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The Experience of Survivorship: Quality of Life for African American Breast Cancer Survivors

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2016

Abstract

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MS, Austin Peay State University, 2004

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Dissertation Submitted in Partial Fulfillment
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Doctor of Philosophy
Public Health

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Abstract

African American breast cancer survivors are at a greater risk of experiencing disparities in mortality, treatment, and quality of life. The purpose of this phenomenological study was to explore the impact that breast cancer had on the quality of life of African American breast cancer survivors from a psychosocial, physical, spiritual, and economic perspective. Face-to-face, in-depth interviews were conducted with 9 volunteers who met the eligibility criteria of being breast cancer survivors of African American decent. The sample of survivors ranged in ages 45 to 80 and was between 6 to 30 years postdiagnosis. Giorgi's phenomenological method was used to extract themes or meaning units. Thematic analyses led to 4 established quality of life categories and 2 empowerment emerging themes. The quality of life categories were psychosocial (body image, acceptance), physical (complications of treatment), spiritual (reliance of God), and economic (insured and uninsured). The empowerment categories and emerging themes were formal social networks (whether a sense of empowerment was encouraged), keep moving, and support from other survivors. The final empowerment category was informal social networks-whether a sense of empowerment was encouraged (friends and family was supportive, husband not involved in care). Positive social change implications include providing African American breast cancer survivors information on social networks to achieve a sense of support.

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Dedication

For I know the plans I have for you, declares the Lord, plans to prosper you…plans to give you hope and a future. I am fully persuaded that, what he had promised, he was able to perform. I am thankful to my Lord and Saviour Jesus Christ for being with me through every step of this journey to its final completion. His desire for me to prosper, and the hope he placed in my heart for a successful end of this milestone convinced me to not give up through the difficult times. Jesus Christ performed his promise through me, and for that I am grateful.

This body of work is dedicated to my paternal grandmother Margaret Bard Phillips Jones who lived out her life without compromise, dedicated to family, friends, and most importantly her Lord and Saviour Jesus Christ. Though breast cancer would ultimately be a gateway for her transition from this life to the one to come, she continued to display great strength and tenacity all the way to the last moments of her life with dignity and grace. She has been a great inspiration to me and I find myself thinking of her often. It is my prayer that her memory lives on forever. I love you Granny!

Acknowledgments

I would like to express my heartfelt gratitude to my committee chairperson, Dr. Mary Lou Gutierrez (Dr. G), who provided me with countless hours of instruction, advice, encouragement, patience, guidance, and tough talk. Thank you Dr. G. for everything, your mentorship proved to be invaluable. Special thanks to my committee member Dr. Robert Palmer, your guidance and expertise proved to be very insightful. I appreciate the part you played throughout this journey. Also, special thanks to Dr. Raymond Thron for serving as my URR, many thanks to you.

Additionally, I would like to thank the Sisters Network of Nashville, for working with me in this endeavor and special thanks to Doris McLay, president of the group, for her support and willingness to help. To my Expert Panelist, Dr. Cheryl Holloway, Dr. Shaunte Griffith-Jackson, and Dr. Omie Shepherd, thank you for your advice and support.

To my dear husband, Pastor Archie Grimmett, this would have been impossible without your help to keep the home going in my absence, your prayers, and your occasional prodding to keep me moving forward. Thank you so much.

To my children, Brianna and Tashaunda, thank you for all the love, endless moments of distractions and laughter. To my granddaughter, Zarianna (Hunny Bunny) thank you for the joy. To my parents: Robert and Helen Phillips. Mom, thank you for keeping me in prayer and encouraging me to continue to move forward. Daddy, a special thanks for believing in me and helping me to believe in myself.

Table of Contents

List of Tables

List of Figures

Chapter 1: Introduction to the Study

Introduction

There are a number of women who have experienced the effects of breast cancer. The American Cancer Society (ACS) estimated there are 3.1million U.S. women who have developed breast cancer as of the year 2014(ACS,2015). According to ACS, for the years of 2003-2012, death rates declined by 1.8% for European American women, 1.5% for Hispanic American women, 1.4%African American women, and 1.0% for Asian Pacific Islander, but rates remained unchanged for American Indians, Alaskan Natives. Over all, breast cancer mortality rates have decreased by 36% from 1989-2012 (ACS, 2015). Past decade mortality rates for breast cancer patients have declined by 1.4%, and survival rates have improved (ACS, 2015). The decline in mortality and the increase in the 5-year relative survival rates resulted in an increase of women living with sequelae of the disease (ACS, 2015). Improvements in cancer treatment, early detection methods, and prevention have led to increased survival rates. Advancements in cancer treatment have turned a usually incurable disease into a curable disease and, for some, a chronic illness (Bodurka & von Gruenigen, 2011). According to Howlader et al. (2011), the 5- year relative breast cancer survival rate for the years of 2002 to 2008 was 89.0 % (para.5). The 5-year relative breast cancer survival rate for European American women was 90.3 and 77.7 for African American women for the same years (Howlader et al., 2011). As seen in the Table1 below, the earlier the diagnosis, the greater the survival rate. More women were diagnosed at the localized stage between the years of 2002-2008.

Table 1

SEER Stat Fact Sheets: Breast Cancer. Stage Distribution and 5-year Relative Survival by Stage at Diagnosis for 2002-2008, All Races, and Females

Stage at Diagnosis	Stage Distribution (%)	5-year Relative Survival (%)
Localized (confined to primary site)	60	98.4
Regional (spread to regional lymph nodes)	33	83.9
Distant (cancer has metastasized)	5	23.8
Unknown (unstaged)	2	50.7

Note. Adapted from “SEER Stat Fact Sheets: Female Breast Cancer,” by National Cancer Institute, 2016. Retrieved from *http://seer.cancer.gov/statfacts/html/breast.html#survival*

An increase in the aging population over the next several decades will impact life expectancy rates. The Baby Boom population in the United States consists of about 75 million people alone and, as this population continues to age, an increase in cancer incidence and mortality rates will also be seen (Reuben, 2004). Approximately 6 million cancer survivors are 65 and over (Reuben, 2004). As survivors grow in number, the need to understand quality of life breast cancer survivor issues becomes imperative.

The increase in the number of survivors places a greater burden on the health care infrastructure to provide care that meets their needs. Medical professionals need to be educated and trained on issues such as cancer recurrence, secondary illness, psychosocial problems, prevention, transition to survivorship, and how to coordinate care with other health care entities (Hewitt, Greenfield, & Stovall, 2005). However, training must be culturally and ethnically sensitive. Cultural competence among health care providers and health care systems is imperative for cancer patients to navigate the many variables presented in multicultural cancer survivorship. Specifically, African American survivors' needs may be difficult to meet due to the lack of representation of ethnic populations in health-related quality of life research (Fatone, Moadel, Foley, Fleming, & Jandorf, 2007). If the health care system is to provide quality postbreast cancer care for African American survivors, researchers must provide accurate data on the burdens associated with quality of life (Russell, Von Ah, Giesler, Storniolo, & Haase, 2008). As suggested by Fisher, Burnet, Huang, Chin, and Cagney (2006), high quality health care involves the inclusion of a culturally sensitive perspective to provide care for "communities of color" (p. 244). Finding culturally sensitive alternatives to integrating African Americans in more quality of life research may be helpful in reducing disparities in this group. As more African American women become survivors of breast cancer, the focus will need to be directed toward quality of life research in an effort to become more knowledgeable about the challenges that this population faces.

There has been little research conducted on African American breast cancer survivors' quality of life and the effectiveness of social networks. Information on the experiences of African American women during treatment and survivorship of breast cancer is limited. Researchers have primarily focused on early detection, staging, incidence, mortality, and epidemiological structures for African American breast cancer patients (von Friederichs-Fitzwater & Denyse, 2012). People suffering from a life threatening disease often seek social networks. The social networks may encourage an attitude of empowerment. The empowerment reflects the survivor's ability to remain positive, maintain her condition, and play an active role in decisions made about her health (van Uden-Kraan, Drossaert, Taal, Shaw, Seydel, & van de Laar, 2008).

Social networks can be an invaluable resource for coping with breast cancer and the dynamics of survival. Social networks may also be instrumental in reducing mortality (Beasley et al., 2010). Breast cancer survivors experience problems from the four areas of survival: psychosocial, physical, spiritual, and economic (Beasley et al., 2010). Survivors of breast cancer face physical pain, depression, fatigue, inability to function at a normal level, decreased cognitive function, insecurity, and fear of recurrence (Cappiello, Cunningham, Knobf, & Erdos, 2007). While there is sufficient documentation on European American woman and social networks, there is little information on African American women. In addition, African American women are less likely to use traditional support networks due to the lack of cultural sensitivity of these groups (Henderson & Fogel, 2003). African American women have been found to use informal support from friends, family, and God.

As the number of breast cancer survivors grows, knowledge of the burden of the disease, racial disparities in breast cancer survivorship, and overall quality of life are topics of interest (Russell et al., 2008). There is a need for more research in these areas. The implications of positive social change include improved quality of life for the survivor and improved knowledge of quality of life sequelae and effectiveness of social networks for health care providers to ensure positive post treatment recovery.

Problem Statement

Breast cancer survivors are the largest population of cancer survivors to date in the United States (Thompson et al., 2009). More women, specifically African American women, are surviving breast cancer. Issues of quality of life as a survivor of breast cancer are challenges. In this study, I explored the impact that breast cancer has had on the quality of life of African American breast cancer survivors from a psychosocial, physical, spiritual, and economic perspective. In addition, I explored the effects of social support groups and their ability to encourage empowerment attitudes of self- efficacy, self-determination, self-capacity, and an over optimistic attitude about their condition. Information gained from this study will help to fill the gap in the literature on African American breast cancer survivors' quality of life and the effectiveness of social networks. The knowledge of quality of life and social networks for European American breast cancer survivors are more recognized than for African American survivors.

There are a significant number of African American women dying of breast cancer each year. The ACS (2013a, 2013b) estimated that 6,080 African American breast cancer deaths will occur in 2013. However, breast cancer death rates have significantly decreased over the past decade. African American women breast cancer deaths decreased 1.4% per year from 2000 to 2009 (ACS, 2013a, 2013b). European American women breast cancer deaths decreased 2.1 % per year (ACS, 2013a, 2013b). The disparity in survival is often attributed to biological (tumor size at diagnosis), behavioral (fatalism, cultural beliefs, late screening, and diagnosis), and social (access to care, health insurance) factors (Russell et al., 2008, p. E37). However, a disparity in survival remains unexplained (ACS, 2013a, 2013b).

Breast cancer is the most commonly diagnosed cancer for women when cancers of the skin are excluded (ACS, 2011a, 2011b). Breast cancer incidence is second only to lung cancer for most common cancer death for African American women (ACS, 2011a, 2011b). African American women have a lower incidence rate of breast cancer after age 40 than European American women, but disproportionately are more likely to die from the disease across all age groups (ACS, 2011a, 2011b, 2012a). Approximately 26,840 cases of breast cancer were expected to occur among African American women in 2011 (ACS, 2012b). An estimated 6,040 African American women were expected to die in 2011 (ACS, 2011a, 2011b).

Purpose of the Study

The purpose of this study was to explore the impact that breast cancer has on the quality of life of African American breast cancer survivors from a psychosocial, physical, spiritual, and economic perspective. In addition, I wished to determine if formal social support groups (Sisters Network) and/or informal social support groups (friends and family) were beneficial or not for encouraging empowerment attitudes such as self-efficacy self-determination, self-capacity, and overall optimistic attitude regardless of the outcome.

Nature of the Study

In this study, I used a qualitative, phenomenological design to explore the impact that breast cancer had on the quality of life of African American breast cancer survivors from a psychosocial, physical, spiritual, and economic perspective in women who belong to the Sisters Network Nashville TN Chapter. Participants were recruited through fliers (Appendix A) posted at the Sisters Network Nashville Chapter and by e-mailing its members. Fliers were also posted at a local support group facility for cancer survivors. The data were collected through in-depth interviews at the local cancer survivors' support group facility. Interviews were digitally audio recorded and transcribed verbatim using Express Script transcription software. Participants were over 18 and were at least 1 year posttreatment stage. Informed consent was obtained before the interview began. The methodology used for this study is defined in greater detail in Chapter 3.

Research Questions

1. How have the lived experiences of African American breast cancer survivors' affected their quality of life from a psychosocial, physical, spiritual, and economic perspective?
2. How have social networks encouraged empowerment attitudes in African American women?
3. Do social networks affect the quality of life of African American breast cancer survivors?

Theoretical Base

The theoretical foundation of this study was Zimmerman's (1995) psychological empowerment theory. According to the empowerment concept, an individual's perceived self-efficacy is enhanced by a new awareness of power in a seemingly powerless situation (Zimmerman, 1995). Empowerment is a motivational phenomenon used to increase self-efficacy, self-determination, self-capacity, and positive attitudes toward self-sufficiency, regardless of possible outcomes (Conger & Kanungo, 1988; Shearer, 2009).

Individuals who take over their situation or are provided with resources that gives them control over their circumstance have a sense of empowerment (Zimmerman, 1995). The level at which a person feels empowered may change over his or her lifespan (Zimmerman, 1995). Over time, a person's level of empowerment may increase or decrease and may differ across life domains such as work, church group, and self (Zimmerman, 1995). A more detailed explanation will be given in Chapter 2.

The conceptual framework shown below in Figure 1 displays the constructs involved and their relationship to the quality of life of breast cancer survivors. Social support groups are often used as a coping mechanism for breast cancer survivors to encourage empowerment or a sense of control over their circumstances. Increased empowerment or control is perceived to have a positive effect on all aspects of quality of life: psychosocial, physical, spiritual, and economic.

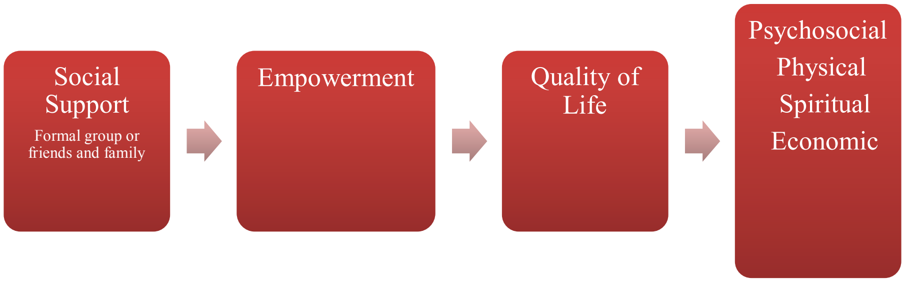


Figure 1. Psychological Empowerment Theory, adapted from Zimmerman

Definitions of Terms

5-year relative survival rate: Accounts for all people alive 5 years after diagnosis (American Society of Clinical Psychology, 2013).

African Americans: Any person who comes from an African racial group (U.S. Census Bureau, n.d.).

Distant breast cancer: Cancer that has metastasized or infiltrated areas beyond the primary site (United States Department of Health and Human Services, 2012).

Localized breast cancer: Cancer that is confined to the primary site (United States Department of Health and Human Services, 2012).

Quality of life: Refers to a patient’s ability to enjoy life and carry out daily activities (Hewitt et al., 2005).

Regional breast cancer: Cancer that has spread to the regional lymph nodes (United States Department of Health and Human Services, 2012).

Sequelae: Conditions that follow or are the consequences of a disease, in this case breast cancer.

Survivor: A person is considered a cancer survivor from the time of diagnosis to the end of life according to the National Coalition of Cancer Survivorship and NCI Office of Cancer Survivorship (as cited in Hewitt et al., 2005).

Survivorship: The state of being a cancer survivor or having survived cancer (ACS, n.d.)

Social network: A source of support for the survivor. The social network serves as a source of support for the cancer survivor. The survivor's social network can be formal (an established group that meets on a schedule), informal, God, friends, and family (Hewitt, Herdman, & Holland, 2004).

Assumptions, Limitations, Delimitations

It was assumed that positive empowerment attitudes increase a survivor's quality of life. Also, assumptions were made that participants answered questions honestly and from their own perspective as a survivor. The use of only the Sister's Network as the social network to recruit participants may have reduced my participant selection to educated middle class women; this could exclude uneducated, lower class, working women. As assumed, most of the women in this study were college educated. Only one participant's education stopped at high school, and one other had some college but not a formal degree. Another possible limitation was generalizability. Because all of the participants were African American, it may not be possible to generalize the findings of this study to other populations. Also, because participants were members of a social network, they may could have had biased attitudes about how effective the network really is, but that was not found to be true.

I focused on African Americans women's issues with breast cancer, and I did not address other racial groups such as Hispanic American, Asian American, or European American women. The focus of the study was on African American women because the gap in the literature concerns African American women and social support groups.

Significance of the Study

Breast cancer is the most common cancer diagnosed for African American women, and it is second only to lung cancer in cancer death (ACS, 2013a, 2013b). In 2013, an estimated 27,060 new cases and 6,080 deaths were expected to occur among African American women alone (ACS, 2013a, 2013b). The increasing number of survivors, 2.9 million as of January 2012, of invasive breast cancer places a burden on the survivor and the medical field to meet the growing needs of the survivor (ACS, 2012a, 2012b, 2012c, 2012d). The sequela of breast cancer impacts the psychosocial, physical, spiritual, and economic ramification on the quality of life of the survivor.

This phenomenological study is significant because of the potential to contribute to the knowledge base of survivor research. The implications of social change are improved quality of life for African American survivors and an improved knowledge of sequelae of breast cancer for health care providers to provide positive quality of life posttreatment care.

Summary and Transition

In Chapter 1, I introduced the study and discussed assumptions, limitations, theoretical base, conceptual framework, purpose of the study, and the overall significance of the study. Chapter 2 provides an overview, literature review, epidemiology of the disease, theoretical model, and conceptual framework for this phenomenological study on survivorship and quality of life for African American breast cancer patients.

Chapter 2: Literature Review

Introduction

The purpose of this study was to explore the impact that breast cancer has on the quality of life of African American breast cancer survivors from a psychosocial, physical, spiritual, and economic perspective. In this chapter, I conceptualize issues related to the psychosocial, physical, spiritual, and economic ramifications of breast cancer on the quality of life of the survivor. In addition, this chapter provides a literature review on the different aspects of breast cancer survival including epidemiology, incidence, racial disparity, and mortality, as well as the impact of survivorship (psychosocial impact, physical impact, spiritual impact, and economic impact).

African American women experience breast cancer at a lower incidence rate than European American women at every age (excluding younger than 45), but are more likely to die of the disease at any age (American Cancer Society, 2013a, 2013b). They are also more likely to develop a more aggressive form of the disease than any other ethnic group (ACS, 2012a). In addition, diagnosis for African American women is usually at a later stage of disease development (ACS, 2012a). Treatment options are generally not as invasive or corrective as with European American women. According to Blackman and Masi (as cited in Rosenzweig, Brufsky, Rastogi, Puhalla, Simon, & Underwood, 2011), the initial treatment for European American women with a breast cancer diagnosis is more aggressive than that of African American women. In addition, only about half of all African American women with breast cancer receive prescribed adjunctive therapy (Hershman et al. as cited in Rosenzweig, Brufsky, Rastogi, Puhalla, Simon, &

Underwood, 2011). This treatment disparity results in higher breast cancer mortality for African American women (Blackman & Masi as cited in Rosenzweig, Brufsky, Rastogi, Puhalla, Simon, & Underwood, 2011). The disparities in mortality, treatment, and diagnosis have a direct effect on the quality of life of the African American breast cancer survivors.

Literature Search Strategy

The literature searches for this review began with searching databases at the Walden University library website. The following databases were used: CINAHL & Medline Simultaneous Search, Health & Psychosocial Instruments, Academic Search Complete/ Premier, Health Sciences: A Sage Full Text Collection, Google Scholar, Proquest, and Thoreau. *Empowerment*, *breast cancer*, *cancer survival and African American women*, *empowerment and breast cancer and African American women*, *empowerment and breast cancer*, *quality of life and breast cancer*, *breast cancer treatment disparity for African American women*, and *breast cancer survivor* were all used in the literature search. Attention was given to articles dated within the last 7 years with the exception of seminal articles dating back to 1994 and 1988.

Epidemiology of Breast Cancer

Breasts are made up of three main parts: lobules, ducts, and connective tissue as shown in Figure 2 below (Center for Disease and Prevention [CDC], 2012). Lobules are glands that produce milk; ducts are small vein like structures that carry milk from glands to the nipple (CDC, 2012). The connective tissue holds other components of the breast (fatty tissue, nerves, veins, and arteries) together (CDC, 2012).

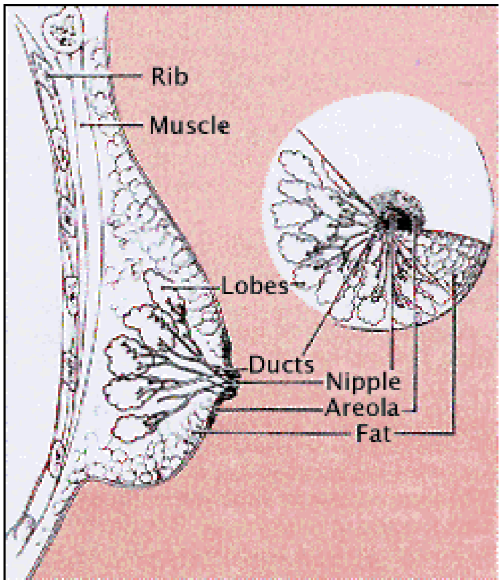


Figure 2. Diagram of the breast. *Note.* Adapted from “Breast Cancer: Basic Information about Breast Cancer,” by CDC, 2012.

Cancer begins when the normal process of cells multiplying, dying, and replacing themselves is interrupted. Cancer cells begin to generate at an abnormal rate into a mass, growth, or tumor (National Cancer Institute [NCI], 2012). Breast tumors can be benign or malignant. Benign tumors are generally not harmful and do not spread to other parts of the body and can be removed (NCI, 2012). Malignant tumors are harmful if not caught at the earliest stage; they can spread throughout the body and may return after removal (NCI, 2012).

Cancer can start in different areas of the breast. Ductal carcinoma begins in the lining of the breast ducts and, if confined to this area, it is called ductal carcinoma in situ (DCIS). This type of noninvasive breast cancer is the most common; 83% of in situ breast cancer cases in 2008-2012 were ductal carcinoma in situ (ACS, 2015). Lobular carcinoma in situ (LCIS) begins in lobules of the breast and is confined there. LCIS is not as common as DCIS and accounts for 11% of in situ breast cancers in 2004-2008 (ACS, 2011a, 2011b). Both types of breast cancer can become invasive and spread from the ducts or lobules into other parts of the breast and body.

A diagnosis of breast cancer is a concern for the patient and the physician. The level of concern is based on the stage the cancer is found. According to the National Cancer Institute (2016), the American Joint Committee on Cancer (AJCC) provides staging categories used to determine treatment options and prognosis. The NCI described each stage of breast cancer beginning with the first Stage 0. Stage 0, called carcinoma in situ, has three types: ductal carcinoma in situ, where abnormal cells are found in the ducts of the breast only; lobular carcinoma in situ, where abnormal cells are found in the lobules of the breast only; and Paget's disease, where abnormal cells are found in the nipple only. The second stage of breast cancer is Stage 1, and it is classified in two groups: Stage 1a where a tumor about 2 centimeters is found in the breast but is not invasive and Stage 1b where cancer has become invasive and has moved to lymph nodes.

The next stage of breast cancer is Stage II, and it is classified into two stages: Stage IIa where the tumor is not more than 2 centimeters and has spread to 3 lymph nodes or tumor larger than 2 centimeters, but has not spread to lymph nodes and Stage IIb where the tumor is up to 5 centimeters, and breast cells are found in lymph nodes or the tumor is larger than 5 centimeters and has not spread to lymph nodes. The next stage is Stage III and, unlike the previous stages, it is classified into three segments: IIIa no tumor is found or the tumor found and size varies with tumors also in 4 to 9 lymph nodes. In addition, the tumor can be larger than 5 centimeters and has spread to lymph nodes. In

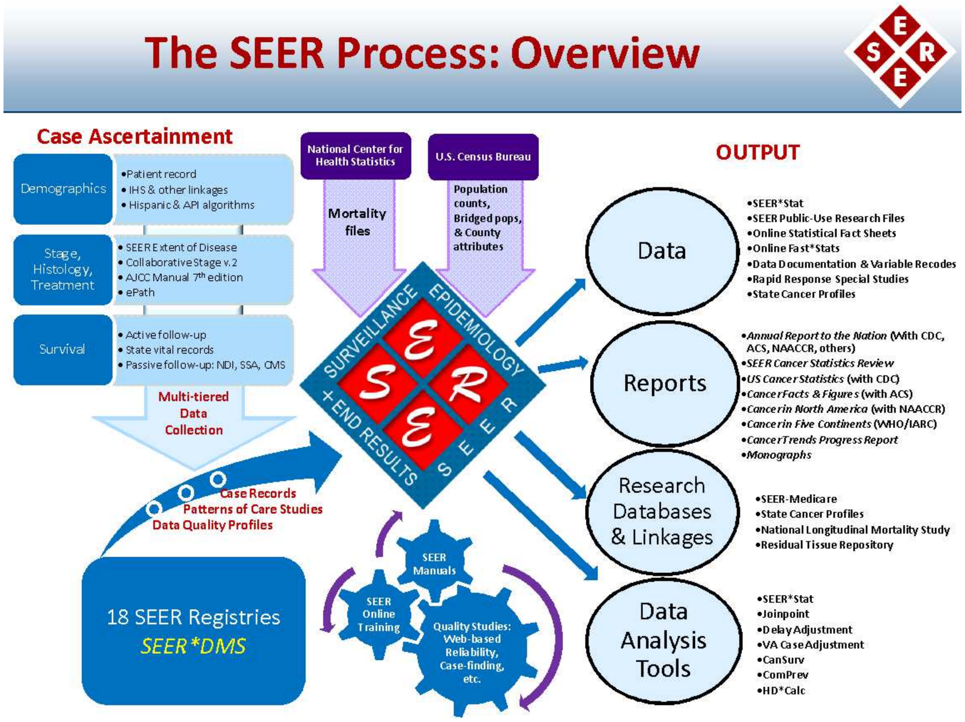
Stage IIIb, the tumor may be any size at this point and has spread to 9 axillary lymph nodes, the chest walls and the skin. The breast is ulcerated and swollen. In Stage IIIc, there may not be a tumor or it can be any size. Cancer has spread to 10 lymph nodes above or below the collarbone and the chest wall, and the skin is ulcerated and swollen. The final stage is IV breast cancer. In Stage IV, the cancer has metastasized to other organs such as the lungs, brain, skeletal system, and liver.

Breast Cancer Incidence and African American Women

Incidence and mortality rates provide information on how many people in a population develop the disease each year or die from the disease. A decrease in mortality rates would increase the need to provide survivors with the care they need psychosocially, spiritually, and physically. A continual decline in breast cancer mortality has been documented since 1989 (ACS, 2013a, 2013b). A decreased rate of 33% was seen between 1989 and 2009 (ACS, 2013a, 2013b). During the years of 2005 to 2009, the most recent-year record reported declines of 3.0% for women less than 50-years-old and 2.0% for women over 50 (ACS, 2013a, 2013b). These statistical figures represent an increase in survivors of breast cancer. In turn, results in a greater need for survivor care and research that will increase the knowledge base for health care providers.

Women with localized breast cancer have a survival rate of 98%, while women with regional breast cancer have a survival rate of 84%; distant breast cancer survival rates are much lower at 23% (ACS, 2010). The 5-year relative survival rate for breast cancer patients has improved from the 1960s until today at a rate of 63% to 90% (ACS, 2010).

Incidence rates are the number of people per 100,000 who develop a disease, in this case breast cancer, during a defined amount of time. There are two federal agencies that collect incidence data for the entire United States: the CDC through their National Program of Cancer Registries (NPCR) and NCI through their Surveillance Epidemiology End Results (SEER) program (HHS, CDC, NCI, 2013). Unlike incidence data, mortality data are collected through a different program called CDC's National Center of Health Statistics (NCHS). Figure 4 shows an overview of the process of incidence and mortality data collection and the end results through the SEER program. Incidence and mortality data are later used in various reports such as the United States Cancer Statistics Incidence and Mortality Web-based Report and the Annual Report to the Nation on the Status of Cancer. These reports are produced in collaboration with multiple entities.



The SEER Process: Overview

Case Ascertainment

Demographics
- Patient record
- IHS & other linkages
- Hispanic & API algorithms

Stage, Histology, Treatment
- SEER Extent of Disease
- Collaborative Stage v.2
- AJCC Manual 7th edition
- ePath

Survival
- Active follow-up
- State vital records
- Passive follow-up: NDI, SSA, CMS

Multi-tiered Data Collection

Case Records
Patterns of Care Studies
Data Quality Profiles

18 SEER Registries
*SEER*DMS*

National Center for Health Statistics
Mortality files

U.S. Census Bureau
Population counts, Bridged pops, & County attributes

SURVEILLANCE EPIDEMIOLOGY + END RESULTS SEER

SEER Manuals
SEER Online Training
Quality Studies: Web-based Reliability, Case-finding, etc.

OUTPUT

Data
- SEER*Stat
- SEER Public-Use Research Files
- Online Statistical Fact Sheets
- Online Fast*Stats
- Data Documentation & Variable Recodes
- Rapid Response Special Studies
- State Cancer Profiles

Reports
- *Annual Report to the Nation* (With CDC, ACS, NAACCR, others)
- *SEER Cancer Statistics Review*
- *US Cancer Statistics* (with CDC)
- *Cancer Facts & Figures* (with ACS)
- *Cancer in North America* (with NAACCR)
- *Cancer in Five Continents* (WHO/IARC)
- *Cancer Trends Progress Report*
- *Monographs*

Research Databases & Linkages
- SEER-Medicare
- State Cancer Profiles
- National Longitudinal Mortality Study
- Residual Tissue Repository

Data Analysis Tools
- SEER*Stat
- Joinpoint
- Delay Adjustment
- VA Case Adjustment
- CanSurv
- ComPrev
- HD*Calc

Figure 4. The SEER process: Overview. Adapted from "Effects of Population Counts on Cancer Rates and Trends," by B. K. Edwards, 2012, Office of Director & Surveillance Research Program, Division of Cancer Control and Population Sciences, National Cancer Institute, of United States Department of Health and Human Performance.

An estimated 226,870 women will develop breast cancer in the United States in 2012 (U.S. Department of Health and Human Services, National Institutes of Health, NCI, 2012). For African American women alone, an estimated 27,060 new cases were expected in 2013 (ACS, 2013a, 2013b). The median age for all newly diagnosed female breast cancer patients between 2005-2009 was 61, the median age for European American women during the same time period was 62, and the median age for African American women was 57 (Howlader et al., 2012). Moreover, age-related incidence increased in rates in the 1980s for women under the age of 50 and women over the age of 50 (ACS, 2011a, 2011b). Women over 50 experienced an increase of 5.4%, and women under 50 experienced an increase of 3.2% per year (ACS, 2011a, 2011b). During the same time frame of 2005-2009, the SEER incidence rate by age group was as follows: under age 20, 0.0%; 20-34, 1.8%; 35-44, 9.9%; 45-54, 22.5%; 55-64, 24.8%; 65-74, 20.2%; 75-84, 15.1%; and 85+ years, 5.7% (U.S. Department of Health and Human Services, 2012). Typically, incidence rates increase with age. The highest rate was seen at the 65-74 age group interval and tapering off with age progression. The decrease in incidence rates with age could be attributed to fewer screenings, previous diagnosis of breast cancer, and or incomplete detection (ACS, 2011a, 2011b).

There was an increase in the incidence of breast cancer for European American and African American women in the 1980s primarily due to the upturn in mammography use, a result of a positive response to screening practices (DeSantis, Ma, Bryan, Jemal, & 2013). Rates for Asian Americans/Pacific Islanders, Hispanic Americans/Latinas, and American Indians/Alaska Natives are 2-year moving averages (U.S. Department of Health and Human Services, National Institutes of Health, & National Cancer Institute, 2012). Data for European American and African Americans are from the SEER nine registries and were adjusted for reporting delays. Data for other races/ethnicities are from the SEER 13 registries. For Hispanic Americans, incidence data do not include cases from the Alaska Native Registry. Incidence data for American Indians/Alaska Natives are based on Contract Health Service Delivery Area (CHSDA) counties.

Breast cancer incidence rates for African American women deviate from that of other ethnic and nonminority women, demonstrating a crossover effect. Women of other races, and in particular nonminority European American women, experience higher incidence rates of breast cancer at an older age. African American women experience higher incidence rates at a younger age. According to Anderson, Rosenberg, Menashe, Mitani, and Pfeiffer (2008), African American and European American women face a phenomenon called *black to white ethnic crossover* or reversing of age-specific incidence rates. This phenomenon has been reported as far back as the 1960s (Joslyn, Foote, Nasseri, Coughlin, & Howe, 2005). The crossover begins at a younger age and at earlier stages of the disease than previously believed (Joslyn et al., 2005). Explanations of the crossover have not been readily explained. However, suggestions of possible relationships to the crossover effect have been established.

There is a relationship between parity and breast cancer incidence at all ages. Palmer, Wise, Horton, Adams-Campbell, and Rosenberg (2003) reported that African American women have an increased risk of breast cancer at 45-years-old and younger due to the young age at first birth and multiple births thereafter. Each birth represents an increased risk of developing breast cancer in younger women because of the consistent exposure to hormones. Consequently, African American women have an increased risk at 45 and under when compared to European American women because the latter bear children at an older age and have fewer children (Palmer et al., 2003). In addition, breast cancer diagnosis in women over 45 with high parity is associated with a decreased risk of breast cancer. African American women diagnosed after 45, with high parity, have a decreased risk of developing breast cancer. This relationship may explain the age differences in African American and European American women incidence rates. African

American women are more likely to have multiple births, a benefit after age 45, opposed to European American women who have fewer births, a risk factor after age 45.

The black white ethnic cross over effect is seen in breast cancer heterogeneity. African American women are more frequently diagnosed with early onset cancer types more often than nonminority European American women (Anderson et al., 2008). At the same time, European American women are more often diagnosed with late onset breast cancer types (Anderson et al., 2008). This is not to say African American women and European American women develop different cancer types; but, the two racial groups are proportionately more likely to develop one over the other (Anderson et al., 2008).

Racial Disparity

The most common cancer diagnosed among African American women occurs in the breast (ACS, 2011a, 2011b, 2012b). The ASC (2013a, 2013b) estimated an additional 27,060 new cases of breast cancer for African American women alone. However, incidence rates for African American women are lower than European American women in the over 40 age group as seen in Figure 6. Incidence rates are higher for African American women when compared to European American women less than 40-years-old (ACS, 2011a, 2011b, 2012b).

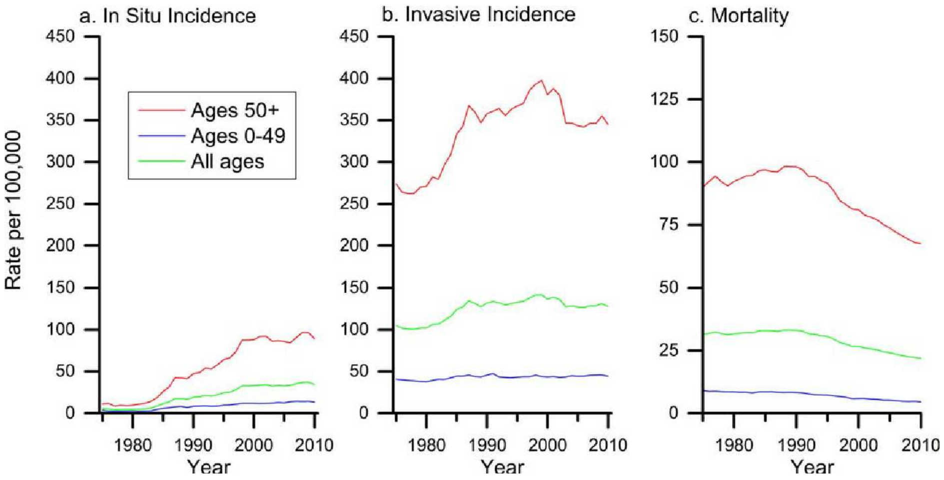


Figure 6. Incidence and mortality rates* of female breast cancer by age, United States, 1975 to 2010. *Rates are age adjusted to the 2000 US standard population within each age group. Adapted from “Incidence: Surveillance, Epidemiology, and End Results (SEER) Program, SEER 9 Registries, 1975-2010,” 2013, NCI, Division of Cancer Control and Population Sciences. Data were adjusted for reporting delay.

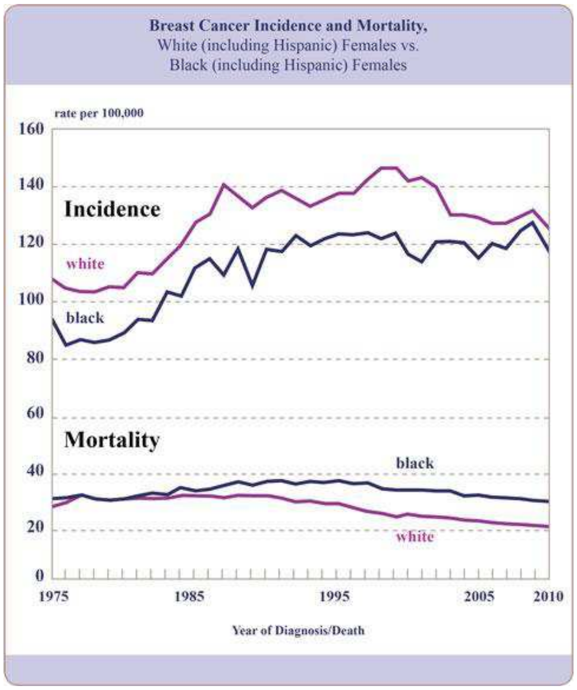


Figure 7. Age-adjusted breast cancer incidence and mortality rates by race. Adapted from “SEER Cancer Statistics Review, 1975-2009,” 2012, by. SEER

The ACS (2011a, 2011b, 2012b) breast cancer trends show an increase in incidence rates for African American and European American women in the 1980s. European American woman reached their peak in 1999 and incidence rates dropped between 2002-2003, thereafter becoming stable (ACS, 2011a, 2011b, 2012b). African American women experienced stabilized rates around 1992 without ever seeing a decrease (ACS, 2011a, 2011b, 2012b). Racial disparity among African American and European American women has become a social and public health issue. Life expectancy for European American women in 1998 was 80.8, while African American women were only at 76.3: a disparity of 4.5 years (ACS, 2010b).

European American women age 45 and over experience a higher incidence of breast cancer than their African American counterparts. African American women younger than age 45 experience higher incidence; however, mortality rates are higher for all ages among African American women (2010) Though the racial disparity remains, African American women’s overall life expectancy has increased from 62.9 to 76.5, which is a gain of 13.6 years (Heron et al., 2009). The rise in life expectancy directly affects the number of survivors of breast cancer, as well as other diseases.

Breast Cancer Mortality and African American Women

Mortality rates are based on the number of people per 100,000 who die of a disease within a given period of time. Unlike incidence rates, mortality rates are collected by the National Center of Health Statistics at the CDC. These data are then compiled with population data provided by the United States Census Bureau (ACS, 2011a, 2011b, 2012a).

An estimated 39,510 women were expected to die of breast cancer in 2012 (U.S. Department of Health and Human Services, 2012). Breast cancer is the second leading cancer cause of death in women, with lung cancer being the first. Mortality rates have been on the decline since 1990, more so for younger women than older women (ACS, 2012a). From 2004-2009, mortality rates decreased for women under the age of 50 at 3.1% per year, but only 2.1% per year for women over 50-years-old (ACS, 2012a). Factors that led to the decline include advances in detection and treatment of the disease (ACS, 2011a, 2011b, 2012a).

The median age of breast cancer death for 2005-2009 was 68 for all women (U.S. Department of Health and Human Services, 2012). The approximate SEER death percentage rate per age group during 2005-2009 was under 20, 0.0%; 20-34, 0.9%; 35-44, 5.6%; 45-54, 14.8%; 55-64, 21.4%; 65-74, 19.9%; 75-84, 22%; and 85+ years, 15.5% (U.S. Department of Health and Human Services, 2012). In addition, the age-adjusted death rate during this time frame for all races was 23.0 per 100,000, for European American women 22.4 per 100,000 and 31.6 per 100,000 women for African American women (U.S. Department of Health and Human Services, 2012). Although there has been a decline in mortality rates for European American and African American women, the decline for African American women has been less. During the years of 2003-2007, African American women mortality rates were 39% higher than European American women regardless of lower incidence rates for the same years (ACS, 2011a, 2011b, 2012b). These differences have often been attributed to differences in screening practices, access to care, tumor size, and tumor genetic characteristics (ACS, 2011a, 2011b, 2012b).

Despite the disparity in mortality rates among African American and European American women, more women are surviving breast cancer. As of January 2012, in the United States alone, 2.9 million women were alive with a history of breast cancer (ACS, 2012a, 2012b, 2012c, 2012d). With these numbers increasing daily, issues relative to the quality of life these women experience each day is relevant and was the focus of this study.

Impact of Survivorship

Quality of life issues are an aspect of survivorship. The manner in which the patient perceives the sequelae of disease contributes to quality of life and survivorship. The racial disparity found among African American women for breast cancer may determine differing outcomes than women of other ethnicities (Russell et al., 2008). As a group, African American women have a history of being diagnosed with breast cancer at later stages than European American women (ACS, 2011a, 2011b, 2012b). This disparity can affect the survivorship experience. Mortality becomes a reality for African American women because of late stage of their diagnosis and discrimination practices found in health care (Kooken, Haase, & Russell, 2007). The racial health disparities that are documented in African Americans directly relate to race, and change resulting from this information has not been apparent in health professionals in the field (Kooken et al., 2007).

Psychosocial Impact

The psychosocial impact of breast cancer includes difficulty coping with negative emotions such as irritability, sadness, and depression (Fatone et al., 2007). In addition, the ability to care for loved ones (especially children) and involvement in regular activities (such as work and family outings) becomes difficult to handle (Fatone et al., 2007). Developing appropriate coping mechanism for handling psychosocial issues of breast cancer survival could have a positive impact on the survivor's quality of life.

The psychosocial needs of African American women may be different from the needs of European American women. African American breast cancer patients are often diagnosed at a later stage than European American breast cancer patients are and, therefore, require more intensive treatment such as total mastectomy and radiation (Eversley et al., 2005). Advanced treatment increases the likelihood of psychosocial impairment to quality of life because of higher levels of depression and pain (Eversley et al., 2005). In a study using a self-report needs assessment survey with 248 outpatient oncology patients 18 and over, Moadel et al. (1999) assessed the psychosocial needs of African American woman and have found that they may need more psychosocial support.

Physical Impact

The physical impact breast cancer has on survivors derives from surgical procedures performed to remove tumors to side effects experienced after receiving adjunctive therapy to shrink or dissolve tumor growths. In addition, menopausal symptoms are often a source of discomfort for survivors (Fatone et al., 2007). These symptoms include hot flashes and vaginal dryness (Fatone et al., 2007). Chemotherapy treatment is often the cause of premature menopause in younger breast cancer patients (Stavrou et al., 2009). Often, physical symptoms such as pain, swelling, and nausea are frequently reported among survivors (Fatone et al., 2007). Mastectomy or complete removal of the breast leads to other physical problems for the patient, particularly younger women. The effects are poor body image, less satisfaction with physical appearance, and feeling sexually undesirable (Stavrou et al., 2009). The physical impact of breast cancer directly affects the survivor's quality of life. Patients educated on what treatment is best for them could have an improved survival period.

Spiritual Impact

Breast cancer survivors often cope with the stresses of the disease by relying on their spiritual faith (Torres, Dixon, & Richman, 2015). Roff, Simon, Nelson-Gardell, and Pleasants (2009) conducted a qualitative study of 18 African American cancer survivors who received spiritual support in various ways such as direct communication with God, family members, church congregation, strangers, and health care providers. A strong faith that God knows and cares about them and their circumstances helped the survivors to accept what God allows because He knows best (Roff et al., 2009). Survivors sometimes view their disease as a means to help others to see what God has done for them as survivors (Torres et al., 2015). Some African Americans have ties to the church and have historically relied on this affiliation as a means of support, information, and guidance. Health educators have begun to use this avenue as a means to provide preventative programs to increase screening and to inform this population of risk factors and other issues related to this disease.

Spiritual support often is related to a variety of elements and sources. In this review, I will primarily focus on a Christian point of view or basis. African American women often use prayer from a Christian perspective as a means of support and comfort.

In a study conducted by Roff et al. (2009), the participants indicated God as a source of support in three different areas. The first was in an assuring way; the feeling of God's presence became comforting and a means to endure a difficult situation. Second, a special knowledge of when to get a mammogram and what surgeon to choose for the procedure was viewed as divine direction from God. Third, participants found it comforting to understand why they developed breast cancer and generally described reasons as a means to become closer to God and to be a testimony to others (Roff et al., 2009).

African American women use their spirituality or faith in God to transform a negative situation into something they view as positive; their faith and belief in God's presence allows them to view their circumstances in a positive way (Gallia & Pines, 2009). Spirituality and the church have been a source of strength to breast cancer survivors. Pastors and female friends have been found to provide positive mentoring to breast cancer survivors while facing issues related to the disease (Gallia & Pines, 2009).

Economic Impact

The economic impact of breast cancer on the survivor can be significant. Survivors face economic problems due to their reduced ability to work compounded with expensive prescriptions, medical equipment, and supplies (Hewitt et al., 2005). In addition, the possible loss of health care insurance or expensive copays can also become a burden to breast cancer survivors. The economic burden of breast cancer is far reaching. This burden is measured by three categories: direct cost, indirect cost, and psychosocial cost (Pisu et al., 2010). According to Pisu et al. (2010), direct costs consist of the cost of physicians, hospitals, transportation, childcare, home alterations, and clothing. Indirect costs include the loss of productivity in usual activities or work, early retirement, use of retirement savings, home downsizing, and change in vacation or educational endeavors (Pisu et al., 2010). Finally, the psychosocial cost refers to depression, martial strain, loss of relationships, anxiety, and an uncertain future (Pisu et al., 2010).

Theoretical Model

The theoretical foundation for this study was Zimmerman's (1995) psychological empowerment theory. The empowerment concept was derived Freire's literacy program for lower class peasants in Brazil (Wallerstein & Bernstein, 1988). Freire's literacy program began in the late 1950s and proved to be successful. The program also served to awaken political consciousness among peasant workers because of Freire's beliefs in social and political participation. The underpinning of Freire's literacy program was based the ideas of empowering education. The main premise of empowering education is to encourage individuals to be participants in society and critical thinkers who fully participate as colearners in charge of their own destiny (Wallerstein & Bernstein, 1988). Freire encouraged a dialogue approach where each group member explores potential root causes for its place in society economically, politically, and so on (as cited in Wallerstein & Bernstein, 1988). After an individual understands his or her place in society, he or she can think of what actions can be taken to move beyond a powerless state to an empowered state (Wallerstein & Bernstein, 1988). This theory has been modified to health education field as written in health promotion in action (Wallerstein & Bernstein, 1988, p. 381)

Freire used a 3-stage method as a foundation for empowering education. The first is listening, the second is participatory dialogue, and the third is action. Other theories considered for this study were the health belief model and social cognitive theory. The health belief model had potential because of its focus on health behavior, but ultimately, was rejected because I found the empowerment theory was more apt to address how a seemingly powerless person can become empowered concerning his or her health problems. Social cognitive theory, another behavioral theory, did not fit the constructs of this study due to the emphasis placed on reinforcement and rewards.

Applications of Empowerment Theory

Empowerment theory is often used in a variety of studies. Mok (2004) performed a study on empowerment and self-help group participation and suggested that members of these groups learn to be empowered and how to cope with life stresses. In my study on African American survivors of breast cancer, the empowerment theory was used to learn how social support groups has or has not positively affected the quality of life of survivors.

The concept of empowerment has evolved over the years in various disciplines, like organizational leadership and management. Conger and Kanungo (1988) discussed the effectiveness of employers and leaders in management positions, empowering employees, and the sharing of power between the employee and employer. The concept of empowerment is seen as beneficial in the workplace (Conger & Kanungo, 1988). Empowerment techniques used in team building have also been found to be effective in building and maintaining the workforce environment (Conger & Kanungo, 1988).

Wallerstein and Bernstein (1988) took Freire's empowering education approach and applied it to health education through a substance abuse prevention program. A traditional health education approach to health promotion, in many ways, is similar to the empowerment education model by starting with a problem, applying educational learning methods, and involving the participant in the learning process (Wallerstein & Bernstein, 1988). Empowerment theory takes the learning process from the teacher or expert and places an emphasis on group sharing.

Empowerment theory's 3-stage methodology is incorporated into community health education. The first stage is called listening; instead of a needs assessment being conducted by a health educator, the community or group is consulted to determine problems and needs (Wallerstein & Bernstein, 1988). The second stage, called dialogue, becomes a structured dialogue process guided by codifications. Codifications are physical depictions of the issue being addressed in the form of "role plays, stories, slides photographs, songs" (Wallerstein & Bernstein, 1988, p. 383). The depictions are used to invoke emotion and social concern for the issue portrayed in order to stimulate discussion. The third stage, called action, is when participants take what they have learned into the community and reflect on it for positive change.

Wallerstein and Bernstein (1988) adapted empowerment theory to an Alcohol Substance Abuse Prevention Program (ASAP) with a goal of reducing morbidity and mortality in New Mexico for middle and high school students. The ASAP program recruited volunteers from area middle and high schools for visits to the emergency room and the local detention center to speak with those who have an alcohol- or drug-related problems (Wallerstein & Bernstein, 1988). Trained volunteers were on hand to help facilitate this process. The visits took place during four separate learning sessions. Additional training was given to teens so they could go back to their schools and communities as peer educators for positive change.

McDonough and Davitt (2011) discussed the long-term care needs of aging adults and proposed the village model as a means to address the needs of this population. The population of older adults is increasing, and the need to make it easier for this group to live in their homes and communities autonomously was the focus of this community-practice-based study. The village model, presented from a social work perspective, was based on community volunteers coming together to provide assistance to ageing community residents by providing services such as transportation, shopping, gardening, and so on (McDonough & Davitt, 2011). Not only were the services provided for the elderly, but the governing and administration of the village model was performed by volunteer residents of the community. The community practice framework emphasized the empowerment theory at the individual and community level. The community as a whole was empowered to become involved for positive change, and the individuals were empowered to get involved with the community effort in order to make their lives and the lives of other elderly members easier to manage.

Summary and Transition

In Chapter 2, I reviewed the breast cancer statistics for African American and European American women under and over the age of 50. In addition, I reviewed the current literature on the impact that breast cancer has on the quality of life of the survivor. In Chapter 2, I introduced the theoretical model used for the study, empowerment theory. I presented the application methods used in implementing empowerment theory in research. Chapter 3 provides the study design and methodology used to complete the research.

Chapter 3: Research Method

Introduction

The purpose of this qualitative, phenomenology study was to explore the impact that breast cancer has on the quality of life of African American survivors from a psychosocial, physical, spiritual, and economic perspective. In addition to assessing quality of life, social networks, and their ability to promote empowerment attitudes among survivors, were examined. In this chapter, I describe the methods including the research design, setting and sample, data collection, data analysis, participant protection, and role of the researcher.

Research Design and Approach

The research design used for this study was the phenomenological tradition, which is a qualitative approach. Qualitative research provides an avenue to understand and discover the personal experiences of individuals and groups as they relate to a given phenomenon (Creswell, 2009). Qualitative research usually takes place in the natural setting of individuals or groups to examine a human problem from the lens of those who have lived the experience (Creswell, 2009). This research design focus is primarily on the participant's view of the problem and not what the researcher believes or what is found in the literature (Creswell, 2009).

Originally, a case study was the research design chosen for this study, but after further consideration, I found that phenomenology was the most suitable. A single case study could have been used, but according to Creswell (1994), it is used to explore a process. Another qualitative research design that was considered for this study was the narrative approach. The narrative design is an in-depth approach to investigating a phenomenon based on storytelling and familial artifacts. According to Creswell (2007), this approach is used when researching one person or a small number of people. The narrative focuses on the individual, which is opposed to the phenomenology where the approach is more on the individual's experience. Therefore, the narrative design was not the best fit for this study because I focused more on the phenomenon of breast cancer survival.

The purpose of this study was to describe the life experiences of those living the phenomenon, which was the quality of life of breast cancer survivors. According to Creswell (2007), phenomenology is a philosophical approach with an intentional focus on a specific phenomenon. In a phenomenological study, individuals are interviewed concerning their lived experiences with the phenomenon. Phenomenology was the most effective qualitative method for this study because of the focus placed on the individual and the ability to explicate the lived experiences of each living being.

Phenomenology is one of many qualitative approaches used by researchers. As described by Giorgi (1985), phenomenologists go out into the world where lived experiences are taking place through various people and circumstances. Phenomenology gives the researcher direct insight into a phenomenon through the everyday lives of the participants. Direct interaction with individuals is common to gather, analyze, and interpret data. Qualitative research is often used for interpretive inquiry. Researchers interpret data collected from individuals for a clearer understanding of the phenomenon being studied (Creswell, 2007).

Phenomenology is divided into two main schools of thought: descriptive or transcendental phenomenology and interpretive phenomenology. Descriptive phenomenologists reduce the lived experiences of individuals into themes and patterns to highlight what is common for those experiencing the same phenomenon (Walden, 2012). Interpretive phenomenologists take the information gained from individuals and analyze it through a psychological and sociological lens to determine the underlining reason for the response (Walden, 2012). For this particular study, the descriptive or transcendental phenomenology was used to determine quality of life factors and feelings of empowerment.

This study was based on the descriptive, phenomenological method developed by Giorgi whose ideas were founded on the premise established by Husserl and Merleau-Ponty (Applebaum, 2009). Giorgi's phenomenological research method consists of five core steps: (a) describing the phenomenon being researched, (b) grasping the whole meaning of the experience, (c) determining meaning units of lived experience, (d) transforming raw data into psychological meaning, and (e) presenting the general structure of the experience (Giorgi, 1985, 2009). Qualitative research is not about numbers, but about philosophical and psychological experiences, both of which require the reasoning and articulation of the ideas being presented. The purpose or aim of this study was to explore the impact that breast cancer has on the quality of life of African American breast cancer survivors from a psychosocial, physical, spiritual, and economic perspective. In addition, I wished to determine if formal social support groups (Sisters Network) and/or informal social support groups (friends and family) were beneficial or not for encouraging empowerment attitudes such as self-efficacy, self-determination, self-capacity, and over all optimistic attitude, regardless of the outcome. Additionally, the aim of this study was to answer the following three questions:

1. How has the lived experiences of African American breast cancer survivors' affected their quality of life from a psychosocial, physical, spiritual, and economic perspective?
2. How has social networks encouraged empowerment attitudes in African American women?
3. Does social networks improved the quality of life of African American breast cancer survivors?

Setting and Sample

The population chosen for this study was African American women 18 or over diagnosed with breast cancer who were at least 1-year posttreatment. Because the purpose of the study was to determine if social support groups were beneficial in encouraging empowerment attitudes, participants were selected from the Sisters Network of Nashville Tennessee, an African American breast cancer survivorship group. This was a small sample, but it was characteristic of a phenomenological study (Creswell, 2007). Giorgi (2009) stated that the number of participants is dependent on the amount of data collected. Giorgi stated, "The greater the amount of data obtained from each subject, the fewer the number of subjects required, but there should always be at least three" (p. 198). Criterion sampling was the sampling method used in this study. Participant selection was based on finding individuals who were survivors of breast cancer and who had been diagnosed and treated and were now experiencing posttreatment survival stages. Eligibility selection was guided by the following criteria: (a) diagnosed with breast cancer at least 1 year ago, (b) identify as an African American female, (c) speak and understand English fluently, (d) willing to be interviewed about lived experience, (e) willing to be interviewed while being recorded, (f) willing and able to give informed consent, (g) member of Sisters Network Nashville, and (h) must be 18 or older.

The President of the Nashville Tennessee Chapter of the Sisters Network distributed fliers to all sister network members via e-mail (see flyer in Appendix A). Six participants were interviewed, and interviewing continued until theoretical saturation was met. Saturation was determined after the initial six interviews were conducted, and three more thereafter, until no new themes were identified.

Potential participants responding to the flyer through telephone and e-mail were screened by eligibility criteria. Participants who met the requirements were given details of the study (Appendix B) over the phone or e-mail. An interview time and date were set. At the time of the interview, participants had an opportunity to ask questions regarding the nature of the study. Once all questions and concerns were satisfied, participants were given an informed consent sheet to sign (Appendix C) and a demographics sheet (Appendix D) to complete. After all paperwork was finished, the in-depth interview began.

Material and Instrumentation

I conducted an in-depth interview using open-ended questions. The interviews were used as a means to collect data concerning participants’ viewpoints on quality of life for survivors of breast cancer. Because this was a descriptive, phenomenological study, in the interview questions, I focused on describing the phenomenon. As a phenomenological researcher, it was imperative to remain focused on the "object of investigation" or lived experience (the quality of life of breast cancer survivors from a psychosocial, physical, spiritual, and economic perspective) and not the actual person describing the experience (Englander, 2012, p. 25). The participant is a priority as a phenomenon host, carrier, or vehicle. The interview is conducted in order to get to know more about the phenomenon and not necessarily the complexity of the participant (Englander, 2012).

In formulating the interview questions, it is vital to ask questions that describe a situation in which the phenomenon takes place. Finding the meaning of the phenomenon (quality of life for survivors of breast cancer from a psychosocial, physical, spiritual, and economic perspective) was connected to their lived experience (Englander, 2012). The Student-Derived Interview Guide (F) consists of descriptive questions about the phenomenon (quality of life from survivors of breast cancer from a psychosocial, physical, spiritual, and economic perspective). In addition, the interview guide included descriptive questions about social networks' ability or inability to encourage empowerment attitudes.

Data Collection and Analyses

Data were collected through a series of open-ended questions with participants consenting to be a part of the study. The individual interviews were conducted at a local support group location unless a more convenient location was suggested by the participant. The interviews were digitally recorded and later transcribed using Express

Scribe transcription software. Transcribed data were saved on two separate computer hard drives. In addition, a hard copy of the transcribed data was printed and saved in a locked box at my home. The original interview audio recordings were saved as mp3 files on two separate password-protected computer hard drives. Additional copies of data will be used as a backup if any of the original data are destroyed. Interviews were estimated to last between 45 minutes to 1 hour per person, but no official time limit was placed on the interview to allow participants the liberty to express themselves adequately. As a means of maintaining privacy, each survivor was given a random number selected by the digital recorder at the beginning of each interview, and I later attached survivor to each participant's number. The numbers were used in place of real names on all identifying documents.

The interview began with an inquiry of the participant's feelings about being diagnosed with breast cancer as a means to start questioning related to phenomenon. Questions developed for the interview process were based on six categories that were as follows: (a) impact breast cancer has had on quality of life, (b) psychosocial quality of life, (c) physical quality of life, (d) spiritual quality of life, (e) economic quality of life, and (f) formal and informal social support group's impact on empowerment attitudes.

Data were analyzed incorporating Giorgi's phenomenological method as mentioned in the research design and approach section of this chapter. In order to embrace phenomenological principles, it was necessary to put away all preconceived notions or beliefs about the phenomenon in order freely investigate, without preconceived knowledge, the quality of life issues of breast cancer survivors. The process of setting aside prior knowledge and beliefs of phenomenon is a process called epoche (Moustakas, 1994). A more commonly used word for epoch is bracketing. Bracketing is the process of stripping away all bias or prior knowledge and separating the phenomenon from interferences and thoroughly inspecting it (Wojnar & Swanson, 2007). Table 2 below demonstrates Giorgi's research methods the bases for data analysis of this study.

Table 2

Giorgi's Phenomenological Research Method

Core Steps	**Data Elements**
Step 1	Selection of participants, Survivors of breast cancer Members of Sister's Network of Nashville, TN
Step 2	Read transcribed data in its entirety to get a sense of the whole lived experience
Step 3	Read transcribed data over for clarification and to establish meaning units (i.e., descriptive lived experiences divided up into units of meaning.).
Step 4	Transformation of meaning units into a language that reflects the science of the researcher (e.g., public health, psychology, education etc.).
Step 5	Insights gained from meaning units are synthesized into general Structure for presentation of findings of survivors of breast cancer (i.e., generalized meaning of the whole phenomenon.).

Each individual interview was transcribed verbatim, and a printed copy was read and reread to get a sense of the whole lived experience of African American women's quality of life after breast cancer as suggested by Giorgi's phenomenological research method. After getting a sense of the whole experience (Step 2), the transcribed interview was read again to discover meaning units (Step 3).

Meaning units involves taking the descriptive lived experience and dividing it up into “units of meaning” (Giorgi, 2009, p. 129). I was mindful of the phenomenon, quality of life, from a phenomenological view while reading transcripts. Every time there was a shift in meaning, a mark was made to distinguish it from other units of meaning. This process continued until the end of the transcribed data was reached. Descriptive meaning gained through interviews is vast and much too difficult to be handled holistically (Giorgi, 2009). Breaking description down into smaller parts or meaning units makes it easier to analyze data into relevant themes. This practice was implemented for each transcribed interview.

The fourth phase of analysis (Step 4) began with organizing themes gained from the previous step and transforming them into integrated expressions of the lived experiences of breast cancer survivors. This step gave a clearer understanding of the phenomenon being researched, quality of life of African American breast cancer survivors. The final phase (Step 5) blended the lived experience of each participant to establish a generalized meaning of the whole phenomenon.

Trustworthiness

Credibility of the findings of this qualitative study was taken very seriously. Safe guards were put in place ensure the accuracy of the data. Creswell (2009) expressed the importance of validity and reliability in a research study. Validity is defined as the accuracy of the findings. Reliability is a consistency of the research approach among other researchers and studies (Creswell, 2009). These terms, although accurate and compatible with qualitative research, are most often used and developed for quantitative research. Lincoln and Guba (1985) proposed that qualitative researchers use alternative terms to express validity and reliability in research studies such as credibility (internal validity), transferability (external validity), dependability (reliability), and confirmability (objectivity). For the purpose of this study, trustworthiness was established through three strategies: rich thick description, discrepant case analysis, and expert panel review of interview guide. Creswell (2007) suggested using at least two strategies to establish trustworthiness of the study. A rich thick description, as stated by Creswell (2007), gives the reader detailed information about the participant, setting, process, and manner in which the study is conducted. Creswell (2009) also explained that providing a look into the subject or theme of the study from several different perspectives gives the findings a more realistic impression. Rich thick description adds to the trustworthiness of the study (Creswell, 2009).

Another strategy to establish trustworthiness is the use of discrepant case analysis. During the analysis of the data for themes and patterns, the researcher will be cognizant of data that do not fall in line with the main findings of the study. Discrepant cases are findings that contradict the main theme of the study. According to Patton (1999), cases that do not fall in line with the main theme or findings of the study can lead to a better understanding of the phenomenon being studied. Including discrepant cases lends to the credibility of the study, therefore increasing its validity (Creswell, 2009).

Furthermore, as an additional strategy, the Student-Derived Interview Guide (Appendix F) was examined by three expert panel members to determine the trustworthiness of the instrument. The Panel of Expert Evaluation Form (Appendix E) was e-mailed to all three perspective members, and their review and input was integrated in the final copy of the instrument.

Role of the Researcher

I was responsible for preparing surveys and setting up interview times with the participants. In addition, I collected all data for the study and was responsible for data analysis. The development, word processing, and printing of all relevant documents (such as interview questions, informed consent form, demographic sheet, and transcripts) were all executed by me. I transcribed the recordings of the interviews in an effort to better understand and familiarize myself with the data to be analyzed. I did not have a personal or professional relationship with any of the participants of this study. Bias related to power over participants, work environment, or conflict of interest did not apply in this study.

Protection of Human Participants

All participants were treated according to the guidelines set forth by the Walden Institutional Review Board (IRB). Upon IRB approval, fliers were posted at the Sister's Network of Nashville and e-mailed to all Sisters' Network members. In addition, fliers were posted at an additional cancer support group location. This location also served as a place to meet and conduct interviews. Before the interviews were conducted, participants were asked to consent to the interview process by reading and signing the informed consent form (Appendix C). Participants of the study were assured that they could withdraw from the study at any time without negative consequences and confidentiality. To further ensure the confidentiality of transcripts, journal writings, and audio tape, each survivor was given a random number selected by the digital recorder at the beginning of each interview. I later attached survivor to each participant's number and this number was used to identify participants. Information gained and related material from the study will be safeguarded in a locked box for 5 years.

Dissemination of Results

The results of the study will be disseminated to support Walden's commitment to social change. The results of the study will be disseminated to the Sisters Network and through publication of the dissertation and submission to appropriate peer-reviewed journals in the field of public health. Submission to conferences for poster presentation, and other organizations looking for information on breast cancer survival and social networks, will also be used to disseminate data.

Summary and Transition

This chapter provided a description of the qualitative method used for this study. Descriptive phenomenology method, as designed by Giorgi, was used as a guideline for the research, interview, and data analysis process. Participants in this study were African American women 18 and over diagnosed with breast cancer at least 1-year posttreatment. Participants were asked a series of open-ended questions related to the phenomenon. I recorded and transcribed the answers. Chapter 4 will provide an in-depth discussion of the results of the study.

Chapter 4: Results

Introduction

The purpose of this qualitative, phenomenological study was to explore the impact that breast cancer had on the quality of life of African American breast cancer survivors from a psychosocial, physical, spiritual, and economic perspective. In addition, I wished to determine if formal social support groups, (Sisters Network) and/or informal social support groups (friends and family) were beneficial or not for encouraging empowerment attitudes such as self-efficacy, self-determination, self-capacity, and overall optimistic attitude regardless of the outcome. In this chapter, I describe the recruitment process, provide a descriptive examination of the data collection and data analysis process, and establish meaning units transformed into units of meaning.

Participant Characteristics

Recruitment fliers (Appendix A) were e-mailed to the president of the Sisters Network of Nashville Tennessee Chapter. She e-mailed or distributed the flier to members of the Sisters Network of Nashville Tennessee. I only had one participant to respond and complete an interview. In addition to her e-mailing the fliers, she invited me to one of their monthly meetings so I could introduce myself and explain the study to the members in attendance. A total of six volunteered that evening. Of the six volunteers, four completed the interview process. The remaining four participants in the study contacted me through e-mail or phone call. Instead, a five to six pool of nine participants was interviewed for my study. Of the nine volunteers, all nine met the eligibility requirements. In spite of the low participant outcome, my standards set for saturation was met. According to Guest, Bunce, and Johnson (2006), it is possible to achieve saturation with a small number of participants in a phenomenological study of their lived experience. Table 3 details the demographics of participants in this study.

Table 3

Participant Demographic and Breast Cancer Characteristics

Randomly selected survivor number	Age	Marital status	Race	Gender	Education highest level completed	Income level	Stage at diagnosis	Year's post diagnosis	Year's since last treatment
Survivor-30	45	Married	African American	Female	Masters	$80,000 to $99,999	2	15	14
Survivor-32	64	Divorced	African American	Female	High school	>$25,000	2	16	15
Survivor-34	62	Married	African American	Female	Some college	<$100,000	4	10	2 1/2
Survivor-39	53	Single	African American	Female	2-year degree	>$25,000	2	8	8
Survivor-42	55	Married	African American	Female	4-year degree	$25,000 to $39,999	0-1	6	5 1/2
Survivor-45	51	Single	African American	Female	2-year degree	$25,000 to $39,999	Not sure	12	12
Survivor-48	65	Married	African American	Female	Masters	$40,000 to $59,000	2	12	11
Survivor-52	64	Divorced	African American	Female	Some college	$25,000 to $39,999	early	30	30
Survivor-56	80	Married	African American	Female	Masters	$25,000 to $39,999	advanced	9	1

While conducting this study and after interacting with the participants, I realized that the best way to identify them was by survivor. From this point on, participants of this study will be referred to as survivor or survivors.

The survivors were nine women who had been diagnosed and treated for breast cancer. They were recruited from the Sisters Network of Nashville Tennessee as previously described. All of the survivors had surgery that consisted of at least a mastectomy, but only four had reconstruction surgery. They were well over 1-year postdiagnosis from 6 years to 30 years out. The survivors' lived experiences were based on varying stages of the disease. As seen in Table 3, the stage at diagnosis ranged from early 0-1 to 4 advanced. All survivors were women of African American descent.

I was grateful for the opportunity to interview each survivor. At the beginning of each interview, I expressed my gratitude by thanking them for taking the time to be interviewed. In addition, I re-emphasized that they could discontinue the interview at any point without negative feedback. The interviews were conducted at varying locations. Two were conducted at the local library, two at the survivor's home, and the remaining five were at a local church in one of two private classrooms. These locations proved to be the most requested and convenient for survivors. Each interview was recorded on a digital recorder. The interviews were at varying lengths, from 24 minutes to 1 hour and 21 minutes. The range in time in the interviews was primarily due to how in-depth the survivor was and how talkative she was. Due to the nature of the subject, some expressed more emotion and recalled situations connected to the subject matter. In keeping with confidentiality protocols, each survivor was given a random number selected by the digital recorder at the beginning of each interview, and I later attached survivor to each participant's number. If the number 24 was randomly selected by the digital recorder, I then added the word survivor to the assigned number. An example would be Survivor-24 and so on.

The interview was guided by a list of already prepared questions (Appendix F). Interview data were digitally recorded and transcribed and saved electronically and printed to be read as much as needed. No identifying information was recorded on transcripts for the sake of anonymity.

Thematic Analyses

Quality of Life

Each interview recording was reviewed several times with the printed transcript for accuracy. The transcripts were then read and reread for the purpose of establishing themes. The transcripts were broken down and reviewed for themes based on already established categories of quality of life: psychosocial, physical, spiritual, and economic. The themes or meaning units emerged from each transcript for each category listed above. Throughout the process of establishing meaning units, I was careful to bracket previous knowledge of related topics associated with the phenomenon of breast cancer. This was necessary in order to ascertain an unbiased perspective of the phenomenon being studied. The process of identifying meaning units was time consuming due to the abundance of data collected for all nine survivors.

From the beginning of this study, there were four areas used to categorize the impact that breast cancer had on the quality of life of breast cancer survivors. The categories were psychosocial, physical, spiritual, and economic. A section of questions on the Interview Guide (Appendix F) was designed to assess each category. The emerging themes were identified for each category. Category 1 was psychosocial: body image, acceptance, fear, and anger. Category 2 was physical: complications of treatment. Category 3 was spiritual: reliance on God. Category 4 was economic: insured, uninsured, and managing the financial ramifications of treatment.

Category 1: Psychosocial

Theme 1: Body image. Breast cancer survivors experienced body image dissatisfaction. Body image can be defined as the subjective concept of a person's physical appearance based on self-observation and reactions of others (Body Image, 2007). After diagnosis and surgery, survivors experienced changes in their appearance. Some become dissatisfied with their bodies. Although a temporary body image issue, loss of hair had a significant emotional impact on the survivors' quality of life. Some of the survivors were more affected by the loss of hair than they were about having their breast removed.

> Survivor30: I think the biggest emotional impact I had was when my hair started falling out I think I took that harder than having my breasts removed. I just remember crying and crying and crying when my hair started coming out. That really, I think that was my biggest emotional impact that I had.

Beauty is often based on the outer appearance and, once altered it can negatively impact a person's quality of life. The hair is a source of pride for many African American women who have a substantial amount of it, and losing it extinguishes feelings of pride and self-worth. The devastation of this loss was immeasurable as noted with this survivor: Survivor34: "This was my hair. That was really long and when I lost that, that was harder, I think than me losing my breast."

> Survivor34: Before my hair fell out, another good friend of mine took me to get wigs. She came by and I had the wigs, but that was the

> hardest thing when it started coming out like this and then one of my daughters just cut it off, because it was falling. When I saw all this hair in the tub, I screamed.

Other factors contributing to feelings of dissatisfaction included the comments of strangers in a public setting. One survivor had experienced uncomfortable comments from strangers about one of her arms being swollen due to lymphedema. The constant remarks made her feel self-conscious about her appearance. She compared it to someone who is large around the midsection being asked when the baby is due when they are not pregnant.

> Survivor52: A lot of times I changed, where I was self-conscious about it. At that time, I'm not anymore. I would just wear long sleeves because the arm was fat on one side, the right arm was bigger than the left arm and people would kind of look and your hand.… The folks would say like "Oh does that hurt?" You are totally not thinking about it, you are just standing somewhere and now out of the blue someone "Oh does that hurt or what did you do to yourself?" If anything I learned that if no one tells you that they are ill it is sort of like people who go up to a person who is somewhat fat in the middle section and says when is the baby due. I'm just thinking they mean well and so you just, I don't know, it's getting well, it's better now. It doesn't hurt. "Oh it look so painful", I hate that so I just wear long sleeves to sort of… and I had gotten to that point because when people just keep saying things it makes you self-conscious about it.

The actual loss of the breast also had a significant impact on body image. One survivor had concerns about how having one breast would affect her ability to actively date. She had concerns if a potential mate would accept her with one breast. This concern kept her from freely dating because she worried that she would not be acceptable as she is now. For this reason, she was not fully able to accept her mastectomy.

Another survivor talked about changes she experienced with her body image. She mentioned she looked in the mirror at herself often with dissatisfaction. She did not like what she saw, and she did not feel good about herself. As time went on, she realized that if she was ever going to move forward she would have to make the best of what she had.

> Survivor42: I had to come to that place over time to just say, “You know, God, I appreciate the fact that I have two arms that I can raise, and maybe things are not looking like perhaps some of the magazines or whatever, but I’m grateful that I have what I have and, need be, I can work with it.”

Theme 2: Acceptance. Some of the survivors came to the conclusion that life goes on after breast cancer. One of the survivors was a young mother and college student at the time of her diagnosis, but she remained enrolled in her degree program and took on a new job while still in treatment. It was important to her to keep moving forward with life and continue with her daily routine as much as possible. Survivor30 stated, “I mean, I had breast cancer, but life went on and here I am today.”

Another survivor described her breast cancer experience as not something she expected to get but she was not at all surprised either. Her family had a high prevalence of cancer and that fact diminished the shock factor out of her diagnosis. She also mentioned that the women in her family were strong women, and they did what they had to do to survive. Time was not spent crying and feeling sorry for each other, but a desire to live with their current circumstances.

> Survivor56: No, I didn't cry, I've been a person who always accepts things. I've been able to accept things pretty good. I've had several major illnesses. Haven't had a nervous breakdown yet, thank God…after teaching …Anyway, no, I just accepted it because cancer has been prevalent in our family one way or the other for years.

Theme 3: Fear. Fear was a theme among women diagnosed with breast cancer. Some survivors experienced the fear of the unknown. They questioned if they would survive, if they would live long enough to see their children graduate high school, if they would be at their children's wedding, and if they would be around for grandchildren. One survivor had a fear of driving. She was afraid she would get sick while driving. She had others to drive her around until she was confident enough to get behind the wheel again. After about 5 years, she decided to start driving again and, soon after, she went back to work. Another survivor experienced fear and anxiety when she had to go in for a second mammogram. She was unsure of what was happening. Upon arriving home late one night, her doctor's office left a message on the answering machine explaining that she did have cancer. She spent the weekend frightened and alone.

> Survivor32: When I found out about it, I was home. I was alone. I t was a Friday evening, pretty late, and they left a message on the answering service that, you do

> have cancer. All through that whole weekend, I had to go through the anxiety. I couldn't believe it, but it made me so sad that I cried.

One other survivor experienced fear due to already being scheduled for a hysterectomy and finding a lump in her breast. The lump was cancer. She had two major surgeries at the same time, a hysterectomy and a mastectomy.

> Survivor48: The surgery was… it was frightening. I had to have hysterectomy because my gynecologist had told me months before I was going to need a hysterectomy. He was going to schedule it and I found a lump in my breast and I'm going "Oh my goodness." He sent me to a surgeon and I have breast cancer. I thought, I have two major surgeries, I want to get them over with at the same time and the doctors were able to schedule both.

Breast cancer placed an emotional toll on most of the women in this study. Some women were concerned about losing one or both of their breasts. Women became unsure of whom they were without their breast. They questioned if they would be accepted by others and by their husbands. One survivor questioned where her marriage would end up after her husband found out she had breast cancer.

> Survivor34: She stated, "My husband was one, everything had to be physical. He was like perfect, because he's physically shaped, so he had that perfect body. I said where is my marriage going to be and I was thinking about that."

Theme 4: Anger. After a diagnosis of breast cancer, a variety of emotions can ensue. Anger was an emotion experienced by some survivors of cancer. One survivor experienced anger after her daughter was diagnosed with breast cancer a few years later.

Cancer was prevalent on the maternal side of her family. Her mother, an older sister, three aunts, and two cousins all had cancer. She was angry because she reported her history of cancer on all of the medical history forms given to her to fill out by all of her doctors. Not one of her physicians suggested she be tested or scheduled her appointment to be tested for the breast cancer (BRCA) gene. Later, after her daughter was diagnosed, her doctor set her up for an appointment to be tested for the gene. She decided to be tested also. They were both positive for the BRCA mutation.

> Survivor48: Actually, both of us got the test because that's how she got it. It came from me. I got really mad at them because had they made the appointment for me then I could have been aware and I told my daughter. There are preventive things and she possibly would not have gone through the whole diagnosis and everything. I let them know. I let all of them know in a letter, and personally, that I didn't appreciate that they hadn't done it.

The BRCA 1 and BRCA 2 genes are responsible for developing protective proteins that repress the radical formation of breast cancer cells into tumors. When a mutation of this gene occurs, instead of acting as a breast cancer suppressor, it can reproduce cells that can lead to the formation of cancer (NCI, 2015). A person who carries this mutation has a greater chance of developing cancer. BRCA1 and 2 are genetic mutations that can be inherited from an individual's mother or father. If a person has a genetic predisposition to be a carrier, testing is available to identify BRCA mutation in the body.

Anger was also expressed because of the lack of support from family members during her diagnosis, treatment, and early years of survival. Feelings of resentment, anger and frustration were held toward family members. Survivor39 “I felt like they should have been more loving and giving to me like they were with others in the family.”

Category 2: Physical

Theme 1: Complications of treatment. Breast cancer treatment is necessary for survival. However, along with treatment come complications that can have a significant impact on the survivor’s quality of life. Some expressed feelings of extreme tiredness after chemo and radiation therapy. This level of exhaustion was unexpected and altered the everyday routine of several of the women in this study. One survivor expected to continue with social interactions and obligations, but soon found out that it was not possible physically. She went to work and came home and was not able to do much else. Another survivor had a similar experience with exhaustion. She arranged to have her chemo and radiation treatment on Friday so she could have the entire weekend to recover and return to work on Monday. One survivor claimed that she was totally exhausted and not capable of doing absolutely anything. Another common complication of treatment was lymphedema. Survivors experienced this complication most often after they had a mastectomy. Lymphedema causes swelling, usually in the arm. In order to keep swelling down, a compression sleeve is worn, and care has to be taken when using the arm for lifting and other weight bearing activities.

> It bothers me sometimes (lymphedema) when I do, like I say, I can't do a lot of heavy lifting and anything like that. I have to rest and relax a little bit to keep the swelling down, but wearing a garment, that does help.

Another survivor had lymphedema, and her doctor suggested that having reconstructive surgery would improve her condition. The surgery improved the lymphedema, but because the surgeon removed muscles from her shoulder for the reconstruction, her range of motion is now limited.

> Survivor52: I can only reach up and back just like to here. Swimming was a little different because the right arm won't go. When I put my clothes on I have to start with the right arm because there is no muscles, no elasticity.

Other complications that affected the quality of life of breast cancer survivors were medications prescribed to them by their doctor. Tamoxifen, an estrogen inhibitor, is often used in breast cancer patients to reduce the risk of recurrence. As with any drug, side effects are a possibility. One survivor described her experience using Tamoxifen.

> Survivor34: When I was on the Tamoxifen after the first time and radiation, now that really affected my quality of life. I was so sick, I couldn't walk. Sometimes I couldn't walk. I couldn't sit up. I was just sick. It just messed me up completely. I stayed on it. You're supposed to stay on it for 5 years. I stayed on it for 2-1/2 years.

Category 3: Spiritual

Theme1: Reliance on God. Some African American women depend on their relationship with God to get them through difficult times. I selected spirituality as a category to determine what, if any, impact breast cancer had on the survivor's quality of life from a spiritual perspective. One survivor expressed that after breast cancer, she was more spiritual because of her reliance on faith. She believed she is still here because her experience can help others in this situation.

> Survivor32: I think I'm more spiritual, because relying mostly on faith and knowing what God can do, I'm still here, and he has maybe for a reason. I think probably that, that is to express to others some of the things I've gone through.

Survivor34 stated, "It made me closer to God. It made me realize what's more important. It's not about status. It's not about the title, it's about God." Survivor39 claimed, "Actually, I'll tell you I feel it has brought me somewhat closer, not to say that I wasn't already close, but it just seals the deal."

> Survivor42: Well, I did have to just get quite before the Father and just sit in his presence and think about this information I've now received. I wondered why, why is this the way it is? Sometimes it just takes one or two scriptures; you've just got to hold onto them. I believe it was the scriptures, Psalms, and Proverbs. I can't remember. It's Psalms 17 or somewhere around there and just says…" I shall live and not die and declare the works of the Lord". When I got a hold of that scripture, even now there's times I have to pull that back out.

Survivor56 stated, "Not really. No, because I already had a strong faith. Well, I've been through a lot in my life already, before breast cancer."

Category 4: Economic

Theme 1: Insured. Those who had health insurance had some peace of mind that their medical bills were paid to the percentage allowed by the policy. Patients may have a copay or a small percentage of the total bill for which they are responsible. However, the majority of the medical costs are covered by the insurance policy. Survivors who were covered explained:

> Survivor: 30 I stayed in the hospital for 5 days and all my treatments that I got; I don't think I had a bill. If it was, it was so minimal that I don't even remember what it was.
>
> Survivor32: I've had some good insurance, for one thing, and good doctors. With the financial part of it, I didn't have to pay other than my 20%. I still had my job and with the insurance that I had, that was a blessing.
>
> Survivor52: I had primary and a secondary, I was fortunate, that is why I said all I could do is just pray, Praise God that I had insurance. It covered the surgeries it covered the hospitalizations, it covered whatever I needed.

Theme 2: Uninsured. Eight of the nine survivors were insured at the time they were diagnosed with breast cancer. One of the eight insured at the time of diagnosis lost coverage due to being off work for a long period of time and was not in a position to afford Cobra. Survivor39 stated, "After I was off work having the stent put in my insurance ran out. I couldn't afford the Cobra." She later was eligible for TennCare, Tennessee’s Medicaid managed care program. This program provides coverage for breast and cervical cancer patients in need of treatment.

The one survivor who was completely uninsured had to apply for Medicaid and then disability. After 6 months of waiting for approval, she finally received disability payments.

> Survivor45: I was like they were waiting on me to die, because they didn’t want to give out the money. They were waiting for me to die, before they gave me disability, and I’ve been working a long time, but they waited.

Theme 3: Managing financial ramifications of treatment. Although most of the survivors had insurance coverage at the time of diagnosis and treatment, there were some out-of-pocket expenses left over. One survivor explained how discomfiting it was to have medical bills coming in and not enough money to pay them at the time. She was on paid medical leave from her job, but was not receiving her full salary, only a percentage of what she usually received. She was earning less money, and she now had more bills to pay.

> Survivor42: “Yes it affects you economically. It affected me because you’re not taking in you full wages and you already have other bills that you pay. You have to prioritize. What are you going to do first? You’re going to have food. You’re going to pay you utilities. You’re going to do all of that…”

In addition, this survivor felt harassed because of the calls from medical billing departments for payment that, often time, had not reached its due date. Handling the amount of medical bills coming in was overwhelming and time consuming.

Moreover, the time spent calling medical insurance to find out why they have not paid only to find out they were double billed. This type of incompetence by billers, adds more stress to an already high stress situation. After a period of time, unpaid medical bills are sent or sold to collection agencies, now there are calls coming in from those companies.

One other survivor experienced a lack of income. She had enough savings to pay her regular household bills, such as rent and utilities, for 6 months, but struggled with not having enough money for food. She reached out to churches, food banks, and others to get her through the crisis. After 6 months, she began to receive disability payments. This helped ease her economic burden until she was well enough to return to work.

> Survivor45: I called churches. Churches gave me money to help. I went to food banks. People brought food, all kinds of stuff, but still had to go to food banks because I'm by myself. I don't make a whole lot of money, so I have to do what I have to do. But I'm okay with that. I'm okay, because I know he's going to provide, so I don't worry about it.

Another survivor was unable to afford her large family home after diagnosis and treatment. Eventually, she relocated to another state where the cost of living was cheaper. Survior34 stated, "It did effect financially. That's another reason I moved. My taxes are so expensive…."

Empowerment

In addition to the four categories used to assess breast cancer impact on quality of life, two subsequent categories were used to assess the helpfulness, if any, of formal social networks or informal social networks for encouraging a sense of empowerment. The empowerment theory was selected for this study as a means to ascertain the usefulness of social networks to provoke an empowerment mentality through the empowerment theory's three stage methodology of listening, dialogue, and action (Wallerstein & Bernstein, 1988). The transcripts were read and reread for the purpose of uncovering meaning units or themes.

Category 5: Formal Social Networks – Encouraging a sense of empowerment or not.

Theme1: Remain active and involved. The formal social network in this study was the Sisters Network of Nashville Tennessee. The Sisters Network is a group of women from all occupations and ages, with one important thing in common. They are all survivors of breast cancer. Members of the group are encouraged to remain active in their everyday lives and be involved in activities initiated by the network. The group sponsors various activities designed to promote early detection, the dissemination of educational material, and breast cancer screening. The many activities give members an opportunity to reach out to others and to be consistently involved in outreach. In addition, the comradery experienced among this group of women who have survived breast cancer becomes the support system needed to encourage a sense of empowerment. Survivor 32 stated, "Yes I thank God. That helps a lot. You're strong as all of us together, but it gives you that power and that little strength to step out a little bit, and do things." Survivor 34 stated, “It keeps me going, the laughter, the talking. That keeps me going. It branches me out to try new places…” Survivor 30, “So I think Sisters Network has helped me be more aware of health issues from breast cancer and everything else, I think I’m more aware. And again, I love being able to go in the community with help fairs or even workshops just to share stories and just let women know that, hey you got to take some charge of yourself.”

Theme 2: Support of other breast cancer survivors. Some of the survivors felt a sense of empowerment through their connection with other people with their same or similar experience. A few survivors acknowledged that having the support of other survivors helped ease the feeling of loneness during and after recovery.

> Survivor:34 Also I guess it keeps me going too, because there’s other women that are going through, so I’m not here by myself. I have been able to make friends and acquaintances, not like I had…, but people, and it just gives me the empowerment to go on.
>
> Survivor45: Despite all we go through with this breast cancer, they strong women. I mean they are some mighty women, and I look at them, I can do it too. I can do it too, and we in this together, we in this together. We’re not by ourselves.

Survivor45: stated, “Just I guess looking at others and to see how they are making it after 10 years, 15 years, some of these are 26 years, is empowering in itself.”

Theme 3: Getting the word out and educating others. The Sisters Network of Nashville not only encourages and supports members of the group, but serves as an advocate by disseminating educational material and information to at-risk persons in the community. The advocating branch of this organization gives its members an opportunity to inform the public of the risk of breast cancer, the importance of early detection, and yearly screening procedures necessary for early detection. Survivors feel a sense of empowerment reaching out to inform others about breast cancer prevention and screening. Survivor30 stated, "I just love seeing these women share and share with other women to try to get them to be more educated, It's just I can't describe it. It's just a great feeling."

> Survivor34: My most favorite thing to do is the block walk, where you go door to door and knock and talk to people face to face…I love talking to my own people because we need it the most. That has been a blessing. I had the church support, but when I wanted to speak about it in the church, some of the elder church mothers saying, "Shh. That's something you hide. You don't speak about it." I said, "Yes, I say, I understand, It's no disrespect to you Mother's but I have to speak out about it because I can save somebody's daughter, somebody's sister, somebody's aunt, somebody's grandmother." That's the thing I had to do and then after a while they got comfortable. It took a while, but then they came to me and they said, "You're right". I had to step out on faith and do it, because I was led by God to do that, so I had to step out.

Category 6: Informal Social Networks – Encouraging a sense of empowerment or not.

Theme 1: Friends and family were supportive. Support of an informal social network, such as friends and family, can be a vital aspect of recovery and survival. Having the support of those closest to them can encourage a sense of empowerment. Survivors expressed feeling empowered with the support of family and friends. Survivor42 stated, “Empowerment, the ability to take charge of circumstances, most definitely, yes. Continue on, don’t give up, these kinds of words come from family and friends, yes.” Another participant, Survivor45 stated, “Yeah because I know they got my back, I know they go my back.” And Survivor30 claimed, “My family and friends were very supportive. They kind of went to the appointments with me and wrote down notes for me, because at my age, I wasn’t…Being sick, per se, wasn’t something that I was used to.”

Theme 2: Husbands disconnect and are not involved in care. Husbands were often seen as a significant part of the survivor’s support system. Survivors with husbands in this study reported husbands as being supportive, although there seemed to be some level of emotional disconnect by some husbands. It seemed their concern was directed to the financial ramifications of the disease, and the rest was a female issue that they could not do anything about. Those with husbands who were not as supportive emotionally expressed feelings about their husbands’ disconnect.

> Survivor52: Oh, I told him what the diagnosis was, and what she said what I would need to do and the decisions that we would need to make. He just said I don’t know anything about the woman’s body, why do you all tell me? To him that was like why are you telling me about breast cancer for?

> He would come sit in the room, settle the bill or whatever but as far as, speak to me I don't know anything about breast cancer.

Survivor48 stated, "My husband did not go and I got sort of pissed at him about that. He's very supportive, very much so, in other ways. (She needed her husband to take her for a treatment session)."

Theme 3: Family and friends cannot identify with what survivor is going through. Though most of the women reported family and friends as being supportive and encouraging, there were moments of disconnect because survivors felt that their loved ones could not really understand what they were going through. Survivors explained how family and friends cannot identify with what they were going through.

> Survivor32: When I was going through it, I've been the only one in the family with the cancer. Sometimes, they didn't understand and they didn't know what I was going through until I explained it to them…My family was really understanding, but they couldn't really know unless they've gone through some of the same things.
>
> Survivor39: I didn't share a lot of my experience with any of my friends. With family, no, because I always held things against them because I felt like they should've been more loving and giving to me like they were with others in the family. But like I said because I with a guy, living with a man, they felt like that was his responsibility.

Discrepant Data

Discrepant data contradicts or opposes emerging patterns of the study. All participants in the study felt empowered by the Sisters Network of Nashville and supported by family and friends. One participant reported that she did not feel empowered by the Sisters Network, and she was not supported by family and friends. One other participant stated that friends did not support her. Her friends disappeared and were no longer involved in her life. These discrepancies may subsist because the participant is empowered by other means. Furthermore, her feelings of having not received support by family and friends could have existed because of her idea of what support was or was not.

Summary and Transition

Chapter 4 included a review of the purpose of the study to explore the impact that breast cancer had on the quality of life of the survivor from a variety of categories: psychosocial, physical, spiritual, and economic. In this chapter, I reviewed the process of participant location, steps taken in data collection, and analysis of data into meaning units. Nine participants were asked a series of questions to explore the impact that breast cancer had on quality of life from four categories: psychosocial, physical, spiritual, and economic perspective. The emerging themes were (a) (psychosocial) body image, acceptance, fear, anger; (b) (physical) complications of treatment; (c) (spiritual) reliance of God; and (d) (economical) insured, uninsured, and managing financial ramification of treatment. In addition to the four quality of life categories, two additional empowerment categories were reviewed. The empowerment categories and emerging themes of (e) (formal social networks- encouraging a sense of empowerment or not) remain active and involved, support of other breast cancer survivors, and getting the word out and educating others. The final empowerment category was (f) (Informal social networks encouraging a sense of empowerment or not) friends and family was supportive, husband disconnect-not involved in care, and friends and family could not identify with what survivor is going through. Chapter 5 will be a brief overview of findings and interpretation, implications of social change, and recommendations for future study and action.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

The purpose of this qualitative, phenomenological study was to explore the impact that breast cancer had on the quality of life of African American breast cancer survivors from a psychosocial, physical, spiritual, and economic perspective. In addition, I wished to determine if formal social support groups (Sisters Network) and/or informal social support groups (family and friends) were beneficial or not for encouraging a sense of empowerment. Few studies existed at the time of this writing on the quality of life of African American breast cancer survivors and their association with social support groups. The phenomenological approach was used because it was important to capture the lived experience of the survivor. The phenomenological design not only allowed me to capture the lived experience, it allowed for a more in-depth view of each survivor. This approach to qualitative study permitted a much smaller participant pool due to the amount of data collected and analyzed.

To answer the research questions, nine African American women between the ages of 45 and 80 were interviewed. The questions were all open-ended, and participants spoke for as long as they deemed necessary. Prompts were used as needed to pull more information out of the participants and to keep them on topic. The quality of life of the survivor was affected in all areas: psychosocial, physical, spiritual, and economic. In addition, formal and informal social networks played a significant role in encouraging a sense of empowerment and quality of life. The following themes emerged from the data within already established categories as seen below in Table 4.

Table 4

Quality of Life Domain and Empowerment Themes

Quality of Life Domain	Empowerment Themes
Psychosocial	(1) Body image, (2) Acceptance, (3) Fear, (4) Anger
Physical	(1) Complications of treatment
Spiritual	(1) Reliance on God
Economic	(1) Insured, (2) Uninsured, (3) Managing financial ramifications of treatment
Formal social networks encouraging a sense of empowerment	(1) Remain active and involved, (2) Support of other breast cancer survivors, (3) Getting the word out, educating others
Informal social networks encouraging a sense of empowerment	(1) Friends and family are supportive, (2) Husbands disconnect, not involved in care, (3) Family and friends cannot identify with what survivor is going through

Interpretation of Findings

The findings from this study contribute to the body of knowledge on breast cancer survivors and their lived experience during and after breast cancer. In this section, I will integrate the findings of this study with the current literature. The findings of this study will be discussed by categories and emerging themes in light of the current literature.

Category 1: Psychosocial

To determine whether the lived experience of breast cancer survivors affected their quality of life in the psychosocial domain, survivors were asked to describe the emotional impact that breast cancer had on their quality of life and to describe how breast cancer affected their social life. Within the psychosocial domain, several themes emerged including body image, acceptance, fear, and anger. The number of themes that emerged was consistent with current literature. According to Eversley et al. (2005), African American woman are at a later stage at diagnosis and often require a more intensive treatment, such as a mastectomy. Advanced treatment increases psychosocial impairment to quality of life. The psychosocial impact that breast cancer had on the survivors in this study was due to advanced treatment, body image, fear of the unknown, and anger. However, a number of survivors had resolved to a place of acceptance of this phase in life.

Category 2: Physical

The physical domain was used to determine the impact that breast cancer had on the survivor from a physical perspective. The survivor was asked to describe how breast cancer affected them physically as it related to treatment, surgery, and cosmetic changes. I found a theme of complications of treatment. The theme was consistent with current literature. Symptoms such as pain and swelling are often reported amid survivors (Fatone et al., 2007). Knowledge on the best choices of treatment for individual treatment could provide positive outcomes for long-term survival.

Category 3: Spiritual

The themes that emerged from the spiritual domain were reliance on God, part of God’s plan, and why did this happen to me. The theme reliance on God emerged as a direct reflection of the participant’s spiritual connection with God and the need for a deeper and greater dependence on Him. This theme also answered one of the main research questions for this study based on the spiritual perspective: How have the lived experiences of African American breast cancer survivors; affected their quality of life form psychosocial, physical, spiritual, and economic perspective? An increased reliance on God was how survivors were affected spiritually. This was consistent with current literature. Torres et al. (2015) stated that survivors cope with the stresses of breast cancer by relying on their spiritual faith.

Category 4: Economic

The themes that emerged from the interview data were insured, uninsured, and managing financial ramifications of treatment. As with any serious illness or disease, cost of care or treatment becomes a factor in the process of healing and getting better. The survivors in this study spoke of how their lives were affected economically as a result of the breast cancer diagnosis and prognosis.

The themes were congruent with the focus of this study and the literature. When asked to describe the economic impact that breast cancer has had on their quality of life, the majority conveyed that they had insurance coverage, and two had secondary insurance. The majority of those who had insurance were not negatively affected financially. The small amount left over after an insurance payment was found to be affordable. However, some participants still struggled financially because of a cut in pay while off work on medical leave. Though most survivors had insurance coverage of some kind, one participant was completely uninsured. This participant suffered a financial burden. One other participant was insured at the beginning of treatment, but lost coverage due to being off work for an extended period. She could not afford to pay for the offered alternative, Cobra. At that point, she was placed on TennCare for a short amount of time, and later Medicaid covered some of her medical cost. This participant’s experiences with breast cancer left her with a significant financial burden also experienced by the uninsured survivor.

The third resulting theme was managing the financial ramifications of treatment. These findings are consistent with what Pisu et al. (2010) found in that breast cancer survivors are faced with economic burdens that can be divided into three categories: (a) direct cost, consisting of out-of-pocket expenses associated with the cancer diagnosis, for example: physician, or prescription cost; (b) indirect cost, including cost associated with lifestyle changes, such as early retirement or downsizing the family; and (c) psychosocial cost, described as the burden that breast cancer puts on the survivor's emotions, relationships, and the unseen future. These three categories manifested in the lives of the survivors in this study. Participants in this study expressed their experience with out-of-pocket expenses and the impact they had on their lives. Indirect costs of survivors were early retirement, downsized from a large family home, and relocated to another state. Psychosocial costs consisted of the loss of a long-time companion who was unable to cope with the diagnosis emotionally and friends who no longer came around.

Category 5: Formal Social Networks-Encouraging a Sense of Empowerment

The Sisters Network of Nashville Tennessee was the formal social network in this study. Members of the group were asked if being a part of the Sisters Network of Nashville had given them a sense of empowerment or not. The purpose of this study was to determine if formal social support groups, such as the Sisters Network of Nashville Tennessee, were beneficial to encouraging empowerment attitudes. The 3-part empowerment methodology seen in the empowerment theory was listening, dialogue, and action (Wallerstein & Bernstein, 1988). As a social network, the Sisters Network functioned through not only listening to the experiences of survivors across the country, but also by providing an ongoing dialogue and action. Dialogue became a vehicle that led the survivor out from the world of silence into an avenue of self-empowerment. After a review of the data collected through the interview process, three themes emerged: remain active and involved, support of other breast cancer survivors, and getting the word out and educating others.

Category 6: Informal Social Networks- Encouraging a Sense of Empowerment

The breast cancer survivors in this study were asked about their informal support group and if they encouraged a sense of empowerment for the survivor. An informal support group typically consists of close family or friends. A support network is important to the needs of the survivor. Three themes developed in this area: friends and family were supportive, husbands disconnect and are not involved in care, and family and friends cannot identity with what survivor is going through.

Implications of Social Change

More women are surviving breast cancer and are living long lives after diagnosis and treatment. African American women, in particular, are more often surviving this disease. This phenomenon leads to the necessity to understand their needs in order for their quality of life to be maintained. In this study, I set out to understand the lived experiences of breast cancer survivors from a psychosocial, physical, spiritual, and economic perspective. In addition, I wished to determine if formal or informal social networks were instrumental in encouraging empowerment attitudes. I provided insight into the struggles and challenges of the survivor from the four previously mentioned perspectives. The findings of this study indicated that specific areas of the survivors' quality of life were affected by breast cancer. In the psychosocial domain, some of the survivors had quality of life issues associated with body image. The loss of hair had an effect on breast cancer survivors, even more severe than the loss of a breast. According to

Yeager and Olsen (2011), the anticipation and the realization of hair loss due to chemotherapy treatment has been a well-known cause of anguish and distress. More should be done to alleviate the added burden of hair loss on their quality of life.

This research study was designed to discover the effects of breast cancer on the quality of life of the survivor. This information will help fill the gap in the literature on the quality of life of African American women who have survived breast cancer and the effectiveness of social networks. This study may provide relevant data to the knowledge base of survivor research. Additionally, the information gained from this research effort can be used to develop cultural-specific survivor care. Program planning by health care providers and health education specialists who incorporate quality of life measures for this population may lead to improved quality of life.

Recommendation for Further Study

This phenomenological study contributes to the literature on the quality of life of breast cancer survivors and the effect of social networks' ability to give participants a sense of empowerment. The quality of life of the survivor is compromised by breast cancer. The sequelae or side effects of treatment and the disease itself have a lasting outcome on the survivor that may not show up for months or years after cancer treatment.

Care for the needs of the survivor has become important as medical science continues to find more innovative ways to treat cancer. This study examined six quality of life categories to determine the affect breast cancer had on each one. It was discovered through the phenomenological methodology used in this study that body image was a "lived experience" of survivorship with breast cancer. Survivors expressed the impact breast cancer and treatment had on their body image. The loss of hair was considered more devastating than the loss of the breast in the lives of a number of survivors. This is particularly important in the African American culture. The hair is viewed as a crown of glory and is very important as an expression of femininity and beauty. Future study should focus on the many aspects of surviving breast cancer from an African American woman's point of view. Health care providers and educators should consider the emotional and psychological effects of treatment as identified in this study. Hair loss has a significant impact on body image and quality of life. Future studies should consider a more in-depth look at hair loss and its effect on body image and the impact it has on quality of life of African American women.

Conclusion

Advances in modern day breast cancer treatment have given way to long-term survivors. The survivor is not without posttreatment concerns. These concerns are the sequelae of breast cancer. They are symptoms and ailments that the survivor will live with indefinitely. The focus on the survivor is eminent to their quality of life from a psychosocial, physical, spiritual, economic perspective.

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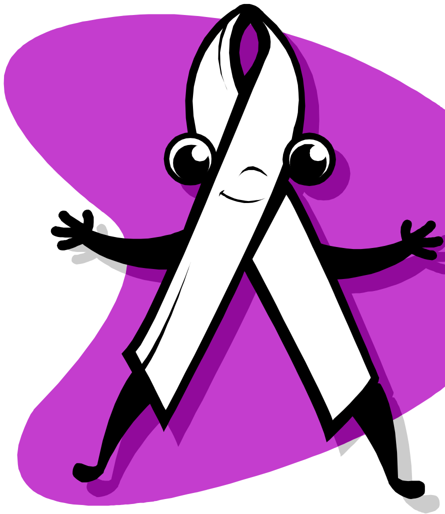
Appendix A: Recruitment Flyer

Are you a breast cancer survivor?



Are you African American?

Are you a woman 18 or older?

Have you experienced a difference in your quality of life?

Are you a member of the Sister’s Network Nashville Chapter?

Come make a difference in breast cancer survivor research for social change!

If you answered yes to these questions you maybe eligible to participate in a breast cancer survivor research study. Make a difference by volunteering today.

The purpose of this study is to explore the impact breast cancer has on the quality of life of African American breast cancer survivors from a psychosocial, physical, spiritual, and economic perspective. In addition, to determine if formal social support groups like the (Sisters Network) are beneficial or not for encouraging empowerment attitudes.

I will be conducting in-depth interviews with African American Breast cancer survivors. If you are interested in participating in this research study. Please contact me: Angela Grimmett, Walden University Doctoral Student at 931-216-8495, or angela.grimmett@waldenu.edu

Your name and personal information will be kept confidential.

Appendix B: Eligibility Criteria Check List

(1)___ Diagnosed with breast cancer at least one year ago.

(2)___ Identify as African American female.

(3)___ Member of Sister’s Network Nashville.

(4)___ Must be 18 or older.

Appendix C: Informed Consent

Conformed Consent

You are invited to take part in a research study of breast cancer survivors. The researcher is inviting African American women breast cancer survivor's one year post treatment who are members of the Sisters Network of Nashville to be in the study. This form is part of a process called "informed consent" to allow you to understand this study before deciding whether to take part.

This study is being conducted by a researcher named Angela Grimmett who is a doctoral student at Walden University.

Background Information:

The purpose of this study is to explore the impact breast cancer has on the quality of life of African American women breast cancer survivors from a psychosocial, physical, spiritual, and economic perspective. In addition, is to determine if social support groups are beneficial in encouraging a sense of empowerment to survivors of breast cancer.

Procedures:

If you agree to be in this study, you will be asked to:

One face to face interview

Interview will last 45 min to one hour.

The interview will be audio taped.

Here are some sample questions:

Has breast cancer changed your life?

How has breast cancer changed your life?

Has the Sister’s Network helped you as a breast cancer survivor?

Voluntary Nature of the Study:

This study is voluntary. Everyone will respect your decision of whether or not you choose to be in the study. No one at Sisters Network will treat you differently if you decide not to be in the study. If you decide to join the study now, you can still change your mind later. You may stop at any time. You must be 18 or older to participate.

Risks and Benefits of Being in the Study:

Being in this type of study involves some risk or minor discomfort that can be encountered in daily life, such as embarrassment, sadness, or mild stress due to the questions being asked.

The benefit of your participation is to contribute information to the public health community on the impact breast cancer has on your quality of life. This may assist public health practicitioners and other medical professionals on how to improve the quality of life for breast cancer survivors.

Privacy:

Any information you provide will be kept confidential. The researcher will not use your personal information for any purposes outside of this research project. Also, the researcher will not include your name or anything else that could identify you in the study reports. Data will be kept secure by being kept in a locked file box. Data will be kept for a period of at least 5 years, as required by the university.

The interview will be tape recorded. Identifying information will be deleted from the audio tape. The researcher will not share any of you individual responses with anyone other than research committee.

Contacts and Questions:

You may ask any questions you have now. Or if you have questions later, you may contact the researcher via [redacted] or angela.grimmett@waldenu.edu. If you want to talk privately about your rights as a participant, you can call Dr. Leilani Endicott. She is the Walden University representative who can discuss this with you. Her phone number is 1-612-312-1210. Walden University's approval number for this study is **IRB will enter approval number here** and it expires on **IRB will enter expiration date.** The researcher will give you a copy of this form to keep.

You will not be compensated for participation in the study, nor is there any charge or cost to you.

Statement of Consent:

I have read the above information and I feel I understand the study well enough to make a decision about my involvement. By signing below I understand that I am agreeing to the terms described above. I am 18 years or older and consent to participate in this study.

Printed Name of Participant ______________________________
Date of consent ______________________________
Participant's Signature ______________________________
Researcher's Signature ______________________________

Appendix D: Demographic Form

Please do not write your name on this form. Information collected here will be kept separate from any other identifying forms given during this study and will in no way be connected your responses. The information gained from this form will only be used to help us to describe the sample.

Please answer the following questions as accurately as possible.
What is your age? __________________
Are you: (check one)
______Married
______Divorced
______Separated
______Single

What is the highest level of education you have completed? (check one)
______Elementary School
______Some high school
______Completed high school
______Some College
______Completed two year degrees
______Completed four year degrees
______Some graduate school
______Completed Masters
______Advanced degree Doctoral

How long has it been since you were diagnosed with breast cancer? ________
How long has it been since your last breast cancer treatment? __________
What stage of disease were you at the time of diagnosis? ________________
What do you expect your 2013 income level to be? (Check one)
______Under $25,000
______$25,000 to $39,999
______$40,000 to $59,999
______$60,000 to $79,999
______$80,000 to $99,999
______Over $100,000

Appendix E: Panel of Experts Evaluation Form

Form for Review and Evaluation of Validity and Reliability by a Panel of Experts for Qualitative Instrumentation of (research topic …..)

Instructions: Please review the attached Qualitative Interview Guide of *(research topic* …..) and respond to the following questions regarding the construction, validity and potential reliability for the Qualitative *(research topic* …..) in light of the phenomenon being researched, examined, assessed, evaluated or measured. Please pace an "X" in the corresponding box.

Expert 1: Dr. Cheryl Holloway-CEO/Founder of Succourer Breast Health Education

Section A. VALIDITY EVALUATION

A test, survey, questionnaire, evaluation or assessment instrument is valid to the extent that the instrument measures the construct(s) that the instrument purports to measure.

Instrument Construction:

Are the instructions for completing the instrument clear?

a)

	Yes
	No (if no, please explain):
	Yes, provided the following actions are taken: Provided additional prompts

b) Is the application and results of the Qualitative Interview Guide of *(research topic* …..) adequately reflected in this instrument?

	Yes
	No (if no, please explain):
	Yes, provided the following actions are taken: See additional prompts.

{c} What items would you add?

	See additional prompts.

(d) What items would you delete?

	None.

Content Validity:

Will the potential themes yielded by the Qualitative Interview Guide of *(research topic …..)* adequately represent the content or conceptual domain of the construct being measured? In other words, does the instrument have adequate and appropriate items that constitute a representative sample of the complete domain of items used to generalize the construct being measured?

	Yes
	No (if no, please explain):
	Yes, provided the following actions are taken: See suggested additional prompts.

3. Item Bias

Does the wording or placement of an item avoid affecting someone's response?

(This includes the avoidance of double-barreled items, words or phrases, which raise emotional red flags, ambiguous wording, gender bias, racial/ethnic bias, and the manipulative placement of an item or wording of an item)

	Yes
	No (if no, please explain): No red flags, gender, racial, or ethnic bias noted.
	Yes, provided the following actions are taken:

6. Consequential Validity

Does the Qualitative Interview Guide of *(research topic …..)* instrument embody desirable values and have potentially positive consequences for the discipline or field it reflects?

	Yes
	No (if no, please explain):
	Yes, provided the following actions are taken: Also review additional prompts.

Section B. RELIABILITY EVALUATION

A test, survey, questionnaire, evaluation or assessment instrument is reliable to the extent that whatever construct(s) the instrument measures, it measures the construct(s) consistently.

1. Internal Consistency

Are the items that make up the Qualitative Interview Guide of *(research topic* …..) internally consistent with each component and/or the constructs being examined, assessed, evaluated or measured?

	Yes
	No (if no, please explain):
	Yes, provided the following actions are taken: Review additional prompts.

2. Potential for Reliability (Potential for Consistent Responses)

Understanding that research participants completing this Interview Guide will vary in their understanding and experience with the *(research topic* …..) and thus vary in their responses, is there anything about this instrument that would lead you to believe that this instrument would not consistently measure *(research topic* …..).

	Yes
	No (if no, please explain): The instrument is reliable with the additional prompts.
	Yes, provided the following actions are taken:

Please provide any additional comments, suggestions for improvement, and/or any other thoughts regarding the construction, how the survey can be made easier to complete, validity and/or reliability of the Qualitative Interview Guide of *(research topic* …..).
Review the additional prompts and add selectively to add reliability and validity to the instrument.

Panel Member Name:	Cheryl Holloway, PhD
Expertise:	Public Health
Title:	CEO/Founder
Organization	Succourer Breast Health Education
Telephone:	313-319-2491
E-mail:	cdh991@att.net
City, State, Zip Code:	Farmington Hills, MI 48331
Signature:	Cheryl Holloway, PhD
Date:	8/24/2013

Appendix F: Student-Derived Interview Guide

Research question for the study as a whole is as follows: How have the lived experiences of African American breast cancer survivors changed quality of life from a psychosocial, physical, spiritual, and economic perspective. In addition, to determine if social support groups such as Sister's Network of Nashville and or informal social support groups such as friends and family, are beneficial or not beneficial in encouraging empowerment attitudes.

The following interview questions and prompts will be asked in an effort to satisfy the research question:

Impact of Breast Cancer:

Can you describe the impact breast cancer has had on your quality of life?

Prompts:

How did being a cancer patient feel?
How did it make you family feel?
How has your life changed?
How has your life not changed?
Are you concerned about cancer recurrence?
Were you alone when you received your diagnosis?
Do you have other family members that could be impacted by you diagnosis?
Were you alone when you received your diagnosis?
Do you have other family members that could be impacted by your diagnosis?

Psychosocial Quality of Life:

Can you describe the emotional impact breast cancer has had on your quality of life. Is there a particular situation when you were affected emotionally? Can you describe how breast cancer has affected your social life? Is there a particular situation you can relate to this question?

Prompts:

Who is your primary support person?
What do you now have to do differently?
Did you share in the decisions for your treatment plan?
Were you satisfied with your pre and post treatment plans?
If married, did your spouse share in the decisions of your treatment plans?

Physical Quality of Life:

Please describe the physical impact of breast cancer on your quality of life? Is there a situation the physical impact was more noticeable or not?

Prompts:

How did your treatment affect your daily activities of life?
Were there physical changes that require additional treatment or surgery?

Did you require cosmetic physical changes such as head or breast prosthesis?

Spiritual Quality of Life:
Can you describe how breast cancer has affected your spiritual life or not affected your spiritual life?
Prompts:
Did you have the support of your church family?
Was your faith diminished by the breast cancer diagnosis?
Did you question God?
Were you able to attend church services?
Did your church family visit you during your recovery?

Economic Quality of Life:
Can you describe the economic impact breast cancer has had on your quality of life.
Prompts:
Did you have access to healthcare?
Did your employer provide paid sick time?
Did your employer provide the Family Medical Leave Act?

Formal and Informal Social Support Group's Impact on Empowerment Attitudes:

Has being a part of the Sister's Network of Nashville given you a sense of empowerment? If yes how so? Has family and friends given you a sense of empowerment?

Prompts:
How has the support of family and friends given you a sense of empowerment?
How do you feel empowered?

Expert 2: Dr. Shaunte Griffith-Jackson-Professor of Public Health and Microbiology
Section A. VALIDITY EVALUATION
A test, survey, questionnaire, evaluation or assessment instrument is valid to the extent that the instrument measures the construct(s) that the instrument purports to measure.

Instrument Construction:
Are the instructions for completing the instrument clear?

a)

		[✓ Yes]
		No (if no, please explain):
		Yes, provided the following actions are taken:

b) Is the application and results of the Qualitative Interview Guide of *(research topic* …..) adequately reflected in this instrument?

	Yes
	No (if no, please explain):
	Yes, provided the following actions are taken:

{c} What items would you add?

	Add a question at end asking interviewee to share thoughts on things that you may not have asked but that they feel is important to the topic. You would be surprised at unpredictable themes that may emerge

(d) What items would you delete?

	None

Content Validity:

Will the potential themes yielded by the Qualitative Interview Guide of *(research topic* …..) adequately represent the content or conceptual domain of the construct being measured? In other words, does the instrument have adequate and appropriate items that constitute a representative sample of the complete domain of items used to generalize the construct being measured?

	Yes
	No (if no, please explain):
	Yes, provided the following actions are taken:

3. Item Bias

Does the wording or placement of an item avoid affecting someone's response?

(This includes the avoidance of double-barreled items, words or phrases, which raise emotional red flags, ambiguous wording, gender bias, racial/ethnic bias, and the manipulative placement of an item or wording of an item)

	Yes
	No (if no, please explain):
	Yes, provided the following actions are taken: For the first question

	ascertaining the impact of breast cancer, ask them “Has it impacted the quality of life, and if so, how”. Instead of asking if they can describe the impact on quality of life which suggests that it has definitely had an impact.

6. Consequential Validity

Does the Qualitative Interview Guide of *(research topic* …..) instrument embody desirable values and have potentially positive consequences for the discipline or field it reflects?

	Yes
	No (if no, please explain):
	Yes, provided the following actions are taken:

Section B. RELIABILITY EVALUATION

A test, survey, questionnaire, evaluation or assessment instrument is reliable to the extent that whatever construct(s) the instrument measures, it measures the construct(s) consistently.

1. Internal Consistency

Are the items that make up the Qualitative Interview Guide of *(research topic* …..) internally consistent with each component and/or the constructs being examined, assessed, evaluated or measured?

	Yes
	No (if no, please explain):
	Yes, provided the following actions are taken:

2. Potential for Reliability (Potential for Consistent Responses)

Understanding that research participants completing this Interview Guide will vary in their understanding and experience with the *(research topic* …..) and thus vary in their responses, is there anything about this instrument that would lead you to believe that this instrument would not consistently measure *(research topic* …..).

	Yes
	No (if no, please explain):
	Yes, provided the following actions are taken:

Please provide any additional comments, suggestions for improvement, and/or any other thoughts regarding the construction, how the survey can be made easier to

complete, validity and/or reliability of the Qualitative Interview Guide of *(research topic …..).*	
Comments are written within interview guide below	
Panel Member Name:	Dr. Shaunte Griffith-Jackson
Expertise:	Public Health, Microbiology
Title:	Professor
Department:	Biology
Organization	Southwestern Community College District
E-mail:	Dr.shaunte@yahoo.com
City, State, Zip Code:	San Diego, CA 92114
Signature:	S.Griffith-Jackson
Date:	8/29/13

Interview Guide

The following interview questions and prompts will be asked in an effort to satisfy the research question:

Impact of Breast Cancer:

Can you describe the impact breast cancer has had on your quality of life?

Has breast cancer had an impact on your quality of life?

Prompts:

How did being a cancer patient feel?

How did it make your family feel?

How has your life changed?

How has your life not changed?

Are you concerned about cancer recurrence?

Also ask about any other concerns they may have related to experience. Again, you may extract very valuable information here if you open it up a bit.

Are there any other concerns you have about your experience?

Psychosocial Quality of Life:

Can you describe the emotional impact breast cancer has had on your quality of life. Is there a particular situation when you were affected emotionally? Can you describe how breast cancer has affected your social life? Is there a particular situation you can relate to this question?

Prompts:

Who is your primary support person?

~~What do you now have to do differently?~~ Ask, “Do you have to do anything differently” Do not suggest things are being done differently.

Physical Quality of Life:

Please describe the physical impact of breast cancer on your quality of life? Is there a situation the physical impact was more noticeable or not?

Spiritual Quality of Life:

Can you describe how breast cancer has affected your spiritual life or not affected your spiritual life?

Economic Quality of Life:

Can you describe the economic impact breast cancer has had on your quality of life.

Formal and Informal Social Support Group’s Impact on Empowerment Attitudes:

Has being a part of the Sister’s Network of Nashville given you a sense of empowerment? If yes how so? Has family and friends given you a sense of empowerment?

Prompts:

How has the support of family and friends given you a sense of empowerment?

How do you feel empowered?

Include a question that allows interviewees to share any additional thoughts that you may not have asked about.

Do you have additional thoughts or comments you would like to add?

Expert 3: Dr. Omie Shepherd-Professor in the field of health/chair of institutional review board.

Section A. VALIDITY EVALUATION

A test, survey, questionnaire, evaluation or assessment instrument is valid to the extent that the instrument measures the construct(s) that the instrument purports to measure.

1. Instrument Construction:

(a) Are the instructions for completing the instrument clear?

X	Yes
	No (if no, please explain):
	Yes, provided the following actions are taken:

(b) Is the application and results of the Quantitative Interview Guide of *(research topic* …..) adequately reflected in this instrument?

	Yes
	No (if no, please explain):
X	Yes, provided the following actions are taken: Yes, provided the following actions are taken: State the research questions as question and not statements. How have experiences changed…? The second question is not to determine benefit or no benefit from social groups but to explore the effects of social groups on participants' attitudes of empowerment. All questions and prompts should be in the affirmative only. Write an operational definition for "quality of life."

{c} What items would you add?

	Either begin by defining quality of life an empowerment or asking participants to describe what quality of life and empowerment means to them. Begin interview data collection related to topic by asking the participant to describe her experience with breast cancer. Prompt: How did you react when you were first diagnosed with breast cancer? Prompt: Describe key experiences of living with breast cancer. What was life like for you and family and friends after breast cancer diagnosis?

(d) What items would you delete?

	All negatives (the word not) from questions and prompts. State all in the affirmative.
	Under "Impact of Breast Cancer" section I would delete the questions and prompts and begin the interview as described above to the initial responses will be very personal, open, and allow participants to recall experiences before the more directed questions are asked.

Will the potential themes yielded by the Qualitative Interview Guide of *(research topic* …..) adequately represent the content or conceptual domain of the construct being measured? In other words, does the instrument have adequate and appropriate items that constitute a representative sample of the complete domain of items used to generalize the construct being measured?

X	Yes
	No (if no, please explain):
	Yes, provided the following actions are taken:

3. Item Bias

Does the wording or placement of an item avoid affecting someone's response? (This includes the avoidance of double-barreled items, words or phrases, which raise emotional red flags, ambiguous wording, gender bias, racial/ethnic bias, and the manipulative placement of an item or wording of an item)

X	Yes
	No (if no, please explain):
	Yes, provided the following actions are taken:

6. Consequential Validity

Does the Qualitative Interview Guide of *(research topic* …..) instrument embody desirable values and have potentially positive consequences for the discipline or field it reflects?

X	Yes
	No (if no, please explain):
	Yes, provided the following actions are taken:

Section B. RELIABILITY EVALUATION

A test, survey, questionnaire, evaluation or assessment instrument is reliable to the extent that whatever construct(s) the instrument measures, it measures the construct(s) consistently.

1. Internal Consistency

Are the items that make up the Qualitative Interview Guide of *(research topic* …..) internally consistent with each component and/or the constructs being examined, assessed, evaluated or measured?

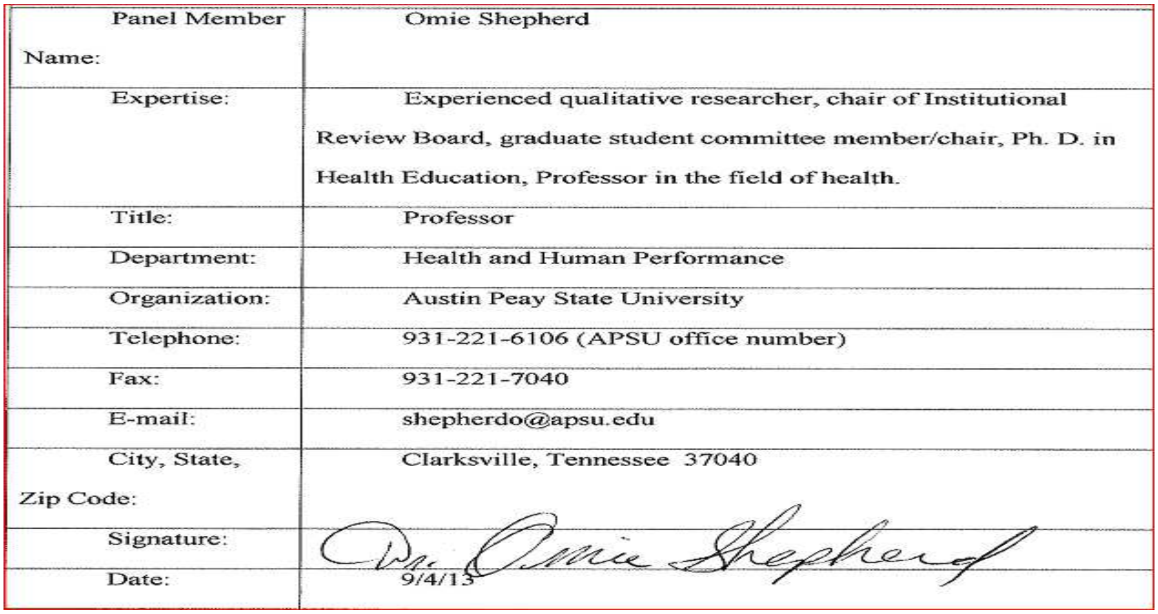
X	Yes
	No (if no, please explain):
	Yes, provided the following actions are taken:

2. Potential for Reliability (Potential for Consistent Responses)

Understanding that research participants completing this Interview Guide will vary in their understanding and experience with the *(research topic* …..) and thus vary in their responses, is there anything about this instrument that would lead you to believe that this instrument would not consistently measure *(research topic* …..).

X	Yes: Individuals may interpret the terms "quality of life" and "empowerment" differently and therefore could result in inconsistencies in responses from participants. Operational definitions for these terms should be discussed with participants prior to the interview questions, or allow participants to explain their interpretation of these terms.
	No (if no, please explain):
	Yes, provided the following actions are taken:

Please provide any additional comments, suggestions for improvement, and/or any other thoughts regarding the construction, how the survey can be made easier to complete, validity and/or reliability of the Qualitative Interview Guide of *(research topic* …..).



Panel Member Name:	Omie Shepherd
Expertise:	Experienced qualitative researcher, chair of Institutional Review Board, graduate student committee member/chair, Ph. D. in Health Education, Professor in the field of health.
Title:	Professor
Department:	Health and Human Performance
Organization:	Austin Peay State University
Telephone:	931-221-6106 (APSU office number)
Fax:	931-221-7040
E-mail:	shepherdo@apsu.edu
City, State, Zip Code:	Clarksville, Tennessee 37040
Signature:	Dr. Omie Shepherd
Date:	9/4/13

Quality of life: The level of enjoyment, satisfaction, and expectation one feels at any given time based on current circumstances.
Empowerment: The ability to take charge of one's circumstances and move toward a final resolve regardless of outcome being positive or negative.

The following interview questions and prompts will be asked in an effort to satisfy the research question:
Describe what quality of life means to you.
Describe what empowerment means to you.

Impact of Breast Cancer:
Describe your experience with breast cancer?
Can you describe the impact breast cancer has had on your quality of life?
Prompts:
How did you react when you were first diagnosed with breast cancer?
Describe key experiences of living with breast cancer. What was life like for you and family and friends after breast cancer diagnosis?

How did being a cancer patient feel?
How did it make you family feel?
How has your life changed?
How has your life not changed?
Are you concerned about cancer recurrence?

Psychosocial Quality of Life:

Can you describe the emotional impact breast cancer has had on your quality of life. Is there a particular situation when you were affected emotionally? Can you describe how breast cancer has affected your social life? Is there a particular situation you can relate to this question?

Prompts:

Who is your primary support person?
What do you now have to do differently?

Physical Quality of Life:

Please describe the physical impact of breast cancer on your quality of life? Is there a situation the physical impact was more noticeable or ~~not~~?

Spiritual Quality of Life:

Can you describe how breast cancer has affected your spiritual life ~~or not affected your spiritual life?~~

Economic Quality of Life:

Can you describe the economic impact breast cancer has had on your quality of life.

Formal and Informal Social Support Group's Impact on Empowerment Attitudes:

Has being a part of the Sister's Network of Nashville given you a sense of empowerment? If yes how so? Has family and friends given you a sense of empowerment?

Prompts:
How has the support of family and friends given you a sense of empowerment?
How do you feel empowered?

Final Interview Guide

Quality of life: The level of enjoyment, satisfaction, and expectation one feels at any given time based on current circumstances.
Empowerment: The ability to take charge of one's circumstances and move toward a final resolve regardless of outcome being positive or negative.

The following interview questions and prompts will be asked in an effort to satisfy the research question:
Describe what quality of life means to you.
Describe what empowerment means to you.
Prompt: How did you react when you were first diagnosed with breast cancer?
Prompt: Describe key experiences of living with breast cancer?
What was life like for you and family and friends after breast cancer diagnosis?

Psychosocial Quality of Life:

Can you describe the emotional impact breast cancer has had on your quality of life.
Is there a particular situation when you were affected emotionally?
Can you describe how breast cancer has affected your social life?
Is there a particular situation you can relate to this question?

Prompts:
Who is your primary support person?

Do you now have to do anything differently?
Did you share in the decisions for your treatment plan?
Were you satisfied with your pre and post treatment plans?
If married, did your spouse share in the decisions of your treatment plans?

Physical Quality of Life:

Please describe the physical impact of breast cancer on your quality of life?
Is there a situation the physical impact was more noticeable?
Prompts:
How did your treatment affect your daily activities of life?
Were there physical changes that require additional treatment or surgery?
Did you require cosmetic physical changes such as head or breast prosthesis?

Spiritual Quality of Life:
Can you describe how breast cancer has affected your spiritual life?
Economic Quality of Life:

Can you describe the economic impact breast cancer has had on your quality of life.
Did you have access to healthcare?
Did your employer provide paid sick time?
Did your employer provide the Family Medical Leave Act?

Formal and Informal Social Support Group's Impact on Empowerment Attitudes:
Has being a part of the Sister's Network of Nashville given you a sense of empowerment? If yes how so?
Has family and friends given you a sense of empowerment?

Prompts:
How has the support of family and friends given you a sense of empowerment?
How do you feel empowered?
Formal and Informal Social Support Group's Impact on Survivor's Quality of Life
Has being a part of the Sister's Network of Nashville had an impact on your quality of life as a whole? If yes how so?
Has the support of family and friends had an impact on your quality of life?

Ending
Do you have any other suggestions or comments about your breast cancer experience you would like to add?