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WOMEN OF FAITH:
ADAPTATION OF AFRICAN AMERICAN WOMEN BREAST CANCER SURVIVORS

by

PEARLINE OKUMAKPEYI

A dissertation submitted to the Graduate Faculty in Nursing in partial fulfillment of the requirements of the degree of Doctor of Nursing Science, The City University of New York

2015

2015

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Abstract

WOMEN OF FAITH:

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by

Pearline Okumakpeyi

Advisor: Professor Catherine Alicia Georges

The purpose of this study was to gain an understanding of the adaptation experience of African American women breast cancer survivors. The African American women's perception of the influence of faith on the breast cancer survivorship experience was explored.

This study utilized the directed qualitative content analysis method, which extracted themes and patterns that emerged in a narrative content. The 15 study participants were self-identified African American breast cancer survivors. The study was conducted using semi-structured interview questions that were derived from the modes of the Roy Adaptation Model (RAM). The discussion was framed within the context of the themes extracted from the transcript of interview responses underpinned by RAM. The qualitative content analysis resulted in the development of themes from the RAM Role Function and Self-Concept adaptive modes. Major themes included: providing guidance and encouragement, reflecting positivity, endurance and steadfast faith; and gratitude and ambition. The participant's coping mechanism through the regulator instinctive physiological processes and the cognator psychological and social coping process was also part of the discussion.

Findings from this study add to the nursing professions' knowledge of how faith can impact African American women breast cancer survivors' coping abilities and quality of life

during the cancer survivorship experience. These findings can be applied in nursing education, research and practice.

Key words: African American, faith, breast cancer, survivorship, coping, adaptation.

Dedication

This work is dedicated to my mother

Rosa Bell Lincoln

who left this earthly realm during my journey toward obtaining this degree.

Thank you for instilling in me the belief that all things are possible and your continued angelic presence with me through this life journey.

Mommy I hope I have made you proud.

ACKNOWLEDGMENTS

I would like to acknowledge the presence of God that has been my stronghold through all of life's vicissitudes.

I would like to acknowledge the commitment and expertise of my entire dissertation faculty committee. I would like to thank my faculty sponsor and chair Dr. Catherine Alicia Georges for her support and encouragement as I worked my way through the world of doctoral education and a special thank-you to Dr. Martha Whetsell for her assistance as I neared the end of this study.

I would like to acknowledge my late pastor the Rev. Lucius Walker, Jr. who was the impetus for my beginning this journey as he admonished me to seek to move from ordinary to extraordinary. I will continue to live our church motto Religion and learning go hand in hand and character increases with knowledge.

I would like to especially acknowledge to my husband, children, grandchildren, and sister who have always had more confidence in my ability than I have in myself. Thank you for believing in me.

I would like to thank my church family, my sister/friends, Sorors and Nigerwives, and co-workers who were extremely supportive. Most importantly I would like to thank the 15 participants whose willingness to share their experiences made this study possible.

God doesn't always come; he sends and performs his works through those who walk among us. To my earthly angel who knows who she is thank you for providing the road map and walking with me on the successful completion of this journey. TO GOD BE THE GLORY.

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Chapter I

INTRODUCTION

Faith is to believe what you do not see;
The reward of this faith is to see what you believe.
(Saint Augustine)

Cancer runs in our family. Truly I was just waiting for my turn. Let's face it we lost two uncles, one to throat cancer and one to prostate cancer. Two of my brothers died from colon cancer and lung cancer just these past few years. But the women, our three aunts with breast cancer, one with stomach cancer and one with uterine cancer, they held on for years always talking about "Child, you got to have faith." When I was diagnosed with breast cancer last year I must admit my faith went out the window. But now it is the one thing that has me living my life. I had cancer but cancer don't have me. This child was listening. It's that mustard seed faith. Each day it grows stronger.

The African American woman who engaged in this conversation was sitting at a table conversing with a group of her cousins after having returned from the burial of her aunt. This aunt was a 35-year breast cancer survivor prior to sustaining a recurrence of the disease at the age of 86. She was the matriarch of the family and had a positive outlook on life despite having grown up in the South during times of discrimination. She often stated, "If those doctors had done right by my brothers, they would have still been here. I told them sometimes you got to pray your way through, but you know those men don't have the faith that we women do." She always attributed her positive outlook on life and continued good health to her faith in a "Higher Power" and His sustaining Power.

African American families in the United States have a high incidence of cancer. The estimated total number of cancer deaths from all sites in the year 2013 is 306,920 in men and 273,430 in women (American Cancer Society Facts and Figures, 2013). African Americans are

disproportionately represented in the cancer statistics (Cancer Facts and Figures for African Americans, 2009-2010; National Center for Health Statistics [NCHS], 2011). The literature has demonstrated that patients diagnosed with cancer who belong to minority racial groups fare less well than Caucasians (Siegel, Naishadhan, & Jemal, 2012). Based on the most recent data, 12.3% of women will be diagnosed with breast cancer in their lifetime. An estimated 2,829,041 women are currently living with breast cancer in the United States (National Cancer Institute, 2013). African Americans have a 5-year survival rate of 78%, as compared with the rate of 90% in Caucasian women for that same period (American Cancer Society Facts and Figures, 2011). A better understanding of this population's perception of the disease, its mode of treatment, and possible outcomes may help to shed light on coping mechanisms used for adaptation during the survival experience. This study sought to understand the African American woman's perception of the role of faith and breast cancer survivorship.

Understanding Breast Cancer

Populations Affected by Breast Cancer

Cancer remains the second leading cause of premature death and suffering after heart disease in the United States (Centers for Disease Control and Prevention, 2013). Statistics from the American Cancer Society (ACS) in 2013 estimated that 232,340 women were newly diagnosed with invasive breast cancer and 64,640 new cases of carcinoma in situ were identified. About 2,240 new cases of invasive breast cancer in men were diagnosed in 2013. In the United States, the estimated death rates were 39,620 women and 410 men exclusively related to breast cancer (American Cancer Society Facts and Figures, 2013). While national trends show improvement, reports also reveal disparities in cancer, with higher morbidity and mortality rates among the African American population (National Center for Health Statistics [NCHS], 2011;

Reis et al., 2004). African American women are 25% more likely to have late stage breast cancer when diagnosed and are 20% more likely to die from their disease than Caucasian women (Gullatte, 2006).

Breast Cancer and African Americans

Breast cancer is the most highly diagnosed form of cancer in African American women. An estimated 26,060 new cases occurred in the year 2013 (American Cancer Society Facts and Figures for African Americans, 2013-2014). African Americans have a 5-year survival rate of 78%, as compared with a rate for 90% Caucasian women for that same period (American Cancer Society Facts and Figures, 2011).

Overall cancer statistics indicate that African Americans have the highest mortality rate for all cancers; 37% of cancer deaths could have been avoided in 2007 by eliminating economic and racial disparities (American Cancer Society Facts and Figures, 2011). The Institute of Medicine (IOM) (Smedley, Stith, & Nelson, 2002) has documented the persistence of racial and ethnic disparities in health outcomes. The cause of this inequity is multifaceted. For example, African Americans are at a greater risk for experiencing life stress and adversity, as compared with other ethnic groups (Utsey, 2007). These stressors include a greater likelihood of living in poverty, experiencing prolonged unemployment, being incarcerated, becoming homeless, living in high-crime neighborhoods, and having access to few financial and social support resources (Center to Reduce Cancer Health Disparities [CRCHD], 2005; Davis, Rust, & Darby, 2013). The increased prevalence of cancer in the African American population is a reflection of social and economic factors more than biologic differences associated with race (Cancer Facts and Figures for African Americans, 2009-2010). Racial and ethnic disparities in health care reflect a context including an ever-present historic as well as contemporary social and economic inequality, with

evidence of persistent racial and ethnic discrimination in many sectors of American life (Jones, 2008; Watts, 2003; Williams, 2008).

Of all racial and ethnic groups, African Americans have the lowest breast cancer survival rate (Gaston-Johansson, Haisfield-Wolfe, Reddick, Goldstein & Lawal, 2013; Howlader et al., 2012; Tate, 2011). Scientific research in the early 1980s supported the concept that personal health behaviors played a major role in premature morbidity and mortality (Levin, Taylor, & Chatters, 2005). There is a need to address this disparity as well as identify the means of closing the gap. Researchers are attempting to understand the sociocultural factors that have an effect on the progression of disease and mortality (Corneil, Corvin, Nupp, Dyer, & Noble, 2013; Holt, Schulz, & Wynn, 2009). There is increased focus on culturally appropriate health promotion. This movement has brought about increased attention to the role of faith practices in health (Gregg, 2011; Leak et al., 2008; Lynn, Yoo, & Levine, 2013).

Current studies have shown that faith beliefs and practices have been increasingly cited as a factor that may influence health behaviors (Giger, Appel, Davidhizar, & Davis, 2008; Gonnerman, Lutz, Yehieli, & Meisinger, 2008; Holt & McClure, 2006; Musgrave, Allen, & Allen, 2002). Generally, the studies have shown a positive relationship between faith practices, positive lifestyle behaviors, and health for African Americans.

African Americans

The study population self-identified as African American females inclusive of continental and diaspora people of Africa. This criterion was necessary because even though the participants may have migrated to the area from different geographical locations, the cultural similarities are greater than the differences. It is difficult to refer to a group of people without mentioning culture.

Culture

The literature reports culture as a vital and potent force through its ability to shape and give meaning to the beliefs of individuals (Walker, Tan, & George, 1995). Culture is a process of understanding and making sense of the world, and through this process, survival is assured (Nance, 1995). Culture is a fundamental creator of meaning through which belief systems can be viewed as the living reality of individuals, which are shared within a group with common interests. Cultural values are an intricate part of the entire sociocultural organization of experience. As such, these values can guide behavior and reaction related to health and illness. The focus of this study is not culture, but faith. Faith does not exist in a vacuum but is embedded in culture.

The Role of Faith and African Americans

Faith plays a vital role in the lives of many African Americans. Attending house of worship services provides a means of social support, and prayer is used to help with life stressors (Holt & McClure, 2006). The incorporation of faith into everyday life has often been depicted as the most distinctive characteristic of African American culture (Underwood & Powell, 2006). Black faith beliefs and Black houses of worship are at the heart of African American culture. Even today, the house of worship is often used as a venue for the sharing of health information and services in the African American community (Holt et al., 2009). House of worship leaders hold positions of prominence in the African American community and may be influential in the dissemination of information leading to positive health outcomes (Giger et al., 2008).

This study's focus was on the perceived adaptive process of faith in the African American breast cancer survivor. The phenomenon was operationalized based on the premise that even though the terms *religion* and *spirituality* are used interchangeably, religion is

primarily associated with organized ritualistic practices or the outward expression of spiritual beliefs, and the goals of spirituality are the internalization of positive values (Chaney, 2008). The term faith has been used to encompass both religious and spiritual attributes, particularly when there is confusion over which word to use or a desire to include both concepts (Holt, Clark, & Osuji, 2006). For many African Americans, faith, religion, house of worship life, and formal devotional rituals comprise a collaborative funnel that leads to the attainment of spirituality (Mattis, 2000). Essentially, religion, spirituality, and faith are mutually supporting constructs that make it possible for African Americans to have quality relationships with others and, most of all, with a “Higher Power” (Mattis, 2000).

Religion/religiosity is a term used to describe one’s external practices and expression of faith. Theoretically, religiosity is conveyed within the creed, hierarchy, and symbols of organized denominations (Holt et al., 2006; Schulz et al., 2008). Religious practices denote public displays of faith and belief that are designed and function through prescribed rites, rituals, and rubrics (Gullatte, 2006; Schulz et al., 2008). It has been acknowledged that religiosity is ambiguous and that a universal definition may not be possible (Holt et al., 2006). Two central criteria are noted as an indication of the existence of religion. The first involves the doctrine and existence of one or more superhuman agents, for example, a “Higher Power”; the second involves psychosocial or functional aspects that provide a sense of meaning and guidance through life. Religion is viewed at both the individual and group level and as involving faith (Holt et al., 2006)

Spirituality is what helps the individual to maintain a relational homeostasis: a connection to a “Higher Power”, interpersonal connections, and an intrapsychic connection (Chaney, 2008; Roff et al., 2009). Spirituality incorporates, goes beyond, and has a wider scope than religiosity. It includes connections to ancestors who have passed away, and through these connections,

benevolence is bestowed (Chaney, 2008, Holt et al., 2003; Mattis, 2000). Spirituality may also be vague and subjective, and involve many disciplines. It overlaps boundaries with religiosity.

Christian spirituality is seen as involving faith (Holt et al., 2006).

Faith is defined in the Bible as the “substance of things hoped for the evidence of things not seen” (Hebrews 11:1, New Kings James Version). This concept is widely embraced in the house of worship-going community, as it emerges in the literature on definitions of religiosity and spirituality. Faith is viewed as multidimensional, as are religiosity and spirituality, and it reflects both religiosity and spirituality. It is often used in the African American community in general as well as in African American houses of worship (Holt et al., 2006). The concept of faith is often used to describe religiosity in the African American community. Faith’s attributes include focusing on beliefs, having a foundational meaning for life, living authentically in accordance with beliefs, and interrelating with self, others, and/or the Divine (Dyess, 2011). Faith appears to be broader than spiritual practices and religious ritual. In this study, the term *faith* was operationalized to be inclusive of religiosity and spirituality.

Role of Faith and African Americans in Illness/Health

Research has indicated that people diagnosed with various forms of cancer tend to use faith to cope with the diagnosis (Holt et al., 2009). In the African American population, explanations of illness and healing have been associated with a “Higher Power” and faith. Those diagnosed with cancer have been known to increase frequency of prayer and house of worship attendance and their faith becomes more pronounced (Holt et al., 2009). African American women were more likely than Caucasian women to report relying on their faith as a coping mechanism (Henderson & Fogel, 2003; Lynn et al., 2013). Faith has been a survival method that has contributed to the resiliency of African Americans in coping with the psychological pain of

racism, discrimination, and oppression (Utsey et al., 2007). In times of trauma, faith has been used as a major vehicle for healing and recovery (Boyd-Franklin, 2010).

A “Higher Power” is perceived to play a role in healing in multiple ways. It is viewed as having a role of direct healer through miracles, as well as providing assistance with healing through answered prayers. Having a close relationship with a “Higher Power” is considered important as well, and is accomplished through adherence to scriptures. A “Higher Power” is also seen as working through health care providers to implement the care necessary for renewed health and healing (Holt et al., 2009). This study explored African American women’s perceptions of faith as related to their breast cancer survivorship experience.

Breast Cancer, African Americans, and Survivorship

The 5-year survivorship for African American women with breast cancer continues to be lower than that for their Caucasian women counterparts (Tate, 2011). Within each stage, the 5-year survival rate is lower among African American women (American Cancer Society Facts and Figures, 2011; Tate, 2011). Factors such as late-stage detection and poor stage survival reveal unequal high-quality treatment of African Americans (Joslyn, 2002; Lund et al., 2008). Socioeconomic factors such as poverty, prolonged unemployment, high-crime neighborhoods, homelessness, higher mortality rates, and stressors often lead to higher incidence of chronic diseases such as high blood pressure and diabetes (Utsey et al., 2007) that may influence the biologic behavior of breast cancer (Carey et al., 2006, Field et al., 2005). Poverty may have an effect on the pathology and genetic markers of disease based on lifelong dietary and reproductive habits (Joslyn, 2002; Lund et al., 2008).

The lives of African American women are represented in the social sciences as being full of life challenges and adversity (Davis et al., 2013; Mattis, 2002). Compared with other racial

and ethnic groups, African Americans are at greater risk for experiencing life stress and adversity (Utsey, 2007). Research has suggested that these women use a variety of strategies in an effort to cope with life challenges. However, reliance on faith has been found to be the most prominent coping strategy that African American women use (Lewis, 2008; Tate, 2011). In the African American community, faith is a central part of the culture (Tate, 2011). African American women use their faith to encourage and comfort themselves and each other, and to overcome a range of adversities including race, class, and gender oppression, financial stress, illness, and psychological stress (Chatters, Taylor, Jackson, & Lincoln, 2008; Mattis, 2002; Tate, 2011).

Significance of the Study

Cancer in general and breast cancer in particular continue to affect a large number of African American women every year. The cost to society is significant. The estimate of total cost of cancer in the year 2008 was \$201.5 billion: \$77.4 billion in direct costs, and \$124 billion due to loss of productivity from premature death (American Cancer Society Facts and Figures, 2011). Over 28% of individuals diagnosed with cancer have a total financial burden of 10% of the family income; 11.4 % of the families spent in excess of 20% (Darby, Davis, Likes, & Bell, 2009). While biomedical research has made many significant advances, the relative lack of scientific understanding of resources for African American women with breast cancer remains.

An article in the December 20, 2013 issue of *The New York Times* (Parker-Pope, 2013) discussed the persistence of this disparity. Despite 20 years of “pink ribbon” awareness campaigns and notable advances in medical treatment that has improved survival rates for women with breast cancer in the United States, the vast majority of these gains have bypassed African American women.

Two frameworks have been the focus of most research on cancer survivorship across populations. One emphasis has been on the biomedical nature of cancer and views of survivorship as a stage-driven process of disease progression. The second framework has focused on cognitive adaptation and coping as related to a problem-solving process in response to cancer as a unified event (Galla & Pines, 2009). Although it has been documented that major stressors are experienced while surviving breast cancer, few studies have been conducted to explore the psychological coping of African American breast cancer survivors (Coggin & Shaw-Perry, 2008).

Few authors have focused on the breast cancer survivor's perception of what it means to survive breast cancer (Document, Trauth, Key, Flatt, & Jernigan, 2012). In a study exploring the meaning of survivor identity, Kaiser (2008) stated that although breast cancer survivors are usually described in terms of "triumphant, happy, healthy, and feminine," this image is not embraced by all women with breast cancer. It is noted that a need exists for research on how the typical breast cancer survivor perceives survivorship in order to contribute to the understanding of the process of adjustment. Morris, Campbell, Dwyer, Dunn, and Chambers (2011) sought to understand the "lived experience" of breast cancer survivors; they found that women identified with the term *breast cancer survivor* at different times during the survivorship period. Given the insufficiency of breast cancer survivorship studies with African American women, research is needed to explore the perceptions of this population's means of adaptation (Lynn et al., 2013).

There have been reports concerning faith in general, but few have documented findings from African American breast cancer survivors. Studies that have been conducted have included small samples of African American women from the Southeast, Midwest, and West coast of the United States (Holt et al., 2009). According to the *Huffington Post* (Barooah, 2012) in an article

citing the most and least religious cities in America, in general 75% of the population in the Deep South and Midwest were identified as possessing strong faith practices. Cities where 35% identified as faith adherent were in the western and northeast sections of the country.

Consequently, there is a need to explore African American women's meaning of faith from a more socioeconomically diverse group within the United States. Also, further study is needed to identify domains or dimensions of faith that are experienced by African American breast cancer survivors (Gibson & Hendricks, 2006).

Faith has been cited as a factor in positive health behaviors (Giger et al., 2008). Thus, African American women's perceptions of faith as an adaptive mechanism in the breast cancer survivorship experience was explored here. The benefits obtained by the application of evidence acquired from this research may assist in identifying important information about the coping mechanisms of the population under study. This new knowledge may assist in decreasing the gap in providing culturally specific interventions in the delivery of care to African American women breast cancer survivors. This study is a first step in identifying a deficiency that can be addressed by nursing.

Relevance to Nursing

Because coping strategies have been linked to adaptation to breast cancer, it is important that nurses develop the ability to assess coping strategies used by African American women with breast cancer. Information on these coping strategies would enable nurses to educate other health care professionals about what the breast cancer experience means to African American women and encourage an interdisciplinary approach to addressing the psychosocial and educational needs of African American women throughout the breast cancer experience (Henderson, Gore, Davis, & Condon, 2003). Incorporating faith into a plan of care is paramount in promoting the

physical and psychosocial well-being of African American women diagnosed with breast cancer (Tate, 2011).

Purpose of the Study

This study sought to gain an understanding of the adaptation experience of African American women breast cancer survivors. African American women's perceptions of the influence of faith on the breast cancer survivorship experience were explored. Themes gathered from this qualitative content analysis study will add to the nursing profession's knowledge of how faith can affect this population's coping abilities and quality of life during the cancer survivorship experience. To achieve this aim, the researcher conducted semi-structured interviews to gain a holistic understanding of the adaptation process. The following research questions were investigated in this study:

1. What is the perceived role of faith in the African American women's breast cancer survivorship experience?
2. What does it mean to be a breast cancer survivor?
3. What is the concept of faith in the life of African American women breast cancer survivors?

Chapter Summary

This chapter provided an introduction to the study, an understanding of breast cancer based on its prevalence in general and in the African American population, the increasing awareness of the role of faith in the African American population, the significance and purpose of the study, and its relevance to nursing.

Chapter II next presents a review of the literature, the historical background of breast cancer, the history of the African American culture in the United States, African Americans' view of health and illness, and survivorship and faith among African Americans.

Chapter II

LITERATURE REVIEW

The historical background of breast cancer was significant to this study because it provided a context in which the perception of the seriousness of the disease for the mortality factor as well as evolutionary treatment can be brought into perspective. The history further addressed the issue that breast cancer has been and still is a life-changing event for anyone diagnosed with the condition. The researcher's aim was to assess the role of faith as an adaptive mechanism used by African American women to deal with this life-changing experience. Knowledge of the disease's past history and present reality may add more weight to understanding the impact it has on the lives of those involved and the need to address the changes it brings to one's life. This will enable those involved in client care to provide more culturally competent care as attempts are made to lessen the disparities in breast cancer survivorship that exist in the African American population.

Historical Background of Breast Cancer

Breast cancer has been reported to be one of the oldest forms of cancerous tumors in humans. One of the first descriptions of cancer was discovered in Egypt and dates back to 1600 B.C. (Sudhakar, 2009). At that time, it was recorded that there was no treatment. The story of breast cancer has been recorded in the acts and artifacts of human struggle against the disease. It follows the concept of illness as a product of evil spirits or the result of offense to the then-known "Higher Power"s that produced identifiable physical causes and the healing arts from mysticism to the tools of modern science (Donegan, 2006).

Greek medicine and surgery increased in sophistication during the Greek and Roman period (460-475 A.D.). The belief that every disease was distinctive and arose from natural causes, not from “Higher Power”’s or spirits, was attributed to Hippocrates (460-375 B.C.). He also believed in the power of nature to heal and in a humoral origin of disease. He advised no treatment for hidden breast cancers because treatment was futile and shortened the patient’s life (DeMoulin, 1983). As time progressed to the Middle Ages (476-1500 A.D.), the age of faith, monks dispensed folk remedies and surgery was discouraged (Donegan, 2006). Houses of worship viewed amputation of the breast as a form of torture (Lewison, 1950). Many miraculous cures were attributed to the intercession of saints. Faith healing through the laying on of hands was among the remedies used. This practice endures to present times (Crammer, Kaw, Gansler, & Stein, 2011; Pew Research, 2009).

Even with the establishment of fine hospitals and influential doctors, there were no new insights into breast cancer (Lyons & Petrucelli, 1978). Albucasis (939-1013) favored the cautery and caustic application for treatment of breast cancer, but admitted that he had never cured a case of breast cancer and knew of no one who had (Hoxey, 1956). Charms, prayers, medicaments, and caustics in conjunction with the then-modern methods of surgical interventions and alternative treatments continued to be implemented. Their use served as a reminder that breast cancer has treatment progressed through history not by substitution, but by addition (Donegan, 2006).

Many advances occurred during the 19th century. Hand washing was promoted and surgical antiseptics and carbolic spray were introduced (Garrison, 1929). With the development of anesthesia, surgical procedures focused more on precision than speed and several theories on the spread of the disease were devised (Sakorafas & Safioleas, 2010). Radical mastectomies were still the predominant treatment for breast cancer. At the close of the 19th century,

mastectomies were better than no treatment, but the survival rate was less than promising (Sakorafas & Safioleas, 2010).

As the century came to a close, two momentous events occurred in the treatment of breast cancer: X-ray and hormone therapy. The discovery of radium added interstitial radiation to the treatment option in addition to hormonal therapy. The benefit was the reduction of the bulk of large tumors and of the recurrence of cancer in treated fields. However, an inferred influence on survival proved elusive (Donegan, 2006).

The late 20th century resulted in a retreat from radical mastectomies and the introduction of mammography and chemotherapy. Clinical trials established that excision of the primary tumor, “lumpectomy,” followed by whole breast irradiation was as effective as total mastectomy in the early stages (Donegan, 2006). At the close of the 20th century, breast cancer was recognized as a disorder of unrestrained growth, with its actual cause remaining an enigma. Genetic predisposition was confirmed; exposure to ionizing radiation increased risk as did hormone replacement therapy.

Breast cancer continues to be a daunting problem, although it has become more accurately defined than in the past. Specialties have been developed for medical oncologist, physician radiotherapy, and surgical oncology. Cancer Institutes are located throughout the country. With screening and modern therapy, the death rate has begun to decline (Donegan, 2006). However, a discrepancy in the 5-year survival rate between African American women and other ethnic groups remains. Compared with other American ethnic groups, African American women have the lowest breast cancer 5-year survival rates (American Cancer Society Facts and Figures, 2013; Darby et al., 2009; Tate, 2011).

A limited amount of literature is available on African American women and cancer survivorship (Lynn et al., 2013). Exploring the meaning of survivorship to African American women as a basis of providing culturally specific care is of utmost importance. Given the lack of breast cancer survivorship studies in African American women, research is needed to explore the perception of this population's means of adaptation (Lynn et al., 2013). Two frameworks have been the focus of most research on cancer survivorship across populations. One emphasis has been on the biomedical nature of cancer and views of survivorship as a stage-driven process of disease progression. The second has been on cognitive adaptation and coping as related to a problem-solving process in response to cancer as a unified event (Galla & Pines, 2009). This study explored African American women's perceptions of adaptation holistically inclusive of the previously mentioned frameworks.

History of African American Culture in the United States

The African American experience in the United States has been shaped by the institution of slavery, dehumanization of Blacks, segregation, pursuit of civil rights, and racism in contemporary American society (Watts, 2003). The first slaves were brought to the Americas on August 20, 1619, by a ship that landed in Jamestown, Virginia (Mellon, 1998; Smith, 1994). The African American experience in America is notably different than that of other immigrants, who have come to this country under different circumstances, or refugees, mainly due to the extended period of the institution of slavery and the issue of skin color as an indication of dehumanization (Bennet, 1993). They came not on a voluntary basis in search for a better life, but chained together as human cargo across the dreaded "middle passage" during the Atlantic slave trade (Thomas, 1997). For more than four centuries, African American people have lived with the effects of slavery, segregation, and discrimination. Matters of race, racism, and racial

discrimination have a foundation in the legacy of slavery and persist throughout contemporary American life (Bennet, 1993).

Inequities relating to race have been documented in slave narratives, historical records, and biographies. References have been made to slave status as a subhuman species with insatiable sexual appetites who lacked intelligence, feelings, and character (D'Emilio & Freedman, 1988). The passage of harsh laws and early rulings of the U.S. Supreme Court, such as the slave Dred Scott case declaring that he was property and not a person, reinforced beliefs about the inferiority and oppressive treatment of the African American population.

During slavery in the New World, African Americans held fast to their faith, which was not destroyed by their 400-year enslavement but rather integrated into their daily coping strategies as they took on new Christian religious rituals and beliefs (Conner & Eller, 2004; Mbiti, 1986; Paris, 1995). Brought to America as slaves without a common language, the Africans were treated as property and denied all human rights. The slaves were forbidden to learn to read or write. On rare occasions, the slave owners would read to them from the Bible. Due to the limited resources available to them, the slaves used oral history and song to communicate with one another. The Black experience in America is distinctively different from that of other immigrants or refugees. For African Americans, their sense of belonging and the essence of who they are are judged by the color of their skin. To be African in America or African American upsets the established categories of what it means to be an American, unhyphenated and seemingly coming from no position or ethnicity (Ellison, 1970; Starwell, 1998).

The Declaration of Independence, signed on July 4, 1776, did not include the plantation system, slavery, or the slave trade. Even women were not included in the decree that all men

were created equal (Bennet, 1993). On January 1, 1863, the historical document, the Emancipation Proclamation, was signed by President Abraham Lincoln freeing the slaves in the rebellious Confederate states. Looking at the chronological timeline from the beginning of slavery to the emancipation, African Americans have spent more time in bondage than in freedom (Franklin & Moss, 2000). Freedom did not bring equality. During the Reconstruction period, passage of “Jim Crow” or segregation laws supported White supremacy and overt discrimination against African Americans. In 1896, the U.S. Supreme Court case *Plessey v. Ferguson* upheld the practice of segregation with the ruling of the “separate but equal” doctrine. This doctrine supporting the separation of the races permeated all segments of society and American life and was the status quo until the 1960s (Edley, 1998).

During the first half of the 20th century, the United States continued to be a racially divided and segregated society. There were disparities in education, housing, employment, judicial system, transportation, and health care. African Americans were relegated to an inferior status of second-class citizenship (Myrick-Harris, 2002). During the second half of the 20th century, the issue of relentless racial segregation in America helped to trigger the Civil Rights Movement, which peaked during the 1960s and lasted almost 17 years (Franklin & Moss, 2000). Legislation such as the Civil Rights Act of 1964, the Voting Rights Act in 1965, and the 1998 advisory board to President Clinton’s “Initiative on Race” attempted to lessen the disparities and promote harmony among the nation’s racial and ethnic groups (Franklin & Moss, 2000). In a comprehensive review and analysis of social science studies on racial attitudes and relations, Bobo (2001) claimed that at the end of the 20th century, Americans tended to accept principles of equality and integration for minorities. Overt racial segregation, discrimination, and overt

oppression of African Americans had been rejected, but a more modern type of racism that reinforced negative stereotypes continued.

A misconception about the African American culture is that the slave experience eradicated all aspects of a pan-African cultural tradition brought to this country as a result of deracination (Akbar, 1996; Ami, 1994; Asante, 1990; Azibo, 1996; Kambon, 1996; Schiele, 1997). What is most noteworthy is that despite African Americans coming here against their will, enslaved, segregated, and excluded from the larger society, they have retained African traditions. They forged a distinct pan-ethnic culture consisting of many African ethnicities and languages, a sense of diversity that was commensurate with the traumatic challenges they faced in the new world. Storytelling was the only means by which they could keep their history alive and connect with one another. They continued to pass on their faith beliefs and practices throughout the generations. Perhaps because of their rich sociopolitical, cultural, and religious heritage, African Americans in general are characterized as having strong faith practices that guide their life decisions, including matters of health. This is an illustration of how the tenacity of culture and its new reinterpretations adapt to fit new and demanding realities in different physical and cultural environments (Borum, 2007).

Faith plays a vital role in the life of many African Americans. Attending house of worship services provides a means of social support, and prayer is used to help with life stressors (Holt & McClure, 2006). Faith has often been depicted as the most prevailing area of the African American culture (Underwood & Powell, 2006). Much of the African American culture was established in the heart of Black religion and the Black house of worship. Even today the house of worship is often used as a venue for the distribution of health information and services in the African American community (Holt, Clark, & Klem, 2007).

The association between faith and health has been well established (Holt et al., 2007; George, Larson, Koenig, & McCullough, 2000; Lie, 2010). There is indication of a positive association between faith and health-related outcomes and diseases, although the specific mechanism is unknown. It has been proposed that several health-related factors are affected by faith practices. These factors include social support, positive health behaviors, and positive psychological states (Gregg, 2011; Oman & Thoresen, 2002). In reviewing the literature, three related concepts emerged. It was estimated that health-related behaviors account for 10% of the variance in the area of health connection; social support accounts for between 5% and 10%; and sense of meaning accounts for between 20% and 30% (George et al., 2000). In a study done by Holt et al. (2009) based on the literature, it was expected that African Americans would perceive a significant role for faith in times of illness. It was also expected that this relationship between faith and health would be positive in nature.

The specific characteristics of the faith-health connection is of vast interest to researchers in a variety of disciplines. Several explanations have been proposed. Positive emotions such as joy may be experienced during worship services or there may be a general feeling of better mental health. These emotions might enable better coping with life stresses, which might result in positive health effects. Faith's association with social support might also influence health. Finally, faith and the adherence to scriptural teachings might assist African American people in leading a healthy lifestyle or engaging in certain health behaviors (Holt & McClure, 2006).

The question remains: in the face of the history of cruel slavery, suffering, and oppression of African Americans, and the inherent forces of evil that have been unrestrained throughout recent history, how does African American faith and historical memory inspire hope (Smith, 1999)? African Americans' faith may be defined as having a wellspring of hope. This hope is in

response to their faith and belief in their relationship to Jesus, the “Holy Spirit”, and a “Higher Power”. The inherent belief in creative responses to radical evil in the community of the faithful and in personal experience lies in the conviction that everyone is a child of a “Higher Power” (Smith, 1999). Evil is a part of the “Higher Power’s” creation and an inescapable entity. Shared experiences of suffering in song and word, coupled with the work of love, justice freedom, ongoing struggle, and service, are among the attributes of African American spirituality. References to the river and water, life-sustaining elements, have provided a way for African Americans to understand what faith, hope, and trust in a “Higher Power” is all about. The river metaphor is only one of many that describe African American faith as a generative power that flows from the ancient past through trials and tribulations, sometimes on mountain tops of joy and other times in valleys of despair (Smith, 1999).

African American faith results in a life lived in gratitude, not because the victory is won but because faith resides in a “Higher Power’s” promise. Such a belief makes a difference in the way African Americans live their everyday lives, interpret historical events, and relate to others. It helps them to transform hatred and violence, build community, and face illness and death (Smith, 1999).

In a study conducted in the southeastern United States to examine the perception of the faith-health connection among African Americans, Holt et al. (2009) used a mixed-method. Participants were randomly selected from both rural and urban settings in the state of Alabama. Both males and females were included in the study. Participants in general had a great deal to say about the role of faith in health. They overwhelmingly agreed there is a positive relationship between faith and health. These beliefs were stronger among women, older adults, and those living in rural counties. This study further explored the role of faith in the adaptive process

during breast cancer survivorship. Participants were African American women recruited from the northeastern urban section of the country.

A focus group study on African American women's perspectives on faith (Banks-Wallace & Parks, 2004) was conducted using a convenience sample of women living in a midwestern city. Twenty-five participants ranging in age from 20 to 70 were included in the study which examined the meaning and function of faith for them. The core component of the women's faith related to a uniquely personalized relationship with a "Higher Power". They had faith that a "Higher Power" would bring about good through all experiences.

Banks-Wallace and Parks' (2004) findings also shed light on the blending of traditional Judeo-Christian theology with African Cosmology, a form of faith that was within the realm of the lived experience of the African American women. The design of the study limited the depth of understanding achievable in relationship to the significance of faith as a determinant of behavior and well-being. The present study investigated African American woman's perceptions of faith as a coping mechanism in adapting to breast cancer survivorship.

African Americans' View of Illness and Health

African American women experience disproportionately high rates of health conditions (Office of Minority Health, 2012). These disparities might relate to how African American women experience and cope with stress (Woods-Giscombe, 2010). Issues in both gender and race influence the stress experiences of African American women (Woods-Giscombe & Lobel, 2008). One factor related to stress and coping that might affect the health of African American women is the "Strong Black Women role", often referred to in the literature as the "Superwoman" role (Hamilton-Mason, Hall, & Everette, 2009; Woods-Giscombe, 2010). This

need to be in control of adverse situations can have both positive and negative effects on one's health status.

In a study done by Woods-Giscombe (2010), a sample of 48 demographically diverse African American women reported that the Superwomen role is multifaceted. They characterized the Superwomen role as an obligation to manifest strength and suppress emotion, a resistance to being vulnerable or dependent, a determination to succeed despite limited resources, and an obligation to help others. According to the women in the study, the "Superwoman" role involves social, historical, and personal relative factors as well as matters of survival and health status (Woods-Giscombe, 2010).

The African American culture has a rich historical perspective of health care and disease management (Revell, 2012). There is a lack of trust in western medicine and its documented treatment of slaves. Even with the current availability of numerous information sources, African Americans may equate good health with social entities such as good luck or success (Giger, Davishizar, & Turner, 1992). Illness or disease may be considered the result of bad luck, fate, or chance. The initial attempt at addressing illness is often home remedies (Revell, 2012), which can be traced back to the time of slavery. Healing concepts carried in the memories of the African villagers were transported to America and used for the slaves who were not offered traditional Western health remedies in managing illness (Revell, 2012). The use of complementary and alternative medicine (CAM) continues in today's society for African American women. In a study by Kronenberg, Cushman, Wade, Kalmuss, and Chao (2006) who studied four ethnic groups in the United States with a sample of 3,068 women over 18 years of age, African American women were found to use complementary medicine 57.4% of the time.

In a study by Kaiser, Cameron, Curry, and Stolley (2013) with focus groups of 40 African American women who have either had a history of breast cancer or reported knowing a breast cancer survivor, it was noted that the failure to seek medical care or undergo treatment for cancer was linked to a cultural tradition of healing illness at home. Their reluctance to go to the doctor was linked with a failure to care for themselves (Kaiser et al., 2013), which is in keeping with the “Superwoman” schema. Research has indicated that in the African American culture, illness is often attributed to natural causes such as ingesting impurities, following an inappropriate diet, or exposing oneself to cold air (Cartwright, 2010). African Americans also placed greater importance on supernatural causes of disease than other ethnic groups (Cartwright, 2010). It is important to note that a large percentage of college-educated participants from culturally diverse groups in the study endorsed supernatural causes, which suggests that these beliefs are independent of education (Cartwright, 2010). Such beliefs about the cause and means of treating illness in general may have an effect on perceptions of breast cancer treatment in African American women.

In a qualitative study using focus groups with African American adults to understand the perceptions of breast cancer treatment in African American women and men, an analysis of 445 participants’ responses revealed a core of themes related to treatment (Masi & Gehlert, 2009). The themes included mistrust of the medical establishment, concern about the effect of racism on treatment quality, a perceived link between health insurance quality and treatment quality, the negative effects of treatment on intimate relationships, and concerns about treatment complications. Many participants expressed a concern that surgery can cause cancer to spread—a cultural belief that has been passed down through the generations (Masi & Gehlert, 2009).

Survivorship and Faith Among African Americans

People are affected by a diagnosis of cancer in part based on the perceived chances of survival. The researcher considered the changes in events that take place based on the stage of the survival experience when selecting the sample for this study. The cancer survival experience has been conceptualized to include three distinctive stages. The stage from diagnosis until termination of therapy is referred to as the acute survival stage. The stage of watchful waiting or extended stage begins when treatment is completed and follow-up with the oncologist is no longer necessary. Care is rendered by an internist or other health care provider. For the cancer patient, there is still uncertainty about recurrence. The third and final stage is permanent survival, also referred to as long-term survivorship, when the likelihood of the cancer returning is small (Mullan, 1985; Siegel et al., 2012). An evolutionary definition of survivorship, from the National Cancer Institute Office of Cancer Survivorship (2001), stated that an individual is considered a cancer survivor from the time of diagnosis through the balance of his or her life. This definition also included family members, friends, and caregivers because they too are affected by the survivorship experience (Feuerstein, 2007; Mullan, 1985). This study's participants were in the permanent survival stage, which is post-5 years from diagnosis of breast cancer. At this time, the cancer survivor no longer has the support of the oncologist whom she had depended on for life-saving measures; rather, she has to rely on her own resources for physiological and psychological health maintenance.

Due to the increasing number of people who are surviving cancer diagnosis, it is now a necessary undertaking for researchers and health care providers to look beyond the cure for cancer and address the multiple needs of the persons living beyond a cancer diagnosis. It has

been reported that the period after completion of active treatment brings challenges that are often unique and poorly understood (Alfano & Rowland, 2006; Stanton, 2012).

Although the end of treatment brings a sense of accomplishment, many survivors are not prepared to manage the long-term or chronic effects of cancer and its treatment. Indeed, survivors have noted that being disease-free does not mean being free of disease (Alfano & Rowland, 2006). Two reports (Hewitt & Greenfield, 2006; President's Cancer Panel, 2004) have established that many survivors are not prepared to manage the long-term or chronic effects of cancer and its treatment such as fatigue, pain syndromes, and change in body image. They are also concerned about adverse effects of cancer that may occur months or years later.

Alfano and Rowland (2006) proposed that further study be done to identify the complex interplay between the physical and psychosocial sequelae of cancer in survivors from diverse race/ethnic and socioeconomic backgrounds. Further efforts should draw attention to those survivors who comprehend the factors that might promote positive adaptation and rehabilitation. This study attempted to take a step further in that direction by focusing on African American women and their perceptions of faith and breast cancer survival.

Current studies have shown that faith has been increasingly cited as a factor that may positively influence health behaviors (Giger et al., 2008; Gonnerman et al., 2008; Holt & McClure, 2006; Holt et al., 2009; Musgrave et al., 2002). Although the results of the research studies cited were not unified, the studies did suggest a positive relationship between faith and physical and psychological outcomes. A study conducted with older adults (Armstrong & Crowther, 2002) conceptualized spirituality as a relationship with a transcendent force that brings meaning and purpose to one's existence, and affects the way in which one operates in the world. Religion is related to interconnectedness with spirituality in the lives of older African

Americans. Despite the limitations of the study, the results provided evidence of the complexity of the role faith beliefs and practices play in contributing to people's physical and emotional health. Further research on the connection between faith and health may help explain the direct and indirect effects of regular house of worship attendance and beliefs about health as a presumed part of a "Higher Power"'s providence in empowering people to develop lifestyles with more health-promoting behaviors and fewer adverse health outcomes (Armstrong & Crowther, 2002; Gonnerman et al., 2008). Generally, the studies show a positive relationship among faith involvement, positive lifestyle behaviors, and health for African Americans (Holt, Clark, Kreuter, & Rubio, 2003; Levin, 1994; Levin & Chatters, 1998; Levin et al., 1995; Levin, Lyons, & Larson, 1993; Levin, Markides, & Ray, 1996; Levin, Taylor, & Chatters, 1994).

The literature has documented a well established positive association between faith involvement and cancer coping. The next step is to determine how faith involvement relates to coping with cancer in culturally diverse populations, or which aspects are important for coping with cancer (Holt et al., 2009). Gaining more knowledge about the role of faith involvement in cancer coping would increase the ability to inform faith-based support efforts and improve their efficacy. The National Institute of Health (NIH) agenda for social science includes directives to expand research on social and interpersonal factors that influence health, including religion, spirituality, and the cultural, social, and biological mechanisms through which they affect health (Holt et al., 2009). This study focused on the perception of African American breast cancer survivors through the lens of nursing theory and shed light on their perspectives of faith as an adaptive process.

Chapter Summary

This chapter provided a historical background of breast cancer treatment, a history of the African American culture in the United States, perceptions of health and illness, and the role of faith in survivorship among the African American population.

Chapter III next examines the theoretical framework of this study.

Chapter III

CONCEPTUAL FRAMEWORK

The purpose of the conceptual framework was to provide a structure for organizing the study and identifying the perspective of the researcher. Additionally, the semi-structured interview guide used the conceptual framework to derive and organize the questions that were be posed to the participants.

Roy Adaptation Model as a Conceptual Framework

This study was based on the Roy Adaptation Model (RAM) (Roy, 2009) to enhance the development of nursing knowledge related to the experience of faith among African American breast cancer survivors. The RAM is an appropriate conceptual framework for this study. The model is especially suitable for oncology patients because it provides a holistic perspective of the person by including physiological components (Andrews & Roy, 1986; Riehl & Roy, 1974; Roy, 2009; Roy & Andrews, 1999). The RAM model describes the person as an adaptive system responding to stimuli that initiate a coping process. This process ultimately has an effect on behavior, leading to responses that are either adaptive or ineffective (Roy, 2009).

According to Roy (1984), individuals respond to a constantly changing environment in two ways. The first way is through instinctive, physiological processes, known as the regulator coping mechanism, whereby the person responds automatically without the need for thought. The second way in which the individual copes or adapts is through the cognator mechanism. This mechanism includes psychological and social coping processes requiring the person to respond to stimuli through cognitive and emotional pathways such as learning and judgment (Roy & Andrews, 2004). The RAM divides the environment into focal, contextual, and residual stimuli

(Roy & Andrews, 1999). The stimuli that immediately confront the person is the focal stimuli; in this study, the focal stimuli consisted of a past diagnosis of breast cancer. Contextual stimuli are other factors that contribute to focal stimuli; in this study, the contextual stimuli were breast cancer survivors as well as such factors as age, ethnicity, marital status, and any other known factors that might emerge during the study. The other stimuli present in the environment that cannot be validated are called residual stimuli (Roy, 1984).

Responses to focal, contextual, and residual stimuli are named modes, of which there are four: physiological, self-concept, role function, and interdependence (Roy & Andrews, 1999). The physiological mode manifests physical responses to the environment. The self-concept mode focuses on the psychological, and spiritual (faith) aspects of the person. This mode entails the need for one to know oneself to embody a sense of unity. The roles people play in society and the need for individuals to understand their relationship to others comprise the focus of the role function mode. The basic need for affection, usefulness, feeling secure in nurturing relationships, and giving and receiving love and respect make up the interdependence mode (Roy & Andrews 1991).

Roy Adaptation Model Assumptions

The philosophical assumptions of the RAM are based on humanism and veritivity. Humanism recognizes the individual and subjective dimensions of human experiences as central to knowing and valuing (Roy, 2009). Veritivity expresses a belief in purpose, value, and high regard for all human life. In the RAM, the term *cosmic unity* refers to the intrinsic relationships between people and the earth (Roy, 2009). The combination of the principles of humanism, veritivity, and cosmic unity lead to the five philosophical assumptions of the RAM which are:

1. Persons have a mutual relationship with the world and God (“Higher Power”).
2. Human meaning is rooted in an omega point convergence with the universe.
3. God (“Higher Power”) is ultimately revealed in the diversity of creation and is the common destiny of creation.
4. Persons use human creative abilities of awareness, enlightenment, and faith.
5. Persons are accountable for the processes of deriving, sustaining, and transforming the universe. (Roy & Andrews, 1999, p. 35)

The RAM model demonstrates an effort to see human beings as objects affected by their environment and subjects with the ability to influence the course of their lives and with the value and meaning they use to make decisions.

Based on the philosophical assumptions of the RAM, the focus of research using the model as a theoretical frame work should be on adaptation. The research should seek to gain an understanding of people adapting within their various life situations. In this study, the stressor (focal stimuli) was breast cancer, which was channeled through the physiologically based regulator manifesting in the physiological coping mechanisms as well as the cognitive and emotional responses through the cognator, triggering the social and psychologically based coping mechanism manifested in the four RAM modes of adaptation. Study findings were analyzed based on the RAM modes of adaptation: physiological mode, role function mode, self-concept mode, and interdependence mode.

The four modes of adaptation included such challenges as fatigue, which is often the most debilitating lingering effect of cancer; possible posttreatment-related cognitive changes; and psychosocial responses to breast cancer, such as stress anxiety, depression or poor body image, and fear of recurrence (Alfano & Rowland, 2006). In this study, the focal was described

as breast cancer. The contextual referred to African American female breast cancer survivors in the permanent stage of survivorship. The focus of this study was on the cognator or coping process within the self-concept mode subsystem of faith (religiosity/spirituality) and how this subsystem affects and was affected by the four modes of adaptation; physiological, role function, self-concept, and interdependence. (Appendix A)

Roy Adaptation Model Adaptive Modes

As stated earlier, a person responds to stimuli. These responses are viewed as behaviors that have been categorized as modes. The four modes provide the perspective of the person as holistic. Although the emphasis of this study was on spirituality (faith), which is part of the self-concept mode, all modes were considered. A key proposition of the RAM is that behaviors in one mode will affect all modes and that the modes are all interrelated and interdependent. Responses in any one mode may have an effect on or act as a stimulus in one or all of the other three adaptive modes (Andrews & Roy, 1986). Behavior in the physiological-physical mode can effect or act as a stimulus for one or all of the other three modes. Also, a given stimulus can affect more than one mode, or a specific behavior can be a means of adaptation in more than one mode. These relationships are indicative of the holistic nature of humans as adaptive systems (Roy & Andrews 1999).

The first mode, the physiological-physical mode, pertains to behavior within the physical aspect of human systems. The physiological mode in the RAM is associated with the way individuals interact with the environment that is manifested in the physiological activities of all the cells, tissues, organs, and systems comprising the human body (Roy & Andrews 1999). The physiological role of adaptation includes individuals' biological behaviors, such as vital signs and clinical laboratory values. The physiological mode includes physical and chemical processes

of the five needs: oxygenation, nutrition, elimination, activity and rest, and protection (Adaptation of Roy Adaptation Model, 2011; Roy & Andrews 1999). Questions derived for the questionnaire for the physiological mode included items such as “Tell me about the symptoms you had with your cancer.”

The self-concept mode pertains to the personal aspects of human system group identity. The self-concept mode is inclusive of both the physical-self and the personal-self (Dobratz, 2008). The personal-self consists of three components: self-consistency, self-ideal, and the moral-ethical-spiritual self (Roy & Andrews, 1999). The basic need of this mode is individual-identified psychic and spiritual integrity. There is a need to know that one is able to exist with a sense of unity (Roy & Andrews, 1999). This mode of adaptation incorporates individual feelings about their bodies and their personal selves (Fawcett, 2009). Self-concept is formed from internal perceptions and the perceptions of others, which direct one’s behavior (Roy & Andrews, 1999). This mode is a composite of beliefs and feelings held about oneself at a given time, with a focus on the psychological and spiritual aspects of the human system. There is a need to know who one is so that one can exist with a sense of unity, meaning, and purposefulness of two modes: physical self and personal self (Adaptation of Roy Adaptation Model, 2011). This mode is the emphasis of the study. Questions derived for this mode were more extensive than some of the others: “How important is your faith to your day-to-day life?” “Where does breast cancer survivorship and your faith fit into your future?” “What role has prayer or meditation played in your ability to cope since your diagnosis with breast cancer?”

The role-function mode is the category of behavior that pertains to the roles of human systems (Roy & Andrews 1999). This mode of adaptation focuses on both individual and group performance of activities associated with the roles they perform in society (Fawcett, 2009). A

role, as the functioning unit of society, is defined as a set of anticipations about how a person occupying one position behaves toward a person in another position (Roy & Andrews, 1999). There is a basic need for social integrity, the need to know who one is in relation to others (Adaptation of Roy Adaptation Model, 2011). Examples of questions derived from this mode are: “How has attending religious functions affected your ability to adapt to being a breast cancer survivor?” “Do any health care practices have a cultural- or faith-based foundation?” “What effect has having breast cancer had on your various life roles? For example, family, work, volunteer activities, house of worship?”

The interdependence mode refers to the category of behavior pertaining to the interdependent relationships of individuals and groups (Roy & Andrews 1999). The emphasis of this mode is on interpersonal relationships and the giving and receiving of social support (Fawcett, 2009). Focus is placed on the close relationships of people and their purpose. There is a reason for the existence of each relationship that involves the willingness and ability to give to others and accept from others. Balance results in the feeling of being valued and supported by others. The basic need is met when there is a feeling of security in nurturing relationships (Adaptation of Roy Adaptation Model, 2011; Roy & Andrews 1999). Examples of questions derived from this mode are: “Please explain to me how you accomplish life tasks, for example, how you make decisions?” Do you rely on friends, family members, past experiences, faith affiliates?”

The RAM was chosen as the conceptual framework to guide this study because the assumptions and concepts are logically comparable with the phenomenon of interest. The model is especially suitable for oncology patients because it provides a holistic perspective of the person by including physiological components (Andrews & Roy, 1986; Riehl & Roy, 1974; Roy,

2009; Roy & Andrews, 1999). Knowledge gained from this study will inform the development of nursing knowledge related to the experience of faith in African American women breast cancer survivors.

Chapter Summary

This chapter provided an in-depth analysis of the theoretical framework for this study, the Roy Adaptation Model. The RAM model is explained and discussed in detail.

Chapter IV next describes the methodology of the study.

Chapter IV

METHODOLOGY

The purpose of this study was to seek to understand the adaptation experience of African American women breast cancer survivors. Specifically, the perception of the influence of faith on African American women breast cancer survivorship experience was explored. A qualitative design was chosen for the research method for this study for several reasons. Qualitative research allows participants to visualize the phenomena through their own eyes and verbalize their experience with their own voice (Munhall, 2012). Qualitative research is an appropriate research strategy when the current state of knowledge about the phenomena is limited or not well understood (Hesse-Biber & Leavy, 2006). Qualitative researchers, through multiple ways of discernment, strive to understand particular phenomena by finding an appropriate method or approach to answer research questions (Streubert Speziale & Rinaldi Carpenter, 2007).

The use of the qualitative approach generates valuable contextualized information that would not be possible to obtain within the confines of quantitative research. Additionally, an advantage of this approach is that it has the unique ability to elicit the participants' own frame of reference and allow the emergence of unanticipated issues significant to the participants' experiences (Patton, 2001).

A qualitative method was suited for this study because it allowed for the systematic documentation of the participants' description of the phenomena and the documenting and analyzing of the language based on the theoretical framework provided by the Roy Adaptation Model (RAM). This study utilized a descriptive qualitative content analysis method, which extracted themes and patterns that emerged in a narrative content. It provided straight description

of the phenomena (Polit & Beck, 2012). The study was conducted using semi-structured interview questions that were derived from the modes of the RAM. The focus of the study was African American women's perceptions of the influence of faith on breast cancer survivorship. The method for data collection was semi-structured interview questions.

According to Polit and Beck (2012), the use of semi-structured interview questions is useful for researchers who do not have a preconceived view of the content or information that the participants will present. This mode of interviewing is conversational and interactive; it is an appropriate choice when the interviewer does not have a clear idea of what there is to know (Polit & Beck, 2012). In semi-structured interviews, the participants are allowed to tell their stories with little interruption from the researcher (Polit & Beck, 2012).

Procedure

Sample

The target population was 10-15 African American women in the New York City urban setting. In this study, African American was inclusive of continental and diasporic people of Africa. The women had a diagnosis of breast cancer and were at least five years post-diagnosis and treatment. The effects of cancer on the person are in part based on the perceived chances of survival. The changes in events that take place based on the stage of the survival experience were considered when selecting the sample for this study. The cancer survival experience has been conceptualized to include three distinctive stages (Mullan, 1985). The stage from diagnosis until termination of therapy is referred to as the acute survival stage. The stage of watchful waiting or extended stage begins when treatment is completed and follow-up with the oncologist is no longer necessary and is less than five years post diagnosis. Care is rendered by an internist or other health care provider. For the cancer patient there is still uncertainty about recurrence. The

third and final stage is permanent survival, which goes beyond five years, when the likelihood of the cancer returning is small. An evolutionary definition of survivorship, from the National Cancer Institute Office of Cancer Survivorship (2005), stated that an individual is considered a cancer survivor from the time of diagnosis through the balance of his or her life. This definition also includes family members, friends, and caregivers because they too are affected by the survivorship experience (Feuerstein, 2007; Mullan, 1985). The participants in this study were in the permanent stage of survival. At this point in the survivorship experience, the primary means of support is no longer coming from the medical professional's interventions. Thus, a clearer picture of what African American woman breast cancer survivors perceive as a coping mechanism allowing for adaptation to this life's stressor can be explored.

Participants were recruited using the snowball technique, beginning with requesting a volunteer from a house of worship congregation known to the researcher. Once a participant was located and agreed to participate in the study, she was given a card with a phone number, using a phone that the researcher specifically rented for this study. Because the focus of the study is on faith, according to the literature on qualitative research, the participants must possess the experiences being studied. Moreover, the house of worship provided an atmosphere of trust when soliciting participants to be a part of research.

Eligible study participants met the following inclusion criteria:

1. self-identification as an African American female inclusive of continental and diasporic people of Africa;
2. ability to speak and read English;
3. an age more than 40 years old (based on the low survival rates for people below 40 years old);

4. diagnosis of breast cancer;
5. at least five years post-cancer diagnosis and treatment; and
6. attendance at a house of worship or report of having faith.

Recruitment of Subjects

Participants were recruited using the snowball technique. Other information shared included the estimated duration of the study and the assurance of Institutional Review Board (IRB) approval. The researcher conducted all the interviews.

When potential participants contacted the researcher, they were screened confirming their study eligibility (Appendix B). Eligible participants were told that the interviews would be audio recorded and they would be required to sign a consent form prior to participating. If they were interested in participating, the researcher made an appointment to meet at a mutually agreed-upon time, date, and venue. The participants received a \$10.00 Metrocard and \$10.00 compensation for participation. Other participants were obtained via recommendations by previous participants.

Data Collection

Informed consent was obtained from study participants prior to each interview. (Appendix C). Once the informed consent form was completed, the researcher conducted a semi-structured open-ended interview. (Appendix D). Each interview was audio recorded to allow for verbatim transcription. After the interviews, participants were required to complete a demographic questionnaire (Appendix E) and a Systems of Belief Inventory (SBI-15R) (Holland et al., 1998) (Appendix F). The researcher obtained permission from the author to use the inventory. The short SBI-15 has been validated to provide a rapid self-report measure for use in research on quality of life, psychosocial factors, and coping with disease. This quantitative piece

helped to inform the qualitative data on the coping ability of people with high spiritual beliefs. This is not a mixed method study. The interviews and questionnaires were completed in 60-90 minutes. Participants were assured that confidentiality would be operant.

Analysis

The researcher continuously evaluated the interviews to allow for recognition of saturation of data. Content analysis was employed. The focus of this analysis was on the participants' perception of the role of faith in their adaptation to breast cancer survivorship. The RAM was used as a guide to develop the initial codes for data analysis.

The researcher used the Atlas software system to aid in the analysis of the data. Atlas, a software that supports qualitative research, allows the researcher to collect and organize content from interviews and audio data. Verbatim transcripts of the interviews were imported into Atlas. The researcher kept notes from any visual observations during the interview. Confidentiality was maintained throughout this process.

Informed Consent and Protection of Human Subjects

The Institutional Review Board (IRB) at the City University of New York (CUNY) at Lehman College provided approval for the study. Each participant was allowed time to ask questions about the informed consent process and written consent forms (see Appendix G). The purpose of the study, the procedures used, any perceived risks, benefits, costs, and compensation as well as voluntary participation/withdrawal and confidentiality were discussed with each participant (see Appendix B).

Given the lack of breast cancer survivorship studies, research is needed to identify the ways African American breast cancer survivors cope with increasing survival. A benefit of participating in this study was the ability to add to that body of knowledge. In the possibility that

participants became upset when talking about their cancer experience, they had the opportunity to be referred to a counselor and/or their own spiritual counselor or health care provider. Upon completion of the study, the researcher provided all participants with a stipend of \$10.00 and a \$10.00 Metrocard.

Confidentiality

Participants' identity were kept confidential. Once participants agree to participate, the researcher assigned a code number to the demographic questionnaire, audiotapes, and transcripts. Study documents were kept in a locked drawer which was inaccessible by anyone other than the researcher. All materials obtained during this study, including audio recordings, will be shredded and destroyed after the successful deposit of the dissertation, according to IRB guidelines.

Qualitative Interview Guide

The researcher developed an interview guide based on the broad criteria of the conceptual framework of the RAM. Each of the broad concepts of the model was identified and given a topical heading from which questions were developed to address each heading. In addition, the interview guide was reviewed by two experts in RAM.

Chapter Summary

This chapter provided the methodology of the study, a synopsis of the procedure, the study sample and inclusion criteria, participant recruitment, data collection, confidentiality, and the qualitative interview guide.

Chapter V next presents the results of this study.

Chapter V

RESULTS

This chapter is composed of two sections. The first section includes a brief description of the study participants and the results of the System of Belief Inventory (SBI). The second section presents the results of the qualitative content analysis of the interviews with 15 participants. The qualitative analysis emphasized the provision of rich descriptions of the beliefs and perceptions of each individual participant, as provided in their answers to open-ended questions. The interviews focused on the research questions:

1. What is the perceived role of faith in the African American women's breast cancer survivorship experience?
2. What does it mean to be a breast cancer survivor?
3. What is the concept of faith in the life of African American women breast cancer survivors?

The content analysis was framed within the context of the applicable adaptive modes of the Roy Adaptation Model: role function mode and self-concept mode.

Section 1: Participant Demographics and System of Belief Inventory

The participant demographics section highlights important information from the participant questionnaire. A total of 15 African American women participated in the study. They ranged in age from 52 years to 80 years old (average age 66.4 years), with 33.5% between the ages of 52 and 65. Eight participants were married/partnered, 3 widowed, 2 divorced, 1 separated, and 1 single. Eight were retired, 6 were employed, and 1 indicated she was unemployed at this time. Data indicating the highest level of education revealed that

3 participants were high school graduates, 4 had some college credits, 1 was a college graduate, and 7 had postgraduate degrees. The years past breast cancer diagnosis ranged from 5 to 34 years, with an average of 11.6 years. Eleven participants were 5 to 15 years post-diagnosis, 2 were 16 to 30 years post-diagnosis, 2 had survived over 30 years. All except one participant reported their income was adequate for their needs.

All of the women participating in this study self-identified as African American. More specifically, 75% self-classified as born in the United States and 25% as Afro-Caribbean. The participants were from various religious denominations including: Baptist (8), Lutheran (2), Roman Catholic (1), Congregationalist (1), Muslim (1), Seventh Day Adventist (1), and No organized religion (1). All participants indicated they considered themselves to be spiritual.

The short System of Belief Inventory (SBI-15) has been validated to provide a rapid self-report measure of quality of life, psychosocial factors, and coping with disease. The purpose of using this quantitative piece was to inform the qualitative data on the participants' high spiritual beliefs and coping ability. The 15 women participating in the study represented six different religious denominations, with one participant denying any religious affiliation. All 15 professed that they considered themselves to be spiritual. The majority of the participants strongly agreed with the 10 items relating to religious rituals, indicating their practices and beliefs in a higher being. Due to the small sample size, no significant statistical data were obtainable.

Section 2: Qualitative Content Analysis

This study used a directed qualitative content analysis research design. Content analysis using a directed approach is guided by a more structured process than in a conventional approach (Hickey & Kipping, 1996). Conventional content analysis is most often used with a study design whose purpose is to describe a phenomenon and when existing theory or research literature on a

phenomenon is limited. The main strength of a directed approach is that existing theory can be supported and extended (Hsieh & Shannon, 2005). In this study, the Roy Adaptation Theory was used as a guide to develop codes for the directed content data analysis.

The recorded interviews were transcribed verbatim by the researcher who analyzed them systematically. Notes kept by the researcher of any visual observations noted during the interview were also available. First, during data analysis, the researcher immersed herself in the data, allowing themes to emerge from the data and conducting a line-by-line analysis of the data in a systematic manner. This repeated reading of the transcripts allowed themes to emerge from the data inductively. On subsequent readings of the transcripts, the RAM theory was used as a guide to develop themes deductively for the data analysis. After identifying the themes, the verbatim transcripts of the interviews were imported into the Atlas computer program to organize and develop the electronic coding manual. During analysis, thematic patterns were apparent among the participants' statements, representing textural meanings and invariant constituents, each of which was coded using an alphanumeric code. These patterns provided the evidence to classify and aggregate the statements into common themes.

A list of all codes and their definitions along with a transcript was given to two other readers. Both readers were expert in the application of the Roy Adaptation Model and the application of content analysis research design. This process allowed for a qualitative analysis version of interrater reliability. Moreover, it allowed for only core themes and concepts that occurred in the majority of the participants' interviews and were relevant and agreed upon by all raters to be included in this research study.

Role Function Mode

The roles people play in society and the need for individuals to understand their relationship to others are the focus of the role function mode. This category guided the assessment of adaptation as it pertained to the roles humans occupy in relationship to each other. A role as the functioning unit of society was defined as a set of expectations about how a person occupying one position behaves towards a person occupying another position (Roy, 1999). As such, this study focused on the role function of the participants regarding their being survivors of breast cancer.

The participants in this study had comparable views of what sustained them during this period of survivorship. It was the consensus that their unwavering faith enabled them to perform their various life roles. Their belief system led them to consider the needs of others in regards to the gift of life they had been given. They often looked for opportunities to be a good person by sharing their experiences with others. They assumed a direction of providing assistance to others and offering encouragement. The participants also accepted their role as providers of guidance and encouragement while maintaining a positive outlook.

Looking for Opportunities to Be a Good Person

Many of the participants verbalized a need to share their experience with breast cancer. They felt it was their role to serve as an example of how one can continue to live life to the fullest after being diagnosed and treated with the disease. Participant 3 discussed how she performed this role:

I let anyone know that I'm a survivor of breast cancer and I was actually a volunteer for the American Cancer Society where I would go to the floor of different institutions and volunteer to talk to them and share my experiences and um one of my jobs I work as a nurse practitioner. And I think being a nurse has helped me a lot too because being able to share experiences with someone and that they could learn from that and make things

easier that helps me too because I feel like even though my experience was horrible that was the good part of it. So maybe I had to go through that experience so I could share with other people. I mean I'm not sure but then thoughts came to my mind from time to time. (P3)

All of the participants referred to their beneficial functional role as sharers of their experience of breast cancer with other individuals. They looked for various opportunities to be a good person and help others. An example of significant statements reflecting this behavior included:

I shared it in church a number of times and ironically behind me two other people were diagnosed and they said it made it easier for them. (P1)

I feel strongly that we should tell our experiences of the Lord is operating in our life in regards to health. (P2)

I would share with anybody if I can help. (P5)

I find myself taking to people that I know that have it or whatever. So that's, that's helped a lot. (P6)

I feel I am able to give someone who had no idea of what to expect a view of what might happen with them. (P9)

I think that it has caused me to be more attentive to family situations because I feel that if God hadn't had mercy on me I wouldn't be here so I try to help people you know who need things family, whoever they are. (P10)

Assuming Direction: Providing Guidance and Encouragement

Many of the participants felt it was their role to embark on a course that would provide guidance and encouragement. They repeatedly stated that their faith belief was a driving force in their lives throughout the breast cancer survivorship experience. They felt it was their role to use the example of their survivorship to provide guidance and encouragement to others as they go through life events. An example of this concept was a statement made by one of the participants:

To me it's something that happened to me but it made me stronger and it gave me a testimony I can tell people you got to have faith. But I say just leave it to God. I tell them

anything I can't handle, God will. And all through my life God has guided me, been there for me, and protected me. (P8)

Participant 15 mentioned church attendance as a place where she gained encouragement and was then able to talk to other people:

I'm at my church. I have a lot of things going on to encourage you know to help you out. Just my Sunday school prayer and the Sunday services and I'm being a nurse at the church with the congregation and trying to speak to other people downstairs and that's where I get my energy from and I pray. (P15)

Participant 10 echoed that sentiment that she gained encouragement through faith and prayer:

I know now that I can go in my room and get on my knees and pray and have a one on one with my Christ, have a one on one with Jesus, have a one on one with me, talk to me. One of my survivors said anoint yourself before you go out the door. You know so faith has played a major role with me because sometime I didn't know what to do, I didn't know where to lean but now I know when I get so crazy just go and be by myself and talk to God because I know he's listening and I know it won't go no further either. (P10)

The participants spoke of fellowship and faith as a refueling that provided them with what they needed to provide guidance and encouragement to others. Several participants made reference to their role of providing guidance and encouragement. One example was:

The doctor who actually did my surgery I work with him now and I would say 98% of our patients become of breast cancer cases. So a lot of them have breast cancer and I am there to guide them through the process and hopefully it helps. I think it does because I know speaking to someone who has been through the experience it takes a big weight off your shoulders because you feel that there's somebody who can understand because you've been there. (P3)

This sentiment of role modeling and teaching prevailed throughout the interviews with the survivors. Samples of their responses are included in the following statements:

I talk about it. So I find that I am a teacher and in my classroom activities I don't hold back. I feel free enough; it has made me knowledgeable enough, this whole process. What we as survivors have to do is be educators. (P7)

I give people a lot of encouragement. I use myself as an example. If I can do it, through God's grace you can too. I can see that from what I had told them they had changed their mind totally on just giving up. (P12)

My life role is that I am protective of people who are sick. Useful in anyway in my daily life. We all don't know when the last day will be. I am just trying to help others go through it. (P15)

Anticipating the Future: Reflecting Positivity

The participants in this study largely agreed that their role as a survivor was to focus on the future by reflecting positivity. This was best done by surrounding themselves with positive-thinking people and giving and receiving support. An example of this was the statement from Participant 6:

By talking, talking to people. Being around people who I know had it or has it. Seem like you could just pour your heart out to that person and that person in details can come back to you or whatever. Like my girlfriend, she just found out she had it. It's been, not even a year, because she just finished up chemo in; let me see, in April. So when she has, starts feeling down or whatever she will call me and say Oh my God I got to. . . I say listen, let's talk and we will start talking and I will lift her up and she will lift me up. (P6)

Participant 3 worked in an area that treated breast cancer patients. She maintained a positive attitude throughout her treatment and served as a role model and positive influence for those she served:

I had a lot of supportive people around me because I worked in the OR and I did the surgery there. Everyone knew the experience that I was going through and they were very comforting and I went to work every day. I stayed home the first three weeks after my surgery and after my first chemo, but then I went to work every day and going to work actually helped me because I could see other people in the same situation as myself and try to be there for them. Share my experience with them and I worked through the whole thing. Thank God I was never too sick to go to work. (P3)

Several of the participants had similar accounts of the effect their positive attitudes have had on others. The following examples are representative of the survivors' role function of reflecting positivity:

I think that by talking about my experience and how I came out of it and what I did and the fact that I still was able to work and go to school and do everything that I was still doing, I think that gave her a whole different perspective on you know, what is possible You know, there's a lot of positive. (P4)

How long am I going to live? Every day after that is oh, I want to live. Oh, I have so much to do. I'm beginning to see the miracle of this thing. God connecting the pieces let me know that I'm going to be all right. (P13)

Just to focus on people who have been cured of cancer before and I think I will be, you know you need to keep that focus. (P14)

I think you should help somebody. Make people aware that there is life after cancer. It's not a death sentence. There are so many cures now. I think that you should embrace yourself and embrace life you know. And if you can, help somebody. (P5)

But I think my faith, my faith has a lot to do with my recovery and not having censored or changing my life. Mostly I'm a positive person so I think that had a lot to do with it too. I'm very positive about how things turn out. No matter what happens I'm always looking on the positive side. It might take forever but it will happen. But faith has a lot to do with it. My faith in God because I pray a lot. (P12)

Self-Concept Mode

The self-concept mode pertains to the personal aspects of human systems group identity.

The self-concept mode is inclusive of both the physical-self and the personal-self (Dobratz, 2008). The personal-self consists of three components: self-consistency, self-ideal, and the moral-ethical-spiritual self (Roy & Andrews, 1999). The basic need of this mode is the individual-identified psychic and spiritual integrity. There is a need to know who one is to be able to exist with a sense of unity (Roy & Andrews, 1999). This mode of adaptation incorporates individuals' feelings about their bodies and their personal selves (Fawcett, 2009). Self-concept is formed from internal perceptions and perceptions of others; these perceptions direct one's behavior (Roy & Andrews, 1999). This mode is a composite of beliefs and feelings held about oneself at a given time, with a focus on the psychological and spiritual aspects of the human system. There is a need to know who one is so that one can exist with a sense of unity, meaning, and purposefulness of two modes—physical self and personal self (Adaptation of Roy Adaptation Model, 2011). The participants in the study addressed many views of how the breast

cancer experience affected their perceptions of their self-concept physically, psychologically, spiritually, and in personal aspects of their lives. The participants expressed the feeling that their identity had not changed stating that “I’m still me.” Their steadfast faith provided a means of enduring difficult circumstances. The greater awareness of a “Higher Power” at work in their lives enabled them to live life abundantly with gratitude and ambition.

“I’m Still Me”: Physical and Personal Self

An overriding view of the participants in the study was that even though the occurrence of having been diagnosed and treated with breast cancer was an extremely trying experience, they realized in the end that the essence of who they were prior to and after the diagnosis had not changed. Consequently, their inherent personality attributes and self-identity were available during their time of need. One aspect of this self-identity was their cultural view of themselves and what it meant to be an African American woman.

One of the criteria for participating in this study was to be an African American woman. All of the participants had to self-identify as African Americans. The following exemplars represent their various means of expressing who they were not only by birthright and physical attributes, but by personality traits.

Participant 15 referred to her ancestral lineage as her self-concept of the African American culture being a part of her personal self:

I was born an African American, as was all my ancestors. I think they told me my mother’s grandfather was of Indian descent but we know nothing about that so as far as I am concerned African American. My father was. My mother was. And yes, I am African American. Don’t want to be anything else. (P15)

Other participants incorporated physical attributes as well as personality traits:

What makes me an African American? The texture of my hair. Well I would say being strong, being I don’t know. Being strong. Being tough. Flexible. You know I won’t ever

have these lines that they have in their face, how their neck changes and how they like to wear scarves to cover the age marks in their necks, certain things I won't have that Caucasian women get, I will never know my melanin is just so different and my shoulders are broad. I don't have a butt, but I know most black women do have a butt and the breast. You know, I never thought much about my breast; truly I never did until I lost it. (P10)

Strength, strong, endure almost anything having faith. Stand on the shoulders of my ancestors. As you can see, I like history. They call me a griot because I like history and in order to, in my church which is rich with history, they teach us that in order to know where you are going, you have to know where you have been, so going back to slavery time which is painful for a lot of people, helped me to get to where I am today. (P13)

Physical changes are another area that can have an effect on one's self-concept. The perception that the breast has in the African American women's view of who she is was mentioned numerous times. Several of the participants verbalized feeling a sense of physical loss after their surgery and treatment for breast cancer, but they later came to the realization they could overcome these things, they had not changed. Their self-concept of who they were remained the same. The following examples address how these women were able to adapt to their various physical changes:

I just looked at it from the point of view of it affecting me as a woman. Breasts are very important to us because it's important as who we are as women. It makes you, it's a big part for making you a woman and to say you are not a man. It's a big part of your appearance, part of who we are, part of our sensuality, so I look at it like that. The most difficult thing for me was vanity. Because I said things that I would never put on all of a sudden looked very attractive to me. They would give you a class on how to fix your eyebrow when the chemo takes all your hair away and how you can put on the false eyelashes and the inside your hand would be black from the chemo and how to take the creams and all that and I'm saying I was never into none of that and now I have to do it more and more. And my hair. Wigs. Now I wear wigs. I wear wigs because my hair is thinning. But people would come up to you and say how you feeling and their eyes would go right to your breast. So for me it was like you know what. I'm going to wear a dress that is off the shoulder. So that part for me that was tough was changing how I wear my clothes and my vanity. Changing how I had to dressing, having to say no you can't wear that anymore. No, you can't bend over even though you like the dresses with the strap that comes over your shoulder or the strap. You can't bend because if you bend they are going to see an empty space. So that was tough for me. But now I just say here's the package, so hey. I can do bathing suits with the tops when I had one breast with the one

shoulder. I never liked night gowns, I always wore pajamas, but I don't, you know, I wanted a night gown. I was just something. So that was tough for me. (P10)

But the only thing that I, I didn't really, I would always wear something up, you know, that covered. I wanted to make sure that one wasn't too high or too low. Now that I have the special bras. I remember when I came home I went to the closet I had some nice things with back out. So I gave them all away. You know I had no one to talk to, you know to say don't give away your things you know. At the time I said you know I'll just give them away. If I had known what I know today, I would have kept those nice dresses with the back out. (P5)

The participants' view of their health status also played a role in their self-concept. The participants described their concept of being healthy not only in physiological terms, but as a reflection of mental and psychological well-being. Participant 7 described her concept of health as follows:

What do I consider to be healthy? I think it starts off with your mind. I think it's a good deal of what goes in. Our belief systems effects how healthy we are, how unhealthy we are. And then I'm not an extreme dieter but I think we all should be self-conscious about what we take into our bodies and our minds and who we associate with because it's a whole big picture. It's not just the food that's put in front of us but it's a lot of other things that contributes to where we are. (P7)

Participant 14 had similar views on what it meant to be healthy:

It's not just about eating good food. It's about mental status, emotional and mental health, stress relief. Relaxation and stuff like that and just physical activity every day. It could be walking or swimming things like that. You just do things that enhance better living in terms of your physical body and of your mental status. And that's how I look at it. And of course now drugs and alcohol, smoking I'm not going to touch that problem. With the young people you talk and explain but the peer pressure is stronger and it seems to be winning. But that's how I see it and I'm not the type of person who worries about things a lot. (P14)

There was mutual agreement among the participants that being healthy did not only encompass consuming the proper diet and exercise, but included mental well-being. The following exemplars are representative of the survivors' self-concept of health:

Health doesn't only mean exercise and diet. It's how you think as well. I feel that your mental state, you know, has a lot to do with being healthy. Some people make themselves unhealthy by the way they think. (P4)

It means I have to take care of myself. Eat right, walk right. Don't eat the salt when I know it's not right. So to me healthy means everything in the world to me. I try to do my best to stay as healthy as I can and God just give me a little while longer. Yeah, a little while longer. (P5)

Health is peace of mind. To me health means peace of mind. Because, if you don't have health, you can't accomplish anything. You can't do anything if you are not healthy. That's what I think. (P12)

What it means to be healthy? To be able to see, walk, talk. Yes all parts of your body working in working condition as the Lord would have it to be. That's it. I need to see. I need to be able to see. My eyes to see not just with my eyes but to see that there is a need for something. I don't have to see with my eyes. My heart and mind should be right. I have arthritis but at least I'm able to touch and feel. With me it's to be healthy not only physically but spiritually. (P15)

The personal-self embraces the concepts of self-consistency, self-ideal, and moral-ethical-spiritual self. This aspect of the self-concept answers the question: In what do I believe? This is related to one's beliefs and value system (Andrews, 1991). All 15 of the study participants made statements regarding the role their faith plays in their view of who they are.

Selected exemplars reflective of this are as follows:

I will say that if you really believe that God is the person who guides things, he is the creator of all things and he can do things through you to keep you well and able to believe that it can be done I think it works. Because I always believe that people who die quick from cancer, especially those who die in a couple of months, I think they just gave up the fight. That's just the way I see it. So I have to put it that way that they gave up, that's just how I look at it. They didn't have the faith. They didn't believe that they can live longer. And some people are scared. The word cancer is a big curse. When they hear cancer they say let me die, so that's how I see it. I just think that if the person believes they can fight they fight for a long time. (P14)

Once I just gave it to God, it just kind of eased a lot of my doubts. I just had to give it to God to just know that it's nothing I could do. It was out of my hands. Nothing that I gave myself, but God doesn't take things away. He just helps you to deal with it, and I just had to rely on God. I had no one else, my family, no one else, so I just trusted God and by me trusting God, it kind of relieved some of my stresses. I feel that everything is

going to be all right. In addition to whatever I'm going through, I feel that everything is going to be all right. (P13)

Role of faith is to give it to the Lord to have faith that the Lord will do what he said he would do. He said he's a comforter, he's a healer, he's a protector, and um he didn't say everyday would be like a bed of roses and to be able to take whatever he issues out to you and also give it to him and let him take care of it. (P15)

The participants were consistent in their belief that a "Higher Power" was at work in their lives and they had unlimited access to this Supreme Being through prayer and meditation.

Participant 13 best summed it up with her statement:

Without prayer, you have no hope. What gives me hope is that God answers prayer. He's a God that answers prayer. (P13)

Endurance—Steadfast Faith

The participants in this study viewed themselves as having the power to endure in times of adversity. The ability or strength to continue and survive the breast cancer experience was referred to in several of the interviews. Many of the participants spoke of their ability to accept their diagnosis of breast cancer. The following exemplars are representative of the participants' perception of how they psychologically viewed their breast cancer diagnosis:

I didn't think of it as, it wasn't to me, it wasn't like a death sentence like, you know, a lot of people think of it as a death sentence, like "Oh my God! I have the big C. I'm not going to live very long." You know, those types. I never had that. I didn't, I never thought of it that way. I always felt that it is something that I can overcome. You know, that's what I'm focused on. (P4)

I didn't get myself frustrated. I know when I first was told that I had cancer, you know how you go through the pity party and then I started thinking about the little children who haven't even lived and they've been diagnosed with cancer and that's what gave me strength, that I had a life already and I had been so fortunate to live the years that I have and I just thought about the little people, little children who didn't get that chance and that's what got me through what I was going through, I suppose. (P9)

Participant 4 referred to difficult circumstances as being manageable and the ability to handle anything due to faith:

You know, your faith is understanding that if you are on the right path, that God will exercise his grace over you and not give you any difficult things to cope with. You know, I think the way you think about the process can definitely contribute to your recovery and help your well-being. So, you know, having faith that you can conquer this, that God can help you through this, definitely, I think, helps. (P4)

Several of the other participants shared the same sentiment about their self-perceived ability to endure and stand strong by relying on their faith and a “Higher Power”. The following exemplars represent this consensus:

Oh yes. I really do believe. Faith plays a major, major part in healing, accepting, and wanting to continue to go on, oh yes. (P6)

My faith knowledge has been applied in every situation. The Lord comes through and fulfils what he said he would do. The role of faith? Well to me faith is everything. Without faith I would be lost, I would be a victim. Because of faith I am a survivor, because of faith in every sense of the word. (P2)

My faith is everything because I think without faith, I wouldn't have made it. I wouldn't. My faith guides me in everything I do all my decisions in how I think, see people, and how I feel about life. Moving. Faith in God. Because if I didn't have faith in God I would not have gotten through that experience. (P3)

Living Life Abundantly: Gratitude and Ambition

The participants were very expressive about the good things and special gifts they had been given in life. They wanted to live their life in a manner that not only showed their appreciation for these gifts, but demonstrated they would live each new day of their lives purposefully. There was a greater awareness of a “Higher Power” at work in their lives.

Statements by two of the participants are representative of this emotion:

You know, just give thanks every day that I'm alive because I know I have a purpose to fulfill. (P14)

Being thankful that God knew what I was going through and he had a plan for me. I think I always knew God was there, but you know when you talk about personal relationships. (P1)

A sentiment of thanksgiving and not taking life for granted resonated throughout the interviews. Several of the participants engaged in daily prayers expressing their gratitude. They were able to find meaning in the breast cancer diagnosis, treatment, and survivorship experience. The following exemplars reflect these feelings:

I'm at the point that you can't even take a breath without God and when I get up in the morning I pray. I thank him for keeping me through the night. I thank him for everything because like I say, you are nothing without God. And I was at the point where I had life but no breath, so I know what it is to be healed and to be touched by God. (P8)

Before I took everything for granted and didn't appreciate what I had and I did not have to survive this and I was able to survive it and I appreciate that. So, yes, I say thank you Lord for giving me these blessings every day. (P9)

I can't start my day without saying thank you God. I thank God for this period in our life that we do have things where we can get help and we have a better space than years ago. So I always look back. It helps me to be stronger. So I'm happy and I'm grateful, and I know now that I had to go through. My setbacks were a set up for where I'm at, to where I am today. So God has to . . . I no longer want to consider myself why me. I realize God uses this to make a difference. (P13)

The study participants took the opportunity to use this gift of survivorship to live life abundantly. They viewed themselves as being ambitious and continuing to pursue life goals.

Two of the participants decided to further their education:

Well, I move on because I end up completing my degree. I got my degree. I finished it up because I had stopped, you know, because I felt that I couldn't do it but I went back and got my degree. Then I also end up with eighteen credits on my Masters. However, I retired but I'm still thinking about going and getting it, you know. I don't know if that's just something in me, but I'm still thinking that I'm going to go back and finish up that little bit. (P6)

My friends just ask, what drives you? I was finishing up my Masters in Health Care Administration and I'm in school and I have to finish up all of that. I then thought I would do some teaching. . . . if I teach them to be good nurses and give back that's my contribution. That's all I want to do with my life. (P14)

Participant 4 continued to work and go to school while pursuing a higher position at her place of employment:

I think a lot of it too has to do with your mental state, you know if you uh walk around feeling sorry for yourself, and you think it's the end of the world, the healing process is quite different from if you have an upbeat attitude, because I, I was actually going to school at the time and I was working full-time and I didn't stop working or stop going to school. I continued doing everything normal. As a matter of fact, my employers didn't even know that there was anything wrong until I had to tell them because I was scheduled to travel to go for training and at the time they wanted to schedule the traveling, I had to take my chemo treatment, so I couldn't go on those dates, so I had to let them know why I couldn't. And they were like totally shocked! I don't think I view myself differently before then, before, during, or after. I feel the same way! The one thing I can say is I'm more health conscious. But outside of that, it's pretty much the same. (P4)

During the interviews, as the participants reflected on their life events, the researcher noted a common thread. The participants viewed the breast cancer experience as life-changing but not life-ending. There was a sense that their new life and purpose had begun and they were going to face it with a joyful spirit. The following two statements made by Participant 13 are reflective of the general consensus of the participants:

It means to just go on with life. That I'm important. That I'm special. That I'm needed in this life, so don't dwell on what's going on with other people. They need me. I feel purpose. I feel that I'm here for a reason. What helped me become a cancer survivor? Just having faith and not standing there moving on with life. Just picking up the pieces and going on and trying to live and make a difference in your life. (P13)

I love people. I love traveling. I love stuff. I am a . . . I love antiques. I love creating. I love all that. My life was pretty happy. During treatment you say, it was a little rough change. Some things that I may have taken for granted, I no longer take for granted. I wake up every day trying to make a difference in someone's life, being grateful for my life, and just living life the best. (P13)

Coping

Coping encompasses accustomed patterns of behaviors to deal with daily situations, as well as new ways of behaving to deal with drastic changes. Regulatory responses are automatic or instinctive responses not requiring cognitive functions. Cognatory responses are cognitive and motional channels, providing for perceptual information processing, learning and judgement (Roy, 1999). The participants instinctively relied on their faith to cope with the physical

discomforts resultant of the breast cancer diagnosis and treatment. This enabled them to continue to engage in their normal activities. The following statement is reflective of the participants' regulatory coping ability:

I don't think I've spoken to God as much as I've spoken to him when I went through this. And now I realize that I can still do that. I don't have to be in the kneeling position, I could be walking down the street and I could start a conversation with him but I feel comfortable doing it. Before probably I wouldn't have. Comfortable as I feel now. You know we always had a time for prayer and that was then but now you know anything that goes on I can strike up a conversation with him, and say, is this your plan or is this my plan. Is this your idea, or is this my idea. I'm in a peculiar situation. I need some guidance. Come up with a solution here I don't have much time. Because I know what I should be doing here. And I find peace in that. (P1)

The participants also continued to engage in their day to day activities.

I am very hard working, I like to stay busy, and very dedicated to my career and that dedication also helped me through the process, because I had a lot of things to do at the job to remain focused on that, took my mind away from thinking about the cancer. I was just really focused on working and going to school, and you know, I think all those things that were going on kind of took my mind off of, I didn't really sit around and lament about what I had. (P4)

An unexpected occurrence for several of the participants was the initial misdiagnosis of their breast cancer. Their cognatory coping mechanism required them to rethink their life plans again relying on their faith for support. Exemplars reflective of the cognatory coping mechanism are as follows:

So finally, maybe I myself could deal with the fact that you have this disease, nothing you are going to do is going to change it. But it wasn't something in the beginning that I talked about, I had to process it in my own mind and this is my period. If I can't process it I don't want to discuss it. Let me process it; figure it out for myself and then I can talk to you about it. (P1)

You know, that God heals and all everything like that and I just don't feel that he is ready for me yet because I have so much to do. You know, and I just keep, Lord you know, you know the journey, you know what I have to do and where I have to go. I know you know I'm not finished yet and just give me the strength and grace to keep on going. (P14)

The participants found that their coping ability aided in reducing life stress which enhanced their adaptation experience.

You know sometimes...I felt like a lot of stressors that we don't even realize that we're harboring, so I try to make sure, especially at work, that I don't let the stress get to me. If I feel that it's coming on or I feel like I'm getting stressed, I stop and like, regroup and try to get away, and I've noticed, too, one of the things I often do, my coworkers, they know me so well, if I see umm another person approaching me and I feel a negative, like negative vibes or stressful attitudes coming my way, I always stop it, like you know, this is my space, and I'm not going to allow you to invade my space with that attitude. Keep it out there. Don't come to me with that. You know, some people come and they're all worked up and sometimes, it's not even that serious, but you know they bring that energy with them and I'm like, I don't want that energy. Please don't bring it to me. I try to keep all of that, you know, the negative energy and the stress away from me as much as possible. (P4)

Chapter Summary

The first section of this chapter briefly described the study participants and the results of the System of Belief Inventory. The second section presented the results of the qualitative content analysis of the interviews with 15 participants. The results focused on the research questions: a) What is the perceived role of faith in the African American women's breast cancer survivorship experience? B). What does it mean to be a breast cancer survivor? and c) What is the concept of faith in the life of African American women breast cancer survivors? Themes that emerged from the Roy Adaptation Model applicable modes of adaptation were addressed. Exemplar quotes were also provided. The discussion of these results is provided in the following chapter.

Chapter VI

DISCUSSION

This study sought to gain an understanding of the adaptation experience of African American women breast cancer survivors. African American women's perceptions of the influence of faith on the breast cancer survivorship experience were explored. As such, this research was closely related to literature that focused on the African American culture in the United States, African American women's view of illness and health, and survivorship and faith among African Americans.

The findings are discussed for the actual beliefs of African American women regarding their breast cancer survivorship experience. The findings are summarized as they apply to the previous literature review and the Roy Adaptation Model (RAM). The strengths and limitations of the study and areas for further study are also identified, followed by implications for nursing practice.

Discussion of the System of Belief Inventory

In the study by Holland et al. (1998), the System of Belief Inventory (SBI 15R) was developed to identify a brief yet solid measure of both the religious and spiritual aspects of coping with life-threatening illness as well as the resulting impact on an individual's quality of life. The SBI-15R was not limited to questions related to religious rituals and practices and belief in a supreme being (10 items), but it included questions about the support one gets from the religious or spiritual community (5 items). One of the limitations cited in the study was that it had been used only with healthy individuals and those being treated for malignant melanoma. The short SBI-15 scale has been validated to provide a rapid self-report measure that can be used

in research on quality of life psychosocial factors and coping with disease. Further work was needed with patients having other life-threatening illnesses. Of additional interest would be to examine different cultures, looking at one with strong religious and spiritual beliefs and practices.

The present study's focus was on African American women breast cancer survivors. Women from this culture are known to have strong religious and spiritual beliefs and practices. The 15 women participating in the study represented six different religious denominations, with one participant denying any religious affiliation. All 15 professed that they considered themselves to be spiritual. Of the 10 items relating to religious rituals, practices and belief in a higher being, the majority of the participants strongly agreed with all of them.

Holt and McClure (2006) found that faith plays a vital role in the life of many African Americans. The similarities of the study participants' responses on the SBI-15 and this population's faith beliefs supports the belief that the African American women have regarding the concept of faith in their life. Due to the small sample size, tests for statistical significance could not be performed in this study. The data collected suggested that the women participating in this study have strong faith beliefs.

African American Women's View of Health and Illness

Health was defined by the study participants in general physical terms such as having no aches and pains, not needing to take medication, being able to just go on with life, and having nothing to bother a person. But there was a common theme that to be healthy, one should also have a good mind. Health is about mental status, emotional and mental health, and stress relief. The participants felt good health starts with the mind, but physical activity every day is also

important. The belief system affects the health status. Participants referred to their prayers to God (“Higher Power”) to sustain their physical and mental health.

The first question asked of the participants was how they discovered their breast cancer. The women all participated in health screenings followed by treatment. One third of the women discovered the first signs of an abnormality via breast self-exam followed by mammography. The remaining participants were diagnosed via breast exams by their health care providers and medical screening procedures such as sonograms. This was contrary to the study previously done by Kaiser et al. (2013) with 40 African American women. In that study, it was noted that African American women failed to seek medical screening or undergo treatment for cancer. Rather, the reluctance to go to the doctor was linked to a failure of African American women to care for themselves. Although the participants in the present study were all very proactive in obtaining the necessary screening and resultant treatment, there were instances where miscommunications led to delay in treatment that jeopardized their continued trust in the health care system.

In the current study, five of the 15 participants’ breast cancers were misdiagnosed. This misdiagnosis led to a delay in treatment in two instances, resulting in an advanced stage of the cancer once positive diagnosis was achieved. In a qualitative study focus groups with African American adults on the perceptions of breast cancer treatment in African American women and men, an analysis of 445 participants’ responses revealed a core of themes related to treatment (Masi & Gehlert, 2009). The themes included mistrust of the medical establishment, concern about the effect of racism on treatment quality, a perceived link between health insurance quality and treatment quality, the negative effects of treatment on intimate relationships, and concerns about treatment complications. This sense of anger and mistrust not only had psychological effects on the participants, but were also accompanied by physical symptoms. Mistrust of the

medical establishment was not an area of focus in this present study, but the findings were reflective of this theme. One participant in the current study felt the need to change her entire health care team, stating that at a time in her life when she needed the most support, she no longer trusted the doctors she had been seeing for years or any of their associates. Another participant had difficulty securing the specialized care she needed because of what she deemed as lack of connections with persons in positions who could get her necessary appointments. Yet another participant cited the mishandling of her health records which were misplaced and never recovered.

The initial response to the cancer diagnosis was shock and disbelief. The diagnosis of breast cancer, though shocking initially, resulted in a need to address this physical change. All of the participants engaged in medical treatment for their cancer diagnosis. They either had surgery, chemotherapy, radiation, or a combination of the three. The physiological side effects from those treatments were many. The most adverse effects resulted from the chemotherapy treatments: reports of extreme nausea and vomiting, physical changes in the skin and nails, and hair loss. The chemotherapy was referred to as poison and one participant described it as “evil.” Some of the participants resorted to alternative means of treatment to alleviate their discomfort. For some of the participants, this reverted to the cultural belief that good health equates with social entities such as good luck or success, as cited in Giger et al.’s (1992) research. Illness or disease may be considered the result of bad luck, fate, or chance. Several of the participants’ shock was based on the belief that they had done everything expected of them. They had their mammography every year; many were non-smokers and lived what they considered healthy lifestyles. Once the initial shock wore off, they began to reflect on past family history and what needed to be done to secure a cure.

Revell (2012) found that the African American culture has a rich historical perspective of health care and disease management. The initial attempt to address illness is often home remedies, which can be traced back to the time of slavery. Healing concepts carried in the memories of the African villagers were transported to America and used for the slaves because they were not offered traditional Western health remedies in managing illness. The use of complementary and alternative medicine (CAM) continues into today's society for African American women. Kronenberg et al. (2006), who studied four ethnic groups in the United States with a sample size of 3,068 women over 18 years old, found that African American women used complementary medicine 57.4% of the time. Several of the participants in this study included alternative means of treatment in conjunction with traditional medical treatment. After being debilitated from chemotherapy, one participant embarked on a treatment with herbs, grains, and fruits to rebuild all the good cells that were destroyed. Another participant went to an herbal doctor for treatment to reduce symptoms from chemotherapy. Yet another participant took a multiple approach: she went to an Indian natural path, drank green drinks every day, and visited a Chinese acupuncturist.

In addition to seeking alternative means of treatment, the study participants continued to perform breast self-exams, except for two participants who confessed they never did breast self-exams and have not done so since being diagnosed. One participant stated she does not perform breast self-exams because she simply does not know what she is looking for. All of the participants continued to attend their scheduled medical exams and mammograms. The participants augmented their medical treatment by living a healthy lifestyle.

The primary concept the participants equated with maintaining a healthy lifestyle was consuming a proper diet. They all referred to dietary changes made after their diagnosis with

breast cancer as a means to maintain health. There was a change from their cultural way of frequently eating fried foods, and a decrease in the consumption of meat, especially red meat which they replaced with fish. They increased their consumption of fruits, vegetables, and salads. One participant was convinced that what people eat has a bearing on their health.

One factor related to stress and coping that might have an effect on the health of the African American woman is the Strong Black Women role, often referred to in the literature as the “Superwoman” role (Hamilton-Mason et al., 2009; Woods-Giscombe, 2010). This need to be in control in adverse situations can have both positive and negative effects on an individual’s health status. The behaviors of the participants in this study concurred with the “Superwoman” role. Several participants met the multidimensional needs of others before focusing on their own.

Survivorship and Faith Among African Americans

In a study by Woods-Giscombe (2010), a sample of 48 demographically diverse African American women reported that the Superwomen role was multifaceted. They characterized the Superwomen role as an obligation to manifest strength and suppress emotion, resist being vulnerable or dependent, determine to succeed despite limited resources, and help others. According to the women, the “Superwoman” role involves social, historical, and personal relative factors as well as matters of survival and health status (Woods-Giscombe, 2010). The participants in the present study relied heavily on their faith to gain the strength needed for their survivorship experience.

The incorporation of faith in everyday life has often been depicted as the most distinctive characteristic of African American culture (Underwood & Powell, 2006). Research has indicated that people diagnosed with various forms of cancer tend to use faith to cope with the diagnosis (Holt et al., 2009). In the African American population, explanations of illness and healing have

been associated with a “Higher Power” and faith. Those diagnosed with cancer have been known to increase frequency of prayer and house of worship attendance, and their faith becomes more pronounced (Holt et al., 2009). Similarly, all 15 participants in the current study made statements related to how faith helped them to deal with their treatment and recovery process. A common repeated premise among the participants was that faith helped them make it through the breast cancer experience; without faith, they would not have survived. Faith played an important part in their healing, accepting, and wanting to go on. The participants’ reference to the role their faith played in their breast cancer experience permeated the interview process. It was a consensus that the faith was always there, but in many instances, it had become more pronounced. There was a more constant communication with God (“Higher Power”) through prayer. Their faith that they were not alone in this time of their life was the one aspect that aided them in continuing to perform their day-to-day activities.

Roy Adaptation Model as a Conceptual Framework

The participants in the study responded to changes that affected their various life roles and their self-concept. According to Roy (1984), individuals respond to a constantly changing environment in two ways. The first way is through instinctive, physiological processes, known as the regulator coping mechanism, whereby the person responds automatically without the need for thought. The second way the individual copes or adapts is through the cognator mechanism, which includes psychological and social coping processes requiring the person to respond to stimuli through cognitive and emotional pathways such as learning and judgment. The RAM divides the environment into focal, contextual, and residual stimuli (Roy & Andrews, 1999). The stimuli that immediately confront the person are the focal stimuli. In this study, the focal stimuli were the past diagnoses of breast cancer. Contextual stimuli are other factors that contribute to

focal stimuli. In this study, the contextual stimuli were breast cancer survivorship and other known demographic data that emerged during the study. The other stimuli present in the environment that cannot be validated are called residual stimuli (Roy, 1984). The analysis of the interview statements resulted in the clustering of significant statements that reflected the role function and self-concept adaptive modes. The role that faith played in the breast cancer survivorship experience was viewed through the lens of the RAM's theoretical framework.

Role Function Mode

The role-function mode is the category of behavior that pertains to roles of human systems (Roy & Andrews, 1999). This mode of adaptation focuses on both individual and group performance of activities associated with the roles they perform in society (Fawcett, 2009). The participants were adamant about their role in sharing the experience they had of diagnosis and treatment of breast cancer with others. One participant spoke of a time she stood up in church and shared her experience, which was something she normally would not have done. Afterwards due to her speech a person from the congregation went to the front of the church and said she needed prayer because she had just recently been diagnosed with breast cancer. The participant felt her sharing made it possible for the person to come forward and receive the support she needed. Several participants' related incidents in which they shared testimony with their church congregations about what God ("Higher Power") had done in their lives relating to their survivorship experience. This sharing was not limited to their religious affiliates, but permeated their day-to-day experiences.

A misconception about the African American culture is that the slave experience eradicated all aspects of a pan-African cultural tradition brought to this country as a result of deracination (Akbar, 1996; Ami, 1994; Asante, 1990; Azibo, 1996; Kambon, 1996; Schiele,

1997). Most noteworthy is that, although African Americans came here against their will, enslaved, segregated, and excluded from the larger society, they retained their African traditions. Through storytelling, they could keep their history alive and connect with one another. They continued to pass on their faith beliefs and practices throughout the generations. Perhaps because of their rich sociopolitical, cultural, and religious heritage, African Americans in general are characterized as having strong faith practices guiding their life decisions, including matters of health (Borum, 2007). The participants in this study kept to this tradition of sharing their story of how faith guided their survivorship experience.

The participants spoke of several venues where they would share their story of survivorship. The experience was shared on their jobs, especially by those who were health care providers and whose clients may have been newly diagnosed with breast cancer. They were more verbal with family members about living a healthy lifestyle and screening for early detection and treatment of any abnormalities. One participant said she would initiate a conversation with anyone, including strangers, and did not mind sharing her experiences. A common premise was that they now embodied the role of teacher. After breast cancer survivorship, it was their role to be teachers and educate others. They felt survivors should be knowledgeable enough to dispel the many myths surrounding the breast cancer experience. The participants had a unifying view of their role in society where they believed their faith in God (“Higher Power”) and His healing power can be extended to everyone.

The current study was reflective of the RAM theory role function mode of adaptation. The participants took on the role of seeking opportunities to share their knowledge and experiences regarding the breast cancer experience. They assumed the responsibility to provide

guidance and encouragement to those who needed their support. Their anticipation of the future reflected positivity that displayed their positive adaptation and coping ability.

Self-concept Mode

The self-concept mode focuses on the psychological and spiritual (faith) aspects of the person. This mode entails the need for one to know oneself to embody a sense of unity (Roy & Andrews, 1991). To be eligible to participate in this study, the participants had to be African American. The black experience in America is distinctively different from that of other immigrants or refugees. For African Americans, their sense of belonging and essence are judged by the color of their skin. To be African in America or African American upsets the established categories of what it means to be an American un-hyphenated and seemingly coming from no position or ethnicity (Ellison, 1970; Starwell, 1998). No assumptions can be made about who fits into this category. The target population was African American women in the New York urban setting. In this study, African American was inclusive of continental and diasporic people of Africa. The participants here were asked to self-identify as African Americans. The rationales for claiming this identity varied. Some participants did not feel their culture had anything to do with their breast cancer diagnosis.

The question “What criteria do you use to describe yourself as an African American?” brought about deep contemplation. It was an inquiry to not only determine the participants’ view of oneself, but later to relate to their various role functions regarding their culture. All participants were adamant in their response of “I am an African American woman.” Some responses related to parentage, family history, and place of birth. Other descriptors were used to describe the participants’ identity as African American women related to physical and personality characteristics such as hair texture, body build, strength, toughness, and flexibility.

Having the strength to endure almost anything while relying on faith was also an attribute mentioned. This endurance was needed to adjust psychologically to the many changes resulting from the diagnosis and treatment of the breast cancer.

Several participants reported on their change in self-concept based on the alteration brought about by the cancer diagnosis and resulting treatment. These changes included removal of a breast, hair loss, nail deformity, and the need to adjust their mode of dress. One participant stated that she looked at the removal of the breast from the point of view of affecting her as a woman. Another participant stated she no longer looked in the mirror and did not like to hug because she was concerned other people would be aware of the prosthesis. The loss of hair was another major concern, as were changes in nail color and texture. The participants all agreed that the one thing helping them through this period of change was their faith and their major connection to their “Higher Power” was through prayer.

African American faith results in a life lived in gratitude, not because all problems have been solved but because of their faith in a “Higher Power’s” promise (Smith, 1999). The belief that one only has to ask God (“Higher Power”) and it shall be given was a driving force in the participants’ prayer and meditation practices. They spoke about being thankful that God (“Higher Power”) knew what they were going through and had a plan for them. Each new day began with prayer, praise, and gratitude. They offered statements related to God’s purpose for one’s life and experiences as a means of changing one’s path in life. They mentioned initially fearing God (“Higher Power”) and their breast cancer as His punishment for wrongdoings, but on further reflection, they came to feel that sometimes God (“Higher Power”) sends a message through these difficult circumstances. They can be the means of causing one to stop certain

unhealthy behaviors and make necessary changes. The participants stated that they gave thanks every day they woke up because they knew they had a purpose to fulfill.

According to the women in Woods-Giscombe's (2010) study, the "Superwoman" role involves social, historical, and personal relative factors as well as matters of survival and health status. The tendency for African American women to seek support versus rely on their own strengths to cope may have a cultural basis. In this current study, several of the participants displayed behavior reflective of the "Superwoman" syndrome, and made minimal changes in their day-to-day existence. Throughout their treatment, they continued to work full-time, often scheduling their treatments around their work schedules. They perceived the need to be strong and self-sufficient while protecting those they loved from unnecessary anxiety. Two participants in the study did not share their diagnosis with their family members, feeling that the burden would be too much for them to carry. One husband was informed only the day before the participant was scheduled to be admitted to the hospital for a mastectomy. Another participant postponed her treatment for three months because her husband had sustained an injury that she felt required her to take care of him. Once she felt he was strong enough, she then informed the family of her own diagnosis. Yet another participant refused to share her diagnosis with her two children; one was leaving to go away to college and another had just started a new job. She stated that she did not want to interrupt their lives. The need to rely on self was indeed present in this study population.

The study participants embraced the belief that despite physical and life changes, they were still the same person they were prior to their breast cancer diagnosis. They had the endurance and steadfast faith to survive any of life's challenges. As such they continued to live life abundantly with gratitude and renewed ambition.

Some of the participants turned to family friends and church members for support. For several participants, this support was not forthcoming. One participant described her relationship with her husband as distant since her diagnosis. She believed he could not handle the fact that she had cancer and that women were stronger and better able to handle stress than men. Furthermore, her husband thought God had punished him and she would die very quickly. Others felt that their husbands were overly supportive, whereas their husbands' sense of doom and wanting to change everything about their lifestyle stifled their positive-attitude faith belief in surviving that they needed to hold on to at this time. Yet others found the constant questioning by friends irritating; the constant inquiries about their health and emotional state were not supportive. What they viewed as support was having someone they could go to and depend on when they felt the need.

Some participants in this study verbalized positive experiences of the support they received after their diagnosis of breast cancer. Some husbands transported them to work daily and took them to their treatments. Participants reported that their children took on more responsibilities with household chores, especially on days when the chemotherapy treatments rendered them physically incapable of performing those tasks on their own. Their friends were there for them to talk to when they felt lonely or discouraged. Mothers played a vital role. Even those participants who had not been in close contact with their mothers prior to their diagnosis found the comfort and nurturing from their mothers during the experience supportive. Family support included an extended family which many African American women categorized as their church family.

Faith plays a vital role in the life of many African Americans. Attending house of worship services provides a means of social support, and prayer is used to help with life stressors

(Holt & McClure, 2006). All of the participants reported attending church services on a regular basis. Even the one participant who stated she had no religious affiliation attended church services with friends in various denominations. They found the support to be invaluable.

Coping

The ability to adapt to the diagnosis of breast cancer encompasses both regulatory or automatic/instinctive responses and cognatory or social/psychological coping mechanisms. The participants in this study viewed breast cancer as another life event. They continued to push through the physical discomforts of the surgery and treatments. The consensus of these women was that to sit around and lament about having breast cancer was counterproductive. Most participants continued to go to work, in addition to taking care of their families and engaging in activities that were customarily a part of their typical lifestyle.

The participants did realize that this diagnosis could have been a life-changing event. They approached each day with gratitude and the drive to live each day to the fullest. The view of what was important in one's life changed. The participants spoke of reducing stress, achieving happiness, and pursuing life goals.

Strengths and Limitations

The strength of this study was its focus on a population that in past research had not been significantly studied. Despite 20 years of "pink ribbon" awareness campaigns and notable advances in medical treatment that has improved survival rates for women with breast cancer in the United States, the vast majority of these gains have bypassed African American women. The perceptions of African American women of the supports needed to adapt to survivorship have not been extensively studied. The present study provided a platform for these women to inform others of their survivorship process. The benefits obtained by the application of evidence

acquired from this study may assist in identifying important information about the coping mechanisms of the population under study. This new knowledge may assist in decreasing the gap in the provision of culturally specific interventions in delivering care to African American women breast cancer survivors. This study is a first step in identifying a deficiency that can be addressed by nursing.

Breast cancer continues to affect a large number of African American women each year. This study reported on African American women's perceptions of the role faith played in their breast cancer survivorship experience. This study can set a foundation for further studies on the breast cancer survivorship process.

The study's limitation was its small sample size related to the qualitative methodology which restricts generalization. The use of the qualitative approach generated valuable contextualized information that would not have been possible to obtain within the confines of quantitative research. In addition, there was a large range of years of survivorship among the participants in the study. Differences in length of time since diagnosis may result in these women having dissimilar, less comparable experiences in light of current advances in early detection, diagnosis, and treatment of cancer. A recommendation would be to repeat this study with a larger sample size.

Implications for Nursing Education, Practice, and Future Research

The findings of this study supports the importance of the role of faith in the breast cancer survivorship experience of African American women. Further, it explored the view that African American women have of their self-concept and resulting role function in society based on their past experiences. The following are implications for the application of these findings to nursing education, research and practice.

Nursing education accrediting bodies mandate that curriculum include cultural, ethnic, and socially diverse concepts from regional, national, or global perspectives. A focus of nursing education is QSEN (Quality and Safety Education for Nurses), which includes patient-centered care and evidence-based practice. The patient is the acknowledged leader in the nurse-patient partnership relationship in providing compassionate and coordinated care. The care provided is based on respect for the patient's preferences, values, and needs. Patient-centered care is best provided with the integration of best current evidence. In this current study, the African American women relied on faith as an adaptive process during their survivorship experience. Faculty can incorporate the knowledge gained from this current study to influence curriculum design. This evidence-based curriculum would be inclusive of objectives and course content to encompass the importance of faith in providing holistic patient-centered care. This strong educational foundation using evidence-based practice of culturally appropriate care for this population will foster a seamless transition of patient-centered care for African American women diagnosed with breast cancer, from nursing theory into nursing practice/health care settings.

Many health care settings are also governed by accrediting bodies as a means of evaluating health care organizations and inspiring them to excel in providing safe and effective care of the highest quality and value. One such body, The Joint Commission on Accreditation of Healthcare Organizations, includes as a standard the assessment of spirituality. The results from this current study, on how the role of faith permeates African American women's views on health and illness, can be incorporated into the development of culturally specific care plans. Many of the questions based on adaptation included in the interview guide would also be appropriate as a guide for the development of a spiritual assessment tool that can be used for data collection in various health care settings.

A concern that arose from the interviews was the repeating premise that there was a disparity with this population in the timely diagnosis and treatment of a number of the participants. An area for future study would include the African American women's perception of the role of the nurse in the breast cancer survivorship experience. Many of the participants in the study verbalized their feelings about their substandard medical care. A repeating theme was that they were often misdiagnosed or what they considered as vital information was not shared with them. No mention was made about the role of the nurse to enhance the survivorship experience or how the nurse could have been of more assistance.

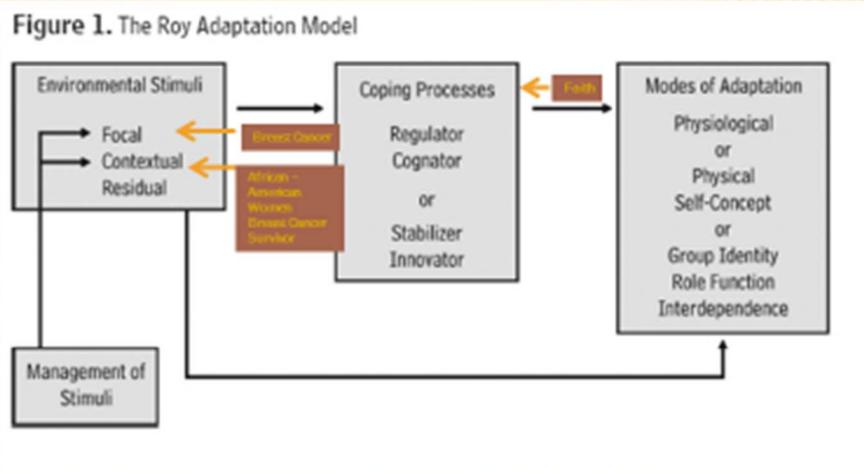
African American women are strongly affiliated with the church. To reach out to this group, nurses can partner with church leaders to develop health education programs that can be presented to the congregations regarding patient rights and the responsibilities of health care providers. Policymakers should also be included in the conversation. Access to health care must be addressed and improved. This would result in more timely diagnoses and treatments. A decrease in this disparity can have a positive financial effect not only for this population, but for society as a whole.

Chapter Summary

This chapter provided a discussion of the actual perceptions of African American women of their breast cancer survivorship experience. The findings were summarized as they applied to the previous literature review and the Roy Adaptation Model. Strengths and limitations of the study and areas for further study were identified. Finally, implications for nursing practice and future research was provided.

APPENDIX A

ROY ADAPTATION MODEL



Adapted from:

Using the Roy Adaptation Model to Guide Research and/or Practice: Construction of

Conceptual Theoretical-Empirical Systems of Knowledge, **Jacqueline Fawcett (2009)**

APPENDIX B

Screener Script for Contacting Respondents

What to say when calling a referred participant:

1. My name is Pearline Okumakpeyi, I am a doctoral student in the department of nursing and I am calling from the CUNY Graduate Center.
2. I am calling because (Insert name) referred you to me about possibly participating in a research study.
3. I am conducting a study about African American female breast cancer survivors. I am interested in understanding faith (religion/spirituality) adaptation process in breast cancer survivorship.
4. Study participation consists of one face-to-face meeting between you and me. At this meeting I ask you to participate in an in-depth interview in which you will talk about your perception of faith and your breast cancer survivorship experience followed by the completion of two brief questionnaires. The entire meeting will last for approximately one and a half hour.
5. The information you give me will be analyzed and the findings will be reported for the benefit of the discipline of nursing and other health care providers. The names of the study participants are never mentioned.
6. We will do the interview at a location that is mutually convenient and agreed upon by you and the interviewer.
7. You will receive a \$10.00 Metrocard and (\$10.00) as a thank you for your time.
8. Each person's experience is very important so I hope I will be able to meet and speak with you further.
9. If you are interested in participating, I need to obtain some preliminary information from you to confirm your eligibility for the study:
 - a. Can you please tell me your age? (Or are you 40 years of age or older?)
 - b. Do you live in the New York Metropolitan area?
 - c. Have you been diagnosed with and completed treatment for breast cancer?

Thank you very much.

Now at this time I would like to set up a day, time, and location for our interview meeting.

Or:

Sorry, but we are only interviewing volunteers who are (insert eligibility criteria that they do not meet). I appreciate you taking the time to speak with me about the study. Goodbye.

APPENDIX C

Consent to Participate in a Research Project

CITY UNIVERSITY OF NEW YORK

Lehman College
Department of Nursing

Project Title: Women of Faith: Adaptation of African American breast cancer survivors

Principal Investigator: Pearline Okumakpeyi, Graduate Student
CUNY Graduate Center, Faculty New York City College of
Technology
300 Jay Street, Room Pearl 505
Brooklyn New York 11201
718 260 5663

Faculty Advisor: Catherine Alicia Georges, Ed.D., Professor
Lehman College, The City University of New York
250 Bedford Park Boulevard West, T-3 Room 209
Bronx, New York 10468-1589
718 960 8799

Site where study is to be conducted: CUNY Graduate Center, Department of Nursing, Room 3317

Introduction/Purpose: You are invited to participate in a research study. The study is conducted under the direction of Pearline Okumakpeyi, CUNY Graduate Center. The purpose of this study is to seek to gain an understanding of the adaptation experience of African American women breast cancer survivors. The African American women's perception of the influence of faith on the breast cancer survivorship experience will be explored. The results of this study may provide information to increase nurses' ability to help African American women who have had breast cancer cope. This information can be shared with other healthcare workers regarding what having had breast cancer means to African American women. It will provide information to support the cultural, emotional, social and learning needs of African American women. The interview will be audio-taped to make sure we understand your answers.

Procedures: Approximately 10-20 individuals are expected to participate in this study. Each subject will participate in completing two questionnaires and an interview session. The time commitment of each participant is expected to be a one-time session of 60-90 minutes. Each session will take place at a location convenient to you and the interviewer.

Possible Discomforts and Risks: Your participation in this study may involve talking about your feelings regarding how you coped with having had breast cancer. In sharing feelings regarding the breast cancer experience, some women may become upset. The interview will be stopped at your request. In the possibility that you become upset talking about your cancer experience, you will be referred to a counselor from a list provided by the researcher and/or your own spiritual counselor or Health Care Provider.

Benefits: There are “no direct benefits, however a benefit of taking part in this study is its possibility of finding ways that African American women mentally cope during surviving the breast cancer experience. It will also add to the understanding of faith’s role in coping as seen by this group of people.

Voluntary Participation: Your participation in this study is voluntary, and you may decide not to participate without prejudice, penalty, or loss of benefits to which you are otherwise entitled. If you decide to leave the study, please contact the principal investigator Pearline Okumakpeyi to inform them of your decision.

Financial Considerations: Participation in this study will involve no cost to the subject. For your participation in this study you will receive a \$10.00 Metrocard and \$10.00 cash as a thank you for your time and participation in this research study on completion of the interview session. Those participants who did not complete the interview will not be compensated.

Confidentiality: The data obtained from you will be collected via audio recording. The collected data will be accessible to the researcher, IRB Members and staff. The researcher will protect your confidentiality by coding the data and securely storing the data. The collected data will be stored in a locked file draw in the researcher’s home. Audiotapes will be destroyed once copied in written format as per IRB guidelines. Consent forms will be kept separate from data. The interview will be audio taped to make sure we understand your answers.

Contact Questions/Persons: If you have any questions about the research now or in the future, you should contact the Principal Investigator Pearline Okumakpeyi, RN. MA, M.Ed. POkumakpeyi@gc.cuny.edu, 347 785-4161. If you have any questions concerning your rights as a participant in this study, you may contact Tara M. Prairie, 718 960-8960, tara.prairie@lehman.cuny.edu

Statement of Consent:

I have read the above description of this research and I understand it. I have been informed of the risks and benefits involved, and all my questions have been answered to my satisfaction. Furthermore, I have been assured that any future questions that I may have will also be answered by the principal investigator of the research study. I voluntarily agree to participate in this study.

By signing this form I have not waived any of my legal rights to which I would otherwise be entitled.

I will be given a copy of this statement.”

Printed Name of
Subject

Signature of Subject

Date Signed

Printed Name of
Person Explaining
Consent Form

Signature of Person Explaining Consent Form

Date Signed

Printed Name of
Investigator

Signature of Investigator

Date Signed

APPENDIX D

Interview Guide

Date: _____

Participant Number Code _____

Initials of Narrator:

Each study participant will be asked the following questions. Other questions that evolve from the participants' responses will be asked to allow for elaboration and unplanned discussion of the content.

Roy Adaptation Model

1. Physiological Mode

- a. How did you discover your breast cancer?
- b. Tell me about what it was like to have breast cancer.
- c. Tell me about the symptoms you had with your cancer.
- d. What was your treatment like?
- e. What physical challenges have you experienced since being diagnosed with breast cancer?
- f. Tell me about adapting or coping with changes brought on by your breast cancer diagnosis.
- g. How did you feel physically and emotionally when you were told your treatment had been completed.
- h. Do you continue to do breast self-exams? If so how often?

2. Role function

- a. Tell me about yourself.
- b. What criterion do you use to classify yourself as an African American?
- c. Do you engage in preventive health practices?
- d. What practices did you engage in before diagnosis, during treatment and now in survivorship?
- e. Do any health care practices engaged in have a cultural or faith-based foundation?
- f. What does breast cancer survivorship mean to you?
- g. How has attending religious functions affected your ability to adapt to being a breast cancer survivor?
- h. What effect has breast cancer had on your various life roles? For example: family, work, volunteer activities, house of worship?
- i. How do you see yourself moving on in life after a diagnosis of breast cancer?
- j. As a survivor how do you see your role in sharing your knowledge with others?

- k. What was it that helped you become a cancer survivor?
 - l. What was the hardest, most difficult thing during your cancer experience?
 - m. What do you feel helped in moving from a woman with breast cancer to where you are now?
3. Interdependent
- a. Please explain how you accomplish life tasks, for example, how you make decisions? Do you rely on friends, family members, past experiences, religious or spiritual affiliates?
 - b. Who do you seek out for support when you feel lonely?
 - c. How does being a breast cancer survivor affect your relationships physically and emotionally in carrying out activities with your family and friends?
 - d. During your illness who provided support? Support comes in different ways from different people. Tell me about them.
 - e. What does this support mean to you?
 - f. How did friendships affect your diagnosis and treatment of breast cancer?
 - g. Describe your family and their role in your illness and survival.
 - h. What were your greatest needs during the entire experience?
 - i. What could have been done and by whom to make this experience better for you?
4. Self-Concept
- a. Tell me about your view of yourself before, after treatment and now since your diagnosis.
 - b. How important is your faith to your day to day life?
 - c. How often do you attend a house of worship?
 - d. What role has prayer or meditation played in your ability to cope since your diagnosis with breast cancer?
 - e. How did your belief change with the impact of the diagnosis?
 - f. Where does breast cancer survivorship and your faith fit into your future?
 - g. Tell me about your feelings regarding breast cancer survivorship.
 - h. Tell me about what faith means to you.
 - i. Tell me about how you understand health.
 - j. How has faith or spirituality affected the experience of breast cancer and survivorship?
 - k. How has this diagnosis and treatment affected you as an African American women?

APPENDIX E

Participant Demographic Sheet Questionnaire

Participant Number Code _____

1. Age _____
2. Marital Status _____ Married/Partnered _____ Single _____ Divorced _____ Widowed
_____ Separated
3. Work Status _____ Employed _____ Retired _____ Unemployed _____ Disabled
_____ Homemaker
4. African American/Black Ethnic Background _____ Yes _____ No

Please indicate further description of African American/Black identity:

Example: _____ United States _____ Afro-Caribbean _____ South American
_____ Other _____

5. Highest Level of School Completed: _____ No formal schooling _____ Primary school
_____ Eighth grade _____ Some high school _____ High school graduate
_____ Some college _____ College graduate _____ Postgraduate
6. Income: _____ Adequate for needs _____ Not adequate for needs
7. Year of Breast Cancer Diagnosis: _____
8. Stage of Disease at Time of Diagnosis (if known): _____
9. Type of Treatment Received: _____ Specific chemotherapy _____ Frequency and
length of radiation therapy _____ Surgery _____ Other _____
Length of treatment _____
10. Date of Completion of Cancer Therapy: _____
11. Religion and faith:
 - a. What is your religious affiliation? _____
 - b. Do you attend a house of worship? _____ Daily _____ Weekly _____ Monthly
_____ Only on major religious holidays
 - c. What house of worship (religious institution) auxiliaries are you a member of or do
you play in house of worship/your religious institution? _____
 - d. Do you see yourself as spiritual? _____

APPENDIX F

System of Belief Inventory (SBI)

Circle the answer that best describes your belief

1. Religion is important in my day-to-day life.
0 – Strongly disagree; 1 – Somewhat disagree; 2 – Somewhat agree; 3 – Strongly agree
2. Prayer or meditation has helped me cope during times of serious illness.
0 – None of the time; 1 – A little bit of the time; 2 – A good bit of the time; 3 – All of the time
3. I enjoy attending religious functions held by my religious or spiritual group.
0 – Strongly disagree; 1 – Somewhat disagree; 2 – Somewhat agree; 3 – Strongly agree
4. I feel certain that God/"Higher Power" in some form exists.
0 – Strongly disagree; 1 – Somewhat disagree; 2 – Somewhat agree; 3 – Strongly agree
5. When I need suggestions on how to deal with problems, I know someone in my religious or spiritual community that I can turn to.
0 – Strongly disagree; 1 – Somewhat disagree; 2 – Somewhat agree; 3 – Strongly agree
6. I believe God/"Higher Power" will not give me a burden I cannot carry.
0 – Strongly disagree; 1 – Somewhat disagree; 2 – Somewhat agree; 3 – Strongly agree
7. I enjoy meeting or talking often with people who share my religious or spiritual beliefs.
0 – None of the time; 1 – A little bit of the time; 2 – A good bit of the time; 3 – All of the time
8. During times of illness, my religious or spiritual beliefs have been strengthened.
0 – Strongly disagree; 1 – Somewhat disagree; 2 – Somewhat agree; 3 – Strongly agree
9. When I feel lonely I rely on people who share my religious or spiritual beliefs for support.
0 – Strongly disagree; 1 – Somewhat disagree; 2 – Somewhat agree; 3 – Strongly agree
10. I have experienced a sense of hope as a result of my religious or spiritual beliefs.
0 – Strongly disagree; 1 – Somewhat disagree; 2 – Somewhat agree; 3 – Strongly agree
11. I have experienced peace of mind through my prayers and meditation.
0 – Strongly disagree; 1 – Somewhat disagree; 2 – Somewhat agree; 3 – Strongly agree
12. One's life and death follows a plan from God/"Higher Power".
0 – Strongly disagree; 1 – Somewhat disagree; 2 – Somewhat agree; 3 – Strongly agree
13. I seek out people in my religious or spiritual community when I need help.
0 – None of the time; 1 – A little bit of the time; 2 – A good bit of the time; 3 – All of the time
14. I believe God/"Higher Power" protects me from harm.
0 – Strongly disagree; 1 – Somewhat disagree; 2 – Somewhat agree; 3 – Strongly agree
15. I pray for help during bad times.
0 – None of the time; 1 – A little bit of the time; 2 – A good bit of the time; 3 – All of the time

Source: Holland et al., 1998. Permission granted by Dr. Jimmie Holland for use in the study.

APPENDIX G

Flyer for Study

Study on Women of Faith: Adaptation of African American Women Breast Cancer Survivors

This research study is being done by a City University of New York (CUNY) Graduate Center doctoral nursing student. The purpose of this study is to seek to understand the adaptation experience of African American women breast cancer survivors. The perception of the influence of faith on African American women breast cancer survivorship experience will be explored.

In order to take part in this study...

- ❖ Self-identified African American
- ❖ Able to read and speak English
- ❖ Age greater than 40
- ❖ Gender – female
- ❖ Be five years post-diagnosis with breast cancer

What does this mean for me?

- 🚦 All information received from you will be kept CONFIDENTIAL
- 🚦 This study involves filling out a questionnaire and participating in a private audio and interview session.
- 🚦 The entire study will take place in approximately 90 minutes
- 🚦 You will receive a \$10.00 Metrocard and \$10.00 as a thank you for your time and participation in this research study!

Please call the investigator, Pearline Okumakpeyi at 347 785-4161 to speak in more details about the Study!

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