Myers, M. (2000). Qualitative research and the generalizability question: Standing firm with Proteus. *The Qualitative Report* [On-line serial], *4*(3/4). Retrieved March 10, 2007, from http://www.nova.edu/ssss/QR/QR4-1/myers.html

National Cancer Institute. (2003). *Fact book.* U.S. Department of Health and Human Services, Bethesda, MD. Retrieved December 8, 2006, from http://www3.cancer.gov/admin/fmb/03Factbk.pdf

National Cancer Institute. (2008). Breastcancer screening. *U.S. National Institute of Health.* Retrieved April 10, 2008, from www.cancer.gov

National Cancer Institute Breast Cancer Screening Consortium. (1990). Screening mammography: A missed clinical opportunity. *Journal of the American Medical Association, 264,* 54-58.

Newman, L. (2005). Breast cancer in African American women. *The Oncologist, 10(1),* 1-14.

Nicotera, A. M., Clinkscales M. J., & Walker,F. R. (2003). *Understanding organization through culture and structure: Relational and other lessons from the African American Organization*. Mahwah, NJ: Lawrence Erlbaum Associates.

Nunkoosing, K. (2005). Pearls, path, and provocation: The problem with interviews. *Qualitative Health Research*, *15*(5), 698-706.

Nutting, P. A., Baier, M., Werner, J. J., Cutter, G., Conry, C., & Stewart, L. (2001). Competing demands in the office visit: What influences mammography recommendations? *Journal of American Board of Family Practice, 14*, 352–361.

Nystrom, M., & Dahlberg, K. (2001). Pre-understanding and openness: A relationship without hope. *Scandinavian Journal of Caring Sciences*, *15*(4), 339-346.

Olsson, A., & Phelps, E. A. (2007). Social learning of fear. *Nature Neuroscience*. *10*(9), 1095-1102.

O’Malley, C. D., Le, G. M., Glaser, S. L., Shema, S, J. & West, D. W. (2003). Socioeconomic status and breast carcinoma survival in four racial/ethnic groups: A population based study. *Cancer, 97*, 1303-1311.

Packard, S., & Polifoni, E. (2002). The nature of scientific truth. *Nursing Science Quarterly 5*(4), 158-163.

Parsons, T. (1985). Talcott Parsons on institutions and social eveolution:Selected writings. Chicago, IL: University of Chicago Press.

Patton, M. (2002). *Qualitative research and evaluative designs* (3rd ed.) Thousand Oaks, CA: Sage.

Peek, M. & Han, J. (2004). Disparities in screening mammography: Current status, interventions, and implications. *Journal of General Internal Medicine, 19,* 184-194.

Peek, M.E., Sayad, J.V., & Markwardt, R. (2008). Fear, fatalism and breast cancer screening in low-income African American women: The role of clinicians and the health care system. *Journal of General Internal Medicine, 23*(11), 1857-1853.

Pender, N. J., Murdaugh, C. L., & Parsons, M. A. (2002). *Health promotion in nursing practice.* Upper Saddle River, NJ: Prentice Hall.

Penley, J. A., Tomaka, J., & Wiebe, J. S. (2002). The association of coping to physical and psychological health outcomes: A meta-analytic review. *Journal of Behavioral Medicine, 25*, 551–603.

Perkins, D., Douglas, D., & Zimmerman, M. (1995). Empowerment theory, research, and application. *American Journal of Community Psychology, 23*(5), 569-580.

Persily, C. A., & Hildebrant, E. (2003). Theory of community empowerment. In M.J. Smith& P. R. Liehr (Eds.), *Middle Range Theory for Nursing* (pp. 111-123). New York: Springer Publishing.

Phillip, J. M., Cohen, M. Z., & Moses, G. (1999). Breast cancer screening and African American women: Fear, fatalism, and silence. *Oncology Nursing Forum*, *26*, 561-571.

Phillips, J., Cohen, M., & Tarzian, A. (2001). African American women's experiences with breast cancer screening. *Journal of Nursing Scholarship, 33*(2), 135-140.

Polit, D., & Beck, C. (Eds.). (2005). *Essentials of nursing research: Methods, appraisal, and utilization* (6th ed.). Philadelphia: LWW.

Pope, C., Ziebland, S., & Mays, N. (2000). Qualitative research in health care: Analyzing qualitative data. *British Medical Journal, 7227*, 114-116.

Powe, B. D., Daniels, E. C., Finnie, R., & Thompson, A. (2005). Perceptions about breast cancer among African American women: Do selected educational materials challenge them? *Patient Education and Counseling , 56*(2), 197-204.

Powe, B. D., & Finnie, R. (2003). Cancer Fatalism. *Cancer Nursing 26*(6), 454-467.

Prothrow-Stith, D., Gibbs, B., & Allen, A. (2003). Reducing health disparities: From theory to practice. *Cancer Epidemiology Biomarkers & Prevention, 12*, 256-260.

Racher, F., & Robinson, S. (2003). Are phenomenology and postpostivism strange bedfellows? *Western Journal of Nursing Research 25*(5), 464–481.

Rappaport, J. (1981). In praise of paradox. A social policy of empowerment over prevention. *American Journal of Community Psychology, 9*, 1-25.

Rappaport, J. (1984). Studies in empowerment: Introduction to the issue *Prevention in Human Services, 3,* 1-7.

Rappaport, J. (1987). Terms of empowerment/exemplars of prevention: Toward a theory for community psychology. *American Journal of Community Psychology, 15*, 121-148.Rawl, S., Champion, V., & Menon, U. (2000). The impact of age and race on mammography practice. *Health Care for Women International, 21*, 583-397.

Richards, M., & Schwartz, L. (2002) Ethics of qualitative research: Are there special issues for health services research? *Family Practice, 19*(2), 135-139.

Richardson, L. (2000). New writing practices in qualitative research. *Sociology of Sport Journal, 17,* 5-20.

Richardson, L. (1993). Poetics, dramatics, and transgressive validity: The case of the skipped line. *The Sociological Quarterly, 34*, 695-710.

Ries, L., Eisner,M., & Kosary, C. (2003). Surveillance epidemiology: End results cancer statistics review, 1975-2001. Bethesda, MD: National Cancer Institute.

Rimer B. (1994). Interventions to increase breast screening. *Cancer Supplement, 74,* 323- 327.

Rojas, M., Mandelblatt, J., Cagney, K., Kerner, J., & Freeman, H. (1996). Barriers to follow up of abnormal screening mammograms among low-income minority women. *Ethnicity & Health, 1*(3), 221–228.

Rolfe, G. (2006). Technical rationality and the theory-practice gap. *Nursing Science Quarterly, 19,* 39-43.

Roosevelt, E. (1961). *The autobiography of Eleanor Roosevelt.* New York:HarperCollins.

Roosevelt, F. D. (1938) Inaugural Address. In S. Rosenman, (Ed.) *The public papers of Franklin D. Roosevelt, Volume Two: The Year of Crisis, 1933* (pp. 11–16). New York: Random House.

Rosenbaum, M. E., & Roos, G. M. (2000). Women’s experiences of breast cancer. In A. S. Kasper & S. J. Ferguson (Eds.), *Society shapes an epidemic: Women, their bodies, and the illness experience* (pp. 153-177). New York: St Martin Press.

Rosenbaum, S., Markus, A., & Darnell, J. (2000). U.S. civil rights policy and access to health care by minority Americans: Implications for a changing health care system. *Medical Care Review*; *57*(1), 236-259.

Rosolowich, V. (2006). Breast self-examination. *Canada Journal of Obstetrics and Gynaecology* , *26*(8), 728–730.

Royak-Schaler, Passmore, S.R., Gadalla, S., Hoy, M.K., Zhan, M., Tkaczuk, K., et al. (2008). Exploring patient-physician communication in breast cancer care for African American women following primary treatment. *Oncology Nursing Forum*, *35*(5), 836-843.

Ruff, C. C., Alexander, I., & McKie, I. (2005). The use of focus group methodology in health disparities research. *Nursing Outlook*, *53*(3), 134-140.

Russell, K. M., Swenson, M. M., Skelton, A. M., Shedd-Steele, R. (2003*).* The meaning of health in mammography screening for African American women. *Health Care for Women International*, *24*(1), 27.

Rutledge, D., Barsevick, A., Knobf, M., & Bookbinder, M. (2001). Breast cancer detection: Knowledge, attitudes, and behaviors of women from Pennsylvania, *Oncology Nursing Forum*, *28*(6), 1032-1040.

Ryan, G., & Bernard, H. (2003). Techniques to identify themes. *Field Methods*, *15*(1), 85-109.

Sabatino, S., Burns, R., Davis, R., Phillips, R., & McCarthy, E. (2006). Breast cancer risk and provider recommendation for mammography among recently unscreened women in the United States*. Journal of General Internal Medicine, 21*(4), 285-291.

Sadan, E. (1994). *Empowerment in the context of community planning: A theoretical development. Unpublished doctoral dissertation*. Technion University, Israel Retrieved January 28, 2009, from http://www.graduate.technion.ac.il/theses/Abstracts.asp?Id=20879

Sadler, G. R., Escobar ,R. P., Ko, C. M., White, M., Lee, S., Neal, T., & Gilpin, E.A. (2007). African-American women's perceptions of their most serious health problems. *Journal of the National Medical Association, 97*, 31–40.

Sandelowski, M. (1995). Focus on qualitative methods: Sample size in qualitative research. *Research in Nursing and Health, 18*, 179-183

Schiele, J.H. (2000). *Human services and the Afrocentric paradigm*. Binghamton, NY: Hawthorne Press.

Schootman, M., Jeffe, D., Baker, E., & Walker, M. (2006). Effect of area poverty rate on cancer screening across US communities. *Journal of Epidemiology and Community Health, 60*, 202-207.

Schwartz, L. M., Woloshim, S., Cox, H. C., Fischloff, B., & Welc, H. G. (2000). US women’s attitude to false positive mammography results and detection of ductal carcinoma in situ: Cross sectional survey. Western Journal of Medicine, 173 (5), 307-12, 313-14.

Shabazz , A.K.(2005). Keeping secrets close to the breast. *Minority Nurse, 12(4),* p. 5-6.

Sharp, P.C., Michielutte, R., Freimanis, R., Cunningham, L., Spangler, J., & Burnette, V. (2003). Reported pain following mammography screening. Archives of Internal Medicine, 163, p. 833-836.

Shenton, A. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information, 22*(2), 63-75.

Sloand, E., Groves, S., & Brager, R. (2004) Cultural competency education in American nursing programs and the approach of one school of nursing. *International Journal of Nursing Education Scholarship, 1*(1,), 6-12.

Smedley, B. D., Stith, A.Y., & Nelson. A. R. (Eds.). (2003). *Unequal treatment: Confronting racial and ethnic disparities in health care.* Washington, DC: National Academies Press.

Smith, R. (2003). American Cancer Society guidelines for breast cancer screening update. *Canadian Cancer Journal for Clinicians, 53,* 141-169.

Smith, M., French, J., & Barry, C. (1995). Ethics in focus groups: A few concerns. *Qualitative Health Research, 5*, 478-486.

Smith-Bindman, R., Miglioretti, D., Lurie, N., Abraham, L., Barbash, R. B., Strzelczyk, J., et al. (2006). Does utilization of screening mammography explain racial and ethnic differences in breast cancer? *Annals of Internal Medicine, 144,* 541-553.

Spence, D. (2001). Hermeneutic notions illuminate cross-cultural nursing experiences. *American Journal of Nursing, 35*(4), 624-630.

Spiegelberg, H. 1982. *The phenomenological movement*. The Hague: Martinus Nijhoff.

Straker, K. S. (2002). *Guidebook for patient counseling*. Shawnee Mission, KS: CRC.

Strauss, A., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques.* Newbury Park, CA: Sage.

Stein, H.F. (2004). A window to the interior of experience. *Families, Systems, & Health, 22*, 178-179.

Stein, R. (2007). *Drug-resistant breast cancer afflicts Blacks.* Retrieved May 25, 2007, from http://www.msnbc.msn.com/id/19360925/from/ET/

Stephenson, R., & Gorey, K. (2008, June). The association of ethnicity with breast cancer screening in Canada and the United States: Meta-analytic suggestion that it is class and education, not race/ethnicity per se nor culture. Roundtable presentation at the annual meeting of the American Public Health Association, Epidemiology Section. Boston, MA.

Stroker, E. (1993). *Husserl's transcendental phenomenology.Stanford, CA: Stanford University Press.*

Swan, J., Breen, N., Coates, R., Rimer, B., & Lee, N. (2003*).*Progress in cancer screening practices in the United States: Results from the 2000 National Health InterviewSurvey. *Cancer 3*(97), *1528*-1540.

Swigonoski, M. E. (1994). Empowerment in community outreach and education. *Journal of Applied Behavioral Science, 30*, 159-175.

Tabar, L., Vitak, B., Chen, H.H., & Yen, M.F. (2000). The Swedish two-country trial twenty years later updated mortality results. Radiologic Clinics of North America, 38(4), p.625-651.

Tangka, F., Dalaker, J., Chattopadhyay, S., Gardner, J. G., Royalty, J., Hall, I. J., et al. (2006). Meeting the mammography screening needs of underserved women: The performance of the National Breast and Cervical Cancer Early Detection Program in 2002-2003 (United States). *Cancer Causes & Control, 17*, 1145-1154.

Thomas, D., Gao, D., Self, S., Allison, C., Tao, Y., & Mahloch J. et al. (1997). Randomized trial of breast self-examination in Shanghai: Methodology and preliminary results. *Journal of the National Cancer Institute, 89,* 355-365.

Thomas, E. (2004). African American women's breast memories, cancer beliefs, and screening behaviors. *Cancer Nursing, 27*(4), 295-302.

Thomas, E. (2006). Ring of silence: African American women's experiences related to their breasts and breast cancer screening. *The Qualitative Report, 11*(2), 350- 373.

Thorne, S. (2000). Data analysis in qualitative research. *Evidence-Based Nursing, 3,* 68-70.

Underwood, S. (2007). Expanding the evaluation of theories, models, and frameworks relevant to the detection and control of breast cancer in African American women: A research imperative. *Journal of National Black Nurses Association, 18*(1), 50-60.

Underwood, S., Buseh, A., Canales, M., Dockery, B., Powe, B., Kather, T., et al (2005). Nursing contributions to the elimination of health disparities among African Americans: Review and critique of a decade of research—part III. *Journal of the National Black Nurses Association, 16*(2), 35-59.

U.S. Department Health and Human Services (USDHHA). (2000). *Healthy People 2010*. Washington, DC: Author.

U.S. Department of Health and Human Services (USDHHA): Healthy People 2010 (2nd ed.). (2001). Understanding and improving health and objectives for improving health. Washington, DC: U.S. Government Printing Office.

van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy.* Albany, NY: State University of New York Press.

Van der Zalm, J., & Bergum, V. (2000) Hermeneutic-phenomenology: Providing living knowledge for nursing practice. *Journal of Advanced Nursing, 31*(1), 211–218.

Wallace, M. (1978). *Black macho and the myth of superwoman*. New York: Dial

Weiss, M. (2007). Breast health and breast cancer. Retrieved February 15, 2008, from www.breastcancer.org

Williams, M. (2001). Promoting early breast cancer screening: Strategies with rural African American women. *American Journal of Health Studies, 20*(6), 389-399.

Wingo, P., Ries, L., Rosenberg, H., Miller, D., & Edwards, B. (1998). Cancer incidence and mortality 1973-1995: A report card for the US. *Cancer*, *82*, 1197-1207.

Woodward, K. (2004). HRT double breast density. *Center News, 10*(21), 264.

Zaner, R., & Ihde, D. (1973*). Phenomenology and existentialism.* New York: Putnam

Zimmerman, M. A. (1995). Psychological empowerment: Issues and illustrations. *American Journal of Community Psychology, 23*(5), 581-599.

Appendix A

Barry University Research with Human Participants Protocol Form

Appendix A
Barry University
Research with Human Participants
Protocol Form

PROJECT INFORMATION

1. Title of Project: *A Phenomenological Inquiry of African American Women's Experiences with Mammography Screening.*

2. **Principal Investigator** (please type or print) Gwendolynn D. Randall, CRNA, MSN, MS.

Name: Gwendolynn D. Randall, CRNA, MSN, MS.
School – Department: School of Nursing

*NOTE: You **WILL NOT** receive any notification regarding the status of your proposal unless accurate and complete contact information is provided at the time the proposal is submitted.*

3. **Faculty Sponsor** (If Applicable)

Name: Jessie Colin, Ph.D., RN.
School – Department: Barry University, School of Nursing
Mailing Address: Weigand Hall 105
Telephone Number: 305-899-3830
E-Mail Address: jcolin@mail.barry.edu

Faculty Sponsor Signature:________________________________Date: _____________

4. **Is an IRB Member on your Dissertation Committee? Yes ___X___ No: __**

5. **Funding Agency or Research Sponsor**
(Name, Address) None

6. **Proposed Project Dates**
Start September 1,2008
End __August 30, 2009

Please Provide the Information Requested Below

A. Project activity STATUS is: (Check one of the following three as appropriate.)

__X_NEW PROJECT
___ PERIODIC REVIEW ON CONTINUING PROJECT
___ PROCEDURAL REVISION TO PREVIOUSLY APPROVED PROJECT
(Please indicate in the **PROTOCOL** section the way in which the project has been revised.

B. This project involves the use of an **INVESTIGATIONAL NEW DRUG (IND) OR AN APPROVED DRUG FOR AN UNAPPROVED USE** in or on human participants.
___ YES __X_NO
Drug name, IND number and company:
____

C. This project involves the use of an **INVESTIGATIONAL MEDICAL DEVICE (IMD)** or an **APPROVED MEDICAL DEVICE FOR AN UNAPPROVED USE.**
___ YES _X__NO

D. This project involves the use of **RADIATION** or **RADIOISOTOPES** in or on human participants.
___ YES _X__NO

E. This project involves the use of Barry University students as participants. (If any students are minors, please indicate this as well.)
___ YES Barry Students will be participants (Will minors be included? ___ YES ___ NO)
__X_NO Barry Students will participate

F. **HUMAN PARTICIPANTS** from the following population(s) would be involved in this study:

___ Minors (under age 18)
___ Abortuses
___ Prisoners
___ Mentally Disabled
___ Other institutionalized persons (specify)
__x_ Other (specify) African American adult women
____

___ Fetuses
___ Pregnant Women
___ Mentally Retarded

G. Total Number of Participants to be Studied: _Maximum of_20______

Description of Project

1. ABSTRACT (200 words or less)

Background: Breast cancer is the second leading cause of cancer deaths among African American women, surpassed only by lung cancer. The incidence rate of breast cancer is 17% lower in African American women than in comparison to White women; however, among younger African American women (under age 40), the mortality rate is 32% higher than among White women. The lower incidence of breast cancer and the higher mortality rate in African American women is a phenomena largely unexplained. Screening can greatly improve the chances for cure, extend life, reduce the extent of treatment needed, and improve quality of life for cancer patients.

Purpose: The purpose of this study is to explore the lived experiences of African American women with mammography screening and to gain an understanding about their everyday lived experience as perceived and comprehended by them.

Method: The hermeneutic phenomenological method of van Manen guided this study. The researcher used purposive sampling of African American women participants to a maximum of 20. The African American women will be individually interviewed utilizing an open-ended interview protocol. For inclusion in this study the women must: self identify as African American; be 25-55 years of age; must speak, read, write, and understand English; have no previous or current diagnosis of breast cancer; have had only one mammogram; live in Palm Beach County; and are willing to participate in the study. The rigor and trustworthiness of the project will be estimated by credibility, dependability, confirmability, authencitity, and transferability of the data.

2. Recruitment Procedures

Describe the selection of participants and methods of recruitment, including recruitment letter if applicable. (**NOTE**: If the investigator has access to participants by virtue of his or her position within the study setting, please provide a brief description of such access.)

The researcher will employ purposive sampling to identify and recruit a maximum of 20 African American women. Criteria for inclusion will include: women will self-identify as African American; women between the ages of 25 and 55; women will be able to speak, read, write, and understand English; no previous or current diagnosis of breast cancer; have had only one mammogram, women will live in Palm Beach County, and a willingness to participate in this study. Participants will be solicited by the use of poster and/or flyers placed in local African American churches, primary care physician offices, ob-gyn physician offices, and housing developments within Palm Beach County, Florida (See Appendix C). The recruitment handouts will clearly identify the researcher as an African American doctoral student. Interested participants will be requested to contact the researcher by phone or mail. The first 20 participants who contact the researcher and indicate verbally that they meet the criteria and are willing and able to participate will comprise the sample for this study. A demographic survey data sheet will be used to collect data in order to describe the study sample (Appendix D). The following data will be gathered: age, education, mammogram history, clinical self examination history, routine self breast examination history, income, and view of chances of getting breast cancer.

3. Methods

Describe procedures to which humans will be subjected. Include a description of deceptive techniques, if used, and debriefing procedures to be used on completion of the study. Use additional pages, if necessary.

The researcher will use a qualitative research design guided by a phenomenological tradition in order to identify, describe and explicate the meaning of the life-worlds of African-American experiences with mammography screening. Participants will be asked to sign the Informed Consent Form (Appendix B) and complete the demographic data survey (Appendix D) prior to the onset of the interview. All sessions will be audio taped with the recorder openly in view. The researcher will conduct one-one-on-one semi-structured, audio-taped interview using open ended questions and following the hermeneutic interview process for the purpose of data collection. The researcher plans to meet with the participants for another one hour session once interview audio-tapes have been transcribed in order for participants to identify, correct, refute, or clarify responses, which is called member checking. The interviews will take place in a mutually agreed upon location, date and time at the convenience of the participant. Participants will be informed they have the right to refuse to answer any questions that makes them feel uncomfortable or request that the tape be stopped and resumed at any point during the interview. There are no perceived risks for your involvement in this study. However, there is always a possibility that something said during the discussions could trigger a distressing emotional response. A referral letter for free psychological evaluation services will be given to each participant at the end of each interview to be used in the event of emotional distress during or after the interview process (see Appendix G).You may drop out of the study at any time.

Prior to transcription, the tapes will be reviewed to validate the ability to understand and hear the participant’s conversation. The audio taped interview, when completed, will be transcribed verbatim using an established transcription service. The transcription service will be required to sign a Third Party Confidentiality Agreement (see Appendix F). Upon return of the transcripts, the transcripts will be reviewed with the tapes to assure accuracy by the researcher. They may also be peer reviewed by members of the Dissertation committee and the Dissertation Chair to guard against bias. Biases will be ensured through journaling of personal assumptions. Overarching themes will be identified. The findings will be correlated to the literature and implications for nurses and health care providers identified. A narrative report of the findings will be developed and reported in the aggregate.

Confidentiality of the participants will be maintained by disguising identifiers with monikers, additionally data will be disseminated in aggregate**.** Monikers, such as Breast Cancer Screening Participant (BCSP-1, BCSP-2, etc.) will be used in transcripts and other identifying details of the project. Identifiers and data will be kept separate. The signed consent forms (see Appendix B) will be kept separate from the data. To ensure confidentiality, the researcher will employ foolproof strategies for the secure storage of tapes and transcripts. Once participants have verified the accuracy of the transcripts, audio tapes will be destroyed within 2 weeks. The transcripts will be kept in a locked file box, in a locked cabinet, in the researcher’s locked home office. Transcripts, demographic data sheets and signed Informed Consent form will be disposed of after 5 years (see Appendix B).

Participants can contact the researcher by cell phone or e-mail for questions or concerns. The participants will be requested to give the researcher the most appropriate means of contact for interview arrangements and review of the transcripts. This may include cell phone number, home phone number or e-mail address.

van Manen's (1990) hermeneutic phenomenological research approach to the human sciences will be used to guide this study. Interplay of six research activities will be followed:

(1) identification of the phenomenon of serious interest to researcher

(2) investigating the lived experience of the participants;

(3) reflecting on the essential themes which characterize the phenomenon;

(4) describing the phenomenon through the art of writing and rewriting;

(5) manipulating a strong and oriented pedagogical relation to the phenomenon;

(6) balancing the research context by considering parts and whole. (pp. 30-31).

Reciprocity

The issue of whether to compensate and how to compensate interviewees involve questions of both ethics and data quality. Researchers can offer participation incentives in the form of a modest gift certificate to compensate the participants for their time and participation, while at the same time praising them for their contribution to research efforts (Patton, 2002). It is the intent of the researcher to offer each participant $20.00 gift certificates to a gas station or Publix supermarket in the local area.

4. **Alternative Procedures**

Describe alternatives available to participants. One alternative may be for the individual to withhold participation.

> Participants may refuse to participate, may refuse to answer any particular question(s), or may ask that the tape-recorder be turned off at any time without fear of retribution.

5. **Benefits**

Describe benefits to the individual and/or society.

There are no direct benefits to the participants. The findings of this study will illuminate the lived experience of African American women with mammography screening. Conducting qualitative research can play a significant role in improving breast cancer rates and outcomes in African American women by gaining an understanding of their breast cancer screening practices. The researcher is hopeful that the information obtained from this study will be instrumental in the development of culturally sensitive teaching strategies to increase the participation of African American women with breast cancer screening tests, therefore, decreasing the mortality**.** This study will serve as a springboard to influence social policies on preventive health behaviors for minorities, collection of useful data, and improving quality of care.

6. **Risks**

Describe risks to the participant and precautions that will be taken to minimize them. Include physical, psychological, and social risks.

While there appears to be no associated risks to participants from this study, there is a possibility of triggering some emotional trauma or distress during the interview process. A referral letter for free psychological evaluation services will be given to each participant at the end of each interview to be used in the event of emotional distress during or after the interview process (see Appendix G).

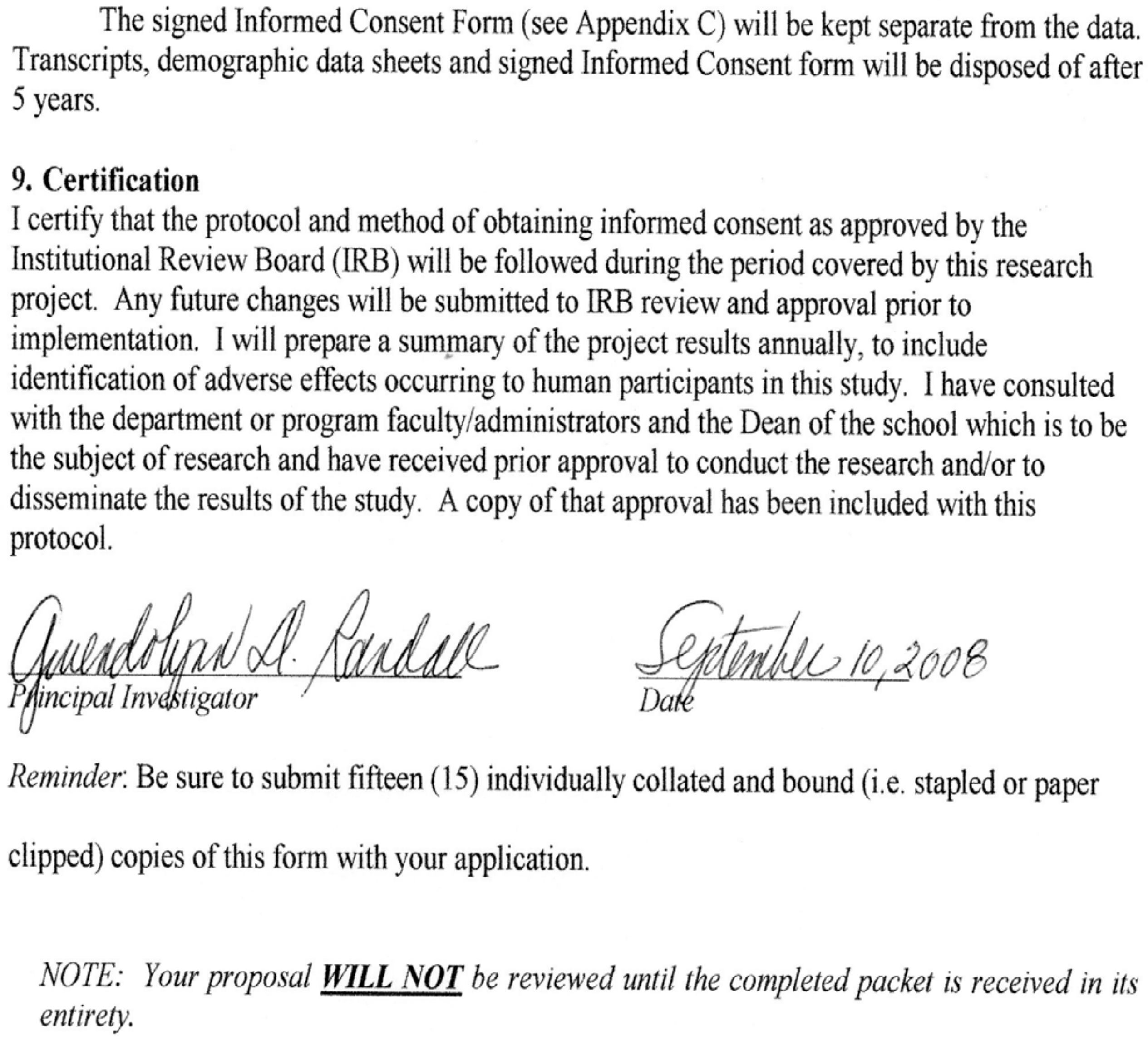
7. Anonymity/Confidentiality

Describe methods to be used to ensure the confidentiality of data obtained.

Anonymity cannot be maintained in this type qualitative study. Confidentiality of the participants will be maintained by disguising demographic identifiers with monikers or pseudo names. The signed consent forms will be kept separate from the data. All documents and tapes will be coded with the moniker of each participant. The audio-tapes will be destroyed after transcription and verification of accuracy by the participants. All data will be stored on the researcher's computer and the hard drive backed up after each transcription. The transcripts will be secured in a locked file box, in a locked cabinet, in the researcher's home office. Transcripts, demographic data sheets and signed Informed Consent form will be disposed of after 5 years (see Appendix C)

8. Consent

Attach a copy of the consent form(s) to be signed by the participant and/or any statements to be read to the participant or informational letter to be directed to the participant. **(A copy of the consent form should be offered to each participant.)** If this is an anonymous study, attach a cover letter in place of a consent form.



The signed Informed Consent Form (see Appendix C) will be kept separate from the data. Transcripts, demographic data sheets and signed Informed Consent form will be disposed of after 5 years.

9. Certification

I certify that the protocol and method of obtaining informed consent as approved by the Institutional Review Board (IRB) will be followed during the period covered by this research project. Any future changes will be submitted to IRB review and approval prior to implementation. I will prepare a summary of the project results annually, to include identification of adverse effects occurring to human participants in this study. I have consulted with the department or program faculty/administrators and the Dean of the school which is to be the subject of research and have received prior approval to conduct the research and/or to disseminate the results of the study. A copy of that approval has been included with this protocol.

Gwendolyn A. Randall
Principal Investigator

September 10, 2008
Date

Reminder: Be sure to submit fifteen (15) individually collated and bound (i.e. stapled or paper clipped) copies of this form with your application.

*NOTE: Your proposal **WILL NOT** be reviewed until the completed packet is received in its entirety.*

Appendix B

Barry University Informed Consent Form

Approved by IRB
Date: SEP 1 5 2008
Signature: MD, FACEP

Appendix B

Barry University Informed Consent Form

Your participation in a research project is requested. The title of the study is *A Phenomenological Inquiry of African American women's experience with mammography screening tests.* The research is being conducted by Gwendolynn D. Randall, CRNA, MSN, MS., a doctoral student in the School of Nursing at Barry University, and is seeking information that will be useful in the field of nursing and breast cancer research. The aim of the research is to explore the lived experience of African American women's with mammography screening tests. In accordance with these aims, one-on-one personal interviews will be scheduled. I anticipate the number of participants to be a maximum of 20.If you decide to participate in this research, you will be asked to do the following: complete a demographic survey form requiring about 5-10 minutes of your time and discuss your experience(s) with breast cancer screening tests during a one hour one-on-one audio taped interview. We will meet at a mutually agreeable place, time and date. Once the research data has been complied, you will be asked to participate in a review of the recorded interview for completeness and accuracy which will require another hour of your time. Your consent to be a research participant is strictly voluntary and should you decline to participate or drop out at any time during the study, there will be no consequences to you. You have the right to refuse to answer a question or request that the tape be stopped and resumed at any point during the interview. A transcription service will be used to transcribe the information obtained during the audio-taped interview.

There are no perceived risks for your involvement in this study. However, there is always a possibility that something said during the discussions could trigger a distressing emotional response. A referral letter for free_psychological evaluation services will be given to each participant at the end of each interview to be used in the event of emotional distress during or after the interview process (see Appendix G).You may drop out of the study at any time.

There are no direct benefits to you for participating in this study. The indirect benefits to your participation in this study will help illuminate the lived experience of African American women with breast cancer screening tests. The findings of this study may be instrumental in the development of culturally sensitive teaching strategies to increase the participation of African American women with breast cancer screening tests, therefore, helping in decreasing the mortality. A $20.00 compensation fee will be paid for your participation in this study.

As a research participant, information you provide will be held in confidence to the extent permitted by law. Any published results of the research will refer to your pseudo name or code and no real names will be used in the study. Data will be kept in a locked file in the researcher's home office. Your signed consent form will be kept separate from the data. The surveys will be destroyed two weeks after data analysis has been completed. The audio tapes will be destroyed after transcription and verification of accuracy by the participants. The signed consent form and transcripts will be disposed of after 5 years.

If you have any questions or concerns regarding the study or your participation in the study, you may contact me, Gwenn Randall, at (561)628-1930, my supervisor, Dr. Jessie Colin at (305) 899-3830, or the Institutional Review Board point of contact, Mrs. Barbara Cook , at (305)899-3020. If you are satisfied with the information provided and are willing to participate in this research, please signify your consent by signing this consent form. As an alternative, you may choose to refrain from participating.

Voluntary Consent

I acknowledge that I have been informed of the nature and purposes of this experiment by Gwendolynn D. Randall and that I have read and understand the information presented above, and that I have received a copy of this form for my records. I give my voluntary consent to participate in this experiment.

____
Participant
Date ____________________

Gwendolynn D. Randall
Researcher
Date ____________________

Appendix C

Recruitment Flyer

Appendix C
Recruitment Flyer

Sista! Sista!

My name is Gwenn Randall. CRNA, MSN, MS, ARNP I am an African American female doctoral student in the School of Nursing at Barry University. I am inviting you to participate in a research project that seeks to explore African American women's experience with breast cancer screening tests.

Breast cancer is the second leading cause of cancer deaths among African American women, exceeded only by lung cancer. Despite all the significant advancements in the area of breast cancer research African American women clearly have not fully benefited.

Eligibility for participation:

- Self identify as African American
- Between the ages of 25-55 years old and pre-menopausal
- English speaking with ability to read, write and understand English
- No previous diagnosis of breast cancer
- Had only one mammogram
- Live in Palm Beach County, Florida
- Willingness to participate in this study

What you will be required to do:

- Participate in two (2) live one-on-one one hour interviews with the researcher.
    - The first interview will be to explore your experiences with breast cancer screening tests and the session will be audio taped.
    - The second interview will be for you to review the transcribed interview and clarify, correct, refute, or delete any information.
    - Complete a survey form requiring about 5-10 minutes of your time.

*If you are interested, please contact Gwenn Randall @ randallg@barry.mail.edu
You may also contact Dr. Jessie Colin @ 305-899-3830 or
Ms. Barbara Cook @ 305-899-3020.
All information provided will remain confidential

****Thank you in advance for your participation**

Appendix D

Demographic Survey

Appendix D
Demographic Survey

1. How many mammograms have you had?
   - ☐ 1
   - ☐ 2
2. How long since your last mammogram?
   - ☐ 1 year
   - ☐ 2 years
   - ☐ >3 years
3. Do you perform breast self examination?
   - ☐ Yes
   - ☐ No
4. Do you have routine clinical breast examinations by your doctor?
   - ☐ Yes
   - ☐ No
5. Has anyone in your family ever been diagnosed with breast cancer?
   - ☐ Yes
   - ☐ No
6. Has anyone in your family ever died of breast cancer?
   - ☐ Yes
   - ☐ No
7. Are you familiar with your family history as it relates to the incidence of breast cancer?
   - ☐ Yes
   - ☐ No
   - ☐ Somewhat
8. Are you aware of breast cancer risk factors?
   - ☐ Yes
   - ☐ No
9. Where do you get your health information?
   - ☐ TV
   - ☐ Radio
   - ☐ Newspapers
   - ☐ Magazines
   - ☐ Friend or relative
   - ☐ Other (please specify) ______________
10. Age (in years)
    - ☐ 25-30 years
    - ☐ 31-40 years
    - ☐ 41-50 years
    - ☐ 51-55 years
11. Education (check appropriate box)
    - ☐ Some high school
    - ☐ High school graduate or GED
    - ☐ Some college
    - ☐ Graduate degree
    - ☐ Doctoral degree
12. With what racial group do you self-identify?
    - ☐ African-American
    - ☐ Caribbean
    - ☐ Haitian
    - ☐ Other (please specify) ________________________________
13. Are you concerned about getting breast cancer?
    - ☐ Yes
    - ☐ No

Comments:
____
____
____
____

Appendix E

Interview Guide

Appendix E
Interview Guide

1. Can you tell me in your own words what breast health means to you?
2. Will you please describe your lived experience with mammography screening?
3. Do you perform monthly breast self examinations?
4. Were you ever prompted to get screened from your physician?
5. Since you have only had one mammogram can you please tell me some of the reasons you have not had another?
6. Is there anything else that you would like to discuss pertaining to this interview?

Appendix F

Confidentiality Agreement for Transcription Services

Appendix F
Confidentiality Agreement for Transcription Services

As a member of the research team investigating the Phenomenological Inquiry of African American women with mammography, I understand that I will have access to confidential information about study participants. By signing this statement, I am indicating my understanding of my obligation to maintain confidentiality and agree to the following:

I understand that names and any other identifying information about study participants are completely confidential.

I agree not to divulge, publish, or otherwise make known to unauthorized persons or to the public any information obtained in the course of this research project that could identify the persons who participated in the study.

I understand that all information about study participants obtained or accessed by me in the course of my work is confidential. I agree not to divulge or otherwise make known to unauthorized persons any of this information unless specifically authorized to do so by office protocol or by a supervisor acting in response to applicable protocol or court order, or public health or clinical need.

I understand that I am not to read information and records concerning study participants, or any other confidential documents, nor ask questions of study participants for my own personal information but only to the extent and for the purpose of performing my assigned duties on this research project.

I understand that a breach of confidentiality may be grounds for disciplinary action, and may include termination of employment.

I agree to notify my supervisor immediately should I become aware of an actual breach of confidentiality or situation which could potentially result in a breach, whether this be on my part or on the part of another person.

______________________________ __________ ____________________________
Signature Date Printed Name

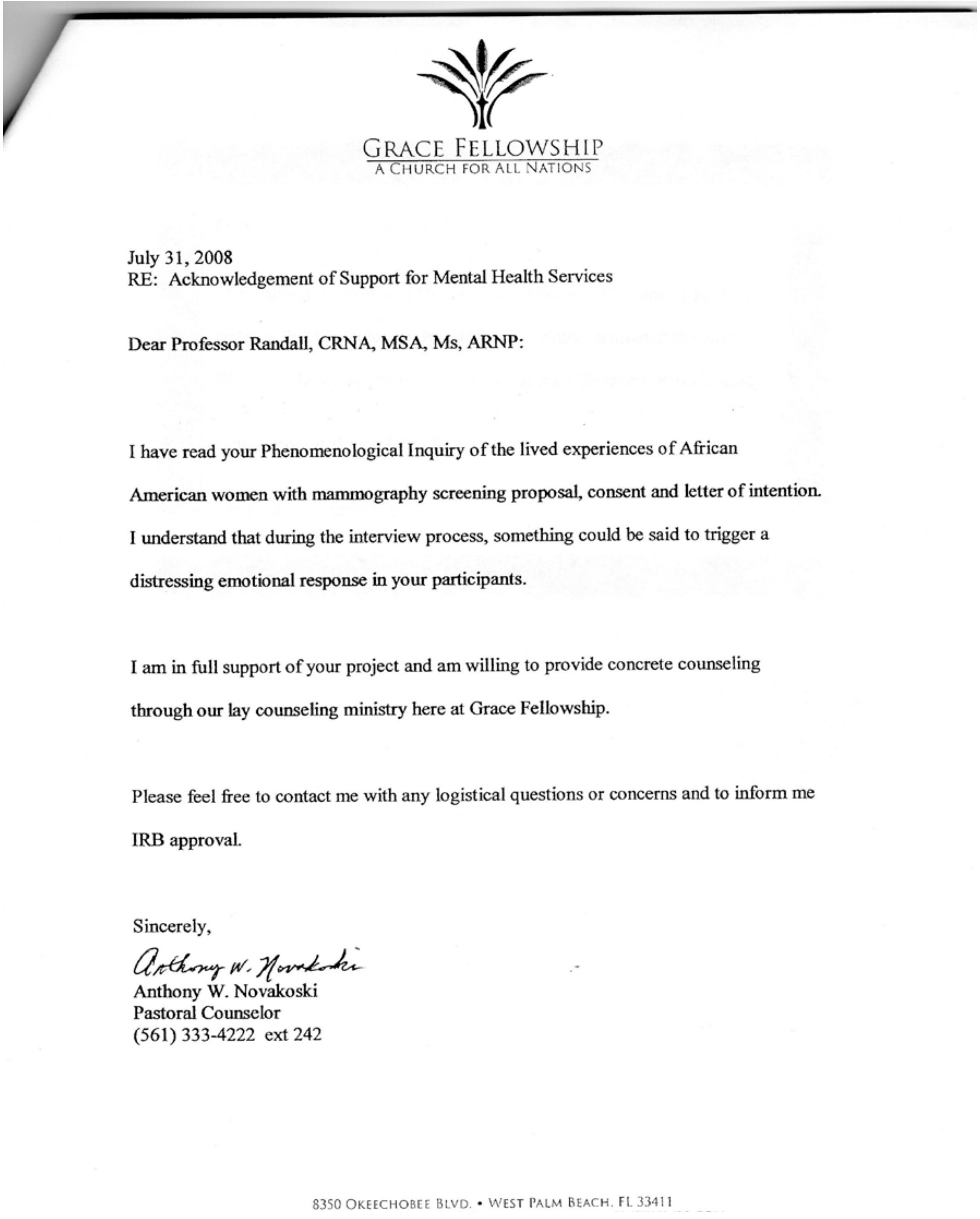
______________________________ __________ ____________________________
Signature Date Printed Name

Appendix G

Letter of Support

Appendix G

Letter of Support



GRACE FELLOWSHIP
A CHURCH FOR ALL NATIONS

July 31, 2008
RE: Acknowledgement of Support for Mental Health Services

Dear Professor Randall, CRNA, MSA, Ms, ARNP:

I have read your Phenomenological Inquiry of the lived experiences of African American women with mammography screening proposal, consent and letter of intention. I understand that during the interview process, something could be said to trigger a distressing emotional response in your participants.

I am in full support of your project and am willing to provide concrete counseling through our lay counseling ministry here at Grace Fellowship.

Please feel free to contact me with any logistical questions or concerns and to inform me IRB approval.

Sincerely,

Anthony W. Novakoski

Anthony W. Novakoski
Pastoral Counselor
(561) 333-4222 ext 242

8350 OKEECHOBEE BLVD. • WEST PALM BEACH, FL 33411

Appendix H
Permission Letter

Appendix H
Permission Letter

BARRY
UNIVERSITY

September 8, 2008

To: Palm Beach County Hospitals
OB/GYN Physician Offices in Palm Beach County
Palm Beach County Surgery Centers
Primary Care Physician Offices

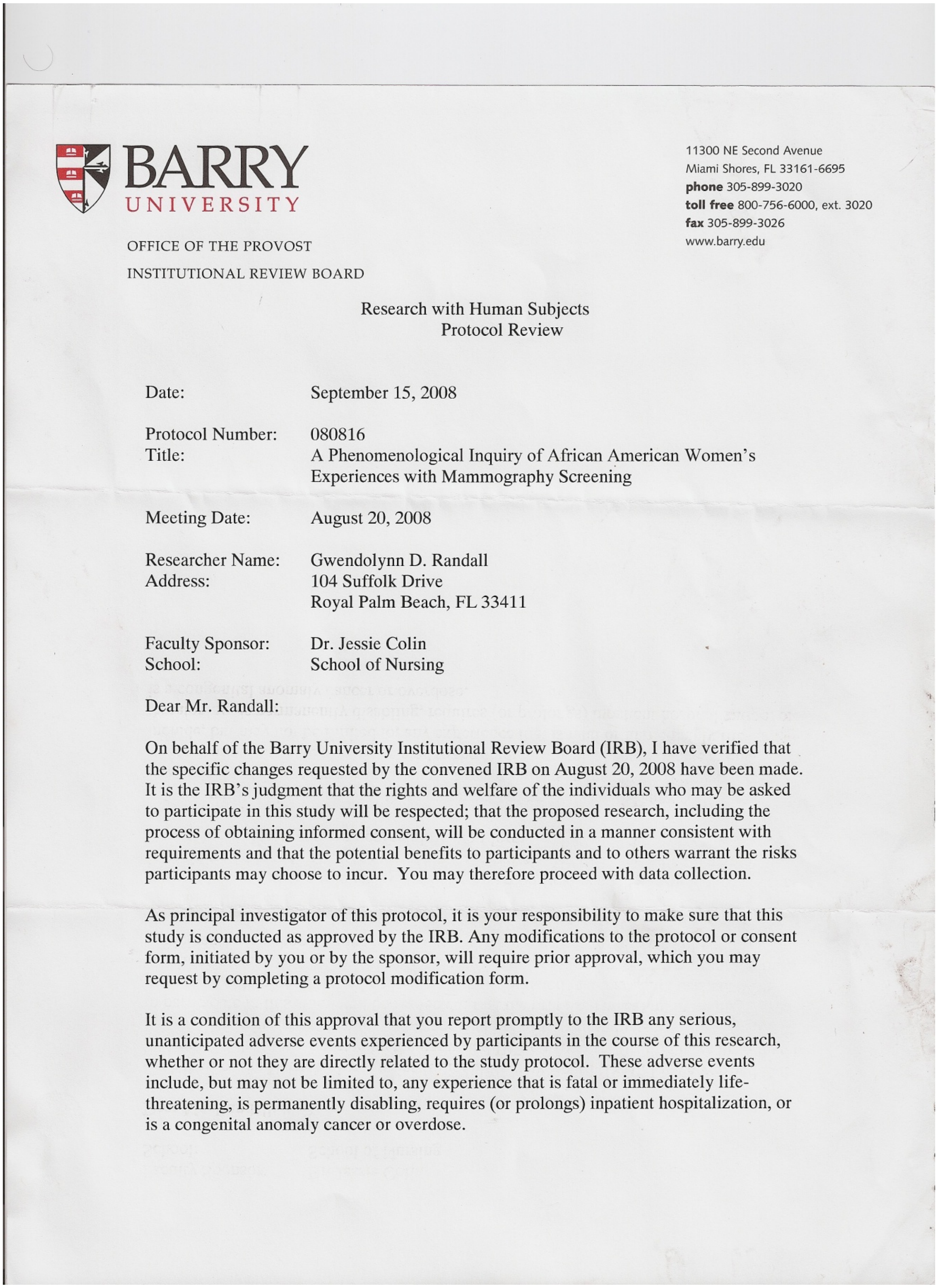
My name is Gwendolynn D. Randall, MSN, CRNA. I am a doctoral student at Barry University in Miami, Florida in the dissertation phase of my studies. My research project is entitled *A Phenomenological Inquiry of African American Women's Experience with Mammography Screening.* The information obtained from this research will be useful in the field of nursing and breast cancer research.

I am hereby requesting permission to place the attached recruitment flyer in your establishments for women to participate in my study. Your cooperation would be greatly appreciated. Should you need further information about the study please e-mail me at randallg@barry.mail.edu.

Thank you very much in advance for your help and cooperation.

Appendix I

Barry University Institutional Review Board Letter of Approval



BARRY
UNIVERSITY

OFFICE OF THE PROVOST
INSTITUTIONAL REVIEW BOARD

11300 NE Second Avenue
Miami Shores, FL 33161-6695
phone 305-899-3020
toll free 800-756-6000, ext. 3020
fax 305-899-3026
www.barry.edu

Research with Human Subjects
Protocol Review

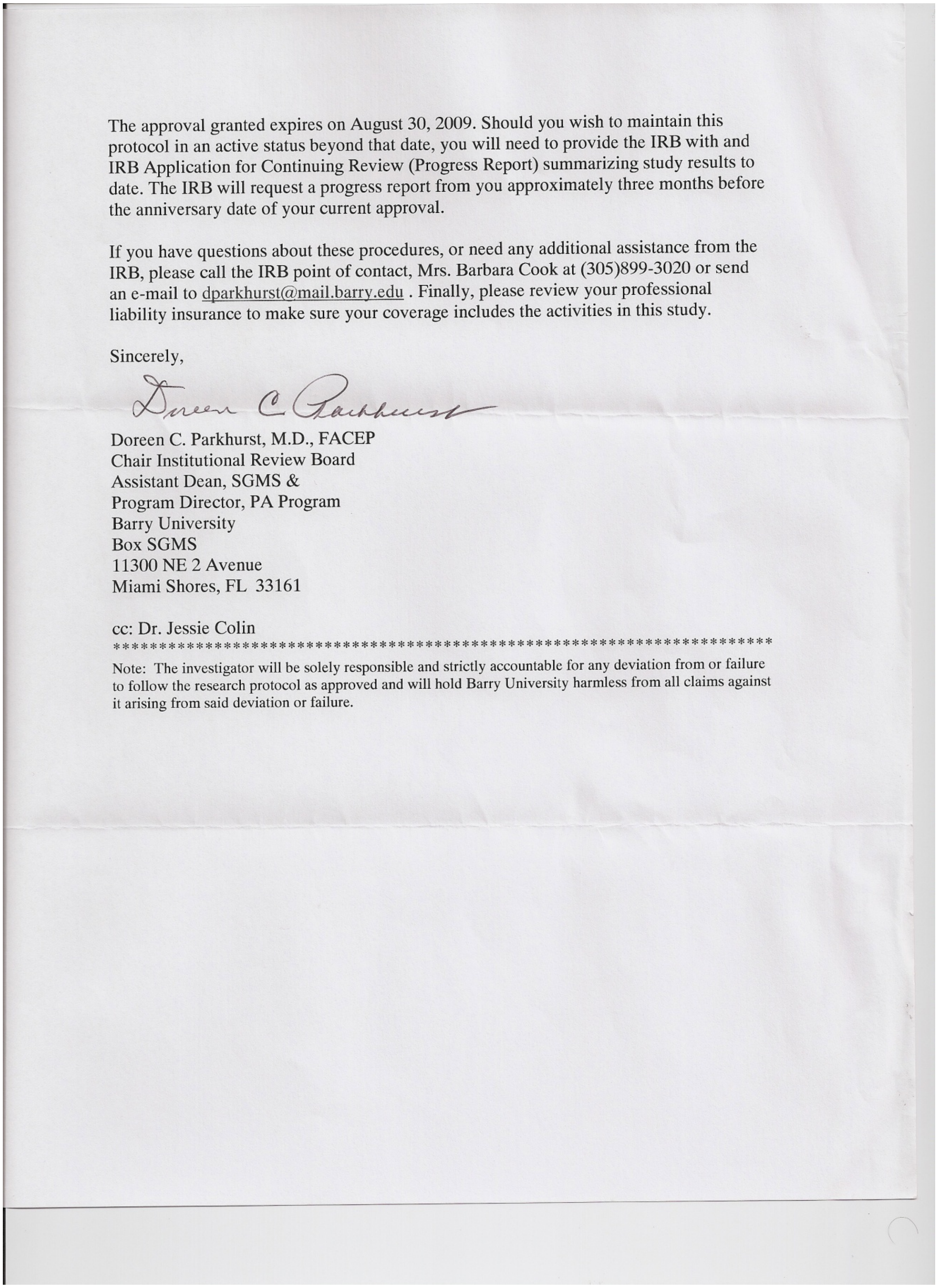
Date:	September 15, 2008
Protocol Number:	080816
Title:	A Phenomenological Inquiry of African American Women's Experiences with Mammography Screening
Meeting Date:	August 20, 2008
Researcher Name:	Gwendolynn D. Randall
Address:	104 Suffolk Drive Royal Palm Beach, FL 33411
Faculty Sponsor:	Dr. Jessie Colin
School:	School of Nursing

Dear Mr. Randall:

On behalf of the Barry University Institutional Review Board (IRB), I have verified that the specific changes requested by the convened IRB on August 20, 2008 have been made. It is the IRB's judgment that the rights and welfare of the individuals who may be asked to participate in this study will be respected; that the proposed research, including the process of obtaining informed consent, will be conducted in a manner consistent with requirements and that the potential benefits to participants and to others warrant the risks participants may choose to incur. You may therefore proceed with data collection.

As principal investigator of this protocol, it is your responsibility to make sure that this study is conducted as approved by the IRB. Any modifications to the protocol or consent form, initiated by you or by the sponsor, will require prior approval, which you may request by completing a protocol modification form.

It is a condition of this approval that you report promptly to the IRB any serious, unanticipated adverse events experienced by participants in the course of this research, whether or not they are directly related to the study protocol. These adverse events include, but may not be limited to, any experience that is fatal or immediately life-threatening, is permanently disabling, requires (or prolongs) inpatient hospitalization, or is a congenital anomaly cancer or overdose.



The approval granted expires on August 30, 2009. Should you wish to maintain this protocol in an active status beyond that date, you will need to provide the IRB with and IRB Application for Continuing Review (Progress Report) summarizing study results to date. The IRB will request a progress report from you approximately three months before the anniversary date of your current approval.

If you have questions about these procedures, or need any additional assistance from the IRB, please call the IRB point of contact, Mrs. Barbara Cook at (305)899-3020 or send an e-mail to dparkhurst@mail.barry.edu . Finally, please review your professional liability insurance to make sure your coverage includes the activities in this study.

Sincerely,

Doreen C Parkhurst

Doreen C. Parkhurst, M.D., FACEP
Chair Institutional Review Board
Assistant Dean, SGMS &
Program Director, PA Program
Barry University
Box SGMS
11300 NE 2 Avenue
Miami Shores, FL 33161

cc: Dr. Jessie Colin

****

Note: The investigator will be solely responsible and strictly accountable for any deviation from or failure to follow the research protocol as approved and will hold Barry University harmless from all claims against it arising from said deviation or failure.

Certificate of Completion

The National Institutes of Health (NIH) Office of Extramural Research certifies that **Gwendolynn Randall** successfully completed the NIH Web-based training course “Protecting Human Research Participants”.

Date of completion: 07/18/2008

Certification Number: 61317

VITA

Gwendolynn D. Randall is a practicing Certified Nurse Anesthetist (CRNA) with a broad background in health care. Originally from Philadelphia, PA, Ms Randall received a bachelor’s in science degrees in pre-med, cum laude, from Howard University in 1974 and medical technology from Norfolk State University in 1979. She holds masters of science degrees in both nurse anesthesia (1995) from St. Joseph’s University and nursing (2000) from Temple University.

She currently lives in Florida where she is the owner and CEO of a private anesthesia practice, Anaesthesia-On-Call. She has been an Assistant Professor in a nurse anesthesia program, an Assistant Professor of Critical Care in an undergraduate nursing program, and currently adjunct professor at Barry University. Ms. Randall has quite an extensive history in management serving as a charge nurse, assistant nurse manager, nurse manager, nursing supervisor, director of nursing, chief nursing officer, assistant hospital administrator, and hospital administrator. Ms. Randall has demonstrated leadership abilities and holds offices in both national and local levels.

Ms. Randall holds memberships in the American Association of Critical Care Nurses, American Association of Nurse Anesthetists, American Nurses Association, Florida Association of Nurse Anesthetists, Florida Nurses Association, and National Black Nurses Association, National Coalition of Ethnic and Minority Association, and Sigma Theta Tau International Honor Society for Nurses.